

**PSYCHOSOCIAL EXPERIENCES OF TRANSITION FROM PAEDIATRIC
TO ADULT WARDS OF ADOLESCENTS RECEIVING ONCOLOGY CARE
AT KENYATTA NATIONAL HOSPITAL**

LINET ACHIENG OBIERO


H56/34048/2019

**A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE CONFERMENT OF MASTER OF SCIENCE IN
NURSING (ONCOLOGY) IN THE DEPARTMENT OF NURSING SCIENCES,
FACULTY OF HEALTH SCIENCES AT UNIVERSITY OF NAIROBI**

NOVEMBER, 2022

DECLARATION

This dissertation is my own personal work and has not been offered in any other institution for examination purposes.

Signature 

Date 30th November 2022

Linet Achieng Obiero

Reg. no: H56/34048/2019

CERTIFICATE OF APPROVAL

The dissertation presented herein is offered for review with our authority as the University supervisors


Dr. Lucy Kivuti-Bitok, PhD

Lecturer

Department of Nursing Sciences

Faculty of Health Sciences

University of Nairobi

Signature..........Date.....29/11/2022.....

Dr. Mary Kamau, PhD

Lecturer

Department of Nursing Sciences

Faculty of Health Sciences

University of Nairobi

Signature.. .....Date.29th Nov 2022

CHAIRMAN, DEPARTMENT OF NURSING SCIENCES

Dr. Emmah Matheka, PhD

Department of Nursing Sciences

Faculty of Health Sciences

The University of Nairobi

Signature..........

DEDICATION

This dissertation is dedicated to my beloved family. To my loving and supportive children and my parents - you were all there for me when the going got tough and I needed someone to push me to carry on. I am immensely grateful for your prayers, love, patience, understanding and reassuring words. I am blessed to have you all. To you all, I am most grateful.

ACKNOWLEDGEMENT

I wish to acknowledge and sincerely thank my supervisors Dr. Lucy Kivuti-Bitok and Dr. Mary Kamau whose great support, effective supervision and guidance, timely feedback, valuable insights, inspiration and expertise were instrumental in the successful development and completion of this dissertation. I am also grateful to the management of Kenyatta National Hospital for allowing me to carry out the study in the facility. I also wish to acknowledge and thank my study respondents for being kind enough and accepting to be part of the study hence its success. I am also grateful to my family, friends and colleagues for their prayers, moral support and words of encouragement.

Above all, I thank the Almighty God for every blessing to me and my family.

TABLE OF CONTENTS

| | |
|---|-------------|
| DECLARATION | ii |
| CERTIFICATE OF APPROVAL | iii |
| DEDICATION | iv |
| ACKNOWLEDGEMENT | v |
| TABLE OF CONTENTS | vi |
| LIST OF TABLES | x |
| LIST OF FIGURES | xi |
| ABBREVIATIONS AND ACRONYMS | xii |
| OPERATIONAL DEFINITIONS | xiii |
| ABSTRACT | xiv |
| CHAPTER ONE: INTRODUCTION | 1 |
| 1.1 Study Background | 1 |
| 1.2 Problem Statement | 2 |
| 1.3 Study Justification | 3 |
| 1.4 Research Questions | 4 |
| 1.5 Study Objectives | 4 |
| 1.5.1 General Objective | 4 |
| 1.5.2 Specific Objectives | 4 |
| 1.6 Significance of the Study | 5 |
| CHAPTER TWO: LITERATURE REVIEW | 6 |
| 2.1 Introduction | 6 |
| 2.2 Level of Preparedness for Transition from Paediatric to Adult Wards of Adolescents Receiving Oncology Care | 6 |
| 2.3 Psychological Experiences of Transition from Paediatric to Adult Wards of Adolescents Receiving Oncology Care | 8 |
| 2.4 Emotional Experiences of Transition from Paediatric to Adult Wards of Adolescents Receiving Oncology Care | 11 |

| | |
|--|-----------|
| 2.5 Social Experiences of Transition from Paediatric to Adult Wards of Adolescents Receiving Oncology Care | 13 |
| 2.6 Summary of Literature Reviewed | 16 |
| 2.7 Theoretical Framework | 16 |
| 2.8 Conceptual Framework | 18 |
| CHAPTER THREE: RESEARCH METHODOLOGY | 20 |
| 3.1 Introduction | 20 |
| 3.2 Study Design | 20 |
| 3.3 Study Area | 20 |
| 3.4 Study Population | 21 |
| 3.5 Inclusion and Exclusion Criteria | 21 |
| 3.6 Sample Size and Sampling Technique | 22 |
| 3.7 Data Collection Instruments | 22 |
| 3.7.1 Pretesting of the Study Tools | 23 |
| 3.7.2 Validity and Reliability of the Study Tool | 23 |
| 3.8 Participants' Recruitment and Consenting Procedures | 23 |
| 3.9 Data Collection Procedures | 24 |
| 3.10 Data Storage | 25 |
| 3.11 Data Analysis | 25 |
| 3.12 Quality Assurance | 26 |
| 3.13 Ethical Considerations | 26 |
| 3.14 Study Limitations | 27 |
| 3.15 Study Findings Dissemination Plan | 27 |
| CHAPTER FOUR: RESULTS | 28 |
| 4.1 Introduction | 28 |
| 4.2 Demographic Characteristics of the Respondents | 28 |

| | |
|---|-----------|
| 4.3 Level of Preparedness for Transition from Paediatric to Adult Wards among the Respondents | 30 |
| 4.3.1 Whether the Respondents were Adequately Counselling of their Impeding Care Transition from Paediatric to Adult Wards | 30 |
| 4.3.2 Whether the Respondents Received Clear Explanations on Reasons for the Care Transition from Paediatric to Adult Wards | 31 |
| 4.3.3 Level of Involvement of the Respondents in Care Transition Decisions from Paediatric to Adult Wards | 31 |
| 4.3.4 Respondents' View as to whether the Transition from Paediatric to Adult Wards was Patient-Tailored | 32 |
| 4.3.5 Respondents' Level of Preparedness for Transition from Paediatric to Adult Wards | 33 |
| 4.4 Psychological Experiences of Transition from Paediatric to Adult Wards among the Respondents | 37 |
| 4.5 Emotional Experiences of Transition from Paediatric to Adult Wards among the Respondents | 43 |
| 4.6 Social Experiences of Transition from Paediatric to Adult Wards among the Respondents | 49 |
| CHAPTER FIVE: DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS | 55 |
| 5.1 Introduction | 55 |
| 5.2 Discussion of Findings | 55 |
| 5.2.1 Demographic Characteristics of the Respondents | 55 |
| 5.2.2 Level of Preparedness for Transition from Paediatric to Adult Wards among the Respondents | 55 |
| 5.2.3 Psychological Experiences of Transition from Paediatric to Adult Wards among the Respondents | 57 |
| 5.2.4 Emotional Experiences of Transition from Paediatric to Adult Wards among the Respondents | 60 |
| 5.2.5 Social Experiences of Transition from Paediatric to Adult Wards among the Respondents | 62 |
| 5.3 Conclusions | 66 |
| 5.4 Recommendations | 66 |

| | |
|--|-----------|
| 5.5 Suggested Areas for Further Studies | 67 |
| REFERENCES | 68 |
| APPENDICES | 72 |
| Appendix 1: Informed Consent Form for the Caregivers | 72 |
| Appendix 2: Fomu ya Kutoa Idhini ya Walezi | 75 |
| Appendix 3: Adolescent's Assent Document | 78 |
| Appendix 4: Fomu ya Makubaliano kwa Mshiriki Aliye Chini ya Miaka 18 | 80 |
| Appendix 5: Questionnaire | 82 |
| Appendix 6: Focus Group Discussion Guide | 87 |
| Appendix 7: Letter to KNH-UoN Ethics and Research Committee | 89 |
| Appendix 8: Letter to the Head of Department - Oncology Unit of KNH | 90 |
| Appendix 9: Work Plan | 91 |
| Appendix 10: Study Budget | 92 |
| Appendix 11: Similarity Index Report | 93 |

LIST OF TABLES

| | |
|--|----|
| Table 4.1: Respondents' demographic characteristics | 29 |
| Table 4.2: Whether the respondents considered the transition from paediatric to adult wards to be patient-tailored | 32 |
| Table 4.3: Respondents' psychological experiences of care transition from paediatric to adult wards | 39 |
| Table 4.4: Respondents' emotional experiences of care transition from paediatric to adult wards | 45 |
| Table 4.5: Respondents' social experiences of care transition from paediatric to adult wards | 50 |

LIST OF FIGURES

| | |
|--|----|
| Figure 2.1: Conceptual framework | 19 |
| Figure 4.1: Whether the respondents were adequately counselled over their impending care transition from paediatric to adult wards | 30 |
| Figure 4.2: Whether the respondents received clear explanations on reasons for the care transition from paediatric to adult wards | 31 |
| Figure 4.3: Respondents' rating of their level of involvement by the healthcare team in care transition decisions from paediatric to adult wards | 32 |
| Figure 4.4: Respondents' view regarding their level of preparedness for transition from paediatric to adult wards | 33 |
| Figure 4.5: Respondents' rating of their psychological experiences in relation to their care transition from paediatric to adult wards | 38 |

ABBREVIATIONS AND ACRONYMS

| | |
|----------|---|
| COVID-19 | Coronavirus Disease 2019 |
| KNH | Kenyatta National Hospital |
| MoH | Ministry of Health |
| SPSS | Statistical Package for Social Sciences |
| US | United States |
| WHO | World Health Organization |

OPERATIONAL DEFINITIONS

Adolescent - Refers to male and female patients aged 13 - 19 years old receiving oncology care at Kenyatta National Hospital

Cancer - A complex group of diseases characterized by the growth of abnormal cells beyond their usual boundaries that can then invade the adjoining parts of the body and/or spread to other parts of the body or organs.

Emotional experiences - Refers to inner feelings that adolescents with cancer have in relation to care transition from pediatrics to adult wards.

Oncology care - Refers to medical care being offered to adolescents diagnosed with cancer at Kenyatta National Hospital

Psychological experiences - Refers to mental thoughts and feelings that adolescents with cancer have in relation to care transition from pediatrics to adult wards.

Social experiences - Refers to social relations aspects that adolescents with cancer go through in relation to care transition from pediatrics to adult wards.

Transition - Refers to the movement of adolescents being treated for cancer from paediatric wards to adult wards in the course of oncology care.

ABSTRACT

Background: Adolescence is a time of considerable physical and emotional changes, and cancer diagnosis during this time can have a profound impact on a child's psychological and physical development and complicates the experiences typical to this life phase. Unfortunately, much of the focus in most of the oncological care settings is on disease management and hence adolescent cancer patients' readiness and psychosocial and emotional experiences often remain largely overlooked.

Objective: To assess the psychosocial experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transition from pediatrics to adult wards.

Methods: This was a sequential mixed-methods study conducted among 60 adolescents on cancer care in Kenyatta National Hospital (KNH) oncology unit. Both quantitative and qualitative data were collected using a questionnaire administered by the interviewer and a focus group discussion (FGD) guide respectively. The study tools were pre-tested at Kenyatta University Teaching and Referral Hospital. The study's quantitative data were analyzed using descriptive measures that included percentages and frequencies using SPSS version 25.0. Association between variables of the study was evaluated using chi-square test at 95% CI. Results were shown in tables and figures. Qualitative data from the FGDs was thematically analyzed using content analysis and presented in narrative form.

Results: Majority (88.3%, n = 53) of the respondents shared the view that their level of preparedness for transition from pediatrics to adult wards was inadequate. Being mentally depressed (66.7%), anxiety (100%), helplessness (63.3%), low self-esteem (81.7%) and guilt (76.7%) were the leading psychological experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from pediatrics to adult wards. Sadness (93.3%), emotional pain (98.3%), anger (93.3%) and fear (96.7%) were the leading emotional experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from pediatrics to adult wards. Social isolation (95%), self-pity (85%), loneliness (100%) and lack of or inadequate social supports (53.3%) were the leading social experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from pediatrics to adult wards.

Conclusions: Adolescents receiving oncology care at KNH underwent a wide range of psychological, emotional and social experiences as they transitioned from pediatrics to adult wards. They also perceived their preparedness for transition from pediatrics to adult wards as being inadequate.

Recommendations: To address the challenge of adverse psychosocial and emotional experiences of transition from pediatrics to adult wards among adolescents on oncology care at KNH, age-appropriate patient tailored psychosocial support systems and services should be initiated prior to, during and in the post transition period for these patients.

CHAPTER ONE: INTRODUCTION

1.1 Study Background

According to the World Health Organization (WHO), cancer places substantial physical, monetary and emotional difficulties on persons, households, the society, and health systems all over the world (WHO, 2021). Cancer is a category of illnesses that can begin in any tissue of the body and spread to other human tissues and organs when abnormal cells proliferate uncontrollably. It is a major global public health concern that affects all ages including adolescents (Chien, Chang & Huang, 2020). Cancer is the second largest cause of mortality worldwide, after cardiovascular disorders, according to WHO figures. It is expected to cause 10 million fatalities by 2020, or approximately one in every six deaths (WHO, 2021). After communicable and cardiovascular diseases, cancer is Kenya's third largest cause of death (MoH, 2021).

Adolescence is a time of substantial physical and emotional changes, and a cancer diagnosis during this time has a significant impact on their psychological and physical growth (Kimberly et al., 2022). When a young adult is diagnosed with cancer, the experiences that are typical of this stage of life can be complicated. This is a time for emotional and financial independence, as well as growing in one's self-assurance, independence, and one's identity; engaging in school, one's calling or job; undergoing communal and sexual closeness; and making sexual and reproductive decisions appropriate for young adulthood (Levin, Zebrack & Cole, 2019). Adolescents diagnosed with cancer may find it particularly difficult to confront mortality and reconcile melancholy in their unfulfilled vision for the future at such a young age (Chien et al., 2020). As a result, the psychosocial needs of patients in this age group differ from those of younger children and older individuals with cancer (Sibulwa, Chansa-Kabali & Hapunda, 2019).

The Society for Adolescent Medicine defines health care transition as the intentional, planned transfer of adolescents and young adults with ongoing medical and physical conditions from child-focused to adult-focused health care systems (Coyne, 2018). It is a 'complex and dynamic phenomenon' that involves the skills, communication,

coordination and education of patients, families, clinicians and caregivers (Gagné, 2019).

In order to improve patient health outcomes and wellbeing, an efficient transition process can offer the patient right quality; much needed continuous health care services. It can also serve as a platform for interactions between the various parties involved in the care of the patient including pediatricians, healthcare providers in adult settings and other healthcare professionals, the support staff as well as the patients and the family members/caregivers (Mulder et al., 2016). Indeed, transitioning of patients is a holistic active endeavour that focuses on the educational, social, mental, treatment and life's exigencies of adolescent and young adult patients and their families or caregivers as they advance to adult-centered care systems and practice (Ryan, Chafe & Moorehead, 2021).

Adolescents in cancer treatment face extremely demanding life changes as a result of their potentially terminal illness and extensive and physically draining therapy. Detachment from family and relatives during treatment admissions, as well as other psychological, social, and emotional pressures, has been associated to such alterations (Avutu et al., 2022). Further, given that the majority of patients in oncological care clinics and wards are either adults or younger children, adolescents are likely to feel more alienated and out of place, further exacerbating their psychosocial distress or problems (Mertens & Marchak, 2015). Unfortunately, much of the focus in most of the oncological care settings is on disease management and hence adolescent cancer patients' care transition readiness level as well as psychosocial and emotional experiences often remains largely overlooked (Ander et al., 2018).

1.2 Problem Statement

To enable childhood and adolescent cancer survivors to successfully and amicably transition from child-centered to adult-oriented healthcare systems, care transition should be an active, well-planned, coordinated, comprehensive, multidisciplinary process that is patient centered (Ryan et al., 2021). The care shifting process should be adaptable, developmentally appropriate, take the psychosocial, educational, treatment and employment needs of the patients, their families, and caregivers into

consideration, and encourage healthy living and better managing one self (Campbell et al., 2016). However, while this is a laudable standard, existing evidence suggests that transition support and services for adolescent survivors of malignant tumors in most instances fail to meet prevailing benchmarks and represent a ‘cast off’ instead of being a process that is clear, harmonious and well integrated (Sadak et al., 2020).

At Kenyatta National Hospital (KNH), it is a policy that adolescents automatically shift from pediatric oncology care units once they turn 13 years to adult oncology care units. The transition process was however fraught with challenges as incidences had been reported of adolescents on oncology care resisting to move to the adult care oncology unit due to lack of psychosocial counseling and preparation or very limited preparation. Reports of patients and their parents being emotionally and psychologically disturbed over the transition from pediatrics to adult wards were also common (KNH Oncology Register, 2021). Unfortunately, not much is understood about the preparedness level and psychosocial and emotional experiences relating to shifting to adult from children’s wards of adolescents receiving oncology care at KNH, hence a research gap existed.

1.3 Study Justification

Adolescents are diagnosed with cancer at a critical developmental stage in their lives. Both sickness and treatment have a major and long-term impact on their mental well-being. While the need of psychosocial support for cancer patients is becoming more widely recognized, the psychosocial and emotional experiences of adolescents receiving oncology care, particularly in poor countries, are relatively unknown. While investigations shows that a notable number of adolescents suffering from malignant tumors don’t experience significant hurdles in their social and mental developing during their illness, there is recognition that adolescents receiving oncology care face greater psychosocial difficulties than other age groups, which has significant implications for their psychosocial development and well-being.

Investigating the psychosocial and emotional experiences of oncology care transition from pediatrics to adult wards among adolescent cancer patients is important in order to better understand their wellbeing psychosocially. An exploration of the psychosocial and emotional experiences during shifting to adult from children’s wards of adolescents

receiving oncology care is important not only for understanding the ramifications of tumors in adolescents but as well for providing critical guide on measures that could improve better planning and delivery of psychosocial care to the affected adolescents and their families. There is need for health care systems to understand how and why cancer diagnosis can jeopardize the optimal psychosocial and emotional developmental milestones in adolescents, so they can be modified to appropriately support this vulnerable population in more positive and empowering ways.

1.4 Research Questions

1. What is the level of preparedness for transition from pediatrics to adult wards of adolescents receiving oncology care at Kenyatta National Hospital?
2. What are the psychological experiences of transition from pediatrics to adult wards of adolescents receiving oncology care at Kenyatta National Hospital?
3. What are the emotional experiences of transition from pediatrics to adult wards of adolescents receiving oncology care at Kenyatta National Hospital?
4. What are the social experiences of transition from pediatrics to adult wards of adolescents receiving oncology care at Kenyatta National Hospital?

1.5 Study Objectives

1.5.1 General Objective

To analyze the psychosocial experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from pediatrics to adult wards.

1.5.2 Specific Objectives

1. To determine the level of preparedness of adolescents receiving oncology care at Kenyatta National Hospital for transition from pediatric to adult wards.
2. To analyze the psychological experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transition from pediatrics to adult wards.

3. To assess the emotional experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transition from pediatrics to adult wards.
4. To establish the social experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transition from pediatrics to adult wards.

1.6 Significance of the Study

This investigation's outcomes may illuminate or lead to review of guidelines on oncology care for adolescent cancer patients at Kenyatta National Hospital through offering valuable insights on psychosocial and emotional experiences of these patients as they are transitioned from pediatrics to adult wards. This may in turn lead to development of psychosocial adaptation models for adolescents receiving oncology care in the hospital. The study findings may also inform cancer care nursing practices for adolescent cancer patients at Kenyatta National Hospital through implementation of age-appropriate care services for these patients with greater emphasis on positive psychosocial and emotional experiences during their transition from pediatrics to adult wards. The findings may also inform nursing education with insights generated from the study helping nurses gain understanding of the psychosocial challenges adolescents on oncology care go through. This may in turn act as a basis for formulation of nurses and clinicians training tools and guides on meeting the psychosocial needs of the adolescent cancer patients. Lastly, the findings from this study may also inform research by acting as a reference point and a basis for further research on the study subject among other scholars and academicians.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Transitioning to adult from children's wards involves the process of patient-centered model of health care from a pediatric to adult based model of health care in a healthcare setting, with or without change of the health care team (Mulder et al., 2016). It involves preparation, planning, tracking and monitoring of set transition plans, transfer, and integration of adolescent patients from pediatrics into adult-centered health care (Coyne, 2018). The objectives of transition of care are to increase the capacity of young adults and adolescents, including those without and with unique health care exigencies, to take care of their own care needs and make effective use of health services. They also include ensuring that pediatric and adult health care practices follow a structured procedure to facilitate effective transition planning, care shifting, and achieving proper incorporation of the adolescent patients into adult wards (Otth et al., 2021). A review of empirical literature on adolescents level of readiness for transitioning from pediatrics to adult oncology care wards as well as their psychological, emotional, and social experiences of transitioning from pediatrics to adult wards receiving oncology care is outlined in this chapter. The chapter also presents the study's theoretical and conceptual frameworks.

2.2 Level of Preparedness for Transition from Paediatric to Adult Wards of Adolescents Receiving Oncology Care

This section contains a review of empirical literature on level of preparedness for transition from pediatrics to adult wards among adolescents receiving cancer care.

A qualitative study performed in US sought to establish the indicators of successful transitions of adolescent cancer patients from pediatrics to adult-oriented care settings. Twenty-nine adolescents on oncology care were interviewed using phone-based structured interviews and data were analyzed using thematic-content-analysis. Most of the participants felt they were inadequately prepared for transition to adult-centered care settings. Possible interventions for improving transition of these patients to adult-oriented care set-ups were cited as making the transition practices more flexible and patient-tailored, maintaining effective communication throughout the

transition process, continuity of care-providers during the transition and addressing the patients' psychosocial well-being (Sadak et al., 2020). This showed that there were gaps in preparation of adolescents with cancer for transition from pediatrics to adult wards even in high resource settings such as reported by Sadak et al. study.

On their part, Parfeniuk et al., (2020) undertook a systematic review on transition readiness for adolescents with cancer to adult-oriented care settings from pediatrics ones. The review was based on data extracted from published articles drawn from various online and institutional academic databases. Findings of the review showed high prevalence of sub-optimal preparedness levels of adolescent cancer patients for transition to adult care. The review showed that in most of the settings, adolescents with cancer were barely counseled on their transition to adult care and their healthcare needs during the transition were inadequately addressed. The study concluded that there was need for improvement in care transition of adolescents on oncology care from pediatrics to adult care through shared decision making, effective communication and counselling. It is apparent from this review that more needed to be done to ensure adequate preparedness of adolescents with cancer for transition to adult-oriented care settings.

A study conducted in US evaluated the level of perceived preparedness for transition from pediatrics to adult care setting among adolescents undergoing in-hospital cancer care. The participants were interviewed using a questionnaire and data was analyzed using descriptive and regression analyses. From the findings, the proportion of the participants that had received any form of preparation for care transition from pediatrics to adult wards was less than 40%. The findings of the study suggested that most of the adolescents on oncology care received limited education and preparation regarding key elements of healthcare transition to adult-oriented care settings (Dwyer-Matzky, Blatt, Asselin & Wood, 2018). It is thus evident that more awareness creation and training were required before adolescents diagnosed with cancer were transferred to adult oriented care settings.

Coyne (2018) undertook a review on transition of adolescents with cancer from childhood cancer care units to adult ones. The study noted that transitioning to adult care is very challenging for many adolescent cancer patients as it entails developmental,

situational and role change transitions. It also noted that many of the adolescents with cancer have unmet needs in relation to transition preparation. To provide high quality person-centered care, it is essential that adolescents with cancer are provided with the necessary knowledge and skills to make a smooth transition and to successfully manage their own healthcare needs within the adult healthcare services. Nurses as key members of the multidisciplinary team can play a significant role in preparing and coordinating the transition process. It is thus clear from Coyne's review that better care for adolescents with cancer can be achieved if they were adequately prepared for care transition from pediatrics to adult care settings.

A study conducted in Taiwan evaluated the status of transitional care from pediatrics to adult health care for adolescent patients with cancer. Data for the study was extracted from adolescents undergoing inpatient and outpatient oncology care in selected hospitals in the country. Findings from the study showed that there were significant gaps in the preparation of adolescent cancer patients for transition from pediatrics-oriented care to adult-oriented care. According to the study, only a small proportion of the patients felt that they were adequately prepared for transitioning to adult care settings. The study called for greater patient and their families' involvement in care transition decisions including sufficient counselling and information sharing regarding the transition while ensuring care continuity (Jin, Chen & Chien, 2016).

2.3 Psychological Experiences of Transition from Paediatric to Adult Wards of Adolescents Receiving Oncology Care

This section presents reviewed empirical literature on psychological experiences of transition from pediatrics to adult wards of adolescents receiving oncology care. The psychological experiences reviewed include depression, anxiety, helplessness, low self-esteem and guilt, as captured in the subsequent sub-sections.

2.3.1 Depression

One of the psychological experiences of adolescents undergoing cancer treatment on transition from pediatrics care to adult-oriented care is depression. For instance, in a study carried out in Sweden exploring experiences of adolescent cancer patients during transition to adult care, a significant proportion were found to be depressed expressed

in form persistent sadness, loss of interest in earlier enjoyable activities and poor concentration (Svedberg et al., 2016). Similarly, symptoms of depression that included disturbed sleep and feeding patterns, decreased energy, poor concentration and persistent feelings of sadness were also noted among adolescents on cancer care during transition to adult care settings in studies by Nandakumar et al.,(2018) and Holland et al.,(2021). It is thus evident that depression remained one of the adversepsychological experiences that adolescents endured following care transition from pediatric to adult care settings.

2.3.2 Anxiety

Anxiety is another form of psychological experience identified among adolescents with cancer when transitioning from pediatric-oriented care to adult-oriented care. In two qualitative studies on oncology care transition from pediatrics to adult settings undertaken in US, surveyed adolescents indicated that they felt worried and unease over the transfer of care responsibilities from the pediatrics to adult settings (Sadak et al., 2020; Ryan, Chafe &Moorehead, 2021). Similarly, anxiety was also cited as one of the psychosocial challenges experienced by adolescents diagnosed with cancer on transition to adult-oriented care as reported by Abrams et al.,(2017) and Avutu et al., (2022). In these studies, anxiety among the adolescent cancer patients over transition to adult care settings was attributed to their limited preparation over the transition and concerns over what to expect in the new care setting.

2.3.3 Helplessness

The inability to help oneself and/or to act effectively, or simply helplessness, is also cited as one of the psychological experiences noted among adolescents with cancer during transitions from pediatrics to adult-oriented care. As reported by Gagné (2019), feelings of helplessness were highly prevalent among adolescent patients on oncology care and particularly during transition from pediatrics to adult based care settings. Similarly, in studies performed by Coyne (2018) and Jones et al., (2020), adolescents undergoing treatment for cancer indicated that they felt powerless and unable to effectively manage their health situation and decried their high dependence for care and support from their parents and care-providers. Not being able to take control over one's

health status and well-being was also a common theme in adolescent diagnosed with cancer during transition to adult care in studies by Sibulwa et al., (2019) and Thornton et al., (2020). These studies showed that helplessness was one of the psychological challenges that adolescents undergoing care transition from pediatrics to adult care settings experienced.

2.3.4 Low Self-Esteem

Loss of self-confidence and feelings of low self-worth also constitute a commonly identified psychological experience among adolescents diagnosed with cancer during oncological care shift from pediatrics to adult care settings. This was so reported in a US study which explored psychosocial issues affecting adolescent cancer patients during transition to adult care. The study identified low self-esteem as a common theme in surveyed participants and noted that more needed to be done to address the psychosocial needs of this patient population (Levin, Zebrack & Cole, 2019). Jin, Chen and Chien (2016) also identified psychological issues including low self-esteem as having significant effect on Taiwanese adolescent cancer patients' transition to adult care, sentiments also echoed by Gray et al., (2018) in US. Low self-esteem challenges were attributed to physical effects of cancer treatment on these patients and inadequate reassurance from close family members and the care team.

2.3.5 Guilt

Another psychological experience identified among adolescent patients undergoing cancer care during transitions to adult care settings is the feeling of guilt or self-blame. In an integrative review of psychological issues among adolescents on paediatric to adult transitional cancer care, feeling of guilt emerged as a common theme among surveyed participants (Thornton et al., 2020). This psychological experience was also identified among adolescent cancer patients on transfer from pediatrics wards to adult wards in studies by Nandakumar et al., (2018) and Sadak et al., (2020). This psychological experience was attributed to these patients perceiving themselves as being a burden to their families owing to their constant need for caregiving and associated implications on their families. These studies therefore offered evidence to

the fact that guilt was one of the psychological challenges that adolescents with cancer suffered as a result of care transition from pediatrics to adult care settings.

2.4 Emotional Experiences of Transition from Paediatric to Adult Wards of Adolescents Receiving Oncology Care

This section includes a review of empirical literature on the emotional experiences of transition from pediatrics to adult wards of adolescents receiving oncology care. The emotional experiences considered include sadness, emotional pain, anger, fear and surprise or shock, as highlighted in the subsequent sub-sections.

2.4.1 Sadness

One of the emotional experiences observed in adolescents with cancer during transition from pediatrics to adult care is sadness. This could be attributed to their concern and worries over their health condition and ongoing treatment and its disruptive effects on their normal life (Koutná & Blatný, 2020). Patterson et al., (2015) in a review of issues affecting adolescent cancer patients during transfer from pediatrics to adult care contexts identified sadness as one of the emotional experiences these patients exhibited. Sadness, attributed to long courses of treatment and the ailment's disruptive effects on normal life activities of adolescents with cancer was also a common psychosocial experience among this population as reported in studies by Ander et al.,(2018) and Lopez (2021). It is thus evident that sadness was one of the emotional challenges that adolescents undergoing care transition from paediatric to adult care settings did experience.

2.4.2 Emotional pain

Emotional pain is also another of the emotional experiences observed in adolescents with cancer while under transition from pediatrics to adult-oriented care. It was so identified in reviews by Tuchman et al., (2018), Levin et al., (2019) and Sibulwa et al.(2019) in which adolescents undergoing through cancer care and who were transitioning to adult care did agree that experienced emotional pain which they attributed to concerns and fear over the disease. Chien, Chang and Huang (2020) did also identify emotional distress as one of the major emotional experiences highlighted

by adolescents undergoing oncology care. Similar observations were noted in studies by Nandakumar et al., (2018) and Avutu et al., (2022) who also found emotional distress as one of the emotional experiences commonly exhibited by adolescents on cancer treatment undergoing transition from pediatrics to adult care. This was attributed to their concern over the illness prognosis and lost opportunity in normal social interactions.

2.4.3 Anger

Anger is also cited as one of the emotional experiences exhibited by adolescent cancer patients during transitioning to adult care settings. Various studies did note disappointment and anger among adolescents on cancer care during transition from pediatrics care settings to adult ones which they attribute to lack of shared decision making during planned care transitions of these patients (Ander et al., 2018; Kosir et al., 2019; Gagné, 2019). Anger over transition to adult-based oncology wards was also noted among affected adolescents with cancer in studies by Jones et al. (2020) and Parfeniuk et al.,(2020) which they attributed to disagreement and disappointment over the transition decision especially without adequate consultation with the patient and the patient's family. Anger in these patients was attributed largely to their perceived exclusion in decisions relating to the transition, decreased opportunity to do as their willed and the loss of their earlier acquired familiarity with their care settings.

2.4.4 Fear

Another commonly identified emotional experience observed among adolescents on cancer treatment during transitioning to adult care settings is fear. For instance, in studies exploring psychosocial experiences during transition from pediatrics to adult care among adolescents receiving cancer care, fear was a common theme among participating adolescents (Svedberg et al., 2016; Abrams et al., 2017). Fear over transition to adult-based oncology wards was also noted among adolescents with cancer in studies by Chien et al., (2020) and Holland et al.,(2021). In these studies, unfamiliarity with the new care setting and the new care team, continued hospitalization and side effects of the treatment were found to positively contribute to the fear among these patients.

2.4.5 Surprise

Surprise or shock constitutes another form of emotional experience reported among adolescent cancer patients undergoing transition from pediatrics to adult care. Mertens and Marchak (2015) in their study on experiences of adolescent cancer patients during care transition to adult wards identified shock as one of the commonly cited experience among adolescents with cancer during care transitions in health settings. During care transitions, shock was also established as a leading psychosocial experience among adolescents undergoing oncology care in studies by Coyne (2018) and Jones et al., (2020). Shock in these patients was attributed largely to care transitions undertaken without adequate consultation with the patient and the patient's family.

These studies therefore offered evidence that sadness, emotional pain, anger, fear and surprise or shock, were leading emotional challenges that adolescents with cancer experienced as a result of care transition from pediatrics to adult care settings.

2.5 Social Experiences of Transition from Paediatric to Adult Wards of Adolescents Receiving Oncology Care

This section includes a review of empirical literature on the social experiences of transition from pediatrics to adult wards of adolescents receiving oncology care. The social experiences reviewed include social isolation, stigma, self-pity, loneliness and lack of social support, as outlined in the subsequent sub-sections.

2.5.1 Isolation

One of the leading social experiences reported among adolescents diagnosed with cancer during care transitions is social isolation. For instance, Levin et al., (2019) in a review of psychosocial issues experienced by adolescent cancer patients during care transitions in US identified social isolation as a common experience among these patients following transition to adult care wards. Granek et al., (2021) in a review of psychosocial variables that impacted adolescent cancer patients' care transition from pediatrics to adult care also established social isolation as one of the adverse psychosocial experiences that these patients endured. Other studies that also identified social isolation as a leading psychosocial experience during care transition to adult

wards among adolescents being treated for cancer included those by Campbell et al., (2016) and Sadak et al., (2020). Social isolation thus was one of the adverse social experiences encountered by adolescents receiving oncology care undergoing transition from pediatrics to adult wards.

2.5.2 Stigma

Stigma, denoting a negative perception towards a person or group of people on account of a distinct characteristic or attribute, is also one of the psychosocial experiences identified among adolescents with cancer during care transitions to adult care settings (Thornton et al., 2020). Sibulwa et al., (2019) in a review of experiences during care transition from pediatrics wards to adult care ones among adolescents with cancer in Zambia also identified stigma associated with cancer as one of the adverse experiences that these patients encountered while under treatment. Similarly, in two studies conducted in the US, stigma was identified as one of the negative psychosocial experiences that were commonly cited by adolescents diagnosed with cancer on transition to adult care from pediatrics care (Gray et al., 2018; Ryan et al., 2021). Other studies that also established stigma as one of the negative social experiences that adolescents with cancer endured during care transitions were those by Campbell et al., (2016) and Lopez (2021). It is thus evident that stigma remained a leading social related challenge associated with transition from pediatrics to adult wards for adolescents undergoing cancer care.

2.5.3 Self-Pity

Self-pity is another psychosocial experience identified during paediatric to adult care transitions among adolescents under oncology treatment in numerous settings. Svedberg et al., (2016) observed in a study carried out in Sweden observed that most of the adolescents under cancer treatment suffered from self-pity following their shift from pediatrics care to adult care settings. Following transition to adult care from pediatrics care, self-pity was also evident among adolescent cancer patients in Canada and US according to studies by Jones et al., (2020) and Tuchman et al., (2018), sentiments also shared by Nandakumar et al., (2018) in an Australian study. These studies therefore offered evidence to the fact that self-pity was one of the social

challenges that adolescents with cancer suffered as a result of care transition from pediatrics to adult care settings.

2.5.4 Loneliness

In studies carried out by Levin et al., (2019) and Coyne (2018), loneliness emerged as one of the leading themes with respect to experiences of adolescent cancer patients transitioning to adult care from pediatrics care. Similar observation was made in a study conducted by Jin et al., (2016) in Taiwan where interviewed adolescents who were undergoing cancer treatment cited feelings of loneliness as one of the experiences, they went through following movement from pediatric to adult care settings. Similarly, adolescents with cancer enrolled in studies by Parfeniuk et al., (2020) and Sadak et al., (2020) did also note that most of the adolescents suffered from loneliness following their transition from pediatric to adult care settings. Feeling lonely was also identified as one of the adverse psychosocial experiences associated with cancer care transition of adolescents from pediatric to adult care setting.

2.5.5 Lack of Social Support

Lack of or inadequacy of social support constitutes another social related experience reported among adolescents with cancer following transition from pediatrics to adult care settings (Nandakumar et al., 2018). As espoused by Svedberg et al., (2016) and Ryan et al., (2021), inadequate social support following transition to adult care set-ups among adolescents with cancer, either from their care-providers or from their families, remained a challenge. They averred that considerations for social support should be emphasized during care transition decisions for adolescents undergoing cancer treatment. Thornton et al., (2020) in an integrative review of appropriate psychosocial interventions for adolescents diagnosed with cancer under transition to adult care settings cited the area of social support as requiring further attention as most of these patients were inadequately supported socially. Studies by Sibulwa et al., (2019) and Parfeniuk et al., (2020) did also identify lack of or low social support as one of the social experiences that adolescent cancer patients in many settings endured. These studies therefore offer evidence to the fact that lack of social support remained a

pertinent social challenge experienced by adolescents with cancer that were undergoing care transition from pediatrics to adult care settings.

2.6 Summary of Literature Reviewed

The above reviewed empirical literature indicated that there was perceived sub-optimal preparedness for transition from pediatrics to adult care settings among adolescents receiving cancer care across numerous settings. In many of the studies, most of the adolescents with cancer reported as being inadequately prepared for the transition from pediatrics to adult care settings. The reviewed empirical literature also indicated that transition from pediatrics to adult cancer care wards occasioned a wide range of psychological, emotional and social experiences among adolescents under treatment for cancer. Core among them included depression, anxiety, feelings of helplessness, emotional distress, fear, isolation, stigma and inadequate social support. However, the reviewed studies were largely performed in developed countries such as US, Canada, Sweden and Australia and none was conducted in the Sub-Saharan Africa region. It was evident from the literature reviewed that there was paucity of local empirical literature on the level of readiness as well as psychosocial and emotional experiences of care transition to adult care settings among adolescents receiving oncology care. Consequently, to address this existing research gap, the current study sought to determine the readiness level and psychosocial and emotional experiences of transition from pediatrics to adult wards of adolescents receiving oncology care at Kenyatta National Hospital.

2.7 Theoretical Framework

The Psychosocial Oncology Framework was the driving force behind this study, which is the theoretical paradigm that governs the provision of high-quality psychosocial care services for cancer patients. The Institute of Medicine's Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs standard from 2008 is the foundation for this theoretical approach. This theoretical model advocates for a multidisciplinary approach to cancer care in response to the distress experienced by cancer patients and their families, and it encourages cancer programs to develop, review, and revise psychosocial support services offered to cancer patients and their families/caregivers. Before solving

he patient's health needs, the theoretical model emphasizes the significance of treating psychosocial health needs in both the patient and caregiver/family (Macdonald et al., 2012). Several theories are included in the theoretical model;

Domain A—Awareness creating: Psychosocial Care Defining and Understanding

At all phases of the illness trajectory, psychosocial therapy for patients and their families should be regarded as a vital and standardized aspect of cancer care. It is important to encourage strategies that raise awareness of the importance of psychosocial health care demands and the use of psychosocial health services.

Domain B—Standard 1 of 1 Care

Care for cancer that is comprehensive should incorporate the right psychosocial medical care through ensuring proper communication between health caregivers and patients and their families; identifying patients' and families' psychosocial health needs; designing and implementing a plan that connects patients and families with needed psychosocial health care services, coordinates biomedical and psychosocial health care, and engages and supports patients and families to effectively manage their health and medical conditions; and systematic evaluation, monitoring and re-evaluating plans.

Domain C—Health Care Providers

The psychosocial standard of care for cancer patients and their families is the duty of all cancer care providers.

Domain D—Patient and Family Education

Cancer patients and their families should be taught to anticipate, and when necessary, request, psychosocial health-care-related cancer care.

Domain E- Quality Oversight and Monitoring Progress

It is necessary to establish oversight tools that can be utilized to assess and report on the quality of psychological healthcare.

Domain F- Workforce Competencies

Educational institutions, accrediting agencies, licensing bodies, and professional societies should all require professional competencies in the delivery of psychological healthcare.

Educational bodies should assess their standards, licensing and certification criteria with the goal of finding and developing competencies in providing psychosocial healthcare in accordance with a model that combines biological and psychosocial care as thoroughly as possible.

Domain G- Standardized Nomenclature

A consistent trans-disciplinary taxonomy and terminology for psychosocial health services is required.

Domain H- Psychosocial Research

Continued research on psychosocial health services is required.

This theoretical model was pertinent to the current study because it attempts to assist healthcare clinicians at both the provider and system levels in meeting the psychosocial and emotional needs of cancer patients and their families/caregivers.

2.8 Conceptual Framework

The conceptual framework is a diagrammatic description of the studied variables' relationship. The conceptual framework provides a visual representation of the study's independent variable(s) and dependent variable, allowing for a quick summary of the study's most important factors (Mugenda & Mugenda, 2003).

The independent variables of the study included level of preparedness for care transition from pediatric to adult wards, psychological experiences, emotional experiences and social experiences. The dependent variable for the study was health care transition outcomes for oncology adolescent patients from pediatric to adult wards. The

intervening variables of the study included the adolescents' gender, age and disease duration. The outcome variable of the study was positive or negative transition outcomes. The conceptual framework was as illustrated in Figure 2.1.

Independent variables

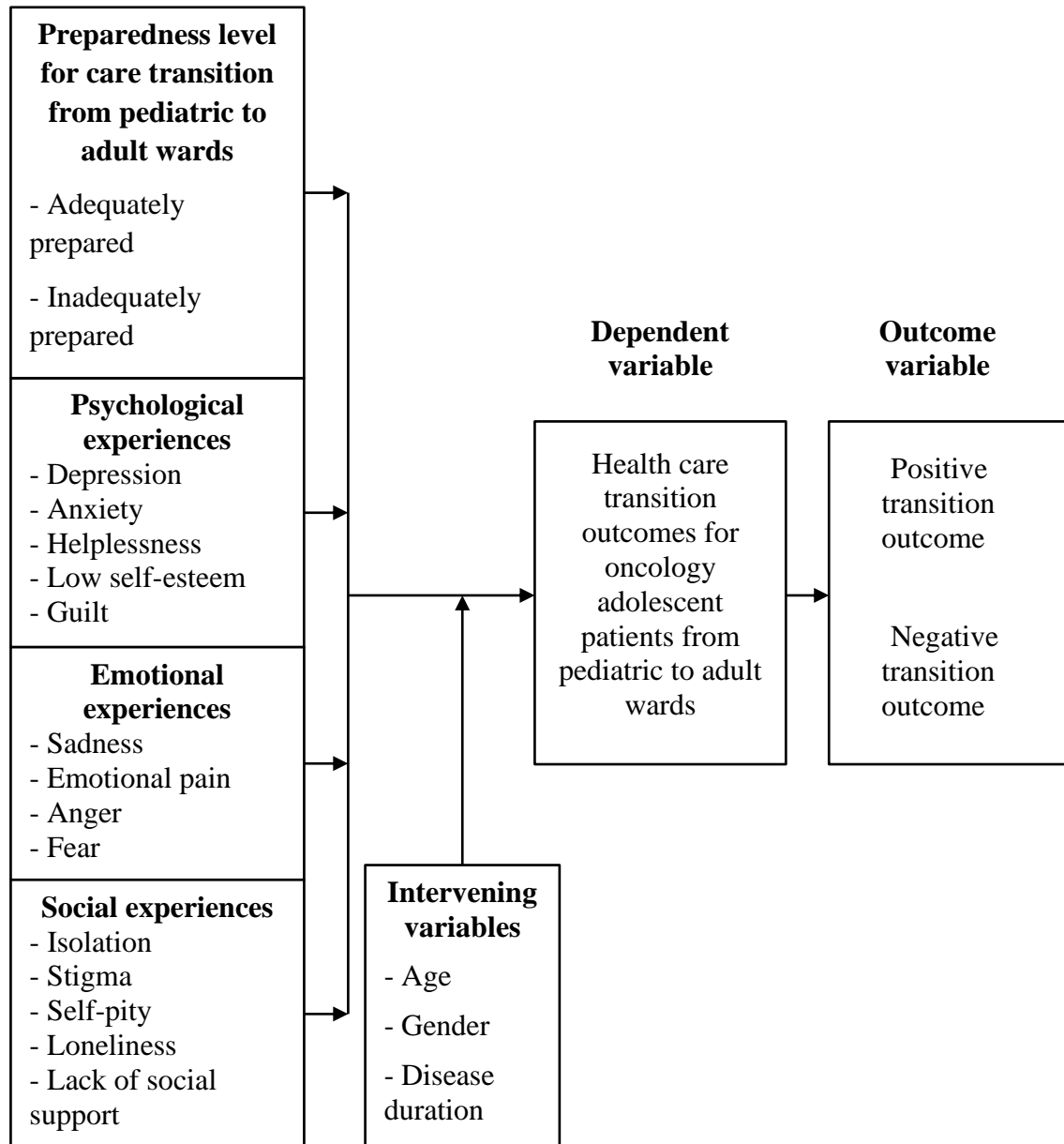


Figure 2.1: Conceptual framework

Source: Researcher, 2022

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Introduction

This chapter describes the research materials and methods that were used to undertake the study. The chapter thus presents the study design, study area, study population, the criteria for inclusion and exclusion, sample size and sampling technique, the instruments of data collection, procedures for data collection, pretesting, the research tool validity and reliability, data analysis, study findings dissemination plan, ethical considerations and study limitations.

3.2 Study Design

This was a sequential mixed-methods study as it utilized both quantitative and qualitative data. The two data components were executed sequentially starting with the collection of the quantitative data then followed by collection of the qualitative data. As observed by Creswell (2012), an approach of undertaking research that utilizes mixed methods design implies that the study attempts to assess the research problem under review using both quantitative and qualitative data and research-techniques. Hence, this research design was considered appropriate for this study as it allowed the researcher to enrich the quantitative data on the study subject with qualitative data hence deriving a more in-depth view of the study subject (Kothari, 2010).

3.3 Study Area

Kenyatta National Hospital (KNH) Oncology Unit is where this research study was conducted. KNH is the oldest and largest teaching and referral hospital in Kenya. It was founded in 1901 with 40 patients with the hospital having grown over the years to its current bed capacity of about 2,000. The hospital is situated on Hospital Road a few kilometers from Kenya's capital. KNH provides largely specialist medical services to both out and inpatients in areas such as surgical interventions of the heart and brain, plastic and reconstructive surgeries, orthopedics, care for cancer patients, care for patients with diabetes and kidney disease, serious paediatric medical conditions and management of accidents and burns patients among others. It's also involved in the

training of medical practitioners, research work and plays an active role in healthcare design and shaping in the country.

KNH's oncology unit is the largest in the country and serves patients with different kinds of cancers from across the country and beyond on a referral basis. Within the oncology unit, children diagnosed with cancer are cared for in the pediatrics oncology wards. However, when they turn to adolescents, KNH has a policy for their transition to adult oncology wards. As such, adolescents with cancer are cared for alongside adults with cancer in the adults' oncology wards. Kenyatta National Hospital was selected as the study area because despite the facility being a leading care centre for adolescents with cancer, the status of psychosocial and emotional experiences of transition from pediatrics to adult wards among adolescents receiving oncology care at the hospital remained unexplored.

3.4 Study Population

Those targeted as participants in this investigation were adolescents receiving cancer care at KNH's oncology unit. Hospital records indicated that, on average, there were approximately 60 adolescents undergoing treatment for cancer in KNH's adult oncology wards in every quarter of each year (KNH Oncology Unit Records, 2022). This constituted the study population.

3.5 Inclusion and Exclusion Criteria

3.5.1 Basis for Being Included

All adolescents on oncology care at KNH's oncology unit, at the time of the study, and who individually (or via their care takers) consented to take part in the study.

3.5.2 Based for Being Excluded

Those left out included adolescents with tumor who were mentally incapacitated, those that were critically ill and those who declined to consent to participate in the study either individually or via their care takers.

3.6 Sample Size and Sampling Technique

The researcher used census method whereby all adolescents undergoing treatment for tumor at the cancer care setting of KNH were recruited to the study. Kothari (2004) espoused that an entire target population may be used as the study sample if it was small. Hence, the study sample comprised of the 60 adolescents on cancer care in the oncology unit of KNH.

3.7 Data Collection Instruments

The data collection instruments for this study were a semi-structured questionnaire consisting of closed ended questions on respondents' demographic information, perception of preparedness for transition from pediatrics to adult wards and on psychological, emotional and social experiences of transition from pediatrics to adult wards, and a focus group discussion (FGD) guide consisting of open-ended questions on the respondents' psycho-social experiences of transition from pediatrics to adult wards. The two study tools were interviewer-administered. The questionnaire contained questions based on the objectives of the research study. It is structured into 5 parts. Section A contained questions on the respondents' demographic information. Section B contained questions regarding the perception of preparedness for transition from pediatrics to adult wards among the respondents. Section C contained questions on the psychological experiences of transition from pediatrics to adult wards among the respondents. Section D contained questions on the emotional experiences of transition from pediatrics to adult wards among the respondents while Section E contained questions on the social experiences of transition from pediatrics to adult wards among the respondents.

On its part, the FGD guide contained open-ended questions based on the study objectives. The FGD guide sought to gather the opinions of the study participants regarding the study subject. It provided the study's qualitative data whose purpose was to complement the study's quantitative data gathered through the questionnaires. It allowed the researcher to probe in a more in-depth way the psychosocial and emotional experiences of the study participants in relation to their transition from pediatrics to

adult oncology wards. This way, it helped enrich the study's quantitative data. The FGD interviews were audio-taped.

3.7.1 Pretesting of the Study Tools

The study tools' pre-testing was undertaken among six (6) adolescents receiving oncology care at the Kenyatta University Teaching and Referral Hospital representing 10% of targeted participants. Mugenda and Mugenda (2003) pointed that 10% of sampled respondents was sufficient for assessing the appropriateness of adopted study tools. Insights from the pre-testing were used to refine the study tools into the versions used in the main study.

3.7.2 Validity and Reliability of the Study Tool

A study tool's ability to effectively assess the aspect it was prepared for (Kothari, 2010) or whether the conclusions gained from data analysing represent the subject being researched is referred to as validity (Denscombe, 2014). Tools for gathering data got made available to the investigator's supervisors, who assisted in establishing whether the tools adequately captured the aspects being studied.

Reliability is a data collection instrument's capacity to yield similar outcomes on several attempts (Nsubuga, 2006). Reliability of the data gathering tools was evaluated using the Cronbach's Alpha Coefficient based on data from the study tools' pretesting. Reliability values of at least 0.70 were accepted. Appropriate changes were made on items with low coefficient values to improve on the reliability of the study tools.

3.8 Participants' Recruitment and Consenting Procedures

To recruit the study participants, the researcher following relevant authorization from KNH's oncology unit approached the targeted respondents during their rest breaks. The researcher utilized these short encounters to introduce herself, inform the targeted participants about the study's purpose; emphasize on the selection criteria and disclose where she could be found within the unit for further details on the study as well as details on consenting procedures for the study.

Part of the consenting procedure entailed the patients providing their informed consent (for those aged 18 years and above) and assent (for those aged below 18 years) plus their parental/care takers informed consent prior to participation in the study. The considerations of the consenting environment included voluntary participation, respect for the dignity and autonomy of the participants, ensuring confidentiality of any information provided and ensuring that the study participants feel at ease during the data collection exercise.

3.9 Data Collection Procedures

The study's quantitative data was gathered through administration of the questionnaire to the adolescents receiving oncology care at Kenyatta National Hospital. This was by allowing them to respond to the queries as contained in the questionnaire with the respondents' responses being noted down by the principal researcher.

For the qualitative data part, the 60 adolescents on cancer care at KNH's oncology unit were organized into 4 focusgroup discussions each comprising of 15 members. The process of collecting the qualitative data entailed interviewer administration of the FGD guide among the respondents during the FGDs. The focus group discussions were audio-taped. This was complemented by the researcher's field notes which were prepared through the researcher's note-taking during the FGD interviews. The FGDs were held in a confidential interruption-free counselling office located within the hospital's oncology unit. Thereafter, the audio recordings of the FGD interviews were safely kept prior to analyzing of the data collected. The FGD interviews lasted for approximately 30 to 60 minutes. At the end of every FGD interview, the participants were given an opportunity to comment on or identify any part of the interview that should not be included in the final analysis of the data.

Ministry of Health's Covid 19 prevention and control guidelines were observed including social distancing 1.5m apart, proper wearing of face mask and hand hygiene during the data collection process. The data collection exercise took approximately four weeks.

3.10 Data Storage

The responded to study tools and informed consents were safely locked in a cupboard accessed only by-the researcher. The data in the filled-in questionnaires was also entered into Ms Excel and was stored in a password protected computer only used by the researcher. Further, a copy of the data was also saved in a password protected flash disk kept by the researcher as back-up. All these were done to ensure safety of the study data.

3.11 Data Analysis

Data cleaning and entry preceded analysis. The study's quantitative data was analyzed using the Statistical Package for Social Sciences (SPSS version 25.0). The study data was analyzed through descriptive statistics in form of frequencies and percentages. Further, association between the study's independent and dependent variables was assessed using the chi-square test at 95% confidence interval. Quantitative data study findings were presented in tables, graphs and charts, as appropriate.

Qualitative data emanating from the FGDs with the study respondents was analyzed through thematic analysis. The thematic analysis followed Braun and Clarke's (2006) six-step process for identifying, interpreting, and reporting themes in data. An inductive strategy was used to identify codes. The following six stages were followed: (a) the interviews were transcribed verbatim and reviewed numerous times to become comfortable with the facts. (a) To improve uniformity and credibility of the coding, the two research assistants developed initial codes independently of one another. It was computed a coding comparison between the codes they generated. (c) The codes were then grouped into possible themes, and a theme map was created to ensure that the themes were compatible with the coded extracts and data collection.(d) The topics were then examined and discussed until (e) appropriate theme definitions and titles were established, and (f) the final report was completed. The qualitative analysis was conducted using the software package NVivo 12 Pro. The findings of qualitative data were given verbatim.

3.12 Quality Assurance

Quality assurance in empirical research context refers to strategies and policies for ensuring that data integrity, quality, and reliability were maintained at every stage of the research project. Quality assurance in this study was ensured through;

- i. Adequate documentation of all research procedures and methods
- ii. Validation of the study questionnaire through pretesting
- iii. Ensuring that research assistants were properly and adequately trained on the study tool and data collection procedures
- iv. Undertaking data cleaning prior to performing analysis of the data

3.13 Ethical Considerations

This study was ethically approved by the KNH-UoN ERC. The researcher also sought permit to collect data among the targeted respondents from the Head of the Oncology Unit at KNH. Participants aged 18 years and above were required to provide their own written consent prior to participating in the study while for those aged below 18 years, parental informed consent and patient's assent were required prior to their inclusion in the study. All information derived was held in confidence. Anonymity was observed by coding the FGD responses and exclusion of any personal identification information. Participants took part voluntarily and could leave the study at any point with no being victimized. The participants were not paid or in any way rewarded to participate in this study. There was no any intended health risk or any other harm to participants for participating in this study. However, study participants that suffered emotional or psychological distress for participating in this study were referred to a counselor for appropriate help by the researcher. Dissemination of the study's findings would only be done as per the University's guidelines and anonymity and confidentiality of the participants shall also be ensured during the finding's dissemination. Safety of the audio recordings of the FGD interviews was ensured. Ministry of Health's COVID-19 prevention guidelines were followed during data collection.

3.14 Study Limitations

The study findings were limited to Kenyatta National Hospital, and hence their generalization may be limited. A wider study on the study subject involving other healthcare facilities locally has been recommended for the findings to be compared and generalized.

Some respondents were hesitant to participate in the study due to fear of victimization and sensitivity of the issue under study. To address this limitation, an assurance that the all information offered would be treated with utmost confidence and that the information given would only be used for academic purposes only. They also responded to the study tools anonymously.

3.15 Study Findings Dissemination Plan

The study findings shall be shared via providing the final dissertation document to the University of Nairobi's Department of Nursing Sciences, to UoN's Library and to Kenyatta National Hospital's oncology unit and Research & Programs. The study findings shall also be presented in organized workshops and conventions. The research work shall also be published in a relevant peer-reviewed journal.

CHAPTER FOUR: RESULTS

4.1 Introduction

Outlined in this chapter are results in accordance with the study's aims. The findings presented were on the preparedness level as well as psychosocial and emotional experiences of transitioning to adult from children's wards of adolescents receiving oncology care at Kenyatta National Hospital. The chapter's contents includes results on number of participants, findings on their demographic attributes as well as results on the objectives of the investigation.

4.1.1 Response Rate

An aggregate of 60 adolescents on cancer care in the oncology unit of KNH were recruited as respondents. From the interviews held, sufficient feedback was received from all the 60 respondents yielding a reply rate of 100%. This feedback rate was considered to be appropriate as it conformed to Mugenda and Mugenda (2003) assertion that a feedback rate of seventy percent and above was exceptional.

4.2 Demographic Characteristics of the Respondents

The study sought to establish the demographic profile of the respondents. The demographic attributes considered were gender, age, education level, cancer type and duration under cancer treatment.

The respondents' gender distribution findings showed that 51.7% (n = 31) of the respondents were female while 48.3% (n = 29) were male, denoting that the study participants were male and female adolescents receiving cancer care at KNH.

Results on respondents' age distribution showed that most (68.3%, n = 42) of the respondents were aged 16 - 19 years with the remaining being aged 13 - 15 years. This denotes that the study participants were adolescents undergoing cancer treatment at Kenyatta National Hospital.

With respect to the respondents' education level, half (50% n = 30) of the respondents had Secondary education while the other half had Primary education, illustrating that the study participants had a basic education background.

On the cancer types the respondents had, 45%, (n = 27) of the respondents were being treated for leukemias, 31.7% (n = 19) were being treated for lymphomas while 13.3% (n = 8) were being treated for brain and central nervous system (CNS) tumors, denoting that these three classes of cancers were the most commonly diagnosed among the study participants.

Regarding the respondents' cancer treatment duration, slightly over half (53.3%, n = 32) of the respondents had been under cancer treatment for 1 - 5 years while 36.7% (n = 22) had been under cancer treatment for 6 - 10 years, implying that most of the study participants had been under treatment for cancer for a considerable duration. The results are as shown in Table 4.1.

Table4.1: Respondents' demographic characteristics

| | | Frequency | Percent |
|---------------------------|---|------------------|----------------|
| Gender | Male | 29 | 48.3 |
| | Female | 31 | 51.7 |
| | Total | 60 | 100.0 |
| Age | 13-15 years | 19 | 31.7 |
| | 16-19 years | 42 | 68.3 |
| | Total | 60 | 100.0 |
| Education level | Primary | 30 | 50.0 |
| | Secondary | 30 | 50.0 |
| | Total | 60 | 100.0 |
| Cancer type | Leukemias | 27 | 45.0 |
| | Lymphomas | 19 | 31.7 |
| | Brain & central nervous system (CNS) tumors | 8 | 13.3 |
| | Others | 6 | 10.0 |
| | Total | 60 | 100.0 |
| Cancer treatment duration | Less than 1 year | 2 | 3.3 |
| | 1 - 5 years | 32 | 53.3 |
| | 6 - 10 years | 22 | 36.7 |
| | Over 10 years | 4 | 6.7 |
| | Total | 60 | 100.0 |

4.3 Level of Preparedness for Transition from Paediatric to Adult Wards among the Respondents

The first objective of the study sought to determine the perceived preparedness of adolescents receiving oncology care at Kenyatta National Hospital for transition from paediatric to adult wards. The results were as described in the subsequent subsections.

4.3.1 Whether the Respondents were Adequately Counseled of their Impeding Care Transition from Paediatric to Adult Wards

The respondents were asked whether they were adequately informed or counseled of their impending care transition from pediatrics to adult wards. From the results, a significant proportion (48.3%, n = 29) of the respondents indicated that they were not adequately informed or counseled of their impending care transition from pediatrics to adult wards, denoting possible gaps in level of preparation of adolescents undergoing oncology care for transition from paediatric to adult wards at KNH. Figure 4.1 contains the findings.

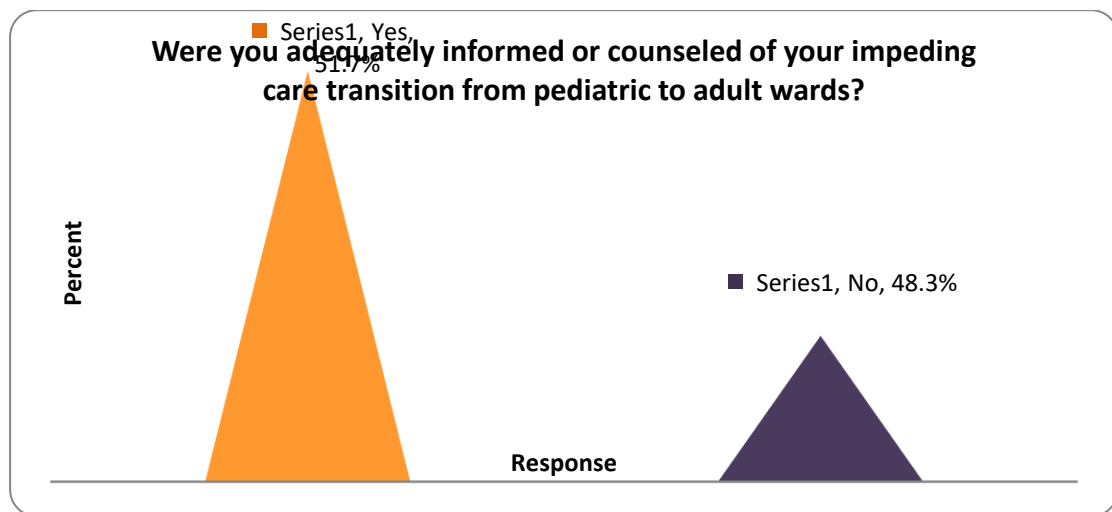


Figure4.1: Whether the respondents were adequately counseled over their impending care transition from pediatric to adult wards

4.3.2 Whether the Respondents Received Clear Explanations on Reasons for the Care Transition from Paediatric to Adult Wards

The respondents were asked whether they were offered clear explanations by the medical team on reasons for the care transition from pediatric to adult wards. From the findings, slightly over half (51.7%, n=31) of the respondents indicated that the reasons for the care transition from pediatric to adult wards were not clearly explained to them by the medical team. This denoted that a considerable proportion of the study participants had not been offered clear explanations regarding reasons for the care transition from pediatric to adult wards.

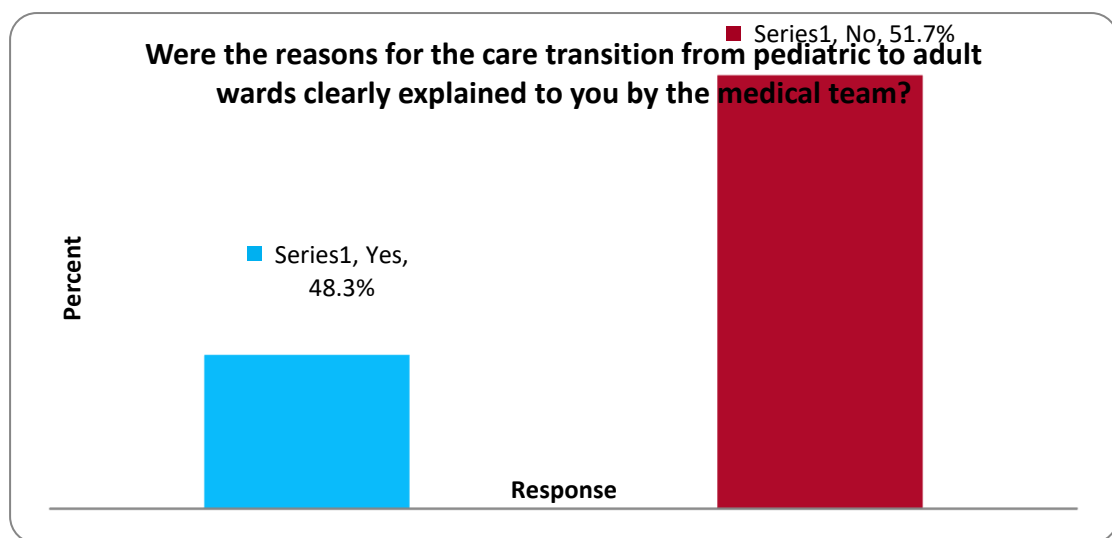


Figure 4.2: Whether the respondents received clear explanations on reasons for the care transition from pediatric to adult wards

4.3.3 Level of Involvement of the Respondents in Care Transition Decisions from Paediatric to Adult Wards

The respondents were requested to rate their level of involvement by the healthcare team in care transition decisions from pediatric to adult wards. According to the results, above half (53.3%, n = 32) rated their level of involvement by the healthcare team in care transition decisions from pediatric to adult wards as unsatisfactory while 21.7% (n = 13) rating it as average. Only (18.3%, n = 11) of the respondents rated their level of involvement by the healthcare team in care transition decisions from pediatric to adult wards as satisfactory. This depicted that most of the adolescents undergoing oncology

care at KNH felt that they were inadequately engaged in care transition decisions from pediatric to adult wards by the healthcare team.

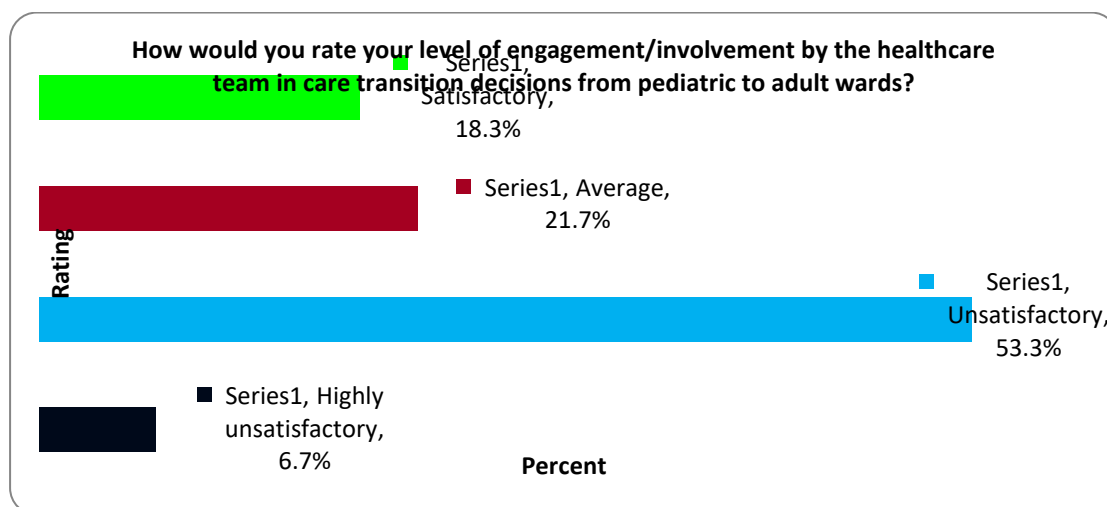


Figure4.3: Respondents’ rating of their level of involvement by the healthcare team in care transition decisions from pediatrics to adult wards

4.3.4 Respondents’ View as to whether the Transition from Paediatric to Adult Wards was Patient-Tailored

The respondents were requested to indicate whether they would say that the transition from paediatric to adult wards was patient-tailored (that is, sensitive to their needs and concerns). Majority (96.7%, n =58) of the respondents indicated that, in their view, the transition from pediatric to adult care settings was not patient-tailored (that is, it was not conscious to their needs and concerns), as is shown in Table 4.2.

Table4.2: Whether the respondents considered the transition from pediatric to adult wards to be patient-tailored

| | Frequency (n) | Percent (%) |
|--------------|----------------------|--------------------|
| Yes | 2 | 3.3 |
| No | 58 | 96.7 |
| Total | 60 | 100.0 |

4.3.5 Respondents' Level of Preparedness for Transition from Paediatric to Adult Wards

The respondents were asked whether, in their view, their level of preparedness for transition from pediatric to adult wards was adequate or satisfactory. From the findings, majority (88.3%, n = 53) of the respondents shared the view that their level of preparedness for transition from pediatric to adult wards was not adequate or satisfactory. This denoted that there were gaps in preparation of adolescents receiving cancer care at KNH for transition from pediatric to adult wards.

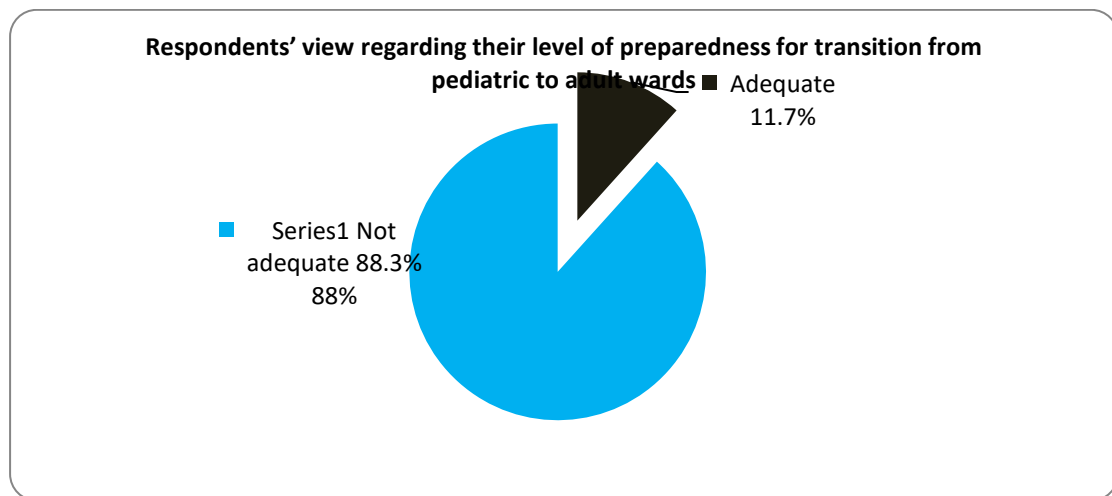


Figure 4.4: Respondents' view regarding their level of preparedness for transition from pediatric to adult wards

The findings on inadequate preparedness of the adolescents receiving cancer care at Kenyatta National Hospital for care transition from pediatric to adult wards were also corroborated by discussions held with the participants in focus group discussions as enumerated in the following FGD excerpts;

FGD Group 1, participant 003 said:

“I was not notified in time of the impending transition to adult wards from paediatric wards and no any explanations were offered to me regarding the move to an adult ward.”

FGD Group 1, participant 007 noted:

“Indeed, at no point was I involved in decisions regarding being moved to the adult ward. It all happened, without my consent.”

FGD Group 2, participant 001 opined:

“Yes, I was informed that I would be transferred from the pediatric ward to an adult ward. However, clear reasons for the transition were not offered. I was only told I was no longer a child and hence could no longer be cared for within the pediatric ward.”

FGD Group 3, participant 006 also pointed:

“I really wish we were adequately informed in advance over the impending care transition from pediatric to adult wards. One would be better prepared for the shift. The entire transition was a fuss.”

FGD Group 3, participant 009 added:

“Honestly, I expected better procedures for the care transition from pediatric to adult wards. The lack of explanation on reasons behind the transition and lack of counselling around the care transition to adult wards was to me - disappointing.”

FGD Group 4, participant 002 pointed:

“... I felt totally unprepared for the transition to adult wards. Why couldn't they prepare us well in time? They needed to have informed and counseled us about the shift to the adult ward from early on and not just at when it's time to move. I felt terrible over the whole experience.”

FGD Group 5, participant 004 pointed:

“It is not until when it was time to shift, was I informed that I would be transferred to an adult ward. I tried to ask why I was being transferred to an adult's ward and all I was told was that it's hospital policy for persons of my age to be transferred to adult wards. What the hell?”

FGD Group 6, participant 005 pointed:

“To be honest, the whole experience of transitioning to adult wards from pediatric wards was unpleasant. The manner in which the information was passed regarding the care transition from pediatric to adult wards was inadequate and not patient friendly/oriented. It left a lot to be desired.”

FGD Group 6, participant 008 pointed:

“I thought one becomes an adult at 18 years. Why was I being transferred to an adult ward at 14 years? I’ve never got that around my head. Somebody should have cared to explain that to me or to my mum.”

The respondents were also requested to cite areas of preparedness for transition from pediatric to adult wards that should be improved. Two major themes arose from the discussions held with the study participants within the focus group discussions, namely, effective communication and patient involvement in care transition decisions. This was as captured in the following FGD excerpts;

Theme 1 -Effective communication

This theme relates to level of information sharing and communications made by the health care team to the adolescent patients and their families regarding care transition from pediatric to adult wards. There was a general feeling among most of the adolescent patients that the level of communication by the health care team regarding transitioning from pediatric to adult wards was sub-optimal. This was as elaborated by the following verbatim;

FGD Group 1, participant 001 said:

“I would suggest that the health care team ensure they offer adequate explanations regarding care transitions for pediatrics’ from pediatric wards to adult wards in a timely manner.”

FGD Group 1, participant 006 noted:

“They should inform patients and their caregivers of the impending transfer from pediatrics to adult wards well in advance to allow for the patient and the family to adequately prepare for the transition.”

FGD Group 2, participant 002 opined:

“More should be done to improve communication between the healthcare providers and patients and their caregivers regarding the care transition from pediatricsto adult wards.”

FGD Group 2, participant 005 also pointed:

“To improve patient care transition experience, healthcare providers should endeavor to effectively communicate and discuss the care transition decision with the patients and their caregivers.”

FGD Group 4, participant 003 averred:

“The care transition process from pediatrics to adult wards could be enhanced through greater emphasis on clear communication including adequate explanations to patients and their families of reasons behind the transition. This should be done in good time.”

FGD Group 5, participant 002 added:

“Improving on communications between the healthcare providers and the patients and their caregivers would significantly help to streamline the care transition process, making it more efficient and patient sensitive.”

FGD Group 6, participant 001 noted:

“The care transition process from pediatrics to adult wards could be enhanced through greater emphasis on clear communication including adequate explanations to patients and their families of reasons behind the transition. This should be done in good time.”

Theme 2 -Patient involvement in care transition decisions

This theme relates to the level of engagement of the adolescent patients and their families in the care transition decisions by the health care team. Most of the study participants felt that they were inadequately involved in care transition decisions by the health care team, as is illustrated in the following FGD excerpts;

FGD Group 1, participant 010 pointed:

“The healthcare providers should endeavor to involve patients and their caregivers in care transition decisions.”

FGD Group 2, participant 003 asserted:

“There is need for meaningful engagement and collaboration between healthcare providers and patients and their families on decisions of transitioning to adult wards from the pediatric wards.”

FGD Group 3, participant 003 added:

“Patients and their families should not be viewed as passive users of oncology care. Health care providers should ensure that patients and their families actively participate in all key decisions affecting the patient’s care including on patient’s transition from pediatric to adult wards.”

FGD Group 4, participant 007 argued:

“The need for adequate participation of patients and their caregivers in care transition decisions cannot be overemphasized. It’s indeed paramount - that’s an area they need to look into.”

FGD Group 5, participant 001 pointed:

“I would suggest that healthcare providers ensure that there is deliberate meaningful engagement of patients and their caregivers in care transition decisions. It’s important that patients and their family views regarding the transition are offered due consideration.”

FGD Group 6, participant 003 shared that:

“Adequate involvement of patients and their caregivers in care transition decisions needs to be emphasized and not just on paper but practically.”

4.4 Psychological Experiences of Transition from Paediatric to Adult Wards among the Respondents

The second objective of the study sought to analyze the psychological experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transition from pediatrics to adult wards.

The respondents were requested to rate their psychological experiences in relation to their care transition from pediatrics to adult wards. From the findings, most (86.7%, n = 52) of the respondents indicated that they rated their psychological experiences in relation to their care transition from pediatrics to adult wards as being negative. This showed that most of the adolescents receiving oncology care at KNH suffered negative psychological experiences in relation to their care transition from pediatrics to adult wards. Figure 4.5 shows the findings.

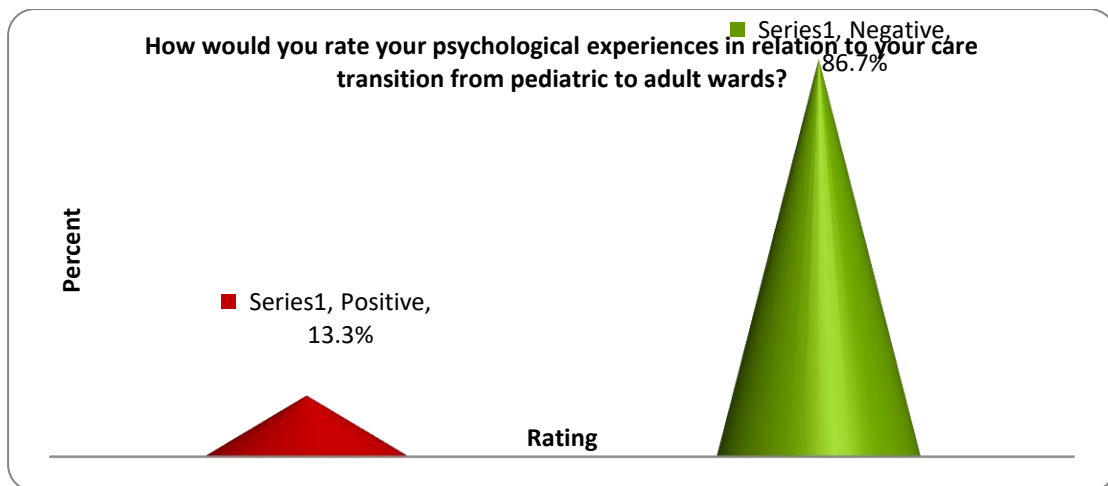


Figure 4.5: Respondents’ rating of their psychological experiences in relation to their care transition from pediatrics to adult wards

The respondents were further requested to indicate various forms of psychological experiences that they went through following their transition from pediatrics to adult wards. From the findings, the psychological experiences borne by the respondents in relation to their care transition from pediatrics to adult wards included feeling mentally depressed as cited by 66.7% (n = 40) of the respondents; feelings of mental exhaustion/fatigue as cited by 28.3% (n = 17) of the respondents; feelings of persistent sadness as cited by 78.3% (n = 47) of the respondents; feeling anxious and overly worried as cited by all (100%, n = 60) of the respondents; feeling nervous and restless as cited by all (83.3%, n = 50) of the respondents; feeling helpless, powerless and not in control as cited by 63.3% (n = 38) of the respondents; feelings of passivity and low persistence as cited by 70% (n = 42) of the respondents; feelings of low self-worth as cited by 81.7% (n = 49) of the respondents; loss of self-confidence as cited by 85% (n = 51) of the respondents; losing interest in activities earlier enjoyed as reported by 73.3% (n = 44) of the respondents; loss of appetite or disturbed feeding patterns as cited by 68.3% (n = 41) of the respondents; not being able to sleep well reported by half 50% (n = 30) of the respondents; poor concentration reported by 61.7% (n = 37) of the respondents and feelings of self-blame for being a burden to their family as cited by 76.7% (n = 46) of the respondents. Results are as shown in Table 4.3.

Table 4.3: Respondents’ psychological experiences of care transition from pediatrics to adult wards

| Kinds of psychological experiences | | Yes | | No | |
|---------------------------------------|---|------------------------------------|------|-------|------|
| | | Freq. | % | Freq. | % |
| Depression | Feeling mentally depressed | 40 | 66.7 | 20 | 33.3 |
| | Feelings of persistent sadness | 47 | 78.3 | 13 | 21.7 |
| | Losing interest in activities earlier enjoyed | 44 | 73.3 | 16 | 26.7 |
| | Loss of appetite or disturbed feeding patterns | 41 | 68.3 | 19 | 31.7 |
| | Not being able to sleep well | 30 | 50.0 | 30 | 50.0 |
| | Poor concentration | 37 | 61.7 | 23 | 38.3 |
| | Anxiety | Feeling anxious and overly worried | 60 | 100.0 | 0 |
| Feeling nervous and restless | | 50 | 83.3 | 10 | 16.7 |
| Feelings of mental exhaustion/fatigue | | 17 | 28.3 | 43 | 71.7 |
| Helplessness | Feeling helpless, powerless and not in control | 38 | 63.3 | 22 | 36.7 |
| | Passivity & low persistence | 42 | 70.0 | 18 | 30.0 |
| Low self-esteem | Feelings of low self-worth | 49 | 81.7 | 11 | 18.3 |
| | Loss of self-confidence | 51 | 85.0 | 9 | 15.0 |
| Guilt | Feelings of self-blame for being a burden to their family | 46 | 76.7 | 14 | 23.3 |

Similar views, on various psychological experiences attributable to transition from pediatric to adult wards, were also shared by the FGD participants. Five major themes were identified relating to the study participants’ psychological experiences following transition from paediatric to adult wards. These were depression, anxiety, helplessness, low self-esteem and guilt. These are as captured in the following FGD excerpts;

Theme 1 - Depression

Depression represented a wide range of adverse feelings including feelings of persistent sadness, feeling mentally distressed, loss of interest in activities earlier enjoyed, poor appetite, disrupted sleep patterns/not being able to sleep well and poor concentration.

FGD Group 1, participant 002 said:

“Being moved from pediatrics ward to adult ward made me feel terrible. I was constantly depressed and in low moods. I am still yet to recover.”

FGD Group 1, participant 004 noted:

“For me, having cancer itself has been a depressing experience. Being moved to an adult ward only made it more profound.”

FGD Group 3, participant 001 opined:

“I experience persistent sadness and grief over my health condition. Being moved to an adult ward has exacerbated these feelings. I feel I am worse off psychologically.”

FGD Group 5, participant 007 also noted:

“Since being transferred from pediatrics to adult wards, I feel like I am sad most of the time and experience bad thoughts regularly. I feel nervous and no longer enjoy some of the things I used to.”

Theme 2 -Anxiety

Anxiety represented feelings of intense worry, nervousness and being restless.

FGD Group 3, participant 007 pointed:

“Ever since coming to this adult oncology ward, I have been experiencing episodes of restlessness and feelings of intense worry. The experience has not been nice and I feel like I’m always on the edge.”

FGD Group 2, participant 005 asserted:

“... the transitioning to adult wards from the pediatrics wards has left me more nervous and anxious. I honestly feel that I was ill prepared for the shift to an adult ward. I am literally apprehensive.”

FGD Group 5, participant 004 added:

“Following my transition to an adult ward from a pediatrics one, I have been more tense and fearful. Can't tell if it's because of an unfamiliar environment or increased concerns about my health status, but I'm sure that I have been more jittery and nervous post-transition.”

FGD Group 5, participant 008 argued:

“Coping with the transition to a completely new care environment has not been easy. I have occasionally experienced episodes of anxiety. I am at times full of worry and become quite anxious and restless. It's has been a rough ride, this far.”

Theme 3 - Helplessness

Helplessness represented feelings of frustration, powerlessness and not being in control as well as being overly passive and low in persistence.

FGD Group 2, participant 005 pointed:

“I hate that, even after being transferred to an adult oncology ward, I remain highly dependent on my mom and doctors to keep things under control. It's frustrating”

FGD Group 3, participant 009 shared that:

“In my healthcare providers' decision to shift me to an adult oncology ward, I felt powerless and literally helpless. I wish I had a voice over the decision.”

FGD Group 4, participant 003 shared that:

“I have been unable to take hold of things since being moved from the pediatrics care unit to an adult ward. It caught me unawares, and I feel drained and completely helpless.”

FGD Group 4, participant 006 shared that:

“There’s no worse feeling to knowing that there’s nothing you can do about a given situation. The transition was such an experience to me. I felt powerless, helpless and inconsequential - such a nasty experience.”

Theme 4 -Low self-esteem

Low self-esteem represented feelings of low self-worth, having self-doubt and being low in self-confidence.

FGD Group 1, participant 006 said:

“I consistently struggle with low self-esteem. Often, I feel I hate myself and wished all this would end.”

FGD Group 5, participant 002 noted:

“Personally, having cancer has no doubt significantly eroded my self-belief. I do not feel very confident about myself and occasionally I do struggle with self-doubt. The transition hasn’t helped me deal with who I am and why me being sick with this condition?”

FGD Group 6, participant 007 opined:

“I feel like I am so fragile at times. Being brought to an adult’s ward made me feel vulnerable and less self-confident. I feel like I still need lots of self-assurance to get going. It’s really tough.”

Theme 5 - Guilt

Guilt represented feelings of self-blame, perceiving oneself as being a burden to the family as well as sadness, irritability and worry.

FGD Group 1, participant 009 averred that:

“My illness has been so hard on my family. It has indeed taken a toll on everyone including my parents and siblings. I feel guilty but what do I do?”

FGD Group 2, participant 002 shared:

“I can feel the burden of my illness to my parents. I know it has not been easy on them. Wish there’s anything I could do to ease the burden. It’s awful.”

FGD Group 6, participant 001 opined:

“I always ask - but why me. For God’s sake, why me? What wrong did I do to deserve this illness? It hurts me so much thinking about it.”

FGD Group 5, participant 008 opined:

“I have struggled with guilt ever since I was diagnosed with cancer. Seeing my family struggle so much with my treatment and caring for me, hurts me. It’s burdensome, but I am ever grateful for their kindness and love.”

FGD Group 1, participant 008 opined:

“Many at times I blame myself for being sick. I see myself as a burden to my family and more so to my parents. My family has been through so much following my cancer diagnosis. What did I do to deserve this? What did our family do to deserve this? This is a question I have never been to able to answer.”

4.5 Emotional Experiences of Transition from Paediatric to Adult Wards among the Respondents

The third objective of the study sought to examine the emotional experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transition from pediatrics to adult wards.

To achieve this objective, the respondents were requested to indicate whether they experienced a set of identified emotional experiences following their transition from pediatrics to adult wards.

According to the findings, majority (93.3%, n = 56) of the respondents agreed that they experienced sadness following their transition from pediatric to adult wards. They attributed this feeling to leaving behind their familiar friends in the pediatric wards, greater apprehension of the seriousness of their health condition and seeing adult cancer patients succumbing to the illness.

From the findings, nearly all (98.3%, n = 59) of the respondents agreed that they experienced emotional pain following their transition from paediatric to adult wards. They attributed this feeling to meeting more severely ill patients in the adult care setting, witnessing the great pain and suffering that some of the adult cancer patients

underwent and from seeing some of the adult cancer patients succumbing to the illness on a regular basis.

From the findings, majority (93.3%, n = 56) of the respondents agreed that they experienced anger following their transition from pediatric to adult wards. They attributed this feeling to being inadequately prepared for the transition from pediatric to adult wards, being separated from their family caregivers who took care of them while they were in pediatric wards, the complex nature and care demands of their illness, separation from earlier bonds forged during their stay in pediatric wards, lack of amenities such as TV and books in the adult care settings unlike the case with pediatric care settings and feelings of frustration and helplessness over the disease.

Further, almost all (96.7%, n = 58) of the respondents did also agree that they experienced fear following their transition from pediatric to adult wards. This feeling was largely due to their fear of death from the disease especially after witnessing adult cancer patients succumbing to the illness in the adult wards on regular occasions. The feeling of fear was also due to being in not so familiar care setting, being transitioned to care settings where they met 'strangers' (other patients they did not know), fear of being commanded and reprimanded by the elder patients and health care team members, fear of being in pain either from the disease or the treatment and general safety concerns especially at night.

Results also showed that most (65%, n=39) of the respondents also concurred that they experienced shock/surprise following their transition from pediatric to adult wards. This feeling was attributed largely to witnessing the great pain and suffering that some of the adult cancer patients suffered due to the condition. Other aspects highlighted as contributing to the feeling of shock among the respondents following transition to adult wards from the pediatric wards included poorer standards/levels of cleanliness and general hygiene in the adult wards compared to in their previous care settings, higher levels of congestion within the adult wards compared to in pediatric wards and no social amenities previously enjoyed in the pediatric wards such as TVs, books and allocated times for play/social interactions. Results are as presented in Table 4.4.

Table 4.4: Respondents’ emotional experiences of care transition from paediatric to adult wards

| Emotional experiences | Yes | | No | |
|-----------------------|-------|------|-------|------|
| | Freq. | % | Freq. | % |
| Sadness | 56 | 93.3 | 4 | 6.7 |
| Emotional pain | 59 | 98.3 | 1 | 1.7 |
| Anger | 56 | 93.3 | 4 | 6.7 |
| Fear | 58 | 96.7 | 2 | 3.3 |
| Shock/surprised | 39 | 65.0 | 21 | 35.0 |

Similar views, on various emotional experiences attributable to transition from pediatric to adult wards, were also shared by the FGD participants. Four major themes were identified relating to the study participants’ emotional experiences following transition from pediatric to adult wards. These were sadness, emotional pain, anger and fear. These are as captured in the following FGD excerpts;

Theme 1-Sadness

Sadness represented an emotional experience characterized by being unhappy and sorrow or low spirits.

FGD Group 1, participant 006 said:

“Ever since being brought to this adult oncology ward, I have persistently experienced feelings of sadness mainly due to seeing so many adult patients suffering from cancer.”

FGD Group 2, participant 005 noted:

“For me, I occasionally experience profound sadness especially when a ward mate loses their life from cancer. Unfortunately, it happens all the time and so I am often sad.”

FGD Group 4, participant 007 opined:

“It’s hard to get a day when feelings of sadness are not overwhelming. Seeing so many people suffer as I do from cancer disheartens me.”

FGD Group 4, participant 009 shared:

“The reality and gravity of my illness hit me following my transition to adult oncology ward. And I have been sad almost daily ever since.”

FGD Group 6, participant 003 opined:

“You cannot fail to feel sad when put in a setting where so many patients suffer daily from the ravages of cancer. I am most saddened when a patient loses the battle and dies. But even seeing other patients in great pain and in critical conditions also make me very sad.”

Theme 2 - Emotional pain

Emotional pain represented an emotional experience characterized by feelings of deep pain or anguish, feeling hurt, emotional distress and disconnecting from loved ones.

FGD Group 1, participant 001 opined:

“The situation I found when I was moved to the adult oncology ward was terrible and disheartening. Seeing so many elder patients in great pain and suffering as a result of cancer and other dying right in front of my eyes was extremely emotionally painful - to say the least.”

FGD Group 1, participant 007 asserted:

“Not once, twice or thrice, I have suffered emotional turmoil and deep pain for witnessing patients I knew and with whom I had shared memories, lose the battle to cancer. It still haunts me every time I think of or witness it.”

FGD Group 2, participant 001 shared:

“I guess I am an emotional wreck. The emotional pain I have had to endure as a result of witnessing so many people suffer and die from cancer is beyond words. I am surprised I’m still sane.”

FGD Group 5, participant 008 added:

“It’s both emotionally painful and exhausting to endure the motions of having cancer and being under treatment. At times, you’re so hopeful and other times, at your lowest point.”

FGD Group 6, participant 006 noted:

“Emotional hurt remains one of the greatest pains I have had to endure in this journey. Mine is largely due to apprehension of the severity and gravity of my health status. I don’t see how this will end well. It hurts but I will soldier on.”

Theme 3 - Anger

Anger represented an emotional experience characterized by feelings of antagonism, displeasure, annoyance or hostility towards others.

FGD Group 6, participant 002 pointed:

“How can I not be angry when all they (that is, health care team) did was to separate me with my mom who took care of me and my friends with whom we were being treated in the pediatric wards?”

FGD Group 6, participant 007 asserted:

“I feel angry because I see no light at the end of the tunnel. It’s all treatments and treatments and treatments. For how long? I feel disappointed and overwhelmed.”

FGD Group 2, participant 004 shared:

“What angers me about this disease is its immense care demands and frequent hospitalizations. Doctors, nurses and my parents try to reassure me that all shall be well, but it’s hard to see how it will happen. It makes me feel so angry.”

FGD Group 3, participant 002 shared:

“It’s no fun being in hospital from time to time, as I do. How then can one not be angry? It’s frustrating and annoying, but you have to keep your chin up, regardless.”

Theme 4 - Fear

Fear represented an intensely unpleasant emotional experience in response to the perceived threat of transition to an unfamiliar care setting for the adolescent cancer patients and characterised by feelings of terror, fright/panic and apprehension.

FGD Group 5, participant 004 indicated:

“I have witnessed people dying from cancer in the adult oncology care. Every time it happens, I too fear that I am on the line.”

FGD Group 5, participant 006 pointed:

“I fear interacting with the older patients in the ward I was taken to. I have always had this challenge of interacting with persons not known to me. The fear is real and holds me back.”

FGD Group 3, participant 009 said:

“I am yet to fully familiarize with my new care settings in the adult oncology wards. The patients I found there are unknown to me. I am not yet at ease with them.”

FGD Group 4, participant 001 averred:

“I honestly fear that the treatment I am receiving will one day fail and that will be the end of the road for me. The thought of death in itself is horrifying.”

FGD Group 1, participant 008 averred:

“Witnessing other patients losing the battle to cancer and knowing that you are ailing the disease terrifies me to the bones. How can I escape this reality that the disease will one day put me down?”

FGD Group 1, participant 009 averred:

“Just being informed that I would no longer be with my family members in the transitioned ward, being put amidst patients who were ‘strangers’ to me and seeing so many patients either suffering greatly or dying from cancer, filled me with lots of fear.”

FGD Group 3, participant 002 averred:

“I honestly fear that cancer will kill me. I honestly do.”

4.6 Social Experiences of Transition from Paediatric to Adult Wards among the Respondents

The fourth objective of the study sought to establish the social experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transition from paediatric to adult wards.

To achieve this objective, the respondents were requested to indicate whether they experienced a set of identified social experiences following their transition from paediatric to adult wards.

From the findings, majority (95%, $n = 57$) of the respondents agreed that they experienced social isolation following their transition from paediatric to adult wards. They attributed this feeling to frequent interruptions to their normal social life due to frequent hospitalizations, being separated from their familiar friends in the paediatric wards, being separated from their families due to the frequent admissions, difficult interactions with the elder patients they found in the adult oncology wards and being transferred to a care setting where they met 'strangers' -that is, other patients they were not familiar to.

Results also showed that about half (51.7%, $n = 31$) of the respondents agreed that they experienced stigma following their transition from paediatric to adult wards. They attributed this feeling to cultural stereotypes that cancer is a fatal or incurable disease, misconceptions about cancer such as cancer being contagious, adverse effects of cancer treatment on their physical appearance, a discredited/threatened social identity and negative depictions of cancer as a "battle" or "struggle" in various information sources including both mainstream and social media platforms.

From the findings, most (85%, $n = 51$) of the respondents agreed that they experienced self-pity following their transition from paediatric to adult wards. They attributed this feeling largely to the effects of the disease and its treatment on their bodies/physical appearance, worries over the course of the disease and its prognosis, perceived unusual attention from others evidenced in perceived excessive sympathy or compassion from other people and at times non empathic interactions, perceived deadly nature of the disease and limited physical functioning.

Further, all (100%, n = 60) of the respondents did also agree that they experienced loneliness following their transition from pediatric to adult wards. The respondents attributed this feeling to being transitioned to a care setting where they met ‘strangers’ (other patients they did not know), separation from their friends or fellow patients in the pediatric wards, being separated from their family caregivers who took care of them while they were in pediatric wards, disrupted normal social life and not being able to take part in activities they used to enjoy.

Results also showed that slightly over half (53.3%, n = 32) of the respondents also concurred that they experienced lack of or inadequate social support following their transition from pediatric to adult wards. The respondents attributed this feeling to having inadequate time with their families and friends, not being offered psychosocial support services such as counseling or being in social support groups, medical teams’ greater emphasis on disease treatment with little to no focus on their social wellbeing, feelings of social isolation and inadequate interactions with their medical care teams. Results are as shown in Table 4.5.

Table 4.5: Respondents’ social experiences of care transition from pediatric to adult wards

| Social experiences | Yes | | No | |
|--------------------------------------|-------|-------|-------|------|
| | Freq. | % | Freq. | % |
| Social isolation | 57 | 95.0 | 3 | 5.0 |
| Stigma | 31 | 51.7 | 29 | 48.3 |
| Self-pity | 51 | 85.0 | 9 | 15.0 |
| Loneliness | 60 | 100.0 | 0 | 0.0 |
| Lack of or inadequate social support | 32 | 53.3 | 28 | 46.7 |

Similar observations, on various social experiences attributable to transition from paediatric to adult wards, were also shared by the FGD participants. Four major themes were identified relating to the study participants’ social experiences following transition from paediatric to adult wards. These were social isolation, self-pity, loneliness and lack of or inadequate social support. These are as captured in the following FGD excerpts;

Theme 1 -Social isolation

Social isolation represented a social experience characterized by lack of or few social contacts/connections.

FGD Group 3, participant 008stated that:

“Being transitioned from pediatric to an adult ward ruined close social ties I had cultivated with my former counterparts and friends in the pediatric wards.”

FGD Group 3, participant 005 noted:

“For me, the transition to an adult ward meant that I was no longer able to have closer interactions with other pediatric patients who we had grown fond of each other in my earlier ward.”

FGD Group 4, participant 003 opined:

“I feel socially isolated as I am no longer able to spend as much time with my caregivers, in my new care setting, as I used to when I was in the pediatric ward.”

FGD Group 5, participant 002 shared:

“My interactions with the new patients I found in the adult ward are not as frequent and warm as I had with my former friends in the pediatric ward. Socially, I feel isolated.”

FGD Group 5, participant 007 opined:

“Being frequently admitted in hospital always disrupts my normal social life as I do not get the opportunity to be with my home friends and my family.”

Theme 2 - Self-pity

Self-pity represented a social experience characterized by one’s excessive focus on own troubles, suffering or unpleasant situation.

FGD Group 4, participant 002said:

“Seeing how cancer has affected my body and particularly my physical appearance makes me pity myself.”

FGD Group 3, participant 003 added:

“Cancer and its treatment has had significant adverse effects on my normal body functioning. I am no longer able to perform some basic activities and therefore rely on help from my parents, siblings and the health care providers. It makes me feel bad and at times makes me experience self-pity.”

FGD Group 5, participant 006 added:

“I don’t like it when people show me excessive sympathy and compassion. It does not always feel genuine.”

FGD Group 5, participant 008 noted:

“Sometimes, receiving unusual attention from other people when they learn of my health condition and their excessive acts of sympathy towards me makes me pity myself.”

Theme 3 - Loneliness

Loneliness represented a social experience characterized by distress or discomfort over perceived gaps between one’s desire for social contacts/connections and their actual experiences with regard to those social connections.

FGD Group 1, participant 003 averred:

“Being transitioned from pediatric to an adult ward left me lonely as I was no longer able to meet and interact with friends I had made during my stay in the pediatric wards.”

FGD Group 2, participant 002 highlighted:

“On numerous occasions, I have felt lonely as I am no longer able to have close interactions with other pediatric patients with whom I had grown fond of during my stay in the pediatric wards.”

FGD Group 4, participant 001 shared:

“I experience loneliness for not being able to be with my mom or dad or my siblings or my relatives and friends as many times as I used to have during my time in the pediatric ward.”

FGD Group 5, participant 008 noted:

“My normal social life has been severely curtailed by my frequent admissions in hospital. This has left me lonely.”

FGD Group 3, participant 002 shared:

“I feel lonely because I was taken to a ward in which I barely know anyone. The older patients also see me as a child and do not interact with me as regularly as they do with each other.”

FGD Group 4, participant 005 stated:

“Not being able to participate in activities that I used to enjoy, reduced contacts with my significant others and separation with earlier mates with whom I was close in the pediatric ward makes me feel lonely.”

Theme 4 - Lack of or inadequate social support

Lack of or inadequate social support represented a social experience characterized by deficiency in network of (or comfort from) family and friends that was available to the adolescent with cancer during transition from pediatric to adult wards.

FGD Group 3, participant 004 stated that:

“I have not enjoyed sufficient social support due to inadequate time I have with my family and friends following the transition to the adult oncology ward.”

FGD Group 2, participant 005 noted:

“Following the transition to the adult oncology ward, my social support has been adversely affected as I now have reduced interactions with family and friends.”

FGD Group 1, participant 006 opined:

“My interactions with the healthcare team, though good, are far from individualized and patient-oriented; hence I feel they are gaps in my social interactions with them.”

FGD Group 6, participant 001 shared:

“Lots of the doctors and nurses’ attention are on the medical treatment aspect. I strongly feel that they neglect or don’t offer due consideration to my social wellbeing.”

FGD Group 6, participant 001 shared:

“I have not been lucky to join a social support group nor do I get an opportunity to undergo counseling as often as I would wish. I therefore feel inadequately supported socially.”

CHAPTER FIVE: DISCUSSIONS, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter presents discussion of findings, conclusions and recommendations of the study in line with the study objectives. The study evaluated the preparedness level as well as psychosocial and emotional experiences of transition from pediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital.

5.2 Discussion of Findings

5.2.1 Demographic Characteristics of the Respondents

The study respondents were male and female adolescents receiving cancer care at KNH mostly aged 16 to 19 years, in elementary education level, with leukaemia and lymphomas who had been under cancer therapy for mostly one to ten years. Similar demographic attributes were observed among respondents of studies by Nandakumaret al. (2018) and Sibulwa et al. (2018) in which adolescents on cancer care that were reviewed were of both genders, were in elementary levels of schooling and were being treated for lymphomas and blood connected cancers. Similarly, in studies by Frederick et al. (2017), Gray et al. (2018) and Ander et al. (2018), the respondents were largely adolescents undergoing treatment for lymphomas and leukemias, who were in elementary school levels and who had been under oncology care for a considerable period. From this, it was inferred that leukemias and lymphomas were the most prevalent cancers among adolescent cancer patient majority of whom were in elementary school level.

5.2.2 Level of Preparedness for Transition from Paediatric to Adult Wards among the Respondents

According to the study findings, the level of preparedness of the adolescents receiving cancer care at Kenyatta National Hospital for care transition from pediatric to adult wards was inadequate. This was evidenced by the findings that close to half of the respondents indicated that they were not adequately informed or counseled of their impending care transition from pediatric to adult wards. Slightly over half of the

respondents indicated that the reasons for the care transition from pediatric to adult wards were not clearly explained to them by the medical team. Over half of the respondents rated their level of involvement by the healthcare team in care transition decisions from pediatric to adult wards as unsatisfactory. Majority of the respondents also shared the view that the transition from pediatric to adult care settings was not patient-tailored (that is, it was not conscious to their needs and concerns); with majority of the respondents holding the view that their level of preparedness for transition from pediatric to adult wards was not satisfactory. The evidence on the inadequate preparedness of the adolescents receiving cancer care at KNH for transition from pediatric to adult wards was also espoused in the FGD discussions with the participants indicating that they were not offered adequate explanations regarding the transition to adult wards from pediatric wards.

The researcher attributes the inadequate preparedness of adolescents receiving oncology care at Kenyatta National Hospital for care transition from pediatric to adult wards to possible neglect and lack of appreciation among the health care teams of how essential adequate preparation of these patients is for effective care transition to adult care settings from the pediatric care settings. Similar findings were reported by Jin et al. (2016) who in a study conducted in Taiwan established that there were significant gaps in the preparation of adolescent cancer patients for transition from pediatric-oriented care to adult-oriented care, with the level of preparedness being largely inadequate. Similarly, Coyne (2018) in a review on transition of adolescents with cancer from pediatric to adult based care settings observed that the level of preparedness of the adolescent patients with cancer for the transition was inadequate as most of the surveyed adolescents had unmet needs in relation to transition preparation. A study by Dwyer-Matzky et al. (2018) also established that most of the adolescents on oncology care received limited education and preparation regarding key elements of healthcare transition to adult-oriented care settings. Similar observations were also made by Parfeniuk et al. (2020) and Sadak et al. (2020) in whose studies, most of the surveyed adolescents felt they were inadequately prepared for transition to adult-centered care settings. In contrast, a significant proportion of adolescents with cancer reported that they were adequately prepared for care transition from pediatric to adult wards in studies by Svedberg et al. (2016) and Ryan et al. (2021). In these two studies, most of

the adolescents pointed that they were adequately counseled on their transition to adult care and reported that most of their needs and concerns relating to the transition were adequately addressed.

5.2.3 Psychological Experiences of Transition from Paediatric to Adult Wards among the Respondents

From the findings, the leading psychological experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from pediatric to adult wards included depression, anxiety, helplessness, low self-esteem and guilt.

From the findings, depression was one of the psychological experiences suffered by the respondents in relation to cancer care transition from paediatric to adult wards. This was evidenced by the findings that most of the respondents acknowledged experiencing feelings of persistent sadness, losing interest in activities earlier enjoyed, inability to concentrate, inability to sleep well, loss of appetite or disturbed feeding patterns and feeling mentally depressed. This was also evident in insights derived from the focus group discussions with participants indicating that they were mentally distressed and were sad over being transferred from pediatric to adult wards. This could be attributed to their own concerns over their health status, possible effects of the cancer treatment and/or being inadequately prepared for the transition to adult wards from pediatric ward. Similarly, symptoms of depression that included disturbed sleep and feeding patterns, decreased energy, poor concentration and persistent feelings of sadness were also noted among adolescents on cancer care during transition to adult care settings in studies by Nandakumar et al. (2018) and Holland et al. (2021). Studies by Svedberg et al. (2016), Ander et al. (2018) and Sibulwa et al. (2019) also observed that a significant proportion of adolescents on cancer care experienced feelings of depression including persistent sadness, loss of interest in earlier enjoyable activities and poor concentration during and post transition to adult care settings from pediatric care settings.

From the findings, anxiety was another psychological experience noted among the adolescents receiving oncology care at Kenyatta National Hospital in relation to care transition from pediatric to adult wards. This was evidenced by the findings that all of the respondents acknowledged as having felt anxious and overly worried, with a

significant proportion of the respondents indicating that they felt nervous and restless and experienced mental fatigue over the decision for them to transition to adult care setting from the pediatric ward. This was also notable in insights derived from the focus group discussions with participants indicating that they suffered episodes of restlessness and feelings of intense worry and nervousness over transitioning to adult wards from the pediatric wards. The study attributes this finding to the respondents' inadequate preparation for the transition and possible concerns over what to expect in the new care setting. Similar observations were made in studies by Sadak et al. (2020) and Ryan et al. (2021) which reported that majority of the surveyed adolescents undergoing cancer treatment indicated that they felt worried and unease over the transfer of care responsibilities from the pediatric to adult care settings. Similarly, anxiety was also cited as one of the psychosocial challenges experienced by adolescents diagnosed with cancer on transition to adult-oriented care in studies by Abrams et al. (2017) and Avutu et al. (2022).

Helplessness was another psychological experience noted among the study respondents in relation to care transition from pediatric to adult wards. This was evidenced by the findings that most of the respondents acknowledged feeling helpless, powerless and not in control. A significant proportion of the respondents also acknowledged experiencing feelings of frustration, passivity and low persistence in relation to care transition from pediatric to adult wards. This was also noted in insights derived from the focus group discussions with participants indicating that they felt powerless and helpless over the decision of being moved to adult from pediatric wards. This study attributes this feeling to low empowerment of these patients and their low engagement in decisions over the care transition. Similar findings were reported by Gagné (2019) who noted that feelings of helplessness were highly prevalent among adolescent patients on oncology care and particularly during transition from pediatric to adult based care settings. Similarly, in studies performed by Coyne (2018), Jones et al. (2020), Sibulwa et al., (2019) and Thornton et al., (2020) most of the adolescents undergoing treatment for cancer indicated feeling powerless and not in control during care transition from pediatric to adult care settings.

In this study, low self-esteem was also identified as one of the psychological experiences suffered by the study respondents in relation to transitioning from pediatric

to adult wards. This was evident in the findings that most of the respondents acknowledged as having experienced loss of self-confidence, feelings of low self-worth and expressing having self-doubt. This was also evident in insights derived from the focus group discussions indicating that the participants did not feel confident about the move to adult from pediatric oncology wards. The study attributes this finding to inadequate preparation of the adolescents for the transition to adult wards, possible adverse effects of cancer treatment on these patients' physical appearance or normal body functioning and possible inadequate reassurance from their caregivers and the health care team. Similar findings were reported by Levin et al. (2019) who identified low self-esteem as a common theme among surveyed adolescent cancer patients during transition to adult care in selected US hospitals. Other studies that also identified low self-esteem as one of the psychological experiences reported among adolescents receiving oncology care as they transitioned from pediatric to adult wards were those by Jin et al. (2016), Gray et al. (2018) and Sibulwa et al. (2019). However, in studies by Svedberg et al. (2016) and Ryan et al. (2021), adolescents on cancer care were not found to experience low self-esteem during transition from pediatric to adult wards.

This study also established that guilt was also one of the psychological experiences noted among the study respondents in relation to care transition from pediatric to adult wards. The results indicated that most of the respondents did experience feelings of self-blame for being a burden to their family coupled with feelings of sadness, irritability, restlessness and worry. This was also evident in insights derived from the focus group discussions with participants indicating that they felt guilty over burdening their parents and families with the illness. This study attributes the guilt experience to these patients perceiving themselves as being a burden to their families owing to their constant need for caregiving and associated implications on their families. Similar findings were also reported by Thornton et al. (2020) who in a review of psychological issues among adolescents on transition from pediatric to adult cancer care observed feelings of guilt as a common theme among the surveyed participants. Guilt as a psychological experience was also identified among adolescent cancer patients on transfer from pediatric wards to adult wards in studies by Nandakumar et al., (2018) and Sadak et al., (2020). In contrast, adolescents on cancer care were not

found to experience guilt in relation to care transition from pediatric to adult wards in studies by Ander et al. (2018) and Parfeniuk et al. (2020).

5.2.4 Emotional Experiences of Transition from Paediatric to Adult Wards among the Respondents

From the findings, the leading emotional experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from pediatric to adult wards included sadness, emotional pain, anger and fear.

From the findings, majority of the respondents agreed that they experienced sadness following their transition from pediatric to adult wards. They attributed this feeling to leaving behind their familiar friends in the pediatric wards, greater apprehension of the seriousness of their health condition and seeing adult cancer patients succumbing to the illness. This was also evident from insights derived from the focus group discussions with the participants indicating that they regularly felt sad over having the disease and over being to unfamiliar care settings. The findings were in line with those of Patterson et al. (2015) and Koutná and Blatný (2020) who also identified sadness as one of the emotional experiences that adolescent cancer patients exhibited during care transitions from pediatric to adult wards. Sadness, attributed to cancer's disruptive effects on normal life activities of adolescents with cancer and their witnessing of others suffer from the disease was also a common psychosocial experience among adolescent cancer patients as reported in studies by Ander et al., (2018) and Lopez (2021).

Emotional pain was another reported emotional experience of transition from pediatric to adult wards among the study participants. In this study, almost all of the surveyed adolescents undergoing oncology care at Kenyatta National Hospital acknowledged that they experienced emotional pain following their transition from pediatric to adult wards. This was largely due to witnessing the great pain and suffering that some of the adult cancer patients underwent and seeing some of the adult cancer patients succumbing to the illness from time to time. Similar sentiments were also espoused by the participants in the focus group discussions with some indicating that they had experienced emotional turmoil and deep pain following their transition from pediatric to adult wards. This study attributes this feeling to possible greater apprehension among

the transitioned adolescents of the gravity and seriousness of the illness and their witnessing of the sufferings of elder cancer patients within the adult care settings. The findings agreed with those of Nandakumar et al., (2018) and Avutu et al., (2022) who also reported emotional pain/distress as one of the psychosocial experiences commonly exhibited by adolescents on cancer treatment undergoing transition from pediatric to adult care. Similarly, Tuchman et al., (2018) and Chien et al. (2020) did also identify emotional pain as one of the major psychosocial experiences highlighted by adolescents undergoing oncology care as they shifted to adult oncology care settings, sentiments also shared by Levin et al., (2019) and Sibulwa et al. (2019). These studies attributed the emotional distress among the patients to their concern over the illness prognosis, lost opportunity in normal social interactions and seeing others suffer from the illness.

Anger was another emotional experience of transition from pediatric to adult wards established among the study participants. In this study, majority of the surveyed adolescents undergoing oncology care at KNH indicated that they experienced anger following their transition from pediatric to adult wards. They were angry due to being inadequately prepared for the transition from pediatric to adult wards, being separated from their family caregivers who took care of them while in pediatric wards, the complex nature and care demands of their illness, separation from earlier bonds forged during their stay in pediatric wards and lack of amenities such as TV and books in the adult care settings. From sentiments shared, ill preparation of the adolescent cancer patients for the care transition from pediatric to adult wards, disruption of social ties with their family caregivers and friends in their earlier care setting as well as general frustrations with the illness and its care demands were responsible for this psychosocial feeling. Similar observations were made by Ander et al. (2018), Kosir et al., (2019) and Gagné (2019) who noted that anger and disappointment were prevalent among adolescents on cancer care following transition from pediatric to adult care settings. Jones et al. (2020) and Parfeniuk et al. (2020) did also observe elevated anger among adolescent cancer patients for being moved to adult care settings. These studies attributed this emotional feeling to lack of shared decision making or inadequate involvement of these patients and their families by the health care teams in decisions on care transitions of these patients from pediatric to adult care settings.

Another emotional experience of transition from pediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital was fear. From the findings, almost all of the study participants concurred that they experienced fear following their transition from pediatric to adult wards. They attributed their fear to worrying of death from the disease especially after witnessing adult cancer patients succumbing to the illness in the adult wards on regular occasions, being in unfamiliar care setting, meeting ‘strangers’ (that is, other patients they did not know) in their new care setting, fear of being in pain either from the disease or the treatment and general safety concerns especially at night. This study attributes this to the participants’ apprehension of death from the illness and their being transferred to unfamiliar care setting. Fear was reported to be a common experience among adolescents with cancer during care transition from pediatrics to adult wards in studies by Svedberg et al. (2016) and Abrams et al. (2017), a finding also reported in studies by Chien et al. (2020) and Holland et al. (2021). These studies attributed fear among these patients to unfamiliarity with the new care setting and the new care team, continued hospitalization and side effects of the treatment were found to positively contribute to the fear among these patients.

5.2.5 Social Experiences of Transition from Paediatric to Adult Wards among the Respondents

From the findings, the leading emotional experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from paediatric to adult wards included social isolation, self-pity, loneliness and lack of or inadequate social support.

Social isolation was one of the social experiences of transition from paediatric to adult wards among the study participants. This study established that majority of the surveyed adolescents on oncology care at KNH agreed that they experienced social isolation following their transition from pediatric to adult wards. They attributed this feeling to frequent interruptions to their normal social life due to frequent hospitalizations, being separated from their familiar friends in the pediatric wards, being separated from their families due to the frequent admissions, difficult interactions with the elder patients they found in the adult oncology wards and being transferred to an unfamiliar care setting. This study attributes their social isolation feeling to interruption of these patients’ social ties and bonds with their family caregivers and friends in their earlier

care setting. Social isolation as a psychosocial experience among adolescents with cancer being transitioned from paediatric to adult wards was also noted in studies by Campbell et al. (2016) and Sadak et al. (2020). Levin et al., (2019) in a study carried out in US also identified social isolation as a common psychosocial experience among adolescent cancer patients following transition from pediatric to adult care wards. Other studies that also cited being isolated socially as a concern among adolescents undergoing cancer care due to care transitions from pediatric to adult wards were those by Coyne (2018) and Granek et al. (2021). These studies attributed the social isolation problem to disruption of these patients' normal social interactions and activities due to cancer care demands.

Self-pity was another social experience of transition from pediatric to adult wards reported among the study participants. From the findings, most of the surveyed adolescents on oncology care at KNH did agree that they experienced self-pity following their transition from pediatric to adult wards. They attributed this feeling largely to the effects of the disease and its treatment on their bodies/physical appearance, worries over the course of the disease and its prognosis, perceived unusual attention from others evidenced in perceived excessive sympathy or compassion from other people and at times non empathic interactions, perceived deadly nature of the disease and limited physical functioning. Similar sentiments were shared by those who participated in the FGDs who argued that excessive sympathy and compassion shown was not helpful. This study opines that this feeling could largely be due to uncharacteristically high acts of sympathy and attention that cancer patients in hospitals tend to receive from others who come to learn of their health condition and to possible effects of the disease and its treatment on their bodies. Similar findings were reported by Svedberg et al. (2016) who in a study done in Sweden observed that most of the adolescents under cancer treatment suffered from self-pity following their shift from pediatric to adult care settings. Following transition to adult care from pediatric care, self-pity was also evident among adolescent cancer patients in studies by Jones et al. (2020), Tuchman et al. (2018) and Nandakumar et al. (2018). These studies linked self-pity among the adolescent cancer patients during care transition to adult care from paediatric wards to the rigors of the disease on the patients' health and to possible

excessive compassion and sympathy which is generally directed towards patients with cancer.

Loneliness was another social experience of transition from pediatric to adult wards reported among the study participants. From the findings, all of the surveyed adolescents on oncology care at KNH did agree that they experienced loneliness following their transition from pediatric to adult wards. They attributed this feeling largely to being transitioned to an unfamiliar care setting, separation from their friends or fellow patients in the pediatric wards and from their family caregivers who took care of them while they were in pediatric wards, disrupted normal social life and not being able to take part in activities they used to enjoy. Similar sentiments were as well espoused by those who participated in the FGDs who also acknowledged suffering loneliness following the shift from pediatric to adult wards. This study opines that this feeling could largely be due to the patients' transfer to unfamiliar care settings where they met other patients they were not familiar with, interrupted social ties and bonds with their friends or fellow patients in earlier care setting and with their family caregivers, disrupted normal social life and normal life activities due to frequent hospital visits. Loneliness was also determined to be a leading psychosocial experience among adolescents with cancer undergoing care transition from pediatric to adult wards in studies by Jin et al. (2016) and Coyne (2018). Similarly, in an empirical study by Levin et al., (2019), loneliness emerged as a leading theme with respect to experiences of adolescent cancer patients transitioning to adult from pediatric care wards, an observation also espoused by Parfeniuk et al., (2020) and Sadak et al. (2020) who also noted that a significant proportion of adolescents diagnosed with cancer suffered from loneliness following their transition from pediatric to adult care settings. These studies attributed the loneliness among these patients to disruptions on their social relations and interactions as a result of the shift from pediatric to adult care settings.

Another social experience of transition from pediatric to adult wards reported among the study participants was lack of or inadequate social support. In this study, a significant proportion of the surveyed adolescents on oncology care at KNH concurred that they experienced lack of or inadequate social support following their transition from pediatric to adult wards. They attributed this feeling largely to having inadequate time with their families and friends, not being offered psychosocial support services

such as counseling or being in social support groups, little emphasis accorded to their social wellbeing by the healthcare team, feelings of social isolation and inadequate interactions with their medical care teams. Similar sentiments were also shared by those who participated in the FGDs who shared the feeling that their social support had been adversely affected by the care transition as they no longer had sufficient interactions with their family and friends as was the case earlier. This study avers that this feeling could be attributed to interruptions in social relations between these patients with their family caregivers and friends from earlier care setting and possible inadequacy of existing psychosocial support systems and services for this group of patients in regard to care transition from paediatric to adult care settings. The findings were similar to those reported by Svedberg et al. (2016) and Ryan et al. (2021), who noted that inadequate social support among adolescents with cancer following transition to from paediatric to adult care set-ups remained a key challenge with most adolescent cancer patients reporting that they experienced inadequate social support. Studies by Thornton et al. (2020) and Nandakumar et al. (2018) also shared the view that the domain of social support for adolescent cancer patients required further attention as most of these patients were inadequately socially supported especially during their transition to adult care settings from pediatric ones. Studies by Sibulwa et al., (2019) and Parfeniuk et al., (2020) did also identify lack of or low social support as one of the social experiences that adolescent cancer patients in many settings endured. These studies attributed the loneliness among these patients largely to disruptions on their social relations as well as disruptions to their social support systems arising from the care transitions from pediatric to adult care wards.

5.3 Conclusions

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

1. Adolescents receiving oncology care at Kenyatta National Hospital felt that they were inadequately prepared for the transition from pediatric to adult wards.
2. Depression, anxiety, helplessness, low self-esteem and guilt were the leading psychological experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from pediatric to adult wards.

3. Sadness, emotional pain, anger and fear were the leading emotional experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from pediatric to adult wards.
4. Social isolation, self-pity, loneliness and lack of or inadequate social support were the leading social experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transitioned from pediatric to adult wards.

5.4 Recommendations

Efforts are required on the part of Kenyatta National Hospital to institute appropriate care transition measures such as trainings and inductions for the adolescent cancer patients to ensure they are adequately prepared for the transition from paediatric to adult care settings.

To address the challenge of adverse psychological experiences of transition from pediatric to adult wards among adolescents on oncology care at KNH, age-appropriate patient tailored psychosocial support services should be initiated prior to, during and in the post transition period for these patients.

To address the challenge of adverse emotional and social experiences of transition from pediatric to adult wards among adolescents on oncology care at KNH, existing social support systems and programs for this cohort of patients should be strengthened and emphasized.

There is also need to strengthen shared decision making, collaborations and engagements between health care teams, the patients and their caregivers during care transitions for the adolescents undergoing oncology care at KNH to allow for smooth transitions.

KNH should also develop clear policy guidelines regarding care transition of adolescents with cancer from pediatric to adult wards that is sensitive to the needs and concerns of these patients.

5.5 Suggested Areas for Further Studies

This was a single hospital study that assessed the readiness level and psychosocial experiences regarding transitioning from children to adult care settings of adolescents receiving oncology care at Kenyatta National Hospital. Therefore, for this study's findings to be compared and generalized, a more broad empirical investigation among other hospitals locally is hereby recommended. Further, an empirical review of the social and mental support requirements of adolescents undergoing oncology treatment and those of their family carers at Kenyatta National Hospital would equally be illuminating.

REFERENCES

1. Abrams, A. N., Hazen, E. P., & Penson, R. T. (2017). Psychosocial issues in adolescents with cancer. *Cancer treatment reviews*, *33*(7), 622-630.
2. Ander, M., Thorsell Cederberg, J., von Essen, L., & Hovén, E. (2018). Exploration of psychological distress experienced by survivors of adolescent cancer reporting a need for psychological support. *PLOS ONE*, *13*(4), e0195899. <https://doi.org/10.1371/journal.pone.0195899>
3. Avutu, V., Lynch, K. A., Barnett, M. E., Vera, J. A., Glade Bender, J. L., Tap, W. D., & Atkinson, T. M. (2022). Psychosocial Needs and Preferences for Care among Adolescent and Young Adult Cancer Patients (Ages 15–39): A Qualitative Study. *Cancers*, *14*(3), 710-719.
4. Campbell, F., Biggs, K., Aldiss, S. K., O'Neill, P. M., Clowes, M., McDonagh, J., ... & Gibson, F. (2016). Transition of care for adolescents from paediatric services to adult health services. *Cochrane Database of Systematic Reviews*, *1*(4), 1-9.
5. Chien, C.-H., Chang, Y.-Y., & Huang, X.-Y. (2020). The Lived Experiences of Adolescents With Cancer: A Phenomenological Study. *Clinical Nursing Research*, *29*(4), 217–225. <https://doi.org/10.1177/1054773818799226>
6. Coyne, I. (2018). Transition for adolescents and young adults with Cancer. In *Nursing Adolescents and Young Adults with Cancer* (pp. 173-198). Springer, Cham.
7. Dwyer-Matzky, K., Blatt, A., Asselin, B. L., & Wood, D. L. (2018). Lack of preparedness for paediatric to adult-oriented health care transition in hospitalized adolescents and young adults. *Academic Paediatrics*, *18*(1), 102-110.
8. Frederick, N. N., Bober, S. L., Berwick, L., Tower, M., & Kenney, L. B. (2017). Preparing childhood cancer survivors for transition to adult care: the young adult perspective. *Paediatric Blood & Cancer*, *64*(10), e26544.

9. Gagné, T. (2019). What have we learned on adolescent transitions? *International Journal of Public Health*, 64(2), 147–148. <https://doi.org/10.1007/s00038-019-01207-2>
10. Gray, W. N., Schaefer, M. R., Resmini-Rawlinson, A., & Wagoner, S. T. (2018). Barriers to transition from paediatric to adult care: a systematic review. *Journal of Paediatric Psychology*, 43(5), 488-502.
11. Holland, L. R., Walker, R., Henney, R., Cashion, C. E., & Bradford, N. K. (2021). Adolescents and young adults with cancer: barriers in access to psychosocial support. *Journal of adolescent and young adult oncology*, 10(1), 46-55.
12. Jin, Y. T., Chen, C. M., &Chien, W. C. (2016). Factors influencing transitional care from adolescents to young adults with cancer in Taiwan: A population-based study. *BMC paediatrics*, 16(1), 1-8.
13. Jones, J. M., Fitch, M., Bongard, J., Maganti, M., Gupta, A., D'Agostino, N., &Korenblum, C. (2020). The needs and experiences of post-treatment adolescent and young adult cancer survivors. *Journal of clinical medicine*, 9(5), 1444.
14. Kimberly A. Pyke-G, Linda S. F, Bonnie H.F, Robert E. G, Roberta S. R.(2022). Day-to-Day Decision Making by Adolescents and Young Adults with Cancer. *Journal of Paediatric Hematology/Oncology Nursing*, 39(5), 290-303.
15. Kosir, U., Wiedemann, M., Wild, J., & Bowes, L. (2019). Psychiatric disorders in adolescent cancer survivors: a systematic review of prevalence and predictors. *Cancer Reports*, 2(3), e1168.
16. Koutná, V., & Blatný, M. (2020). Socialization of Coping in Paediatric Oncology Settings: Theoretical Consideration on Parent-Child Connections in Posttraumatic Growth. *Frontiers in Psychology*, 11, 2406.

17. Levin, N. J., Zebrack, B., & Cole, S. W. (2019). Psychosocial issues for adolescent and young adult cancer patients in a global context: A forward-looking approach. *Paediatric blood & cancer*, 66(8), e27789.
18. Lopez, A. D. (2021). *Transition experiences of adolescent survivors of childhood cancer: A qualitative investigation*. University of South Florida.
19. Mertens, A. C., & Marchak, J. G. (2015). Mental health status of adolescent cancer survivors. *Clinical Oncology in Adolescents and Young Adults*, 5, 87-95.
20. Mulder, R. L., Van Der Pal, H. J. H., Levitt, G. A., Skinner, R., Kremer, L. C. M., Brown, M. C., ... & Frey, E. (2016). Transition guidelines: an important step in the future care for childhood cancer survivors. A comprehensive definition as groundwork. *European Journal of Cancer*, 54, 64-68.
21. Nandakumar, B. S., Fardell, J. E., Wakefield, C. E., Signorelli, C., McLoone, J. K., Skeen, J., ... & Cohn, R. J. (2018). Attitudes and experiences of childhood cancer survivors transitioning from paediatric care to adult care. *Supportive Care in Cancer*, 26(8), 2743-2750.
22. Otth, M., Denzler, S., Koenig, C., Koehler, H., & Scheinemann, K. (2021). Transition from paediatric to adult follow-up care in childhood cancer survivors - a systematic review. *Journal of Cancer Survivorship*, 15(1), 151-162.
23. Parfeniuk, S., Petrovic, K., MacIsaac, P. L., Cook, K. A., & Rempel, G. R. (2020). Transition readiness measures for adolescents and young adults with chronic health conditions: a systematic review. *Journal of Transition Medicine*, 2(1), 1-16.
24. Patterson, P., McDonald, F. E., Zebrack, B., & Medlow, S. (2015). Emerging issues among adolescent and young adult cancer survivors. In *Seminars in oncology nursing* (Vol. 31, No. 1, pp. 53-59). WB Saunders.
25. Ryan, D., Chafe, R., & Moorehead, P. (2021). Transition from paediatric to adult aftercare for survivors of paediatric cancer in Newfoundland and Labrador: a

- qualitative study. *Canadian Medical Association Open Access Journal*, 9(2), E309-E316.
26. Sadak, K. T., Gameda, M. T., Grafelman, M., Neglia, J. P., Freyer, D. R., Harwood, E., & Mikal, J. (2020). Identifying metrics of success for transitional care practices in childhood cancer survivorship: a qualitative interview study of survivors. *BMC cancer*, 20(1), 1-12.
 27. Sibulwa, S., Chansa-Kabali, T., & Hapunda, G. (2019). “Every part of me has changed”—shared lived experiences of adolescents living with cancer in Zambia. *Health Psychology Open*, 6(1), 33-37.
 28. Svedberg, P., Einberg, E. L., Wärnestål, P., Stigmar, J., Castor, A., Enskär, K., & Nygren, J. M. (2016). Support from healthcare services during transition to adulthood—Experiences of young adult survivors of paediatric cancer. *European Journal of Oncology Nursing*, 21, 105-112.
 29. Thornton, C. P., Ruble, K., & Kozachik, S. (2020). Psychosocial interventions for adolescents and young adults with cancer: an integrative review. *Journal of Paediatric Oncology Nursing*, 37(6), 408-422.
 30. Tuchman, L. K., Slap, G. B., & Britto, M. T. (2018). Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child: care, health and development*, 34(5), 557-563.
 31. WHO (2021). *Cancer – Fact sheets*. Geneva: WHO publication. Accessed from <https://www.who.int/news-room/fact-sheets/detail/cancer>

APPENDICES

Appendix 1: Informed Consent Form for the Caregivers

Title of Study: Psychosocial experiences of transition from paediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital

Principal Investigator\and institutional affiliation: Linet Achieng Obiero, University of Nairobi

Supervisors: Dr. Lucy Kivuti-Bitok & Dr. Mary Kamau, University of Nairobi

Introduction

My name is Linet Achieng Obiero a student at the University of Nairobi pursuing a Masters of Science Degree in Oncology Nursing. I am carrying out a research study on: psychosocial experiences of transition from paediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital.

Purpose of the study

The purpose of this study is to assess the preparedness level as well as psychosocial and emotional experiences of transition from paediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital.

Description of the research

I'm requesting for your child's participation in this study by giving his or her views and opinions about the research subject through the study tool. If you consent that he or she participates, the researcher will request your son or daughter to respond to a series of questions based on the research objectives.

Confidentiality

All information provided will be handled and processed with utmost confidentiality. All information given herein will only be used for purposes of the research study. Your child's name or anything else that may identify him/her will not appear anywhere in the study.

Voluntary participation

Your child's participation in this study is voluntary i.e. on their own free will and without any coercion.

Right of withdrawal

Should he or she feel/wish to terminate his/her participation in this study, they will have the right to do so at any time without facing any consequences/penalties.

Benefit

This research work is for academic purposes only and if you consent for your child's participation, the information that he/she will provide will be of great importance in informing development of necessary psychosocial adaptation models for adolescents receiving oncology care in KNH with a view of improving their psychosocial and emotional experiences during care transition from paediatric to adult wards. However, there will be no monetary gains or any other form of payment for participating.

Risks

There is no any intended health risk or any other harm to your child for participating in this study. However, in the event that he/she suffers emotional or psychological distress for participating in this study, the researcher will refer him/her to a counselor for appropriate help.

Contacts

For any queries regarding this research study, kindly contact;

Principal researcher: Linet Achieng Obiero, Cell: 0722 685493, Email:

linetobiero@students.uonbi.ac.ke

Or

First supervisor: Dr. Lucy Kivuti-Bitok, Cell: 0724 205 419, Email:

kivutibitok@uonbi.ac.ke

Or

Second supervisor: Dr. Mary Kamau, Cell: 0727736 810, Email:

kwanjira@uonbi.ac.ke

Or

Secretary, KNH-UoN ERC, Telephone: 020-2726300, Email:

uonknh_erc@uonbi.ac.ke, P.O. Box 19676 – 00202 Nairobi

Caregiver’s Declaration

I have been fully informed about the nature of the study, I know the benefits, and understand that there are no risks involved. I hereby give my consent for my child to participate in this study.

Signature of participant

Date

Researcher’s Declaration

I have fully disclosed all the relevant information concerning this study to the study respondent.

Signature of researcher

Date

Appendix 2: Fomu ya Kutoa Idhini ya Walezi

Kichwa cha Utafiti: Uzoefu wa kisaikolojia wa mabadiliko kutoka wodi za watoto hadi za watu wazima za vijana wanaopata huduma ya saratani katika Hospitali ya Kitaifa ya Kenyatta

Mpelelezi Mkuu na uhusiano wa kitaasisi: Linet Achieng Obiero, Chuo Kikuu cha Nairobi

Wasimamizi: Dkt. Lucy Kivuti-Bitok na Dkt. Mary Kamau, Chuo Kikuu cha Nairobi

Utangulizi

Jina langu ni Linet Achieng Obiero mwanafunzi katika Chuo Kikuu cha Nairobi anayesoma masomo ya Shahada ya Uzamili ya Sayansi katika Uguzi wa Saratani. Ninafanya utafiti kuhusu uzoefu wa kisaikolojia na kijamii wa mabadiliko kutoka kwa wodi za watoto hadi za watu wazima za vijana wanaopata huduma ya saratani katika Hospitali ya Kitaifa ya Kenyatta.

Madhumuni ya utafiti

Madhumuni ya utafiti huu nikutathmini uzoefu wa kisaikolojia na kijamii wa mabadiliko kutoka kwa wodi za watoto kwenda kwa wodi za watu wazima za vijana wanaopata huduma ya saratani katika Hospitali ya Kitaifa ya Kenyatta.

Maelezo ya utafiti

Ninaomba kushiriki kwa mwanao katika utafiti huu kwa kutoa maoni yake kuhusu somo la utafiti kupitia zana ya utafiti. Ukikubaliashiriki, mtafiti ataomba mwanao kutoa majibu ya msururu wa maswali kulingana na malengo ya utafiti huu.

Usiri

Taarifa zote zitakazotolewa zitashughulikiwa na kuchakatwa kwa usiri mkubwa. Taarifa zote zitakazotolewa hapa zitatumika tu kwa madhumuni ya utafiti. Jina lakeau kitu kingine chochote ambacho kinaweza kumtambulisha hakitaonekana popote katika utafiti.

Ushiriki wa hiari

Kushiriki kwa mwanao katika utafiti huu ni kwa hiari yake yaani kwa hiari yake nabila shuruti yoyote.

Haki ya kujiiondoa

Iwapo atajihisi/atataka kusitisha kushiriki kwake katika utafiti huu, ana haki ya kufanya hivyo wakati wowote bila kukabiliwa na matokeo/adhabu zozote.

Faida

Kazi hii ya utafiti ni kwa madhumuni ya kitaaluma tu na ikiwa utakubali mwanao kushiriki katika utafiti huu, maelezo ambayo atatoa yatakuwa ya umuhimu mkubwa katika kufahamisha maendeleo ya miundo muhimu ya kuboresha uzoefu wakisaikolojia na kihisia baina ya vijana wanaopata huduma ya saratani katika hospitali ya kitaifa ya Kenyatta. Hata hivyo, hakutakuwa na faida za kifedha au malipo kwa kushiriki.

Hatari

Hakukusudiwi kuwa kutakuwa na hatari yoyote kwa mwanao kwa kushiriki katika utafiti huu. Hata hivyo, ikiwa mwanao atapata matatizo yoyote ya kihisia na kisaikolojia, basi mtafiti atamuelekeza kwa mshauri wa kisaikolojia kwa usaidizi ufaao.

Mawasiliano

Kwa maswali yoyote kuhusu utafiti huu, tafadhali wasiliana na:

Mtafiti mkuu: Linet Achieng Obiero, Simu: 0722 685 493, Barua pepe:

linetobiero@students.uonbi.ac.ke

au

Msimamizi wa kwanza: Dkt. Lucy Kivuti-Bitok, Simu: 0724 205 419, Barua pepe:

kivutibitok@uonbi.ac.ke

au

Msimamizi wa pili: Dkt. Mary Kamau, Simu: 0727 736 810, Barua pepe:

kwanjira@uonbi.ac.ke

au

Katibu, Kamati ya maadili na utafiti ya KNH na UoN, Simu: 020-2726300, Barua

pepe: uonknh_erc@uonbi.ac.ke, Sanduku la posta 19676 – 00202 Nairobi

Tamko la Mshiriki

Nimefahamishwa kikamilifu kuhusu aina ya utafiti, najuama nufaa, nakuelewa kwamba hakuna hatarizi na zohusika. Kwa hivyo natoakibalicha mwanangu kushiriki katika utafiti huu.

Sahihiyamshiriki Tarehe

Tamkolea Mtafiti

Nimeeleza kikamilifu taarifa zote muhimu kuhusu utafiti huu kwamhoji wawa utafiti.

Sahihiyamtafiti Tarehe

Appendix 3: Adolescent's Assent Document

Project Title: Psychosocial experiences of transition from paediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital

Investigator: Linet Achieng Obiero

I am undertaking a research study about the psychosocial experiences of adolescents receiving oncology care at Kenyatta National Hospital as they transition from paediatric to adult wards.

Permission has been granted to undertake this study by the Kenyatta National Hospital-University of Nairobi Ethics and Research Committee (KNH-UoN ERC Protocol No. _____)

This research study is a way to learn more about the level of preparedness as well as social, emotional and mental experiences of young people on cancer treatment during transition from paediatric to adult wards at KNH. At least 60 adolescents (both male and female) will be participating in this research study with you.

If you decide that you want to be part of this study, you will be asked to respond to a series of questions contained in a questionnaire regarding your mental, emotional and social experiences of transition of care from paediatric to adult wards.

There are some things about this study you should know. These are:

- Your participation is on a voluntary basis
- Your name or any other personal detail will not appear anywhere in this study
- All the information you will provide will be treated with utmost confidentiality
- The information you will provide will be used for purposes of the research study only
- In case you experience any mental or emotional discomfort for taking part in this study, you will be accorded support in form of counselling by a counselor.
- There will be no direct benefit in form of monetary rewards or otherwise for taking part in this study. However, the information that you will provide will be useful in informing development of appropriate models that will help young

people undergoing cancer treatment have a much easier and effective transition of care from paediatric to adult wards at KNH.

When we are finished with this study we will write a report about what was learned. This report will not include your name or that you were in the study.

You do not have to be in this study if you do not want to be. If you decide to stop after we begin, that's okay too. Your parents know about the study too.

If you decide you want to be in this study, please sign your name.

I, _____, want to be in this research study.

Signature/Thumb stamp Date

Appendix 4: Fomu ya Makubaliano kwa Mshiriki Aliye Chini ya Miaka 18

Kichwa cha utafiti: Uzoefu wa kisaikolojia wa mabadiliko kutoka wodi za watoto hadi za watu wazima za vijana wanaopata huduma ya saratani katika Hospitali ya Kitaifa ya Kenyatta

Mtafiti mkuu: Linet Achieng Obiero

Ninafanya utafiti kuhusu uzoefu wa kisaikolojia wa mabadiliko kutoka kwa wodi za watoto hadi za watu wazima za vijana wanaopata huduma ya saratani katika Hospitali ya Kitaifa ya Kenyatta.

Ruhusa imetolewa kufanya utafiti huu na Kamati ya Maadili na Utafiti ya Hospitali ya Kitaifa ya Kenyatta na Chuo Kikuu cha Nairobi (KNH-UoN ERC Nambari yaItifaki. _____)

Utafiti huu ni kwa ajili ya kupata maarifa kuhusu uzoefu wa kisaikolojia na kijamii wa mabadiliko kutoka kwa wodi za watoto kwenda kwa wodi za watu wazima za vijana wanaopata huduma ya saratani katika Hospitali ya Kitaifa ya Kenyatta. Takribani vijana sitini(60) (wa kiume na wa kike) watashiriki katika utafiti huu pamoja nawe.

Ikiwa utakubali kushiriki katika utafiti huu, mtafiti atakuomba kutoa majibu yako kwa msururu wa maswali yaliyoko kwenye dodoso la utafiti huu yanayoangazia maswala ya kisaikolojia, hisia na mahusiano uliopitia wakati wa kuhamia wodi ya watu wazima kutoka kwa wodi ya watoto ndani ya matibabu yako.

Kuna mambo kadhaa unayohitaji kujua kuhusu utafiti huu. Mambo haya ni:

- Kushiriki kwako ni kwa hiari (kwa kupenda kwako bila kusurutishwa)
- Jina lako au kitu kingine chochote ambacho kinaweza kukutambulisha hakitaonekana popote katika utafiti
- Taarifa zote utakazotoa zitashughulikiwa na kuchakatwa kwa usiri mkubwa
- Taarifa zote utakazotoa hapa zitatumika tu kwa madhumuni ya utafiti huu.
- Ikiwa utajihisi vibaya au upate matatizo yoyote ya kifikira kwa ajili ya kushiriki katika utafiti huu, basi utapewa msaada kwa namna ya ushauri nasaha na mshauri.

- Hakutakuwa na faida ya malipo ya kifedha au mengineo juu ya kushiriki katika utafiti huu. Walakini, maelezo ambayo utatoa yatakuwa ya umuhimu mkubwa katika kufahamisha maendeleo ya miundo muhimu ya kuboresha uzoefu wakisaikolojia baina ya vijana wanaopata huduma ya saratani katika hospitali ya kitaifa ya Kenyatta.

Tukimaliza na utafiti huu, tutaandika ripoti kuhusu yale tuliyosoma. Ripoti hii haitakuwa na jina lako au haitasema kuwa ulishiriki katika utafiti huu.

Iwapo utahisi/utataka kusitisha kushiriki kwako katika utafiti huu, una haki ya kufanya hivyo wakati wowote, na ni sawa tu. Wazazi wako wamefahamishwa kuhusu utafiti huu pia.

Ukiamua ungependa kuwa katika utafiti huu, tafadhali saini jina lako.

Mimi, _____, nataka kushiriki katika utafiti huu.

Sahihi/Muhuri wa kidole gumba Tarehe

Appendix 5: Questionnaire

Study title: Psychosocial experiences of transition from paediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital

Code

Date

Section A: Demographic information

1. What is your gender? Male () Female ()

2. What is your age (in completed years)?

3. What is your education level?

Primary education () Secondary education ()

College education ()

4. Kind of cancer being treated:

5. Period/duration over which you have been on cancer treatment?

Section B: Preparedness level for transition from paediatric to adult wards

6. Were you adequately informed or counseled of your impending care transition from paediatric to adult wards?

Yes () No ()

7. Were the reasons for the care transition from paediatric to adult wards clearly explained to you by the medical team?

Yes () No ()

8. How would you rate your level of engagement/involvement by the healthcare team in care transition decisions from paediatric to adult wards?

Highly unsatisfactory () Unsatisfactory () Average ()

Satisfactory () Highly satisfactory ()

9. Would you say that the transition from paediatric to adult care settings was patient-tailored (that is, conscious of your needs and concerns)?

Yes () No ()

If no, why?

.....
.....
.....

10. In your view, was your level of preparedness for transition from paediatric to adult wards adequate or satisfactory?

Yes () No ()

Kindly elaborate your answer

.....
.....
.....

Section C: Psychological experiences of transition from paediatric to adult wards

11. How would you rate your psychological experiences in relation to your care transition from paediatric to adult wards?

Positive () Negative ()

Kindly explain your response

.....
.....
.....

12. Indicate whether you experienced the following psychological related experiences following your transition from paediatric to adult wards?

| Forms of psychological experiences | Yes | No |
|--|------------|-----------|
| feeling mentally depressed | | |
| feelings of mental exhaustion/fatigue | | |
| feelings of persistent sadness | | |
| feeling anxious and overly worried | | |
| feeling helpless | | |
| feelings of low self-worth | | |
| loss of self-confidence | | |
| losing interest in activities earlier enjoyed | | |
| loss of appetite or disturbed feeding patterns | | |
| not being able to sleep well | | |
| poor concentration | | |
| feelings of self-blame for being a burden to your family | | |

Section D: Emotional experiences of transition from paediatric to adult wards

13. Indicate whether you experienced the following emotional experiences following your transition from paediatric to adult wards?

a) Sadness Yes () No ()

If yes, why did you feel so?

.....
.....

b) Emotional pain Yes () No ()

If yes, why did you feel so?

.....
.....

c) Anger Yes () No ()

If yes, why did you feel so?

.....
.....

d) Fear Yes () No ()

If yes, why did you feel so?

.....
.....

e) Shock/surprised Yes () No ()

If yes, why did you feel so?

.....
.....

Section E: Social experiences of transition from paediatric to adult wards

14. Indicate whether you experienced the following social experiences following your transition from paediatric to adult wards?

a) Social isolation Yes () No ()

If yes, why did you feel so?

.....
.....

b) Stigma Yes () No ()

If yes, why did you feel so?

.....
.....

c) Self-pity Yes () No ()

If yes, why did you feel so?

.....
.....

d) Loneliness Yes () No ()

If yes, why did you feel so?

.....
.....

e) Lack of or inadequate social support Yes () No
()

If yes, why did you feel so?

.....
.....

End

Thank you

Appendix 6: Focus Group Discussion Guide

Study title: Psychosocial experiences of transition from paediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital

Code

Date

1. How would you describe your preparedness for care transition from paediatric to adult wards?

.....
.....
.....

2. Expound on areas of preparedness for transition from paediatric to adult wards that should be improved?

[Probe for aspects such as: whether they were adequately notified in time of the impending transition to adult wards from paediatric wards, whether they were counseled about the care transition, whether they were involved in the care transition decisions among others]

.....
.....
.....

3. How would you describe your mental experiences of transition from paediatric to adult wards? (Kindly elaborate)

[Probe for aspects such as: depression, anxiety, helplessness, low self-esteem, guilt among others]

.....
.....
.....

4. How would you describe your emotional experiences of transition from paediatric to adult wards? (Kindly elaborate)

[Probe for aspects such as: sadness, emotional pain, anger, fear among others]

.....
.....
.....

5. How would you describe your social experiences of transition from paediatric to adult wards? (Kindly elaborate)

[Probe for aspects such as: social isolation, stigma, self-pity, loneliness, lack of social support among others]

.....
.....
.....

End

Thank you

Appendix 7: Letter to KNH-UoN Ethics and Research Committee

Linnet Achieng Obiero,
Reg. No.: H56/34048/2020,
Department of Nursing Sciences,
Faculty of Health Sciences,
University of Nairobi.

The Secretary,
KNH/UoN - Ethics and Research Committee,
P.O. Box 20723-00202,
Nairobi.

Dear Sir/Madam,

RE: Approval To Conduct A Research Study

My name is Linet Achieng Obiero a student at the University of Nairobi's Department of Nursing Sciences undertaking a Master's of Science Degree in Oncology Nursing. I am hereby requesting for your approval to carry out a research study entitled "psychosocial experiences of transition from pediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital", as a requirement in partial fulfillment for the award of the said degree.

Thank you in advance.

Yours faithfully,

Linnet Achieng Obiero

Appendix8: Letter to the Head of Department - Oncology Unit of KNH

Linet Achieng Obiero,
Reg. No.: H56/34048/2020,
Department of Nursing Sciences,
Faculty of Health Sciences,
University of Nairobi.

The Head of Department,
Oncology Unit - KNH,
Nairobi.

Dear Sir/Madam,

RE: Authority to Carry Out a Research Study at KNH Oncology Unit

My name is Linet Achieng Obiero a student at the University of Nairobi's Department of Nursing Sciences undertaking a Master of Science Degree in Oncology Nursing. I am undertaking a research study entitled "psychosocial experiences of transition from paediatric to adult wards of adolescents receiving oncology care at Kenyatta National Hospital", as a requirement in partial fulfillment for the award of the said degree.

I am therefore hereby requesting for your authorization to conduct data collection among adolescents on oncology care in the hospital.

Yours faithfully,

Linet Achieng Obiero

Appendix 9: Work Plan

| Activity | 2022 | | | | | | | |
|---|------|-----|-----|-----|-----|-----|-----|-----|
| | Apr | May | Jun | Jul | Aug | Sep | Oct | Nov |
| Development of the concept | | | | | | | | |
| Proposal writing and presentation | | | | | | | | |
| Submitting the proposal to ERC | | | | | | | | |
| Pretesting the study tool | | | | | | | | |
| Collecting the study data | | | | | | | | |
| Data analysis, report writing and corrections | | | | | | | | |
| Defense of the project | | | | | | | | |

Appendix 10: Study Budget

| Component | Description | Item | Quantity | Unit Cost (Ksh) | Total (Ksh) |
|--------------------------------|------------------------------|--------------------------------|----------|-----------------|----------------|
| Literature Review | Literature search | Airtime | 6 Months | 1,000/Month | 6,000 |
| | | Internet | 6 Months | 2,000/Month | 12,000 |
| | Stationery | Laptop | 1 | 50,000 | 50,000 |
| | | Flash disc | 1 | 2,000 | 2,000 |
| | | Pens, Pencils, Eraser, Folders | 10 | @ 100 | 1,000 |
| Principal investigator's costs | | Transport allowance | 20 days | @ 500 | 10,000 |
| | | Lunch allowance | 20 days | @ 500 | 10,000 |
| Proposal | Related costs | Plain paper | 2 reams | @650 | 1,300 |
| | | Printing | 1 Draft | @750 | 750 |
| | | Photocopying | 2 Drafts | @250 | 500 |
| | | Binding | 3 Drafts | @100 | 300 |
| Approval | KNH Data ERC | | 1 | @500 | 500 |
| | | | 1 | @ 2,000 | 2,000 |
| Research Phase | Pretesting of questionnaire | Printing | 10 | @ 50 | 500 |
| | Consent Form and FGD guide | Printing, photocopy | 60 | @20 | 1,200 |
| | Data collection | Research Assistants | 2 | @ 5,000 | 10,000 |
| | Data Processing and analysis | Statistician | 1 | @ 40,000 | 40,000 |
| Report Phase | Final Report | Printing | 1 copy | @ 1,000 | 1,000 |
| | | Photocopying | 4 copies | @ 500 | 2,000 |
| | | Binding | 5 copies | @ 100 | 500 |
| Publishing | | | | | 30,000 |
| Sub Total | | | | | 181,550 |
| Contingencies | 10% of sub-totals | | | | 18,155 |

| | |
|--------------------|----------------|
| Grand Total | 199,705 |
|--------------------|----------------|

Appendix 11: Similarity Index Report

Psychosocial Experiences Of Transition From Paediatric To Adult Wards Of Adolescents Receiving Oncology Care At Kenyatta National Hospital

ORIGINALITY REPORT

13%

SIMILARITY INDEX

10%

INTERNET SOURCES

8%

PUBLICATIONS

1%

STUDENT PAPERS

PRIMARY SOURCES

1

erepository.uonbi.ac.ke

Internet Source

3%

2

touro scholar.touro.edu

Internet Source

1%

3

"Health Care Transition", Springer Science and Business Media LLC, 2018

Publication

1%

4

cdr.lib.unc.edu

Internet Source

1%

5

"Transition from Pediatric to Adult Healthcare Services for Adolescents and Young Adults with Long-term Conditions", Springer Science and Business Media LLC, 2020

Publication

1%

6

www.researchgate.net

Internet Source

<1%

7

effectivehealthcare.ahrq.gov

Internet Source

<1%

| | | |
|-----------------|--|------|
| 8 | Ali Judd, Mary-Ann Davies. "Adolescent transition among young people with perinatal HIV in high-income and low-income settings", <i>Current Opinion in HIV and AIDS</i> , 2018 | <1 % |
| Publication | | |
| 9 | su-plus.strathmore.edu | <1 % |
| Internet Source | | |
| 10 | Didem YÜKSEL YILMAZ, Figen YARDIMCI, Firdevs ERDEMİR, Rana KARABUDAK. "Defining the Experiences of Adolescent Patients with Multiple Sclerosis in Transition from Pediatric Care to Adult Care", <i>Multiple Sclerosis and Related Disorders</i> , 2022 | <1 % |
| Publication | | |
| 11 | Samantha Calabrese, Sonia Lee, Michelle A. Mollica, Lori Wiener, Susan Mendley, Lynn Adams, Dara Blachman-Demner. "Navigating Pediatric to Adult Healthcare Transition: A National Institutes of Health Workshop", <i>The Journal of Pediatrics</i> , 2022 | <1 % |
| Publication | | |
| 12 | ugspace.ug.edu.gh | <1 % |
| Internet Source | | |
| 13 | canadianoncologynursingjournal.com | <1 % |
| Internet Source | | |
| 14 | ir.jkuat.ac.ke | <1 % |
| Internet Source | | |