ADOLESCENT PERSPECTIVES TOWARDS REPRODUCTIVE HEALTH CONCERNS DURING CHEMOTHERAPY AND RADIOTHERAPY TREATMENT AT MUHIMBILI NATIONAL HOSPITAL, DAR ES SALAAM TANZANIA

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By

Irene Ngowi

A Dissertation Submitted in (Partial) Fulfilment of the Requirements for the Degree of Masters of Science (Oncology Nursing) of

Muhimbili University of Health and Allied Sciences
October, 2024

CERTIFICATION

The Undersigned certifies that they have read and hereby recommendation for acceptance by Muhimbili University of Health and Allied Science a dissertation entitled; **"To explore Adolescent perspectives towards reproductive health concerns during Chemotherapy and radiation therapy at Muhimbili National Hospital",** in (partial) of requirement of the degree of Master of Science (Oncology Nursing) of Muhimbili University of Health and Allied Science.

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_____

Date

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Co-Supervisor

_____

Date

DECLARATION AND COPYRIGHT

I **Irene Eliaringa Ngowi**, declare that this **dissertation** is my original work it has not been presented and will not be presented to any other university for a similar or any other degree award.

Signature……. **Date**…….……..

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DEDICATION

I dedicate this dissertation to Almighty God for without him, this would not be possible. All efforts and good work were due to his everlasting grace and love. Additionally, I dedicate this work to my previous working station the Cancer Care Center at Kilimanjaro Christian Medical Center, KCMC.

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ABSTRACT

Background: Adolescent age is the peak age of identifying concerns regarding self-identity and sexuality. Concerns about reproductive health are heightened by the potential gonadotoxic effects of chemotherapy and radiation therapy, however they face unique needs and significant challenges including managing their illnesses.Their future life aspirations often exacerbate insecurities particularly concerns on their future reproductive health and potential lifelong toxicities.

Adolescents have a limited understanding of fertility health and potential gonadotoxic effects following cancer treatment. Addressing these challenges is vital for their mental health, psychological well-being and ensuring their future childbearing opportunities.Their overall quality of life is of paramount important mostly improving their survivorship.

Aim: To explore adolescent perspectives towards reproductive health concerns during chemotherapy and radiotherapy treatment at Muhimbili National Hospital Dar-es-salaam, Tanzania.

Methodology: A qualitative study, with descriptive design conducted at the pediatric oncology unit during clinic visits. Participants were adolescents aged 15-19 years and were recruited purposively excluding all critically ill or unconscious participants. Data was collected through in-depth interviews in the Swahili language. Interviews with Semi-structured open-ended guided questions were employed and recorded using audio tapes, later transcription was done verbatim and data information was analyzed using deductive and inductive content analysis. Ethical clearance was sorted by the Research and Ethical Committee of Muhimbili University of Health and Allied Science (MUHAS).

Results: A total of 11 participants were enrolled, the majority of them male had secondary education level, participants aged between 15-19 years. Key concerns identified were uncertainties about gonadotoxic effects due to prolonged exposure to systemic therapies,

pubertal growth alterations exacerbating concerns about future reproductive ability and they expressed a need for better health knowledge and reassurance about future fertility.

Conclusion: Findings have shown that adolescents have reproductive health concerns linked to uncertainties on infertility risks following long-term exposure to mostly systemic therapies leading to pubertal disruptions These concerns are often overlooked at the start of treatment, therefore this study adds knowledge to the existing literature on potential reproductive toxicities and also it provides a voice of expression to this affected population.

Keywords: Gonadotoxic side effects, Gonad-toxicity,Reproductive disparities, Infertility risks, Reproductive health concerns, gonadal function, Health Care providers**.**

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LIST OF ABBREVIATIONS

ASCO	American Society of Clinical Oncology
ASFR	Age Specific Fertilitly Rate
GnRH	Gonadotrophin Releasing Hormones
HCP	Health Care Provider
HR	High Risk
ICU	Intensive Care Unit
IP	Irradiation Patient
LMIC	Lower Middle-Income Countries.
MUHAS	Muhimbili University of Health and Allied Sciences
NCI	National Cancer Institute
NGOs.	Non- Governmental Organizations
ORCI	Ocean Road Cancer Institute
RHC	Reproductive Health Concerns
SIOP	Society of International Oncology pediatrics'
TDH	Tanzania Demographic Health Survey.
WHO	World Health Organization

OPERATIONAL DEFINITIONS

Adolescents;	These individuals both male and female from age 15-19 years old were included in the study, according to WHO statistics puberty/maturity is marked of secondary Sexual characteristics typically begins between 10-19 years of Age.
DALY;	These are the total number of years lost to early death and years spent disabled as a result of a sickness or health condition that is common among the population.
Gonadotoxic Chemoradiotherapy;	This refers to the chemotherapy and radiation therapy that has potential effects of infertility due to damage of the gonads (the female ovaries and male testes)
High Risk;	These are individuals (adolescents) receiving systemic therapies with potential gonadotoxic effects such as alkaline-based, platinum based compounds as used in the study.
Pubertal growth	This refers to development of secondary sexual characteristics as part of maturity among adolescent patents from age of 15 to 19yrs.
Pubertal growth Alterations.	These are altered pubertal growth changes among adolescents that have either diminished/altered due exposure to gonad toxicity effects caused by gonadotoxic cancer treatment as used in the study
Reproductive Health concerns;	These are concerns that aligns with potential gonado-toxicity side effects following exposure of gonadotoxic chemotherapy and radiotherapy treatment as used in this study.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Cancer is an emerging and major health concern among children and adolescents worldwide (GLOBALCAN,2022.). It is substantively contributing to an increase in Disability-adjusted life years, these are sum of years of potentially life lost due to premature mortality (World Health Organization, 2021).

The incidence of malignancy is increasing yearly about 400,000 in both children and adolescents from (0-19yrs), however 80% of the population diagnosed with malignancies are from Low and Middle-Income Countries (LMIC) this is because they are diagnosed at advanced stages leading to poor prognoses (Majaliwa et al., 2023) .

Adolescents often face a unique spectrum of cancers including hematological malignancies and sarcomas, which requires specialized treatment approaches. Other common malignancies seen in adolescents include CNS tumours, Hodgkin's non-Hodgkin's lymphoma, leukemia, gonadal germ cells and bone/soft tissue sarcoma. (Kohi et al., 2019).

Treatment-related Reproductive health concerns in (LMIC) low and Middle income countries aligns with puberty, sexuality and emotional impacts following cancer treatment. Cultural stigma surrounding cancer disease still impedes early diagnosis and treatment this also exacerbates other health disparities however, treatment-related reproductive health concerns are left unsaid. Efforts are primarily made at increasing awareness, early detection of cancer and curative measures more than reproductive concerns.

Unlike in HICs, typically in developed countries where they have more resources for early detection and comprehensive cancer care with more established frameworks for research and advocacy on adolescent cancer care compared to LMICs, leading to better awareness and policy changes (Parkin & Stefan, n.d.)

Furthermore, their technological advancements has attributed to high cure intents among clinicians that goes along with securing the fertility potential. The existing researches in LMICs have insufficient studies addressing the unique challenges faced by adolescent (Meacham et al., 2020).

Adolescents may experience psychological impacts such anxiety about their future fertility due to long cancer treatment , complexity of treatment and its side effects ,however treatments with gonadotoxic chemotherapy can disrupt endocrine function, impacting puberty, sexual development and overall health leading to future potential infertility risks however ddelayed or arrested hormone production in adolescents due to gonado-toxic effects of cancer treatment impairs reproductive growth and future potential (Glazer & Schulte, 2022)

Reproductive challenges that are likely to be encountered by adolescent patients can have a major psychological impacts impact such as distress, depression and also affect their mental health and potentially decreasing their quality of survival (Purdy & Roomaney, 2023).

Studies have shown among cancer survivors 46% of men and 13% of women achieved long-term side effects of infertility risks. Discussions about reproductive health often remain under looked in the context of cancer treatment for adolescents generally, reproductive health challenges/concerns that are commonly to be encountered in due to exposure of long-term systemic therapy that would potentially affect their future fertitly (Meacham et al., 2020).

Adolescents ‘malignancies treated with alkylating agents and platinum-based compounds are associated with the highest risk of infertility, hormonal insufficiency, diminished/cessation of pubertal growth. Radiation therapy such as TBI, abdominal pelvic and cranial radiation tends to affect the pituitary gland and hypothalamus depleting the gonadotrophin realising hormone, which helps in the development of normal sexual growth (Marques et al., 2022).

Gonado-toxic effects varies in the degree of its effects depending on the type of chemotherapeutic agent either is high, intermediate or low risk, alkaline and platinum

compounds are said to be highly gonadotoxic. The systemic treatment with high gonad toxicity has a high chance of impairing the gonads leading to infertility. (Himpe et al., 2023).

Moreover, fertility concerns have not been practically addressed enough, however adolescents adapt coping strategies towards managing their illness and often most of diagnostic discussions are typically parents or caregivers centered more rather than adolescents centered even with the treatment complexity and poor disease progress that they are predisposed which later can manipulate their coping strategies during illness. (Canzona et al., 2021).

Despite of increased survival rates for childhood cancers, reproductive health concerns still remain significant and frequently overlooked (Pampanin et al., 2021). Studies have shown adolescents to have the least developed understanding of fertility health due to the tension between survivorship and getting a cure for the disease (Lemmen et al., 2023).

Therefore, Future life aspirations often exacerbate insecurities particularly concerns on their future reproductive health and potential lifelong toxicities. Addressing the global burden of cancer among adolescents and the associated reproductive health concerns is critical for enhancing quality of life and their future long-term health outcomes.

1.2 Problem Statement

Reproductive health plays a great role in human life and fertility aspect. Reproductive health concerns among adolescents goes in parallel with long-term exposure of systemic therapies and radiation therapy that have potential impacts of infertility. Cancer treatment with chemotherapy-based alkaline agents and Platinum compounds are commonly known to be potentially gonadal-toxic even with a curative dose (Canzona et al., 2021).

The gonado-toxic side effects have a chance of impairing the gonads leading to diminished/cessation of pubertal growth and potential infertility risks. The Gonadotoxic effect leads to a range of reproductive challenges including infertility, hormonal imbalances and impaired sexual growth .

Adolescents girls are at risk of primary ovarian insufficiency (POI) and early amenorrhea while adolescent boys are at risk of azoospermia (decreased quality and quantity of sperm) that may be irreversible even after remission due to the reproductive systems having a lower tolerance to gonadal-toxic chemotherapy (Himpe et al., 2023).

Studies have shown adolescents to have the least developed understanding on potential gonado-toxicity effects due to the tension between survivorship and getting a cure for the disease this is because reproductive health concerns have not been practically addressed enough despite of the reproductive challenges that are likely to be encountered by adolescent patients that can have a major impact as can decrease their quality of survival as it limits their childbearing opportunity (Lemmen et al., 2023).

What is acknowledged about adolescents (15-18yrs) undergoing cancer treatment at tertiary settings face puberty, sexuality and self-identity challenges yet few studies explore their reproductive health concerns. Hence this study highlights the intersection between cancer treatment and reproductive health concerns. Adolescents often lack counseling on reproductive risks, leaving them unprepared for long-term side effects. (Marques et al., 2022

1.3 Conceptual Frameworkk

1.3.1 Description of the conceptual framework

This framework of the study was adopted from previous studies literature by (Canzona et al., 2021). Showing the three interconnected themes that explore how individuals navigate the reproductive issues and their several reproductive concerns towards gonado-toxicity effects following cancer treatment and how they perceive them differently.

Despite of all these trajectories adolescents desire to secure their future reproductive ability but also, they still have limited information on reproductive health discussions that directly hinders the communication pathway among clinicians, patients themselves and the parents/caretakers

This framework has highlighted the gonadotoxic treatments that can significantly impact reproductive health, necessitating discussions about fertility preservation before treatment However, lack of clear and accessible information about reproductive options can lead to confusion and anxiety regarding choices.Uncertainty about fertility status, treatment effects, or future family planning can create significant stress, complicating the decision-making process.

Furthermore, different age groups may have varying tolerances to certain treatments, Younger patients might face different emotional and social challenges compared to older adults, influencing support systems and treatment adherence.

The Biological and hormonal alterations following gonadotoxic therapy lead to delayed puberty or diminished pubertal growth underscores the interplay between age, disease characteristics, and treatment-related effects, highlighting the importance of personalized approaches in cancer treatment, however, the disease prognosis and disease stage by itself has contributed further to hormonal fluctuations or changes.

This framework also illustrates the complex interplay between reproductive uncertaint and parenthood aspirations, addressing these themes holistically can help develop supportive interventions that enhance coping strategies, improve communication, and provide comprehensive care in reproductive health contexts**.**

Therefore, dealing with reproductive health concerns during the treatment journey can help to minimize worries or uncertainties on future reproductive health among adolescents in the whole continuum of treatment. Adolescents fail to anticipate reproductive disparities due to unmet reproductive health concerns such as uncertainties, depression, poor psychological health/self-isolation which may lead to reduced quality of life, which may arise in the dynamics of their future survivorship but will also affect the quality of survivorship.

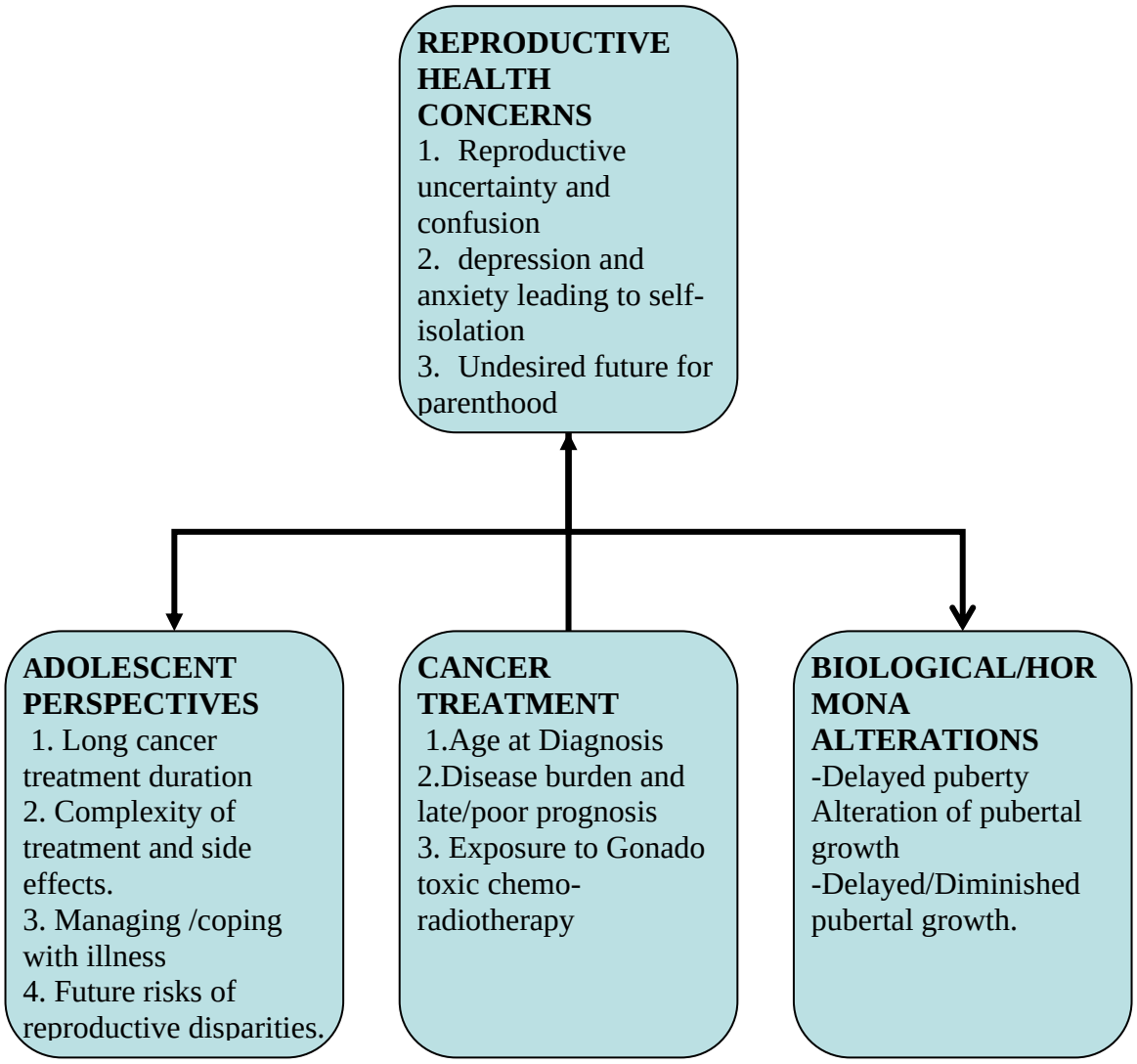


Figure 1: The Diagram above shows a description of the Conceptual framework adapted from (Canzona et al., 2021)

1.4 Rationale of the study

It will help to highlight the perceived need for a comprehensive approach to address RHC among adolescents, providing valuable insights for HCP to provide comprehensive care to adolescent cancer patients, offering strategies to manage and mitigate the impacts where possible.

This study will enhance the importance of integrating RHC into the overall care plan for these young individuals and study will help to foster reproductive counselling sessions among high-risk adolescent patients before treatment in the long run as per the risk stratification tools and this will help patients to navigate these changes and support their overall development.

The study will add knowledge to the scope of cancer treatment hence promoting adolescent to access information in the context of their reproductive health concerns during a prolonged treatment hospitalization and this will become unique in approaching a tailored adolescent care. However, the findings of this study will help a team of HCPs especially clinicians to clearly address reproductive health concerns in relation to gonadal-toxicity effects cancer therapies that may narrow down their future fertility ability.

This will also raise a compressive approach in adolescent care as part of nursing implication in this study that will involve sub sequent counselling sessions during treatment in order to address aspects of cancer long term effects and how to mitigate. Furthermore, this will necessitate the use of stratification assessment tools among adolescent patients of high risk and those of reproductive age as they will be triaged, assessed and counselled on the potential effects.

This approach will enhance the need for deliberate Reproductive health care approach in cancer treatment continuum and this will also add knowledge to the existing literatures on potential gonadotoxic effects. This will basically aim at meeting their needs and providing them with the voice of expression following cancer disease their reproductive health and the treatment journey itself.

1.5 Research Question

1.5.1 Broad Research Question

What are the adolescent perspectives on reproductive health concerns during treatment with gonadal-toxic chemotherapy and radiotherapy at Muhimbili National Hospital Dar-es-salaam, Tanzania**?**

1.5.2 Specific research questions

i. What are their pubertal alterations observed during cancer treatment among adolescents in relation to their future reproductive health at Muhimbili National Hospital, Dar-es-salaam, Tanzania?
ii. What are the adolescent concerns towards reproductive health during chemotherapy and radiotherapy at Muhimbili National Hospital, Dar-es-Salaam?
iii. What are perceived thoughts by adolescents towards their future reproductive health during chemotherapy and radiation therapy at Muhimbili National Hospital Dar-es-Salaam, Tanzania?

1.6 Objectives

1.6.1 Broad Objective

To explore adolescents' perspectives towards reproductive health concerns with gonad toxicity with chemotherapy and radiotherapy at Muhimbili National Hospital, Dar-es-salaam, Tanzania

1.6.2 Specific objectives

i. To explain the pubertal alterations observed during cancer treatment among adolescents in relation to their future reproductive health at Muhimbili National Hospital, Dar-es-salaam, Tanzania.
ii. To describe the adolescent concerns towards reproductive health during chemotherapy and radiotherapy treatment at Muhimbili National Hospital, Dar-es-salaam Tanzania**.**
iii. To identify the perceived thoughts among adolescents towards their future reproductive health during chemotherapy and radiotherapy at Muhimbili National Hospital Dar-es-salaam, Tanzania.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Overview

Adolescence is a transition period from childhood to adulthood, usually occurring between the ages of 14-18 years.Girls start puberty around 10-12yrs while boys start around 13-14 years which is a peak age of developing secondary sexual characteristics (World Health Organization, 2021) .

The Tanzania Demographic Health Survey, TDHS 2023 shows the Age Specific Fertility Rate is at peak from 25-29yrs in 3years survey but it starts from 15-19yrs of age hence this accounts for the fertility aspect as one among key areas not to be negotiated during human growth (TDHS, 2022).

In LMIC, many adolescents are diagnosed at advanced stages due to a lack of awareness and understanding of cancer symptoms among patients, parents and healthcare providers, leading to poorer prognose. In sub Saharan countries there is inadequate access to early detection, diagnosi and treatment exacerbating the burden of cancer ,unlikely in HICs were advancement treatment has majorly increased survivorship(Parkin & Stefan, n.d.)

The treatment of malignancies includes chemotherapy, surgery, and radiation these therapies are cytotoxic and tend to cause the death of the cancer cells and cause destruction to other healthier cells. The reproductive growth and development of young adolescents are affected once the production of hormones is being delayed/arrested thereby reducing the reproductive potential (Glazer & Schulte, 2022).

The hhuman reproductive system is fragile and has a low tolerance to toxicity therapy even with a minimal dose can lead to irreversible impacts with lifelong effects. However, An adolescent can have delayed puberty already due to disease prognosis for example malignancies infiltrating leads to an increase in the risks of hypoandrogenism which is Low production of the androgen hormone in males (Mobley et al., 2020)

Gonadotoxic treatments can significantly impact reproductive health, necessitating discussions about fertility preservation before treatment. Reproductive toxicity is said to be up to 30% just with curative therapy among children and later in adolescence age (Santen, 2020).

Assessment and triaging the patient's prior treatment journey, as before oncological treatment begins it is important to estimate how much fertility is at risk as the ASCO (Madeleine van der Perk et al., 2021). In the Netherlands, studies have shown major reproductive concerns such as significant reduction of sperm quantity (spermatogonia) among pre-pubertal boys with haematological malignancy even before treatment with a prevalence of 48.5% versus 31% of the controls. However, the highest prevalence of infertility was among those with CNS tumors (Masliukaite et al., 2023).

In China, a scooping review conducted in 2022 showed reports of reproductive concerns among adolescents and young adult cancer survivors ranging from 44% to 86% and 28% to 44% of the survivors experienced moderate to severe reproductive concerns (Xie et al., 2022)

In Africa, particularly South Africa, Patients who are high risk are identified early, triaged, and informed along with their families for possible counselling and are referred to onco-fertility specialists(Purdy & Roomaney, 2023) In LMIC, particularly Sub-Saharan countries studies have shown mmost clinicians during treatment focus on high cure intents moreover, diagnostic talks are more are parent -cantered leaving adolescents behind however, they deserves a well-informed knowledge on the potential risks of reproductive toxicities so as to mitigate their uncertainties. Studies have shown also there is lack of established clinical policies/guidelines in the provision of holistic care in our settings (Lemmen et al., 2023) .

Other findings showed that adolescent patients need a good quality of life and highly desire childbearing opportunities later in life rather than adoption (Takae et al., 2019). Also at the adolescent age they usually perceive a role of personal/self-identity, sexuality, attraction and building up social relationships which lead to marriage later in life therefore discussing their reproductive concerns is important because Fertility status among adolescent patients on treatment is important because complete maturation begins at 14 years of age (Nielsen et al.,

2023).Furthermore, results showed developing intimacy can occur in the long run as they undergo maturity their body undergoes both physical psychological, and emotional changes that are caused by hormonal production in the body which is important since reproductive health plays a great role in human life.

2.2 Pubertal Alterations Facing Adolescents During Chemotherapy and Radiotherapy Treatment

In females, alterations such as the lost normal pattern of the menstrual flow usually gonad - toxicity effect leads to ovarian depletion or in cases Where an adolescent patient is subjected to radiation on the abdominal-pelvic area and exposure to some scattered radiations, especially in patients with diffused B large cell lymphoma has a 50% chance of ovarian depletion and insufficiency (Marques et al.,2022).

In males, they lead to damage of the seminiferous epithelium and lowers testosterone levels by causing damage to Leydig cells and lowering the average sperm count (Marques et al.,2022). This was observed clinically among young adolescent boys who had an exposure to gonadal-toxic chemotherapy where at high risk compared to those who an no exposure to alkaline based chemotherapy agents.

In general, adolescents experience a delayed puberty than a normal pattern, especially In patients undergoing chemotherapy as alkaline agents like cyclophosphamide and dacarbazine are cytotoxic leading to the destruction of gonads in females and males. Studies have shown an increase in 13-fold of females developing early menopause than normal (National Cancer Institute, 2020).

2.2.1 Adolescents' Concerns During Chemotherapy and Radiotherapy Treatment Towards Reproductive Health

Failure to develop social relationships with the opposite sex due to fear/anxiety of stigma during interactions/gatherings; social relationships are easier to initiate with the same sex than are with the opposite sex when undergoing cancer diagnosis and treatment. (Mcloone et al.,2021).

Adolescents have a high need for future fertility health; Fertility concerns can be more distressing than the cancer diagnosis itself. The majority of female adolescent cancer patients desire future children, and around 50% of adolescent cancer patients experience frustration over cancer-related fertility concerns (Glazer & Schulte, 2022)

They often experience communication barriers towards their reproductive health issues during cancer treatment however, fertility discussions are insufficient in many clinical settings. The majority of female adolescent cancer patients desire to be aware of the impacts of their cancer treatment on fertility health

Mostly common in female adolescents, they perceive a desire to have 'normal fertility health' after cancer treatment and be able to start a family in the future. Adolescents also experience difficulties in making life into their dreams due to the prolonged hospital stay and disease burden however, their goals are deprived due to illness (Oh et al., 2019).

2.2.2 Adolescents Perceived Thoughts Towards Their Future Reproductive Health During chemotherapy and radiation therapy.

Adolescent perceive a limited time/opportunity for future childbearing, especially in females usually risk of premature ovarian insufficiency and infertility even in the post-pubertal patient (Pampanini et al., 2021), in males Fertility potential once affected leads to azoospermia. Gonadotoxic chemotherapy especially alkalyting agents increases vulnerability to fertility impairment also the disease itself can predispose one to infertility.

Furthermore, cancer patients with malignancy of the testicles due to the immune system itself leads to the production of lymphotoxin cascades in the lymphatic system that results in release of cytokines that cause inhibition of spermatogenesis and accelerate germ cell apoptosis (Nielsen et al., 2023).

Fear of the future delaying conception usually after developing an interest in the opposite sex which results that later results into fear to be judged by their partners, they feel unfit and develop low self-esteem that create uncertainties which makes them unhappy and reduce their future desire to raise a family. However, also they had perceived thoughts that risks for

infertility alterations were high due to an altered/delayed menstrual cycle (Canzona et al., 2021) Likely in males, Poor quality of sperm/few sperm count affects their fertility ability and were clinically distinguished from fertile men (Kenney et al., 2012)

CHAPTER THREE

3.0 METHODOLOGY

3.1 Study design

This was a hospital-based study whereby a descriptive qualitative investigation was employed to explore the adolescent's perspectives towards reproductive health concerns during chemotherapy and radiation therapy at Oncology Paediatrics, Muhimbili National Hospital.

3.2 Study area and setting

This study was conducted at MUHIMBILI NATIONAL HOSPITAL Upanga in ILALA, Municipal, Dar-es-Salaam-Tanzania. MNH is a tertiary and National hospital situated at Upanga West of ILALA District. It provides specialized health service and is the leading center of academic excellence and research. The Muhimbili National Hospital offers speciality care in all aspects of clinical medicine and has several units/ departments one among them is the oncology paediatric unit provides care for about more than 500 Children yearly diagnosed with different malignancies coming in as referral cases from near and far regions in the country (Masika et al., 2020). The oncology unit has two wards the UPENDO and TUMAINI whereby the Upendo ward, receives patients as referral cases, newly admitted and seriously ill patients while at Tumaini ward, receives patients who are in ongoing treatment but in stable condition.

The pediatric oncology unit is supported by the TLM foundation, (Tumaini La Maisha) this is a non-government organization that works in hand and provides funds for childhood cancer treatment. The unit comprises several HCPs such as Paediatric oncology specialists' nurse specialists, pharmacists, Clinical Oncologists, haemato-oncologists and oncology pharmacists.

Treatment of childhood cancer includes invasive procedures such as taking blood samples, BMA, and other procedures including chemotherapy and Radiation therapy to which children

are mainly referred at ORCI. The pediatric unit can care for approximately 50 children, on each bed with a single patient staying with their caregivers/parents.

Treatment and care for children and adolescents are provided under a specialized team of health care providers and follow-up clinics that run on weekdays, usually done for those who have completed treatment and are due for follow-up visits.

3.3 Study population

The participants involved were adolescent cancer patients aged 15-19 years because this is a group age of population where secondary sexual characteristics is at peak and most of them are undergoing pubertal growth changes. Participants were recruited purposively for the research study at the pediatric Oncology clinic, National Hospital, Dar-es-Salaam**.**

3.3.1 Exclusion criteria

In this study, adolescent participants who were seriously ill/unconscious patients and those who were unwell at a particular moment such as those who were unable to talk and those who had less than three months in their treatment were excluded.

3.4 Sample size and sampling technique

3.4.1 Study sample size

In the study, the sample size was determined based on the adequacy of the data. No new information was discovered beyond the 11^{th} participant, once there no new findings were noted, the principle of saturation point was applied. This sampling method was used in qualitative study once the researcher was no longer able to generate new information from the interview (Konstantina Vasileiou et al., 2018).

3.5 Study Sample Technique

In this study, the participants were selected through purposive sampling, the main reason for using this method is that it helps to sort participants who would enable the researcher's questions to be answered adequately (Rai and Thapa., 2019). Participants were obtained from

the clinic on Tuesdays and Fridays with assistance from the Oncology pediatric nurse, the nurse helped to identify participants that were likely to provide noble information. Participants were identified by name and age. Later after attending their clinic visits, they were informed each one separately about the study and were consented to participate in the study.

3.6 Data collection method and tool

3.6.1 Data Collection Method

In this study, adolescent participants were selected among those who were attending at Pediatrics oncology clinic on Tuesday and Friday, participants who were able to provide detailed information and answer the research questions were identified and chosen with assistance from the clinic nurse during the clinic visits. Participants were approached and consented while they were waiting to be attended during the clinic hours. Each participant was interviewed independently for about 30-45 minutes in a quiet private room to minimize external distractions.

Consent forms were signed willingly by caretakers/parents for those under 18yrs participants and those above 18yrs signed on their own. The interview was conducted in the Swahili language with open-ended guided interview questions and probing questions for the participants to discuss and give detailed information that was helpful to expand participantnts' perspectives towards reproductive health concerns during the treatment of chemoradiotherapy.

The concept of data saturation was utilized to determine the appropriate number of IDIs to conduct, however the in-depth interviews were captured through audio recordings, whereby this was the main method for gathering data through verbal communication. The audio recordings were secured and stored in a computer folder then later transcribed verbatim, data was kept on a password-protected computer to ensure confidentiality and security.

3.6.2 Data collection tool

Semi-structured open-guided questions that were adopted from the study done by (Canzona et al., 2021) as seen (in Appendix IV). The Swahili language were used to guide the interviews with embedded probing questions to fetch more details. An interview guide was used during the data collection process from the filled area independently by each participant. The tool had total of 15 questions including the demographic section, general questions, specific questions, and the conclusion part. They had probe questions in-order to enable the participants to give out more detailed information that aimed to explore more on the reproductive concerns among adolescents during cancer treatment. The tool questions were modified as to meet participants level of understanding throughout the study.

3.7 Data management and analysis

3.7.1 Data Management

In this study, the interview sessions were recorded and stored well in a computer folder with a security password to ensure data safety and this will be accessible to the researcher only. Any filed notes that was taken during the interview was stored safely. During the interview on the first day, the audio recordings were transcribed and analyzed to check the quality of the information that was been expressed by participants and also helped to improve the interview guide questions.

3.7.2 Data Analysis

In this study data analysis was inspired by (Graneheim & Lundman, 2004) , in which content analysis was employed, which involved inductive and deductive approaches. In which on inductive approach was used developing categories while the deductive approach was used in generating codes using the research objectives and the framework. However, the transcribed data was well-reviewed well to capture a deeper understanding.

During content analysis, it was guided by six phases, these are

Phase 1; **Familiarization;** this involves fully iimmersing in the information by reading and re-reading the transcript to understand a general idea from the data collected, also non-verbal utterances noted during the interview were used by the researcher to get a richer understanding of the meaning of data.

phase 2; Creating meaning units and condensed meaning Units; A meaning unit as words, sentences or paragraphs containing aspects related to each other through their content and contexts. were generated, which helped to identify data that appeared to be interesting and meaningful.

Phase 3; Generating codes; the researcher created codes from the condensed meaning units that appeared alike with the same meaning. In which the deductive approach was employed in relation to specific objectives. Codes were translated from Kiswahili to English.

Phase 4; Generating sub-categories and categories; The researcher involved generating clearly the subcategories and later categories from the codes that had the same meaning, after understanding them.

Phase 5; Presenting results and report writing The identified categories were used to guide the writing a concise logical report that accounts for adolescent perspectives towards reproductive health concerns during chemotherapy and radiation therapy. The information be summarized and relevant quote(s) were connected with each category for writing a report.

3.8 Trustworthiness of the study

In this qualitative study, trustworthiness is paramount, since a good qualitative study is guaranteed in four items these are credibility, dependability, transferability, and compatibility with the data collection and data availability (Shenton.,2004).

Therefore, in this study, the principal investigator had a include a consent form for the interviewers in the Swahili language. The study had maximized enough time to collect all rich

information from the participant also building rapport and clear language with precise words were used. The researcher earned the trust of the informants to make the environment friendly for the interviewers.

3.8.1 Credibility

In the study, the researcher assured credibility by passing through the in-depth interview guide questionnaire tool and the pre-test survey before the actual day for fieldwork of data collection in order to validate the tool in relevance to their contest Also, the researcher shared the tool with the clinical supervisor to test its adequacy.

The researcher had built rapport which will enable me to fetch real data from the research participants being studied. The interview sessions were recorded during the interview using a digital recorder and later transcribed verbatim and the researcher spent more time reviewing the transcribed data and field notes taken to gain more insight into the data.

3.8.2 Conformability

Conformability is the extent to which the findings of the research study could be confirmed by other researchers, the researcher ensured conformability of the transcribed data and field notices that were reviewed by the clinical supervisor and interpreted by the researcher and later by the supervisor. The finding was presented verbatim with quotes from participants to increase conformability.

3.8.3 Transferability

To ensure transferability in the study setting, the principal investigator will be clear, and describe the aim of the study to the participants prior. The verbatim quotations from interviewees were done to compare the findings and their relevance to the study. All findings were presented accordingly including the participant's details to gather all the important information.

3.8.4 Dependability

To ensure dependability the principal investigator was consistent during interviews the in-depth interview guide was well-reviewed and modified to capture factual information during

data collection and ensure that data collection and interpretation remained within the participants' sociocultural perspectives.

3.9 Ethical considerations

Ethical approval was sought from the Research and Ethics Committee at Muhimbili University of Health and Allied Science(Appendix VI). Permission to conduct research at MNH was obtained from MNH administration (Appendix VII)All participants were recruited after signing an informed consent form in which participants under 18yrs of age parents/caretakers were asked to consent on behalf while those individuals above 18yrs old has signed themselves .The consent forms provide details of the right to participate and withdraw from the study, risks, benefits and an audio recordings of the interview (Appendix II). All participant's ID were treated anonymously and confidentiality was ensured by the researcher throughout the study.

CHAPTER FOUR

4.0 RESULTS

4.1 Participants characteristics

A total of 11 participants were enrolled in the study majority of them being male participants (n= 6,55%) aged between 15 to 18yrs, with secondary school education (n=9,81.8%).More than half of the study participants were diagnosed with hematological malignancies (n=5, 50%) malignancies of which were diagnosed at mainly 17-18yrs of age (n=6,54.5%) and many of them have been on chemotherapy treatment basis (n=7, 63.6%) for more than three months, mostly from 3-6months (n=4,36.3%) at pediatric oncology..

Table 1: Demographic characteristics of the study participants(N=11)

Demographics characteristics	Frequency	Percentage (%)
Age		
16yrs	1	8.3%
17yrs	5	41.7%
18yrs	4	33.3%
19yrs	1	8.3%
Sex		
Male	6	55%
Female	5	45%
Education level		
Primary Education.	2	18.2%
Secondary Education	9	81.8%
College/University	0	0
Type of malignancy		
Leukemia	5	45.4%
Lymphoma	3	27.2%
Sarcomas	2	18.1%
Testicular Germ cell	1	9%
Duration in treatment		
3months	2	18.1%
3-6 months	4	36.3%
1-2yrs	3	27.2%
More than 2 yrs	2	18.1%
Type of treatment		
Chemotherapy	7	63.6%
Chemotherapy and radiation	3	27.2%
Surgery	1	18.1%
Age at diagnosis		
Less than 10yrs	2	18%
Above 10yrs	9	82%

4.2 Categories in the study

There are four (4) categories identified in the study and about eight (8) sub- categories that merged under the major objectives.

Table 2: A table of Analysis showing the Condensed meaning Units, Codes, Subcategories, and Categories.

Condensed meaning units	Codes	Sub Categories	Categories
-Prolonged Treatment Impact - Emotional and Psychological Impact following treatment - Patient and Family Perspectives - Endocrine/hormonal Disruption during treatment	-Reproductive health Concerns -Uncertainty and Future Reproductive ability	i) Risks of future reproductive disparities due to long cancer treatment journey ii)Pubertal growth alterations during treatment leading to uncertainties on reproductive health	**Concerns on Reproductive uncertainties**
- Supportive role to the family and Desire for Children - Health Compatibility and future family aspirations -Psychological Adjustment after treatment - Resuming the academic journey	- Preference or choice of partner's health -Physical Recovery - Resuming academic journey	i**)** Health recovery and resuming the academic journey ii)Preference on partner's health status and future family aspiration	**Concerns on future improved quality of life**
- Comprehension of Medical Information - Patient Involvement in Decision-Making - Timing of Information and - Source of Information on toxicity and reproductive reassurance	- Awareness of Gonadotoxic Risks - Gaps on informed knowledge.	- Informed knowledge on Gonado toxic side effects and Fertility reassurance	**Perceived need for informed knowledge and fertility reassurance**
- Decision-Making about Parenthood - Need for Genetic counseling before starting a family - Concerns about future Child's Health	-Awareness of future health risks -Emotional Impact of disease Relapse -Understanding of Genetic Risks	- Risks of future disease relapse and Genetic inheritance to their biological children	**Perceived risks for disease relapse and future inheritance**

4.3 Description of categories and sub-categories

4.3.1 Description of categories

4.3.1 Concerns on reproductive uncertainties

4.3.1.1.1 Experienced pubertal growth changes and later alterations during treatment that lead to uncertainties on future fertility health

The study findings revealed that adolescents had experienced certain pubertal changes during adolescent age, as in their normal pattern of growth and development, in which girls started at the age of 12 years while males started puberty at 14 years up to 15 years of age. The common pubertal changes that are experienced by the majority of males, were the growth of pubic hair, wet dreams during the night, mood changes and changes in behaviour patterns,

However, other respondents on their side, stated that cancer treatment has impacted their normal trend of pubertal growth/pattern where they had experienced cessation or diminished pubertal changes as per body image after treatment initiation, however the commonest among males participants was reduced sexual growth that had occurred just after they had being on consecutive treatments. this was narrated by one respondent as follows

*''There were changes in my body, I noticed when I was my doing personal hygiene, I noticed they were no growth hair as it was in the beginning also, I had no feeling sexually as I was in the beginning, I was worried if I had already affected and become impotence''. (**p08**)*

4.3.1.2 Risks of future reproductive disparities due to gonad toxicity effects of chemotherapy and radiation therapy

From the study, it indicated that adolescents had concerns about their future fertility health and also had experienced anxiety due to cancer related fertility concerns that leads to uncertainties. Also, it was more exacerbated while managing their illness at the same point in time, as one of one respondent said that

*''Using this chemotherapy for a long time can later hinder the ability to have children because it can affect the reproductive system''(**p01**)*

Female respondents, merge with a concern on inability to carry pregnancy and give birth safely can be limited due to their illness specifically the once they encounter episodes of low hemoglobin levels during pregnancy that may hinder from delivering safely and even the ability to carry the pregnancy due to complications that maybe related to their health status. This was said by the respondent as

*"This illness that ma suffering from is usually is associated with low blood levels, so when you think of reproductive health, when I become pregnant, it can bring problems to the child or even the mother (me) caring the child''(**p11**)*

4.3.2 Concerns on future improved quality of life

4.3.2.2 Participants had concerns of future health recovery and resuming their academic journey

Participants also experience a high need for future health for resuming their academic journey Also, they experience challenges in thriving for their academic journey due to school drop-outs following long hospital stays and disease illness, they have expectations for successful treatment, and getting cured so as to fully carry on activities (studies or other) for their daily living after treatment

As the participant states that '

'' *what I think these drugs we are using they will help as well and later I will improve and live as a normal person. so I will perceive myself as health person who has not been suffering and people will not know if I have been sick. and I will be able to interact well with people and perform normal activities as any other person even when I go back to school''.**(p 10)***

'' *Am thinking about his cancer treatment and my studies, it has been interrupted, because I can skip school days or weeks due to treatment, I wish if return to school.*(**P 04)**

"I am thinking how will my life be after cancer treatment sometimes I can seem to be happy, with others but in deep thoughts am thinking how will my life be, if I don't have any means of income, I stopped going to school" (***P03)***

4.3.2.3 Concerns about preference on partner's health status and Future family Aspirations

In the study, many of the participants had a perceived thought of establishing a family in the future with a partner who is well aware of Cancer but with no history of cancer illness. this was said by the respondents as stated below.However, the preference for future partner's choice has been perceived differently among participants, mostly seen as the reason behind partner characteristics was the risk of malignancy to a health child once the other partner is also affected.

Also participants had concerns about future role to being parents and having biological children, this was seen in participants as they accomplished treatment they highly desire to be future parents and start a family as this brings joy in their life and makes life meaningful. Furthermore some participants wished to complete school first , have a job and later start a family.

In the study, many of the participants had a perceived thought of establishing a family in the future with a partner who is well aware of Cancer but with no history of cancer illness. this was said by the respondents as stated below

'' I would be with a partner who have awareness of cancer diseases, so that when I get ill, it will be well known already and he/she can provide help'(***P07)***

Other participants stated **''***I will like to have a partner who have aware of cancer but has not suffered from cancer so as he can know how to help me when I get ill like which hospital I should attend, and also he will give me hope about the future health.''.(* ***p11)***

However, the preference for future partner's choice has been perceived differently among participants, mostly seen as the reason behind partner characteristics was the risk of malignancy to a health child once the other partner is also affected.

Participants had also concerns about future role to being parents and having biological children, this was seen in participants as they accomplished treatment they highly desire to be future parents and start a family as this brings joy in their life and makes life meaningful. Furthermore, some participants wished to complete school first, have a job and later start a family.

4.3.3 The Perceived need for informed knowledge and reassurance of future fertility health

4.3.3.1 Lack of enough information concerning the gonad toxic effects in relation to chemotherapy and radiation therapy

The study has shown a high need for reproductive health discussions among adolescents, this was revealed more by the respondents as they were not sure of the information that they had that was not conveyed adequately by clinicians instead they overhead such information from their fellow patients. this was narrated as follows,

*''I have just heard from people telling me that when you receive radiation therapy on adolescent age, you reduce your chances of fertility and even shorten your life span especially radiation therapy, about chemotherapy I don't know much about its effects but I would the doctor to explain to me if this is true or not'' (**p06**)*

However, there was lack of Informed -seeking behaviors concerning cancer treatment side effects on reproductive health was attributed due to some the adolescents being overwhelmed with disease burden, treatment complexity and long hospitalization all these outweighed their fertility-related health concerns and it was difficult to seek information from clinicians at that particular moment. As the respondent said as

" *Due to this long cancer treatment, I have never asked the doctor concerning future fertility ability and long cancer treatment side effects, although on my side am much focusing on health and being alive as for now but later when I will have that problem I will seek medical attention.''* ***(p05)***

4.3.4 Perceived risks of future disease relapse and genetic inheritance

4.3.4.3 Participants had a perceived risk of future disease relapse and genetic inheritance to their children

This is because they are informed on genetic inheritance as a risk factor for malignancy disease, there any incomplete remission that they will encounter, they are likely to be predisposed to relapse and eventually it will decrease the quality of life and lower the disease-free survival, furthermore, those patient with complete remission will, however have a genetic susceptibility to their future children as they will desire to start a family. This is seen as one of the participant's states;

''Some people are coming back here to the hospital with disease relapse after completing treatment which creates many worries upon me, but also am worried later I might also get relapse or if I will have a child and the child will inherit the disease.'' (***P 09)***

CHAPTER FIVE

5.0 DISCUSSION

5.1 Overview

This study aimed to explore the adolescent perspectives towards reproductive health concerns during cancer treatment at MNH. This study was conducted to unveil concerns of young adults first during diagnosis and later while on treatment as they experience a range of emotions once they receive cancer diagnosis as the first thing in their life and cope while managing the illness (Mcloone et al., 2021).

A cancer diagnosis has brought a fundamental impact on the physical, psychological and social development of adolescents. It has led to distress and social withdrawal throughout due to long term effects and disease burden. Other impacts include school dropout due to illness that has contributed to future low academic achievements. All these are majorly affecting their psychological health (Peleg Nesher et al., 2022).

As much as concerns about the treatment longevity and complexity are a threat among childhood cancers, there is also an increase in the likelihood of concerns regarding cancer treatment side effects mostly those potentially affecting fertility (Farrag et al., 2023).

In sub-Saharan countries, the gradual increases in survival rate come at a price when the adolescent patients become candidates for lifelong treatment toxicities, such as potential risks of infertility in which an individual's childbearing opportunity is compromised since the human reproductive system is fragile once damaged, or affected can cause irreversible impacts and sometimes lifelong effects, (Nielsen et al., 2023).

5.2 Adolescents facing on pubertal alterations after treatment Initiation

In this study, the findings revealed that most adolescent patients aged 15-19 years have undergone significant pubertal growth. This period is marked by the development of secondary sexual characteristics, which are a key part of their biological and physical changes.

These changes are primarily driven by sex hormones, which play a crucial role in the maturation process. However, when adolescents are undergoing cancer treatment, the typical trajectory of these developmental changes can be disrupted. The clinical features of the cancer type and the treatment pathways adopted significantly shape the patient's experiences during this crucial growth phase.

The impact of cancer treatment on pubertal development and overall maturation cannot be overstated. As adolescents undergo treatment, the side effects of cancer therapies, particularly chemotherapy, can have profound effects on their growth and sexual maturation. This disruption is particularly concerning as it can lead to delayed or altered development, affecting not just physical growth but also emotional and psychological well-being.

Supporting these findings, a study done by (Marques et al., 2022), showed gonadotoxic chemotherapy, in female patients undergoing chemotherapy such as alkaline agents like cyclophosphamide, ifosfamide, dacarbazine, are gonadotoxic leading destruction of gonads which are responsible for ovarian stimulation in ovulation, hence leading to insufficient ovarian simulations ending in amenorrhea. Young female adolescents may be at risk of fertility alterations, such as disturbed or lost menstrual cycle, and others encounter late menstruation periods or delays due to the alterations.

However, in males chemotherapy can damage the seminiferous epithelium and lower the testosterone levels by causing damage to Leydig cells, it was found that even at lower doses, some patients developed azoospermia, this is said to be irreversible even after treatment the average sperm count may tend to recover by 12 weeks after therapy in patients treated with non-alkylating. (Masliukaite et al., 2023).

Therefore, this implies an increasing gonadotoxic potential in cancer therapies as it maximizes its efficiency in controlling the diseases and increasing survival but also exaggerates the risks of future reproductive function disparities, (Peleg Nesher et al., 2022).

5.3 Adolescents' Concerns Towards Reproductive Health During Chemotherapy and Radiation therapy

Adolescent concerns during cancer treatment focused on long exposure to chemotherapy and its side effects on the body similar to the finding in the study done by ((Kenney et al., 2012). This implies that after accepting the cancer diagnosis, adolescents begin to cope with their condition and their whole perspectives of life begin to change, they begin to sense insecurities about their future health,

The majority of female adolescent cancer patients express a strong desire to understand how their cancer treatment may impact their fertility. This concern is deeply rooted in their aspirations for the future, particularly their wish to become parents and have biological children. Despite the uncertainties surrounding their health and the potential challenges they may face, these adolescents hold on to the hope of experiencing parenthood, just like their healthy peers who are also navigating the complexities of pubertal growth.

The desire for future childbearing opportunities is a significant concern for adolescent cancer patients. They are acutely aware that their treatment may have lasting effects on their fertility, yet this does not diminish their aspirations to start a family. For many, the prospect of having their own children is intertwined with their overall quality of life, representing a sense of normalcy and fulfillment that they strive to achieve despite their medical history (Glazer & Schulte, 2022) .

This is different from the study done by (Canzona et al., 2021) whereby some had fear of engaging in social relationships and dating, once they will have to disclosed their health conditions to their loved ones, however, some had a fear of delaying conception among adolescents who were of high risks. This was different from the context of this study since adolescents showed positive energy on social interaction despite of their illness, but some of them could not be able to disclose to their friends about their illness rather they would employ a coping mechanism to hide their cancer diagnosis and substitute it as saying it just fever, long term fever.

The concerns expressed by these adolescents highlight the complex interplay between their experiences with cancer, their aspirations for the future, and the decisions they make regarding relationships and family planning. The desire to become parents and have healthy children is a powerful motivator that influences their choices and priorities. At the same time, their experiences with cancer have made them acutely aware of the potential risks associated with genetic predispositions to the disease, leading them to carefully consider their partner's health status and its implications for their future family.

In conclusion, the majority of female adolescent cancer patients are deeply concerned about the impact of their cancer treatment on fertility. These concerns are closely tied to their aspirations for future parenthood and their desire to have biological children. The uncertainty surrounding their health does not diminish their hope for a fulfilling family life. Instead, it shapes their preferences and decisions, particularly regarding their partner's health status, as they strive to reduce the risk of cancer recurrence in their future families. These considerations reflect the broader desire of adolescent cancer patients to achieve good quality of life while navigating the challenges posed by their medical history.

5.4 Adolescents' Perceived Thoughts Towards Future Reproductive Health Abilities During Chemotherapy and Radiation Therapy

Participants in the study expressed a strong perceived need for informed health knowledge, particularly concerning the gonadotoxic effects of cancer treatments and the reassurance of future fertility from clinicians as they begin their treatment. This aligns with findings by (Xie et al. 2022), which highlighted that adolescents often face communication barriers regarding their potential infertility. Furthermore, the study found that fertility discussions are frequently insufficient, even at the time of diagnosis, leaving adolescents more likely to report unmet needs for fertility-related information.

In addition to fertility concerns, participants in this study also expressed a desire to be informed about aspects of sexual intimacy while undergoing treatment. This finding contrasts with other studies, such as (McLoone et al. 2021), which reported that adolescents undergoing

cancer treatment often struggled to engage in social relationships, particularly with the opposite sex. Many found it easier to form friendships with the same sex, likely due to the challenges and insecurities posed by their treatment. This suggests that despite the intensive treatment efforts and high cure intent among clinicians, these efforts come with the cost of raising new concerns regarding adolescents' future reproductive health and sexual development.

The adolescents in the study also reported a perceived risk of disease relapse and were concerned about subjecting their future children to a genetic predisposition to cancer. They expressed a strong desire to have healthy children free from cancer to ensure a good quality of life and the ability to live their dreams. However, the impacts of cancer treatment become particularly challenging when there is a poor disease prognosis or when there is a late response to treatment, leading to relapse or treatment failure.

These factors significantly limit their chances of having healthy children highlighting the need for a proactive, multidisciplinary approach to ensure that adolescents receive comprehensive knowledge about their health and future childbearing opportunities. In addition, there is a critical need for psychological support both during and after cancer treatment (Burgers et al., 2022).

This situation is mirrored in a study by (Farrag et al. 2023), which compared the presentation and outcomes of patients in low- and middle-income countries (LMICs) with those in European countries. The study suggests that managing childhood cancers remains a significant challenge in developing countries compared to developed countries, often leading to poorer prognoses, higher rates of disease relapse and greater genetic susceptibility in future generations.

5.5 Study Limitations and Mitigations

1. 1.There researcher bias in interpreting and categorizing data.
2. To mitigate the limitation, the categorization of data was reviewed by the supervisors to minimize the potential researcher bias.
3. Participants encountered judgmental fear in their explanations regarding several aspects that required them to explain according to their knowledge at some point during the interview. To mitigate the limitation, I spent more time to build rapport and make them more comfortable, however, adolescent participants were eager to share their stories in an interview process despite it not being possible for them to share their stories in formalized support groups because cancer treatment with the associated treatment toxicities has impacted them in different profound ways.

CHAPTER SIX

6.0 CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Cancer is a traumatic experience for anyone, adolescent patients in this study also described it to be challenging to cope with the diagnosis and manage the illness as well as a persistent fear of cancer recurrence and difficulties with returning to normal life post-treatment.In this study, findings showed that adolescents had reproductive health concerns that go in parallel future risks of infertility following pubertal alterations.

However the results of this research suggest that adolescent patients had concerns about the future risks of infertility and for that purpose there might be a need in the future to integrate in onco-fertility care so as to promote their reproductive health.

These gonado-toxic effects due to systemic therapies had raised concerns that lead to uncertainties, furthermore it was more exacerbated when they had experienced pubertal alterations deviated from the normal pattern that had led to diminished or cessation of pubertal growth. However treatment is sometimes intensified leading to gonadal damage hence they needed to have fertility reassurance and future genetic susceptibility to their next generation

Adolescents had perceived need for health knowledge on gonado-toxicity effects thus calling for more in-depth clinical discussions during diagnosis, providing young people with a voice to express their experiences not only acknowledges the significant impacts of cancer treatment and its complexity on their lives this study raises a clinical implication about the unique needs of this population.

Furthermore, the findings of this study add further data to the literature demonstrating the effects of cancer experiences and the dynamic process of coping with the illness also the study uncovered how these concerns can fluctuate during cancer treatment counseling needs are to be reconsidered this calls for more research study.

6.2 Recommendations

This study has surfaced the significant impacts of cancer treatment and its complexity but also adds knowledge to the existing literatures on unique needs of this population and the cancer treatment-related gonadotoxic side effects leading to gonadal damage, especially those malignancies treated aggressively with high-risk systemic therapies such as the platinum and alkylating compounds.

Based on the findings and conclusions, the following recommendations are made;

1. HCP should adopt a multidisciplinary care approach that involves collaboration among various specialists, including oncologists, reproductive endocrinologists, psychologists, and social workers such collaboration enables holistic care that addresses not only the physical aspects of the illness but also psychological and reproductive health, ultimately leading to better patient well-being and improving overall treatment outcome.
2. Clinicians should integrate Proactive discussions that will help to Initiate conversations about reproductive health on early in the treatment planning, including informed decision**,** treatment options, and potential long-term effects.
3. Adolescents should be involved on Peer Support programmes, that connects adolescents in groups this can help them to feel less isolated and provide a platform for sharing experiences and new coping strategies during cancer diagnosis and treatment, this will enhance their psychological health and mental being.
4. Furthermore, clinicians need to necessitate the establishment of Onco-fertitly care in the near future as part of adolescent care and patients of reproductive age during cancer survivorship clinics in oncological settings. This will help to tackle their uncertainties that they are potentially encountering after treatment completion and it will promote their mental health and improve their quality of life**.**
5. Lastly, this study has highlighted the unique challenges faced by adolescents and the broader implications on the quality of life also demonstrating the effects of cancer experiences and the dynamic process of coping with the illness by uncovering how the concerns that can fluctuate during cancer treatment,however comprehensive

counseling needs are to be reconsidered alongside before treatment and this calls for further research studies on magnitude of the gonado-toxic effects and its impacts on social cultural perspectives.

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APPENDICES

Appendix I: Consent Form (English Version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED HEALTH SCIENCES DIRECTORATE OF RESEARCH PUBLICATIONS AND INNOVATIONS

ID. NO ……

This is a Consent Form for Participating in a Research Study

My name is Irene Ngowi, am a postgraduate student; pursuing a Master of Science in Oncology Nursing at Muhimbili University of Health and Allied Sciences (MUHAS) in the School of Nursing. I am researching the Adolescents' perspectives towards reproductive health concerns during chemotherapy and radiation therapy at pediatrics Oncology at MUHIMBILI NATIONAL HOSPITAL, DAR-ES-SALAM.

The aim of the Study

This study aims to explore Adolescent's perspectives on reproductive health concerns during treatment with gonadal-toxic chemotherapy and radiotherapy at a pediatric oncology clinic, at Muhimbili National Hospital, Dar-es-Salaam, Tanzania.

The findings of this study will help to add knowledge to existing literatures and highlight the unique needs of this population on reproductive health concerns particularly the gonad toxicity effects. Also will add knowledge among the HCPs about treatment-related reproductive concerns that brings uncertainties. Also will help promote and address adolescent's unique needs and hence this will initiate the best approach by meeting their needs differently from the pediatrics. However, adolescents

have a right to access such information concerning their body image, changes in sexuality, and behavior patterns toward the opposite sex, especially at this peak age of 15-19 years of age

Procedure

I would like you to participate in this study., as you are an adolescent receiving treatment attending the oncology unit, you will be required to answer several questions in this in-depth interview that will take about 40 minutes. You are free to share your perspectives concerning adolescents) receiving cancer treatment and reproductive health concerns

Confidentiality

All responses will be kept confidential. Your responses will only be used for research and shared with MUHAS when necessary. I will make sure that all the information included in this research report does not identify you in person as the respondent., however, no names will be included both during the interview and on the reporting findings of this paper.

Right to refuse or withdraw

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

Study benefits

Participating in this study may not benefit you personally, but it will increase knowledge and provide useful information in our oncology clinical settings and also improve the quality of life and foster good reproductive health among adolescent cancer survivors

Risks

There will be no harm to you as a result of your participation in this study.

Whom to contact

In case of any inquiry please contact the researcher, **Irene ngowi** from MUHAS, P. O. BOX 65001, Dar es Salaam, mobile number 0742397294. If you ever have questions about your rights as a participant, you may contact the Director of Research and Publications, at MUHAS. P.O. Box 65001, Dar es Salaam-Tanzania.

Signature

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

Participant disagrees ☐

I, ……... have read the contents of this form and understood. My questions have been answered; I agree to participate in this study.

Signature of participant…….

Date…….

Signature of researcher ……. Date…….

Appendix II: Consent Form (Swahili Version)

CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI

KURUGENZI YA UTAFITI NA MACHAPISHO

FOMU YA RIDHAA YA KUSHIRIRKI UTAFITI HUU

Habari, mimi, ni IRENE NGOWI mwanafunzi wa mwaka wa pili, ninayeshiriki katika utafiti wenye lengo la Kuchunguza Mitazamo ya Vijana kuelekea Masuala ya Afya ya Uzazi wakati wa matibabu yao katika Kliniki ya Saratani ya Watoto, Hospitali ya Taifa ya Muhimbili, Dar-es-salam, Tanzania.

Dhumuni la utafiti

Dhumuni la kufanya utafiti huu ni kutaka kujua mtazamo wako kuhusiana na Maulizo juu ya afya ya uzazi wakati matibabu ya saratani .

Matokeo ya utafiti yatasaidia kuboresha zaidi huduma za matibabu ya saratani . Unaombwa kushiriki katika utafiti huu. Kama utakubali kushiriki, utaulizwa maswali ambayo utayajibu kulingana na uelewa wako ili kusaidia kupata taarifa za kutimiza malengo ya utafiti.

Ushiriki unaohitajika

Utakapo kubali kushiriki katika utafitii huu utahitajika kujibu maswali. Utasomewa maswali hayo ili uweze kuyajibu.

Usiri

Taarifa utakazo zitoa zitatunzwa kwa usiri na zitatumika kwa malengo ya utafiti huu tu. Hautatakiwa kuandika jina lako ila tutatumia namba ya utambulisho/namba ya kitambulisho

chako chakazini. Taarifa zitazokusanywa kwenye dodoso letu tutaziingiza kwenye compter na sisi pekee ndio tutakuwa na mamlaka ya kuzitumia taarifa hizo na si vinginevyo

Faida yakushiriki katika utafiti

Kushiriki kwako katika utafiti huu kuna faida, kwani taarifa utakazozitoa zitawezesha na kuboresha utoaji huduma katika kliniki yetu ya saratani kwa Watoto.

Madara

Hatutegemei kuwa utapata madhara kwa kushiriki katika utafiti huu.

Haki ya Fujita

Ushiriki wako katika utafiti huu ni wa hiari. Kama utakataa kushiriki katika utafiti huu au kujitoa muda wowote ule hata kama mwanzoni uliridhia kushiriki, hakutakuwa na hasara yeyote kwako wewe binafsi.

Kama una maswali kuhusu utafiti huu wasiliana na mratibu wa utafiti huu Irene Ngowi

S.L.P 65000, Dar es Salaam, Simu: 0742397294

Kama utakuwa na swali kuhusiana na haki zako kama mshiriki wa utafiti huu wasiliana na Mwenyekiti wa kamati ya utafiti ya chuo S.L.P 65001, Dar-es-Salaam Simu; 0742397294.

Je umekubali? ndiyo…… Hapana…… Mimi……. nimesoma na kuelewa yaliyomo katika fomu hii. Maswali yangu yamejibiwa, nimekubali kushiriki katika utafiti huu.Sahihi ya mshiriki ……

Sahihi ya mtafiti/ mtafiti msaidizi…… Imesainiwa leo tarehe……....

Appendix III: In-depth interview guide (English version)

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED HEALTH SCIENCES

DIRECTORATE OF RESEARCH PUBLICATIONS AND INNOVATIONS.

This is a patient's in-depth interview guide for **Exploring Adolescent Perspectives towards Reproductive Health Concerns during Chemotherapy and Radiotherapy Treatment at the Paediatric Oncology Clinic, Muhimbili National Hospital, Dar-es-salam, Tanzania.**

Part I: Introduction

You have been selected for this interview, knowing that you will be able to respond with fear/hesitation I would like also to remind you that, this interview will be recorded for easy remembering of what you shared, and it will take about 30-45 minutes.

Part II: Demographic Information;

Identification number……..,

1)Sex;…… 2) Age……..,

3)Educational level; ……

Part III; General questions.

1) Age at diagnosis…….

2) Type of malignancy diagnosed…….

3) Duration of treatment …..

4)What treatment have you been through ……

A)SPECIFIC QUESTIONS ON PUBERTAL ALTERATIONS AMONG ADOLESCENTS.

1. Please share with me your experience, on any pubertal alterations that you have encountered during treatment and before treatment. **Probe; Please share any of your experiences/notices and whether there are any disparities or unusual/stopped changes after treatment.**

2. What are your experiences about pubertal changes and long-term cancer treatment side effects about your future fertility health later in life?

Probe; Please, tell me, in females, any changes in the menstruation cycle such as delayed/ cessation of menstrual flow(women)

In males, any diminishes/cessation of pubertal growth/changes.

B) SPECIFIC QUESTIONS ON ADOLESCENT CONCERNS TOWARDS REPRODUCTIVE HEALTH DURING CHEMOTHERAPY AND RADIATION THERAPY.

3. What are your biggest concerns regarding cancer treatment and your reproductive health as an adolescent (male or female)

Probe; Please tell me in detail what are your worries about future pregnancy (women)

(Male) ;Do you think you might have any risks of infertility?

4. What are the facilitators towards communicating with you doctors concerning potential long-term reproductive side effects associated with treatment?

Probe; Please explain what you would like the conversation to be about, and why?

5.What are your thoughts regarding on engaging oneself in sexual activity with an opposite sex while on cancer treatment?

Probe; **what are your thoughts concerning disease transmission and other health risks during this treatment period**

C)SPECIFIC QUESTIONS ON ADOLESCENT PERCIVED THOUGHTS TOWARDS THEIR FUTURE REPRODUCTIVE HEALTH DURING CHEMOTHERAPY AND RADIATION THERAPY

6. How is social life and your degree interaction with friends at school or at home during cancer treatment, have you been able to create more friends especially those of an opposite sex? **Probe; Are you comfortable to share with your friend about what you are passing through during treatment rather than family members?**

7.Share with me your thoughts regarding dating/relationship with an opposite with the aim to have a family in the future? **probe; please why have you thought about it.**

8. What are your thoughts towards what is best for you , to having a life partner with the same diagnosis of Cancer or with no diagnosis of cancer so as you can start a family?

probe; Do you prefer to be with a life partner with the same diagnosis, if YES why and if NO why?

9. How has the cancer treatment journey impacted your thoughts towards your future reproductive ability and the desire to have children in the future? **Probe; have you thought about future fertility health and cancer treatment? Would like to have your own biological children/ adopt?**

ENDING; 9) Do you have any other information concerning the study that you find important and would like to share with me during this interview.

Appendix IV: In-depth interview guide (Swahili version)

CHUO KIKUU CHA AFYA NA SAYANSI SHIRIKISHI MUHIMBILI

KURUGENZI YA UTAFITI NA MACHAPISHO

FOMU YA RIDHAA YA KUSHIRIRKI UTAFITI HUU

Huu ni mwongozo wa kina wa mahojiano ya mgonjwa kwa ajili ya Kuchunguza Mitazamo ya Vijana kuelekea Masuala ya Afya ya Uzazi juu Tiba ya Kemotherapi na Tiba ya Mionzi katika Kliniki ya Saratani ya Watoto, Hospitali ya Taifa ya Muhimbili, Dar-es-salam, Tanzania.

Sehemu ya Kwanza : Utangulizi

Umechaguliwa kwa usaili huu, ukijua kuwa utaweza kujibu kwa woga/kusita, ningependa pia kukukumbusha kuwa, mahojiano haya yatarekodiwa kwa urahisi wa kukumbuka ulichoshiriki na itachukua takribani 30-45 dakika.

Sehemu ya Pili : Taarifa za makazi;

Nambari ya Utambulisho ……..

Jinsia;.a) Mwanaume b) Umri wa kike……. Anwani…….

Kiwango cha elimu; ……a) ngazi ya msingi b) Ngazi ya sekondari c) ngazi ya chuo kikuu/chuo

Sehemu ya II; Maswali ya jumla.

IA) Umri katika utambuzi ……. B) Aina ya ugonjwa ……..

2) Muda wa matibabu .... a) Miezi 2 b) Miezi 4 c) Miezi 6 d) mwaka na zaidi

3)Umepitia matibabu gani a) chemotherapi b) Radiotherapi c) Yote kwa pamoja

SEHEMU YA TATU: Maswali Binafsi juu Mtazamo

1.Ni mabadiliko gani ya kawaida ya kubalehe ambayo umekutana nayo wakati wa ujana, na ni umri gani uliona mabadiliko ya kubalehe?

2. Tafadhali shiriki nami uzoefu wako, kuhusu mabadiliko yoyote ya kubalehe au mabadiliko ambayo umekumbana nayo wakati wa matibabu na kabla ya matibabu.
Uchunguzi; Tafadhali shiriki uzoefu/maarifa yoyote na kama ilikuwa kabla ya matibabu au wakati wa matibabu

3. Je, umefikiria kuhusu mabadiliko ya balehe na matibabu ya saratani ya muda mrefu kuelekea afya ya uzazi baadaye maishani?
Uchunguzi; Tafadhali, niambie, nini maoni yako

4.Je, unafikiri matibabu ya saratani yanaweza kuathiri uwezo wa kuwa na uzazi bora?
Uchunguzi; Tafadhali, eleza jinsi unavyojua kwa undani.

5. Je, ungependa kuwa na mwenzi aliye na utambuzi juu ya maswala ya saratani au asiye na utambuzi wa maswala ya saratani baadae maishani na kuanzisha familia?
uchunguzi; Tafadhali niambie kama NDIYO, kwa nini na kama Hapana, kwa nini?

6.Je matibabu ya saratani yameathiri mtazamo wako juu ya Afya ya Uzazi na uwezo wa kupata watoto?

Uchunguzi; Tafadhali, nieleze zaidi juu ya hilo

7. Je ni mambo gani hasa hukupa wasiwasi juu matibabu ya saratani kuhusianisha na afya ya uzazi kwa umri wako wewe kama kijana wa kike/kiume?

Uchunguzi, tafadhali , nieleze zaidi , ni mambo gani hasa yanakutatanisha.

8. Je, ungependa kuzungumza na daktari wako kwa uwazi kuhusu uzazi wako, na ikiwa kuna madhara yoyote ya uzazi ya muda mrefu yanayohusiana na matibabu?

Uchunguzi; Tafadhali eleza kwa nini ungependa mazungumzo, kuna faida yoyote?

SEHEMU YA V: KUISHIA

9) Je, una taarifa nyingine yoyote kuhusu utafiti ambayo unaona ni muhimu na ungependa kushiriki nami wakati wa mahojiano haya?

Appendix V: Ethical Clearance form from MUHAS

UNITED REPUBLIC OF TANZANIA

MINISTRY OF EDUCATION, SCIENCE AND TECHNOLOGY

MUHIMBILI UNIVERSITY OF HEALTH AND ALLIED SCIENCES

OFFICE OF THE DIRECTOR – RESEARCH, PUBLICATIONS AND INNOVATION

Ref. No.DA.282/298/01.C/2122 Date: 07/05/2024

MUHAS-REC-04-2024-2122
IRENE NGOWI
SCHOOL OF NURSING
MUHAS

RE: APPROVAL FOR ETHICAL CLEARANCE FOR A STUDY TITLED: ADOLESCENTS' PERSPECTIVES TOWARDS REPRODUCTIVE HEALTH CONCERNS DURING CHEMOTHERAPY AND RADIATION THERAPY TREATMENT AT MUHIMBILI NATIONAL HOSPITAL, DAR-ES-SALAAM TANZANIA.

Reference is made to the above heading,

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

APPROVAL DATE: 29/04/2024
EXPIRATION DATE OF APPROVAL: 29/04/2025

STUDY DESCRIPTION:
Purpose:
This is a qualitative study aimed at exploring the perspectives on reproductive health concerns during chemotherapy and radiation therapy treatment at Muhimbili National Hospital, Dar-es-salaam Tanzania.

The approved protocol and procedures for this study is attached and stamped with this letter, and can be found in the link provided:
https://irb.muhas.ac.tz/storage/Certificates/Certificate%20-%2015363.pdf and in the MUHAS archives.

The PI is required to:

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

Muhimbili University of Health and Allied Sciences
DIRECTOR
Research, Publications & Innovations
Box 65001

Dr. Nahya Masoud,
Chairperson, MUHAS Research and Ethics Committee

Appendix VI: Permission letter –MNH

THE UNITED REPUBLIC OF TANZANIA

MINISTRY OF HEALTH

MUHIMBILI NATIONAL HOSPITAL

In reply please quote:

Ref. No.: MNH/CRTCU/Perm/2024/204 Date: 08th May, 2024

Block Manager,
NPC – II
Muhimbili National Hospital

RE: PERMISSION TO COLLECT DATA AT MNH

Name of PI	**Irene Ngowi**
Title	**"Adolescent's Perspectives Towards Reproductive Health Concerns Chemotherapy and Radiotherapy Treatment at Muhimbili National Hospital, Dar es Salaam Tanzania"**
Institution	Muhimbili University of Health and Allied Sciences
Supervisor	Dr. Beatrice Mwilike (MUHAS)
Co – Investigators	Rehema H. Lait (MNH) Mr. Hamza Lilenga
Period	08th May 2024 to 30th June, 2024

Approval has been granted to the above principal investigators to collect data at MNH. Dissemination of study findings at MNH shall be overseen by **Dr. Rehema H. Laiti (**MNH) supervisor.

Kindly ensure the named principal investigator abide to the ethical principles and other conditions of the research approval.

Sincerely,

Dr. Sima Rugarabamu
For: Head of Clinical Research, Training and Consultancy Unit

c.c DNS
c.c Dr. Rehema H. Laiti
c.c **Irene Ngowi**

Upanga West, Kalenga Street, Plot No. 10480/3, P.O. BOX 65000, Dar es Salaam, Tanzania
Telephone: +255-22-2151367-9, Telephone: +255-22-2151351-2
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Appendix VII: Plagiarism Certificate

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PERSPECTIVES TOWARDS REPRODUCTIVE HEALTH CONCERNS AMONG ADOLESCENTS UNDERGOING CHEMOTHERAPY AND RADIOTHERAPY TREATMENT AT MUHIMBILI NATIONAL HOSPITAL, DAR-ES-SALAAM TANZANIA.

Irene E. Ngowi

Masters of Science in Oncology Nursing Dissertation,
Muhimbili University of Health and Allied Sciences

June, 2024

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