THE CHANGING LANDSCAPE IN FUNDING OF HIV/AIDS PROGRAM; PERSPECTIVES AND EXPERIENCES OF CAREGIVERS OF PEDIATRIC PATIENTS AT KISII REFERRAL AND TEACHING HOSPITAL

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THIS DISSERTATION IS SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE DEGREE OF MASTER OF SCIENCE IN PEDIATRIC NURSING SPECIALITY, DEPARTMENT OF NURSING SCIENCES, UNIVERSITY OF NAIROBI

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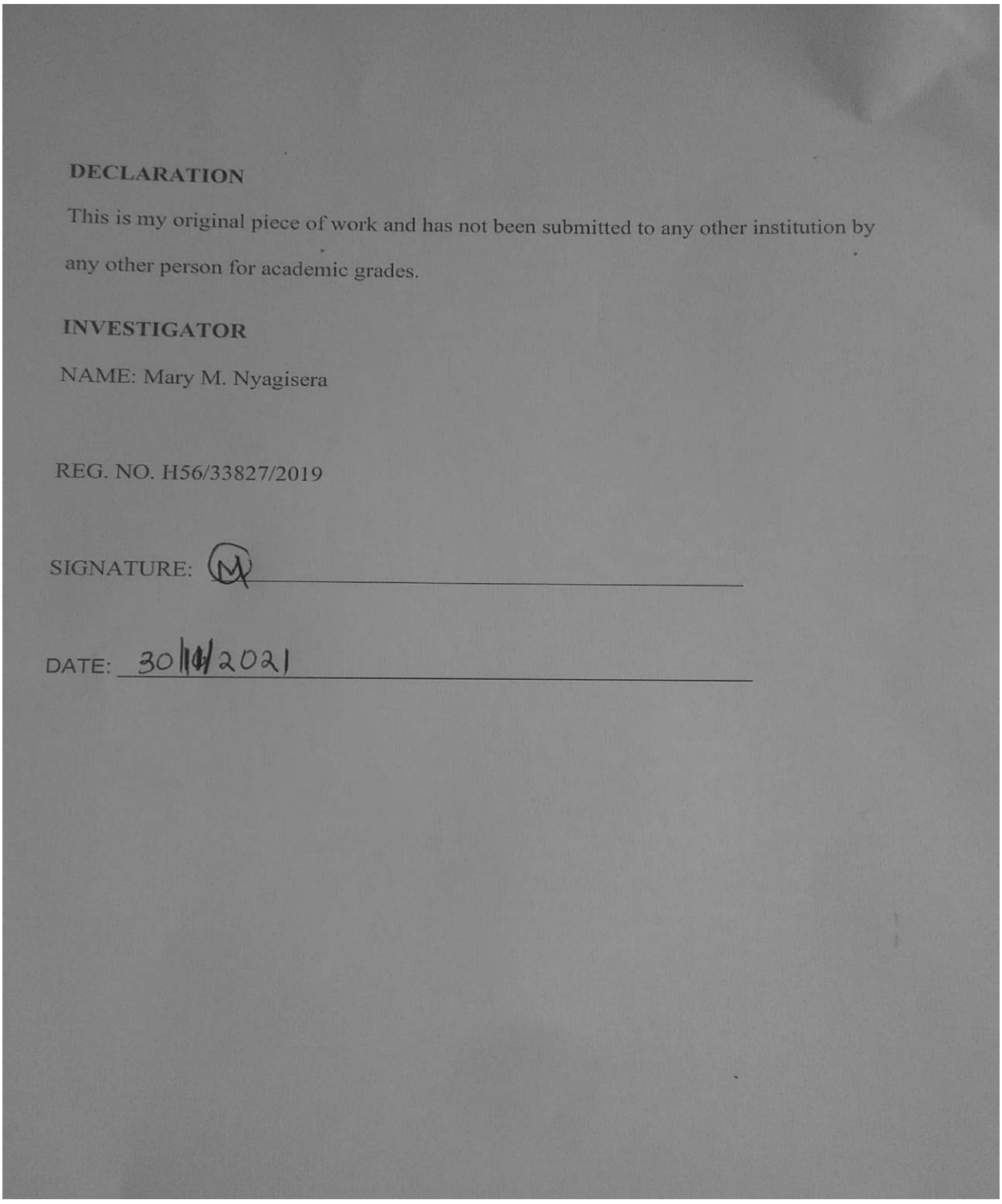
DECLARATION



DECLARATION

This is my original piece of work and has not been submitted to any other institution by any other person for academic grades.

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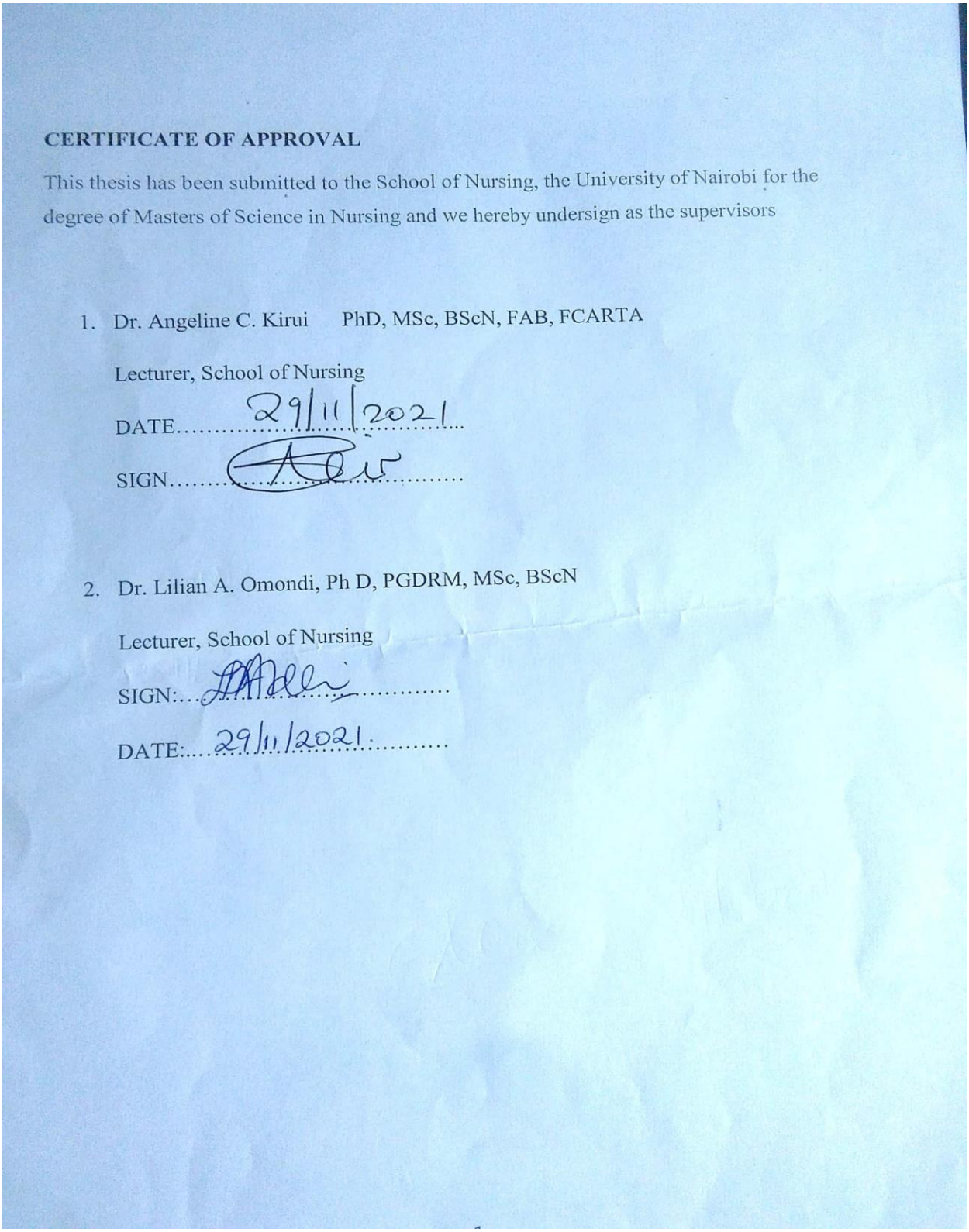

CERTIFICATE OF APPROVAL

This thesis has been submitted to the School of Nursing, the University of Nairobi for the degree of Masters of Science in Nursing and we hereby undersign as the supervisors

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DEDICATION

I dedicate this dissertation first to my God, Jehovah, and Ebenezer for his providence to mother and friend Margaret Kemuma my siblings, friends, and colleagues for the support, they gave me throughout the process.

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I am humbled to take this opportunity to express my gratitude to all those who made this study dissertation a success. My heartfelt appreciation to my supervisors, Dr. Angeline Kirui and Dr. Lilian Omondi for their undeniable encouragement, moral support, and thorough monitoring of my research work. Indeed, it was fruitful.

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OPERATIONAL DEFINITION

Caregivers of Pediatric Patients - Any person taking care of a pediatric patient or client/one responsible for pediatric patients or clients' social, psychological, physical, and mental aspects

Pediatric patients-Children who are HIV positive on care

Perspectives - A point of view or a specific attitude concerning something.

Experiences - Meaning and impressions or realities of events as lived.

Vertical Transmission - This is HIV transmission between the mother and the child/fetus either before or after birth.

LIST OF ABBREVIATIONS AND SYMBOL

AIDS- acquired immunodeficiency syndrome

ART - Antiretroviral Therapy

ARV-Antiretrovirals

CLWH - Caregivers of Children Living with HIV

CSOs - Civil society organizations (CSOs

HIV - Human Immunodeficiency Virus

LIC-Low-Income Countries

LMICs - Low and Middle-Income Countries (LMICs

NACC - National Aids Control Council

NGOs – Non-Governmental Organizations

ODA-Official Development Assistance

PEPFAR - US President's Emergency Plan for AIDS Relief

UNAIDS - United Nations Program on HIV and AIDS

UNICEF - United Nations International Children's Emergency Fund.

WHO-World Health Organization.

$ - United States Dollar symbol

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ABSTRACT

Background: Acquired immunodeficiency syndrome (AIDS) secondary to Human immunodeficiency virus (HIV) infection remains one of the most serious public health challenges as it is associated with high rates of mortality and morbidity. The cost of care is enormous and most treatment services have been offered successfully through donor funding. However, a reduction in funding opportunities has been reported and this may affect the quality of caring for children living with HIV/AIDS.
Objective: This study describes the experiences and perspectives of caregivers of pediatric patients with HIV/AIDS at Kisii Teaching and Referral Hospital (KTRH).
Methodology: A cross-sectional descriptive design with a phenomenological approach was used to conduct a study at Kisii Teaching and Referral Hospital, whereby data was collected to saturation levels using an in-depth interview on consenting participants. Purposive sampling technique was used to select potential participants from in-patient and Comprehensive care centers and an in-depth interview (IDIs) was conducted on those who met the inclusion criteria. The audio files for the IDIs were transcribed into a Microsoft text document then transferred into an R version 4.0.2 type of software by the researcher and thematic review was done. The field notes and interview transcripts were read and re-read for an understanding of the general impression of emerging themes, whereby a qualitative data analyst was engaged for assistance in the analysis, and findings were presented narratively.
Findings: All the respondents asserted in one form or the other that the transition from a robust donor funding of HIV/AIDS regime to a reduced one had significant challenges. The reduction of funds had reduced the frequency of drugs disbursement from 6 months to just two weeks supply and nutritional supplement programs being terminated. Some caregivers had tried to cope by farming, table banking, and casual laboring.
Conclusion: The study showed that a significant transition challenge occasioned by reduced donor funding of HIV/AIDs programs led to compromised care of children living with HIV and increased caregivers' expenditure exacerbating the negative experiences that caregivers have with children post-funding. However, it is a reality to them and as a result some have resorted alternatives for survival though with straining.

Recommendations: A multi-sectoral collaboration of local facilities, non-governmental organizations, and the county health facilities to come up with policies for resource mobilizations to aid in funding the HIV Programs. The government through its non-governmental agency to emphasizes empowerment programs that would help caregivers of children with HIV/AIDS to learn to be independent.

CHAPTER ONE: INTRODUCTION

1.1 Background Information

Human Immunodeficiency Virus (HIV) remains one of the most serious public health problems and has affected many lives and households including children across the world. It has taken a toll in low- and middle-income countries (LMICs), with the existing beneficial interventions like Prevention of Mother to Child Transmission (PMTCT), empirical pediatric care, and Antiretroviral Therapy (ART) lessening new infections while improving the general health of children living with HIV (CLWH)(Skeen et al., 2017). Throughout the world, it is estimated that 2.8 million children are infected with HIV, 90% of children are from Sub-Saharan Africa and those who have been left without parents because of the effects of AIDS are about 13.4 million (Short & Goldberg, 2015); (UNICEF, 2015).

The treatment of HIV requires long-term plans in terms of therapy costs since it is a chronic condition that requires clinical consideration for the entire life of a patient. Furthermore, as a chronic condition, it requires a well-supported system for it to be managed effectively.

Human Immunodeficiency Virus' burden has an impact on society as well as health care service delivery as described in the literature; consequently, it has led to the recognition of urgent prevention and control measures. To implement this, many countries have started putting their patients on ART; thereby they not only need human but financial resources as well. The result of human and financial resource deficit threatens and undermines the scaling up of treatment. Amid these concerns, there are still Sub-Saharan African countries (nations with high prevalence and burden of HIV/AIDS) that have not outlined a comprehensive human resource strategy; thus, the

increased ART provision scalability lacks the personnel to do the job and give services to the patients(Short & Goldberg, 2015); (UNICEF, 2015).

The primary caregiver of HIV-infected children are too often weary and lack enough resources to carry their obligations(Kidman & Heymann, 2016). The social, economic, and psychological strain of providing the needed care and support for HIV-infected children as well as the negative impact these factors have on child outcomes can be attested from the growing pile of literature. Therefore, child wellness can be improved if we only take the obligation to support their caregivers as well as giving support to family surroundings or the environment where these children reside (Richter, 2010). Globally, communities have taken steps in addressing the HIV-affected children and family needs over the past decade, although there has been financial aid through well-constructed and targeted programs, they have not been able to fully address these needs. However, individual countries have made policies and protections as an alternative way of reaching these children and families (Richter, 2010).

There has been adequate documentation on the perspectives and experiences of the caregivers of patients under the African context (informal care of the sick), and this is essential for people living with chronic diseases. The caregivers of children living with HIV have an important role in a potent therapy force that leads to recovery and for the achievement of psychological, spiritual, and social needs as much as death is inevitable as in HIV(E. Asuquo et al., 2017).The experiences and perspectives of caregivers of people living with HIV (PLWH) are that they receive confrontation on grounds of religion, cultural and social issues that are associated with giving care; self-isolation; stigma; lack of enough knowledge on HIV; together with frustrations, fear, and anxiety(Lundberg et al., 2016)**.**The study will explore the perspectives and experiences

of caregivers of pediatric patients to help meet their needs and improve the management of children infected with HIV.

1.2 Problem Statement

Despite expanding services in medical care bringing about extension and some improvement in essential medical services, the HIV/AIDS service delivery Program has not reached a level that can be considered "as near to Universal Access as possible". There should be increased interest in HIV/AIDS programs by all countries(Yu et al., 2008). Since 2018, there has been a decrease in HIV financing to LMIC countries even though there is a 25% addition in the population of individuals living with HIV; further investigation showed that the future support for HIV from donors is questionable today than in recent times related to competing monetary interests (Banigbe et al., 2019a) (Joint United Nations Programme on HIV/AIDS (UNAIDS, 2017)).The external funding cutbacks to Sub-Saharan Africa are slowly being implemented and this is associated with compromised quality of care, staff shortages, and reliance on fee-based care for historically free services; a phenomenon that calls for urgent sustainable HIV services funding models (Banigbe et al., 2019b). Funding of HIV programs is reported to have reduced from7% from 2017 to US$ 18.6 billion which is a 30% short of the US$ 26.2 billion supposedly to respond to HIV in 2020 (UNAIDS, 2020). The already strained and weak health systems in Sub-Saharan Africa are bound to get worse with reduced external funding, and families of HIV-infected children endure the most reduced access to subsidized HIV care services. They may need to dig deeper into their pockets to finance the health needs and support for children living with the disease. Due to this observation, the researcher seeks to assess the caregivers of pediatric patients' experiences and perspectives on HIV/AIDS care and service delivery following a reduction in external funding to HIV/AIDS programs.

The affordability of the necessary medical care is a significant determining factor to the access to HIV care service(Asfaw & Braun, 2005); (Awiti, 2014)hence, with reduced funding, many people may be forced to visit alternative health care facilities that may not offer the best quality of care. Lack of access to the health care facilities which could be attributed to geographical and financial barriers, scarcity of resources, and shortage of drugs, equipment, and human capital limits health care services in many countries in terms of coverage, range, and impact in Africa(Gillam, 2008).In this manner, essential health care, which was the driving force built upon the Alma-Ata declaration, is hardly achieved.

Financial resource deficiency coupled with the non-existence of essential data has led to a surge of HIV infection, non-execution of prevention programs to the expected scale in the Sub-Saharan region(Joint United Nations Programme on HIV/AIDS (UNAIDS, 2017). Caregivers of Pediatric patients could encounter challenges while giving care to the children living with HIV due to declining financial resources and this includes caregivers' lack of information, their own physical needs, lack of sleep, and mental problems(Pallangyo & Mayers, 2009)**.**

1.3 Research Questions

1. What are the perspectives and experiences of caregivers of pediatric patients on reduced funding for HIV/AIDS programs at KTRH?

2. What are the coping strategies of caregivers of pediatric patients of HIV/AIDS at KRTH towards reduced funding?

1.4 Research Objectives

1.3.1 Broad Objective

To describe the perspectives and experiences of caregivers of pediatric patients on funding reduction of HIV/AIDS programs at Kisii Referral and Teaching Hospital.

1.3.2 Specific Objectives

1. To establish perspectives of caregivers of pediatric patients on reduced funding for HIV/AIDS programs at KTRH.

2. To determine the experiences of caregivers of pediatric patients on reduced funding for HIV/AIDS programs at KTRH.

3. To establish coping strategies of caregivers of pediatric patients of HIV/AIDS at KTRH towards reduced funding.

1.5 Justification of the Study

Perspectives and experiences of caregivers of pediatrics patients on reduced HIV-funding programs have not been well documented. This information is critical in the provision of

effective pediatrics treatment care and decision-making both at the national and facility levels. There is a gap in identifying suitable interventions to mitigate the effects of reduced funding. Caregivers of patients have an integral role when it comes to chronic conditions as their contributions at a greater extent lead to the wellbeing of patients costing them health-wise and financially (Davidson et al., 2018) (Law et al., 2021).The caregivers of children with chronic conditions have limited time for themselves and long term jobs as they spend most of the time in informal care and so supportive initiatives are suggested which can include legislation of the caregivers' perspectives and experiences (Kelly & Hewson, 2000; Moreira et al., 2017)

1.6 Significance of the study

Over years, there has been a dependency of developing nations on external funding of HIV programs. However, there have been competing global needs like the COVID-19 pandemic and non-communicable conditions which have led to the shifting of funds to other programs. This calls for the creation of awareness and understanding of caregivers of pediatric HIV patients' perspectives and experiences for continuity of care and proper interventions. The study findings will enable healthcare providers to develop and adopt a framework that is patient-centered, effective, and efficient for the care of children with HIV/AIDS. Moreover, the study will provide new knowledge that will be useful for the formulation of policies, decision making, health care sector regulation, strategic planning concerning the management of pediatric patients

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

This chapter focused on previous literature related to the study based on the study objectives. The chapter began with the progression of HIV in children, the scope of funded HIV/AIDS care services for children, and then did a review of past studies relating to effects of the reduction in funding of HIV/AIDS treatment programs, then lastly the conceptual framework. The data was searched in Google Scholar and Research Gate.

2.2 Progression of HIV in children

As per the World Health Organization, Division of HIV and AIDS, an approximated 3.4 million children are living with HIV around the world, out of which 90% live in Sub-Saharan Africa. Many children's lives are endangered due to continuous exposure to HIV due to the global prevalence of HIV disease among women of reproductive age. In sub-Saharan Africa, 58 % of individuals living with HIV are women of reproductive age(Kharsany & Karim, 2016). Children can contract HIV during pregnancy, birth, and postnatally through breastfeeding; these transmissions are preventable when laid down procedures are adhered to like early diagnosis and treatment in pregnant women. Regardless of the way that antiretroviral treatment (ART) can significantly cut down the number of vertical HIV transmissions, breastfeeding remains an exceptionally high-hazard technique and a study has revealed that there is an overall risk of Mother-Child Transmission by 14% and 29% in established maternal HIV infection and in acute maternal infection respectively (Hampanda, 2012); (UNAIDS, 2020)

During the first periods of life, the immune system of an infant is immature hence not as effective as that of an adult although innate immunity plays a role in neonatal defenses(Slyker et

al., 2012).The previous studies have shown that immune cells are compromised during HIV infection and so the increased morbidity and mortality in children(Sandberg et al., 2002);(Unutmaz, 2003). As the disease progresses from an acute to chronic disease, it impacts the neuro-cognitive and psychosocial development of children worsening the general health of the child(Brown et al., 2000).

Literature has proven that HIV-positive children are affected mentally, developmentally, psychosocially and educationally. Although treatments are increasing the lifespan, the effects of the virus are long-term and so demand special care (Wachsler-Felder & Golden, 2002)These children may continue to be adversely impacted by factors such as poverty, inadequate medical services, and a lack of social support (Brown et al., 2000).

2.2.1 Nutrition and developmental milestones

Nutritional status affects growth and development in children as revealed by studies because factors affecting one, also tend to affect the other(Jimoh et al., 2018)The effects of nutrition in HIV-exposed children begins in utero, particularly towards the end of pregnancy and with increasing severity of maternal illness. Low birth weight is a common problem and after delivery, HIV infection results to early and progressive decrements in the rate of linear growth, which may be diagnosed as early as 3 months of age. The child becomes stunted, underweight and wasted and can continue throughout childhood, unless adequate care in terms of nutrition and ART is given(Hendricks et al., 2007).A study done in Nairobi showed that 28.6 per cent of children with HIV and AIDS were underweight compared with an average of 20 per cent for the general population, and 39.1 per cent were stunted compared with 30 per cent among the general population. (United Nations Children's Fund Eastern and Southern Africa Regional Office, 2008).

A similar study in Malawi and South Africa revealed that 58.8% of children were stunted compared to 27.4% in the uninfected population, and 18.7% to 7.1% underweight in the HIV-infected and in the uninfected population respectively(Sherr et al., 2018).

There is a risk of developmental and behavioral challenges although environment can play a role. There is rapid growth and development during infancy whereby several milestones related to motor, cognitive and behavior occur. This phase is very sensitive and with HIV disease process it causes a disruption in both motor and cognitive development resulting to problems in cognitive development, stagnation of growth ,neurological abnormality ,learning difficulties, speech and language problems.(Ngoma MS, 2015) .A study on developmental challenges, showed that 81% had some form of cognitive delay for HIV positive children compared to controls. (s Sherr et al., 2014)Majority of these HIV affected children have unrecognized neuro-developmental disabilities which need substantial interventions and support to survive and develop(Knox et al., 2018).

2.3. HIV/AIDS Program Funding

Sub-Saharan Africa is the most affected by the HIV/AIDS pandemic; in 2019, 38 million people were approximated to be living with HIV among which 1.8 million were children. The epidemic has claimed over 32 million lives as a result of AIDS-related infections globally and over 75 million living with HIV(UNAIDS, 2015);(Joint United Nations Programme on HIV/AIDS (UNAIDS, 2017). HIV has continued to be the fifth global cause of morbidity and mortality and is now the second in sub-Saharan Africa (Murray et al., 2017a).In the 1980s and early 1990s the world's response to HIV/AIDS was hopeless and the condition was a death sentence. During this

period, the world expense was less than $300 million annually on AIDS-related programs in developing countries. In 1996, antiretroviral therapy drugs (ARVs) were discovered but the cost was high (approximately $16,000 a year) and so treatment remained inaccessible for the majority of the world's HIV population especially in the developing countries till World Health launched a program to improve HIV/AIDS programs in Africa and encourage recipient governments to focus attention on designing and implementing a national response to the pandemic (Schneider & Garrett, 2009)Some factors have been attributed to the high prevalence of HIV infection and include; historical, political, economic, and cultural factors. These factors have led to coping strategies like encouraging behavior modifications through education, voluntary counseling and testing, community involvement, ensuring antiretroviral availability, collaboration with the non-governmental organizations in prevention, treatment, care, and support of those who have been infected(Lau & Muula, 2004).To deal with these factors, Sub-Saharan Africa needs external support as it cannot generate sufficient resources for efficiency and improvement of government revenues(Remme et al., 2016).

The President's Emergency Plan for AIDS Relief (PEPFAR), was established in 2003 by the US government to address the global HIV pandemic (June 28 & 2021, 2021). However, since 2010, PEPFAR financing between 2010 and 2017 increased by 27% followed by a decline of 15% by 2019. As per UNAIDS (2017), putting HIV/AIDS to an end relies to a great extent upon the financing level and capacity of every nation to give HIV treatment to all who need it(Joint United Nations Program on HIV/AIDS(Joint United Nations Programme on HIV/AIDS (UNAIDS, 2017). Undermining the HIV/AIDS program may be calamitous(Samji et al., 2013); extreme poverty and underdevelopment among others worsen the HIV plague(Joint United

Nations Programme on HIV/AIDS (UNAIDS, 2017). Many countries have grown economically in the past 10 years and so have invested in health care. Notwithstanding, the current budget on domestic health in lower-income countries (LICs) and lower-middle-income countries (LMICs) to improve and maintain progress to an acceptable level of Universal Health Care is deficient. These countries need to be supported to transit gradually from donor financing(K. McDade et al., 2021).

2.3.1 Reduced HIV/AIDS program Funding

Financing from PEPFAR in Ethiopia for HIV/AIDS program is seriously declining and is prone to negatively influence the accessibility of HIV drugs and other related support. Right now, on account of this spending cut, numerous HIV prevention, and care programs are being eliminated. Notwithstanding, deficiency in terms of resources is yet an issue influencing improvements in HIV/AIDS programs like the community-based programs on prevention measures, the planning and purchasing of ART for the infected individuals, support for HIV test labs, support for orphans and vulnerable children (OVC and training for behavioral changes among others(Kates et al., 2016).

The elimination of HIV programs is a result of the decline in worldwide donor support. This has been contributed by an increasing and competing financial need to support non-communicable diseases like cancers and diabetes and international refugee emergencies coupled with progressive financial strains in several countries**.** For example, between 2014 and 2015, a 13% HIV financing level decreased internationally(Joint United Nations Programme on HIV/AIDS (UNAIDS, 2017).A recent study showed that a 6-month interruption of supply of antiretroviral therapy (ART) drugs on HIV infected population who are on treatment would be expected to lead to a 1·63 times increase in HIV-related deaths over a 1-year period compared with no

disruption. The Covid-19 pandemic is one of the disruptors which is thought to paralyze HIV services and increase a risk of number of new HIV infections in Sub-Saharan Africa(Jewell et al., 2020).

Kenya's health system has a concentrated donor landscape, with four donors funding nearly 90% of all external aid (the United States, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the United Kingdom, and Gavi, the Vaccine Alliance (K. McDade et al., 2021).

The recent study findings revealed that the US President's Emergency Plan for AIDS Relief (PEPFAR) is the primary funder of HIV response. It is reported to have contributed more than half of total funds and over 80% of funding from donors since 2012. In 2017, the US made up 29% of all ODA, 62% of all health Official Development Assistance (ODA), and 84% of health ODA focused on the control of sexually transmitted diseases (STDs), inclusive of HIV/AIDS (Joint United Nations Programme on HIV/AIDS (UNAIDS, 2017).

Notwithstanding, this primary funder has significantly cut the disbursement to Kenya by almost three-quarters in the past four years, from Sh17.3 billion in 2016 to Sh4.9 billion in 2019. Previous analyses conducted by the Center for Global Development (CGD) found that Kenya potentially faces a reduction of 44% in actual disbursed funds from PEPFAR from 2017 to 2020. As reported by one of the clients regarding the fund cuts, in 2020, they were hit with a shortage of cotrimoxazole. This has brought anxiety among clients who have lost their incomes as well and depend on well-wishers for food donations. The ARVs are now issued monthly compared to previous years where clients could get medications that could last for three months. The cost of ARV drugs is estimated to be about Sh7,000and Sh19,000 for first line for an adult and second line respectively, and Sh16,000 for a child(Osweta, 2021).

2.4 Burden of caregivers

Those who take care of the HIV-positive children have been seriously affected by the scourge both mentally and financially. The human immunodeficiency virus has had the highest mortality rates among populations where it is endemic like in Sub Saharan Africa(Alebel et al., 2021).There is a burden borne in caregivers, particularly the elderly, who must care for both children who have had such an altered immune system by HIV and the orphaned grandchildren. They are affected in terms of household economics, health, physical and psychological well-being, and can lead to short-term weight loss, physical pain, and depression (Osafo et al., 2017). The understanding of what the epidemic means and how it affects the caregivers in poorly-resource settings is critical now that family-centered approaches to HIV/AIDS are being energized. This has placed an enormous care giving burden on the extended family (Njororai & Njororai, 2013).

Caregivers' mental health is key in a child's psychological, mental, and physical wellbeing. Children of caregivers with depression are at a high risk of stunted growth and malnutrition although no study has been done to show how poor child growth and health may influence the caregiver' mental health(Murray et al., 2017a): studies have been done on the mental health of caregivers who are critically ill but are limited to English-speaking high-resource country populations. The studies revealed that the family had overlooked stressors and needs and so should be noted by the health providers and ensure they rest, acquire nutrition and hydration, and include them in the care of the sick child (Shudy et al., 2006a).

A study in Nigeria, West Africa, investigated the encounters of informal caring of PLWHIV by women and findings revealed that care giving strains especially in women are brought about by joblessness, poverty, singlehood coupled with heading roles as well as being breadwinners of

those families. Moreover, the report showed that not only do they experience physical stress and mental problems but they also run a high risk of being infected with HIV. The investigation was dominated by a high prevalence of women and the near absence of men was attributed to inflexible traditional gendered divisions of labor (E. Asuquo et al., 2017).In another study done to explore the experiences of caregivers of families of persons with serious mental health problems**,** Stigma, financial needs among others were revealed to affect the caregivers' experiences and so policies need to include mental health care of caregivers through primary health-care services to improve the care giving burden and quality of life of family caregivers(Jack-Ide et al., 2013).

Among the over 1.4million people living with HIV in Kenya, nearly 5.6% are children. Health Policy Plus, an organization that advances health policy priorities, reveals that generally, health expenses have increased over time though not enough to compensate for reduced donor support. Kenya Population-based HIV Impact Assessment (KENPHIA) data reveals a need for children living with HIV to be educated on their status, access treatment, and as well be retained in this program of HIV management(Green et al., 2020a)

The funding cuts resulted in an inability to retain programs that significantly increased the initiation of treatment of children with HIV from 43% to 93%. This has led to a surge in the number of new infections among children because pediatric patient caregivers across the country need support for adherence in treatment as well as reduce the number of transmissions(Green et al., 2020a)((UNAIDS-KENYA, 2018). No literature or study has been done to explore the

perspectives and experiences regarding the financial cuts on HIV programs and how it has affected the care of children living with HIV.

2.5. Theoretical Framework

Health Belief Model is a mental model that endeavors to clarify and anticipate wellbeing practices. It originates from a behavior change framework that is used globally. This model is the basis interventions to gain knowledge of health hazards, enhance perceptions of personal risk, encourage actions to decrease or eliminate the risk, and building a sense of self-efficacy to undertake the needed changes(Green et al., 2020a).This is the same as the six main constructs: perceived severity, perceived susceptibility, perceived benefits, perceived barriers, cues to action and self-efficacy(Chin & Mansori, 2019a).

Perceived susceptibility and perceived benefit can be critical toward preventative behaviors; health beliefs and self-efficacy have a positive impact towards preventative measures(Huang et al., 2020). In this study, the perceived susceptibility and perceived severity which pose as threats to perception refer to the experiences regarding the reduction in HIV/AIDS programs. Perceived benefits refer to the coping strategies towards the effects of the reduction in HIV/AIDS.

Cue to Action involves the external events that trigger actions and help in the decision-making process in accepting health guidelines. HBM suggests that patients are more likely to adhere to health guidelines when sensitized through trusted media, public announcements and press meetings. Self-efficacy is a belief that the recommended health guidelines are realistic. Through an interview ,the service care provider can identify and address challenges, and empower clients to follow health guidelines**(**(Evans, 2008)**;**(Kim & Kim, 2020). The strength of HBM is that it helps identify areas in which discussion and teaching are needed to change patient

behavior(Evans, 2008)**.** Cues to action in this study refers to the government policies in place regarding changes in the management of HIV/AIDS as well as hospital policies. Caregivers who believe that they can still partner with Kenyan Government to maintain CLHIV are more likely to cope positively with the funding reduction.

2.5. Conceptual framework

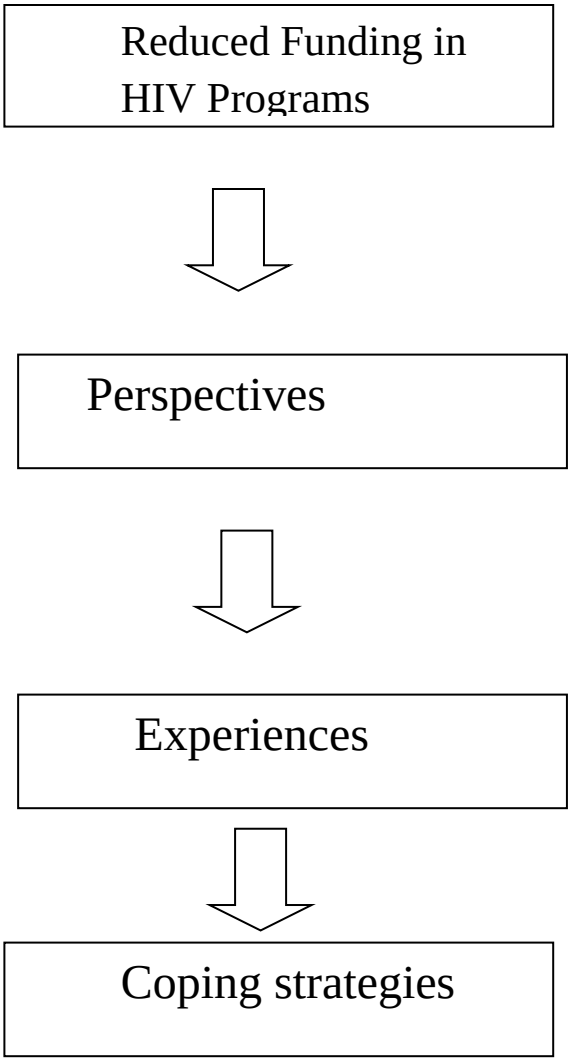

FIGURE .1

Source: Author

CHAPTER THREE: METHODOLOGY

3.1 Study Design

This was a cross-sectional descriptive qualitative study done to describe the perspectives and experiences of caregivers of pediatric patients on funding reduction of HIV/AIDS programs at Kisii Referral and Teaching Hospital.

3.1.1Methodological Approach

A descriptive phenomenological approach was used that aims to gain an understanding of people's situation at their conscious states and describe emotions, thoughts, and actions with no explanation; supposition is not necessary (Umanailo, 2019). The approach supports inquiry and is powerful, suitable for exploring problematic challenges as it sets a base for a better understanding of the nature of a phenomenon (Neubauer et al., 2019). An in-depth interview was used to gain varied information and the researcher explored in detail the perspectives and experiences of pediatric patient caregivers on reduced funding**.**

3.2 Study area and Site Description

The study site was Kisii Teaching and Referral Hospital (KTRH) pediatric wards and Comprehensive Care Centre, level 6,the main teaching and referral hospital in Kisii County. Currently, the Hospital has a 700bed capacity and is located in Kisii County. The hospital has both outpatient and inpatient services and the catchment area is South Nyanza and Western Kenya Counties. The Hospital has 24 medical specialists in various fields; gynecologists,

orthopedic, internal medicine, pediatrics, and ophthalmologists. The Hospital has a pediatric ward with a bed capacity of 100 and 60 cots; and the ward has a daily average occupancy of 300. children. On staffing, the pediatric ward has one pediatric consultant,6 nurses, and 2 clinical interns; The comprehensive center has 3 clinicians,3 nurses,2 data officer,3 adherence officers,8 peer navigators and 4 mentor mothers who are managing a total of 4673 active clients of which,311 are clients below 19 years

3.3 Study Population

The target population was the caregivers of pediatric patients on treatment for HIV infection in pediatric wards and at the Comprehensive Care Centre in (KTRH), who met the eligibility criteria.

3.3.1 Inclusion Criteria

i. All caregivers of pediatric patients with HIV/AIDS who consented to participate.

ii. Caregivers who had been taking care of the patient for more than six months continuously.

iii. Caregivers who had been identified as the next of kin in the patient's file for the patient and has been taking care of the patient continuously

3.3.2 Exclusion Criteria

i. Caregivers with mental disorders and not oriented to time, place, and person.

ii. Caregivers who had symptoms of Covid 19.

iii. Caregivers who could not understand or express themselves in either Swahili and English languages

vi. Care-givers who were less than 18 years

3.5 Sample Size Determination

The sample size was determined based on the principle of data saturation. This concept was borrowed from grounded theory and is meant to determine whether the sample size is appropriate through an ongoing analysis. Adequate sample size determines the quality of research but there is no exact size of a proper sample. The sample is proper if it is sufficiently satisfying the researcher's curiosity and so to achieve the aim of the study The data was collected through an in-depth interview to saturation until no new information was acquired(Dunarea de Jos University of Galati, Romania & Rusu Mocănașu, 2020);(Malterud et al., 2016).Determining the saturation number depends on the following factors; the quality of data, the scope of the study, the nature of the topic, the amount of useful data obtained from each participant, the number of interviews per participant, the use of shadowed data, and the qualitative method and study design used. Phenomenological approach has a large amount of data for each participant and so few participants (perhaps 6 to 10)(Morse, 2000).

3.6 Sampling Technique

In strict adherence to the Kenyatta National Hospital-University of Nairobi Ethics Research Committee, Covid-19 guidelines (appendix 4), a non-probability purposive sampling method was

used to select the study participants from inpatient and comprehensive care centers in (KTRH). This enabled the researcher to preselect the study subjects relevant to this study. The caregivers of pediatric patients who met the inclusion criteria and consented for the study were sampled for interview.

3.7 Screening, recruiting, enrolment and consenting procedure

The potential participants who met the criteria were provided with information by the researcher about the study using the participant information and consent form (see appendix 1), and addressed concerns that arose. The researcher clarified to the potential participants the; background of the study, the purpose of the study, objectives, nature of the study, benefits and potential risks, harms and discomfort of participating in the study. The researcher allowed the potential participants to ask questions that pertained the study to clarify concerns. Those that were willing to be participants taken through the declaration consent form (appendix 2), after an expression of an understanding of all information about the study and terms of participating, informed consent was obtained and a consent form signed by participant.

3.8 Data collection procedures

The researcher organized prior with the ward/department in charge for a private quite room to minimize interruptions and for proper quality of the audio-tape. Then a face-to-face interview was conducted using an in-depth interview guide (see appendix 3) on the consented adult caregivers of pediatric patients. The demographics of age, sex and relationship of the participant to the pediatric patient, occupation and level of education was taken and written down on the coded participant notes before turning on the audio-tape. The researcher short and precise to

minimize bias and ensure quality data, probing questions were used to explore all information pertaining objectives of the study. The audio of the interview was recorded using Maxell UR 90 Minute Blank Audio Cassette Tape by the researcher who took notes as well.

3.8.1 Pretesting of data collection tool

The interview guide tool was critiqued by my supervisors to ensure that it was fit to gather data to answer study questions. The tool was then pretested at Moi Teaching and Referral Hospital at the comprehensive care center among four caregivers of pediatric patients of HIV/AIDS. The tool was adjusted as per the results of pretest and experts' inputs.

3.10 Materials

Audiotape recorder

Unstructured in-depth interview guide-An interview with no specific set of predetermined questions that lasted 45 minutes.

3.11 Quality Assurance

Ethical approval was obtained before conducting the study. This study stuck to the set protocols, followed ethical considerations and used Lincoln and Guba (1985) criteria of credibility, transferability, dependability, and confirmability as follows:

A pretested in-depth interview guide was used for participants who met the criteria and minimal or no interruptions was ensured during the interview session. Purposive sampling using inclusion and exclusion criteria ensured that the participants had the characteristics required according to the study objectives. This helps to enhance the trustworthiness.

Coding of data and analysis was done by different persons i.e., the researchers, qualitative data analysts with the assistance of R- computer software for qualitative data analysis. The purpose was to compare the codes and categories of which new codes were included while some were merged or unmerged (Nowell et al., 2017). The analysis process generated six themes (see page 27 and 28).

3.12 Ethical Considerations

The approval to conduct research was obtained from the Kenyatta National Hospital – University of Nairobi and and Kisii Teaching and Referral Hospital Ethics Review Committees. Permission to access the study population was obtained through a formal letter to the in-charges of the Comprehensive Care Center and pediatric ward. The adult caregivers of pediatric patients who consented to the study were interviewed after the purpose of the study was explained fully according to the ethics committees' guidelines on good conduct of human research (appendix 1). To maintain confidentiality, personal identifiers for the participants were concealed and participants were given reference numbers. Likewise, the transcripts from each participant were also numbered accordingly. The audio recordings and transcripts were kept under lock and key and information in soft copy stored in passworded folders in the computer. The interview was conducted in counseling rooms at inpatient and Comprehensive care centers and participation was voluntary. The participants did not receive money or any form of benefits to give information.

3.13 Data Management

The participants who met the criteria were interviewed using an in-depth interview guide in a quiet counseling room and obtained data were compared and categorized as themes**.** The

audiotapes were stored safely and were only accessible to authorized study personnel then translated and transcribed into a Microsoft text document (transcript verbatims) by the researcher. The complete transcription was read by the researcher while listening to the recording and corrected appropriately to tarry with the audiotape. The researcher engaged peer researchers in listening to the audiotape and going through the transcripts to ensure what was transcribed were the perspectives and experiences of caregivers of pediatric patients as described. It was then transferred into an R version 4.0.2 software by the researcher for coding and thematic review. The field notes and interview transcripts were read and re-read for an understanding of the general impression of emerging themes. The themes and subthemes with common views were derived from coding. A qualitative data analyst was engaged to assist and the findings were presented narratively. The entire analysis process was led by Colaizzi 1798 steps of phenomenological data analysis (Praveena & Sasikumar, 2021).

3.14 Dissemination of Results

A report of the study findings will be submitted to the (KTRH) comprehensive care center and the pediatric ward, for health professionals in the respective units to be appraised. The researcher will present the findings in the scientific conferences, avail copies to the UON digital repository as well as publish in a reputable journal for dissemination

CHAPTER FOUR-FINDINGS

4.1 Introduction

This section presents data analysis findings which were obtained through R-software based on the study's broad objective which was to: describe experiences and perspectives of caregivers of pediatric patients with HIV/AIDS at Kisii Referral and Teaching Hospital. Coding was done to generate the themes and sub-themes that emerged from the study using the R software version 4.0.2. There were 6 themes and 3 sub-themes identified. The study presents the demographic data followed by the perspectives of caregivers on reduced funding for HIV/AIDS programs; experiences of caregivers on reduced funding for HIV/AIDS programs, and finally, the coping strategies used by caregivers.

4.2 Socio-Demographic characteristics

The study collected data from 8 caregivers who had varied genders, ages and occupation. Table 1 below shows the results of the demographic data.

Table 1: Demographic Information of participants

Categories	Frequency (n)	Percentage (%)
Gender		
Male	2	25
Female	6	75
Age		
30-35 years	4	50
36-40 years	0	0
41-45 years	3	37.5
46-50 years	1	12.5
Level of education		
High school certificate	3	37.5
College Education	5	62.5
Occupation		
Farmer	4	50
Teacher	3	37.5
Community health worker	1	12.5
Family role		
Mother	6	75
Father	2	25

Code-Book

Objectives	Theme	Sub-theme	Descriptions
Perspectives of pediatric patient caregivers after reduction in funding.	1.Transition Problems	1.Lack of preparedness	Respondents described the challenges they perceived in regard to reduction in funding compared the care before and after.
		2.Frequency of drugs disbursement and elimination of nutritional supplements	Respondents described how reduction has led to unavailability of drugs and the effects on nutrition to the children on care
Perspectives of pediatric patient caregivers after reduction in funding.	2.Solutions to the funding gap		The respondents described and explained what they wished was immediate response to deal with the funding gap.

Experiences of pediatric patient care givers after reduction in funding.	3. Job loss and street life 4. Child health care deterioration 5.Funding reduction effects on education	3.Experiences before and after the reduction of funding**.**	Respondents described how reduction in funding affected them economically and tried to compare before and after reduction. Respondents explained in detail how the reduction affected the care of children on care in terms of nutrition and hospital check-ups The respondents described how some children were affected academically due lack of funding in terms of fees which was provided before.
Coping strategies to the reduced funding	6.Adjustments to reduced funding		The respondents described and explained how they were trying to handle the reduction funding effects

3. Perspectives

To effectively access the theme that touched on perspectives of caregivers and reduced funding, certain specific codes were used. Some of the notable codes included ‘worries,’ ‘views,’ ‘concerns,’ ‘transition problems,’ and ‘opinions.’ From these codes, the following themes related to caregivers’ perspectives on reduced funding for HIV/AIDS programs were identified.

Theme 1- Transition Problems

The first theme that related to perspectives of caregivers was transition problems or issues that emanated from the reduced funding regime and the consequent taking over by the government agencies. All the respondents asserted in one form or the other that the transition from a robust donor funding of HIV/AIDS regime to a reduced one had significant challenges.

Sub-theme 1. Lack of preparedness

One of the respondents with a HIV/AIDs child who had previously benefited from donor funds for instance asserted that:

> *“I see there is still a challenge for the Kenyan government to oversee this project. I don't see it being as successful as when the donor agencies were in charge of the HIV/AIDS projects. If I compare the government only without any outside support, it's still a challenge” (Interview 002, 2021).*

The respondent is here comparing the donor funded regime against the present government control and sees a significant gap. Part of the reason for the gap is attributed to lack of preparedness by government agencies to deal with the issues that the HIV/AIDS program sought to address.

This is best elucidated by another respondent speaking on the transition problems noted that:

"*Most county governments are not prepared for the transitioning in case there's a changeover. This means that maybe we will be affected in such a way that we will not get all the services that we used to get when the donor funding was there" (Interview 007, 2021).*

The same respondent offers a succinct elaboration of the lack of preparedness when she observes that:

...like now they're now implementing "partners are changing hands." Yet, the new incoming partner has not stepped on the ground but the outgoing partner has already left. And the gap has been left there between offering the services like there's a continuation but some of the services are not being done" (Interview 007, 2021)

There seemed to be challenges in terms of check-up packages as asserted by a 49-year-old mother that:

"...another thing I had forgotten, there was this thing about the transition where you'd be issued with drugs. A child was supposed to have a blood test every six months but it's no longer available nowadays. Since the onset of the Covid-19 pandemic, they say that there'll be no more blood tests. Now it's almost one year. Viral load now shoots up too, because as they say, the machines are broken...those are the challenges I now have. And another thing you may come and find those things I have mentioned, drugs are lacking you're told that viral load is high. If the child's health has deteriorated, and you want them to do a check up to find out what's up; if they test let's say like the kidney, you'll be forced again to pay" (Interview 001, 2021).

On Comparing of before and after funding problems, some respondents asserted

There were also responses that clearly highlighted the perspectives of caregivers regarding reduced funding to HIV/AIDS programs. This was done in a more comparative manner with the respondents describing what used to happen before the reduction happened and what is happening after the funding reduction. A caregiver who doubles up as a mother to an infected child for instance observed in an elaborative manner that:

> *"In my view, I have two children who are on ARVs. Before when we'd be offered support by other NGOs, you'd be given drugs for two months then you come back and get a month supply but nowadays, according to this transition, drugs nowadays are issued that only lasts for two weeks supply and you are asked to come again. The problem is, if the child's school is far away, one has to come many times to the hospital to access the drugs" (Interview 002, 2021).*

Then she goes on to say that:

> *"Another thing, for instance with my firstborn, we'd be given food supplements to help add weight if you see the child has a deficiency, the child would be given and they'd take it. They'd eat, and those supplements would help increase their body build. ARV drugs need someone to take them on a full stomach. Nowadays those things are no longer available. Now they affect the child that when you give them drugs, they see them as something bitter. My last-born child is three but now those drugs, if you don't give them something sweet afterwards, they view taking them as a challenge" (Interview 002, 2021).*

Sub-Theme 2. Frequency of drugs disbursement and nutritional supplements

What is clear is that the reduction of funds has reduced the frequency of drugs disbursement from 6 months to just two weeks supply. However, the assertion that the frequency of drugs disbursement has been reduced from 6 months to just two weeks supply seems to disagree with assertions by a 49-year-old mother with a HIV/AIDS child who strongly expressed on drugs dispensing that:

> *"You're given drugs for up to six months! For one who is stable and runs a business a great distance away. It helps reduce the clinic visits. Especially for this Covid-19 period, we're so grateful. And another good thing is HIV and sexual reproductive health integration where everything is done in one place just like in a supermarket" (Interview 001, 2021).*

Nonetheless, more respondents appear to support the earlier assertion of two weeks drug issuance when the father who is also a peasant farmer observed that:

> *"Sometimes I go to the hospital to get the drugs. I find that I don't get a three months' supply of drugs as before.... I go and I'm issued a two weeks supply" (Interview 004, 2021).*

Others support a one-month issuance of drugs with a teacher and a mother of a HIV/AIDS child noting that:

> "*We used to be given three months' supply of drugs, but now we get only a month's supply. And for food, especially for children who are malnourished, they used to boost with food supplements, but now there are no supplies. Sometimes we sleep hungry at home. And about the food, we can't tell how the children are doing (Interview 008, 2021).*

The two weeks supply and in some cases a one-month supply as opposed to a six months' supply is problematic to caregivers especially because it increases the transportation costs needed to access those drugs, a caregiver who is also both a teacher and a mother observed that:

"It becomes a challenge to us, doctor, because we used to go to the health center to pick the drugs for three months' supply, it'd be long before we go back to pick more. In the process we'd have saved fare if we were coming from far. So, this one-month supply of drugs becomes a challenge because of the short interval and therefore we are unable to afford fare to travel to pick the drugs because they get used up fast" (Interview 008, 2021).

A respondent opined that:

> *"...now as we're speaking, we have a shortage of ARVs. When we ask, we're told it's KEMSA that hasn't been supplied with the drugs, sometimes it's said that the donor hasn't cleared the pending tax. It's a problem because in the past we didn't have such a challenge because the donors used to give us full support" (Interview 001, 2021)*

This means that reduced period within which drugs could be disbursed meant that more resources were being spent on transportation which made it unaffordable to most caregivers.

On the aspect of lack of nutritional supplements as a result of reduced funding, a respondent who is also a mother to a HIV/AIDS child noted that:

> *"These days we work so hard so as to get money for food. You see, with these drugs, if you take them and you don't have a proper meal, and your body doesn't have strength, you won't be healthy. We used to be given food and given drugs. But these*

days we're only given drugs. We don't even have fare to go to the clinic. Sometimes we miss going to the clinic but we still persevere, and strive and go to the clinic" (Interview 005, 2021).

What is clear is that nutritional supplements subsidy is gone as a result of reduced funding. Sub-theme 1increased costs charged on them. Basically, the costs are also high: a teacher strongly and emphatically asserted that:

"For children with HIV/AIDs, their tests are expensive. For instance, sometimes you're asked to do a blood test, a blood hemogram so that they tell the level of blood in the child's body. It's costly. You do a urine test too, you do for the liver - liver function test, these tests are expensive, and we can't manage them!" (Interview 005, 2021)

The keying in of the concern keywords also presented more concerns by the caregivers. One, a father engaged in peasant farming was more emotional based on what he noted:

"I have suffered. And I'm not alone! Those people that I'd come to the clinic with; have suffered because when we observe, we see that there's a possibility that one day we'll be told that there are no drugs. And there are other times I see, even as our children grow older, they'll come to say, "If that's the case, its better we die." (Interview 004, 2021)

A respondent buttresses the assertions made above when she notes that, based on the reduced funding;

"We'll have more viremic cases and then we will also have children who will not even be able to reach hospitals to access those drugs. And if they don't access those

drugs then we'll not have a healthy ratio. If you don't have a healthy child ratio then you don't have any nation" (Interview 007, 2021).

But then again, from the responses, it was clear that other organizations had come in to try and fill the funding gaps. Some caregivers were asked about their perspectives regarding the other organizations that have come in. One caregiver, a 32-year-old college educated teacher and mother to a HIV/AIDS infected child very directly asserted on the issue of the capacity of the other organizations to fill the funding gap, that:

"No, they don't have the capacity. The current organizations that took over from the former donor from 2008 to 2021 as we speak don't have that capacity to support children as much, because they too depend on CDC and AMREF and Global Fund. Because, back in the day, the donor would supply the supplement but now as we speak, the children have a challenge because there is no nutritional support at all" (Interview 001, 2021)

Theme 2. Solutions to the funding gap

Another theme that was identified was based on what the respondents wished was immediate response to deal with the funding gap. One of the teacher respondents offered a summarized version when she noted that what was needed was:

"An adequate drug supply stock, adequate nutritional support, and for the lab tests to be made available; let it not be that when someone's sent to the lab, they're told that a particular thing is unavailable. That's what I'll emphasize on" (Interview 001, 2021)

The respondent interviewed on her part spoke of the need to include HIV/AIDS patients in the Universal Health Coverage scheme. While another respondent who is also a mother spoke of

reinstating of food supplements, school fees payments and effective follow-up. She observed that:

> *"The government should reinstate the earlier program which would serve us food wise and also help us access school fees and few school items that used to be provided. When I also get some money, I could contribute to clearing school fees and in buying some food at home. But now that it's not provided, in my view, the government should come in and follow up on matters. They used to follow up on how we live and how we take our food, and our drugs when our food was exhausted, they'd give us more supplies. But these days they don't follow up. Let them change their mind and reinstate the earlier program and follow up on how we live "(Interview 007, 2021*).

Others spoke of efforts to address the stigma that accompanies the HIV/AIDS condition in Children. A mother acting as a caregiver of an infected child asserted that:

> *"...We need also to educate the closer relatives to understand that this condition is just a medical condition that can be managed at a certain point. And also, anybody can be in that condition. They should know that a child was born with it. A child may never have had sex or contaminated himself/herself. Maybe the problem may have largely happened at the point of delivery or when the mother was expecting" (Interview 003, 2021).*

Further, the mother adds as a means to offer practical solutions that:

> *"If the government could form a kitty, that is sustainable, if those NGOs could gang up and maybe send their monies into one pool, basically through the government; I*

think this thing will be sustainable and we'll be able to support our kids" (Interview 003, 2021).

4.4 Experiences of caregivers and reduced funding for HIV/AIDS programs

To effectively access the theme that touched on experiences of caregivers on reduced funding, certain specific codes were used. Some of the notable codes included 'experience,' 'happening,' 'what you do.'

Theme 3. Job loss and street life

The respondents responded on what the reduction of funds has meant for parents and the child alike. One of the respondents offered an elaborate response on this when she said:

"Yes, well, for example we had pediatric mothers who used to be attached to the clinic and they were being given a stipend every month. However, they were laid off because of the transitions, because of the reduction of funds. Now, they don't have another source of income. Before someone gets to build themselves up again and get to the place they were before becomes tough. Life becomes very difficult than bearable. In fact, some of them have gone to the streets. They're now street children; street parents (Interview 007, 2021).

The reduction of funds has according to the respondent created loss of jobs for caregivers but also taken them to street life as a result of that loss of a job. But also, the caregivers are experiencing tight budget concerns as is evidenced by one of the caregivers who observed that:

"To get here in Kisii to access drugs, I use Ksh 150; to and from I use Ksh. 300. Ksh 300 to and from, when you're with the child, you must use and additional Ksh 300. My income is low, so I see it's difficult to visit the clinic as required" (Interview 002, 2021).

Theme 4. Child health care deterioration

Other respondents spoke of what the reduction of funds has meant for child care. One of the caregivers who has had more than 5 years duration dealing with a child with HIV/AIDS notes that:

> *"Now you know, when a child fails to take his drugs properly his viral load doesn't decrease, you find he has a high viral load because he doesn't get drugs, sometimes he tells me, "No mama I'm not trekking. I'm not trekking, I want us to go by motorbike. And I don't even have that money to take a motorbike. See? So, then we trek. We walk in the sun; at 2pm it rains, a lot of mud going on. Plus, lack of food bothers us a lot" (Interview 005, 2021).*

Basically, the health of the child has deteriorated due to the reduced funding and has exacerbated the negative experiences that caregivers have with children post funding reduction.

Other respondents spoke about the experience they have with the type of food they take. The 35-year-old caregiver added:

"We used to be given plump nuts, weighed and height measured and if they got your child's weight was amiss from the graph they used at the clinic, they would inform you that you needed nutritional intervention. You'd be given plump nuts and flour. But these days all these are gone. We don't know how it happened. So, these days we fend for ourselves, we're only recommended what to get. The nutritionist gives us a list, only tells us to buy omena, buy that and that and they don't want to know if we reside in town or in the upcountry. It's difficult. It's true; they don't care if you have the money" (Interview 005, 2021)

Another respondent interviewed for instance observed emphatically the issue to do with lack of nutritional support and the experience of hunger that the victims faced. In this regard she noted that:

"Many deaths have resulted, especially among children, because they lack the support that they'd get from the donor, regarding drugs, nutrition and much more. And for these drugs, ARVs, you cannot take them on an empty stomach! These drugs need one to eat properly for them to work effectively. Taking these drugs on an empty stomach contributes to affected children dying. And now, many deaths have resulted but we are quick to attribute all deaths to Covid-19. But you may find that the child could have been infected with HIV but failed to get proper nutrition, and as soon as they took the drugs, the immunity got further compromised" (Interview 001, community health worker, 2021).

One of the caregivers speaking on reduced check-ups noted that:

> *"A lot of times we'd come to the hospital and we'd have checkups. Now we're affected. Every three months we'd have checkups. We gauge checkups. We see the weight; how the child is fairing, how the adults are faring on, so that you're advised and given guidance and counseling accordingly. But you see, if we raise money and send one of us, it means that those who will have remained behind will not have the checkups to know how we're fairing" (Interview 008, 2021).*

The reduction seemed to have elicited stigma as one of the caregivers put it succinctly:

> *"…You know, raising a child who has some medical conditions is very difficult. And again, you know, we live in the world of stigma. Kisii's stigma is still alive." (Interview 003, mother 2021)*

Summarily, the reduction of funds has created loss of jobs for caregivers but also taken them to the streets as a result of that loss of a job. But also, the caregivers are experiencing tight budget concerns. The health of the child has deteriorated due to the reduced funding and has exacerbated the negative experiences that caregivers have with children post funding reduction. Further, one other important issue that has correlated with the caregivers' experience was that aspect of stigma. Other significant experience by the caregivers touch on reduced check-ups and testing

Sub theme 3- Experiences before and after the reduction of funding.

One respondent speaks of refreshments and the 200kshs fair withdrawal and observes that:

> *"Like earlier on, we would have all the tests for free but now we pay for all the tests but in the past the donor would cover it" (Interview 001, 2021).*

Another of the respondents, a 49-year-old mother observes that:

> *"Back then and now there's a difference. If you observe the children; they have missed the benefits they'd get, like nutritional support. They miss good nutrition because they have no supplies. A child walks in here with a low immunity and they need food supplements to help boost immunity but now there are no supplies and that's why children now have high viral loads. The viral load test has not been done since the onset of Covid-19 pandemic. It's been two years since the blood tests. Basically, viral load tests are on hold and viral load is important because it helps manage the HIV patient." (Interview 001, 2021)*

The caregiver continues to assert that:

"In the past we'd do tests including kidney function to gauge if the drugs are causing the kidneys any harm. But since the transition, it has been now on the parents. And when they go to the lab and are asked to pay say Ksh 1000 for the tests, yet some even Ksh 200, they can't afford it. They used to be free of charge." (Interview 001, 2021).

Another responded said:

For instance, I have a child here with whom we have had lots of "missed appointments". Because sometimes it's time to pick drugs, and we don't have a fare to come to pick the drugs. Earlier on, Nuru ya Watoto, a funded program for children, would give us fare to the clinic. But now it's not available" (Interview 005, 2021).

Theme 5. Funding reduction effects on education

One of the fathers who responded to the interview was more concerned about school fees and how the transition has affected it, so he says:

"We have a problem because in the past we'd be supported even in paying school fees. However, since the changes occurred, I've never gotten that support in payment of school fees. I have two children whose school fees has not been paid so I'm affected" (Interview 005, father, 2021).

Clearly, the funding helped caregivers in some way offset the school fees burden, lack of which led to inaccessibility to educational opportunities by the children under HIV care.

Another important experience that is comparatively described is the training that existed before when funding was there and the lack thereof following reduction of funding. One caregiver, who has lived with AIDS for 22 years noted on this that:

> *"...I thank God because I have children. I have 1 out of 6 who is affected by HIV. For us we were able to get the teachings earlier on and know how to handle the children. Back then when the organizations were powerful. They'd even pay us a visit in the rural areas, in our homes and offer us advice. They'd visit my home and ask to know how I was fairing. They interviewed me and where I had a challenge, they'd support me. But now we don't have an organization that does that anymore. Now that there aren't enough funds, the government hasn't taken up that role. That's why I'm saying if the government would like to be of help, it should take up the responsibilities that were handled by the donors" (Interview 001, 2021).*

In fact, another caregiver reinforced the idea of training by saying:

> *"Like I described, we lack food, we miss going to the clinic, and another challenge we've experienced in taking care of children is this thing of "health education". You know in the past, we used to be grouped by OTZ according to the age of the child and then we're taught. Through education, the child knows the importance of taking his drugs, and what the drugs do to reduce the viral load. Nowadays we don't have health education; we don't have those programs where we'd meet up, now we are troubled. (Digresses) And now Viral load isn't even done. It should be done after six months. But now it's not done anymore" (Interview 005, 2021).*

4.5 Coping strategies used by caregivers

The following theme was noted;

Theme 6 -Adjustments to reduced funding.

Farming appears to be one of the most significant coping strategies used by caregivers to effectively deal with the pressures occasioned by reduced donor funding for HIV/AIDS programs. One caregiver simply said:

> *"I am just a subsistence farmer. I grow sweet potatoes and some maize for family use." (Interview 002, 2021)*

Another caregiver, in order to cope, chose to engage in switching of crops. He, speaking of this, said:

> *"I ensure I have switched crops from the farm. I buy them vegetables; I was told they should eat vegetables in plenty. I also buy oranges from the market when I go to sell other crops. I try! I am now trying" (Interview 004, 2021*)

Some use encouragement as one of them said that:

> *"Now, what we do these days to be able to give the child his drugs properly are through encouragement. When the child knows why he's on drugs, the child will push himself. Even when he doesn't have the appetite, he forces himself to eat and take the drugs because he now understands the importance of the drugs to his body "(Interview 002, 2021).*

> Facility staff and parents use their own money to try and offset the funding gap. However, it still does not fill that gap adequately. One of the respondents for instance asserted that:

"So, for facility staff, it gets to a point where they have to chip in from their pockets to support. When a child walks in who needs food supplements and nutritional support, it pushes them as a facility to try and support where they can. They give a little support and the parents do the remaining part. So now it's the support of both the facility and the parents. But it still doesn't meet the targets (Interview 001, 2021)

One respondent said:

"We do casual jobs and buy foods that we can afford, those that we can't we let alone. And we ask the nutritionist to list foods that are available here in our area." (Interview 005, 2021)

Some pull resources together as one of those who are in a group said:

"*We formed groups at the clinic for mothers who have little children. We agreed that there will be months where we will be picking drugs for one another. There are months that we're personally expected to go to the clinic for tests such as viral load when it's back or when a child has an opportunistic infection, you know the child himself will need to go the clinic for a serum* sample if his weight is not improved. But these groups that we have are called community-based groups. There's one called Fast Track* that do community dispensing of these drugs that help us to get the drugs for their dispensed for exactly a month and they're not even slightly extended!" (Interview 005, 2021)*

Among those who pooled resources, one made it clearer by asserting that:

"Where we live, you'll find there are neighbors and those we're acquainted with when we go for the drugs. So, we can raise money and send one person to pick drugs for the rest of us and deliver them to us including for our children. Because they go with

a card, if they read it and know them, they give them drugs for all of us instead of all of us going there and incurring a lot of costs in fare. Further, we raise the money and send one of us to go pick the drugs for the rest of us."

In an interesting twist, the introduction of new drug appears to be one of the ways specially to deal with motivation for drug intake among the children. One of the caregivers observed that:

"First, I want to thank the government so much for introducing a new type of drugs-dolutegravir-for the children. Children used to be given lopinavir* and ritonavir* pellets, which were bitter. But now that dolutegravir* has been introduced, I see now we'll have viral suppression in our children as it has flavor and it's not bitter in the mouth. A child will even remind you to give them the drugs. The second thing, I want to thank for optimization being done and dolutegravir* being given to children who are less than 20kg. I see that, that greatly helps" (Interview 005, 2021).*

Table banking or what is colloquially referred to as 'chama**,'** is also one of the coping mechanisms.

One respondent said that:

"I joined a chama or table banking, it can raise up to Ksh 20,000 at once. So, I got my turn and started a small business even though it's picking, I still get some profit. I then use it to feed my family including the child and also able to attain medical attention to my child who had been receiving some aid from the NGOs'' (Interview 003, 2021).

Some asked for assistance as some rationed food.

This is evidenced by the assertion of one of the caregivers that:

“So, when I can't afford fare... I get to ask for assistance so that I can afford fare to the clinic. Even just for fare to the clinic then I can trek back” (Interview 006, 2021).

On food rationing one the respondents said:

“*Since the changes, I am forced to go and work extra apart from the usual work which is farming and my small business. I must look for something else to do like casual jobs so that I earn some money to take care of these children. I'd do other side hustles like poultry farming but I was forced to reduce the number of chickens now that feeding them is hard....and another thing, I've found that life has begun hardening. I'm forced, if it's food to eat, I'd have to reduce their portions so that they don't eat like we used to back then. So, these changes in funding I see has put me in a position that isn't good” (Interview 006, 2021)*

CHAPTER FIVE-DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

The discussions are derived from the themes and sub-themes that emerged from the study; the perspectives and experiences of caregivers of pediatric patients at KTRH as described. The recommendations and conclusions were based on the study purpose and the study findings.

5.2 Socio-demographic data

Based on the demographic data it is clear that the study assessed perspectives and experiences from both genders, despite the female being the predominant gender. The perspectives and experiences were obtained from a cross-section of age groups and caregivers who at least had a KCSE or CPE certificate. Also, perspectives and experiences regarding the reduction of funding for HIV/AIDS programs were assessed from caregivers who form the most direct linkage to children with HIV/AIDS and thus understand more deeply how the reduction of funding affects them. The characteristics of gender, age, occupation, level of education, and family roles noted from the above result show that the study was able to access qualitative data from a cross-section of respondents. This helps to enhance the trustworthiness, dependability, and confirmability of the results**.**

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5.3 Experiences and Perspectives of pediatric caregivers

The burden created by the reduction of funds; burdens characterized by unavailability of drugs, removal of nutritional supplements and high associative costs creates stressful circumstances to caregivers. This agrees with literature that had argued that caregivers' mental health is key in a child's psychological, mental, and physical wellbeing(Murray et al., 2017b), and that of studies done on the mental health of caregivers who are critically ill but are limited to English-speaking

high-resource country populations. The studies revealed that the family had overlooked stressors and needs and so should be noted by the health providers and ensure they rest, acquire nutrition and hydration, and include them in the care of the sick child (Shudy et al., 2006b). Further, the findings agree with (E. F. Asuquo et al., 2017) who in a study in Nigeria investigated the encounters of informal caring of PLWHIV by women and findings revealed that care giving strains especially in women are brought about by joblessness, poverty, singlehood coupled with heading roles as well as being breadwinners of those families. Moreover, the report showed that not only do they experience physical stress and mental problems but they also run a high risk of being infected with HIV. The transition challenges identified by the caregivers agrees with literature that shows that Kenya's health system has a concentrated donor landscape, with four donors funding nearly 90% of all external aid (the United States, the Global Fund to Fight AIDS, Tuberculosis and Malaria, the United Kingdom, and Gavi, the Vaccine Alliance (K. K. McDade et al., 2021)

An examination of the perspectives and experiences of the caregivers shows that they have examined the severity, cues to action, the susceptibility and benefits that relate to their children's wellbeing following the reduction of donor funding. This implies that the findings are aligned to the Health Belief Model which is a model that endeavors to clarify and anticipate wellbeing practices; and which offers the basis of interventions to gain knowledge of health hazards, enhance perceptions of personal risk, encourage actions to decrease or eliminate the risk, and building a sense of self-efficacy to undertake the needed changes (Green et al., 2020b) (Chin & Mansori, 2019b)

5.4 Coping strategies

From the foregoing, farming, switching of crops, and encouragement are some of the predominant coping strategies used by caregivers to deal with the reduction of donor funding for HIV/AIDS programs. Another coping mechanism noted from the qualitative data is where facility staff and parents use their own money to try and offset the funding gap. Engaging in other casual jobs, formation of groups, pulling of resources also help the caregivers to cope with their situation. In an interesting twist, the introduction of a new drug appears to be a coping strategy specially to deal with motivation for drug intake among the children. Finally, table banking, asking for assistance, and rationing food are other coping strategies used.

5.3 Conclusions

The study showed that there was a significant transition challenge occasioned by reduced donor funding of HIV/AIDs programs that led to reduced frequency and amounts of drugs for their children, removal of nutritional supplements, and increased caregivers' expenditure. Moreover, it created lost opportunities for free check-ups and screening. The reduction of funds further has created joblessness, tight budget concerns, and child deterioration exacerbating the negative experiences that caregivers have with children post-funding reduction. This has led some to cope through farming, engaging in casual jobs, pulling of resources table banking, and to extreme cases some asking for assistance and rationing of food.

5.4 Recommendations

A multi-sectoral collaboration of local facilities, non-governmental organizations, and the county health facilities to come up with policies for resource mobilizations to aid in funding the HIV Programs. This will not only help to reduce and manage HIV/AIDS cases especially in children but will help the caregivers to effectively cope with the situation. The government

through its non-governmental agency to emphasize empowerment programs that would help caregivers of children with HIV/AIDS learn to be independent.

5.5 Suggestions for Further Research

From the foregoing, this study suggests that further studies be done to examine the perspectives and experiences of the donors themselves when dealing with pediatric care. Further, a significant gap in the present study is the lack of multiple data triangulation since the study depended solely on interviews as a means to collect qualitative data. It is suggested that to add on to the reliability and credibility of results, further study should include quantitative elements like questionnaires, observation schedules and document analysis to examine the same constructs as the present study.

5.5 Study Limitations

This is a qualitative study that recruited study participants from inpatient and outpatient clinics of KTRH, and so the study findings may not be representative of those that seek their services elsewhere hence not generalizable to all caregivers of pediatric patients with HIV in other areas. The result findings may change over time and so may not be dependable.

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APPENDICES

Appendix 1: Participation Consent Form

Dear participant'

I am Mary Mokeira Nyagisera a student from the University of Nairobi pursuing a master's degree in pediatrics Nursing.

Informed consent

The purpose of this consent form is to give you the information you will need to help you decide whether or not to be a participant in the study. You feel free to ask any questions about the purpose of the research, what happens if you participate in the study, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When I have answered all your questions to your satisfaction, you may decide to be in the study or not. This process is called 'informed consent. Once you understand and agree to be in the study, I will request you to sign your name on this form or thumbprint. We will give you a copy of this form for your records.

May I continue? YES / NO

This study has been approved by The Kenyatta National Hospital-University of Nairobi Ethics and Research Committee protocol No……

Note the following general principles which apply to all participants in medical research:

i. Your decision to participate is entirely voluntary

ii. You may withdraw from the study at any time without necessarily giving a reason for your withdrawal

iii. Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities.

About the study

I am carrying out a study on the Changing landscape in Funding of HIV/AIDS Program; Perspectives and Experiences of Caregivers of Pediatric Patients at Kisii Referral and Teaching Hospital. I will be interviewing caregivers of HIV pediatric patients at inpatient and Comprehensive Center who are willing to participate. The study is sensitive at the same time requiring honest answers, and so involves sensitive questions and conversations. The data obtained will be confidential and used mainly for knowledge on views of caregivers of HIV pediatric patients for effective management of pediatric patients.

I will record the interview after capturing your personal information; age, sex, relationship to the child and write some notes during the interview but your identifications will not appear anywhere on the notes.

May I continue? YES / NO

Study background: Human Immune Virus (HIV) and acquired immunodeficiency syndrome (AIDS) remains one of the most serious public health challenges as it is associated with high rates of mortality and morbidity. The perspective and experiences of caregivers under the informal caring of the children living with chronic diseases like HIV/AIDS are crucial.

The purpose of this study: To obtain data on Experiences and perspectives of caregivers of pediatric patients and coping strategies towards the funding cuts**.** This data is critical in the provision of effective pediatrics HIV treatment care and decision-making both at the national and facility levels.

Objective: To determine experiences and perspectives of caregivers of pediatric patients with HIV/AIDS at Kisii Referral and Teaching Hospital.

Benefits: In light of the caregivers of pediatric patient's perspectives and experiences on the changing landscape on funding of HIV/AIDS treatment programs, the researcher hopes that the findings of this study will inform policymakers and health providers in decision making and creation of awareness for the sustainability of HIV treatment and care in the pediatric population. There are no monetary or material benefits involved.

Potential Risks, harms, and discomfort: There are neither risks nor harm anticipated on the participants when having this interview as the study aims to use honest personal experiences and perspectives of the participants which will be self-reported in the anonymity of the actual information given to protect their right to anonymity in the study. The audiotapes will be stored safely and will only be accessible to authorized study personnel. However, answering questions in the interview may be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to stop the interview or ask any questions during the interview. It may be emotional, stressful, and embarrassing and you are free to withdraw from the study at any time without any fear of victimization.

Thank you for your time.

Fomu ya Idhini ya Kushiriki

Mpendwa mshiriki ’

Mimi ni **Mary Mokeira Nyagisera** mwanafunzi kutoka Chuo Kikuu cha Nairobi anayefuata shahada ya uzamili ya Uuguzi wa watoto.

Idhini iliyojulishwa

Madhumuni ya fomu hii ya idhini ni kukupa habari utakayohitaji kukusaidia kuamua ikiwa ni mshiriki wa utafiti huo au la. Unajisikia huru kuuliza maswali yoyote juu ya madhumuni ya utafiti, nini kinatokea ikiwa unashiriki katika utafiti, hatari na faida zinazowezekana, haki zako kama kujitolea, na chochote kingine juu ya utafiti au fomu hii ambayo haijulikani wazi. Wakati nimejibu maswali yako yote kwa kuridhika kwako, unaweza kuamua kuwa kwenye somo au la. Utaratibu huu unaitwa 'idhini ya habari. Mara tu utakapoelewa na kukubali kuwa kwenye utafiti, nitakuomba utie sahihi jina lako kwenye fomu hii au alama ya kidole gumba. Tutakupa nakala ya fomu hii kwa kumbukumbu zako.

Naweza kuendelea? NDIO/ LA

Utafiti huu umeidhinishwa na Hospitali ya Kitaifa ya Kenyatta-Chuo Kikuu cha Nairobi Maadili na Itifaki ya Kamati ya Utafiti No ……

Kumbuka kanuni zifuatazo zinazotumika kwa washiriki wote katika utafiti wa matibabu:

i) Uamuzi wako wa kushiriki ni wa hiari kabisa

ii) Unaweza kujiondoa kwenye utafiti wakati wowote bila kutoa sababu ya kujitoa kwako

iii) Kukataa kushiriki katika utafiti hakutaathiri huduma unazostahiki katika kituo hiki cha afya au vituo vingine. Kuhusu utafiti

Ninafanya utafiti juu ya Mazingira yanayobadilika katika Ufadhili wa Programu ya VVU / UKIMWI; Mitazamo na Uzoefu wa Walezi wa Wagonjwa wa Watoto katika Hospitali ya Rufaa

ya Kisii na Ualimu. Nitahojiana na walezi wa wagonjwa wa watoto wa VVU katika Kituo cha Wagonjwa wa Inpatient na kina ambao wako tayari kushiriki. Utafiti ni nyeti wakati huo huo unahitaji majibu ya kweli, na kwa hivyo unajumuisha maswali nyeti na mazungumzo. Takwimu zilizopatikana itakuwa za siri na zitatumiwa hasa kwa maarifa juu ya maoni ya walezi wa wagonjwa wa watoto wa VVU na watoa huduma za afya kwa usimamizi mzuri wa wagonjwa wa watoto.

Nitarekodi mahojiano hayo baada ya kunasa maelezo yako ya kibinafsi; umri, jinsia, uhusiano na mtoto na andika vidokezo wakati wa mahojiano lakini vitambulisho vyako havitaonekana popote kwenye noti.

Naweza kuendelea? NDIO /LA

Kusudi la utafiti huu: Kupata data juu ya Uzoefu na mitazamo ya walezi wa wagonjwa wa watoto na mikakati ya kukabiliana na kupunguzwa kwa ufadhili. Takwimu hizi ni muhimu katika utoaji wa matibabu bora ya matibabu ya watoto na kufanya maamuzi katika ngazi za kitaifa na kituo.

Lengo: Kuamua uzoefu na mitazamo ya walezi wa wagonjwa wa watoto wenye VVU / UKIMWI katika Hospitali ya Rufaa ya Kisii na Kufundisha

Faida: Kwa kuzingatia walezi wa mitazamo na uzoefu wa mgonjwa wa watoto juu ya mazingira yanayobadilika juu ya ufadhili wa mipango ya matibabu ya VVU / UKIMWI, mtafiti anatumai kuwa matokeo ya utafiti huu yatawajulisha watunga sera na watoa huduma ya afya katika kufanya maamuzi na kuunda mwamko kwa uendelevu wa matibabu na utunzaji wa VVU kwa idadi ya watoto. Hakuna faida za kifedha au nyenzo zinazohusika

Hatari zinazowezekana, madhara, na usumbufu:

Hakuna hatari wala madhara yanayotarajiwa kwa washiriki wakati wa kuwa na mahojiano haya kwani utafiti unakusudia kutumia uzoefu wa kibinafsi na mitazamo ya washiriki ambayo itajiripoti katika kutokujulikana kwa habari halisi iliyopewa kulinda haki yao ya kutokujulikana katika kusoma. Sauti zitahifadhiwa salama na zitaweza kupatikana tu kwa wafanyikazi walioidhinishwa wa utafiti. Walakini, kujibu maswali kwenye mahojiano inaweza kuwa mbaya kwako. Ikiwa kuna maswali ambayo hautaki kujibu, unaweza kuyaruka. Una haki ya kusimamisha mahojiano au kuuliza maswali yoyote wakati wa mahojiano. Inaweza kuwa ya kihemko, ya kufadhaisha, na ya aibu na uko huru kujiondoa kutoka kwa masomo wakati wowote bila hofu yoyote ya kudhulumiwa.

Asante kwa muda wako

Appendix 2: Consent Certificate

Respondent's consent

I hereby wish to declare that I have read and understood and also the investigator has explained to me about the study and that all my concerns have been addressed to my satisfaction. My signature is proof that I have voluntarily given an informed consent to participate in the study and that there will be recording of the conversation between me and the researcher.

Signature of Participant_____

Thumb print (if participant cannot read) _____

Date of signed consent_____

Contacts:

If you have any questions please do not hesitate to ask. Clarifications may be sought from the following:

Mary Mokeira (Principal investigator)

Cell phone no. 0725554235, or email: marryane4@gmail.com

Or Dr. Angeline C. Kirui (Lead supervisor)

Lecturer School of Nursing (University of Nairobi)

Cell phone 0720440665 or email: chepchirchir@uonbi.ac.ke

Or Kenyatta National Hospital and University of Nairobi Ethics Research Committee secretariat P.O. Box 20723-00202 Nairobi.Telephone:726300-9 Ext44102

Cheti cha Idhini

Idhini ya wahojiwa

Nataka kutangaza kuwa nimesoma na nimeelewa na pia mchunguzi amenielezea juu ya utafiti huo na kwamba wasiwasi wangu wote umeshughulikiwa kwa kuridhika kwangu. Saini yangu ni uthibitisho kwamba nimetoa idhini ya hiari kushiriki katika utafiti na kwamba kutakuwa na kumbukumbu ya mazungumzo kati yangu na reseacher ..

Saini ya Mshiriki_____

Kuchapisha gumba (ikiwa mshiriki hawezi kusoma)

Tarehe ya idhini iliyosainiwa _____

Mawasiliano:

Ikiwa una maswali yoyote tafadhali usisite kuuliza. Ufafanuzi unaweza kutafutwa kutoka kwa yafuatayo:

Mary Mokeira (Mchunguzi wa kanuni)

Simu ya mkononi no. 0725554235, au barua pepe: marryane4@gmail.com

Au Dk Angeline C. Kirui (Msimamizi Kiongozi)

Mhadhiri Shule ya Uuguzi (Chuo Kikuu cha Nairobi)

Simu ya rununu 0720440665 au barua pepe: chepchirchir@uonbi.ac.ke

Au Hospitali ya Kitaifa ya Kenyatta na sekretarieti ya Kamati ya Utafiti ya Maadili ya Chuo Kikuu cha Nairobi P.O. Sanduku 20723-00202 Nairobi. Simu: 726300-9 Ext44102

Appendix 3: In-depth interview guide for caregivers of pediatric patient caregivers

1. How can you describe what the changing landscape in the funding of HIV/AIDS means to you?
2. How has this change affected the care of children with HIV/AIDS?
3. Briefly describe your perspectives in care of the children with HIV/AIDS since the change was implemented
4. Briefly describe your perspectives in care of the children with HIV/AIDS since the change was implemented
5. What types of concerns do you have about the change?
6. How are you coping with the change?
7. Is there any other information about the change in HIV/AIDS program that you think would be useful for me to know?

Appendix 4: KNH-UoN ERC-guidelines on conduct of research during the covid-19 Pandemic.

Introduction

Given the highly infectious nature of SARS-Cov-2 and the rapidly changing circumstances around COVID-19 containment, mitigation, and management strategies in Kenya, the priority for all study activities should be to uphold public health obligations, and continue care of the research participants while guaranteeing the safety of the participants, the research team, and the general public. This is the obligation of the Principal Investigator (PI) to work together with the other members of the research team. The scenario calls for a need to revise standards related to research interactions with human research participants with a strong push towards interacting **remotely.**

General considerations

1. ***Adherence to COVID-19 related public health directives***: Researchers should remain aware of, and abide by all applicable COVID-19 related public health directives, policies, and recommendations as issued by the World Health Organization, Ministry of Health, or other Kenyan government agencies on what to do in case they encounter participants reporting **possible COVID-19 exposure or symptoms during a study visit** or those particularly vulnerable to COVID-19 disease.
2. ***Public Health and Clinical Activities***: Actions taken for public health or clinical purposes as part of the COVID-19 prevention, control, or management are not considered research procedures and therefore do not require KNH-UoN ERC approval before being implemented. For example, mandatory clinical screening procedures in health facilities as directed by the Ministry of Health or other designated public health authorities for

purposes of identifying, monitoring, assessing/investigating, or managing the COVID-19 outbreak, and sharing of such screening results with the participants and public health authorities do not require ERC approval.

3. ***Research changes made to mitigate the risk of COVID 19 disease transmission:*** - Researchers will need to implement changes to previously approved research to mitigate the risk of the COVID-19 disease pandemic.
4. Essential research visits or procedures: -

1. A study procedure or visit is deemed essential if it is required to ensure participants' health, safety, or wellbeing. Such procedures include administration of certain types of study interventions, safety evaluations, and management of serious adverse events or laboratory tests to monitor possible adverse effects of drugs.
2. The determination of what constitutes an essential study visit or procedure shall be made in line with the current public health guidance regarding the COVID-19 pandemic in Kenya.
3. Research visits should continue remotely as much as possible. In the absence of feasible remote options for essential visits or procedures, face-to-face interactions may continue **but investigators must** adhere to current public health guidelines to reduce COVID-19 exposure to research participants and staff.
4. The PI shall be responsible for providing this service in the safest way possible, based on good clinical practice and optimal social distancing. The following guidance should be considered:

1. Immediately before the face-to-face visit, the participants should be remotely screened for symptoms of respiratory illness and other key defining symptoms of COVID-19 disease such as fever, cough, and shortness of breath, or difficulty in breathing as well as possible recent exposure to individuals with COVID-19 disease. Participants with possible exposure or symptoms suggestive of respiratory disease should not be invited for face-to-face visits/procedures until COVID-19 has been ruled out. Such participants should be immediately referred to the Ministry of Health for further diagnostic procedures and possible isolation, as necessary.
2. All research staff who conduct face-to-face visits or procedures with participants should, on a daily basis, be screened for COVID-19 exposure and symptoms including daily temperature checks. Only staff who are symptom-free with no history of exposure to COVID-19 should take part in face-to-face interactions.
3. At the site of the face-to-face visits/procedures, appropriate infection prevention control measures should be ensured as follows:

1. Temperature checks for all participants and other individuals arriving at the research site using a non-contact thermometer should be taken.
2. A hand-washing station and hand sanitizers for all to use should be availed.
3. Avail 3-ply face masks for participants and research staff to use during the face-to-face interactions
4. The physical distancing of a minimum of 1.5 meters in the waiting room and procedure rooms should be maintained.

5. Staff should use appropriate personal protective equipment as recommended in the MOH infection prevention and control (IPC) guidelines when conducting close-contact or invasive procedures and handling bio-specimens.
6. Staff should be trained on appropriate cleaning and infection control procedures necessary to mitigate COVID-19 spread at the study site.

5. Contingency Planning:

1. Each research study team should have a contingency plan in place to continually assess the effect of any disruptions arising from the research protocol changes which might impact the safety of their research participants.
2. All approved studies that require face-to-face interactions must submit an amendment to the KNH-UoN ERC indicating measures taken to minimize COVID-19 exposure to research participants, staff, and the community.
3. Study visits and procedures should be conducted remotely through phone-based or internet-based methods using KNH-UoN ERC-approved tools that define when, how, where, why and by whom each online process will be carried out.

Responsibilities of Principal Investigator

1. KNH-UoN ERC -approved studies where study procedures such as consenting and data collection are to be conducted remotely can continue and submit a notification in case of changes with regards to adherence to MOH COVID-19 guidelines.

2. KNH-UoN ERC-approved studies that had indicated in their protocols that they would conduct in-person study visits or procedures should submit an amendment to request the change from in-person to remote visits/procedures as necessary.
3. Research requiring ongoing in-person visits/procedures /interactions with participants should submit an amendment/modification to KNH-UoN ERC indicating the measures that shall be taken to minimize the risk of COVID-19 exposure to participants and staff. KNH-UoN ERC approval is required before affecting the changes.
4. If there is a need to modify the schedule of study procedures to accommodate COVID-19 related measures, this should be done through an amendment application to KNH-UoN ERC.
5. Participants should promptly be informed of cancellations of study visits and reasons why and assured that they would be contacted if the visits are rescheduled. The cancellations and rescheduling of visits should be submitted to ERC as notifications.
6. If a study has been or needs to be temporarily paused to fulfill COVID-19 related containment measures, the following should be considered:

1. If temporarily halting research activities has or will have no effect on the safety or welfare of participants, this should be reported as a notification to ERC.
    1. If temporarily halting research activities could result in an increased risk of harm or affect the welfare of participants, the researcher must submit a protocol amendment for ERC review and approval.
    2. For a study that had temporarily halted research activities and noted an increased risk of harm / negative effect on the welfare of participants, the researcher must

complete a protocol violation report and submit a detailed declaration of the risk /harm suffered including any mitigation on the same

3. The researcher should clearly indicate the short-and long-term effect(s) that the pausing of research activities could have on research participants.

Appendix 5: Permission Letter

Mary Nyagisera

University of Nairobi,

College of Health Services,

School of Nursing Sciences.

20/05/2021

To the Director,

Kisii Referral and Teaching Hospital.

P.O Box 92,

Kisii, Kenya

Dear Sir,

Ref: Permission to carry out research in your institution

I am a student at the University of Nairobi pursuing a master's degree in nursing. I am carrying out a research project **The Changing Landscape in Funding of HIV/AIDS Program; Perspectives and Experiences of Caregivers of Pediatrics Patients at Kisii Referral and Teaching Hospital**

I hereby request for your permission to proceed. Thank you in advance.

Yours Faithfully,

Mary N. Mokeira

Reg. No: H56/33827/2019

Appendix 6: Letter of approval from KNH-UoN Ethics Committee

UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/320

14th September, 2021

KENYATTA NATIONAL HOSPITAL APPROVED 14 SEP 2021 KNH/UoN-ERC P. O. BOX 20723 - 00202 NAIROBI

Mary Mokeira Nyagisera
Reg. No.H56/33827/ 2019
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Mary

RESEARCH PROPOSAL: THE CHANGING LANDSCAPE IN FUNDING OF HIV/AIDS PROGRAM; PERSPECTIVES AND EXPERIENCES OF CAREGIVERS OF PAEDIATRIC PATIENTS AT KISII REFERRAL AND TEACHING HOSPITAL (P406/05/2021)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH-UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 14th September 2021 – 13th September 2022.

This approval is subject to compliance with the following requirements:

i. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
ii. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
iii. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
iv. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
v. Clearance for export of biological specimens must be obtained from KNH- UoNERC for each batch of shipment.
vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (Attach a comprehensive progress report to support the renewal).
vii. Submission of an executive summary report within 90 days upon completion of the study.

Protect to discover

Appendix 2: Research Budget

No.	Item	Quantity	Frequency	Unit Cost*	Total Cost (KSH)
1	1 Principal Investigator (PI) transport	1	2	2,000	4,000
2	Internet provision and Airtime	1	1	5,000	5,000
	Focused group discussion	2	2	2,000	8,000
3	Printing and photocopying of FGD guide	10	10	3	550
4	Production of consent forms	100	5	3	15,000
5	IREC Clearance Fee	1	1	5,000	5,000
6	NACOSTI License Fee	1	1	2,000	2,000
7	County Research Clearance Fee	1	1	10,000	10,000
8	Tape Recorder	2	2	13000	13000
9	Moderator	1	1	20	20000
10	Data clerks	2	2	20,000	40,000
11	Data analyst	1	1	50,000	50,000
12	Transport for movement Moderato	1		10,000	10000
13	Thesis Printing and Binding	5	1	2000	10000
	Dissemination fee	1	1	15000	15000
	Total				**207,550**

Appendix 1: Gantt Chart (2021)

Year / Month	2021								
	Jan 2021	Feb - March 2021	April 2021	May 2021	August 2021		Sept 2021	October 2021	Nov-Dec 2021
Problem identification									
Literature review and proposal writing									
Proposal defense									
Proposal review by IREC									
Data collection									
Data analysis and dissertation writing									
Submission									
Draft thesis defense									
Thesis examination(external examiner)									
Correction									
Submission and graduation									

Plagiarism Report

THE CHANGING LANDSCAPE IN FUNDING OF HIV/AIDS PROGRAM; PERSPECTIVES AND EXPERIENCES OF CAREGIVERS OF PEDIATRIC PATIENTS AT KSH REFERRAL AND TEACHING HOSPITAL

ORIGINALITY REPORT

10%	10%	1%	%
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24/11/2021

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CHAIRMAN
29 NOV 2021
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