LIVED EXPERIENCE ON ADJUVANT HORMONAL THERAPY AMONG BREAST CANCER PATIENTS AT OCEAN ROAD CANCER INSTITUTE IN DAR ES SALAAM, TANZANIA.

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Lived experience on Adjuvant Hormonal Therapy among breast cancer patients at Ocean Road Cancer Institute in Dar es Salaam, Tanzania.

By

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A dissertation submitted in (partial) fulfillment of the requirement for the degree of Master of Science in Oncology Nursing of Muhimbili University of Health and Allied Sciences

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CERTIFICATION

The undersigned certify that they have read and hereby recommend for acceptance by Muhimbili University of Health and Allied Sciences a thesis entitled ***Lived experience on adjuvant hormonal therapy among breast cancer patients at Ocean Road cancer Institute Dar-es-salaam, Tanzania*** in (Partial) fulfillment of the requirements for the degree of Master of Science in Oncology Nursing of Muhimbili University of Health and Allied Sciences.

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DECLARATION AND COPYRIGHT

I, **Thereza Gideon** declare that this dissertation/thesis is my own original work, and it has not been presented and will not be presented to any other University for a similar or any other degree award.

Signature…… Date……

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ABSTRACT

Background

Cancer is a public health concern globally, with an estimated 18.1 million new cases and 9.9 million deaths in 2020. Breast cancer is the fifth leading cause of cancer deaths worldwide, representing 11.7% of all cancer deaths. It is the second leading cancer in Tanzania with 3,992 (19.9%) new cases in 2020.

Adjuvant hormonal therapy (AHT) is the systemic therapy given to breast cancer patients with positive Estrogen and progesterone receptors. 20-50% of all patients on AHT are non-adherers regardless of the good impact of the treatment on reducing the risk of disease recurrence and mortality. Different interventions should be employed by both patients and healthcare providers towards improving adherence to medications and promoting individualized patient care.

Aim of the study: This study explored the lived experience on Adjuvant Hormonal Therapy among breast cancer patients at Ocean Road Cancer Institute in Dar es Salaam, Tanzania.

Material and methods: A qualitative design using a phenomenological approach was employed in this study. Twelve (12) participants were purposefully selected among breast cancer patients aging 18 years and above on Hormonal therapy and regular follow up at ORCI breast cancer clinic. In depth interview was used, using probing questions from a semi structured interview guide. Interviews were audio recorded and transcribed verbatim; data were analysed using thematic analysis.

Results: Participants understand the benefits of adjuvant hormonal therapy (AHT) in preventing cancer recurrence and maintaining hormonal balance, along with the range of potential side effects, including gastrointestinal issues, emotional and reproductive health concerns. Desire to live long; disease free, family support, and encouragement from healthcare providers facilitates AHT adherence meanwhile financial concerns on treatment expenses, reported treatment side effects and desire for future fertility hindered adherence.

Breast cancer patients use coping mechanisms to manage AHT, including surveillance and follow ups, medication switching on and off strategies and employing several measures to overcome side effects. Adherence is facilitated by integrating medication into daily routines, and support from healthcare providers this is crucial for guiding patients through treatment.

Conclusion: Although most women in this study took their medication as prescribed and were knowledgeable on the benefits of AHT on preventing cancer recurrence. Many incurred a complex interplay of side effects and financial constraints without seeking support and guidance since medication adherence monitoring and support were minimally offered on their routinely follow-up clinics. Developing a comprehensive education program detailing the importance of AHT, establishing a financial assistance plan to help patients afford their medication could further improve medication adherence.

Key words: Adjuvant hormonal therapy, breast cancer, adherenc**e**

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ABBREVIATIONS

AHT	Adjuvant hormonal therapy
AI	Aromatase inhibitor
ER	Estrogen receptor
HBM	Health Belief Model
MUHAS	Muhimbili University of Health and Allied Sciences
ORCI	Ocean Road Cancer Institute
PI	Principal Investigator
PR	Progesterone receptor
SSA	Sub-Saharan Africa
WHO	World Health Organization

OPERATIONAL DEFINITIONS

Adherence: The degree to which a person's behavior, such as persistence in taking the prescribed medications for the required time, eating in a certain way, or changing their lifestyle, complies with established advice from a healthcare professional

Adjuvant Hormonal Therapy: Systemic therapy given to breast cancer patients with positive Estrogen and progesterone receptors

Cancer: Deregulation or loss of equilibrium in the control of the cell cycle which can result in the proliferation of cells that can be localized to an organ and a region or can spread throughout the body.

Cancer survivors: Individuals diagnosed with cancer, on cancer treatment and who has completed cancer treatment

Experience: An event that is actually lived through, as opposed to one that is imagined or thought about

Perceived susceptibility: Individual’s belief about the likelihood of experiencing a harmful condition

Perceived severity: How much an individual feels threatened by a medical condition

Perceived benefits: Beliefs regarding the effectiveness of recommended actions make up the perceived benefits

Perceived barriers: negative aspects associated with taking a healthy action

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background of the study

Cancer is a public health concern globally, with an estimated 18.1 million new cases and 9.9 million deaths in 2020 (1). The burden is expected to increase in the next 20 years in Sub-Saharan (SSA) countries to 1.5 million new cases, with a mortality of 1 million from the current data with an estimated 801,392 new cases and 520,158 cancer deaths in 2020 (2). According to (3), cancer data in East Africa estimated 331,233 new cases and 222,189 cancer deaths in 2020.

Breast cancer is the leading cause of mortality among women with breast cancer worldwide, with an incidence of 2.2 million in 2020 (4). Breast cancer is the fifth leading cause of cancer deaths worldwide, representing 11.7% of all cancer deaths. In SSA breast cancer is the most diagnosed cancer with 129, 400 cases in 2020 (2), this is due to improved efforts on cancer registration, detection through screening, and changes in the pattern of risk factors (5). In East Africa, breast cancer contributes to 22.4% of all cancer cases (3). Female breast cancer is the second leading cancer in Tanzania with 3,992 (19.9%) new cases in 2020 (3).

Ocean Road Cancer Institute (ORCI) receives an average of 565 breast cancer patients who need treatments per month. In 2020, 492 new cases of breast cancer patients were diagnosed and on treatment (ORCI Cancer Registry and Chemo Report book). Cancer treatment in Tanzania is categorized into five modalities: chemotherapy, hormonal therapy, biological, and radiotherapy (6). Breast cancer treatment depends on the stage (early and late stage). In the early stage, treatment begins with surgery followed by radiotherapy then adjuvant hormonal therapy for 10 years, while in late-stage treatment starts with neo-adjuvant chemotherapy followed by surgery, radiotherapy then adjuvant hormonal therapy (7). Adjuvant hormonal therapy (AHT) is the systemic therapy given to breast cancer patients with positive Estrogen and progesterone receptors, Anastrazole for postmenopausal women and Tamoxifen for premenopausal women (6).

Treatment with AHT efficiently reduces the risk of disease recurrence and mortality after primary treatment of breast cancer (8,9). Regardless of the good impacts of AHT use, adherence to these medications is low. Studies show 20-50% of all patients on AHT are non-adherers to their medications (8,10–13). Adherence is the degree to which a person's behavior, such as persistence in taking the prescribed medications for the required time, eating in a certain way, or changing their lifestyle, complies with established advice from a healthcare professional (14).

Studies show that adherence to AHT is suboptimal (8,9,13). A study in Ethiopia revealed that in every 2 women taking AHT, one does not adhere to the treatment regimen (15). Factors such as lack of information on medication side effects, older or younger age, burden of treatment side effects, lack of follow-up information, forgetfulness, lack of insurance, and lack of supportive relationship throughout treatment contribute to AHT non-adherence (8,9,13,15). In addition, psychological distress was among the factors for non-adherence in women with pre-existing affective and pain disorders. Several studies have revealed reduced quality of life, increased disease recurrence, mortality, and poor survival as the complications associated with non-adherence or early discontinuation of AHT among breast cancer patients (13,16,17). There are several interventions used to improve AHT adherence. One of the identified interventions to prevent AHT adherence is sending patients daily text messages to remind them to take the prescribed doses (18,19). Patients received two weekly texts reminding them about treatment adverse effects, taking their prescribed drugs, and how to deal with obstacles to treatment adherence (20).This intervention had mixed results for instance, while some patients reported increased awareness and intention to adhere, actual adherence rates did not significantly improve in several studies, this suggests that while reminders can enhance intention, they may not address underlying barriers such as psychological distress or side effects (21,22)**.** The use of oncology nurses as navigators to improve adherence by assessing the possible barriers to adherence and reminders through phone calls to patients before follow-up appointments showed improved adherence to AHT (23). However, the success of this intervention may depend on the availability of resources and the ability of nurses to effectively engage with patients (24). Supply of educational

materials among breast cancer patients 9 times per year which contained information on medication benefits and side effects, however merely supplying educational materials is insufficient if patients do not fully comprehend the information or if it does not resonate with their personal experiences seen (25)

Regardless of different approaches revealed in studies on improving adherence to AHT, non-adherence to AHT among breast cancer patients is still a concern in Tanzania. Most studies done on AHT among breast cancer patients are quantitative and investigate the factors and impacts of non-adherence. Little is known based on individual patients' lived experiences with AHT which are described with qualitative studies. Therefore, this study aims at exploring the individual lived experience of AHT adherence among breast cancer patients on AHT.

1.2 Problem statement

Adjuvant Hormonal Therapy adherence among breast cancer patients has been a major challenge. There is an increase in the number of hormonal receptor-positive patients (40%) among Tanzanian women with breast cancer which renders treatment with AHT(15). AHT is prescribed after completion of primary treatment (surgery, radiation, and chemotherapy), at this time there is a reduced frequency of follow-up visits to cancer care and monitoring of patient adherence (9,26,27).Follow-up appointments should be planned every three months for the first two years after the start of AHT, every six months for the following two years, and once a year for the following six years (6). ORCI receives an average of 507 breast cancer patients who need cancer care annually. Out of these 88% attend their clinics as per scheduled regimen while the remaining 12% don’t (Tanzania ORCI Cancer Registry and Chemo Report book 2020). Among the factors contributing to not attending their scheduled visits are treatment side effects, distance from the cancer center, lack of knowledge of the importance of medication adherence, and forgetfulness.

Breast cancer patients with AHT experience alterations in different life domains including physical, psychosocial, and spiritual which are predictors of health outcomes (28). Most women try harder on their own to manage treatment side effects with minimal assistance

from healthcare providers, which may adversely affect adherence to treatment regimens (29,30). The prevalence of non-adherence to AHT among breast cancer patients in Tanzania is 12% (Tanzania ORCI Cancer Registry and Chemo Report book 2020). A total of 1973 (7.3%) deaths were reported making the disease the 4th leading cause of all cancer deaths in Tanzania (3). Several interventions such as routinely frequent follow-up, encouraging oncologist consultation rather than general practitioner Daily text messages, use of oncology nurses as navigators in assessing the possible barriers, and phone calls have been done as an attempt to improve AHT adherence (18,19,23). These efforts have shown limited success in improving adherence due to factors such as inconsistent follow-up and lack of personalized support. Non-adherence remains at 12% (Tanzania ORCI Cancer Registry, 2020).

Most studies done on AHT among breast cancer patients are quantitative and investigate the factors and impacts of non-adherence (12,13,15,16,31–33).In Tanzania, there are limited qualitative studies on patterns of individual's lived experiences on AHT adherence. A lack of understanding of individual patient's experiences throughout treatment may contribute to an increased burden of non-adherence. Due to the scarcity of information from previous studies in Tanzania, particularly ORCI which serves as a hub for cancer care in the country, this call for action to improve the adherence to adjuvant hormonal therapy among breast cancer patients. The current study aims to explore the patient’s lived experiences on AHT adherence among breast cancer patients, which will help identify different interventions to be employed by both patients and healthcare providers towards improving adherence to medications and promoting individualized patient care.

1.3 Theoretical framework

The Health Belief Model

This study was guided by Health Belief Model (HBM) which was developed during in the 1950s by Rosen stock (34). Its purpose was to provide insight into individual decision-making regarding health-related behaviors. Specifically, the HBM aimed to shed light on why people may or may not seek out health services, follow through with medical recommendations, or adhere to prescribed medical regimens.

The HBM outlines conditions and components determining an individual's psychological readiness to act on a specific health condition. This includes their perception of susceptibility to the condition, their understanding of the severity of the consequences of contracting the condition, and their evaluation of the proposed health action's feasibility and effectiveness. These perceptions are balanced against potential psychological and practical "barriers" or costs of taking action. Ultimately, a stimulus or cue, whether internal or external, is necessary to prompt the appropriate health behaviors (35)

HBM comes from a social psychological theory created by Lewin. He thought that two things influence behaviour: how important a result is to someone and how likely they think their actions will make it happen.

The HBM has four main parts that explain why people make health-related choices: how likely they think it is that they will get sick, how bad they think getting sick would be how much they think a particular choice will help them, and what problems do they think they might run into?

The model says what people presume is more important than what is "actually" happening around them. "what someone thinks are real matters more than what is real" (36).

Perceived susceptibility: This includes People's belief about the likelihood of experiencing a harmful condition. It is a subjective perception of the risk of contracting a particular condition (37).

Perceived severity refers to how much a person feels threatened by a medical condition. This includes how much the condition affects their life, such as the medical consequences

(disability, pain, disfigurement) and the social consequences (effects on family, work, and social relationships) (38)

These two dimensions make up the individual's psychological state of readiness to take action. "Action will not occur unless the individual believes in both personal susceptibility and the serious repercussions of illness, should it occur"(39).

Perceived benefits: Beliefs regarding the effectiveness of recommended actions make up the perceived benefits (40). An individual assesses the practicality and effectiveness of the recommended action in reducing the perceived threat.

Perceived barriers: When someone thinks about taking a healthy action, they might also think about the negative aspects associated with it. These negative aspects are called barriers. They can be related to money, physical ability, or feelings. In other words, barriers are beliefs that someone holds about the costs of taking a healthy action.

The model has been refined over the past years, and two additional concepts have been added to strengthen it further: health motivation and confidence. In 1974, Becker suggested adding the concept of health motivation to the model, which is an individual's degree of interest in and concern about health matters. People generally more aware of and interested in health are more likely to engage in healthy behaviours. The addition of confidence has been proposed as a separate independent variable (34) .Confidence is defined as "the belief that one can successfully execute a behaviour that will then lead to a desirable outcome." Confidence is equivalent to Bandura's self-efficacy construct (41). The addition of these two concepts has helped to enhance the effectiveness of the health belief model.

In putting the concepts together into a coherent whole, the combination of susceptibility and severity determines the impetus for action, while the perception of benefits and reduced barriers determines the preferred course of action. In addition, an internal or external cue is required to prompt action, with the necessary intensity of the cue varying inversely with an individual's psychological readiness.

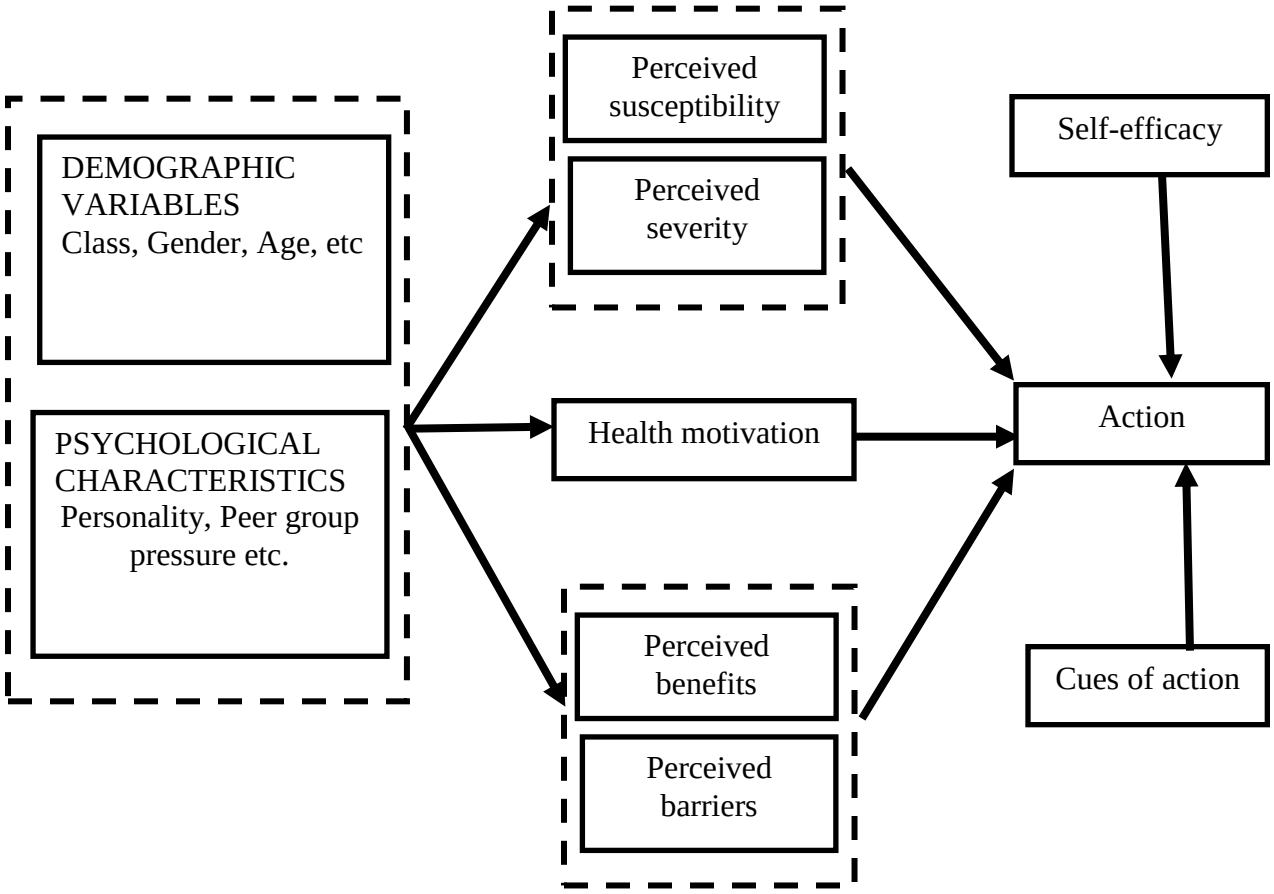


Figure 1: Health belief model

Conceptualization of the framework

To adhere to AHT, an individual's readiness depends on two psychological dimensions, (perceived susceptibility and severity of cancer recurrence). The severity of the illness and the individual's susceptibility to it should be understood before taking action.

The combination of susceptibility and severity is called the perceived threat, which is necessary to motivate an individual to adhere to AHT. Individuals will only take action if they believe in their susceptibility and the severe repercussions of illness (42).

The perceived benefits to AHT depends on individuals belief on efficacy of the drugs (43), example of perceived benefits to AHT are reduced chances of cancer recurrence

The negative aspects associated with the use of AHT are referred as perceived barriers; they may lead to poor adherence to AHT they include; the Desire for fertility among reproductive age survivors.

Additionally, there must be a stimulus or cue to trigger the action. Cues can be internal (i.e. body states, symptoms) or external (i.e. mass media, advice, reminder cards). The cue intensity needed to initiate action is inversely proportional to the individual's psychological readiness.

The present study used health motivation and confidence as indicators of knowledge. With health motivation as a reflection of one's level of awareness and confidence representing one's belief in one's ability to accomplish tasks and achieve goals (i.e. self-efficacy). Together, these two concepts provide an operationalization of knowledge, as shown in the figure below.

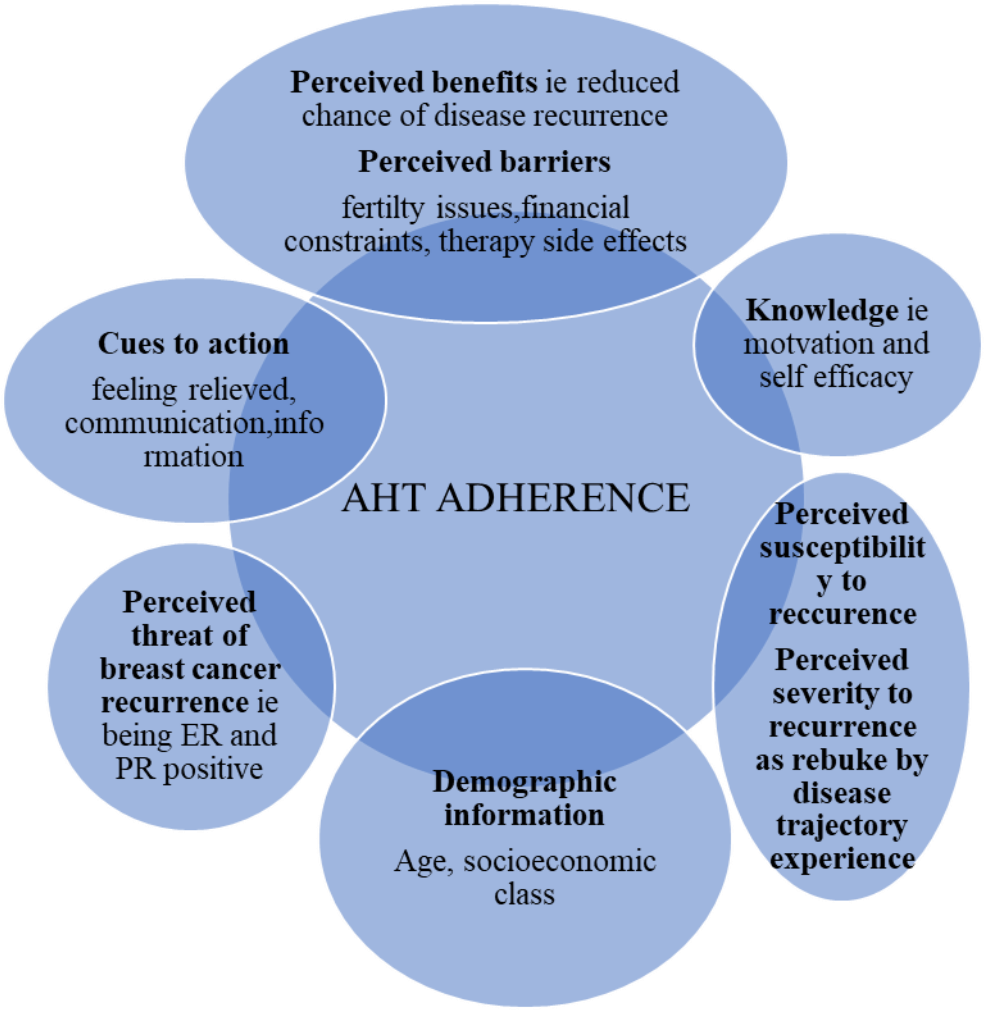


Figure 2: Modified Health belief model for AHT usage to reduce risk of breast cancer recurrence among breast cancer patients

1.4 Rationale of the study

Many breast cancer patients on AHT face a lot of challenges without seeking assistance, advice, and support from healthcare providers. This leads to an increasing number of non-adherence and treatment-related complications. The current study explored the patient's lived experiences on AHT among breast cancer patients at ORCI which serves as a hub for cancer care in Tanzania, it will help to identify different interventions to be employed by both patients and healthcare providers towards improving adherence to medications and promoting individualized patient care.

1.5 Research questions

1.5.1 Overall research question

The overall research question for this study was what is the lived experience on adjuvant hormonal therapy among breast cancer patients attending Ocean Road Cancer Institute in Dar es Salaam, Tanzania?

1.5.2 Specific research questions

1. What is the understanding of breast cancer patients on the benefits and side effects of adjuvant hormonal therapy at Ocean Road Cancer Institute in Dar es Salaam, Tanzania?
2. What are the facilitators to adjuvant hormonal therapy adherence among breast cancer patients at Ocean Road Cancer Institute in Dar es Salaam, Tanzania?
3. What are the barriers to adjuvant hormonal therapy adherence among breast cancer patients at Ocean Road Cancer Institute in Dar es Salaam, Tanzania?
4. What are the coping mechanisms employed by breast cancer patients on adhering to adjuvant hormonal therapy at Ocean Road Cancer Institute?

1.6 Study objectives

1.6.1 Broad objective

The main research objective of this study was to explore the lived experience on adjuvant hormonal therapy among breast cancer patients attending Ocean Road Cancer Institute in Dar es Salaam, Tanzania.

1.6.2 Specific objectives

1. To describe an understanding on the benefits and side effects of adjuvant hormonal therapy among breast cancer patients at Ocean Road Cancer Institute in Dar es Salaam, Tanzania
2. To describe the facilitators to adjuvant hormonal therapy adherence among breast cancer patients at Ocean Road Cancer Institute in Dar es Salaam, Tanzania.
3. To describe the barriers to adjuvant hormonal therapy adherence among breast cancer patients at Ocean Road Cancer Institute in Dar es Salaam, Tanzania
4. To identify coping mechanism employed by breast cancer patients to help them adhere to adjuvant hormonal therapy at Ocean Road Cancer Institute in Dar es Salaam, Tanzania.

CHAPTER TWO

2.0 LITERATURE REVIEW

Introduction

This chapter will review on difference studies conducted on the use of AHT among breast cancer survivors, it will narrate the findings concerning the lived experiences of breast cancer survivors on AHT from the specific studies and the recommendations given to improve adherence.

2.1 Overview

Adjuvant hormonal therapy (AHT) is the systemic therapy given to breast cancer patients with positive Estrogen and progesterone receptors; This includes Anastrazole for postmenopausal women and Tamoxifen for premenopausal women (6).

Treatment with AHT efficiently reduces the risk of disease recurrence and mortality after primary treatment of breast cancer (8,9). Despite the good impacts of AHT use, adherence to these medications is still low. A systematic review of 29 studies found that the prevalence of adherence ranged from 41-88% among Tamoxifen users and 50-91% for aromatase inhibitor users (44). Studies show 20-50% of all patients on AHT are non-adherers to their medications (8,10–13). Results from several studies concluded that adherence to AHT is suboptimal (8,9,13). A study in Ethiopia revealed that in every 2 women taking AHT, one does not adhere to the treatment regimen (15). Factors such as lack of information on medication side effects, older or younger age, burden of treatment side effects, lack of follow-up information, forgetfulness, lack of insurance, and lack of supportive relationship throughout treatment contribute to AHT non-adherence (8,9,13,15).

We can comprehend how medication affects patients' beliefs, actions, health, and well-being when we have firsthand experience with AHT (45). Patients and healthcare providers can make better judgments, maximize adherence, and achieve better therapeutic outcomes by incorporating this experience into clinical decision-making (46).

2.2 Understanding of adjuvant hormonal therapy

There is a definite need for knowledge regarding side effects and how to handle them (47). On the other hand, while the adverse effects of AHT are often less severe than those of other treatments, such as chemotherapy, it should be remembered that the duration of treatment with AHT is significantly longer, typically lasting five to ten years (48) this increases the effects of AHT on one's quality of life and contributes to poor adherence.

AHT presents a risk of several adverse effects, including menopausal side effects and sexual dysfunction, which can have a detrimental impact on a woman's day-to-day life (49). Musculoskeletal symptoms like pain all over the body (50–52), hot flashes and night sweats resulting to loss of sleep, general lack of energy, body image issues brought on by weight gain are some of the most common side effects related to physical health (53). Cognitive side effects like memory loss and concentration difficulties (54).

AHT is a crucial treatment for breast cancer survivors to prevent the recurrence of cancer (55). However, studies have shown that many survivors have limited knowledge about the benefits and side effects of this therapy(56–58). To ensure the effectiveness of the treatment, survivors must be well-informed about the purpose and duration of the therapy, as well as the potential side effects that may arise. They must adhere to the treatment regimen and receive regular follow-up care.

A recent cross-sectional study conducted in Europe aimed to assess the proportion and level of knowledge of breast cancer survivors regarding adjuvant hormonal therapy (59). The study included 1,000 breast cancer survivors who had completed adjuvant hormonal therapy. The findings of the study showed that 70% of the participants had a good understanding of the benefits of adjuvant hormonal therapy. However, only 50% of the participants had a good understanding of the side effects of the therapy. The study also found that younger survivors and those with a higher level of education had a better understanding of the therapy (59).

A Nigerian study has shown that a significant number of breast cancer survivors are not aware of adjuvant hormonal therapy. Only 38.5% of breast cancer survivors knew about the

therapy (60), while in Tanzania, there is scarcity of breast cancer survivors understandings of endocrine therapy. Therefore, it is crucial to educate breast cancer survivors about adjuvant hormonal therapy to ensure that they make informed decisions about their care and adhere to the treatment regimen. Breast cancer survivors who are undergoing adjuvant hormonal therapy should be well-informed about the purpose and duration of the therapy, as well as the potential side effects that may arise. They must adhere to the treatment regimen and receive regular follow-up care. To make informed decisions about their care, they should discuss any questions or concerns with their healthcare provider.

2.2.1 Facilitators to AHT adherence

A qualitative study done in Boston to explore the experience of women with early breast cancer on AHT, the role of treatment side effects, motivators and barriers towards adherence concluded that Patients want and require psychosocial support as well as skill development to manage the adverse effects of medications to ensure adherence and prevent breast cancer recurrence (53).

A systematic review from 24 qualitative studies identified that breast cancer patients adhered to their medication since they had no options and feared of cancer recurrence (47). Also emphasized on the value of assistance and education in helping them cope with treatment side effects and enhance their quality of life (47), In hand with this they felt that additional knowledge about the adverse effects and management techniques would aid them in sticking to and continuing with AHT (61,62). Several educational interventions have shown success in improving AHT adherence among breast cancer survivors. For instance, structured educational programs that include one-on-one counseling sessions, informational brochures, and multimedia resources about AHT's benefits, side effects, and management strategies have led to better adherence rates (63,64).These interventions can be tailored to meet individual needs, and studies have found that personalized education significantly improves patient understanding and engagement with their treatment plans (65,66). Furthermore, digital interventions such as mobile applications and online platforms have proven effective by providing reminders for medication intake and facilitating continuous

communication between patients and healthcare providers. Such tools help reduce forgetfulness and increase adherence (63,64). In addition to education on side effects, incorporating strategies like motivational interviewing and cognitive-behavioral techniques have been effective in helping patients navigate emotional barriers and empowering them to stay on track with their medication regimen (78). This emphasizes how crucial patient education is, in the initial phases of therapy. For this reason, it's critical to offer women enduring AHT side effects evidence-based assistance (67).

2.2.2 Barriers to AHT adherence

A 10-year period of taking AHT among breast cancer patients is overwhelmed with alterations in physical, social, psychological, and spiritual perspectives of life (28). These have an impact on adherence to the medication hence increasing the risk for disease recurrence and mortality (13,16,17). lack of information on medication side effects, older or younger age, burden of treatment side effects, lack of follow-up information, forgetfulness, lack of insurance, and lack of supportive relationship throughout treatment contribute to AHT non-adherence (8,9,13,15).

One of the issues with AHT adherence is the belief and perception of medicine efficacy. Some women have skepticism and unfavorable opinions about the effectiveness of the drugs, which makes them less motivated to follow through (43). According to findings from a Chinese study on patients' adherence to AHT, those with poor adherence did not even realize that endocrine therapy was necessary; instead, they thought that their breast cancer had healed and that the oral pills had no use (43). Additionally, another study concluded on the perceived importance of AHT in reducing their risk of developing recurrent breast cancer which was reported by both Black and White women in Chicago (68).

A study done in Chicago reported on the desire for future fertility among premenopausal women, and concern negatively on medication adherence (69). This renders fertility preservation measure options for these women to comply with their medication schedules.

An increase in hospitalization frequency is one of the factors that were shown to make patients less likely to stick with their treatment plan (70).It is mostly seen in older age patients greater than 65 years since they have an increased risk for concomitant comorbidities such as depression, osteoporosis, and diabetes as reported in a study done in Germany investigating age-related differences in Tamoxifen adherence (71).

Social support is an important aspect of patients receiving AHT. A study conducted in Northern California found that women with low levels of personal social support were less likely to adhere to AHT, whereas high levels of support seemed to reduce the probability of non-adherence (72).

Adherence behavior is challenging among Patients with pre-existing depressive disorders, this is associated with the use of hypnotic and sedative agents which may impair patient's cognitive abilities in making decisions and following through with the medications regimen (73,74).

Adverse effects can have a significant impact on quality of life, and it was discovered that persons with more severe symptoms that impact their quality of life are more likely to fail to adhere (75).

2.3 Coping mechanism to enable AHT adherence

AHT side effects are common among breast cancer survivors and are the leading factor affecting treatment adherence (67). Most women try harder on their own to manage treatment side effects with minimal assistance from healthcare providers, which may adversely affect adherence to treatment regimens (29,30). They frequently employ a variety of techniques that may not be supported by research to self-manage the adverse effects of AHT (76). Among the reported strategies are involvement in physical activity for women experiencing fatigue, weight gain, and musculoskeletal adverse effects from treatment, relaxation therapy and use of supplements for women experiencing hot flushes, the use of vaginal lubricants for those experiencing vaginal dryness (77–79).

The necessity for AHT feels more urgent among women struggling with the fear of cancer recurrence. Focus groups conducted by J Van Londen revealed that women taking adjuvant Hormonal Therapy felt it was necessary for their future health but experienced unanticipated symptoms, leading to uncertainty about their decision and dissatisfaction with their healthcare providers (29).

Self-actualization in patient-provider interactions creates a favorable environment for asking questions and understanding the information given regarding treatment and treatment side effects (80), additionally, the perceived importance of using the medication among women with breast cancer aids in coping with different challenges experienced during treatment, especially the intolerable treatment side effects and valuing the opinions and different instructions given by the healthcare providers regarding the medications (68). A study conducted in Ethiopia on adherence to AHT and associated factors concluded that good therapeutic communication between patients and the healthcare provider about their treatment improved treatment adherence 4.6 times as compared to those with no thorough therapeutic communication (15).

2.4 Summary

Breast cancer treatment has significantly advanced with the use of AHT, yet many women struggle to stick to the recommended 5-10-year treatment plan, which can negatively impact their chances of survival. Improving adherence to AHT is critical for enhancing treatment effectiveness and patient outcomes however many survivors have limited knowledge about the benefits and side effects of this therapy. Although some factors influencing adherence have been identified such as lack of information on medication side effects, older or younger age, burden of treatment side effects, lack of follow-up information, forgetfulness, desire for future fertility and lack of supportive relationship, it's crucial to investigate the experiences and views of breast cancer survivors to develop supportive strategies that will help them remain committed to these therapies and maintain their quality of life.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study design

This study employed phenomenological design using qualitative approach. Phenomenological design refers to a philosophical framework as well as a methodology that can inform educational practice and research (81). It seeks to reveal and understand how phenomena may be experienced as they are actually lived in the everyday world, or what some phenomenologists refer to as the lifeworld (82). Phenomenological philosophy suggests that everything in the lifeworld is inextricably connected in a social context, and so phenomenology aims to be more attentive to such meaningful connections or intentional relations within lived experiences and to illuminate them as a means to deeply understand the experience of the phenomenon under focus (83). This design was chosen because it helped to gain thick and deep understanding of lived experiences of breast cancer survivors on AHT, including factors influencing medication adherence and the coping mechanisms employed to different challenges faced on adhering to medications.

3.2 Study area

This study was conducted at ORCI outpatient clinic. ORCI is a tertiary public cancer treatment hospital located in Dar es Salaam, Tanzania around 200 meters from the beach. It offers comprehensive cancer care services to patients in Tanzania and the surrounding region such as Malawi, Zambia and Congo. ORCI offers inpatient and outpatient services including laboratory services, diagnostic imaging, chemotherapy, radiation therapy, palliative care services and screening services for cancer and HIV/AIDS. It has 8 Departments (clinical oncology, Pharmacy, Nursing, Laboratory, Radiology and imaging, medical physics, radiotherapy technology and palliative care) with the bed capacity of 219. There are 110 nurses and 21 Clinical oncologists (84).

Breast cancer is one of the most common type of cancer treated at ORCI, with approximately 13% reported in 2018 (85). More than half (51%)of the breast cancers cases at ORCI are hormonal positive (86).

ORCI has been providing endocrine therapy for breast cancer patients since the early 2000s, which has been an integral part of the center's comprehensive treatment plan. ORCI receives around 200 breast cancer survivors each month, with the most common subtype being Luminal A (50 survivors), followed by Luminal B (30 survivors), HER2-enriched (20 survivors), and Triple-negative (10 survivors) subtypes.

ORCI's dedicated breast clinic provides routine follow-up visits for breast cancer patients who have completed their treatment, including physical exams, mammograms, and other diagnostic tests to monitor their ongoing health. The frequency of these visits varies, but typically, patients are seen every three months for the first two years after the start of AHT, every six months for the following two years, and once a year for the following six years.

3.3 Target population

Breast Cancer survivors on AHT in Tanzania. Cancer survivors are individuals diagnosed with cancer, on cancer treatment and who has completed cancer treatment (87). Survivorship encompasses a cancer journey from diagnosis to the end life (87). This population included pathologically confirmed disease with positive ER/PR status and treated with chemotherapy/radiation or surgically, with a current or previous prescription for AHT for at least one year. The hormonal therapy lived experience study targeted breast cancer survivors in Tanzania on AHT to gain insights into their unique experiences and challenges with this treatment. Focusing on this population in a specific cultural context provided an insight in the development of more effective treatment and support strategies.

3.4 Study population

Breast Cancer survivors who were on regular clinical follow-ups and continuing with AHT at ORCI in Tanzania.

3.5 Inclusion criteria

Patients aged 18 years and above who have been receiving AHT at ORCI at least for 1 year participated in this study.

3.6 Sampling and sample size

The study used purposive sampling to select breast cancer survivors on AHT at ORCI. This selection technique's primary objective was to choose participants who will best help the researcher address the study objectives (88). The purposive selection aimed to ensure a diverse sample of breast cancer survivors in terms of socioeconomic status, age, cancer stage, and socioeconomic background. Lists of patients who attend breast cancer clinic were obtained from the unit in-charge. After that, the researcher spoke with each potential informant one-on-one in order to secure their consent to participate. Participants were selected based on specific criteria such as age, cancer stage, pathologically confirmed disease with positive ER/PR status and treated with chemotherapy/radiation or surgically, with a current or previous prescription for AHT for at least one year (whether currently using AHT or stopped).

The estimated sample size was 15 interviewees who were using AHT selected from breast cancer clinic. However, the process of data collection ended at the 12^{th} interviewee where the researcher had collected enough data to fully understand the experiences and perspectives of the participants about the research questions, at this point there was no any new information gained or emerged from the interviewees. This was guided by the principle of saturation in qualitative research by indicating the point at which collecting more data is unlikely to yield new or different information (89). Experience was explored to a diverse range of socioeconomic and demographic background among the survivors to ensure a diverse sample. Majority of recruited participants fallen in the 35+years category and only one participant aged 34 was obtained, therefore experience was further explored considering the type of AHT used and years to which the participant has been using the therapy.

3.7 Data collection tool

The tool for data collection was a semi-structured in-depth interview guide. The individual face to face interview method was used to collect information from study participants. The interview guide was adapted to fit the context of this study from similar like this thesis in Ethiopia (90)**.** The study in Ethiopia focused on Breast Cancer patients adhering to Endocrine Therapy, examining their journey from diagnosis to treatment.

The interview guide was translated into Swahili, to make the questions clear and understandable as it is the common language spoken by majority of study participants. The interview guide was divided into two parts. The first part was demographics such as age, employment status, and residence. The second part consisted of eight main questions and related probes exploring lived experience adjuvant AHT. The questions explored the understanding on breast cancer including the risk factors and management, adherence to medication schedule, including missed doses and challenges faced while adhering to the schedule, descriptions on the understanding of treatment side effects, how it has affected their daily life also the coping mechanism and suggestions to improve AHT adherence.

In addition, field notes were taken during the interviews to capture non-verbal cues and contextual information that were no captured in the audio recording. The field notes were written in a structured format, with sections for recording the date, time, location, and other relevant details about the interview.

3.8 Data collection methods

Data collection at the breast cancer clinic was the researcher's responsibility; participants were selected based on eligibility criteria from the attendance register. The PI purposively selected participants and provided them with an explanation of the study's purpose and associated risks, as well as the freedom to withdraw consent at any point during the interview (consent form appendix I). Participants were asked to sign a consent form before moving to the interview room, where the face-to-face, in-depth interviews were conducted for 16-55 minutes. The interviews took place in a cool room within the clinic where they were minimal interactions with the routine activity of the clinic which ensured participant’s

comfortability and privacy on the provided information, with the principal investigator (PI) pre-reviewing patient records to ensure compliance with inclusion criteria. The interviews were conducted face-to-face in a private room, following the signing of a consent form. A guide containing probing questions facilitated the in-depth conversation between the interviewer and the participant. The interviewer actively listened to the participant's responses and asked follow-up questions to understand their experiences and perspectives better. The interview was conducted respectfully and professionally to ensure participants feel comfortable sharing their thoughts and feelings.

3.9 Data management

In order to guarantee the privacy and security of the data gathered, all audio recordings and transcripts were stored in a password-protected computer folder that is only accessible by the researcher. Hard copy notes were kept in researcher's file. To ensure the quality of the data gathered, the researcher listened to, transcribes, and analyzed the audio-recorded interview. This assisted the researcher in finding any material that was lacking and enhancing the interview guide as they go.

3.10 Trustworthiness

Qualitative research is a powerful tool for gaining insights into complex phenomena. However, to ensure that the findings are trustworthy and reliable, the researchers adhered to four key elements of trustworthiness: credibility, transferability, dependability, conformability. By giving the interviewees ample time to establish a rapport, get more information from the field, and speak to them in their own language (Kiswahili), the researcher gained the trust of the informants.

3.10.1 Credibility

Is essential for ensuring the study's findings are believable and trustworthy. In a study exploring breast cancer survivors on endocrine therapy, credibility was achieved by carefully selecting participants based on specific criteria, prolonged engagement in the field to build trust with the participants and gained deeper understanding of the context and phenomena under study.

3.10.2 Transferability

Ensures the study's findings can be applied to other contexts or settings. In this breast cancer survivor study, transferability was achieved through a detailed description of the study context, selecting participants that were information rich, data collection methods and clear documentation of research process.

3.10.3 Dependability

Ensure consistency and stability of the findings over time. In breast cancer survivor study, dependability was achieved using consistent data collection and analysis methods. Researcher kept a detailed audit trail of the research process to ensure the findings are replicable and dependable. Also, the researcher discussed with the supervisors on the codes and agreed on the appropriate codes to use. When there was inconsistency in coding, and the whole process of analysis a discussion was held, and consensus was reached.

3.10.4 Conformability

Critical for ensuring the study findings are free from researcher bias. In this breast cancer survivor study, conformability was achieved by allowing the same data coded at different times or by different researchers to check for consistency in the coding process, also the researcher maintained a detailed audit trail of all the research decisions, data collection processes, and data analysis steps. This includes raw data, field notes, coding processes, and any other documentation that shows how data were collected and analyzed.

3.11 Data analysis

The audio recorded interviews were transcribed verbatim in Swahili and transcripts were reverse translated into English by principal investigator. The researcher started by familiarizing with the data set to gain deeper understanding of the participant’s experiences. This was done without the researcher pre imposing her ideas about the subject under study. Framework analysis was developed. All the important data were captured and presented in Microsoft excel sheet which made the analysis process easier and efficient. Data were analyzed using inductive and deductive thematic analysis (91).

The codes were identified independently from each transcript according to the aim of the study. The principal investigator discussed with the supervisors on the codes and agreed on the appropriate codes to use. When there was inconsistency in coding, a discussion was held, and consensus was reached. The principal investigator stayed close to the text to achieve more concrete description and abstraction.

Table 1: Coding process

Interview excerpt	**Codes**
There is a feeling of nausea, and you can vomit too. You get numbness and they also prevent you from getting your period, and they also make you infertile. Because you don't get your period	• Nausea • Vomiting • Numbness • Missed periods

After generating codes; the pattern of codes, words and sentences containing aspects related to each other and had similar meaning were grouped together to form subthemes with which they were sorted and abstracted into pre-determined themes from research objectives and the theoretical framework (deductive reasoning) ensuring that they closely reflect the experience of the participants as shown in table 2 below.

Table 2: sub-theme and theme generation

Codes	**Sub-theme**	**Pre-determined theme**
Nausea	Understanding of AHT Side effects	participants understanding on AHT side effects
Missed periods		
Numbness		
Vomiting		

3.12 Ethical Considerations

Ethical approval was obtained from the Research and Ethics Committee of the Muhimbili University of Health and Allied Sciences (MUHAS). Permission to conduct research at ORCI was obtained from ORCI teaching and research unit. All participants were recruited after signing an informed consent form which provided details of the right to participate and withdraw from the study, risks, benefits, and an audio recording of the interview. Informants' identities were treated anonymously and confidentiality was ensured by the researcher throughout the study.

CHAPTER FOUR

4.0 RESULTS

4.1 Introduction

This chapter describes experience of study participants with regard to adherence to AHT. It includes participant's socio demographic information followed by their experience particularly on understanding on AHT, facilitators and barriers to AHT adherence, coping mechanisms and recommendations on AHT use.

4.2 Participants demographic information

This study included a total of twelve (12) informants in which nine (9) were married. Out of 12 participants nine (9) had primary level of education, with eight (8) of them diagnosed with stage 2 breast cancer and aged 40-54 seven (7) participants were living in Dar-es-salaam while the others were upcountry. Employment status was dominated with unemployed participants (8) since most of them lost their jobs and capacity of doing especially the manual work which requires physical energy and strength due to disabilities they acquired through their treatment journey especially those undergone mastectomy. Only one (1) participant did not undergo this treatment modality. Among twelve (12) participants nine (9) were using Tamoxifen who were in pre-menopausal stage all while only three (3) participants were using Anastrazole as their hormonal therapy since they had reached menopauses. All study participants were currently using their medications and attends their follow up clinics as scheduled. See table 3 below

Table 3: socio-demographic characteristics of participants (Breast cancer patients on AHT)

S/N	Age	Employment status	Marital status	Treatment received		Years on AHT	Type of AHT
				Surgery, chemotherapy, radiation	Chemotherapy and radiation		
P1	34	Employed	Married	√		3	Tamoxifen
P2	54	Unemployed	Married	√		1	Anastrazole
P3	48	Unemployed	Married	√		6	Tamoxifen
P4	49	Employed	Married	√		4	Tamoxifen
P5	50	Unemployed	Widow	√		6	Tamoxifen
P6	61	Unemployed	Widow	√		3	Anastrazole
P7	43	Unemployed	Married	√		2	Tamoxifen
P8	59	Unemployed	Married	√		5	Tamoxifen
P9	45	Unemployed	Single	√		2	Tamoxifen
P10	48	Unemployed	Married		√	1	Tamoxifen
P11	52	Employed	Married	√		1	Anastrazole
P12	39	Employed	Married	√		6	Tamoxifen

Table 4: Themes and corresponding sub-themes Emerged from interview

THEMES	**SUB-THEMES**
Participants understanding on AHT	a) Benefits of AHT b) side effects of AHT
Facilitators to AHT adherence	a) Family support and personal initiatives b) Encouragement from healthcare providers c) Desire to live long; disease free
Barriers to AHT adherence	a) Reported side effects associated with AHT medications b) Cancer treatment with AHT is costly c) Desire for future fertility
Coping mechanisms employed by breast cancer patients to Adherence to AHT	a) Medication switching on and off strategies b) Measures used to overcome AHT side effects c) Surveillance and follow-up d) Employing medication Adherence behaviours

1. Participants understanding on AHT

The participants were asked to say what they understand about the benefits and side effects of AHT. Two sub-themes emerged from this pre-determined theme; a) understanding on benefits of AHT and b) understanding on side effects of AHT**.**

a) Benefits of AHT.

Participants stated that AHT helps to prevent cancer from returning and spreading, they also reported that the medication helps in maintaining hormonal balance this is evident from the following participant's excerpt.

"My understanding is that this drug helps to prevent cancer from recurring, they prevent hormones from being too much in the body. Because they told me that my cancer is caused by too many hormones" (P12)

Additionally, participants shared on their improved wellbeing with the use of AHT and expressed that the medication is their protection against cancer recurrence. A participant narrated:

"Since I'm doing well, I understand the medicine; I use it as my protection so that cancer doesn't come back. And yes, the doctor has told me that. Its biggest advantage is that the disease does not recur" (P5)

Despite of the elaborated benefits of AHT few participants reported on just taking the medication but they don't know what it helps or what will happen when they stop using them, they further expressed of being afraid to ask the HCP on the medication they are being given.

"The doctor didn't explain it to me well, he just told me that there are medicines that you will continue to take for five years and you are not allowed to stop them, you have to use one pill every day and I told him ok. I didn't find the instructions maybe what they help or what they do and I couldn't ask the doctor too much because sometimes you become afraid" (P2)

b) Side effects of AHT.

Most participants reported on the side effects that one may experience nausea and vomiting, numbness and missed periods. One respondent expressed:

"There is a feeling of nausea, and you can vomit too. You get numbness and they also prevent you from getting your period, and they also make you infertile" (P9).

They further reported on the possibility of experiencing anger, feeling sad and sometimes crying as stated below.

"They can make me get angry; at other times I can just cry a little" (P11)

Additionally, they described that AHT may cause reduced sexual desire, vaginal dryness and irregular periods.

"They told me I will experience reduced sexual desire; I will find myself drying up to my private parts and I will no longer see my periods" (P1)

Interestingly, some participants also reported on experiencing an increasing force and demand to meet their partners sexually; they reported that this condition was not there before. A participant said:

"I often experience increased sexual urges, but I think it's due to the drugs I'm taking. I may find myself wanting to meet my partner; it may come at a different speed than how I used to be" (P2)

2. Facilitators to AHT adherence

Participants were asked on the things motivated and helped them continuing taking their medications. Three sub-themes emerged; a) Perception of AHT benefit b) Family support and personal initiative c) Encouragement from HCP

a) Desire to live long; disease free.

Participants mentioned on continuing taking medications and believed it extends their lives, therefore they feel motivated to continue taking medications.

"Knowing that sticking to my treatment could extend my life gives me the strength to continue"(P12).

Similarly, another participant expressed of continuing taking her medication by fearing cancer recurrence.

"*The fear of cancer returning pushes me to continue taking my medications"(P1)*

b) Family support and personal initiatives.

Participants expressed that their family members insisted them to continue taking medication and when they forget to take medications they were reminded. A respondent said:

"*My husband reminds me to take my medication" (P7)*

Furthermore, one participant reported on putting her medication under the pillow so that she takes them every morning while awaking ensuring she don't miss the medications.

"I put my pills under my pillow so that I could take in the morning every day to ensure I don't miss my doses"(P11).

c) Encouragement from healthcare providers.

Participants reported that they were told by their healthcare providers (HCP) to continue taking their medication so as to prevent cancer spread and therefore, they stick to the advice given.

"*My doctor told me that continuing my medication is crucial to prevent the cancer from spreading, and that advice stays with me"(P9).*

Similarly, another participant stated on continuing taking her medications after hearing from the healthcare provider that cancer may recur if she doesn't take medications as instructed.

"Hearing from my healthcare provider that non-adherence could lead to a recurrence make me vigilant about my treatment"(P5).

3. Barriers to AHT adherence

In this theme participants were asked to share the barriers they encountered towards adhering their medications. Three sub-themes emerged; a) Reported side effects associated with AHT b) cancer treatment with AHT is costly c) desire for future fertility

a) Reported side effects associated with AHT

Participants reported on experiencing nausea, loss of appetite, and excessive tiredness which made them stop taking medications and fail to do their daily activities.

"If I take my medications continuously, I feel tired, I can't even do my work well, I feel dizzy, my whole mouth is sore, and I feel completely tired so I stop taking them" (P5)

Meanwhile, they expressed on feeling hotness all over the body, decreased desire to satisfy their partners sexually, and excessive sleeping caused discomforts and made them stop taking medications. A participant said

"I was feeling very bad, my body is on fire, sometimes I put this cold water in the tub and then I step on it, there is no peace, I use to stop taking medicine when the side effects are severe" (P8).

b) Cancer treatment with AHT is costly

Participants expressed of not taking medication that she faces difficulties to afford medications due to the price.

I have to pay ninety thousand to get three boxes, now I fail. I have not taken the medication for like three months ago" (P9)

They further narrated that they don't come to take medications at hospital since medications are expensive at hospital settings and cheaper to local street pharmacies.

"I can't come to take medications at this hospital the cost is high, so I have to go to pharmacies at the Streets. I can get it there for a cheaper price" (P9)

c) Desire for future fertility

Most of pre-menopausal participants said that the medication will cause them not to have children in their life because they don't see their days anymore, they expressed that sometimes they used to stop taking medication because they want to have children.

"I want to have a baby, what will happen if the period has stopped and I have been using these drugs for about five years, will it really be possible. So, some days I plan to stop the medicine" (P4)

4. Coping mechanism to Adhere to AHT

Participants were asked to share different mechanism they employ so as to stick to their treatment regimen. Six sub-themes emerged namely: a) Switching on and off strategies b) Measures used to overcome side effects c) surveillance and follow-up d) Medication Adherence e) Perceived benefits of AHT.

a) Medication switching on and off strategies

Participants reported on stopping taking medications because of experiencing body pain, excessive tiredness and feeling of hotness all over the body while taking the medications. They reported to resume on their medications when they feel they need to live and continue caring their children. A participant said:

"Sometimes I decide to stop taking medication because of the problems I get from those pills. I can stay for a week without taking it.so I sit and think but this is my therapy, heee! I want to live; I have my children and I am raising them. So, I take it again" (P8)

b) Measures used to overcome side effects

Measures used to overcome AHT side effects is another significant sub-theme. A Participant shared that she used to stay alone and avoided talking to people when she was feeling pain as narrated below:

"I was feeling pain, I don't even go outside if I go outside, I don't like the weather outside so I go back inside. I don't even want to talk to people; I see trouble and stay by myself." (P8)

Participants further expressed; stepping on cold water when they felt their body was on fire and others tried to insert their fingers in the throat to induce vomiting when they had a feeling to vomit.

"When I feel like vomiting, I pass my finger into my throat to induce vomiting but nothing comes out" (P2).

"I was feeling very bad, my body is on fire, sometimes I put this cold water in the tub and then I step on it" (P8)

Moreover; participants reported they had nothing to do with the side effects they were experiencing rather they stayed still and used to pray for relieve of the symptoms.

"There is no way to stop the side effects I just stay still and pray to the almighty God for relieve" (P3)

c) Surveillance and follow-up

Participants reported on being tested while attending their regular clinics, they were told that they are doing well. They believed that the medication improves their wellbeing:

"Every time I get tested, I am told that I am doing well, every time I do clinical tests I am doing well until now I have been out for three months, I have been told to come every six months, so I believe that I am doing well." (P6).

d) Employing medication adherence behaviours

Participants reported on preferring taking their medication during evening time, they demonstrated on forgetting to take the medication at other times during the day as stated below:

"I like to take the medicine in the evening. If I say morning or afternoon I forget, so I like to take it in the evening" (P10)

Another participant reported on waking up at late night to take forgotten medication after falling asleep. She said:

"There was a day when I fell asleep and woke up late night and took the medication" (P7).

CHAPTER FIVE

5.0 DISCUSSION

5.1 Discussion

Adjuvant hormonal therapy (AHT) is recognized for its critical role in preventing breast cancer recurrence and maintaining hormonal equilibrium, despite its associated side effects. Adherence to AHT is facilitated by personal initiatives, familial and healthcare support and desire to live long disease free. Treatment side effects, medication cost and desire for future fertility are the barriers towards AHT adherence. Patients employ various coping strategies to manage AHT, such as medication switching and off strategies, dealing with side effects, surveillance and follow-ups, employing adherence behaviors to medication and often relying on healthcare guidance. A comprehensive approach to AHT involves diligent medication management coupled with strong emotional and psychological support systems, emphasizing the importance of integrating treatment into daily life, informed decision-making, and the support of family and personal beliefs for overall well-being.

5.1.1 Understanding on AHT

The study's findings reveal a clear comprehension among participants regarding the advantages of adjuvant hormonal therapy. This understanding is pivotal, as it underscores the therapy's role in enhancing treatment outcomes for hormone-responsive conditions. By situating these findings within the broader context of medical research, it becomes evident that this awareness could lead to increased adherence to treatment protocols, a critical factor often highlighted in literature as a determinant of therapeutic success (92). Moreover, the study echoes the sentiments of prior research, which has consistently advocated for patient education as a means of optimizing treatment efficacy (93,94). The implications of these findings are significant, suggesting that informed patients are more likely to engage with their treatment plans actively, thereby potentially improving their health outcomes. This insight not only contributes to the existing body of knowledge but also underscores the importance of patient education as a cornerstone of effective healthcare.

5.1.2 Facilitators to AHT adherence

The perception of the benefit of AHT and desire to live long critically influences patients' adherence. When patients have a clear understanding of how AHT can improve their prognosis, they are more likely to adhere to their treatment regimen. Comparing with previous studies, the result is similar as previous studies have emphasized education plays a crucial role in shaping this perception, as well-informed patients can make empowered decisions about their health (15,95,96). Healthcare providers must, therefore, prioritize patient education and open dialogue to reinforce the importance of AHT and its role in the broader context of breast cancer management.

Family support is an indispensable factor in the adherence to AHT. The emotional, physical, and sometimes financial support provided by family can significantly ease the burden of ongoing cancer treatment. Previous studies have reported that this family support, a supportive family environment can enhance a patient's resilience and adherence to treatment by providing encouragement, assisting with medication management, and attending to the patient's emotional well-being during this challenging time (97–99).

Information from HCP is pivotal in influencing AHT adherence. The trust and rapport between patients and their healthcare providers can greatly affect treatment decisions. The findings of our study is similar with others which have reported that providers who communicate effectively, show empathy, and offer tailored advice can foster an environment where patients feel supported and understood (100–102). This relationship is fundamental to ensuring that patients follow through with their prescribed AHT regimen, as it can provide them with the confidence and reassurance needed to navigate their treatment journey.

5.1.3 Barriers to AHT adherence

Reported side effects are a primary concern affecting adherence to adjuvant hormone therapy (AHT) in breast cancer patients. The spectrum of these side effects can be broad, ranging from discomforting to debilitating, and their impact on daily living can be profound.

Patients who experience severe side effects may find themselves weighing the benefits of AHT against the quality-of-life disruptions they endure. This findings is in line with prior studies that has found that balancing act between taking medicine and side effects is delicate and personal, often requiring adjustments in treatment plans and supportive care to mitigate adverse effects and maintain the patient's commitment to therapy (103,104).

Financial concerns constitute another significant barrier to AHT adherence. The cost of medication and the associated care can be a heavy burden, particularly in the absence of adequate insurance coverage or in low-resource settings. The financial strain can lead to stress, which may compound the already challenging situation of managing a breast cancer diagnosis and treatment. Ensuring that patients have access to financial resources and support is essential to prevent cost from becoming a prohibitive factor in adherence. This study is in hand with the study conducted in Nigeria which involved 225 breast cancer patients to establish common reason for non-adherence to treatment; the study reported that non adherence rate was 80.9 % while financial difficulties accounted 45% (105)

The desire for future fertility represents a significant barrier to the adherence and acceptance of AHT in premenopausal women. They often face the dual challenge of addressing their immediate health needs while considering long-term life goals, including the potential for future childbearing. This finding underscores the complexity of treatment decision-making processes in this demographic and highlights the need for a nuanced approach to patient counseling and management. This study findings is in hand with a study done in Chicago which reported on the desire for future fertility among premenopausal women concerned negatively on medication adherence (69).

5.1.4 Coping mechanisms employed to adhere to AHT

The study highlights strategic medication management as a critical coping mechanism, where patients meticulously plan and execute their medication regimens. This finding is interpreted as a proactive measure to maintain treatment efficacy, aligning with literature that emphasizes the importance of adherence in therapeutic success (102,106,107). The

context of chronic disease management provides a backdrop for understanding these behaviors, suggesting that such strategies are not unique to breast cancer patients but are common across various long-term conditions (108). Healthcare systems must prioritize support for strategic medication management to improve patient outcomes.

Measures used to overcome side effects are identified as a significant aspect of patient experience during hormonal therapy. This finding reflects the reality of the physical and psychological challenges patients face, which is consistent with literature on the impact of side effects on treatment adherence (102,106,107). The broader context of patient quality of life provides a lens through which these coping strategies can be understood, highlighting the need for comprehensive care approaches that address side effects. The implication for practice is the necessity of developing supportive interventions that can mitigate the adverse effects of treatment.

Surveillance and follow-ups emerge as a vital self-management strategy, with patients actively involved in tracking their health indicators. This finding interprets patient engagement as a key factor in detecting deviations from expected health trajectories, resonating with literature on the benefits of patient involvement in health care. The context of proactive health management frames these behaviors, connecting them to broader discussions on patient empowerment (109,110). The implication is the potential for improved health outcomes through enhanced patient-provider communication and collaborative care planning.

Routine integration of therapy into daily life is found to facilitate adherence, highlighting the importance of consistency in treatment administration. This finding interprets routine as a psychological anchor that supports patients in maintaining their treatment schedules, which is supported by literature on the psychological benefits of routine in chronic illness management. The context of daily life challenges underscores the practicality of this coping mechanism, linking it to the necessity of adaptable treatment plans. The implication is that treatment protocols should be designed with the flexibility to fit into patients' diverse lifestyles.

Finally, the support from healthcare providers is crucial in guiding patients through their treatment journey. This finding interprets the provider's role as multifaceted, offering both education and emotional support, which is corroborated by literature on the importance of a strong patient-provider relationship. The context of healthcare delivery systems provides a framework for understanding the impact of provider support, connecting it to the wider goal of patient-centered care. The implication is a call for healthcare systems to enhance the capacity of providers to offer personalized, empathetic support to patients.

The study underscores the significance of a comprehensive approach to adjuvant hormonal therapy in breast cancer patients, emphasizing not only the precision in medication management but also the necessity of a strong support system. It echoes the sentiment that informed decision-making and consistent medication routines are bolstered by familial involvement and personal belief systems. This research aligns with broader literature that advocates for a multifaceted treatment strategy, integrating medical, emotional, and mental health considerations (108). The implications suggest that such an approach could lead to improved patient outcomes and adherence to treatment protocols.

5.2 Strength

The study shed light on local context on how Hormonal therapy affects patient’s quality of life which is an essential consideration in treatment planning and patient support services.

5.3 Study limitations and mitigations

The limitation of this study is the potential for bias, the researcher’s background and beliefs can have an influence on interpretation of participant’s experience.

The researcher set aside preconceptions to reduce bias, encourage more on exploration of participant’s experience, also ensuring diversity and representation as sampling strategy which aided the richness of data.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

The study conclusively demonstrates that while adjuvant hormonal therapy (AHT) is a critical component in the management of breast cancer, ensuring adherence to treatment is multifaceted and requires a comprehensive approach. The benefits of AHT in preventing recurrence and maintaining hormonal balance are well-understood by participants, but adherence is influenced by a complex interplay of side effects, financial constraints, desire for future fertility, personal initiatives and familial support, and healthcare guidance. Patients have developed various coping strategies to manage the therapy effectively, which includes meticulous medication management and leveraging support systems. The dual approach of combining medication management with support for overall well-being, as recommended by patients, underscores the necessity of a holistic treatment model. This model not only addresses the medical aspects of breast cancer treatment but also the emotional, mental, and social factors that contribute to a patient's quality of life. Therefore, it is imperative that healthcare providers foster an environment that supports informed decision-making, routine medication integration, and provides robust support systems to enhance adherence and patient outcomes in breast cancer treatment.

6.2 Recommendations

To enhance adherence to adjuvant hormonal therapy (AHT) and manage its side effects, the following are the practical recommendations

i. Developing a comprehensive education program for patients, detailing the importance of AHT in preventing cancer recurrence, managing hormonal balance, and outlining potential side effects.
ii. Establishing a financial assistance plan to help patients afford their medication, thereby reducing the financial burden and improving adherence.
iii. Introducing a medication management app that helps patients track their medication schedule, side effects, and appointments, which can also provide reminders and educational material.

REFERENCES:

1. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global Cancer Statistics 2020 : GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. 2021;71(3):209–49.
2. Lyon F. Cancer in sub-Saharan Africa : building local capacity for data production , analysis , and interpretation. 2022;2045(313):4–5.
3. Globocan. 445 405 578. 2020;560:2020–1.
4. Wilkinson L, Gathani T. Understanding breast cancer as a global health concern 1 1. 2022;(October 2021):7–9.
5. Stanisławek A. Breast Cancer—Epidemiology, Risk Factors, Classification, Prognostic Markers, and Current Treatment Strategies— An Updated Review. 2021;1–30.
6. Guidelines T a NCT. National-Cancer-Treatment-Guidelines2.pdf. 2020.
7. Sood R, Masalu N, Connolly RM, Chao CA, Faustine L, Mbulwa C, et al. Invasive breast Cancer treatment in Tanzania : landscape assessment to prepare for implementation of standardized treatment guidelines. 2021;1–11.
8. Dragvoll I, Bofin AM, Søiland H, Taraldsen G, Engstrøm MJ. Predictors of adherence and the role of primary non‐adherence in antihormonal treatment of breast cancer. BMC Cancer. 2022;1–12.
9. Brett J, Boulton M, Fenlon D, Hulbert-williams NJ, Walter FM, Donnelly P, et al. Adjuvant endocrine therapy after breast cancer : a qualitative study of factors associated with adherence. 2018;291–300.
10. Atkins L, Fallowfield L. Intentional and non-intentional non-adherence to medication amongst breast cancer patients. Eur J Cancer. 2006;42(14):2271–6.

11. Brown MT, Bussell J, Dutta S, Davis K, Strong S, Mathew S. Medication Adherence : Truth. 2016;351(4):387–99.

12. Brett J, Fenlon FD, Ed C, Boulton AM, Ma FMW, Bchir MB, et al. Factors associated with intentional and unintentional adherence to adjuvant endocrine therapy following breast cancer. 2016;(September):1–9.

13. Hershman DL, Shao T, Kushi LH, Kwan M, Lin S, Alfred G. Early discontinuation and non-adherence to adjuvant hormonal therapy are associated with increased mortality in women with breast cancer. 2011;529–37.

14. WHO. A D H E R E N C E TO LO N G - T E R M T H E R A P I E S World Health Organization 2003. 2003;

15. Wako Z, Mengistu D, Dinegde NG, Asefa T, Wassie M. Breast Cancer : Targets and Therapy Adherence to Adjuvant Hormonal Therapy and Associated Factors Among Women with Breast Cancer Attending the Tikur Anbessa Specialized Hospital , Addis Ababa Ethiopia , 2019 : A Cross-sectional Study. 2021;383–92.

16. Makubate B, Donnan PT, Dewar JA, Thompson AM, Mccowan C. Cohort study of adherence to adjuvant endocrine therapy , breast cancer recurrence and mortality. Br J Cancer. 2013;108(7):1515–24.

17. Inotai A, Ágh T, Maris R, Erdősi D, Kovács S, Conceptualisation ZK, et al. Systematic review of real-world studies evaluating the impact of medication non-adherence to endocrine therapies on hard clinical endpoints in patients with non-metastatic breast cancer. Cancer Treat Rev. 2021;102264.

18. Hooi E, Li A, Wong A, Chien C, Wong P, Huang S, et al. Improving medication adherence with adjuvant aromatase inhibitor in women with breast cancer : A randomised controlled trial to evaluate the effect of short message service (SMS) reminder. The Breast. 2020;53:77–84.

19. Krok-schoen JL, Naughton MJ, Young GS, Moon J, Poi M, Melin SA, et al.

Increasing Adherence to Adjuvant Hormone Therapy Among Patients With Breast Cancer : A Smart Phone App-Based Pilot Study. 2019;26:1–10.

20. Hershman DL, Unger JM, Hillyer GC, Moseley A, Arnold KB. original reports abstract Randomized Trial of Text Messaging to Reduce Early Discontinuation of Adjuvant Aromatase Inhibitor Therapy in Women With Early-Stage Breast Cancer : SWOG S1105. 2020;38(19).

21. Kiguhe Mchidi N, P. Oyore J, Ogweno G. Effectiveness of Short Message Service Support on Adherence to Chemotherapy Treatment among Patients Attending Cancer Treatment Facilities in Kenya. Open J Nurs. 2024;14(03):93–113.

22. de Aguiar YPM, de Souza AES, e Silva CDL, do Carmo Queiroz SO. Adherence to oral anticancer therapy of oncology patients attending the pharmaceutical office of a public hospital in the lower Amazon region. Ecancermedicalscience. 2022;16:1–12.

23. Castaldi M, Safadjou S, Elrafei T, Mcnelis J. A Multidisciplinary Patient Navigation Program Improves Compliance With Adjuvant Breast Cancer Therapy in a Public Hospital. 2016;

24. Chalela P, Munoz E, Inupakutika D, Kaghyan S, Akopian D, Kaklamani V, et al. Improving adherence to endocrine hormonal therapy among breast cancer patients: Study protocol for a randomized controlled trial. Contemp Clin Trials Commun [Internet]. 2018;12(June):109–15. Available from: https://doi.org/10.1016/j.conctc.2018.10.001

25. Markopoulos C, Neven P, Tanner M, Marty M, Kreienberg R, Atkins L, et al. Does patient education work in breast cancer ? Final results from the global CARIATIDE study. 2015;11:205–17.

26. Harrow A, Dryden R, Mccowan C, Radley A, Parsons M, Thompson AM, et al. A hard pill to swallow : a qualitative study of women ' s experiences of adjuvant endocrine therapy for breast cancer. 2014;1–10.

27. Flanagan J, Tetler D, Habin K. The Experience of Initiating Oral Adjuvant Treatment for Estrogen Receptor–Positive Breast Cancer. 2016;43(4):143–52.

28. Kugbey N, Meyer-weitz A, Oppong K. Patient Education and Counseling Access to health information , health literacy and health-related quality of life among women living with breast cancer : Depression and anxiety as mediators. Patient Educ Couns. 2019;102(7):1357–63.

29. Londen GJ Van, Donovan HS, Beckjord EB, Cardy AL, Bovbjerg DH, Davidson NE, et al. Perspectives of Postmenopausal Breast Cancer Survivors on Adjuvant Endocrine Therapy-Related Symptoms. 2014;41(6):660–8.

30. Flanagan J, Winters LN, Habin K, Cashavelly B. Women's Experiences With Antiestrogen Therapy to Treat Breast Cancer. 2012;39(1).

31. Seneviratne S, Campbell I, Scott N, Kuper-Hommel M, Kim B, Pillai A, et al. Adherence to adjuvant endocrine therapy: Is it a factor for ethnic differences in breast cancer outcomes in New Zealand? Breast. 2015;24(1):62–7.

32. Rosso R, D'Alonzo M, Bounous VE, Actis S, Cipullo I, Salerno E, et al. Adherence to Adjuvant Endocrine Therapy in Breast Cancer Patients. Curr Oncol. 2023;30(2):1461–72.

33. Corter AL, Broom R, Porter D, Harvey V, Findlay M. Predicting nonadherence to adjuvant endocrine therapy in women with early stage breast cancer. Psychooncology. 2018;27(9):2096–103.

34. Rosenstock IM, Strecher VJ, Becker MH. Social Learning Theory and the Health Belief Model. Heal Educ Behav. 1988;15(2):175–83.

35. Maiman LA, Becker MH. The Health Belief Model: Origins and Correlates in Psychological Theory. Heal Educ Monogr VOL. 1984;2(4):336–53.

36. Jones SL, Jones PK, Katz J. Health belief model intervention to increase compliance with emergency department patients. Med Care. 1988;26(12):1172–84.

37. Champion VL. Instrument development for health belief model constructs. Vol. 6, ANS. Advances in nursing science. 1984. p. 73–85.

38. Janz NK, Becker MH. The Health Belief Model: A Decade Later. Heal Educ Behav. 1984;11(1):1–47.

39. Mikhail B. The health belief model: a review and critical evaluation of the model, research, and practice. Adv Nurs Sci. 1981;65–82.

40. Ann K, Melynk M. Barriers: A critical Review of Recent Literature. Nurs Res. 1988;196–201.

41. Bandura A, Bandura A, Bandura A. Bandura 1977.pdf. Vol. 84, Self-efficacy beliefs of adolescents. 2006. p. 307–37.

42. Mikhail1981.

43. Gao P, You L, Wu D, Shi A, Miao Q, Rana U, et al. Adherence to endocrine therapy among chinese patients with breast cancer: Current status and recommendations for improvement. Patient Prefer Adherence. 2018;12:887–97.

44. Murphy CC, Bartholomew LK, Carpentier MY, Bluethmann SM, Vernon SW. Adherence to adjuvant hormonal therapy among breast cancer survivors in clinical practice: A systematic review. Breast Cancer Res Treat. 2012;134(2):459–78.

45. Talens A, Guilabert M, Lumbreras B, Aznar MT, López-Pintor E. Medication experience and adherence to oral chemotherapy: A qualitative study of patients' and health professionals' perspectives. Int J Environ Res Public Health. 2021;18(8).

46. Mohammed MA, Moles RJ, Chen TF. Medication-related burden and patients' lived experience with medicine: A systematic review and metasynthesis of qualitative studies. BMJ Open. 2016;6(2).

47. Clancy C, Lynch J, OConnor P, Dowling M. Breast cancer patients' experiences of adherence and persistence to oral endocrine therapy: A qualitative evidence synthesis.

Eur J Oncol Nurs. 2020;44(November 2019):101706.

48. Peddie N, Agnew S, Crawford M, Dixon D, MacPherson I, Fleming L. The impact of medication side effects on adherence and persistence to hormone therapy in breast cancer survivors: A qualitative systematic review and thematic synthesis. Breast. 2021;58:147–59.

49. Johnsson A, Fugl-meyer K, Bordas P, Åhman J, Wachenfeldt A Von. Side Effects and Its Management in Adjuvant Endocrine Therapy for Breast Cancer : A Matter of Communication and Counseling. 2023;

50. Kiehn O, Car. 乳鼠心肌提取 HHS Public Access. Physiol Behav. 2017;176(3):139–48.

51. Moon Z, Moss-Morris R, Hunter MS, Hughes LD. Understanding tamoxifen adherence in women with breast cancer: A qualitative study. Br J Health Psychol. 2017;22(4):978–97.

52. Leysen L, Beckwée D, Nijs J, Pas R, Bilterys T, Vermeir S, et al. Risk factors of pain in breast cancer survivors: a systematic review and meta-analysis. Support Care Cancer. 2017;25(12):3607–43.

53. Jacobs JM, Walsh EA, Park ER, Berger J, Peppercorn J, Partridge A, et al. The Patient's Voice: Adherence, Symptoms, and Distress Related to Adjuvant Endocrine Therapy After Breast Cancer. Int J Behav Med. 2020;27(6):687–97.

54. Cahir C, Guinan E, Dombrowski SU, Sharp L, Bennett K. Identifying the determinants of adjuvant hormonal therapy medication taking behaviour in women with stages I-III breast cancer: A systematic review and meta-analysis. Patient Educ Couns. 2015;98(12):1524–39.

55. Pruthi. S MD. et al. Mayo Clinic. 2022. Breast cancer - Diagnosis and treatment - Mayo Clinic.

56. Lambert LK, Balneaves LG, Howard AF, Chia SK, Gotay CC. Understanding

adjuvant endocrine therapy persistence in breast Cancer survivors. BMC Cancer. 2018 Jul;18(1):1–13.

57. Kyvernitakis I, Ziller V, Hars O, Bauer M, Kalder M, Hadji P. Prevalence of menopausal symptoms and their influence on adherence in women with breast cancer. Climacteric. 2014;17(3):252–9.

58. Gomaa S, Lopez A, Slamon R, Smith R, Telushi E, Lapitan E, et al. The lived experience of breast cancer patients on adjuvant endocrine therapy: Side effects and coping strategies during the first year of medication initiation. Res Sq. 2023;

59. Peixoto M, Póvoa S, Mariano M, Broco S, Madeira P, Pêgo A, et al. An observational cross-sectional study on breast cancer patients' knowledge of their disease: A likely cause of depression and anxiety. F1000Research. 2022 Sep;11:992.

60. Jedy-Agba E, McCormack V, Olaomi O, Badejo W, Yilkudi M, Yawe T, et al. Determinants of stage at diagnosis of breast cancer in Nigerian women: sociodemographic, breast cancer awareness, health care access and clinical factors. Cancer Causes Control. 2017 Jul;28(7):685–97.

61. Xu H, Zhang X jie, Wang D qiu, Xu L, Wang A ping. Factors influencing medication-taking behaviour with adjuvant endocrine therapy in women with breast cancer: A qualitative systematic review. J Adv Nurs. 2020;76(2):445–58.

62. AlOmeir O, Patel N, Donyai P. Adherence to adjuvant endocrine therapy among breast cancer survivors: a systematic review and meta-synthesis of the qualitative literature using grounded theory. Support Care Cancer. 2020;28(11):5075–84.

63. Neugut AI, Hillyer GC, Kushi LH, Lamerato L, Leoce N, Nathanson SD, et al. Noninitiation of adjuvant chemotherapy in women with localized breast cancer: The breast cancer quality of care study. J Clin Oncol. 2012;30(31):3800–9.

64. Ziller V, Kalder M, Albert US, Holzhauer W, Ziller M, Wagner U, et al. Adherence to adjuvant endocrine therapy in postmenopausal women with breast cancer. Ann

Oncol. 2009;20(3):431–6.

65. Hershman DL, Kushi LH, Shao T, Buono D, Kershenbaum A, Tsai WY, et al. Early discontinuation and nonadherence to adjuvant hormonal therapy in a cohort of 8,769 early-stage breast cancer patients. J Clin Oncol. 2010;28(27):4120–8.

66. Hadji P, Blettner M, Harbeck N, Jackisch C, Lück HJ, Windemuth-Kieselbach C, et al. The patient's anastrozole compliance to therapy (PACT) program: A randomized, in-practice study on the impact of a standardized information program on persistence and compliance to adjuvant endocrine therapy in postmenopausal women with early breast cance. Ann Oncol. 2013;24(6):1505–12.

67. Hall LH, King N V., Graham CD, Green SMC, Barber A, Neal RD, et al. Strategies to self-manage side-effects of adjuvant endocrine therapy among breast cancer survivors: an umbrella review of empirical evidence and clinical guidelines. J Cancer Surviv. 2022;16(6):1296–338.

68. Bhatta SS, Hou N, Moton ZN, Polite BN, Fleming GF, Olopade OI, et al. Factors associated with compliance to adjuvant hormone therapy in Black and White women with breast cancer. Springerplus. 2013;2(1):1–7.

69. Llarena NC, Estevez SL, Tucker SL, Jeruss JS. Impact of Fertility Concerns on Tamoxifen Initiation and Persistence. 2015;107:1–9.

70. Krotneva SP, Ramjaun A, Reidel KE, Eguale T, Trabulsi N, Mayo N, et al. Use of hormonal therapy in senior breast cancer patients treated with or without radiotherapy. Curr Oncol. 2013;21(1):105.

71. Jacob L, Hadji P, Kostev K. Age-related differences in persistence in women with breast cancer treated with tamoxifen or aromatase inhibitors in Germany. J Geriatr Oncol. 2016;7(3):169–75.

72. Kroenke CH, Hershman DL, Gomez SL, Adams SR, Eldridge EH, Kwan ML, et al. Study population. 2019;170(3):623–31.

73. Cahir C, Barron TI, Sharp L, Bennett K. Can demographic, clinical and treatment-related factors available at hormonal therapy initiation predict non-persistence in women with stage I–III breast cancer? Cancer Causes Control. 2017;28(3):215–25.

74. Wulaningsih W, Garmo H, Ahlgren J, Holmberg L, Folkvaljon Y, Wigertz A, et al. Determinants of non-adherence to adjuvant endocrine treatment in women with breast cancer: the role of comorbidity. Breast Cancer Res Treat. 2018;172(1):167–77.

75. Pistilli B, Paci A, Ferreira AR, Di Meglio A, Poinsignon V, Bardet A, et al. Serum detection of nonadherence to adjuvant tamoxifen and breast cancer recurrence risk. J Clin Oncol. 2020;38(24):2762–72.

76. Peate M, Saunders C, Cohen P, Hickey M. Who is managing menopausal symptoms, sexual problems, mood and sleep disturbance after breast cancer and is it working? Findings from a large community-based survey of breast cancer survivors. Breast Cancer Res Treat. 2021;187(2):427–35.

77. María D, López L. cancer survivors : An update. 2022;13(2):71–101.

78. Ke R, Rickett K, Feng S, Vagenas D, Ne W. Exercise therapies for preventing or treating aromatase inhibitor- induced musculoskeletal symptoms in early breast cancer (Review). 2020;

79. Rada G, Capurro D, Pantoja T, Corbalán J, Moreno G, Lm L, et al. of breast cancer (Review). 2010;

80. Liu Y, Malin JL, Diamant AL, Thind A, Maly RC. Adherence to adjuvant hormone therapy in low-income women with breast cancer: The role of provider-patient communication. Breast Cancer Res Treat. 2013;137(3):829–36.

81. Heyns L, Gie RP, Kling S, Samaai P, Schaaf HS, Beyers N. Management of children with tuberculosis admitted to a pediatric intensive care unit. Pediatr Infect Dis J. 1998;17(5):403–7.

82. Introduction PA, Moran D. Husserl ' s Crisis of the European Sciences and

Transcendental Edmund Husserl : The Crisis of the European Sciences and Transcendental Phenomenology : An Introduction Dermot Moran School of Philosophy ,. 2015.

83. Sharp CA. Qualitative Research and Evaluation Methods (3rd ed.). Vol. 3, Evaluation Journal of Australasia. 2003. p. 60–1.

84. ORCI. www.orci.or.tz. 2023. About ORCI.

85. Dharsee NJ, Wiseman T. Understanding breast cancer survivorship in Tanzania. 2020;42–5.

86. Burson AM, Soliman AS, Ngoma TA, Mwaiselage J, Ogweyo P, Eissa MS, et al. Clinical and epidemiologic profile of breast cancer in Tanzania. Breast Dis. 2010;31(1):33–41.

87. Survivors of breast and other cancers.

88. Rai N, Thapa B. A study on purposive sampling method in research. KathmanduKathmandu Sch Law. 2019;1–12.

89. Konstantina Vasileiou, Julie Barnett, Susan Thorpe, Terry Young. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. BMC Med Res Methodol. 2018;18(1):1–18.

90. Amari RO. Breast Cancer and Endocrine Therapy Adherence in Ethiopia: Diagnosis, Treatment, and Breast Nurse Intervention. Martin Luther University of Halle-Wittenberg; 2023.

91. Braun V, Clarke V. Using thematic analysis in psychology. 2014;(January).

92. Conn VS, Enriquez M, Ruppar TM, Chan KC. Adherence Intervention Research. 2016;40(2):155–71.

93. Bellamy R. An introduction to patient education : theory and practice.

2004;26(4):359–65.

94. Bhattad PB, Pacifico L. Empowering Patients : Promoting Patient Education and Health Literacy. 2022;14(7).

95. Saad AH, Rabeea IS, Salih HN. Adherence and Beliefs to Adjuvant Hormonal Therapy in Patients with Breast Cancer: A Cross-Sectional Study (Conference Paper)#. Iraqi J Pharm Sci. 2021;30:31–9.

96. Yang S, Park SW, Bae SJ, Ahn SG, Jeong J, Park K. Investigation of Factors Affecting Adherence to Adjuvant Hormone Therapy in Early-Stage Breast Cancer Patients: A Comprehensive Systematic Review. J Breast Cancer. 2023;26(4):309–33.

97. Tomi SD, Malenkovi G. Sociodemographic , Clinical Characteristics , and Social Support among Breast Cancer Patients in Serbia. 2023;

98. Liu Y, Li Y, Chen L, Li Y, Qi W, Yu L. Relationships between family resilience and posttraumatic growth in breast cancer survivors and caregiver burden. Psychooncology. 2018;27(4):1284–90.

99. Aprilianto E, Lumadi SA, Handian FI. Family social support and the self-esteem of breast cancer patients undergoing neoadjuvant chemotherapy. J Public health Res. 2021;10(2).

100. Brennan N, Barnes R, Calnan M, Corrigan O, Dieppe P, Entwistle V. Trust in the health-care provider-patient relationship: A systematic mapping review of the evidence base. Int J Qual Heal Care. 2013;25(6):682–8.

101. Panahi S, Rathi N, Hurley J, Sundrud J, Lucero M, Kamimura A. Patient Adherence to Health Care Provider Recommendations and Medication among Free Clinic Patients. J Patient Exp. 2022;9:1–7.

102. Kwame A, Petrucka P. A literature-based study of patient-centered care and communication in nurse-patient interactions : barriers , facilitators , and the way forward. BMC Nursing [revista en Internet] 2021 [acceso 2 de setiembre de 2023];

20:158. 2021;1–10.

103. Fleming L, Agnew S, Peddie N, Crawford M, Dixon D, MacPherson I. The impact of medication side effects on adherence and persistence to hormone therapy in breast cancer survivors: A quantitative systematic review. Breast. 2022;64(May):63–84.

104. Andreu Y, Soto-Rubio A, Ramos-Campos M, Escriche-Saura A, Martínez M, Gavilá J. Impact of hormone therapy side effects on health-related quality of life, distress, and well-being of breast cancer survivors. Sci Rep. 2022;12(1):1–9.

105. Adisa A, Lawal O, Adesunkanmi A. Evaluation of patients\' adherence to chemotherapy for breast cancer. Afr J Health Sci. 2008;15(1):22–7.

106. Chatoo A, Lee S. Association of Coping Strategies and Medication Adherence: A Systematic Review. Inov Pharm. 2022;13(3):10.

107. Cadel L, Cimino SR, von den Baumen TR, James KA, McCarthy L, Guilcher SJT. Medication management frameworks in the context of self-management: A scoping review. Patient Prefer Adherence. 2021;15:1311–29.

108. Jiakponna EC, Agbomola JO, Ipede O, Oluebubechi L. Psychosocial factors in chronic disease management : Implications for health psychology Psychosocial factors in chronic disease management : Implications for health psychology. 2024;(July).

109. Bombard Y, Baker GR, Orlando E, Fancott C, Bhatia P, Casalino S, et al. Engaging patients to improve quality of care : a systematic review. 2018;

110. WHO. Operational Framework for Primary Health Care. World Health Organization. 2020. 1–132 p.

APPENDICES

Appendix I. Consent form (English version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

DIRECTORATE OF RESEARCH AND PUBLICATION

ID NO

Consent form for participating in a Research study.

Greetings, my name is Thereza Gideon a postgraduate student; pursuing a Master of science in Oncology Nursing at Muhimbili University of Science and Allied Sciences (MUHAS) in the school of Nursing. I am researching the lived experience on Adjuvant Hormonal Therapy among breast cancer patients at Ocean Road Cancer Institute in Dar-Es-Salaam Tanzania.

The aim of the study

This study aims to explore the lived experience on Adjuvant Hormonal Therapy among breast cancer patients at Ocean Road Cancer Institute, Dar-Es-Salaam, Tanzania.

The study findings will help to identify different challenges experienced by breast cancer patients on adherence to AHT and appropriate interventions to be employed by both patients and healthcare providers to improve adherence to AHT at ORCI which serves as a hub for cancer care in Tanzania.

Procedure

I would like you to participate in this study. You are selected because you are among the patients who have been prescribed to use AHT for more than a year and that your experience on using this medication may have an impact on improving care and adherence

to AHT. If you choose to participate you will be interviewed for about 45 minutes and will be audio recorded in order not to miss any information and the researcher can't be quick enough to write everything you say.

Confidentiality

All responses will be kept confidential. This means that your response will only be used for research and shared with MUHAS when necessary. I will ensure that any information included in my report does not identify you as the respondent. No names will be included both during the interview and reporting findings.

Right to refuse or withdraw

It is your choice to participate in this study. Also, you don't have to talk about anything you don't want and you may stop the interview at any time for any reason without repercussions. However, I encourage you to participate because your experience is very important in this study.

Benefits

Participating in this study may not benefit you personally, but might provide useful information that will benefit others and improve adherence to AHT.

Risks

There will be no harm to you as a result of participation in this study although some questions may be personal.

Whom to contact

In case of any inquiry please contact the researcher, Thereza Gideon, from MUHAS, P.O. BOX 65001, Dar-Es-Salaam, mobile number 0754358801 or via email therezagideon1993@gmail.com If you ever have questions about yours rights as a participant, you may contact the Director of Research and Publications, at MUHAS P.O. BOX 65001, Dar-Es- Salaam-Tanzania.

Signature

Do you agree to participate? Put a tick in the appropriate box

Participant agrees ☐ participant does NOT agree ☐

I, …….. have read the contents of this form and Understood.

My questions have been answered; I agree to participate in this study.

Signature of participant……. Date……

Appendix II. Fomu ya ridhaa (kwa Kiswahili)

CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI

KURUGENZI YA UTAFITI NA MACHAPISHO

Namba ya utambulisho

Fomu ya ridhaa ya kushiriki katika utafiti.

Habari, naitwa **Thereza Gideon,** mwanafunzi wa shahada ya uzamili; nasoma Shahada ya Uzamili ya Sayansi katika Uuguzi wa magonjwa ya saratani katika Chuo Kikuu cha Afya na Sayansi Shirikishi Muhimbili (MUHAS) katika shule ya Uuguzi. Ninatafiti juu ya matumizi ya Tiba ya Adjuvant Hormonal miongoni mwa wagonjwa wa saratani ya matiti katika Taasisi ya Saratani ya Ocean Road jijini Dar-Es-Salaam Tanzania.

Lengo la utafiti

Utafiti huu unalenga kuchunguza uzoefu ulio hai juu yay a matumizi ya Tiba ya Homoni ya Adjuvant miongoni mwa wagonjwa wa saratani ya matiti katika Taasisi ya Saratani ya Ocean Road, Dar-Es-Salaam, Tanzania.

Matokeo ya utafiti yatasaidia kubainisha changamoto mbalimbali zinazowakabili wagonjwa wa saratani ya matiti kuhusu ufuasi wa AHT na afua zinazofaa zitakazotumiwa na wagonjwa na watoa huduma za afya ili kuboresha ufuasi wa AHT katika Taasisi ya Saratani Ocean Road ambayo ni kitovu cha huduma za saratani nchini Tanzania.

Utaratibu

Ningependa ushiriki katika utafiti huu. Umechaguliwa kwa sababu wewe ni miongoni mwa wagonjwa ambao wameagizwa kutumia AHT kwa zaidi ya mwaka mmoja na kwamba uzoefu wako wa kutumia dawa hii unaweza kuwa na mchanago katika kuboresha huduma na ufuasi wa AHT. Ukichagua kushiriki utahojiwa kwa takriban dakika 45 na utarekodiwa sauti ili nisikose taarifa yoyote na maana siataweza kuandika kila kitu unachosema kwa haraka.

Usiri

Majibu yote utakayotoa yatakua siri, hii inamaana kwamba majibu yako yatatumiwa na mtafitikwa lengo la utafiti huu tu na kama kunaulazima yatatumiwa na Chuo Kikuu Muhimbili.yatawekwa siri.Ninakuhakikishia kwamba taarifa zote zitakazojumuishwa katika utafiti hazitakufanya ujulikane kama ndiye mshiriki, majina yako hayataandikwa katika mahojiano wala ripoti ya utafiti.

Haki ya kukataa au kujitoa

Ushiriki katika utafiti huu ni wa hiari. Pia hulazimishwi kuongea jambo lolote ambalo usingependa kuliongea. Unaweza kusitisha mahojiano wakati wowote endapo utaona ni vyema kufanya hivyo bila athari yoyote. Licha ya hayo ningependa ushiriki wako katika utafiti huu kwani uzoefu wako ni muhimu katika utafiti huu

Faida

Kushiriki katika utafiti huu kunaweza kusiwe na manufaa kwako binafsi, lakini kunaweza kutoa taarifa muhimu ambayo itawasaidia wengine na kuboresha ufuasi wa AHT.

Madhara

Hakuna madhara yoyote yanayoweza kukupata kwa kushiriki kwako katika utafiti huu japo

baadhi ya maswali utakayoulizwa yaweza kuwa ya binafsi zaidi.

Watu wa kuwasiliana nao

Kama una maswali katika utafiti huu tafadhali wasiliana na mtafiti, Thereza Gideon, kutoka MUHAS, P.O. BOX 65001, Dar-Es-Salaam, nambari ya simu 0754358801 au kupitia barua pepe therezagideon1993@gmail.com

Sahihi

Je, unakubali kushiriki? Weka tiki (√) kwenye kisanduku kinachofaa

Ndiyo ☐ Hapana ☐

Mimi…….. nimesoma yaliyomo kwenye fomu hii na Nimeelewa. Maswali yangu yamejibiwa; Ninakubali kushiriki katika utafiti huu.

Saini ya mshiriki ……

Tarehe……

Saini ya mtafiti ……...

Tarehe……

Appendix III: In-depth Interview Guide for Patients (English Version)

TITLE: Lived experience on Adjuvant Hormonal Therapy among breast cancer patients at Ocean Road Cancer Institute in Dar es Salaam, Tanzania.

Basic information about the interview:

Thank you for agreeing to participate in this interview. Your participation will build a therapeutic bridge between healthcare providers and patients regarding different experiences with the use of adjuvant hormonal therapy at ORCI. As cancer survivors there are challenges you may have faced while adhering to this treatment which has an impact on your daily life and the disease prognosis. With the understanding of your experiences on AHT, individualized care and improved treatment outcomes will be fostered.

Purpose of the interview:

To explore the lived experience on Adjuvant Hormonal Therapy among breast cancer patients at Ocean Road cancer Institute in Dar-es-salaam. Multiple aspects will be covered based on the experience of this particular medication including, patient's understanding on AHT side effects, benefits and the role of adherence, Different factors influencing AHT use and the coping mechanisms towards the barriers on AHT use and finally to explore on different recommendations from patient's perspective to improve AHT use to fellow survivors or to healthcare providers. This aims to bring about good treatment outcomes and improve quality of life among breast cancer patients on AHT.

Time of Interview:

Date:

Name of Interviewer:

ID Number:

Recording and Storing Information

This interview will be audio-recorded for research purposes. All information collected will be stored securely on a computer accessible only with a password, limited to the researcher.

Introduction

1. Introduce Yourself: Provide your name, role, and affiliation with the study.
2. Explain the Purpose of the study: Clarify that the interview focuses on lived experience on AHT use among breast cancer patients at Ocean Road Cancer Institute.
3. Obtain Informed Consent: Request the interviewee's signature on the informed consent form.
4. Describe the Interview Structure: Outline the interview format, including audio recording, taking notes and assure confidentiality and anonymity.
5. Ask for Questions: Invite the interviewee to ask any questions or seek clarification.

PART I: Demographic Information

Objective: Exploring lived experience on Adjuvant Hormonal Therapy among breast cancer patients.											
Demographic Information of the Participants											
Participant	Age	Marital status	Education	Employment status	Residence	Breast cancer stage	Treatment received	AHT medication	Years of AHT	Ever missed medications	Current medication taking status
		a) Married b) single c) widow	a) primary, b)secondary, c)	a)Employed, b) unemployed, c) Retired	a) Rural, b) Urban	a)I, b) II, c) III	a)Lumpectomy, b) mastectomy, c)	a)Tamoxifen, b) Anastrozole	a) 1 year, b) 2-4 years, c) 5-10 years	a) No, b) Yes	Yes, b) stopped temporarily, c) Stopped permanently
P1											

P2											
P3											
P4											
P5											
P6											
P7											
P8											
P9											
P10											
P11											

P13											
P14											
P15											

PART II

1. Kindly, share what do you know about breast cancer?
   Probe: what are the risk factors to breast cancer?
   Probe: How to prevent from getting breast cancer?
   Probe: How is breast cancer being managed?
2. What are your experiences living with breast cancer? (Social life, sexual life, role relationship, daily living patterns)
3. Kindly, share your experience of being diagnosed with breast cancer and receiving AHT?
4. What do you understand about AHT?
   Probe: what does it treat?
   Probe: How long should it be taken?
   Probe: What are your expectations from taking AHT? (Benefits)
5. Share your experiences of taking AHT as prescribed?
   Probe: AHT adherence experience (if not adhering ask why)
   Probe: AHT side effects experience
   Probe: AHT management of side effects

6. What are your thoughts on the possibilities that the future might hold for you?
7. What are the suggestions to improve AHT adherence?
8. What are your recommendations for improving the management of symptoms and discomfort resulting from the use of AHT?

Conclusion:

Is there anything else you would like to share about your experience with adjuvant hormonal therapy?

Thank you for your time and participation in this interview. Your insights will help us better understand the challenges faced by breast cancer patients on adjuvant hormonal therapy and identify ways to improve adherence and management of side effects.

Appendix IV: In-depth Interview Guide for Patients (Swahili Version)

Huu ni mwongozo wa mahojiano ya kina kati ya mtafiti na mgonjwa kuhusu uzoefu juu ya matumizi ya Tiba ya Hormonal Adjuvant miongoni mwa wagonjwa wa saratani ya matiti katika Taasisi ya Saratani ya Ocean Road jijini Dar es Salaam, Tanzania.

Maelezo ya msingi juu ya mahojiano:

Asante kwa kukubali kushiriki katika mahojiano haya. Kushiriki kwako kutajenga daraja la kimatibabu kati ya watoa huduma za afya na wagonjwa kuhusu tajriba tofauti za utumiaji wa tiba ya homoni za adjuvant katika Taasisi ya saratani Ocean Road. Kama waathirika wa saratani kuna changamoto ambazo unaweza kuwa umekumbana nazo wakati unazingatia matibabu haya ambayo yanaweza kuwa yameathiri maisha yako ya kila siku na kudhoofishwa ufuasi mzuri wa dawa. Kwa uelewa na uzoefu wako kwenye matumizi ya AHT utasaidia matokeo bora ya matibabu baina ya wagonjwa wa saratani ya matiti wanaotumia AHT.

Madhumuni ya mahojiano:

Kuchunguza uzoefu wa moja kwa moja wa Tiba ya Adjuvant Hormonal kwa wagonjwa wa saratani ya matiti katika Taasisi ya saratani ya Ocean Road jijini Dar-es-salaam. Mambo mengi yatashughulikiwa kulingana na uzoefu wa dawa hii ikiwa ni pamoja na, uelewa wa mgonjwa juu ya maudhi yatokanayo na matumizi ya AHT, faida na jukumu la ufuasi, mambo tofauti yanayoathiri matumizi ya AHT na njia za kukabiliana na vikwazo vya matumizi ya AHT. Hatimae kuja na mapendekezo kutokana na mtazamo wa mgonjwa ili kuboresha matumizi ya AHT kwa jamii ya wagonjwa wa saratani ya matiti wenzao au kwa watoa huduma za afya. Hii inalenga kuleta matokeo mazuri ya matibabu na kuboresha ubora wa maisha kati ya wagonjwa wa saratani ya matiti wanaotumia AHT.

Muda wa Mahojiano:

Tarehe:

Jina la Mhojaji:

Nambari ya utambulisho:

Kurekodi na Kuhifadhi taarifa.

Mahojiano haya yatarekodiwa kwa sauti kwa madhumuni ya utafiti. Taarifa zote zilizokusanywa zitahifadhiwa kwa usalama kwenye kompyuta inayopatikana tu kwa nenosiri, pekee kwa mtafiti

Utangulizi

1. Jitambulishe: jina lako, jukumu, na uhusiano wako kwenye utafiti.

2. Eleza Madhumuni ya utafiti: Fafanua kuwa mahojiano yanazingatia uzoefu wa moja kwa moja wa matumizi ya AHT miongoni mwa wagonjwa wa saratani ya matiti katika Taasisi ya Saratani ya Ocean Road.

3. Pata Idhini ya Taarifa: Omba saini ya mhojiwa kwenye fomu ya ridhaa ya kushiriki kweny utafiti.

4. Eleza Muundo wa Mahojiano: Eleza muundo wa mahojiano, ikijumuisha kurekodi sauti, kuandika madokezo na hakikisha usiri na kutokujulikana.

5. Uliza Maswali: Alika mshiriki kuuliza maswali yoyote au kutafuta ufafanuzi.

SEHEMU YA I: Taarifa za Kidemografia

Lengo: Kuchunguza uzoefu juu ya matumizi ya Tiba ya Adjuvant Hormonal kati ya wagonjwa wa saratani ya matiti
Taarifa za Kidemografia za Washiriki

M6	M5	M4	M3	M2	M1		Washiriki
							umri
						a)Umeolewa, b)hujaolewa c)mjane	Hali ya ndoa
						a)Elimu ya msingi, b) sekondari, c) chuo, d) Chuo	Elimu
						a)Umeajiriwa b) Hujajiriwa, c) umestaafu	Kazi
						a)kijijini, b) Mjini	Makazi
						a)I, b) II, c) III	Hatua ya saratani ya matiti
						a)Lumpectomy, b) mastectomy, c)	Matibabu aliyoyapata
						a)Tamoxifen, b) AI: Anastrozole	Aina ya dawa za AHT
						a)Mwaka 1 , b) miaka 2-4 , c) miaka 5-10	Miaka ya matumizi ya AHT
						a)Hapana, b) Ndiyo	Umewahi kukosa kutumia dawa
						a)Natumia, b) Nimeacha kwa muda, c) Nimeacha kabisa	Hali ya matumizi ya dawa kwa sasa

M7											
M8											
M9											
M10											
M11											
M13											
M14											
M15											

SEHEMU YA II

1. Tafadhali, shiriki unachojua kuhusu saratani ya matiti?

Chunguza: Visababishi vya saratani ya matiti

Chunguza: Jinsi ya kuzuia kupata saratani ya matiti

Chunguza: Je, saratani ya matiti inadhibitiwa vipi?

2. Je, una uzoefu gani kuishi na saratani ya matiti? (Maisha ya kijamii, maisha ya ngono, uhusiano wa jukumu, mifumo ya maisha ya kila siku)

3. Tafadhali, shiriki uzoefu wako wa kugunduliwa na saratani ya matiti na kupokea AHT?

4. Unaelewa nini kuhusu AHT?

Chunguza: inatibu nini?

Chunguza: Inapaswa kutumiwa kwa muda gani?

Chunguza: Je, matarajio yako ni nini kutokana na kutumia AHT? (Faida)

5. Shiriki uzoefu wako wa kutumia AHT jinsi ulivyoagizwa?

Chunguza: Uzoefu wa ufuasi wa AHT (ikiwa hauzingatii uliza kwa nini)

Chunguza: Uzoefu wa athari za AHT

Chunguza: njia za kukabiliana na maudhi yatokanayo na AHT

6. Je, una maoni gani kuhusu hali ya maisha ya baadaye?

7. Je, ni mapendekezo gani ya kuboresha ufuasi wa AHT?

8. Je, ni mapendekezo gani ya kuboresha udhibiti wa dalili na maudhi yatokanayo na matumizi ya AHT?

Hitimisho:

Je, kuna kitu kingine chochote ungependa kushiriki kuhusu uzoefu wako na tiba ya homoni ya adjuvant? Asante kwa muda wako na ushiriki wako katika mahojiano haya. Maarifa yako yatatusaidia kuelewa vyema changamoto zinazowakabili wagonjwa wa saratani ya matiti

kuhusu tiba ya homoni ya adjuvant na kutambua njia za kuboresha ufuasi na udhibiti wa athari.

Appendix V: Ethical clearance -MUHAS

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATION

Ref. No.DA 282/298/01.C/2064 Date: 26/02/2024

MUHAS-REC-02-2024-2064
THEREZA GIDEON
MUHAS

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: LIVED EXPERIENCE ON ADJUVANT HORMONAL THERAPY AMONG BREAST CANCER PATIENTS AT OCEAN ROAD CANCER INSTITUTE IN DAR ES SALAAM, TANZANIA

Reference is made to the above heading.

I am pleased to inform you that the Chairman has on behalf of the University Senate, approved ethical clearance of the above-mentioned study, on recommendations of the Senate Research and Publications Committee meeting accordance with MUHAS research policy and Tanzania regulations governing human and animal subjects research.

APPROVAL DATE: 26/02/2024
EXPIRATION DATE OF APPROVAL: 26/02/2025

STUDY DESCRIPTION:
Purpose:

To explore lived experience on adjuvant hormonal therapy among breast cancer patients attending Ocean Road Cancer Institute in Dar es Salaam, Tanzania.

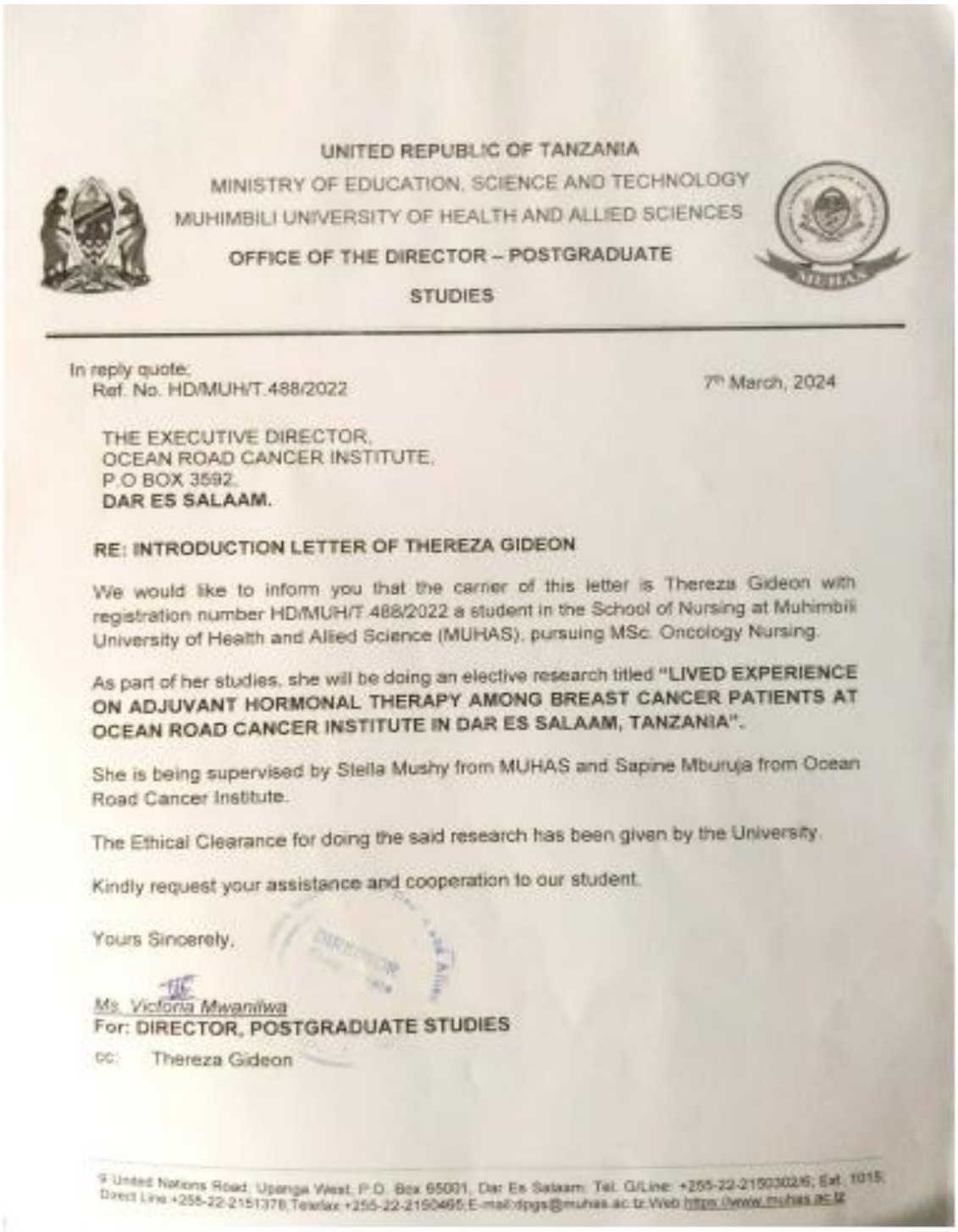
The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided: https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%2014554.pdf and in the MUHAS archives.

The PI is required to:

1. Submit bi-annual progress reports and final report upon completion of the study.
2. Report to the IRB any unanticipated problem involving risks to subjects or others including adverse events where applicable.
3. Apply for renewal of approval of ethical clearance one (1) month prior its expiration if the study is not completed at the end of this ethical approval. You may not continue with any research activity beyond the expiration date without the approval of the IRB. Failure to receive approval for continuation before the expiration date will result in automatic termination of the approval for this study on the expiration date.
4. Obtain IRB amendment (s) approval for any changes to any aspect of this study before they can be implemented.
5. Data security is ultimately the responsibility of the investigator.
6. Apply for and obtain Data Transfer Agreement (DTA) from NIMR if data will be transferred to a foreign country.
7. Apply for and obtain Material Transfer Agreement (MTA) from NIMR, if research materials (samples) will be shipped to a foreign country.
8. Apply for and obtain permission to publish the results from National Institute for Medical Research. The application should be before submitting to a publisher and not concurrently through the email publications@nimr.or.tz.
9. Any researcher, who contravenes or fail to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III section 10 (2)
10. The PI is required to ensure that the findings of the study are disseminated to relevant stake holders.
11. PI is required to be versed with necessary laws and regulatory policies that govern research in Tanzania. Some guidance is available on our website https://drp.muhas.ac.tz/.

Dr. Nahya Salim Masoud,
CHAIRPERSON, MUHAS RESEARCH AND ETHICS COMMITTEE

Appendix VI: Introduction letter



UNITED REPUBLIC OF TANZANIA
MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY
MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES
OFFICE OF THE DIRECTOR – POSTGRADUATE STUDIES

In reply quote:
Ref. No. HD/MUH/T.488/2022

7th March, 2024

THE EXECUTIVE DIRECTOR,
OCEAN ROAD CANCER INSTITUTE,
P.O BOX 3592,
DAR ES SALAAM.

RE: INTRODUCTION LETTER OF THEREZA GIDEON

We would like to inform you that the carrier of this letter is Thereza Gideon with registration number HD/MUH/T.488/2022 a student in the School of Nursing at Muhimbili University of Health and Allied Science (MUHAS), pursuing MSc. Oncology Nursing.

As part of her studies, she will be doing an elective research titled **"LIVED EXPERIENCE ON ADJUVANT HORMONAL THERAPY AMONG BREAST CANCER PATIENTS AT OCEAN ROAD CANCER INSTITUTE IN DAR ES SALAAM, TANZANIA".**

She is being supervised by Stella Mushy from MUHAS and Sapine Mburuja from Ocean Road Cancer Institute.

The Ethical Clearance for doing the said research has been given by the University.

Kindly request your assistance and cooperation to our student.

Yours Sincerely,

Ms. Victoria Mwaniwa
For: DIRECTOR, POSTGRADUATE STUDIES

cc: Thereza Gideon

9 United Nations Road, Upanga West, P.O. Box 65001, Dar Es Salaam. Tel. G/Line: +255-22-2150302/6; Ext. 1015; Direct Line +255-22-2151378;Telefax +255-22-2150465;E-mail:dpgs@muhas.ac.tz;Web https://www.muhas.ac.tz

Appendix VII: Permission letter -ORCI

UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH

OCEAN ROAD CANCER INSTITUTE

ORCI OCEAN ROAD CANCER INSTITUTE

On Reply Please Quote:

Ref: 10/VOL.XXI/2128 Date: 18th March, 2024

INSTITUTIONAL ACADEMICS, RESEARCH, PUBLICATIONS AND ETHICS COMMITTEE

Thereza Gideon
Reg no: HD/MUH/T.488/2022
MSc. Oncology Nursing
School of Nursing
MUHAS

Re: Approval to collect data for the study "Lived experience on adjuvant hormonal therapy among breast cancer patients at Ocean Road Cancer Institute in Dar es salaam"

Reference is made to the above heading, this is to let you know that the Institute Academics, Research, Publications and Ethics Committee has granted you permission to conduct this study. For a period of one year ending; March 2025.

Upon successful completion of the study, you are obliged to submit a copy of the final document of this research project to the IARPEC.

Yours Sincerely,

OCEAN ROAD CANCER INSTITUTE ACADEMIC UNIT P.O. Box 3592 DAR ES SALAAM

Dr. Mamsau Ngoma
Academic Unit, ORCI.

Ocean Road Cancer Institute; Junction of Luthuli / Barack Obama Roads; P.O. Box 3592; Dar Es Salaam -Tanzania;
Tel: +255-22-2127597; Fax: +255-22-2118704; Email: info@orci.or.tz; Website: www.orci.or.tz