

**EFFECT OF A STRUCTURED CHEMOTHERAPY-EDUCATION-
INTERVENTION VERSUS STANDARD-OF-CARE ON
KNOWLEDGE AND SELF-CARE AMONG CANCER PATIENTS
AT MOI TEACHING AND REFERRAL HOSPITAL**

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REQUIREMENTS FOR THE AWARD OF THE DEGREE OF
MASTER OF MEDICINE IN INTERNAL MEDICINE, MOI
UNIVERSITY.**

DECLARATION

Student's declaration:

I declare that this is my original thesis and that it has never been presented for a degree in any other University. No part may be reproduced without prior permission of the author and/or Moi University.

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LIST OF ABBREVIATIONS

GLOBOCAN	Global Cancer observatory
ECOG	Eastern Cooperative Oncology Group score
KNH	Kenyatta National Hospital
RCT	Randomized Controlled Trial.
WHO	World Health Organization
LMICs	Low- and Middle-Income countries
MSAS	Memorial Symptom Assessment Scale
MTRH	Moi Teaching and Referral Hospital
NHL	Non-Hodgkin's Lymphoma
SEMT	Side-effect Management Techniques
NIH	National Institutes of Health
NCCN	National Comprehensive Cancer Network
CTEP	Cancer Therapy Evaluation Program
QOL	Quality of Life
CIN	Chemotherapy-Induced Neutropenia

DEFINITION OF OPERATIONAL TERMS

Self-Care: Patients' involvement in self-observing, recognizing, and labeling symptoms and judging their severity, assessing, and adopting treatment choices, and evaluating the efficiency of to alleviate symptoms (Levin 1978). Involves partnership working, in which both patients and healthcare professionals contribute to care planning and is a means to empower individuals, families and communities for informed health decision-making.

Structured Chemotherapy-Education-Intervention: A comprehensive and systematic education program combining written instructions and supportive material with clinician-led teaching sessions on cancer, chemotherapy, potential chemotherapy side-effects and self-care with weekly follow-up telephone calls.

Knowledge: Facts, information and skills on chemotherapy and potential chemotherapy side-effects acquired through the education intervention.

Standard-of-care: A solely clinician-centered diagnosis and management of a patient's medical complications arising from illness and treatment. This involves patients being passive recipients of health care services instead of being active agents in their health care.

Chemotherapy: Treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing

Cancer: The unusual growth of abnormal cells in the body occurs when the control mechanism in the body ceases to work and as a result old cells do not die but instead grow uncontrollably, developing new, abnormal cells.

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ABSTRACT

Background: Cancer is the 3rd leading cause of mortality in Kenya. The increasing prevalence of cancer has necessitated administration of chemotherapy in an outpatient setting. Therefore, any debilitating and distressing chemotherapy side-effects are experienced by patients at home. Self-care refers to patients' ability to self-observe, recognize and label symptoms, judge their severity, undertake treatment options and evaluate the effectiveness of the intervention undertaken. This study set out to determine whether a well-structured and standardized chemotherapy-education-intervention will further improve knowledge on chemotherapy side-effects and self-care compared to a non-standardized standard-of-care.

Objective: To determine the effect of standardized-chemotherapy-education compared with the standard-of-care on patients' knowledge and self-care on chemotherapy side effects among ambulatory cancer patients

Methods: This was an open-label randomized controlled study conducted at the ambulatory cancer unit of Moi Teaching and Referral Hospital (MTRH). The study recruited 366 newly diagnosed solid cancer patients who were equally distributed between the intervention and control arms. The intervention arm received a standardized chemotherapy-education which followed the National Comprehensive Cancer Network (NCCN) guidelines with supportive written material and weekly follow-up phone calls while the control arm received unstructured and non-standardized clinician-centered education. Socio-demographic data and clinical characteristics of the participants were collected using an interviewer-administered questionnaire. Participants were subjected to a pre-piloted interviewer-administered questionnaire before receiving 1st chemotherapy treatment (T1) and before the 2nd chemotherapy treatment (T2), 1-4 weeks apart. They were asked to provide information on their knowledge of chemotherapy side effects and self-care behavior taken to alleviate the side-effects. Data were analyzed using STATA version 16. Knowledge score was summarized using means and their corresponding standard deviations. Difference-in-difference test was used to compare the knowledge gained between the two arms of treatment between T1 and T2. Proportion of correct actions taken was summated as a percentage score. The scores were summarized as medians and their corresponding interquartile ranges. Wilcoxon rank-sum test was used to assess the differences in proportion of correct action taken between the two arms of treatment.

Results: There was a significant increase in knowledge from baseline for the intervention arm (T1 mean score 5.034; T2 mean score 9.743) compared to the control arm (T1 mean score 5.429; T2 mean score 8.611) with a difference-in-difference analysis mean score of 1.527 (95% CI: 0.963-2.091; $p < 0.001$). The intervention group was able to take 42.9% correct self-care actions to alleviate symptoms compared to control group who managed 33.3%. The difference between the two median scores was statistically significant -4.850 ($p = 0.001$).

Conclusion: A well-structured and standardized chemotherapy-intervention-education program improves chemotherapy side-effects knowledge and implementation of self-care behaviours among ambulatory cancer patients undergoing chemotherapy treatment compared to an unstructured standard-of-care clinician-centered education.

Recommendations: A well-structured and standardized educational package should routinely be in use for ambulatory chemotherapy-naïve patients scheduled for chemotherapy treatment. Future prospective studies to assess cumulative gain in knowledge and self-care throughout full course of chemotherapy treatment should be done.

CHAPTER ONE: INTRODUCTION

1.1 Background

Cancer is the second leading cause of death worldwide (GLOBOCAN, 2018). In 2018, the International Agency for Research on Cancer (IARC) reported that the burden of cancer was estimated to have risen to 18.1 million new cases globally and accounted for 9.6 million deaths (Release, 2018). In Kenya, cancer is the third leading cause of death after cardiovascular and respiratory diseases attributing to 47,887 cases reported annually (Juma et al., 2017).

Cancer treatment has advanced significantly in response to the increasing incidence of cancer diagnoses and deaths and as a result chemotherapy administration, one of the primary cancer treatments is also predicted to rise. After applying optimal chemotherapy utilization to the cancer incidence data published by IARC in 2018, Wilson et al observed that the number of individuals requiring first-course chemotherapy yearly rose from 9.8 million in 2018 to 15 million by 2040 (Wilson et al., 2019). This is a 53% increase in the number of patients expected to start chemotherapy.

The annual increase in cancer patients requiring chemotherapy has put pressure on healthcare systems, particularly in low-and-middle-income countries (LMICs). To counterbalance this rising burden, chemotherapy administration has steadily migrated from inpatient to outpatient settings. Over the last 25 years, there has been great advancement in the realm of oncology with improved safety of chemotherapy administration in an outpatient setting. An article published in the *Oncology Pharmacist* quotes that outpatient chemotherapy cuts patients' unnecessary costs of bed stays and improves patient satisfaction (Huynh & Trovato, 2014). In addition, oncology patients have compromised immunity from cancer itself and the treatment

modalities, therefore are prone to infections with every inpatient admission for chemotherapy. This has especially been true during the Covid-19 pandemic era (Sabbagh Dit Hawasli & Nabhani-Gebara, 2020). Healthcare and oncology program costs have also been reduced with the relief of bed crunches in inpatient setting with the availability of these beds to individuals in dire need of inpatient care. However, this brings forth concerns on how to effectively provide chronic care to patients outside of hospital settings.

Chemotherapy has been associated with several cytotoxic effects as it also damages healthy cells. These side effects include nausea and vomiting (Ruggeri et al., 2007), hair loss, loss of appetite, depression and generalized fatigue which vary from person to person depending on the cancer type, location, the type of chemotherapeutic drugs and their dosages, not to mention, the general health of the individual (Williams & Schreier, 2004). Complications of cancer therapy have accounted for up to 55% of hospital admissions in most hospitals in high-income countries (Atkins & Fallowfield, 2006). This has also been evident in low-and middle-income countries. including Kenya where a study quoted that drug-related problems accounted for 5-10% of KNH admission of cervical cancer patients (Degu et al., 2017). In addition, 15.4% of these patients were reported to have poor adherence to medication citing debilitating side effects of therapy. These frequent hospital visits and admissions caused by poorly managed cancer side effects lead to interruptions in cancer care and are laborious for patients. This eventually leads to debilitating and distressing effects for patients living with cancer who are still trying to cope with their cancer diagnosis while still taking part in their day-to-day responsibilities.

Moi Teaching and Referral Hospital (MTRH) caters to approximately 3,000 new cancer patients annually and provides daily outpatient cancer services including chemotherapy administration within the Cancer Unit. It has been observed at MTRH that patients with cancer are admitted to the medical ward comprised of patients who have either complication of the disease or side effects from chemotherapy. These include dehydration due to intractable vomiting and diarrhea, anemia with or without bleeding complications, poorly controlled pain, and worsening dyspnea due to lung and other infections or fluid in the lungs. Some of the more severe adverse effects include sepsis (neutropenic fever) and septic shock due to low immunity from cancer or chemotherapy. This has been the noted trend in other studies where characterized hospital admissions for most patients with cancers, in general, have been documented with most causes of hospitalization including sepsis, febrile neutropenia, anemia and dyspnea (Numico et al., 2015; Yu et al., 2019). Some of these complications can be avoided through close monitoring and early treatment modification. Previous research has provided insight into patients' perspectives on re-admission and highlighted that decisions for re-admission happen due to unmanageable needs experienced by patients that can be addressed by building stronger clinician-patient bonds and empowering patients and their families (Zibelli et al., 2020).

Patient empowerment involving engagement and education on early identification strategies of chemotherapy side effects are paramount in the completion of cancer treatment. Self-care is an example of such strategies that have been used for millennia and has been shown to enhance coping during cancer management (Qian et al., 2012). Self-care refers to patients' involvement in self-observing, recognizing, and labeling symptoms and judging their severity, assessing, adopting treatment choices, and evaluating the efficiency of self-care (Qian et al., 2012). The concept of self-care was

first tested in a study by M. Dodd et al. that assessed whether information influences a patient's chemotherapy knowledge, self-care behaviors and general affective state. The study found that patients who received information knew when to act promptly before side effects become severe (Marylin J. Dodd, 1984). This is crucial because self-care significantly reduces hospital admissions from life-threatening complications of chemotherapy and thus minimizes treatment interruptions.

The present standard of care in many health care settings including what is offered in MTRH Cancer unit is focused on verbal communication, which provides generalized counsel mostly provided before chemotherapy and is infrequently repeated during treatment (Meulen et al., 2010). Any additional issues regarding care are discussed as patients report them in their subsequent visits. As a result, most information provided in the first chemotherapy cycle visit is forgotten. According to a report from one of the annual American Society of Clinical Oncology (ASCO) meetings, more than half of the time, what patients are advised on differs from what they comprehend about chemotherapy side effects (Carlson & Doctors, 2001). Multiple studies suggest that for cancer education to be effective, it must include well-structured information concerning chemotherapy, potential side effects, and well-articulated instructions on self-care practices. The use of written information such as self-care management tools has been shown to reduce distress from cancer treatment and improve adherence and overall quality of life (QoL) (Jaenicke et al., 2019). Currently, there is no set of guidelines that have been recognized to optimally provide educational content to patients with cancer, however, there are numerous strategies and teaching approaches including the use of verbal, written, video, and group discussions and frequent visits and follow-ups have been shown to improve retention and guide self-care behavior (Pearce et al., 2017).

Therefore, the purpose of this study was to present a well-structured educational intervention in addition to the current standard-of-care to patients with cancer receiving ambulatory chemotherapy. This will provide information on patients' knowledge and ability to monitor, control and prevent the worsening of potential chemotherapy and cancer-related symptoms to ultimately improve comprehensive clinical assessment and service delivery. Not to mention create an advance in the field of science by demonstrating the utility of a patient-filled validated tool aimed at assessing patients' ability in self-observing, recognizing and labeling symptoms and judging symptom severity in a LMIC. The Memorial Symptom Assessment Scale (MSAS) is one such systematic and multi-dimensional tool that demonstrated utility in measuring the severity of symptoms in patients undergoing outpatient treatment for cancer developed and used in High-Income countries (HICs) but has yet to be routinely in use in Sub-Saharan Africa.

1.2 Problem Statement

The provision of chemotherapy is progressively on the rise due to increasing cancer cases globally. However, despite its merits, chemotherapy is well known to have side effects. Patients with information on chemotherapy side effects show an improvement in self-care behaviors that allows them to promptly act on noted side effects before worsening or becoming persistent (Fee-schroeder et al., n.d.-a). It is for this reason that WHO has cited self-care as the most promising concept in healthcare that improves the general well-being of patients. It provides patients with opportunities to carry out informed decisions pertaining to their health and care. Therefore it is then crucial that patient education regarding chemotherapy is administered before the start of the first course of chemotherapy in most hospitals in Kenya including MTRH.

However, as is often the case in many Low and Middle-income countries (LMICs) including MTRH Cancer Unit in Kenya, patient education generally relies on verbal communication for advice on chemotherapy and its potential adverse effects. Nevertheless, this form of patient education procedure is lacking as most patients have reported forgetting the information offered during the session. Additionally, there is no structured follow-up session offered to patients that can help patients recap their knowledge, thus creating a gap in the continuity of the patient's healthcare awareness. Furthermore, the information provided often fails to adequately cover all the needs of the patient with clinicians citing high workloads with time constraints, deficient healthcare systems and a lack of standardized approaches to side-effect management (Botti et al., 2006). It has also been observed that the design of the education delivered to patients is clinician centered with the type and quantity of information provided often being decided upon by the healthcare professionals. This results in poor delivery of information thus reducing its efficiency and quality.

Therefore, the current clinician-centered patient education on chemotherapy's potential side effects and self-care practices offered at MTRH can be cited as lacking in terms of structure and quality as it does not meet the patient's information demand and as a result, it is ascribed as one of the main reasons for a high number of cancer patients admitted to hospitals due to chemotherapy side effects. This can be attributed to the lack of clear guideline and patient education materials that offers basic information on cancer and chemotherapy. Currently what is offered in MTRH oncology unit is a verbal discussion between the clinician and the patient or the caregiver. This structure of information delivery (standard-of-care) is yet to be formally evaluated as efficient in providing the utmost care to our patients.

A review of the literature has shown that patient-centered structured education that involves a combination of information materials such as verbal, visual and written materials is much more effective. Additionally, the inclusion of follow-up sessions has been shown to improve information retention by patients. In regards to this, several education interventions have been tested using different methodologies and in a variety of locations worldwide to assess their effectiveness when compared to current patient education procedures to address the issue of lack of standardized education on chemotherapy side-effects education that allows for a productive learning structure.

A comparison of the results between the two education designs; usual standard-of-care patient education and the new proposed patient education intervention, will highlight the potential usefulness of a well-structured patient education design concerning chemotherapy side effects.

1.3 Study Justification

WHO in a report titled “WHO Consolidated Guideline on Self-Care Interventions for Health”, reported that it anticipates a scarcity of 18 million health workers worldwide by 2030 (WHO23, 2019). This is in part attributed to the increasing number of disease outbreaks worldwide. In particular NCDs such as cancer have been documented to be on a rising trend annually. This trend is continuing globally, with the global cancer burden increasing dramatically as the world's older population grows and cancer-causing behaviors such as physical inactivity, poor diet and exposure to chemo toxic products namely tobacco, become more prevalent. Of concern is the rising number of cancer cases in LMICs which are often associated with limited resources. It is expected that this rising burden of disease in LMICs will lead to a strained healthcare

system. Globally, countries are empowering their health care systems to handle this strain by introducing new approaches to improve healthcare.

There has been a drastic increase in evidence-based trials in education intervention more so in the late 1990s. Self-care interventions, while not a new approach, is anticipated to be beneficial to both the patients and healthcare systems. This approach encourages task sharing between the individual and the healthcare provider thus aiding in supporting healthcare systems, especially those facing limited medical resources. Concerning the patient, multiple education intervention studies have demonstrated that an increase in knowledge is linked to an increase in the correct self-care practices by patients. Two studies, in particular, show that patients who are more informed of potential chemotherapy side effects are involved in the taught self-care behaviors and have fewer hospital admissions, morbidities and mortalities (Arruebo et al., 2011; Krzyzanowska et al., 2019). These self-care practices aid in dealing with cancer symptoms as well as potential chemotherapy side effects by allowing for early detection of chemotherapy side effects before the issue exacerbates. Additionally, the practices allow the patient to deal with the side effects to the best of their ability using scientific information provided to them by the health care providers. In doing so they reduce chemotherapy-related anxiety and allow patients to cope better with their diagnoses and consequently improve their quality of life.

The minimum recommendation of American Society of Clinical Oncology (ASCO) is to provide a standardized verbal and written education to patients before the commencement of the first chemotherapy cycle. However, it is important to ensure a safe link between practicing self-care and access to healthcare when designing self-care education intervention programs. The perspectives of different communities,

cultures, languages and healthcare systems should also be considered to ensure education interventions are designed to fit the people they intend to serve. For this, multiple studies concerning chemotherapy side effects and self-care have been conducted in diverse communities where the benefits of these new well-structured chemotherapy-education interventions over conventional clinician-centered patient education have been highlighted. However, the focus of many of these studies has been limited to high-income countries. Compared to developed countries, chemotherapy adherence by patients in developing countries is poorer (Adisa et al., 2008). This makes generalizability of conclusions difficult due to disparity in health care system organization as well as the difference in resource availability. Furthermore, the majority of the literature has been descriptive cross-sectional studies with some focusing on a single cancer site or a single symptom. As a result, the existing literature is inadequate in providing information on the effects of new chemotherapy education interventions on knowledge and self-care in relation to current patient education on cancer and potential chemotherapy side effects in our local setting.

Therefore, this study aimed to fill the literature gap by conducting a randomized control trial (RCT) comparing a new chemotherapy intervention to the conventional clinician-centered education offered to cancer patients at MTRH. The RCT sought to determine whether the implementation of a standardized interventional program that is primarily focused on the patient's perspective had any significant effect on patients' ability to discern the side effects of chemotherapy and can initiate correct self-care behaviors that elicited positive outcomes in the patients physical and psychological wellbeing when compared to a current clinician centered cancer education practice at

MTRH. The findings of this study would be useful in identifying common distressful and severe chemotherapy side effects symptoms of chemotherapy.

1.4 Research Questions

1. What is the difference in the level of knowledge gained from a standardized chemotherapy education compared to standard-of-care in ambulatory cancer patients at MTRH?
2. What is the effect of a standardized chemotherapy education intervention compared to standard-of-care on cancer patients' self-care?

1.5 Study objectives

1.5.1 Broad objective

To determine the effect of standardized chemotherapy education compared to standard-of-care on patients' knowledge and self-care on expected chemotherapy side effects among ambulatory cancer patients.

1.5.2 Specific Objectives

1. To assess the effect of a standardized chemotherapy education intervention compared to standard-of-care on knowledge of chemotherapy side-effects among ambulatory cancer patients at MTRH
2. To compare standardized chemotherapy education versus standard-of care on patients' self-care among ambulatory cancer patients at MTRH

CHAPTER TWO: LITERATURE REVIEW

2.1: Introduction

Cancer is defined as the abnormal and uncontrollable multiplication of normal body cells with the ability to infiltrate other normal body tissues (metastasis). It can begin from any part of the body, grow beyond its boundaries and invade other tissues and organs (WHO 2018). A tumor is defined as a lump or a growth and can be either benign or malignant. Malignant cancers have the ability to metastasis due to the down-regulation of receptors necessary for cell-to-cell adhesion and the up-regulation of cell motility receptors. Cancers are named based on the origin of the cancer cells (primary site) e.g. Breast cancer, gastric (stomach) cancer, etc. There are two main categories of cancer: Hematologic cancer and Solid cancer (Zhang et al., 2015). Hematologic cancers are cancers of the blood including lymphoma and leukemia while solid cancers are cancers of body organs or tissues e.g. prostate cancer, or colon cancer. Solid cancers fall into 2 main groups, sarcomas and carcinomas. Carcinomas arise from epithelial cells while sarcomas from connective tissue (Mathur et al., 2015). The etiologies of cancers are numerous, known as carcinogens; however, the multiplex process leading to malignancies begins from a primary issue caused by changes in nucleus DNA within the cells, termed mutations (Blackadar, 2016). This leads to the activation of oncogenes and suppression of tumor suppressor genes (Sarkar et al., 2013). This can lead to uncontrolled cell cycle progression and inactivation of programmed cell death (apoptosis). Tumors affect the individual's quality of life and survival when they invade vital tissues and organs. Malignant tumors are screened and categorized into stages (Stages 1-4) based on the size and how far they have metastasized. This is also vital in choosing the best treatment for an individual. Thus the most important aspect when choosing a treatment modality for

cancer has to focus on a cure and if not possible, a treatment that will prolong life and limit the individuals level of suffering (palliation) (Farhat, Aziz Khan. Shad, Salim Akhtar. Muhammad, 2005).

2.2: Burden of Cancer

In the culminating of the millennium developmental goals in 2015 and the inauguration of Sustainable developmental goals (SDG), non-communicable diseases were identified as a major challenge and issue in the sustenance of development (Singh Thakur et al., 2021). Albeit communicable diseases, nutritional deficiencies, together with pregnancy and child-birth-related deaths are the drivers of morbidity and mortality in low and middle-income countries (LMICs) there has been a gradual rise of non-communicable diseases and related deaths (Wells et al., 2021). Cancer in itself presents a major hurdle in LMICs due to the lack of resources and infrastructure geared toward early screening and detection of cancer, poor educational system affecting inertia of seeking health-care services, a cultural taboo view of cancer and limited resources and trained personal in the treatment of cancer (Haier et al., 2019). Although there is the implementation and rolling-out of health insurance in most African countries as a way of promoting Universal Health Care (UHC) criteria, access to primary health care is still a key requirement of UHC that unfortunately is not accessible to the most vulnerable groups (Haier et al., 2019). Cancer, therefore, continues to be a prominent cause of morbidity and mortality in Low and middle-income countries (LMICs) due to the late diagnosis of cancer (List & O'Connor, 2020). Patients diagnosed with cancer continue to grow rapidly with a projected one in eight individuals in the LCIMs experiencing a diagnosis of cancer in their lifetime. Approximately three-quarters of cancer-related deaths are projected to arise from LMICs by the year 2030 (List & O'Connor, 2020; Pramesh et al., 2022). This is due

to lifestyle changes, increasing population life expectancy and growing urbanization (Pramesh et al., 2022).

Cancer is the 2nd leading cause of mortality in the world. (Health, 2017). This carries with it a major public health and economic issue. According to the World health organization (WHO), cancer cases in 2020 had increased to nearly 20 million worldwide and about 10 million cancer-related deaths (one in nearly six deaths). This is projected to rise by over 50% in the next 20 years. Lung cancer is the most diagnosed cancer in both genders (11.1%), with 18.1 mortality rates, followed by breast cancer in the female population (11.6%), prostate cancer (7.1%) and colorectal cancers (6.1%) (GLOBOCAN, 2018). In Kenya, the commonest causes of cancer deaths are lung cancer (1.69 million deaths), liver (788 000 deaths), colorectal (774 000 deaths), stomach (754 000 deaths), and breast (571 000 deaths) (Health, 2017). A cross-sectional retrospective survey conducted at Kenyatta National Hospital (KNH) and Moi Teaching and Referral Hospital (MTRH) from 2008 to 2012 revealed the five common types of cancers were Kaposi's sarcoma (93, 18.6%), breast (77, 15.4%), cervical (41, 8.2%), non-Hodgkin's lymphoma (NHL) (37, 7.4%) and colorectal, chronic leukemia and esophageal cancer all with 27 (5.4%) (Macharia et al., 2018).

Research in Cancer and its treatment unfortunately is heavily skewed towards High-income countries (HIC). There is little research being conducted in LMIC, that is relevant to the problems encountered in these countries (Heneghan et al., 2013). Only 8% of phase 3 trials conducted between the years 2014-2017 were done in LMICs (Wells et al., 2021). This negatively affects contexts and finding generalizability across populations and countries. There is an evident imbalance in knowledge and the application of results of research done in HICs. The information available fails to

address the cancer control strategies available for several cancers. This is due to the differences in health care systems, availability of medication, and sociocultural factors affecting treatment-completion rates. Different ethnicity and regions also present biological differences and cancer incidence E.g. higher incidence of triple-negative breast cancer in LMICs as compared to HICs and involvement of regional environmental factors (infectious e.g. HIV and occupational exposures) (Drake et al., 2018). Hence it's important to consider the context of cancer in LMICs different from those in HICs and this is only possible by conducting our research that addresses local issues and challenges and coming up with solutions that are feasible, acceptable and easily implementable in our region. Randomized clinical trials still remain the most powerful tool in improving clinical practice. With the high number of outpatient chemotherapy education, trial protocols governing chemotherapy administration and education on potential chemotherapy side effects are important to present a true reflection of risk associated with therapy in a low and middle income country hospital.

2.3 Chemotherapy

Treatment of cancer involves different modalities including systemic therapy (chemotherapy, hormonal therapies, and targeted therapies) and radiotherapy. Chemotherapy was identified in the early 20th century however its use in the treatment of cancer was initiated in the year 1930s. The word “chemotherapy” was a term coined by a German scientist by the name Paul Ehrlich which meant treatment of diseases using chemicals (DeVita & Chu, 2008). To date, the term chemotherapy has come to denote the use of intracellular poisons to inhibit cell division (mitosis) or cause cell death through DNA damage. Soldiers who were exposed to mustard gas in the First and Second World Wars had a considerable reduction in leukocytes.

Consequently, this led to researchers investigating whether mustard gas would lead to the suppression of rapidly dividing cells. In 1943, Alfred Gilman and Louis Goodman demonstrated the use of mustard agents in treating lymphomas in mice. Then together with Gustav Linskog, a cardiothoracic surgeon, they injected a less potent form of a mustard agent into a patient with Non-Hodgkin's lymphoma. This marked the use of cytotoxic agents, with the study done in 1943 and published in 1946 (DeVita & Chu, 2008). In the following years after this discover, other chemotherapeutic agents were discovered including alkylating agents like chlorambucil and cyclophosphamide. Conventional chemotherapy agents do not differentiate between cancer/tumor cells and normal cells. Normal cells that rapidly divide are susceptible to chemotherapy which targets highly mitotic cells e.g. bone marrow cells, hair follicles and digestive tracts. This has led to several toxic side-effects sometimes life-threatening leading to discontinuation of treatment and negatively impacts on the patients' quality of life and level of functioning (Altun & Sonkaya, 2018).

The choice of therapy involves the staging and type of cancer and the patient's status. Generally, the primary goal is to cure cancer or to prolong the life of the individual and in doing so maintain the quality of life of the patient. However, the main concern for both patients and clinicians with the use of chemotherapy to treat cancer is the side effects profile and the long-term sequelae of treatment. In as much as there has been significant improvement in chemotherapy, the cytotoxic effects are still a concern in the oncology world and have been a weakening and an obstacle in the management of cancer. Unfortunately with the rising number of outpatient chemotherapy administrations, these effects are experienced by patients while at home (Dickson et al., 2013). The side-effect commonly experienced by patients include nausea and vomiting, decrease in appetite, fatigue, constipation, loss of taste and hair loss

(Arunachalam et al., 2021a; Chan & Ismail, 2014; Nurgali et al., 2018). The diagnosis of cancer comes with changes in physical and emotional status, pain, decrease in the level of self-esteem and dependence. Several studies have addressed these adverse effects but few have centered on the patient's knowledge of their treatment (Coates et al., 2006). Therefore, cancer, being recognized as one of a chronic illness, therefore, requires self-management as an integral part of care (Zucca et al., 2014). Self-care is the ability to recognize symptoms pertaining to poor health, judge the severity and adopt self-care practices to alleviate such symptoms (Marylin J. Dodd, 1984; Qian et al., 2012; Richardson et al., 2010). Self-care behavior practices are a learnt skill that can be implemented by health care professionals through a well-structured education. Clinicians need to encourage self-care behavior during and after chemotherapy and promote their implementation at home. Provision of information on self-care practices is therefore the most important concept when it comes to patients' ability to carry out actions to alleviate the chemotherapy adverse effects which they may experience away from health care facilities.

2.4 Chemotherapy adverse effects

Chemotherapy affects an individual's physical health, emotional health and overall quality of life (De Boer-Dennert et al., 1997; Piotto et al., 2002). The negative quality of life affects an individual willingness to continue with therapy. It has hence been extremely important to integrate the experience and perception of chemotherapy toxicities in the care of patients with cancer (Almohammadi et al., 2019; Feeschroeder et al., n.d.-b). With the increasing number of outpatient chemotherapy administrations, these side effects are experienced at home. Studies have demonstrated the different side effects patients experience (Altun & Sonkaya, 2018; Cleeland, 2007; Degu et al., 2017; Pearce et al., 2017).

Immunosuppression and Myelosuppression

Chemotherapy causes direct damage to the proliferating progenitor cells of the bone marrow leading to a decline in the circulating erythrocytes (anemia), leukocytes (neutropenia), and platelets (thrombocytopenia). This can lead to life-threatening infectious and hemorrhagic risks to patients undergoing treatment. The burden associated with myelosuppression is dose-dependent, however, a reduction in the dose of chemotherapy leads to poor patients outcome (earlier disease recurrence) treatment delays and poor adherence (Maxwell & Maher, 1992). During myelosuppression, prevention and early detection of hematological- associated toxicities such as sepsis and bleeding become the goal to prevent further complications.

Neutropenia is the decrease in white cell count. Leukocytes are the primary line of defense against infections, especially febrile neutropenia. The magnitude of neutropenia and neutropenic fever (fever associated with neutropenia brought about by the inability of low body immunity to fight infections) depends on the chemotherapy administered (Baluch & Shewayish, 2019). Anemia refers to the decrease of hemoglobin from the patient's normal value. Anemia causes symptoms like fatigue and inability to carry out normal activities (Epstein et al., 2021). Anemia can also be caused directly by the suppression of erythropoietin by chemotherapeutic agents. Thrombocytopenia is the decrease of platelet whose mainstay of therapy is transfusions of platelets otherwise it comes with a risk of hemorrhage. Patients are encouraged to identify signs of infections like fever, chills, cough and shortness of breath and approach the nearest emergency unit for management. Fatigue and fainting episodes can be signs of anemia which patients should be on the lookout for together with bleeding tendencies for thrombocytopenia. Routine blood check-ups before each

chemotherapy sessions helps in early identification of complications of myelosuppression (Barreto et al., 2014).

Chemotherapy-induced Nausea and Vomiting

Nausea most frequently occurs in patients undergoing chemotherapy and is described as an impending sensation of vomit while vomiting is the physical expulsion of stomach contents through the mouth (Singh et al., 2016). Nausea and vomiting despite the advance in the use of antiemetics are still reported by patients as the most distressing symptom while undergoing chemotherapy therapy (Dien et al. & Sheean et al., 2008). The risk factors associated with chemotherapy-induced nausea and vomiting include age less than 50, female gender, chemotherapeutic regimen and history of nausea and vomiting. Patients need to recognize this side-effect because it complicates quality of life, interferes with administration of chemotherapy and increases hospital admissions for dehydration and loss of body mass which can implicate directly healthcare costs (Zibelli et al., 2020). As part of the NCCN and ASCO guidelines on chemotherapy induced emesis, patients are encouraged to have lighter meals before chemotherapy, avoid spicy and fatty foods after and take the anti-emetic medications as part of their self-care.

Fatigue

Cancer-related fatigue is described as an excessive unusual feeling of exhaustion unrelated to activity and unrelieved by rest. Cancer patients have an estimated prevalence of fatigue of 10-90% (Muthanna et al., 2021) and this is worse with chemotherapy treatment. This has a profound impact on the quality of life affecting mental health and physical function (Iop et al., 2004). Fatigue is caused by both intrinsic and extrinsic factors. Intrinsic factors include anemia, nausea and vomiting,

anorexia, nutritional deficiencies, and depression while extrinsic factor mostly entails chemotherapy (Schleimer et al., 2020). Fatigue management is limited and the lack of information from clinicians on cancer and therapy-related fatigue affects patients (Kapoor et al., 2015). Patients are encouraged to engage in conserving energy by engaging in small tolerable activities as a form of self-care. Studies have shown some patients modify their wake-sleep pattern while others engaged in psychologically distressing measures (Spichiger et al., 2012).

Peripheral neuropathy

One commonly cited reason for limiting chemotherapy using chemotherapeutic agents is the onset of peripheral neuropathy. Clinically, it presents as variable-intensity impairments in sensory, motor, and/or autonomic systems (Park et al., 2013). Depending on the chemical employed, sensory and painful neuropathy can be seen with cisplatin, and carboplatin, or a mixed sensorimotor neuropathy seen with vincristine, and suramin can be observed (Quasthoff & Hans, 2002). The type of medicine used and the total cumulative dosage both affect neurotoxicity. After just one medication application, neuropathy might develop in certain circumstances. In cases of preexisting nerve damage such as in diabetes and alcohol, it has been shown such patients are often more susceptible to developing chemotherapy-induced neuropathy. Unfortunately, the recovery from symptoms is frequently only partial, and function must be restored after a lengthy time of regeneration. There is currently no medicine that can successfully stop or reverse chemotherapy-induced neuropathy. The most distant regions of the limbs show the largest deficits in sensory complaints. The symptoms include tingling or prickling, “pins-and-needles” sensation (paresthesias) brought on by touch and change in temperatures, as well as numbness and altered touch sensation. Furthermore, unpleasant sensations are commonly

experienced, including sudden scorching or electric shock-like pain. These symptoms may become so severe that they lead to a loss of sensory awareness. Less commonly than sensory symptoms, motor problems typically manifest balance issues, and hindered motions (Bernhardson et al., 2007). Chemotherapeutics harm the neural structures and result in neuropathy through a variety of mechanisms, including DNA damage, mitochondrial damage from oxidative stress, immunological responses, abnormal ion channel function, myelin sheath injury, microtubule disruption, and inflammation to nerves (Zajęzkowska et al., 2019). There is currently increasing interest in non-pharmacological strategies due to the avoidance of drugs and this has led to the research of non-pharmacological alternatives for the prevention or treatment of chemotherapy-induced peripheral neuropathy which are presently gaining more attention. However, evidence of effectiveness for a number of these techniques, such as acupuncture, physical activity and cryotherapy or compression is still lacking (Li et al., 2021).

Hair Loss

Although there are conflicting incidence reports due to the broad use of systemic anticancer medicines, the different drug combinations, and the underreporting of hair abnormalities, these occurrences are common across practically all types of therapy. The prevalence of Chemotherapy-induced alopecia is thought to be around 65%, although it varies depending on the medications and treatment plans (Trüeb, 2009). Chemotherapy-induced alopecia can have terrible psychological effects, yet effective treatment options are still hard to come by. Alopecia caused by chemotherapy typically develops rapidly and initially seems like pattern hair loss, which is most noticeable on the scalp. The scalp regions that exhibit low total hair densities, for example, the frontal hairlines, are particularly affected by the most severe hair

destruction, which appears to be selective. Persistent chemotherapy-induced balding is extremely uncommon, although it is becoming more common in situations where hair regeneration is drastically slowed down or does not happen at all. High-dose chemotherapy is commonly linked to this occurrence. Between chemotherapeutic drugs, there are significant differences in the likelihood of chemotherapy-induced alopecia and the amount of hair loss.

A person's scalp and facial hair give psychological signals that vary from general well-being to social standing, and group affiliations to characteristics including sexual desire, fashion, religion, etc. Chemotherapy-induced alopecia isolates patients by giving them a clear sign that they are unwell and that their appearance is different from what is considered normal. These side effects encourage social disengagement, worsen the psychological toll of cancer, and lower quality of life. The burden of various hazardous side effects associated with chemotherapy is significantly increased. The fundamentals of pathobiology are that chemotherapy-induced hair follicle damage primarily affects rapidly growing, thus most vulnerable, which is extremely sensitive to toxins.

The mainstays of chemotherapy-induced alopecia management include counseling, written information provision, professional psychiatric support, and the suggestion to wear a wig (Rossi et al., 2017). Gentle hair care techniques should be implemented before, during, and after chemotherapy. To prevent further harm, a light shampoo should only be used when required, along with a soft brush. Shaving or shortening hair is not required; however, it may be more comfortable. Patients may benefit from wearing wigs to help them cope with this disease and protect their scalps from the sun and the elements. A similar wig might be utilized by patients, who would have their

hair clipped and implanted on a prosthetic support, to enhance their psychological state and provide them access to their hair (Rossi et al., 2017).

Hypothermic impact of scalp cooling is believed to decrease scalp perfusion and, as a result, the ability of blood-borne chemotherapy to reach the hair follicles, which affects metabolism, drug absorption, and drug cytotoxic effects (Rossi et al., 2017)

There is minimal information available on treatments to stop chemotherapy-induced alopecia. In one research, 5 out of 6 individuals who had a topical treatment of 2% minoxidil (medication to stimulate hair growth and reduce balding) experienced chemotherapy-induced alopecia. However, compared to women who got a placebo, ladies treated with 2 % minoxidil saw faster hair growth (Hesketh et al., 2004). Minoxidil, however, can be used after chemotherapy to accelerate the growth of hair (Suchonwanit et al., 2019).

Pain

Pain serves as a warning sign that something is amiss with our bodies as a protective mechanism. Pain that is not properly managed and/or has no known cause might have detrimental effects on daily activities (Fornier et al., 2007). In combination with other symptoms, pain can cause dread, worry, and hopelessness, all of which can contribute to exhaustion, depression, sleep problems, and stress. According to earlier research, pain appeared to be more pronounced after adjuvant chemotherapy was administered in high doses or concentrations (Fukshansky et al., 2005). Usually, the tumor itself is the source of cancer discomfort. Bone, soft tissue, muscle, and nervous system invasion are all factors in the discomfort that tumors produce. For example, under rare circumstances, a tumor's fast growth or lysis can cause excruciating agony.

Treatment-associated pain, such as chemotherapy-related neuropathic pain, surgical pain syndromes, and post-radiation pain syndromes, is a less common cause of cancer pain. Pain can also manifest as headaches, oral mucosal issues, hand-foot syndrome, and nail abnormalities. Opioids continue to be the mainstay of pharmacotherapy in the fight against cancer-related pain. Physicians now have access to a wider variety of pharmacologic analgesic choices because of an increase in the number of opioid agents and formulations available for the treatment of chronic pain over the past ten years. Based on patients' self-reports of symptom intensity, the WHO recommendations and certain follow-up guidelines, such as those from the National Cancer Care Network (NCCN), give a reasonably straightforward algorithm for the management of cancer pain.

For the management of minor pain, non-opioid medications such as acetaminophen or non-steroidal anti-inflammatories (NSAIDs) are advised. Adjuvant drugs, such as anticonvulsants and antidepressants, are frequently advised for neuropathic pain disorders. An opioid that is weaker than morphine, such as codeine, hydrocodone, tramadol, and propoxyphene, is utilized when these therapies are ineffective in providing sufficient relief. Opioids in this class are used to treat mild to severe pain. For moderate to severe pain, the third rung of the analgesic ladder comprises potent opioids including morphine, hydromorphone, oxycodone, and fentanyl.

2.5 Patients Education

Patient education refers to any intervention carried out by healthcare professionals to enable and equip people with the necessary knowledge and skills concerning their health to encourage effective coping strategies, improve quality of life, and develop independence and self-efficacy (Martínez-Miranda et al., 2021). This involves any series of carefully thought-out educational activities including teaching, counseling,

and behavior modification aimed at enhancing patients' knowledge and health behaviors (Friedman et al., 2011).

Patient education is especially important to cancer patients receiving chemotherapy in outpatient settings where they are required to monitor and report their treatment side effects. However, the delivery of patient education is a complex process that involves determining the patient's needs, organizing the delivery of information, reinforcing it, and evaluating it. Therefore, finding the most effective way to teach patients about their cancer diagnosis is a never-ending issue for oncologists. Nonetheless, a primary focal point for ensuring effective patient education delivery is to ensure patients' preferences are used as the guide to teaching approaches and thus information delivery techniques should be carefully adapted to match patients' requirements. For that reason, clinicians need to have a clear understanding of patient education strategies as effective patient engagement remains a top objective for healthcare providers.

In recent years, reports documenting interventions aimed at supporting patients with their cancer and chemotherapy treatment have been published in the oncology literature. The lack of communication between the patient and the healthcare provider is frequently reported as the root of non-compliance. A lot of these papers have highlighted the benefits of educating patients on the self-management of chronic diseases (Jarvis et al., 2010).

A review of the literature has shown that the provision of a well-structured informational intervention concerning cancer treatment through patient education is the most effective way of encouraging patient participation. As a result, this leads to the development of successful behavior changes. This is because patients who are informed about their health are more likely to employ self-management approaches,

schedule follow-up sessions, and question their doctors about their treatment. Therefore, it can be concluded that patient education is a necessity for the development of self-care practices.

This is supported by Arunachalam et al study, which concluded that increased knowledge of chemotherapy's side effects improves cancer patients' self-care practices (Arunachalam et al., 2021a). Dodd M. also found that the difference between experienced side effects and the initiation of self-care behaviors was attributed to a lack of necessary information and limited knowledge of self-care measures (M. J. Dodd & Miaskowski, 2000). Of the 55 patients recruited for the study, an average of 0.81 self-care behaviors were initiated for an average of 7.69 effects experienced. Patients were not aware of which actions needed to be taken to alleviate their symptoms. Some patients endured the side effects of chemotherapy perceiving it as an expectation to 'cure' the disease (DODD, 2006a).

This concept of patients' education is further supported by an earlier study that was done to measure informational intervention amongst cancer patients. In the study, patients were randomized into four groups, the first group received drug information only, the second, received side-effects management techniques (SEMT), the third received combined education on the drugs and SEMT and the fourth was the control. Pre-intervention average self-care behavior performance score was 3.02 pre-intervention as opposed to the 6.01 post-intervention concluding that cancer patients need more information than they now receive regarding their condition and its effects (Marylin J. Dodd, 1984). From the study, patients that were given information on how to handle side effects initiated correct self-care behaviors that avoided life-threatening complications.

In addition teaching patients reduces their psychological distress and improves their quality of life (Tian et al., 2015). A randomized control trial conducted by S. Aranda et al. to assess the level of patient distress and treatment-related concerns showed there was a significant reduction in the severity and level of distress of chemotherapy-induced vomiting ($p=0.001$) together with psychological concerns ($p=0.027$). In that study, 192 patients with different cancer diagnoses were subjected to a pre-chemotherapy education intervention (ChemoEd) before the first chemotherapy treatment (T1) and before the second cycle of chemotherapy treatment (T2). Information provided during patient education should be detailed. Patients need to understand what to expect from chemotherapy treatments and should also be informed on the self-care management procedures. However, well-detailed information education can still be ineffective despite it being implemented in a clear and elaborate system during clinical practice. This is because a majority of patients have difficulty comprehending the information (Hagerty et al., 2004). This is because, despite using a comprehensive information tool to provide patients with education, too much information can still be overwhelming to patients. Denial can affect a patient's receptiveness to such crucial information while they still try to understand their diagnosis. Moreover, patients acquire information in a variety of ways hence patient education is required to incorporate a variety of instructional methods. Therefore, further assessment of how patients understand the education and information provided is crucial in ensuring patient education is effective.

It has been established that organized instruction is far more successful than informal, ad hoc instruction (Ranmal et al., 2008). Additionally, it has also been discovered that culturally appropriate patient education helps patients learn more (Bailey & Chang, 2007). That being the case the education intervention that served as the basis for the

targeted patient education instruction techniques used in this study used a validated framework by the University Health Network (UHN) Patient Education Task Forum following NCCN guidelines

Components of the new education intervention

Information support tools and patient education materials are crucial tools for improving patients' access to health information. They serve as the foundation for informed participation in decision-making in matters including medical treatments and health. A Cochrane Review has demonstrated that information tools increase awareness of alternative therapies, and reduce anxiety by providing patients with a sense of being well-informed (Ream & Richardson, 1996). This then helps them understand and make informed decisions on the appropriate medical intervention (Gaston & Mitchell, 2005). A crucial component of medical care is educating patients on the use of prescription drugs.

Comprehensive patient education should cover topics such as when, how, and who to contact for medical assistance, how to manage and prevent side effects, the value of adhering to prescribed treatment plans, tools for doing so, and safety concerns. As a result, several programs have been put in place to inform individuals about prescription medications. They involve several techniques that have been employed to make it easier for cancer patients and caregivers to get information from medical providers and other sources to meet these demands. These consist of oral communication, textual materials, phone hotlines, instructional materials, and multimedia aids.

Oral communication

Patients are more interested in information that enhances their sense of well-being and assists them in resolving acute health issues. Patients' knowledge and literacy levels have a significant role in their capacity to engage in their treatment and decision-making and should be taken into account when giving oral communication (Gaston &

Mitchell, 2005). Low health literacy patients rely significantly on oral communication and require assistance in recalling what they are told (Ngoh, 2009). They would rather learn about their health issues through verbal communication rather than read about them. According to research on doctor-patient communication, patients with low literacy may desire and require information to be explained, but they tend to ask fewer questions and may try to hide their poor comprehension out of embarrassment (Ngoh, 2009). However, patients' desires for oral communication and healthcare practitioners' efforts to fulfill these needs may not always overcome communication issues. This is because health practitioners may find it challenging to convey information at times, especially when interacting with patients who may lack basic reading and/or health literacy abilities as a result of the terminology and vocabulary used by medical experts differ significantly to those of their patients (Ngoh, 2009). Many people, even those with high literacy levels, struggle to grasp frequently used medical phrases, concept words and categorization words

During patient education, it is advised to cover several subjects in-depth while discussing oral chemotherapy e.g. name of the drug, including the brand name if applicable. The patient should be told to carefully match the written instructions supplied by the clinic with the prescription bottle and drugstore recommendations. The schedule and dose should be discussed. A pillbox organizer may be useful if the patient's recommended dosage calls for taking several dose-sized tablets or capsules (Hartigan, 2003). Furthermore, patients must be made aware of any special instructions, such as when to take it with food or to avoid food-drug interactions, how important it is to not take two doses at once to make up for a missed one, and how crucial it is to be completely honest when reporting how accurately they have taken their chemotherapy. Patients need to be aware that dosage modifications are made

based on reported adverse effects and that providing inaccurate information may have negative consequences (Hartigan, 2003).

When patients acknowledge mistakes or delays in following oral chemotherapy instructions, they need compassion and reassurance. To aid with adherence, further support and safety measures have to be implemented. In addition to information on the name, dosage, and warnings of the medicine, patients often desire information about the medication's indication, anticipated benefits, length of therapy, and probable side effects (Mills & Sullivan, 1999).

Additionally, to help patients follow their recommended drug regimes, measures focused on enhancing patients' recollection of medical instructions must be implemented because individuals instantly forget more than half of the information from spoken explanations. Recall may be improved by giving instructions understandably and straightforwardly, utilizing concrete and precise guidance, repeating and emphasizing the significance of the counsel's key points, ensuring comprehension, and offering feedback (Friedman et al., 2011).

Written communication

Verbal instruction and dialogues alone are the least efficient teaching methods when it came to particular teaching tactics (Friedman et al., 2011). Theis and Johnson advise against using verbal instruction alone, instead suggesting that it be used in conjunction with other teaching methods (A. Johnson & Sandford, 2005). Therefore, written material can supplement verbal therapy by reinforcing certain directives or cautions. The use of written prescription drug information sheets to support and supplement verbal counseling is a crucial element of many of these interventions (Friedman et al., 2011). Written health information materials are used by medical

professionals as part of patient education or health promotion initiatives, in support of preventative, therapeutic, and adherence goals. Information about side effects, drug interactions, the function of the medicine, what to do in the case of side effects, the anticipated length of therapy, and what to do if a dosage is missed is included in patient education brochures issued by doctors. Additionally, it might offer a way to introduce supplementary material that could be challenging to discuss during a quick therapy session.

Written materials must be written at a suitable reading level for the target audience to give patients the best drug information possible. One of the things that determine a text's value is its readability, or how simple it is to read and comprehend. Most people want straightforward, understandable health advice. By simply giving patients the most important instructions and utilizing everyday language, doctors may make their advice to patients more understandable. For this study, a pamphlet containing a chemotherapy information guide adapted from the University of Health Network (UHN) is one of the written materials frequently used

Follow-up

Telephone-based follow-up post-discharge is one of the most successful and economical ways to follow up on patients and deal with any late concerns. These telephone-based follow-ups, conducted by the pharmacist or other medical experts like nurses, have revealed significant positive outcomes in clinical studies (Sanchez et al., 2015). Clinical results for patients improved in some trials, but they remained clinically equal in others. In a retrospective research conducted in 2013, the effect of a pharmacist phone call made within four days after a patient was discharged from a hospital was examined (Anderson et al., 2013). It was observed that the incidence of readmission back to the hospital within thirty days was much lower. Additionally,

follow-up appointment attendance was greater for patients who were successfully reached for follow-up.

A study randomized trial was performed by Schneider and colleagues with 45 patients receiving oral chemotherapy; the intervention group received standard chemotherapy education plus a specially designed clinician-led phone call every week for the first month, then every two weeks for the following six months, until the end of the treatment. At two and four months, patient adherence rates were evaluated in both groups. The intervention group had greater adherence rates, indicating that the personalized follow-up phone intervention was successful in fostering adherence (Schneider et al., 2014). Additionally, an evaluation of the viability of face-to-face patient education together with a clinician-initiated follow-up phone call and the use of a medication diary to support oral chemotherapy knowledge and medication compliance for gastrointestinal cancer patients was conducted by Sommers and colleagues in a non-experimental descriptive pilot study. The analysis of the data showed that using the follow-up phone call helped with better symptom management (Sommers et al., 2012).

2.6 Theoretical framework

This study was guided by the Common Sense Model (CSM) which was developed by Howard Leventhal and colleagues. The CSM has also been identified as a self-regulation model, this is because CSM progressively evolved during the 1960s and 1970s, with revisions and modifications to the principles and propositions based on actual data collected at the time and was also referred to by different names (Leventhal et al., 2016). The theory provides a framework for examining how an individual's perception of diseases influenced how they coped with healthcare events (J. E. Johnson, 1999). The theory relies on the cognitive processing theory that

proposes that patients' perception or interpretation of the illness affects their ability to cope (Reuille, 2002). These interpretations of the healthcare events are dependent on the patient's experience of illness or perceptions of the individual's normal state of being (Leventhal et al., 2016). The understanding achieved from the mental picture created from these interpretations is then used to control or deal with the threat to their health. Therefore, CSM describes the cognitive processes involved in creating representations, recognizing treatment based on experience and developing an action plan by assuming that the individual's goals are to attain emotional comfort and reduce the health threat.

The Common Sense Model of self-regulation is divided into two pathways that often coincide with each other, that is, the functional response-guided pathway and the emotional response-guided pathway. The two pathways represent two coping pathways; regulation of functional response and regulation of emotional response to deal with the health threats. The model views a patient as a problem-solver placed within an environment that threatens the health and the main goal is to achieve emotional comfort by decreasing these events.

The latter process is initiated by stimuli that are experienced or observed as deviating from the normal function of the individual or differing from the information provided by others. For example, an increased heart rate of 120 beats per minute can act as a stimulus; the individual can identify the deviation from normal heart rate based on the experience of their normal heart rate or from information from healthcare professionals that provide the heart rate range as 60 to 100 beats per minute. The stimuli then activate the cognitive process that results in the generation of mental images that provide an understanding of the situation in terms of five main features; identity, cause, repercussions, potential duration and control and this guides necessary

plans to initiate and implement the treatments. For example, the increased heart rate base on previous experience is caused by anxiety and lasts for 30 minutes; the individual can decide to use calming techniques that previously worked. The success of the outcome of the behavior performed is decided by the individual meaning that the whole process is determined by the individual hence the term self-regulation.

Concurrently, the regulation of emotional response is initiated by the stimuli and occurs simultaneously as the functional response pathway but from a subjective and emotional level meaning that the experience basis for mental picture generation is primarily guided by emotions for example anxiety or fear associated health threat leads to a feeling of vulnerability. If the subjective features of the experience are greater than the objective features, then the interpretation generated will focus on emotional coping mechanisms to achieve emotional comfort. However, since this pathway deals with an individual's emotion it is expected to have a disparity in the interpretations among patients. The outcome will be assessed based on the individual's standards and if not successful changes in the interpretations will be done by the individual and the process repeated until a successful outcome is achieved.

According to Common Sense Model (CSM) theory, the content of a patient's representation of a healthcare experience is critical to the coping process (J. E. Johnson, 1999). Therefore, informational interventions can impact the nature of patients' representations. The CSM guides the idea that accurate information about the experience, for example, the emotional impact of hair fall or fatigue experienced after chemotherapy will allow patients to form correct representations of the experience. Clinicians can play an important role in helping patients in the cognitive process to ensure greater positive outcomes. However, the CSM assumes every experience is unique to the patient, in that each patient will decide how distressing the symptom is

and how to manage it and how satisfactory the outcomes are based on their standards. Clinicians can guide in the interpretation of the symptoms and guide in their diagnosis-based management but ultimately the behavior is guided by the patient's decision.

This study introduces a chemotherapy education intervention that aims to improve cancer patients' quality of life by reducing chemotherapy complications and hospital admissions. The intervention is designed to ensure that patients are armed with the necessary knowledge that allows them to make corrective action plans that ultimately ensure the patients cope with their diagnoses and potential side effects. To achieve this, clinicians are required to provide accurate information to better manage any symptoms that might occur.

Self-regulatory Model: From Theory to Practical

Initially, patients were considered passive recipients of medical care rather than active participants in their treatment process. This affected what is known as “compliance” which states that a patient follows the dispensed or prescribed treatment regimen as dispensed or prescribed by the clinician (“From Theory to Practice: Application of Self-Regulation Model for the Management of Fatigue among Cancer Patients Receiving Chemotherapy,” 2019). This has consequently led to failed medical adherence which of course is seen as the patient's fault. Clinicians earlier on were viewed to only cater to the scientific and technical side of medicine and illnesses and neglect the human side that involved treating the patient's physical and also psychological aspects. Over the years, several clinical trials have tried to focus on an individual's beliefs about health and illness. This has been refined over 30 years where different studies have focused on the oncological side effects of cancer itself and treatment including pain and fatigue. The goal of such studies, including this one,

is to guide the patient in the ability to recognize the features of a symptom experienced from chemotherapy and minimize the effect thereafter and maximize the positive effect that comes with coping with both the emotional and functional outcomes.

As stated above, the theory focuses on two major components: the cognitive and the emotional components. In application, the cognitive involves the patient's use of knowledge acquired from different sources on cancer and chemotherapy to be better placed to pick out any symptom that occurs during management. The emotional aspect involves the accurate interpretation of the symptom that guides an associated behavior that targets and alleviates the symptoms. The self-care opted for by the patient depends on their understanding of their experience. The goal of self-care behavior in this theory will affect both the emotional and the functional status of the patient undergoing chemotherapy. The emotional aspect involves psychological comfort while the functional involves minimal interruption of regular daily activities. These outcomes subsequently affect the patient's quality of life, improve adherence to care and also reduce frequent hospitalization. In a study of mothers of children undergoing cancer treatment, mothers were able to cope with the disease and treatment based on the understanding of the predictability of the changes in children's behavior and appearance during treatment. For example, a patient who develops diarrhea as a side effect of chemotherapy might choose to ignore them if it does not cause major distress or if it interferes with his/her daily activity. He or she will opt to take medication or alter feeding habits as self-care behavior to cope with the symptom. This improves the ultimate goal of emotional and physical comfort in a patient already coping with cancer

The formation of a contractual relationship with patients is supported by Orem's self-care theory (Parissopoulos, 2004). The focus is on what the patients will do to change for the better. Patients and healthcare providers that hold similar perspectives might collaborate to achieve a common goal. Without this connection, healthcare professionals and patients may find themselves at odds regarding the patient's care. Often in a clinician-centered relationship, the needs of the patient are not a priority. In the case of patient education, this type of relationship may lead to ineffective communication resulting in poor knowledge gain relating to their disease or chemotherapy side effects. This then creates information gaps that undercut the effectiveness of the education program.

2.7 Self-care practices

Self-care refers to patients' ability to self-observe, recognize and label symptoms, judge their severity and undertake treatment options and evaluate the effectiveness of the intervention undertaken (Levin & Idler, 1983). Self-care has become a rising issue in recent years because of the rise in chronic illnesses. Most self-management behaviors are initiated subconsciously like taking analgesia when in pain or resting when severely fatigued or avoiding foods that worsen the well-being of an individual, but some of these behaviors can be enhanced by education with the assistance of medical professionals to maintain a level of good health. Research done on self-care practices reveals patients usually wait until symptoms are life-threatening before they seek intervention (DODD, 2006b). However, educational intervention studies demonstrated that a modest level of self-care practices improves the patient's quality of life and reduces anxiety and stress during chemotherapy treatment (Aranda et al., 2012; Williams et al., 2005).

The diagnosis of cancer together with the chemotherapy regimen prescribed may require a patient to acquire new skills to be able to cope with the change in health. This helps in reducing anxiety and psychological distress. Information given to patients on enhancing self-care performance provides a sensation of control over patients' well-being. Over the years information protocols to enhance self-efficacy and coping efforts have been developed and made accessible to patients undergoing treatment (Ream & Richardson, 1996). National Comprehensive Cancer Network (NCCN) designed by National Cancer Institute has an educational program and cancer information guides on self-care available to patients undergoing chemotherapy in different major languages. Subsequently, organizations like the Universal of Health Network (UHN) have created a well-structured information guide that has been used by different facilities (Sheets, 2011). The guide has facts on cancer and information on potential chemotherapy side effects and highlights ways in which patients with cancer undergoing treatment can take care of themselves before, during and after chemotherapy administration (National Cancer Institute, 2018).

Patients' ability to perform self-care is limited by the information presented to them. Often, patients are unaware of what to do when they experience side effects and some avoid engaging in preventive practices, choosing to endure chemotherapy side effects. Results from a study on self-care in breast cancer patients demonstrated women with breast cancer can indeed benefit from interventions that increase their self-control, or reduce the distress from chemotherapy side effects (Duong, 1992). Hence there is a need for health professionals to promote skills in self-care among patients living with cancer.

2.8 The Memorial Symptom Assessment Scale (MSAS)

Patients living with cancer experience a variety of symptoms that can be attributed to their illness or the treatment they undergo. They experience a wide range of physical and psychological symptoms that vary in frequency, intensity, and discomfort. Some symptoms are linked to the disease or therapy, while others are linked to the disease's prognosis. Due to the diverse prevalence of both physical and psychological complaints and the impact of chemotherapy side effects on the quality of life, a symptom assessment scale in the cancer population is indicated (Browall et al., 2013).

Emergency department visits and hospital admissions are precipitated by symptoms. Several symptoms that cause functional impairment and deconditioning in advanced cancer patients are linked to lower survival rates. Therefore, better symptom management could increase survival. To enhance comprehensive symptom management in medical care, a thorough examination is required. Because symptom evaluation is critical for successful and complete cancer care for all patients, health care practitioners are required to routinely analyze patient-reported experiences on just how symptoms vary based on age group and cancer stage. This is because there are so many assessment scales to select from, it is, therefore, crucial to pick one that is appropriate for the intervention's goals and the characteristics of the demographic under investigation.

Prior research has examined the therapeutic benefits that may result from patient reporting of symptoms. These studies have found that patient reporting of symptoms increases the likelihood that patients and clinicians will discuss symptoms, that clinicians will intensify their symptom management in response to patient reports, and that patient reporting of symptoms improves symptom control (Seow et al., 2012). As a result, regular patient reporting appears to improve clinician understanding and can

supplement current symptom management techniques used in normal cancer treatment. In contrast, symptoms may go undiagnosed in the absence of patient self-reporting and result in major problems, hospital visits, restrictions on the safe administration of chemotherapy, and worsening of outcomes, as seen in this study.

Several symptom assessment scales have been developed including Memorial Symptom Assessment Scale (MSAS), Edmonton Assessment Checklist and Lung cancer Symptom scale. However, the MSAS questionnaire was adapted in this study because it comprehensively measures the frequency, severity and distress that cumulatively contribute to the symptom burden in patients with cancer. In palliative care, symptom evaluation is an important part of determining the quality of life (QOL). Symptom burden has been shown to directly be related to QOL and the survival of cancer patients (Cleeland, 2007; Hwang et al., 2004).

The Memorial Symptom Assessment Scale (MSAS) is one of the multidimensional symptom evaluation tools providing characteristics of both physical and psychological characteristics of common symptoms and the impact these symptoms have on the quality of life. This is more effective than one-dimensional symptom checklists used in previous methods of symptom evaluations (Victor T. Chang et al., 2000). The assessment scale is designed to be routinely filled by patients undergoing chemotherapy in the outpatient department to assess the cytotoxic effects of treatment. It is aimed at improving patients' experience and providing a focus for discussion and planning for treatment. The MSAS is a validated 32-item scale filled by patients and has been widely used to assess cancer patients' symptomatology. It was developed in 1994 by Portenoy et al. to provide multidimensional information about a diverse group of common symptoms. It measures 32 common physical and psychological symptoms, their frequencies and their level of distress among patients

with cancer (Portenoy et al., 1994). It has since then undergone cross-cultural adaptation and validation and has been translated into several languages such as Swedish, Chinese, Spanish, Hebrew, Korean, Arabic, and Brazilian (Browall et al., 2013; Victor T. Chang et al., 2000; Haryani et al., 2018).

Several MSAS validation studies have concluded that the MSAS is a valid and reliable assessment scale for frequency, severity and distress among patients living with cancer (V T Chang et al., 2000). The MSAS translated to Indonesian had a Cronbach's alpha coefficients for the total scale and subscales of the MSAS-I ranging from 0.75 to 0.87 (Haryani et al., 2018), while in another study in Lebanon, the Arabic-translated version of the MSAS had a Cronbach's alpha coefficients for the MSAS and its subscales ranged from 0.71 to 0.83 (Abu-Saad Huijer et al., 2015). Therefore, the MSAS is a reliable and valid tool for the assessment of symptom prevalence among cancer patients undergoing treatment. It provides a comprehensive assessment that will be useful in clinical trials aimed to measure symptom epidemiology or studies that incorporate quality of life measures.

CHAPTER THREE: METHODOLOGY

3.1 Study designs

This was a parallel arm; open-label randomized controlled trial, with an allocation ratio of 1:1

3.2 Study site

The study was carried out at the Oncology Unit, located in the Chandaria Cancer and Chronic Disease Centre at Moi Teaching and Referral Hospital. The hospital is the second largest in the country and is located in Eldoret town, Uasin Gishu County, in the western part of Kenya. It is one of the two referral facilities in Kenya as well as a teaching hospital for Moi University, College of Health Sciences. Its catchment area comprises Western Kenya, South Sudan, Eastern Uganda, Northern parts of Tanzania and the Democratic Republic of Congo. This region has a population of about 25 million and is a culturally diverse one. It has urban, rural and suburban populations; and also enjoys ethnic and religious diversity.

The AMPATH Oncology Institute was formed in 2008 as a cancer treatment and prevention center for people in Western Kenya. Later on, Chandaria Cancer and Chronic Disease Centre were opened as a training institution, providing a platform for research and medical care. More than 30,000 patients are seen in the oncology outpatient department within Chandaria annually.

3.3 Study population

The study population of interest was newly diagnosed adult cancer patients above the age of 18 years scheduled to undergo outpatient chemotherapy treatment at the Oncology unit at MTRH, who will go home on the same day of chemotherapy administration. The participants were grouped into two main arms, the Intervention arm and the control arm.

3.3.1 Intervention Arm

This included new patients with cancer set to receive outpatient 1st cycle of chemotherapy. Every patient before receiving the first chemotherapy cycle was first seen by an oncologist present on that day. The oncologist would prescribe chemotherapy based on the histological diagnosis of cancer. Thereafter the patient would receive the standard verbal discussions on the potential generalized chemotherapy side effects from the clinician, which will be documented on the consent form, before allowing the patient to proceed with chemotherapy. However, for this study, the intervention arm on the day of their first chemotherapy administration, the eligible study participants, once consented to be in the study, were then escorted to a private room within the Chandaria chemotherapy unit where the information on the Pre-intervention Interview Questionnaire (T1: Socio-demographic and questions on chemotherapy and chemotherapy side-effects) was captured (*Appendix 3*). In addition to the standard-of-care information, the intervention arm then received NCI/NCCN-guided education on cancer diagnosis, potential chemotherapy side effects and the self-care practices they were to carry out to mitigate any side effects they may encounter while at home. Chemotherapy side effects information was retrieved from the Cancer Therapy Evaluation Program (CTEP) site where resources on each chemotherapy are well outlined and accessible to clinicians and patients. On average it took 15-20 minutes; they then received a brochure on the same which also contained the contacts of the researcher. Instructions were given to patients to call the provided contacts at any time with any questions and clarification on any persistent or severe side-effects (*Figure 1 below*). Patients then proceeded to receive chemotherapy in a designated area in the chemotherapy administration area receive their first chemotherapy and leave for home. Follow-up

phone calls were then made at the end of the first week (Day 7), on day 14 and the evening before their second chemotherapy cycle (day 20 or day 27 depending on 3- or 4- weekly chemotherapy regimen)

Standardized Chemotherapy-Education-Intervention

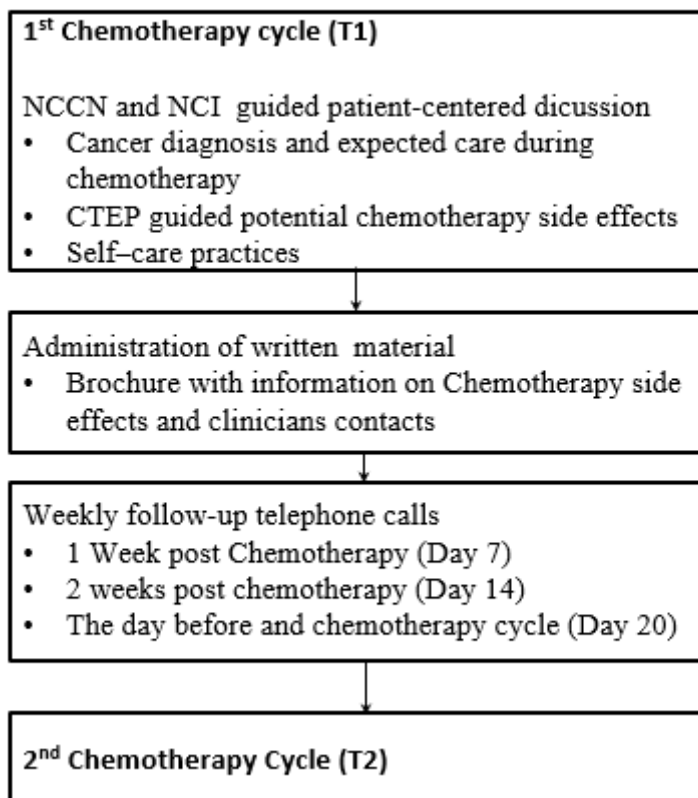


Figure 1: Structured Chemotherapy Education Intervention

3.3.2 Control Arm

This had patients with cancer set to receive outpatient 1st cycle of chemotherapy. Patients in the control arm received the usual standard-of care in Chandaria (explained below). They would first be reviewed by the Chandaria Cancer Unit clinician where chemotherapy was prescribed. After which eligible participants, on the day of the first chemotherapy administration were approached by the researcher to who they would consent to be in the study. They would then be escorted to a private

room within Chandaria where information on the Pre-intervention Interview Questionnaire (T1) was captured (Appendix 3) before proceeding to the general chemotherapy administration area to receive chemotherapy and leave for home. The researcher's contacts were not given to the participants in the control arm.

3.3.3 Standard-of-care

The standard-of care within the oncology department at Chandaria Cancer and chronic center, MTRH, involves clinician-centered care. Patients with cancer set to receive chemotherapy are reviewed by the clinician at the first visit and chemotherapy are prescribed. Patients then receive general information from the clinician prescribing chemotherapy on chemotherapy side effects which is included in the consent form that reports that chemotherapy causes nausea, vomiting, hair loss and fatigue. They are then instructed to call a general Chandaria Cancer and Chronic Centre number with any issues. After the signing of this consent form, patients would then either proceed to the chemotherapy unit to receive chemotherapy on the same day (pay cash) or a few days later for those on government hospital insurance cover (National Hospital Insurance Fund-NHIF). After chemotherapy in the outpatient chemotherapy administration unit, patients were allowed to go home. Emphasis is placed on either returning to MTRH or seeking the nearest hospital services with any chemotherapy side effects experienced. No follow-up is made while at home. Side effects, if any were reported to the clinician in the next visit, if none is reported, it was assumed patients are well and they would then proceed to the next chemotherapy session.

3.4 Eligibility Criteria

3.4.1 Inclusion criteria

- Age of 18 years and above.
- Histological diagnosis of cancer.

- Participants who provide informed consent.
- Chemotherapy-naïve patients with cancer scheduled to undergo outpatient chemotherapy for the first time.

3.4.2 Exclusion Criteria:

- Very ill patients with ECOG performance status >2 (*Appendix 1*)
- CNS metastasis that is interfering with cognitive function.

3.5 Sample size and sampling procedure

The sample size was based on the detection of a small effect on the primary outcome measures (knowledge and self-care behaviors). Hence a sample size calculation was made based on studies on both knowledge and self-care.

Objective 1:

The estimate of the sample size for the first objective (*To assess the effect of a standardized chemotherapy education intervention compared to standard-of-care on knowledge of the expected side effects of chemotherapy among ambulatory cancer patients at MTRH*) was derived from a study by Aranda., et al, who assessed the impact of Chemotherapy Education (ChemoEd) on patient's distress, symptom burden, treatment-related information and support needs on a population of patients with cancer at baseline (T1: pre-education) and immediately preceding treatment cycles 1 (T2) and 3 (T3) (Aranda et al., 2012) using Cohen's d standardized measure of 'small' effect.

The study used calculated the standard deviation for a small size effect (E) was 0.3

$$n = \frac{2(Z_{\alpha} + Z_{\beta})^2}{E^2}$$

Where

- Z_{β} Represents the desired power (80%) =0.84

- $Z_{\alpha/2}$ = Represents the desired level of statistical significance (typically 1.96)
- E = Effect size to detect a size of 0.30 standard deviations (Based on differences between groups- Cohen's d (Brydges, 2019).

Therefore: $n = 174$ (each arm)

Based on the hospital's records, it was estimated that the proportion of patients who don't come for subsequent visits after the first visit was 5% hence the sample size was inflated by the same value to achieve **183** participants in each arm.

Objective 2:

For the second objective, (*To compare standardized chemotherapy education versus standard-of-care on patients' self-care behaviors among ambulatory cancer patients in MTRH*), the estimate of the sample size calculation below was derived from an RCT study on an 8-week intervention on improvement of knowledge and self-care to improve cancer's patients' distress (fatigue, emotional stress and sleep) (Grégoire et al., 2018).

The study used Cohen's d measure of 'large' effect size (number required to measure the strength of the relationship between two variables in a population; large effect size=0.7) to calculate the standardized mean difference between two groups.

$$n = \frac{2(Z_{\alpha/2} + Z_{\beta})^2}{E^2}$$

Where

- Z_{β} Represents the desired power (90%) =0.9
- $Z_{\alpha/2}$ = Represents the desired level of statistical significance (typically 1.96)

- E= Effect size to detect a size of 0.70 standard deviations (Based on differences between groups- Cohen's d (Brydges, 2019).

Therefore: $n = 33$ (each arm)

With the 5% attrition rate, the total sample size from this objective was **35** participants in each arm.

The sample size from the 1st objective of **366 participants** (183 for each arm) was therefore used.

Consecutive sampling was employed.

3.6 Data collection procedure

3.6.1 Recruitment of Participants

Cancer patients who were scheduled to start chemotherapy in MTRH outpatient oncology clinic were identified. The eligible potential study participants were approached by the researcher where the study was then explained and informed and consent was obtained. Thereafter, information about their cancer type and chemotherapy regimen was obtained from the records.

3.6.2 Randomization

The allocation of eligible participants was random in a way that ensured each participant had the same probability of being assigned to either Group A (interventional group) or Group B (control group). Randomization was done using the block randomization technique where a computer-generated algorithm sequence was done using the Stata program. The program assigns participants in blocks of 4 where each block has 4 participants randomly assigned as 'Intervention' or 'Control'. This deters the investigator from predicting the allocation sequence, aids in the equal distribution of participants and eliminates bias and confounders.

3.6.3 Allocation concealment

To reduce selection bias the study utilized allocation concealment using opaque envelopes which were stored away from the primary investigator under lock and key until the moment of assignment. The primary investigator received 10 opaque envelopes daily, from the biostatistician who generated and locked away the envelopes. Any envelope not used by the end of the day was returned to storage until the following day. The envelopes had been numbered in advance and were opened sequentially, only after the participant's name and other details were written on the envelopes.

3.6.4 Blinding

Due to the nature of the two treatment options, it was difficult to blind both the participants and the study investigators during the pre-chemotherapy interview and intervention at T1. However, blinding was done for the research assistant administering questionnaires at T2 (outcome assessor) to assess self-care (The study utilized allocation concealment using opaque envelopes to reduce selection bias.

3.6.5 Study procedure

Once participants came in for their first hospital review, they were assessed to determine if they fulfilled the inclusion criteria. They then underwent the usual initial care that included a vitals check and review by a clinician who would then prescribe the outpatient chemotherapy. Before receiving chemotherapy the participants read or had the consent form read to them, signed and randomized into either the control or the intervention arm.

The intervention group received a standardized chemotherapy education, information on potential chemotherapy side effects during and after chemotherapy administration and what self-care techniques they are required to engage in to alleviate them. The

information was derived from guidelines from National Comprehensive Cancer Network (NCCN) which has clinical practice guidelines on cancer supportive care including illustrations and algorithms on cancer-related side effects. The cancer Therapy Evaluation Program (CTEP) under National Cancer Institute (NCI) provided protocols and tables on possible chemotherapy-related side effects for commonly-used oncology drugs. The information was critiqued and evaluated by 2 oncologists. Patients also received written drug information in the form of brochures (*Appendix 5*) with this information to go home. Patients were then directed to designated chemotherapy slots where they had no interactions with other patients receiving chemotherapy. Follow-up phone calls were done at the end of the first week (Day 7) when symptoms are expected to be worse; on day 14 and the evening before their second chemotherapy cycle (day 20 or day 27). Follow-up calls focused on any symptoms that were experienced and if any action did alleviate them, and reminded them of their upcoming chemotherapy session. Any patients who had any severe symptoms were directed early to the nearest facility or advised to head back to MTRH where an oncologist was consulted. Participants were free to contact the clinician-researcher at any point in the course of the study.

The participants in the control group received the usual standard-of-care and education from the clinician at the oncology clinic and then received chemotherapy as scheduled. They were then tracked via phone call on the day of their scheduled 2nd chemotherapy cycle where they would fill out the knowledge and MSAS questionnaire and provide information on any side effects experienced.

The participants from both groups underwent a pre-intervention (T1) interview with an 11-question questionnaire validated by 2 experts and administered by a trained investigator (*Appendix 2*). The questionnaire also contained a part where the socio-

demographic data of the patients who took part in the study was filled. The questionnaire aimed to assess the patient's knowledge of the potential side effects of chemotherapy and possible self-care behaviors after undergoing routine education. Participants from the intervention group were then guided to a designated area within the chemotherapy administration room to avoid any form of contact with the control group.

The duration of each chemotherapy cycle ranged from 1 week to 4 weeks depending on the chemotherapy regimen. The participants in the intervention group also had access to telephone contact of the primary researcher who, when called on possible chemotherapy side effects symptoms, was able to clinically guide them on their management or refer them to a medical specialist. Follow-up phone calls to these participants were made to ensure participants' symptoms had abated. Just before receiving the second cycle of treatment (T2), the post-intervention questionnaire was administered to both the intervention and control groups to assess retained knowledge. Common side effects of chemotherapy experienced by both groups were then assessed using the Memorial Symptom assessment scale (*Appendix 3*). At this point, there was also an interviewer-administered self-care questionnaire (*Appendix 4*) to assess what self-care strategies the patient undertook to alleviate or lessen the side effects of chemotherapy if any.

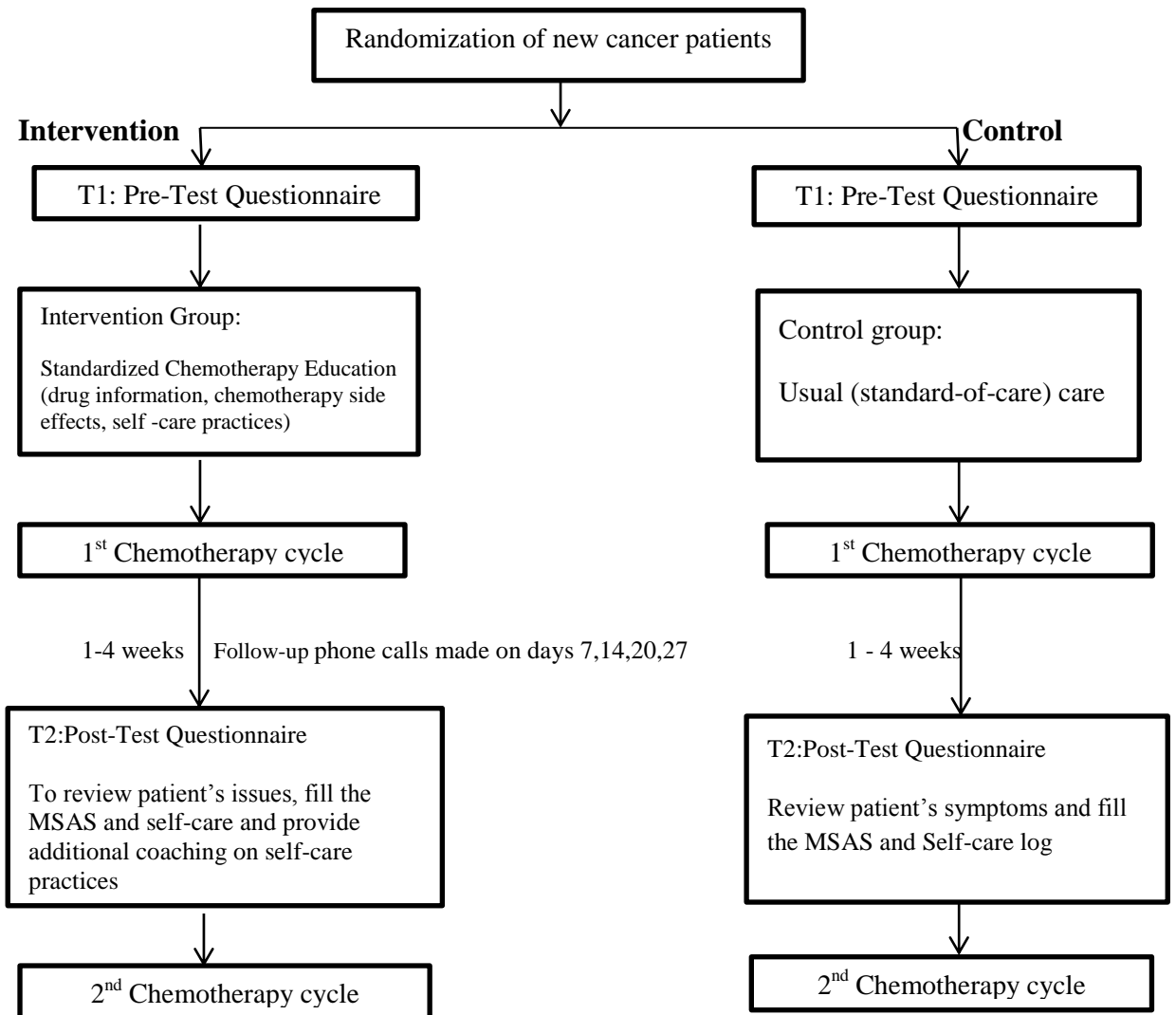


Figure 2: Study Procedure

3.7 Outcome measure

At T1, baseline knowledge assessment was measured using the questionnaire in *Appendix 1* with the highest possible score of 11. Questions focused on chemotherapy treatment's potential adverse events, both physical and psychological and what is expected of patients during the treatment period. Respondents indicated whether the statements were correct or incorrect by indicating 'Yes' or 'No' or just whether they 'Did not know'. In the second cycle of chemotherapy, T2, the same set of questions to assess knowledge was again asked. For analysis of the knowledge measure, scores were generated based on the answers given. A correct score of the question answered was awarded 1 point while an incorrect answer together with an answer not known was awarded a score of zero (No=0, Don't Know=0, Yes=1). The total scores of correct responses were added to a maximum score of 11. Therefore an aggregate of these scores was then used in data analysis where the overall score at T1 and T2 was analyzed to examine the difference in means scores between the two groups.

At T2, common chemotherapy side effects experienced by patients were captured in the Memorial Symptom Assessment Scale (MSAS) tool which is a multi-dimensional (Physical and Psychological assessment) 33-item self-reported validated measure that provided quantitative information about the participants' degree of distress brought on by chemotherapy side effects symptoms (Portenoy et al., 1994). The participants indicated whether they experienced the listed side effects (Yes). If the symptom was present, the participants went ahead to mark on a 5-point Likert scale, the rate of bothersome or severity of the symptoms. (0=Not at all, 4=Very Much)

The participants were then subjected to an interviewer-administered questionnaire that contained the symptom self-care log, before their chemotherapy session where they were asked to provide information on the self-care actions taken to alleviate the side

effects described in the MSAS. The side effects severity was graded on the self-care log according to how bothersome they were to the participants on a 4-point Likert scale ranging from 0 (Not at all) to 4 (Very much). These actions were then filled in the Symptom Self-care Log and assessed based on the information guide as being the correct action is undertaken or incorrect. A 'correct action' was a measure of actions undertaken that completely alleviated the patient's symptoms. Hence any action that the patient undertook to completely clear one bothersome symptom was awarded a score of '1' and actions that did not improve the patient's symptoms were awarded a score of '0' (Correct action=1, Incorrect action=0). Hence if a patient experienced four symptoms a perfect score would be 4/4 if the patient performed tasks that helped to completely clear the symptoms. The participant's responses were not judged by their scientific and therapeutic merit so there were no accuracy scores.

3.8 Data management

3.8.1 Data Collection

Data was collected between August 2020 and March 2021 using a pre-piloted interviewer-administered structured questionnaire (Appendix 1). Patient's medical records were also reviewed to obtain relevant clinical and tissue histology information and entered into the questionnaire. At T1, before 1st chemotherapy session, the variables on the socio-demographic data included age, gender and level of education; cancer characteristics including the type and stage and the patient's performance status (ECOG). Other socio-demographic data were residence, occupation and marital status. Each questionnaire contained a unique case identifier (Case ID) that corresponded to the participant for follow-up purposes.

At T2, just before 2nd chemotherapy cycle, data on the side effects of chemotherapy were captured using a validated tool, MSAS with adequate reliability in subscales

(cronbach's alpha coefficient = 0.83 and 0.88), and self-care practices were entered by the researcher in a validated self-care log tool with a Cronbach's alpha of 0.83 and 0.8 respectively for reliability

3.8.2 Data entry and Validation

Each questionnaire was assessed for completeness before any data entry process. Any inconsistencies and errors were also inspected and corrected. Data were entered in Microsoft Excel.

3.8.3 Data Protection and safety

The questionnaires were stored by the primary investigator under lock and key. Data was stored in a password-protected computer with Kaspersky's antivirus. The data will be kept for a minimum of five years upon the day of publication of the study.

3.8.4 Data Analysis

Data collected through questionnaires were checked for completeness and consistency daily by the researcher. The data was later keyed into a Microsoft Access database. The questionnaires were kept in a locked drawer and the database was password-protected to ensure no unauthorized access.

On completion of data collection, data was exported to STATA version 16 where further data management, coding and analysis were done. Descriptive analysis was used to summarize participants' characteristics where age was summarized as a mean and standard deviation. Other categorical variables such as sex, educational level, occupation, residence, cancer type and stage were summarized using frequencies and proportions. The other data were analyzed as per the objectives.

Objective one (To assess the effect of a standardized chemotherapy education intervention compared to standard-of-care on knowledge of the expected side effects

of chemotherapy among ambulatory cancer patients at MTRH): For each of the eleven questions that were used to assess knowledge of patients. The correct answer was coded as one while the wrong answer was coded as zero. A knowledge score was created per participant by adding all eleven questions. This was done at both Time one (T1: pre-treatment) and Time two (T2: post-treatment). Knowledge score was then summarized using means and their corresponding standard deviations. A comparison of knowledge between the two periods and between the two arms of treatment was done using a *t*-test. Difference-in-difference test was used to compare the gain in knowledge between the two arms of treatment at T1 and T2.

Objective two (To compare standardized chemotherapy education versus standard-of-care on patients' self-care behaviors among ambulatory cancer patients in MTRH to assess patients' self-care behaviors on expected chemotherapy side effects among cancer patients at MTRH): Symptoms experienced by the participants were assessed using Memorial Symptom Assessment Scale (MSAS) tool and the data were summarized as the frequency of participants who experienced each symptom. The self-care log was used to assess the correctness of the actions taken by a participant to alleviate the symptoms where a score of five indicated complete relief. The number of participants who had complete alleviation of each symptom was summarized as frequency and as a percentage of participants who experienced each symptom.

A proportion of correct actions taken were created per participant by dividing the correct actions by the total actions taken and multiplied by 100 to create a percentage score. The scores were summarized as medians and their corresponding interquartile ranges. Wilcoxon rank-sum test was used to assess the difference in the proportion of correct action taken between the two arms of treatment.

All analyses were carried out at a 95 % confidence level, with P values less than 0.05 considered statistically significant.

3.9 Ethical consideration

Approval and authority to carry out the research was granted by the Institutional Research and Ethics Committee. An approval letter was drafted to MTRH, Oncology Unit to obtain permission to carry out the study. Informed consent was sought with no inducement or incentive to the participants. Participants who opted to drop out or withdraw consent during the study were allowed to do so. After the collection of data at T2, information and brochures given to the intervention group were also given to the control group at the end of the study and any symptom experienced was shared with the clinician for optimum care and relief of symptoms.

The information provided was kept confidential at all times and no names were used to identify individual data collected and written reports at the end of the study. Information gathered was only shared with the relevant authorities including the participants' primary clinicians.

There was no conflict of interest.

3.9.1 Data Dissemination

The results of this study shall be presented in seminars and conferences. This thesis will also be submitted to a reputable journal for publishing. A copy of the thesis will be available to the management of MTRH to help in future reference and in the formulation of protocol to aid assess patients' chemotherapy side effects.

CHAPTER FOUR: RESULTS

A total of 484 patients were screened for study eligibility in the period between August 2020 and March 2021. The study recruited 366 newly diagnosed cancer patients who were scheduled to undergo outpatient chemotherapy treatment and were enrolled in the study for eight months. Participants were equally distributed into the two arms, that is, 183 in the control arm and 183 in the intervention arm. Twelve participants were lost to follow-up: 8 in the control arm and 4 in the intervention arm. Therefore the analysis was based on 366 participants of whom 175 were controls and 179 were in the intervention arm (Figure 2).

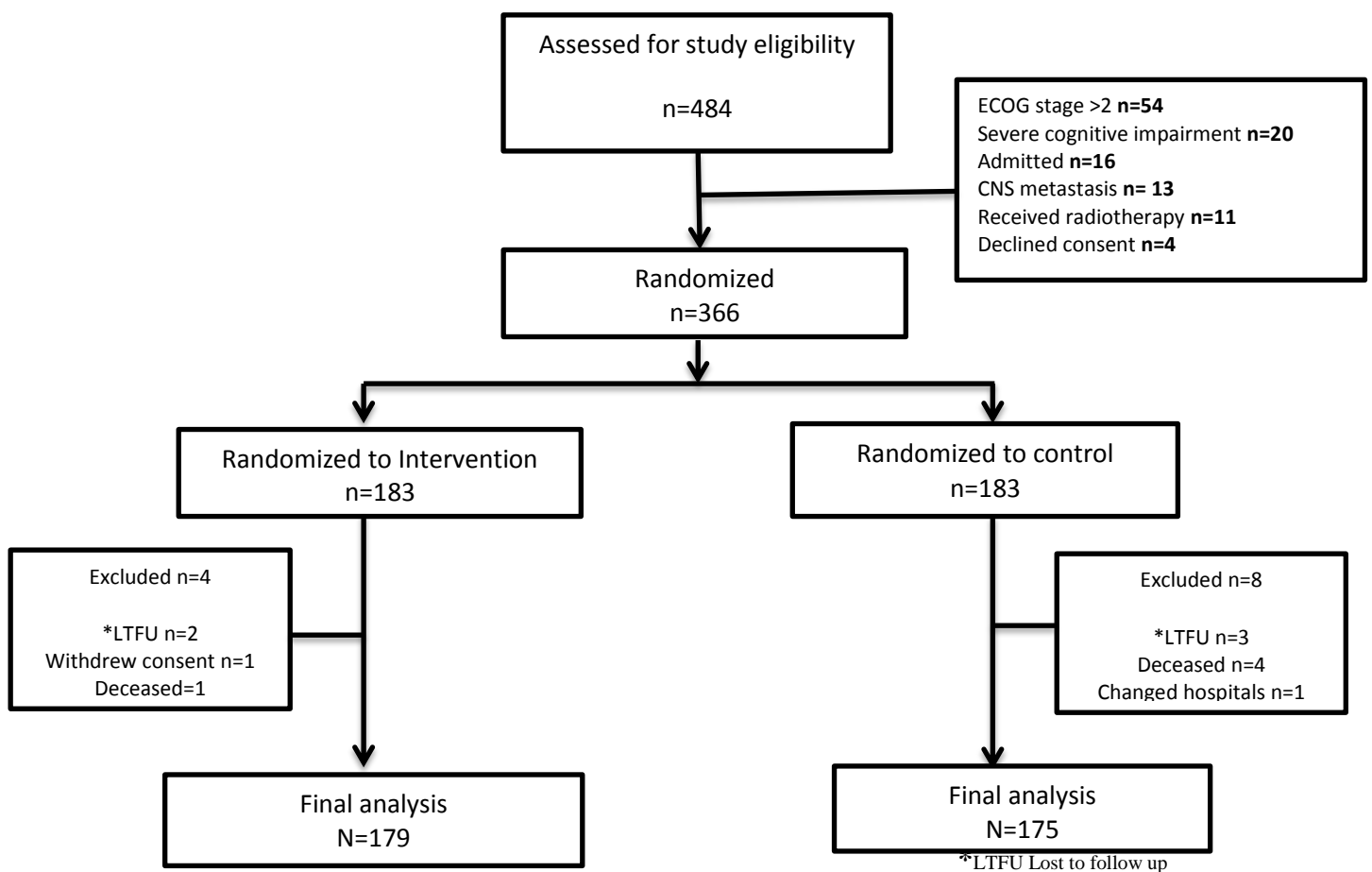


Figure 3: Study flow chart

Table 1: Characteristics of the participants

Variable	Category	Control n=175	Intervention n=179	Total
Age	Mean(SD)	49.7 (15.4)	50.9 (15.2)	50.3 (15.3)
Sex	Male	76 (43.4%)	55 (30.7%)	131 (37%)
	Female	99 (56.6%)	124 (69.3%)	223 (63%)
Marital status	Married	122 (69.7%)	114 (63.7%)	236 (66.7%)
	Single	26 (14.9%)	34 (19%)	60 (16.9%)
	Widowed	15 (8.6%)	21 (11.7%)	36 (10.2%)
	Divorced	12 (6.9%)	10 (5.6%)	22 (6.2%)
Education level	No formal	30 (17.1%)	25 (14%)	55 (15.5%)
	Primary	54 (30.9%)	62 (34.6%)	116 (32.8%)
	Secondary	64 (36.6%)	60 (33.5%)	124 (35.0%)
	Tertiary	27 (15.4%)	32 (17.9%)	59 (16.7%)
Residence	Uasin Gishu	45 (25.7%)	33 (18.4%)	78 (22.0%)
	Trans Nzoia	21 (12.0%)	20 (11.2%)	41 (11.6%)
	Bungoma	16 (9.1%)	17 (9.5%)	33 (9.3%)
	Kakamega	15 (8.6%)	14 (7.8%)	29 (8.25)
	Nandi	11 (6.3%)	9 (5.0%)	20 (5.6%)
	Kisii	10 (5.7%)	20 (11.2%)	30 (8.5%)
	Others	57 (32.6%)	66 (36.9%)	123 (34.7%)
Occupation	Farmer	101 (57.7%)	106 (59.2%)	207 (58.5%)
	Self Employed	22 (12.6%)	33 (18.4%)	55 (15.5%)
	Casual labor	24 (13.7%)	8 (4.5%)	32 (9.0%)
	Formal employment	16 (9.1%)	21 (11.7%)	37 (10.4%)
	Unemployed	12 (6.9%)	11 (6.1%)	23 (6.5%)
Cancer stage	I	9 (5.1%)	9 (5.0%)	18 (5.1%)
	II	36 (20.6%)	33 (18.4%)	69 (19.5%)
	III	64 (36.6%)	58 (32.4%)	122 (34.5%)
	IV	66 (37.7%)	79 (44.1%)	145 (41.0%)
ECOG stage	0	9 (5.1%)	11 (6.1%)	20 (5.6%)
	1	80 (45.7%)	82 (45.8%)	162 (45.8%)
	2	86 (49.1%)	86 (48.0%)	172 (48.6%)

The age of participants ranged from 18 to 85 years with a mean of 50.3 ± 15.3 . The majority, (63%) were women and married (66.7%). About 16% of participants had no formal education while 17% had attained tertiary education level. Most (22%) of the participants reside in Uasin Gishu county followed by Trans Nzoia county (11.6%) while more than half 58.5% were farmers. At diagnosis, 41% of the participants were at stage IV while 34.5% were at stage III, where the ECOG stage was determined to

be 1 and 2 for 45.8% and 48.6% of participants respectively. The participants were equally distributed between the two arms in regard to age, marital status, education, residence, and ECOG stage ($p<0.05$). However, females were more in the intervention arm than the males ($p=0.013$)

Patients' knowledge of the expected side effects of chemotherapy among cancer patients at MTRH

Table 2: Comparing knowledge between the arms

Variable	Category	Control n=175	Intervention n=179	T	p-value
T1	Mean (SD)	5.4 (2.8)	5.0 (2.5)	5.2 (2.7)	0.164
	Median (IQR)	5 (3, 8)	5 (3, 7)	5 (3, 7)	
	Range	0 – 11	0 – 11	0 – 11	
T2	Mean (SD)	8.6 (2.2)	9.7 (1.1)	9.2 (1.8)	<0.001
	Median (IQR)	9 (8, 10)	10 (9, 11)	10 (8, 10)	
	Range	1 – 11	7 – 11	1 – 11	

During the pre-intervention period (T1), the knowledge level for both control and interventional groups were equal ($p=0.164$). During the post-intervention period (T2), the intervention group had a significantly ($p<0.001$) high level of knowledge compared to the control group.

Table 3: Comparing knowledge at T1 and T2 for each arm

Variable	Category	T1	T2	p-value
Control	Mean (SD)	5.4 (2.8)	8.6 (2.2)	<0.001
	Median (IQR)	5 (3, 8)	9 (8, 10)	
	Range	0 – 11	1 – 11	
Intervention	Mean (SD)	5.0 (2.5)	9.7 (1.1)	<0.001
	Median (IQR)	5 (3, 7)	10 (9, 11)	
	Range	0 – 11	7 – 11	

In both control and intervention groups, knowledge scores improved significantly ($p < 0.001$) from T1 to T2.

Table 4: Comparing knowledge gained between the arms

Outcome var.	Mean score	T	p-value
Pre-intervention (T1)			
Control	5.429		
Intervention	5.034		
Diff (T-C)	-0.395	-1.64	0.101
Post-intervention (T2)			
Control	8.611		
Intervention	9.743		
Diff (T-C)	1.132	4.71	<0.001
Diff-in-Diff	1.527	4.49	<0.001

Difference-in-difference analysis test was done to compare knowledge gained between the two arms. The results showed that the intervention arms gained significantly ($p < 0.001$) more knowledge than the control group. Hence the change/gain in knowledge had no external interference other than the chemotherapy education intervention.

Objective two:**Patients' self-care behaviours on expected chemotherapy side effects among cancer patients at MTRH****Table 5: Symptoms experienced recorded in the MSAS**

Symptoms	Control (n=175)					Intervention (n=179)				
	Yes	1	2	3	4	Yes	1	2	3	4
Difficult concentrating	6	4	0	2	0	6	2	0	0	1
Pain	102	28	8	22	18	105	22	3	19	28
Lack of energy	83	11	6	16	28	83	8	4	18	18
Cough	13	7	0	0	3	18	5	0	6	0
Changes in skin	14	10	1	1	1	18	12	0	3	3
Dry mouth	13	0	2	3	5	13	0	1	2	4
Nausea	34	8	1	3	3	27	1	1	0	4
Feeling drowsy	0	0	0	0	0	0	0	0	0	0
Numbness	21	11	3	0	3	11	4	1	0	4
Difficult sleeping	9	8	1	0	0	12	6	0	1	2
Feeling bloated	50	19	2	7	9	46	7	6	9	10
Problem with urination	13	7	1	2	0	9	4	1	0	1
Vomiting	29	2	0	1	1	49	5	0	1	2
Shortness of breath	7	1	0	2	4	4	0	0	1	1
Diarhea	23	2	0	3	0	25	1	0	0	0
Sweats	10	2	1	1	1	8	1	2	1	0
Mouth sores	23	4	2	2	4	34	1	1	3	9
Problem with sexual interest	14	11	1	0	1	22	16	1	3	1
Itching	15	5	1	4	1	11	3	0	3	0
Lack of appetite	66	15	5	13	11	79	9	3	12	18
Dizziness	7	2	1	1	2	4	0	0	1	1
Difficulty swallowing	20	9	2	2	3	32	9	3	3	1
Change in the way food taste	25	5	0	3	3	44	4	0	4	9
Weight loss	2	0	1	1	0	3	2	0	0	0
Hair loss	49	16	0	3	6	68	18	3	3	5
Constipation	38	8	4	3	2	49	11	1	7	7
Swelling of arms and legs	30	10	2	1	7	22	9	1	6	2
I don't look like myself	6	5	1	0	0	10	6	1	2	1
Feeling sad	11	9	0	1	1	7	3	2	0	0
Worrying	27	12	2	7	4	32	22	0	4	2
Feeling irritable	22	16	0	4	1	26	14	2	1	1
Feeling nervous	8	4	0	3	0	4	0	2	0	0

Scale on level of distress/bother of the symptom

1- A little bit 2- Somewhat 3-Quite a bit 4- Very much

Table 5 shows the number of participants who experienced each symptom (side effect) followed by the level of distress measured on a Likert scale MSAS questionnaire that includes distress severity between '1' ("A little bit") and '4' ("Very Much").

Table 6: Number of participants who had complete relief of symptoms

Symptoms	Control		Intervention	
	Experienced side effect	Completely relieved	Experienced side effect	Completely relieved
Difficult concentrating	6	0 (0%)	6	3(50%)
Pain	102	26 (25.5%)	105	33(31.4%)
Lack of energy	83	22 (26.5%)	83	35(42.2%)
Cough	13	3 (23.1%)	18	7 (38.9%)
Changes in skin	14	1 (7.1%)	18	0 (0%)
Dry mouth	13	3 (23.1%)	13	6 (46.2%)
Nausea	34	19 (55.9%)	27	21 (77.8%)
Feeling drowsy	0	0 (0%)	0	0 (0%)
Numbness	21	4 (19%)	11	2 (18.2%)
Difficult sleeping	9	0 (0%)	12	3 (25%)
Feeling bloated	50	13 (26%)	46	14 (30.4%)
Problem with urination	13	3 (23.1%)	9	3 (33.3%)
Vomiting	29	25 (86.2%)	49	41 (83.7%)
Shortness of breath	7	0 (0%)	4	2 (50%)
Diarrhea	23	18 (78.3%)	25	24 (96%)
Sweats	10	5 (50%)	8	4 (50%)
Mouth sores	23	11 (47.8%)	34	20 (58.8%)
Problem with sexual interest	14	1 (7.1%)	22	1 (4.5%)
Itching	15	4 (26.7%)	11	5 (45.5%)
Lack of appetite	66	22 (33.3%)	79	37 (46.8%)
Dizziness	7	1 (14.3%)	4	2 (50%)
Difficulty swallowing	20	4 (20%)	32	16 (50%)
Change in the way food taste	25	14 (56%)	44	27 (61.4%)
Weight loss	2	0 (0%)	3	1 (33.3%)
Hair loss	49	24 (49%)	68	39 (57.4%)
Constipation	38	21 (55.3%)	49	23 (46.9%)
Swelling of arms and legs	30	10 (33.3%)	22	4 (18.2%)
I don't look like myself	6	0 (0%)	10	0 (0%)
Feeling sad	11	0 (0%)	7	2 (28.6%)
Worrying	27	2 (7.4%)	32	4 (12.5%)
Feeling irritable	22	1 (4.5%)	26	8 (30.8%)
Feeling nervous	8	1 (12.5%)	4	2 (50%)

The table above shows the number of patients who experienced each side effect and the proportion that had complete relief after taking an action that was meant to alleviate the side effect. This indicated the percentage of correct actions undertaken.

The effect of standardized chemotherapy side effect education versus standard-of-care on self-care behaviours among cancer patients at MTRH

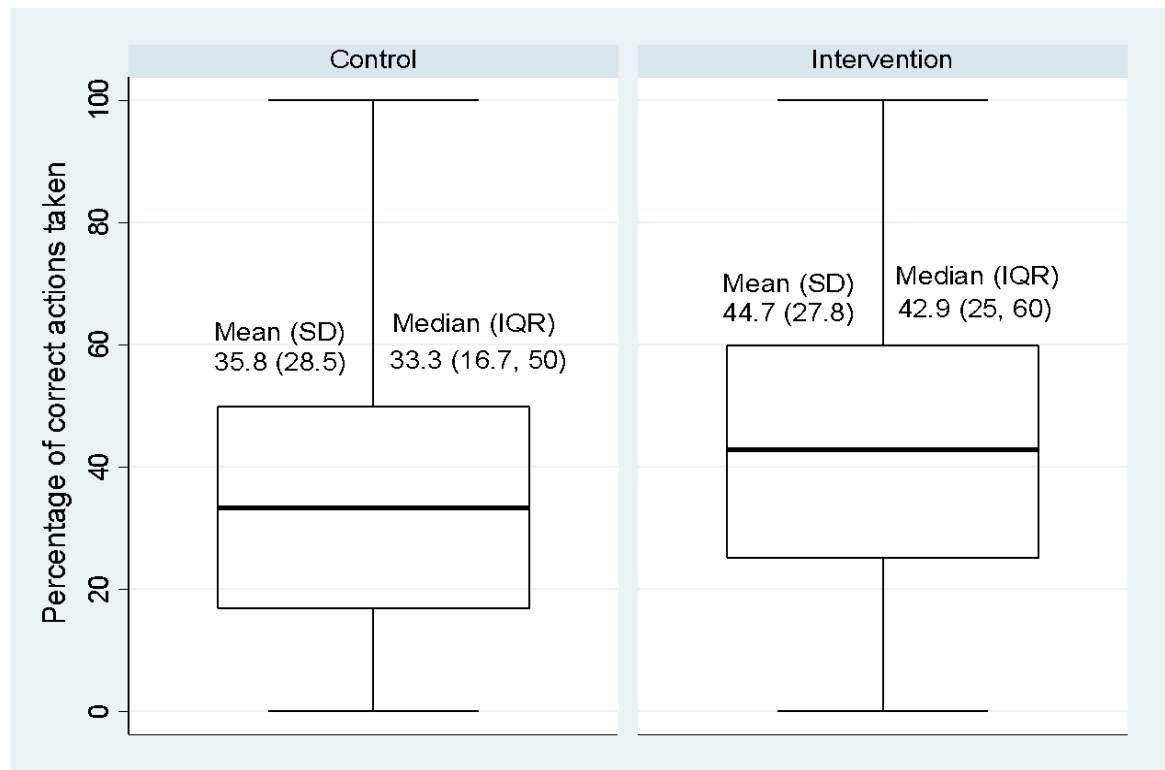


Figure 2: Correct action taken

The proportion of correct actions taken was used to measure the effect of standardized chemotherapy side effect education (intervention) versus standard-of-care on self-care (control) behaviours among cancer patients at Moi Teaching and referral Hospital. On average, controls had a median percentage score of 33.3% compared to the intervention group which had a median percentage score of 42.9%. This means that the intervention group were able to take corrective actions on 42.9% of their symptoms compared to the control group who managed to take 33.3% of correct actions on their symptoms. A Wilcoxon rank-sum test showed that the difference between the two median scores was statistically significant ($p=0.0006$).

CHAPTER FIVE: DISCUSSION

This study sought to establish how a standardized education intervention on chemotherapy side effects would impact knowledge and the self-care behaviors of people undergoing outpatient chemotherapy treatment in Moi Teaching and Referral Hospital as compared to the standard of care. Behavioral education intervention has been shown to have a profound positive impact on patients' self-confidence in the management of potential chemotherapy side effects and the initiation of behaviors that help alleviate their suffering while at home. The intervention education implemented in this study was given through the National Cancer Institute/National Comprehensive Cancer Network (NCI/NCCN) and National Institutes of Health (NIH) Cancer Therapy Evaluation Program (CTEP) guidelines and side effects were captured using validated Memorial Symptom Assessment Scale (MSAS) tool. Self-care behavior and practices put into action were entrenched based on the education and information provided in this study and reinforced by weekly telephone calls. Equal numbers of participants in each arm were recruited during the study period. The findings of this study demonstrated a significant improvement in knowledge and self-care behaviors in the intervention arm to the control arm ($p=0.0006$).

5.1 Socio-demographics

In this study, the demographic variables assessed including age, marital status, residence, level of education, and cancer stage and Eastern Cooperative Oncology Group (ECOG) stages were homogenous and did not affect both knowledge of chemotherapy side effects and self-care behaviors undertaken by patients except for the variables gender and occupation. This is similar to a study done in India where most of the variables assessed were not statistically significant except for Level of education and Body Mass Index (BMI) which this study did not assess (Sivakumar & Susila, 2021).

The majority of the patients were older (mean 50.3) with a majority of them being females (63%). MTRH serves the majority of residents in Western Kenya region, however, retrospective studies have documented male to female ratio of 1:1 (Tenge et al., 2009). However, this study had more females because the number of malignancies was mostly breast and cervical, not to mention ovarian cancer at 30%, 7%, and 2% respectively. This is similar to the GLOBOCAN statistics of cancer distribution in Kenya where the most common malignancy among women is breast and cervical. The findings in participants' characteristics are similar to a study done by Serma Subathra et al who found that the majority of the participants were elderly (58%) comprising the 49-60 years old age bracket. Yuang et al. reported that most cancers affect older people starting at the age of 50 and peaking in the more elderly groups. Studies have also demonstrated cancer is associated with older age due to the accumulation of mutations throughout our lifetime from environmental exposure to carcinogens (UV rays, chemicals, tobacco smoking, and viral infections) (Laconi et al., 2020). National Cancer Institute has included old age as one of the risk factors for cancer with a majority (60%) being above 65 years with a median age of 66 (National Cancer Institute, NCI 2020). Older age has been associated with difficulty in encoding and remembering medical information (Shankar, 2003), however, this and other studies demonstrated that age is not a factor when it comes to chemotherapy side-effects education or the initiation of self-care (Shankar, 2003).

Education also did not affect the outcomes of the study unlike a study in Malaysia which demonstrated that low education and socioeconomic status are associated with a poor attitude towards cancer and a negative quality of life (Chan & Ismail, 2014). Similarly, Berger 2018 found that the type of occupation had a significant impact on knowledge and effect on self-care. However, 71% of participants with a meager

socio-economic background had no association between these variables and the level of chemotherapy education and adverse effects according to a study done in India (Arunachalam et al., 2021b). Studies have demonstrated that individuals with lower income and lower education have been associated with a negative attitude toward cancer and its overall management (Chan & Ismail, 2014). The study demonstrated that participants in paid employment and those with higher education levels had better baseline scores on their knowledge about their disease and treatment hence having a positive impact on their self-care behavior and improved chemotherapy symptom outcomes (Berger et al., 2018). In comparing similar cohorts, Berger was able to associate the participants' higher scores with their daily internet ($p = 0.022$).

5.2 Self-care knowledge of patients treated with Chemotherapy

Participants who underwent standardized education on chemotherapy side effects carried out more self-care actions that overall alleviated their symptoms than those who did not receive standardized intervention education on self-care practices. Having knowledge and understanding of chemotherapy contributes to improved self-care behaviors. Participants in the study were asked questions on general information regarding what was expected of them during the chemotherapy period including their diet, change in both physical and psychological health, and what actions they would engage in to alleviate any effects they would encounter. This would assess patients' level of recall and understanding of the information presented to them by clinicians before the onset of chemotherapy. Subsequently, this information would practically be demonstrated by how participants would correctly carry out self-care practice to completely alleviate their symptoms during their therapy.

The findings in this study demonstrated a high score of knowledge post receiving comprehensive standardized information on chemotherapy side effects in the

intervention group compared to the control group ($p=0.0001$). This could be because this study recognizes that the care of patients encompasses different aspects with a key element being patients' ability to coordinate and in-cooperate individualized treatment and information that considers individual's needs. A lack of structure in providing these needs leads to poor patient adherence and poor utilization of health care. The goal of this study was to use a structured intervention to improve the information given as standard-of-care. It found that it was able to improve performance on a post-test questionnaire. Generalizing information on common cancer and chemotherapy effects (e.g. nausea, vomiting, hair loss, and diarrhea) given to patients within MTRH leaves patients with no information on what to do when different side –effects are experienced while at home. This situation is further exacerbated when patients do not have clear contacts with the hospital cancer team to help with the information required. A lack of enough resources and personnel could have also explained the lower knowledge average scores for the control group. At MTRH, all new patients are seen by one or two oncologists for chemotherapy prescriptions and general information of care during treatment, not to mention they review any complicated returning cases and handle any consultations within the unit. This challenge presents enough pressure and creates a barrier to effective coordination of information delivery. This current study used a minimum of about 20-30 minutes per patient to deliver the NCI/NCCN guideline information on Chemotherapy information and CTEP side effects. Having an oncology care coordinator at pre-treatment (T1) who was only required to provide this information implemented the structured education possible and might have affected the overall knowledge gained by the intervention arm compared to the control arm. With the rising number of patients with cancer expected to increase by 50% in LMICs, implementation of

cancer-care services ought to be streamlined with the utilization of patients' ability to comprehend their health and the intricacies of health care. The introduction of a clinician who timely communicates and discusses information solidifies information transfer between the oncologist or health care specialist and the patient. This study provided that crucial point to patients where support in form of guidance in accessing appropriate information and support services through enhanced telephone calls was given. This is because self-care is a lifelong process where patients with cancer interact with healthcare providers to handle challenges associated with chemotherapy and cancer not only on first contact but also during and after treatment (McCorkle et al., 2011). Information given to patients should not only be of chemotherapy but also techniques to improve self-care are provided to patients to increase the overall correct actions taken to alleviate the potential side effects. A study was done by Dodd et al to measure how information influences patients' knowledge, self-care behavior, and general affective state demonstrated that only 20% of the patients who were given drug information alone were able to correctly associate the chemotherapy side effects with the drugs while participants who received drug information alone with added information on SEMT had a significant improvement in both chemotherapy knowledge and self-care behavior. The study attributed this to poor information recall and suggested patients retain information better if the information is continually reviewed and reinforced by clinicians (Marylin J. Dodd, 1984). The researchers were able to associate additive information on knowledge and self-care had a better impact on self-care behavior than having information on knowledge or self-care alone. It is therefore vital to also assess the type of information given and aim for a holistic additive education to empower patients to become stewards of their health. This current study utilized three aspects of education that was more patient- and clinician-

centered. Clinicians therefore ought to properly equip patients with instructions on activities that will meet their physical, emotional, and mental needs away from hospital settings (Ose et al., 2017).

However, a study by S. Aranda et al failed to demonstrate that patients receiving education on chemotherapy (chemoEd) had decreased levels of distress (Aranda et al., 2012). The study had 102 participants with cancer undergo chemotherapy education in form of a DVD, question prompt list, self-care information, an education consultation before chemotherapy (T1), a telephone follow-up before the second chemotherapy cycle (T2), and a face-to-face interview before commencing the third cycle (T3). The study despite being an RCT had fewer participants than the current study which might have affected the primary outcome variable and opted to limit the cancers category to breast, gastrointestinal and hematological cancers hence affecting generalizability when it came to diverse chemotherapy types for different types of cancer. A major limitation of the study by Aranda et al was the inability to assess patients' monitoring of the use of recommended self-care information in a home environment. The current study mitigated this by using the MSAS and the self-care log as a treatment-related tool that measured the extent to which patients utilized the information to carry out self-care behavior to reduce their level of distress, both physical and psychological stress. The MSAS was easy to administer, takes a few minutes to fill, and was used by both arms to assess for symptoms and their severity. Instruments can therefore cooperate in LMICs health care facilities to guide healthcare professionals in directing therapeutic interventions and tracking clinical changes with intervention.

The change in knowledge score from baseline was significant in both intervention and control groups. The improvement in knowledge seen in the control group, although

not as significant as that of the intervention group, can be attributed to the general standard-of-care information given at T1 by clinicians/oncologists when prescribing chemotherapy. This information was routine for all patients with cancer. Moi Teaching and Referral Oncology Unit current practice of education practice includes a verbal discussion between clinicians regarding cancer diagnosis, therapy, and generalized expected side effects. This study demonstrated that this information could have been enhanced by having a structured approach to chemotherapy side-effect patient education where other resources are included. Berger et al, who were only assessing knowledge in patients with cancer found out that participants' level of knowledge increased significantly from before physician consultation (T1) to post-consultation (T2) by 83% and this gradually increased throughout the 8-12 week study period (T3) (Berger et al., 2018). The study demonstrated that all participants have an overall increase in knowledge from baseline. He deduced that participants with higher education, paid employment, and daily internet access had an overall improved knowledge score than those without.

Unfortunately, it is unclear if the increase in knowledge in the control group was attributed to other sources including family, media, other clinical personnel, and the internet. However, the study established that an increase in chemotherapy knowledge led to sufficient information that was used to decide on chemotherapy side effects and symptoms that improved their discomfort. This study, however, comparing the two groups demonstrated that carrying out a structured reinforced face-to-face education on not only chemotherapy side effects but also the practices on what to do when these events occur, delivers a greater response to identifying and mitigating any discomforts experienced while home and empowers the patient in the involvement in their care.

Teaching that incorporates both technology and patient-education media (print) enhances both cognitive and behavioral knowledge. This study used follow-up phone calls and a chemotherapy side effects brochure (*Appendix 5*). Written information solidifies what is learned through discussion with clinicians. Telephone calls were used by patients to clarify with the physician any symptom and complication that was experienced away from the hospital but more so, to improve patients' information recall. The telephone calls also seem to guide self-care for late complications of chemotherapy and were seen to improve compliance to self-care strategies. Follow-up calls were done to confirm if symptoms were completely alleviated and to remind patients of 2nd cycle visit. This has been shown to improve treatment adherence (Chelf et al., 2001). However, this differs from a study by Craddock et al, who did not find any increase in self-care practices in a study where he included three telephone-call interventions and both oral and written self-care measures to assess the effectiveness of self-care measures (Craddock et al., 1999). This could be because he followed up with patients to the fourth cycle of chemotherapy and hence could not see a cumulative increase in self-care measures.

5.3 Self-care behavior of patients treated with chemotherapy

Self-care behavior suggests that patients use knowledge, positive attitudes, skills, and resources to improve and promote poor health (Mohamed Rashad El-Nemer, 2015). Prevalent symptoms experienced by patients after the first course of chemotherapy were captured in the Memorial Symptom Assessment Score (MSAS) tool. These symptoms were temporal and varied among patients based on cancer type, chemotherapy administered, and severity. In this study, participants in both intervention and control arms were able to identify distressing symptoms that were attributed to chemotherapy side effects. Chemotherapy affects both the physiological

and psychological aspects of patients' lives. Symptoms from cancer and cancer treatment are described as distressing, emotionally and physically exhausting, and interfering with normal human functioning. The main chemotherapy side effects reported from the use of the MSAS tool included nausea and vomiting, change in the way food tastes, lack of appetite, lack of energy (fatigue), hair loss, and constipation. These side effects were similarly reported in both control and intervention arms. Sa'ed Abu El Kass found out that regarding physical complications participants in the study reported more gastrointestinal symptoms including nausea and vomiting, loss of appetite, and change of sense of taste (Abu El-Kass et al., 2021). American Cancer Society also supports these findings when they documented that chemotherapeutic drugs irritate the mucosa of the stomach and duodenum which have numerous nervous communications to the vomiting center in the brain leading to nausea and vomiting (Tsiftsis, 2014). Concerning fatigue in the current study, patients were able to record the symptom in the MSAS tool rating them on how distressing the symptoms were. More participants in the intervention arm (42.2%) had self-care behaviors that completely alleviated fatigue compared to the control arm (26.5%). A study done in Turkey by Ozgur Usta Yesilbalkan et al, revealed that patients had statistically significant improvement ($p=0.05$) in fatigue in subsequent chemotherapy sessions (time T1 and T2) compared to baseline, indicating that patients' awareness of the NCCN algorithm on self-care management of fatigue symptoms improved their QOL (Yesilbalkan et al., 2009) while Kass et al also revealed that fatigue was also majorly reported to contribute to negatively affecting daily activities and quality of life (Abu El-Kass et al., 2021). However, despite these symptoms, the current study demonstrated that a structured educational intervention of not only chemotherapy information but also self-care behaviors and practices lead to more participants in the

intervention group carrying out more correct actions that completely alleviated distressing side effects symptoms as compared to the participants in the control group ($p=0.00006$). This was also reported in a study by M D. Boer Dennert that was aimed at checking patients' perception of the side effects of chemotherapy found participants complained mostly of nausea and vomiting, hair loss, and constipation. There was evidence that the participants in the intervention arm who had received education intervention to alleviate these symptoms carried appropriate self-care behaviors that alleviate the symptoms completely (De Boer-Dennert et al., 1997).

Self-care behavior is a learnt behavior that requires patients to be given information to implement. It empowers patients to know what is done when required. Chronic diseases including cancer affect self-care and the ability to carry out basic activities. This leads to low motivation. Self-care can be improved through structured learning and this has been shown to improve cancer patients' health conditions. Symptoms brought about by the complications of cancer and its therapy lead to a negative impact that can lead to treatment inconsistencies and a low success rate in treatment outcomes. One symptom can lead to the emergence or complication of another symptom making management and coping with the chronicity of cancer illness difficult. Therefore when it comes to symptom management, the primary focus should be the well-being of the patient, quality of life and coping with the disease. Many studies have shown positive results in self-care and the management of chronic diseases (Dickson et al., 2013).

For quality health promotion, clinicians are best placed to educate patients about cancers, its complication, treatment regimens and potential adverse effects. Focus on behavioral change should be vital in these education sessions. Patients need to learn how to develop and maintain positive behavioral change. People who believe they can

influence the positive outcome of their health condition are more likely to take charge of their lives and impact their behavior. This current study helped patients in self-actualization, solve health problems and adapt to new situations. Many studies have demonstrated education interventions on different aspects of chemotherapy side effects; however, the main advantage of this study is that it focused on the specific needs of patients via a structured education through Orem's self-care model (Parissopoulos, 2004). Orem's self-care deficit theory provided the framework for this study. Orem regarded individuals as being able to be responsible for their health and being able to actively engage in their self-care (J. E. Johnson, 1999; Parissopoulos, 2004; Williams & Schreier, 2004). Patients who can maintain their well-being must have a learnt capability of doing so, to be able to meet their needs away from a hospital setting and be able to access resources that enhance this knowledge and information.

Educating patients on self-care practices was the main objective of the structured intervention. The education intervention is cheap, readily available and easy to administer self-care measures. Patients were able to perform self-care behavior before them becoming severe or persistent by following a set of guidelines and instructions on the side effects of chemotherapy and their management techniques. A form of self-care behavior includes tracking and monitoring chemotherapy-related symptoms (Basch et al., 2016). The memorial symptom assessment scale tool was used to track symptoms associated with chemotherapy while the self-care behavior log was a tool that was used to record patients experiencing side effects and if action is taken correctly to alleviate their symptoms. For example, patients who experienced nausea and vomiting would take the appropriate prescribed medication and with no relief, they would either call the researcher/doctor for the way forward or seek the nearest

facility for further treatment before the symptoms got worse. Individuals who received information on appropriate actions to take on specific side effects of chemotherapy performed better in mitigating their discomfort than those who did not receive a standardized education. This result is supported by Sivakumar et al who implemented a self-care symptom management program for patients with cancer to assess their self-efficacy after every session of chemotherapy (Sivakumar & Susila, 2021). The results demonstrated that chemotherapy side effects can significantly reduce the performance of self-care measures and consequently improve the performance status of daily activities of patients receiving an education program. The study was able to compare two groups. The control group had a self-care performance status mean score of 0.94 (SD 0.82), while the experimental group had a pre-test performance status mean score of 0.97 (SD 0.83). The difference between the pre-and post-performance status in self-care practices was statistically significant with a $p < 0.001$ (Sivakumar & Susila, 2021). Hence, a proper educational program improves self-care practices and helps in the reduction of chemotherapy side effects. This has been demonstrated in Moi Teaching and Referral Hospital cancer Unit with the current study where the structured intervention education represents a promising program to promote self-care in patients undergoing outpatient chemotherapy.

In a study by A. Almohammadi et al to assess patients' knowledge in managing side effects, a case of patients in King Abdul Aziz University Hospital found that there is no correlation between the total score of patients' compliance to self-care behavior to manage chemotherapy side effects with their knowledge on chemotherapy where only 36.1% of the participants reported engagement of self-care behavior to alleviate chemotherapy side effects, while 43.1% and 20.8% reported partial and no self-care behaviors respectively. The study assessed different sources of information by

patients and found that patients who had information from variable sources had better scores (mean =22.770 compared to those from one source (mean=21.09). A majority of patients (80.6%) received their information from physicians. Most patients reported they would go to their hospital for treatment with the onset of any adverse effects (51.4%) while others reported they would do nothing (11.1%). The study attributed the findings to age and education where patients with higher education and age greater than 40 had better total mean scores in behaviors toward avoidance or control of chemotherapy adverse effects ($p = 0.086$). However, the study noted the need to have a balance between drug toxicity and loss of quality of life and acknowledged patients should be empowered to check their temperature while at home to avoid complications of chemotherapy-induced neutropenia (CIN) which has significant morbidity and mortality (Almohammadi et al., 2019). The findings of the current study did not show a correlation between variables and self-care behavior scores, however, it sought to reduce hospital visits and help patients manage side effects at home through correct self-care practices.

The current study also differed from Haryani et al who did not demonstrate any statistically significant improvement in self-care despite using a self-care symptom assessment program (SSM) that consists of providing cancer and chemotherapy information, the teaching of skills and providing support via booklets and telephone calls or home visits to 40 cancer patients initiating chemotherapy in a hospital in Indonesia ($p=0.802$) (Haryani et al., 2017). However, despite the use of a quasi-experimental design in their methodology, the researcher noted lack of a control group in the study made it difficult to assess the benefits of the self-care management program compared to the standard of care. The study also lacked a method to assess if self-care skills were implemented.

The current study utilized a self-care log that captured the behaviors and practices initiated by participants to alleviate the side effects faced. The study had only 40 participants which also affected the generalizability of the result. The small sample size was also a limitation in Williams et al study who recruited 78 participants (38 in the experimental group and 33 in the control group) when studying the effect of education on the management of side effects in women receiving chemotherapy. This was only affected by a hurricane in the region despite it being a three-year study period, however, the study employed the use of follow-up telephone calls, similar to the current study, which may have substantially impacted the self-care behavior of patients while at home. Telephone conversations reinforced the self-care behavior skills of the women in the experimental group.

Though there was a statistical improvement in the self-care practice at 42.9% correct actions done on symptoms by the intervention group, this could be enhanced. There was perhaps fatigue from the intervention allocator (clinician) leading the discussion since it would take at most 30 minutes in some participants and the outcome assessor at T2 during the filling of the self-care log. This could have led to less information given or fewer recorded responses at the end. To streamline this, in future studies, or during the application of the study, it is preferable to have 2 or more clinician-led discussions or new patients group discussions, even though this may be cumbersome and expensive. It is important to note that MTRH has a wide catchment area with people of diverse cultural backgrounds and knowledge. This means that the development of education material needs to be focused on the geographical region and translation of the materials to languages that can be comprehended by the majority of the ethnicity. In doing so, the self-care actions demonstrated in this study are bound to improve exponentially not only patients QoL but streamline our health

care systems. There has always been apprehension in the initiation of self-care, despite chemotherapy knowledge being a crucial part of patients learning about potential chemotherapy side effects. Patients must be educated on their chemotherapy and the management of potential side effects before the initiation of chemotherapy and all through the chemotherapy duration to abate the distress and anxiety brought about by the lack of adequate information (Huynh & Trovato, 2014). A structured chemotherapy education can be received by all patients and implemented to alleviate the side effects of chemotherapy despite diverse differences in characteristics. Results from this study demonstrated that it's important to encapsulate a patient-centered approach to chemotherapy side effects awareness and maximize self-care practices that improve adherence and quality of life in cancer patients undergoing chemotherapy.

5.4 Strengths and Limitations

5.4.1 Strengths

1. The study was an open-label randomized control trial with a good sample size and diverse types of cancers with different chemotherapy regimens.
2. Individually tailored chemotherapy intervention and the implementation of written material to enhance recall of self-care behavior.

5.4.2 Limitation

1. The study assumed a high adult literacy rate of 82% according to previous surveys (UNESCO,2021)

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

1. An additional well-structured and standardized chemotherapy education intervention increases the level of knowledge on side effects from chemotherapy compared to the standard-of-care.
2. Standardized chemotherapy education improves self-care behavior and practices among patients receiving outpatient chemotherapy.

6.2 Recommendation

1. Assembly of different cadres (clinicians, pharmacists, educators, psychologists, nutritionists, etc.) to develop and distribute a culturally structured and standardized patient education package on information on cancer and chemotherapy side effects.
2. Further studies that have longer follow-up periods, until the end of the chemotherapy cycle to assess the cumulative gain in knowledge and overall effect on self-care behaviors can be done.

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APPENDICES

Appendix 1 Eastern Cooperative Oncology Group (ECOG) score

ECOG	Description
0	Fully active, able to carry on all pre-disease performance without restriction.
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work.
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours.
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours.
4	Completely disabled. Cannot carry on selfcare. Totally confined to bed or chair
5	Dead

Appendix 2: Consent Form**Title of the study: EFFECT OF A STRUCTURED CHEMOTHERAPY-EDUCATION-INTERVENTION VERSUS STANDARD-OF-CARE ON KNOWLEDGE AND SELF-CARE AMONG CANCER PATIENTS AT MOI TEACHING AND REFERRAL HOSPITAL**

You are invited to participate in a research study conducted by Gathua Beatrice, from Moi University. The purpose of this study is to evaluate patients' knowledge of chemotherapy education and their understanding of the expected chemotherapy side effects. The study will also assess basic self-care behavior that patients engage in to alleviate these side effects. The findings of this study will be useful in identifying bothersome and severe chemotherapy side effects early enough before it affects potential adherence or chemotherapy-related hospitalizations. This is a randomized control study which means you will be randomly allocated to any of the two arms of the study. One arm will receive the usual care offered in MTRH oncology unit and the other arm will undergo a new standardized type of chemotherapy education. The outcomes of both will be assessed with a second questionnaire when you come for your second chemotherapy. I would therefore like to invite you to be part of this research. However, before making a decision, feel free to talk to anyone you feel comfortable with about the research. This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain further. If you have questions later, you can ask me or any research assistant on my team.

Risks and discomfort: There are no known risks associated with this research. We shall just engage you in a discussion as well as request you to fill out a questionnaire related to the study.

Potential benefits: There will be no direct benefit to you, but your involvement will assist us in informing medical professionals on the strengths of educating cancer patients and also identify the gaps in information delivery on chemotherapy treatment. This improves patients' satisfaction which inadvertently improves their quality of life.

Protection of confidentiality: Information obtained in this research study will not be shared with anyone external to the research team. The questionnaires used to obtain information from you will not contain your name but will instead be coded with a number that is unique to you. Only the researchers will know what your number is and the questionnaire will be kept under lock and key in a cabinet. It will not be shared with or given to anyone except me, the main researcher and the research assistant.

Voluntary Participation: your participation in this research study is voluntary. You may choose not to Participate and you may withdraw your consent to participate at any time. You will not be penalized in any way should you decide not to participate or withdraw from this study.

Contact Information: If you have any questions or concerns about this study or if any problems arise, please contact the principal investigator, Gathua Beatrice at 0722522648. If you have any questions or concerns about your rights as a research participant, please contact the Moi University Board of Ethics, IREC at 078772677.

I consent that I have read this consent form and have been allowed to ask Questions. I give my consent to participate in this study.

Participant's Signature: _____ Date: _____

NB: A copy of this consent form should be given to you.

FOMU YA KURIFHIA KUSHIRIKI KATIKA UTAFITI

Chuo kikuu cha Moi Anwani ya utafiti: UTUMIZI WA KUTUMIA UFUNZO WA MAFUNZO YA CHEMOTHERAPY KATIKA MAFUNZO YA KUFANYA MAFUNZO YA SELF-CARE

Maelezo ya utafiti na kushiriki kwako: Umealikwa kushiriki katika utafiti unaofanywa na Gathua Beatrice, kutoka chuo kikuu cha Moi. Azma ya utafiti huu ni kutambua maarifa ya mgonjwa kuhusu elimu ya (kidini) madawa ya kansa na ufahamu wao wa athari za tiba ya kansa. Utafiti pia utaangalia tabia ya msingi ya kujitegemea ambayo mgonjwa hujihusisha ili kupunguza madhara haya. Matokeo ya utafiti huu yatakuwa na manufaa katika kutambua madhara ya kidini na maumivu makali mapema kabla ya kutoendelea na matibabu au kabla ya kulazwa hospitalini kutokana na madhara zinazohusiana na kidini. Kwa huu utafiti unaweza bahatishwa kuwa katika kwa mikono miwili. Mkono mmoja utapata huduma ya kawaida inayotolewa katika kitengo cha oncology cha MTRH na mkono mwingine utafanyika aina mpya ya elimu ya kansa. Matokeo ya wote wawili yatahesabiwa kwa dodoso la pili unapokuja chemotherapy yako ya pili. Hii utasaidia mtafiti kuamua ni mpango gani wa elimu husaidia mgonjwa zaidi kuboresha katika kujitegemea akiwa nyumbani. Hata hivyo, kabla hujafanya maamuzi, uwe huru kuongea na yeyote ambaye unamwamini kuhusu utafiti huu. Fomu hii ya kuridhia huenda ikawa na maneno mengine ambayo ni magumu. Tafadhali niulize nisite kidogo na nitachukua muda kukuelezea. Iwapo utakuwa na maswali baadaye, unaweza kuniuliza au mtafiti msaidizi aliye katika timu yangu.

Hatari na kero: Hakuna hatari zinazojulikana na ambazo zinahusishwa na utafiti huu. Tunakuhusisha tu katika mjadala na tunakuomba utujazie hojaji ya utafiti huu.

Manufaa yanayoweza kupatikana: Hutupatia manufaa moja kwa moja. Lakini kushiriki kwako kunaweza kutusaidia kutambua mapungufu katika utoaji wa habari juu ya matibabu ya kidini. Hii inaboresha kuridhika kwa wagonjwa ambayo inadhihirisha kuboresha ubora wao wa maisha

Kulindwa kwa usiri: Habari ambazo zitapatikana katika utafiti huu hazitapatiwa yeyote ambaye hahusiki katika utafiti huu. Hojaji ambazo zitatumika kupata habari kutoka kwenu hazitakuwa na majina yenu lakini zitapewa nambari zenu za siri. Ni watafiti pekee ambao watajua nambari hizi na hojaji zenyewe zitawekwa salama katika sefu. Hazitapewa mtu mwingine isipokuwa mimi; mtafiti mkuu na mtafiti msaidizi.

Kujitolea kushiriki: Kushiriki kwako katika uafiti huu ni kwa kujitolea. Unaweza kuchagua kutoshiriki na unaweza pia kuondoa kuridhia kwako wakati wowote. Hutaadhibiwa kwa njia yoyote ile iwapo utaamua kutoshiriki au kujiondoa katika utafiti huu.

Nambari za mawasiliano: Iwapo una swali lolote au hangaiko/sikitiko lolote kuhusu utafiti huu au iwapo kutazuka tatizo lolote, tafadhali wasiliana na mtafiti mkuu; Gathua Beatrice kwa nambari hii: **0722522648**. Iwapo una swali zozote au hangaiko lolote kuhusu haki zako kama mshiriki, tafadhali wasiliana na Bodi ya Maadili ya Chuo kikuu cha Moi IREC.

Nimesoma fomu hii ya kuridhia/kukubali na nimepewa nafasi ya kuuliza maswali. Ninatoa ridhaa yangu kushiriki katika utafiti huu.

Sahihi ya mshiriki..... Tarehe.....

Appendix 3 T1: Pre-intervention Interview questionnaire

This questionnaire consists of three parts. Please answer all the questions by ticking (✓) on the spaces provided or use the blank spaces left for you

Questionnaire Number:

Date of Interview:

1.0: Demographic Information:

Case ID:

Date of Birth:

Age:

Gender (Tick as applies) Male

Female

Residence:

Occupation:

Marital status (Tick as applies)

Single Divorced Others

Married Widowed

Level of education: (Tick as applies)

No formal education

Primary education

Secondary education

Tertiary education

University education

Others (please specify _____)

2.0 Clinical Data

Type of Cancer: _____

Stage of Cancer: _____

ECOG stage: (See below) _____

ECOG	Description
0	Fully active, able to carry on all pre-disease performance without restriction.
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work.
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours.
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours.
4	Completely disabled. Cannot carry on selfcare. Totally confined to bed or chair
5	Dead

3.0 Please tick (√) the most appropriate choice

	Yes	No	Don't know
Before receiving chemotherapy, patients need to check blood cells level in the body every time			
After treatment with chemotherapy, the patient does not need to come for a scheduled appointment			
Treatment with chemotherapy would decrease the number of red blood, decrease platelets and decrease white blood cells			
When having one of the following symptoms, such as fever or cough, sore			

throat, burning sensation when urinating, or diarrhea patient should consult a physician before the appointment			
Chemotherapy may cause emotional changes			
Treatment with certain chemotherapy drugs may cause diarrhea			
Treatment with chemotherapy may cause nausea and vomiting			
When having nausea and vomiting, I should eat a soft diet, and avoid fatty or fried foods			
After receiving chemotherapy, I cannot live with other people normally			
With treatment with chemotherapy, I can still exercise			
Treatment with chemotherapy may cause fatigue and tiredness			
When having low white blood cells count, patients should avoid people with colds, and eat cooked food with heat.			

Appendix 4:T2: Post- Intervention Interview Questionnaire

This questionnaire contains three parts that will be assessed:

- 1.Knowledge of chemotherapy side effects
- 2.The side effects of potential chemotherapy experienced using the Memorial Symptom Assessment scale
- 3.Self-care practices undertaken to alleviate the experienced side effects using the Self- care Log

In the Memorial Symptom assessment scale provided please indicate with a tick (√) which side effect you experienced at home and indicate the level of distress it caused you.

	Yes	No	Don't know
Before receiving chemotherapy, patients need to check blood cells level in the body every time			
After treatment with chemotherapy, the patient does not need to come for a scheduled appointment			
Treatment with chemotherapy would decrease the number of red blood, decrease platelets and decrease white blood cells			
When having one of the following symptoms, such as fever or cough, sore			

throat, burning sensation when urinating, or diarrhea patient should consult a physician before the appointment			
Chemotherapy may cause emotional changes			
Treatment with certain chemotherapy drugs may cause diarrhea			
Treatment with chemotherapy may cause nausea and vomiting			
When having nausea and vomiting, I should eat a soft diet, and avoid fatty or fried foods			
After receiving chemotherapy, I cannot live with other people normally			
With treatment with chemotherapy, I can still exercise			
Treatment with chemotherapy may cause fatigue and tiredness			

Patient's Name _____ Date ___/___/___ ID # _____

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

- I. INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom **DURING THE PAST WEEK**, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <u>all</u> the symptoms you have had during the PAST WEEK.	→→ IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some- what [2]	Quite a Bit [3]	Very Much [4]
Difficulty concentrating						
Pain						
Lack of energy						
Cough						
Changes in skin						
Dry mouth						
Nausea						
Feeling drowsy						
Numbness/tingling in hands and feet						
Difficulty sleeping						
Feeling bloated						
Problems with urination						
Vomiting						
Shortness of breath						
Diarrhea						
Sweats						
Mouth sores						
Problems with sexual interest or activity						
Itching						
Lack of appetite						
Dizziness						
Difficulty swallowing						
Change in the way food tastes						
Weight loss						

MEMORIAL SYMPTOM ASSESSMENT SCALE – Short Form [MSAS-SF]

- I. **INSTRUCTIONS:** Below is a list of symptoms. If you had the symptom DURING THE PAST WEEK, please check Yes. If you did have the symptom, please check the box that tells us how much the symptom **DISTRESSED** or **BOTHERED** you.

Check <i>all</i> the symptoms you have had during the PAST WEEK.	→ → IF YES: How much did it DISTRESS or BOTHER you?					
	Yes [✓]	Not at All [0]	A little Bit [1]	Some-what [2]	Quite a Bit [3]	Very Much [4]
Hair loss						
Constipation						
Swelling of arms or legs						
“I don’t look like myself”						
If you had <u>any other</u> symptoms during the PAST WEEK, please list them below, and indicate how much the symptom DISTRESSED or BOTHERED you.						
1. _____						
2. _____						

- II. Below are other commonly listed symptoms. Please indicate if you have had the symptom **DURING THE PAST WEEK**, and if so, how **OFTEN** it occurred.

Check <i>all</i> the symptoms you have had during the PAST WEEK	→ → IF YES, How OFTEN did it occur?				
	Yes [✓]	Rarely [1]	Occasionally [2]	Frequently [3]	Almost Constantly [4]
Feeling sad					
Worrying					
Feeling irritable					
Feeling nervous					

In the Symptom Self-care Log provided please indicate the side effect you indicated on the MSAS form and indicate the actions undertaken to alleviate the above side effect.

Self-Care Log

Side Effects						
Level of distress		Not at all				Very Much
		1	2	3	4	5
Action Taken		Not Relieved				Completely Relieved
		1	2	3	4	5
1						
2						
3						
4						

Action Taken	Correct	Incorrect

Appendix 5: CHEMOTHERAPY INFORMATION GUIDE

What is chemotherapy?

Chemotherapy uses medicine to treat cancer. Many different kinds of medicines are used to cure or control the growth and spread of cancer cells.

The kind of chemotherapy you get depends on:

- the kind of cancer you have and how far along your cancer is
- if you have had other cancer treatments before
- your health

Chemotherapy is different from other ways to treat cancer like immunotherapy and biotherapy. Although you may be taking the medicines the same way, they work differently on your body and need different ways to manage their side effects. Your doctor or nurse will let you know if you are having chemotherapy, biotherapy, or immunotherapy alone, or in combination.

How does chemotherapy work?

- Chemotherapy works best against fast-growing cells, like cancer cells.
- It prevents or stops the cancer cell's ability to multiply and grow, resulting in cell death.
- Chemotherapy can also damage healthy cells and cause side effects. Fast-growing cells like blood cells, hair cells, skin cells, cells that make up the gastrointestinal tract (mouth, throat, stomach, intestines) and cells of the reproductive system are at risk. Damage to these normal cells is the reason for many of the side effects people experience. Luckily, these cells can be repaired or replaced by other healthy cells

How can I prepare for getting chemotherapy?

1 to 3 days before the treatment day

- Check if you need a blood test done before your treatment. Have your blood test done at the hospital 1 to 2 days before your chemotherapy appointment. This is to make sure we have enough time to get your test results back and prepare the medicines. Check with your doctor or nurse to see if your blood work can be done at a lab closer to home.

What side effects may I expect?

- Before you start chemotherapy, a doctor, a nurse or a pharmacist will tell you about the medicines you will get and the side effects you **may** have.

- Not everyone experiences chemotherapy side effects the same way. The side effects you may get will depend on the type and dose of chemotherapy you get. Most of the side effects are temporary and usually get better before your next treatment.
- Keep a diary to help you write down any side effects you experienced during and after your chemotherapy treatment. Write down about:
 - type of symptoms you experienced
 - when the symptoms happened
 - how often the symptoms occurred and how long does it usually stay
 - how bad does the symptom make you feel

Let your healthcare team know about any side effects you have during the chemotherapy. This allows us to manage your side effects early and prevent complications.

Infection

Some chemotherapy can reduce the number of neutrophils in your body. Neutrophils are a type of white blood cell (WBC) to help your body fight infection. When your neutrophil count is low (called **neutropenia**), you are at risk for developing an infection and you can get sick very quickly.

Your neutrophil count is usually lowest at 7 to 10 days after your last chemotherapy treatment. It takes about 1 to 2 weeks for the count to recover. It is important to have a blood test done before starting your chemotherapy to make sure your neutrophil count has fully recovered

You may have an infection if you have one or more of these symptoms

- Fever (temperature higher than 38 °Celsius or 100.4 °Fahrenheit)
- Chills or shakes
- Shortness of breath or trouble breathing
- New cough or a cough that doesn't go away, with or without chest congestion
- Stiff neck or neck pain when moving
- Earache
- Very bad pain in your throat, or having open sores or white patches in your mouth
- Burning or pain when you urinate (peeing), or needing to urinate often

- Redness, rash, swelling, pain or tenderness around a wound, tubes or anywhere in your skin
- Feel burning or pain while urinating (peeing) or see blood in your urine
- Nausea and vomiting (throwing up) with a fever
- Diarrhea (loose or watery poo) that doesn't go away, with or without stomach pain
- Feel dizzy, drowsy, trouble staying awake

Inform your doctor immediately or seek medical attention if you experience the above

Bleeding

Some chemotherapy can reduce the number of platelets your body made. Platelets are a type of blood cell that helps blood to clot and stop bleeding.

If your platelet count is too low, chemotherapy may be harmful to you and your doctor may need to delay your chemotherapy treatment.

How do I know if I have low platelets?

The only way to know if you have low platelet is by having a blood test. You may have low platelets if you have any of these symptoms:

- Easy bruising, tiny red or purple dots on your skin (called petechiae)
- Sudden onset of bleeding (for example, from the gums or nose) that takes longer to stop
- Vaginal bleeding that is different from a normal period and lasts longer

If you have a very low platelet count, you may need a platelet transfusion. You may need a transfusion even if you feel quite well. **Go to the nearest emergency department if you have any of the following:**

- Dizziness, with or without blurred vision Confusion, feeling less alert, loss of consciousness
- Looking pale, feeling clammy (cold sweats) and weak
- Blood in the stool (black stool), urine, sputum, and vomit (looks like coffee grounds)
- Heavy bleeding or bleeding that cannot be stopped, with or without fever (38 °Celsius or 100.4 °Fahrenheit).
 - Headaches: That gets worse

- That is new
- Behind your eyes
- In the back of your head

Anemia

Chemotherapy can reduce the number of red blood cells in your body (called anemia).

A blood test can confirm if you have anemia.

Red blood cells carry oxygen to tissues in your body. When your red cell count is low, there is not enough oxygen for your body to work properly. Your skin, gums lips and under your nails may look pale or bluish. You may feel:

Weak and faint

- weak and faint
- easily short of breath
- your heart is beating fast
- easily tired
- fainting

Inform your doctor or head to the nearest facility if you experience the above symptoms

Fatigue

The fatigue you feel during chemotherapy is different from everyday fatigue. You may feel very tired, worn out, or lack energy. The tiredness often does not go away with rest or sleep. It may last for weeks or months after your chemotherapy treatment is over. The feeling of fatigue can affect your mood and your ability to care for yourself.

Fatigue can have many causes, such as:

- Cancer treatment (chemotherapy, radiation, or surgery) and/or medicines
- Anemia (low red blood cell count)
- Pain
- Infection
- Lack of sleep or sleeping too much
- Too much or lack of physical activity
- Emotional stress like worrying, grieving, or depression
- Poor appetite (not wanting to eat), and not eating healthy foods

How do I manage Fatigue?

1. Get treated for medical conditions or causes that make fatigue worse
2. Get moving. Physical activity is the best way to counter cancer-related fatigue. Whether it's walking, swimming or going to the gym moving your body every day improves fatigue
3. Take time to relax. Schedule rest to conserve energy. Limit to one hour to be able to sleep well at night
4. Eat well
5. Practice good sleep habits
6. Engage in mind-body strategies. Meditation and yoga may help in relaxing the mind
7. Consider therapy and counseling can provide psychological intervention that may help with fatigue
8. Get a massage
9. Ask your family or friends to help you with tasks you find difficult or tiring
10. Save your energy for things you find most important

Mouth and throat changes

Chemotherapy can damage the inner lining that covers your mouth and throat. As a result, you may temporarily experience one or more of the following:

- Taste changes (for example, metallic taste)
- Dryness in your mouth and/or throat
- Pain in your mouth and/or throat
- Trouble chewing, swallowing or talking
- Swelling of the mouth or gums
- Bleeding
- Thick saliva
- White patches that coat the mouth or tongue

These problems can affect how much you want to or can eat. It can also cause you to lose too much weight and impact your body's ability to recover and fight infection.

Maintaining Oral Health

One of the key things you can do to manage mucositis is to take good care of your mouth, including keeping it clean.

Here are some tips:

- Visit your dentist before treatment. He or she can make sure that your mouth is as healthy as possible before you begin treatment and can provide important information to the rest of your healthcare team.
- Choose a soft-bristle brush for brushing your teeth.
- If toothpaste irritates your mouth, use a mixture of a half teaspoon of salt with four cups of water.
- Gargling may also help. Use a solution made up of one-quarter of plain water, a half teaspoon of table salt and a half teaspoon of baking soda.
- Drink plenty of fluids.

Soothing Mouth Pain

There are several options for soothing mouth pain. Before you begin any of these treatments, talk with your doctor about the best ones for you. Some require a prescription:

- Ice chips
- Ibuprofen (such as Motrin), naproxen (such as Aleve and others) or acetaminophen (such as Tylenol) for mild pain
- Over-the-counter oral anesthetics, such as Anbesol, Xylocaine or Bonjela cream. Let your doctor know if you are using them, especially if he or she has prescribed a lidocaine-based mouthwash.

Nausea and vomiting

Depending on the type of chemotherapy you received, you may have nausea (feeling sick to the stomach), vomiting (the actual throwing up), or both.

Nausea and vomiting can also be caused by:

- Cancer treatment (chemotherapy, radiation to the stomach area)
- Cancer itself
- Medicines, such as pain medicine, antibiotics (a medicine used to fight infection)
- Infection
- Constipation
- Anxiety, worrying

Your doctor may prescribe medicine to help prevent nausea and vomiting (called **anti-nausea medicine**). Some anti-nausea medicine must be taken at a scheduled time. Some should only be taken when you feel sick in your stomach or after you

vomit. Check with your nurse or pharmacist on how to take the anti-nausea medicine correctly before the start of your chemotherapy treatment.

What can I do to prevent or manage my nausea and vomiting?

- Eat a light meal or snack before your chemotherapy treatment.
- Eat a small amount of food often and slowly. Avoid drinking too much fluid (for example, water, or juice) immediately before and during meals.
- Limit foods that are spicy, very sweet, creamy or have a strong smell.
- Do what worked before for you to prevent nausea.
- If you tend to be anxious and feel nauseous before your chemotherapy treatment, try to focus your attention on television, music, reading, or chatting with someone. Your doctor can also prescribe medicine to help you relax and have less nausea.
- Tell your doctor or nurse if you cannot take your anti-nausea pills or if you continue to have nausea and vomiting even after taking the pills as prescribed. Your doctor can prescribe a different type of anti-nausea medicine.
 - Take the anti-nausea medicine as ordered by your doctor. If you have nausea and vomiting at a certain time take your anti-nausea medicine at least 30 minutes before that time. For example, if you often have nausea or vomiting before meals, take your anti-nausea pill at least 30 minutes before your meal.
 - If you vomit within 1 hour of taking your anti-nausea pill, you can take another pill

Constipation

Constipation means that you are having fewer bowel movements (going poo) than normal. You may be constipated if you have one or more of the following:

- No bowel movements for 2 days or more from your normal bowel pattern. A “normal” bowel routine is what was normal for you before starting treatment.
- A small amount of leaking stool (poo)

- Small, dry hard stools (poo), which often can be difficult to pass
- Stomach ache or cramps, bloated belly, a feeling of fullness or discomfort
- Passing lots of gas or belching (burping)
- The need to strain (bearing down) when having a bowel movement (poo)
- Nausea or vomiting

What can I do to prevent or manage constipation?

- Drink at least 8 glasses of water or other fluids like fruit juices, warm coffee, or tea during the day only so it won't affect your sleep.
- Eat food high in fiber, like raw vegetables, fruits with skin, whole grain products, popcorns, dried fruits and prunes. **Remember to drink more fluids when you eat high-fiber food.**
- Talk to your doctor about which laxative is best for you. Some laxatives may make constipation worse if you don't drink enough fluid.
- Try to stay active every day. Exercises like walking, yoga or running may help with constipation.
- Tell your doctor or nurse if you have not had a bowel movement for 2 days from your usual bowel movement routine. They can suggest a laxative that is appropriate for you

Nerve damage

Some people on chemotherapy experience numbness or tingling in their hands and feet. Side effects of chemotherapy-related to neuropathy and other types of nerve damage may include:

- Difficulty picking up objects or buttoning clothing
- Problems with balance
- Difficulty walking
- Hearing loss
- A feeling of “pins and needles” or “hot and cold”

How do I manage nerve damage?

- Take care when moving around – you may be more prone to trip and fall if your feet are numb or your legs are weak.

- Use gloves and warm socks to keep your hands and feet warm, or soak your hands and feet in warm water to relieve symptoms.
- Use your elbow to check the water temperature so you don't scald yourself.

Hair Loss

Some people lose all their hair quickly and others lose it after several treatments, while others may lose only a little hair or none at all. When hair loss does occur, it usually starts 2–3 weeks after the first treatment. Before and while your hair is falling out, your scalp may feel hot, itchy, tender or tingly

How do I manage hair loss?

- Keep your hair and scalp very clean. Use a mild shampoo like baby shampoo. If you want to use lotion on your head, check with your nurse before using any other hair or skin care products.
- Comb or brush your hair gently using a large comb or a hairbrush with soft bristles.
- Explain to family and friends, especially children that the chemotherapy may make your hair fall out.
- Cut your hair, especially if it is long before it falls out. Some people say this gives them a sense of control.
- Wear a light cotton turban or beanie to bed if you are cold at night.
- Use a cotton, polyester or satin pillowcase, as nylon can irritate your scalp
- Wear a wig, hat, turban or scarf, or go bare-headed – whatever feels best to you. If you prefer to leave your head bare, protect it against sunburn and the cold

Sex and Fertility

Chemotherapy can have an impact on your desire (libido) or ability to have sex. It may also affect sexual organs and functioning in men and women. This can affect your ability to have children (fertility).

A range of issues can cause people to lose interest in sex while they're having treatment. Aside from feeling tired and unwell, you may feel less confident about who you are and what you can do. There may also be a physical reason for not being able or interested in having sex, e.g. vaginal dryness or erection difficulties. Changes in appearance can also affect feelings of self-esteem and, in turn, sexuality.

How do I manage sex and fertility?

- Talk about how you're feeling with your partner and take time to adapt to any changes.
- Try to see yourself as a whole person (body, mind and personality) instead of focusing only on what has changed.
- If you're worried about the changes to your relationships or sexual functioning, you may find talking to a psychologist or counselor helpful.

Allergic Reaction

Our body's immune response to a foreign substance is potentially a "two-edged sword" it can either protect or harm the host. It protects us from foreign substances such as viruses or bacteria, but it can also bring about an exaggerated (hypersensitive) response when previously sensitized individuals are exposed to the same foreign substance like chemotherapy. These reactions are immediate and may occur in seconds or minutes, especially if the body has been exposed to the foreign substance before and has been "sensitized."

Common symptoms of this type of reaction are:

- **Hives** (urticaria): raised, itchy, red blotches or wheals which may be pale in the center and red around the outside. This is also a common chemo drug reaction usually occurring within 36 hours of drug exposure. The lesions rarely last for more than 24 hours. However, on giving the drug again the lesions may develop within minutes.
- **Swelling** or angioedema may also occur with hives as part of an allergic reaction. It is a vascular reaction resulting in an increased ability for fluid in the cells to "leak" into the layers of the skin causing swelling. This happens much less often than hives alone. The tongue, lips, or eyelids are generally affected. Swelling of the airways can result in difficulty breathing, closing off of the airway and death. If swelling is happening and any sign of breathing difficulty seek help immediately.
- **Itching**
- **Flushing** a temporary redness of the face and neck caused by dilation of the blood capillaries.

- A **maculopapular rash** is the most common type of drug-induced allergic skin reaction. It is described as a combination of reddened macular (small, distinct, flat areas) and papular (small raised lesion) rashes.

How do I manage allergic reactions?

- Notify your healthcare professional of any allergies you may have, including food and drugs. Also, let your healthcare professional know if you have had an allergic reaction to any drugs - specifically chemo treatments
- Be aware of what caused the reaction. Notify health care professionals that this substance causes reactions.
- Take prescribed pre-medications before chemotherapy as directed. If you forget let your healthcare professional know.
- If you develop a rash that is not causing you discomfort, make sure your healthcare professional is aware of the rash so it can be evaluated. Not all rashes require treatment

Chemotherapy-induced Lack of Appetite

- **Poor appetite** describes the feeling of not being hungry, having no desire to eat and/or having no taste for any food.

How to manage a lack of appetite?

- Try to eat small meals or snacks, every two to three hours, instead of three large meals a day (become a grazer). Don't expect to eat regular-size meals.
- Foods that are high in protein or calories are good snacks to have handy. Examples include; milkshakes, cheese, fruits, peanut butter, nuts, crackers and juices.
- Eat foods that are rich in calories and nutrients. Avoid low-calorie foods that fill you up, such as lettuce, broth and diet soda.
- When choosing beverages, select nutrient-dense fluids such as milk, milkshakes, juice and punch-type drinks.
- Avoid heavy meals, greasy or fried foods, and foods that cause gas. Examples of gas-producing foods include beans, cauliflower, broccoli, cabbage, and carbonated drinks.
- Prepare food that is colorful and appealing to the eye.

Appendix 5: Chemotherapy Guide Brochure

EFFECT OF A STRUCTURED CHEMOTHERAPY-EDUCATION-INTERVENTION
VERSUS STANDARD-OF-CARE ON KNOWLEDGE AND SELF-CARE AMONG CANCER
PATIENTS AT MOI TEACHING AND REFERRAL HOSPITAL



What is chemotherapy?

Chemotherapy uses medicine to treat cancer. Many different kinds of medicines are used to cure or control the growth and spread of cancer cells.

The kind of chemotherapy you get depends on:

the kind of cancer you have and how far along your cancer is

if you have had other cancer treatments before

your health

Chemotherapy is different from other ways to treat cancer like immunotherapy and biotherapy. Although you may be taking the medicines the same way, they work differently on your body and need different ways to manage their side effects. Your doctor or nurse will let you know if you are having chemotherapy, biotherapy, or immunotherapy alone, or in combination.

How does chemotherapy work?

Chemotherapy works best against fast-growing cells, like cancer cells.

It prevents or stops the cancer cell's ability to multiply and grow, resulting in cell death.

Chemotherapy can also damage healthy cells and cause side effects. Fast-growing cells like blood cells, hair cells, skin cells, cells that make up the gastrointestinal tract (mouth, throat, stomach, intestines) and cells of the reproductive system are at risk. Damage to these normal cells is the reason for many of the side effects people experience. Luckily, these cells can be repaired or replaced by other healthy cells

Infection

Possible side effects	Symptoms:	What you should do
Infection due to low white blood cells – also called neutropenic sepsis	<ul style="list-style-type: none"> • High temperature • Shivering or flu-like symptoms • Other signs of infection, such as a sore throat or cough 	<ul style="list-style-type: none"> • Check your temperature if you feel unwell • Avoid grazing or cutting your skin
When symptoms may occur	<ul style="list-style-type: none"> • Rash • Diarrhoea 	<p>Contact the hospital immediately – refer to your alert card for contact details if you feel unwell at any time or have a temperature (37.5°C/100°F or higher)</p>
Usually 7–14 days after chemotherapy		

Anemia

Possible side effects	Symptoms:	What you should do
Anaemia (low red blood cells / haemoglobin)	<ul style="list-style-type: none"> • Tiredness • Shortness of breath 	<ul style="list-style-type: none"> • Eat a diet rich in iron <p>Contact your hospital urgently (see page 55 for contact details) if you feel very unwell</p>
When symptoms may occur		
During the course of chemotherapy		

Bleeding

Possible side effects	Symptoms:	What you should do
Bruising or bleeding (due to low platelet count)	<ul style="list-style-type: none"> • Gum / nose bleed • Rarely small groups of red-purple spots on your skin 	<ul style="list-style-type: none"> • If you are taking drugs such as aspirin or clopidogrel, ask your doctor if you should continue • Use a soft toothbrush and an electric razor to prevent damage to your gums and skin • Take care not to cut yourself <p>Contact your hospital urgently (see page 55 for contact details) if you have bruising, bleeding or groups of red-purple spots appear on your skin</p>
When symptoms may occur		
During the course of chemotherapy		

Hair Loss

Possible side effects	Symptoms:	What you should do
Hair loss	<ul style="list-style-type: none"> • Total hair loss • Thinning of hair • Brittle hair 	<ul style="list-style-type: none"> • Use a neutral pH shampoo and conditioner • Cut down on the number of times you wash your hair each week • Order a wig in advance if you are likely to lose your hair • Avoid harsh chemicals, such as hair dyes and perms
When symptoms may occur		
Within a few weeks of beginning chemotherapy		

Sore Mouth

Possible side effects	Symptoms:	What you should do
Sore mouth	<ul style="list-style-type: none"> • Dry mouth and tongue • Sore mouth and tongue • Bleeding from gums, mouth or tongue 	<ul style="list-style-type: none"> • Drink plenty of fluids • Use a mouth wash regularly • Clean your teeth regularly • Keep your lips moist
When symptoms may occur		<p>Contact your GP or hospital (see page 55 for contact details) if you are unable to eat or drink because of mouth ulcers</p>
7–14 days after chemotherapy		

Taste and smell changes

Possible side effects	Symptoms:	What you should do
Taste changes Changes in smell	<ul style="list-style-type: none"> • Changes in the way food and drink taste • Increased awareness of smells that may now become unpleasant, for example, cooking and perfumes 	<ul style="list-style-type: none"> • Suck a strong flavoured sweet if you have an unpleasant taste during an injection • Avoid areas where unpleasant smells are present
When symptoms may occur		
During your course of chemotherapy		

Nausea and Vomiting

Possible side effects	Symptoms:	What you should do
Nausea and vomiting	<ul style="list-style-type: none"> • Feeling sick (nausea) • Being sick (vomiting) 	<ul style="list-style-type: none"> • Take anti-sickness tablets or suppositories regularly, as prescribed
When symptoms may occur		<p>Contact your hospital (see page 55 for contact details) if you continue to have nausea or vomiting. You can be given different anti-sickness drugs that may be more effective</p>
Within a few hours or days up to 14 days after chemotherapy		

Changes in Appetite

Possible side effects	Symptoms:	What you should do
Changes in appetite	<ul style="list-style-type: none"> You may not feel like drinking or eating 	<ul style="list-style-type: none"> Drink plenty of fluids Have small frequent meals or snacks <p>Ask to see the dietitian if you are worried about your diet</p>
When symptoms may occur		
7–14 days after chemotherapy		

Diarrhea and Vomiting

Possible side effects	Symptoms:	What you should do
Diarrhoea or constipation	<ul style="list-style-type: none"> Frequent or loose bowel movements Not able to control bowel action Irregular or hard bowel movements 	<ul style="list-style-type: none"> Drink plenty of fluids <p>Contact your GP or hospital (see page 55 for contact details) if you have diarrhoea (four or more bowel movements more than usual or diarrhoea at night)</p>
When symptoms may occur		
7–14 days after chemotherapy		

Skin Changes

Possible side effects	Symptoms include:	What you should do
Skin changes	<ul style="list-style-type: none"> Sore, dry hands and feet Nails become darker than usual Nails may develop ridges and white lines 	<ul style="list-style-type: none"> Use a moisturiser, such as aqueous cream on dry skin Protect your skin in the sun
When symptoms may occur		
During your course of chemotherapy		

Sex and Fertility

Possible side effects	Symptoms:	What you should do
Changes in your fertility	<ul style="list-style-type: none"> Early menopause (for women) Inability to conceive or father a child (men and women) Some drugs can damage the DNA development of a foetus 	<p>Men can consider</p> <ul style="list-style-type: none"> Sperm banking (if appropriate) <p>Women can consider</p> <ul style="list-style-type: none"> Freezing embryos Freezing unfertilised eggs (oocytes) Freezing ovarian tissue Drugs to protect the ovaries <p>Men and women</p> <ul style="list-style-type: none"> Use effective contraception
When symptoms may occur		
During and following treatment		

Notes and Questions

You may wish to use this space to make notes or write questions, as they occur to you, to discuss with your specialist nurse or your doctor.

Contact details

If you have any queries about your illness or treatment or experience any problems, please contact the team caring for you

Name of consultant.....

.....

Hospital.....

Telephone.....