AN INVESIGATION INTO THE EXPERIENCES OF MANAGING CHILDREN ON ART IN ZIMBABWE. A CASE STUDY OF MAKONDE RURAL DISTRICT, WARD 2.

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APPROVAL LETTER
To be completed by the Supervisor

I certify that I have supervised **ZVIKOMBORERO MAUSHE (B1749698)** for the research titled: **"AN INVESTIGATION INTO THE EXPERIENCES OF MANAGING CHILDREN ON ART IN ZIMBABWE. A CASE STUDY OF MAKONDE RURAL DISRICT WARD 2"**in partial fulfilment of the requirements for Bachelor of Science Honours degree in Social work, and I recommend that it proceeds for examination.

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DEDICATION

I dedicate this dissertation to my loving family, Mr. and Mrs Maushe and my brothers for their unconditional love and support they gave me throughout my educational journey.

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Firstly, I would like to thank the almighty God for the opportunity he granted me to undertake my studies. Through his grace my educational journey was a success. I would also like to thank my family for their unconditional love and support, and the encouragement they gave me to work extra hard in my studies.

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ABSTRACT

This study focused on the experiences of managing children on ART in Zimbabwe, a case study of Makonde district ward 2. The objectives of the study were: to explore the experiences in the management of children on ART by caregivers and different related bodies; to identify the challenges faced by children on ART, caregivers, and different health related boards in management of children on ART; to find the coping mechanisms being used in the management of children on ART by, children on ART, caregivers, and different health related boards in the management of children on ART and to identify measures that can be implemented to improve paediatric ART. Underpinned by Abraham Maslow's theory of needs, the study adopted a qualitative research approach to collect, analyse and present data. A sample of 30 participants was drawn from the targeted population using purposive sampling. The research established that the experience of managing children on ART is characterised with poverty and discrimination to those infected and affected by HIV. The findings indicated that caregivers and children on ART face financial challenges in the management of children on ART which exposes them to poverty and stigma from the society. The findings from the study also signified that nurses face resource challenges running the gamut from human resources to motor vehicles for transporting blood samples. In an attempt to address their financial challenges caregivers are resorting to piece jobs and illegal mining such that they attain daily necessities. The study recommends that HIV affected households in the rural areas be assisted financially, especially those where the patients are children and that caregivers be given care-givers' grants. The study also recommends increasing health care facilities in remote areas, such as rural areas that are staffed with personals that are able to manage paediatric HIV, as well as knowledgeable about antenatal health care. The study also recommends that bottom-up, sound polices be put in place to clearly address the challenges in the management of children on ART, making the experience more manageable.

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CHAPTER 1

INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 Introduction

HIV home-based care is popular in contexts severely affected by the epidemic and exacts a heavy toll on the caregivers. Children have their own distinct experiences with regard to ART. This chapter focuses on the background to the study, research problem, objectives, research questions, justification of the study, assumptions, definitions of key concepts, and chapters outline.

1.2 Background to the Study

The Anti Retro viral therapy has a specific implication on each and every age group. Hence the management of children on ART is associated with many barriers, be they social, cognitive or economic, which makes the management experience a bit complex. Mullen, Leech, O'Shea, Chrystie, Du Mont, Ball, Sharland, Cottam, Zuckerman, Rice and Easterbrook, (2002) are of the view that, despite the increasing introduction of antiretroviral therapy, many children, particularly in the rural communities of Zimbabwe remain vulnerable. They are impacted by non-adherence to ART regimen due to several factors. Martin (2007) argues that the factors include inadequate access to food and nutrition which can be shown by the unbalanced diet and the number of meals they get per day, transportation problems, and long distance commute to hospitals, infrequent visits by the home based care givers (HBCs) and the prevalence of widespread stigma and discrimination.

The HIV/AIDS epidemic in sub-Saharan Africa has had both direct and indirect effects on the population. Caregivers of HIV infected persons have been severely affected by the epidemic. WHO (2015) is of the conviction that, the HIV epidemic has for a long time been one of the primary causes of both child and adult mortality in HIV endemic settings within Sub-Saharan Africa including Zimbabwe.

This has placed an enormous care-giving burden on the extended family. This burden is particularly heavy on older persons who have a double burden of caring for their sick and dying adult children, as well as orphaned grandchildren. The impact of HIV/AIDS and how it has disrupted family structures and affected the roles of family members including elderly

caregivers in Sub-Saharan Africa has been extensively examined, hence this study "an investigation into the experiences of managing paediatric ART, in Zimbabwe, Makonde District, Ward 2" will help get an insight into the experiences in the management of children on ART, and possibly come up with strategies to address those experiences.

1.2 Statement of the Problem

The United Nations Joint Program on AIDS UNAIDS (2008) estimates that over two million children under the age of 15 are living with HIV/AIDS in the world, with nearly 80% of these children living in sub-Saharan Africa. High levels of antiretroviral therapy (ART) adherence are critical for viral suppression and reduced morbidity and mortality among HIV infected children. Anabwani, Woldetsadik & Kline (2005) postulated that ARV administration to children depends solely on caregivers to enhance drug adherence, which poses a challenge most of the time as those same caregivers are also be supposed to be playing the bread winner role hence there will be adherence issues as patients fail to meet dosage times as the caregivers will be participating in income generating activities. Mullen *et.al* (2002) argue that despite the increasing introduction of antiretroviral therapy, many children, particularly in the rural communities of Zimbabwe remain vulnerable. Moreover, government health facilities are understaffed and the clinical capacity needed to perform the Human Immune Virus Deoxyribonucleic Acid Polymerase Chain Reaction, HIV DNA PCR, on infants is very limited especially outside major cities and this poses challenges on the managing and treatment of paediatric ART. It is clear that within the experiences of managing children on ART there are other factors which are social and economic, which are clearly not adherence issues, for example stigma from the society which is mostly common in the context of HIV and AIDs. The study is justified because it can act as a roadmap for the social development department which may use the identified experiences to strengthen HIV social support services. This research seeks to investigate on the experiences being faced in the management of children on ART and to come up with recommendations that can help the children's care givers, NGOs and the Zimbabwean government to come up with strategies to assist in the managing of children on ART.

1.3 Aim of the study

The aim of this research is to investigate the experiences surrounding care givers and children undertaking ART in the management of children on ART in MAKONDE rural district in Zimbabwe.

1.4 Objectives

- To explore the experiences in the management of children on ART by caregivers and different related bodies.
- To identify the challenges faced by children on ART, caregivers, and different health related boards in management of children on ART.
- To find the coping mechanisms being used in the management of children on ART by, children on ART, caregivers, and different health related boards in the management of children on ART.
- To identify measures that can be implemented to improve paediatric ART.

1.5 Research Question

The main key questions to be addressed by this research are:

I. What experiences exist among care givers and different health related boards pertaining to the management of children on ART?

II. What challenges are being faced in the management of children on ART?

III. What coping mechanisms do you use in the management of paediatric ART?

IV. What strategies do you think can be implemented to better the management of children on ART?

1.6 Significance of the study

The research adds more knowledge to the field in study. The research also helps in identifying loopholes in the management of children living with HIV in Makonde district, which may assist different health bodies in coming up with strategies to improve the lifestyle of children living with HIV. The study also helps in identifying social barriers faced by people living with HIV and AIDs at large and addressing them through village headmen. The study benefits the Zimbabwean government and related NGO's through identifying the experiences in the management of ART which helps in policy formulations on ways to better the management of children on ART.

1.7 Assumption of the Study

The study assumes that respondents are cooperative and confident enough to trust the researcher and provide helpful information concerning their experiences in the management of children on ART. It also assumes that the research informs the civil society and different health bodies on the loopholes within the management and treatment of children on ART leading to interventions.

1.8 Limitations of the study

Time was limited and there are so many inconveniences as the student carried out the research during the semester and the researcher was not able to revisit the area again. The research was carried out in the **COVID-19** pandemic hence there was need for the researcher to meet all the safety requirements to carry out the research and these included hand sanitizers and clearance from the police. The data collection instruments used required much paperwork; therefore it was costly to print questionnaires. Because of financial problems it was very difficult for the student to travel to the area where the research was conducted, to seek permission and to mobilise the people. The research was carried out in one day hence too much pressure on both the researcher and the subject. This was as a result of the **CORONA virus** pandemic which came with regulations prohibiting group gatherings; hence for safety reasons the research was done in one day.

1.9 Delimitations of the study

The research was done in Mhangura Township which is in Makonde district Ward 2 in Mashonaland west province because the area is characterised with mining activities which makes it a hotspot for STI's. The area is also close to where the researcher stays making it less expensive to travel. The study focused on the experiences in the managing of children on ART.

1.10Definition of terms

Breastfeeding: "well-known as nursing, is the nurturing of babies and young children with milk from a woman's breast (WHO, 2011)."

Human immunodeficiency virus (HIV) is a virus that attacks the immune system, the body's natural defence system. HIV interferes with the body's ability to fight the organisms that cause disease (McElrath, 2002).

Acquired Immune-Deficiency Syndrome (AIDS) is "a chronic, potentially life-threatening condition caused by the human immunodeficiency virus (HIV) by damaging one's immune system" (McElrath, 2002).

Exclusive Breastfeeding(EB) is defined "as no other food or drink, not even water, except breast milk (including milk expressed or from a wet nurse) for six months of life, but allows the infant to receive drops, and syrups (vitamins, minerals, and medicines) (WHO,2011)."

Prevention of mother-to-child transmission (PMTCT), also known as prevention of vertical transmission, refers to interventions to prevent transmission of HIV from an HIV-positive mother to her infant during pregnancy, labour, delivery, or breastfeeding, Girma, (2016).

1.11 Chapters Outline

CHAPTER 1 (Introduction & Background of the Study)

In this chapter the researcher introduces the topic in study which is the study on the management of children on antiretroviral therapy exploring all the experiences encountered in the management of children on ART.

CHAPTER 2 (Review of the Literature)

This chapter seeks to relate the topic in study to literature that had been already disclosed by other scholars as well as exploration of the theory guiding the study, which is Maslow's human needs theory.

CHAPTER 3 (Research Methodology)

This chapter clarifies and exemplifies how information was obtained on the field, the material, the gathering procedure and the instruments used in both data collection and analysis are further illustrated in this chapter.

CHAPTER 4 (Data Presentation and Analysis)

This section focuses mostly on the presentation of findings from the study and it was presented graphically and in tabular form as well as this form made it easier for analysis interpretation of the study findings.

CHAPTER 5(Conclusions and Recommendations)

This chapter wraps up the whole study. After analysing the findings of the study in this chapter the researcher comes about with possible recommendations which could be of use in improving the area of study.

1.12 Chapter Summary

The chapter provided the statement of the problem, objectives of the study, research questions, significance, assumptions and the definition of key terms. The chapter also focused on the limitations and delimitations of the study.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

Cooper, (2010) Marshall & Rossman, (2011) express that literature review relates a study to the larger, ongoing dialogue in the literature, filling in gaps and extending prior studies. It provides a framework for establishing the importance of the study as well as a benchmark for comparing the results with other findings. It involves surveying (searching & obtaining) the literature in a certain chosen topic, synthesising the information gathered into a summary. Critically analysing information gathered to identify areas of controversy and identify research gaps. The literature review accomplishes several purposes. It shares with the reader the results of other studies that are closely related to the one being undertaken. This chapter focuses on related literature to the topic of study, which is children on antiretroviral therapy, hence the experiences encountered in the management of children ART. There is less literature published regarding the optimal management of children who have been diagnosed with HIV, regarding the systems within which this should occur. In the study's focus area, because children are considered more complex to manage than adults, they were initiated on drug treatment and monitored for a number of years at hospitals under close supervision by doctors. This has been found to be unsustainable.

2.1 Theoretical Framework

According to Abend, (2008) a theoretical framework is the structure that can hold or support a theory of a research study. The theoretical framework introduces and describes the theory that explains why the research problem under study exists.

2.1.1 Abraham Maslow's hierarchy of needs theory

Maslow's hierarchy of needs is a viewpoint of motivation and behaviour developed by the psychologist Abraham H Maslow (1908-1970). Maslow's hierarchy elucidates the behaviour of humans in relation to basic provisions for subsistence and development. These supplies, or essentials, are organised conferring to their prominence for existence and their influence to encourage the individual. The utmost important psychological necessities, such as food, water, or oxygen, establish the lowermost level of the need pyramid. The psychological needs

should be fulfilled earlier than the other higher needs become important to individuals. Needs at the upper levels of the hierarchy are more focused on, just before the mental being and further to emotional security and development. According to Maslow (1943:3) these needs have less power to motivate persons, and they are more influenced by formal education and life experiences. The subsequent hierarchy of needs is habitually represented as a pyramid, by means of mental being prerequisites set at the base of the pyramid and desires for self-actualisation positioned at the uppermost.

2.1.2The hierarchy

- Physiological needs: They are the basic necessities every human being needs for survival and these include food, water, shelter, oxygen and sleep. If these basic needs are not met, then human beings will put an effort to nourishing them and will pay no attention to the higher level of the hierarchy.
- Safety needs: As soon as the person's basic bodily needs are met the need for safety arises and these consist of the need for a sense of safety and certainty in the world. Safety becomes the second priority after an individual satisfies his or her physiological needs. Maslow believed that insufficient satisfaction of these needs might explain the possessed behaviour and other sensitive problems in some people.
- Love and belonging needs: While the individual's biological and safety needs are met the need for love and belongingness emerge. The needs include the desire for an intimate relationship with another person as well as the need to fit to a certain group and to feel recognised. Maslow highlighted that these needs encompass both giving and receiving love.
- Esteem needs: These needs contain both self–esteem and reverence for others. Self-confidence is the sense that one is treasured, educated and self-determining. The esteem of others involves people respecting and raising their value of that person. Once the person has satisfied his or her basic needs, concerns about worthiness emerge. The motivation behind the esteem needs is that the individual conforms to the society's standards and has a meaningful life.
- Self-actualisation needs: These needs are related to apprehending the full potential one has. So, when the needs arise the individual tries to accomplish what he or she is supposed to do in life, evolving his or her talents or skills to the full extent.

2.1.3 RELEVANCE TO THE STUDY

Abraham Maslow in his theory of needs, clearly assert that in the assessment of human needs, there are certain basic needs and requirements that must be met before other needs can be met. The implication of this is that in application of hierarchy of needs as articulated by Abraham Maslow there are, however, certain basic human needs which must usually be met before any consideration is given to other human needs in human environment in the society. This implies to the most basic needs that keep the human body alive such as food and water, where as an individual will not pay attention to any other needs if these physiological needs are not met. Hence this goes in relation to the topic at study, with the theory shedding light on the perceptions into the experiences being faced in the management of children on art in Makonde district Zimbabwe.

The theory of needs explains the experiences being faced in the management of children on ART differently basing on regions as well as countries. Thus in developed countries basic human needs such as food and shelter are cheap and readily available as compared to developing countries where the economy is tough and it is almost difficult to meet the daily basic needs as evidenced by the researcher in Makonde district, hence in relation to this study, such will cause challenges in the management of children on ART. Failure to meet the physiological needs automatically implies that the child will be malnourished, leading to poor management as the child's growth would be disturbed due to poor diet. The hierarchy of needs theory helps explain the experiences in the management of children on ART in both developed and developing countries, explaining why there are variances within the experiences faced, if any.

Within the human needs lies love and belonging needs. The needs include the desire for an intimate relationship with another person as well as the need to fit to a certain group and to feel recognised. Maslow highlighted that these needs encompass both giving and receiving love. In relation to the study, caregivers of children living with HIV, especially mothers could feel unwanted in the society because of the stigma they will get from the society for being HIV positive. This may discourage them from adhering to their medication as well as that of their children, due to the fear of stigma from the society and as well as the need to be loved and the feeling of belonging to a certain group or society. Thus, individuals in the struggle to fulfil their love and belonging needs, they end up dodging hospital visits for the child's

monitoring hence poor management as the child will not be monitored by nurses to see if the child is responding well to treatment.

Abraham Maslow's hierarchy of needs is built on the premise that human behaviour is motivated by the desire to meet specific human needs in the society. Hence it is most likely that when individuals meet the physiological needs they are most likely to be motivated to give concern about other needs, for example their health lifestyle, hence leading to better antenatal care which promotes good management of children on ART through prevention however a certain number might not be able to be prevented through PMTCT hence antenatal health care ensures that certain children receives treatment.

2.2 Global concept on children on ART.

According to WHO (2018) 1.8 million children were estimated to live with HIV in 2017, whereas only 51 % of HIV-exposed infants received early infant diagnoses. According to UNAIDS, (2020) 1,4 million people are living with HIV in Zimbabwe, with 71% of the children diagnosed with HIV initiated on treatment hence there is an improvement in the access to treatment from 51% in 2018 to 71% in 2020 receiving treatment. Viral load suppression remains poor particularly in younger children; this is due to the lack of potent, tolerable ARVs in age appropriate formulations, which remains a critical barrier to the scaling up of paediatric treatment globally. According to UNICEF, (2010) HIV and AIDS have affected the lives of many people at individual and family levels globally, through illnesses and deaths of family members and has been a serious challenge medically, financially and socially.

The 2009 progress report towards universal access, "scaling up priority HIV/AIDS interventions in the health sector", documents the progress made by countries in scaling up antiretroviral therapy (ART) for children. According to WHO, in 2008, over 275 000 children received ART, up from 127 000 in 2006. Such an improvement in ART uptake by children shows that the scaling up interventions was successful as more children were now enrolled into care. UNAIDs (2010) postulated that, HIV and AIDS is of considerable and significant impact to children, yet the attention given to this population is largely overshadowed by the large-scale burden of the epidemic in the adult population. This shows that children on ART are given less attention in the health sector globally than their elderly counterparts. A report

titled “Towards Universal Access Progress” points out that more than 90% of HIV infections in children result from mother-to-child-transmission, where the virus is passed from a mother living with HIV to her baby during pregnancy, childbirth, or breastfeeding. Hence to better manage children on ART there is the need to scale up services that promote the prevention of mother to child transmission (PMTCT). By improving PMTCT programmes, the management of children on ART becomes bearable as majority of the children would be prevented from contacting the HIV virus from the mother.

2.2.1. Regional Concept on Children on ART.

Okoli & Lawson (2019), as cited by Ncube & Msipa (2019) observed that Nigeria and Malawi are laden with socio-cultural barriers to the full implementation of PMTCT with socio-cultural barriers including stigma and discrimination, perception, religious beliefs, family disruption, gender inequality, unstable premarital sexual relationships, unskilled birth delivery by Traditional Birth Attendants (TBAs) and low utilisation of hospital delivery services. They cement that stigma and discrimination appear to be the most important socio-cultural barrier faced by PMTCT.

Due to the stigma glued to HIV by the society, women fear to disclose their HIV statuses hence pregnant or lactating HIV positive mothers may fear being labelled by community members which forces them to default medication by so doing the HIV exposed infant (HEI) is even exposed more to the opportunistic infections (OI) which comes with HIV. Adding value to their research, Ncube & Msipha, (2019) appreciate Okoli and Lansdown, who note that women enrolled in PMTCT programmes hide their HIV status to their partners and family which later leads to them shunning away enrolment into the PMTCT programme. Notable is that women often are vulnerable to physical abuse and violent reactions from partners and families when they enrol in PMTCT programme which in turn makes them lose commitment in adhering to PMTCT therapies or rather going to worst extents of dropping out from the programme.

UNAIDS (2016) outlined that, HIV and AIDS have caused untold suffering in the rural communities of Sub-Saharan Africa with children being the most affected. About 95% of the infected populations in the world currently live in developing countries, particularly in Sub-Saharan Africa. The disease is responsible for reversing decreases in child mortality. Few data exist evaluating the outcomes of the prevention of mother-to-child transmission of HIV

(PMTCT) program. Although PMTCT coverage appears to be low, hospitals are still witnessing large numbers of admissions of HIV-infected children.

Postnatal transmission of HIV is high, reflecting poor sexual reproduction health education in youths and poor maternal health education for the young couple's and expecting mothers. Thus, breast feeding and expecting mothers can be educated on PMTCT and the feeding scheme for the HIV exposed infant through maternal health education reducing the chances of the baby being affected after birth due to poor breast feeding methods or poor drug adherence of the HIV positive mother.

WHO (2015) articulates that antiretroviral (ARV) drug administration requires strict adherence to avoid the development of medication resistance, which would render the drugs ineffective and subsequently lead to morbidity and mortality. Postnatal transmission indicates that the mother of the child has failed to adhere to the requirements of an HIV exposed infant which is supposed to keep the baby negative from HIV infection after birth. In South Africa few infants and children are entering care through early diagnosis, which should be widely available.

WHO (2018), outlined that, cotrimoxazole prophylaxis coverage is inadequate in resource limited areas, contributing to high morbidity and mortality in infants. Within the experiences being faced in South Africa it is evidenced that there is a shortage of drugs to suppress the viral load in children. A few ARV's are available which are compatible for children with Cotrimoxazole prophylaxis as the main drug for postnatal prevention as well as for viral suppression in infants. This makes the management of children on ART more difficult as other drug regimens won't be tolerated by children due to bitterness in test or due to allergies as most of the ARV's are tested on adults. The number of children receiving antiretroviral therapy (ART) is increasing steadily. However, significant inequalities in access to ART exist between and within provinces.

Challenges for paediatric ART include a lack of sufficiently trained health care personnel and inadequate facilities, as well as the complexity of drug regimens and formulations. The compartmentalisation of the ART rollout program hinders PMTCT and makes it difficult for children to be identified and referred into appropriate services.

Skinner (2005), is of the view that PMTCT is a steppingstone to the decrease of HIV new infections in children, however they unearth disappointing discoveries that affect and bedevil

rural areas in South Africa. Skinner et al. (2005) observe that despite free medical access for women and children in South Africa, poor road networks, underdeveloped transport system networks and poor telecommunications in turn countered progress in the implementation of PMTCT.

These named variables are put into the picture by Skinner (2005) in the context that underdeveloped transport system networks and poor road networks become a challenge in the delivery of medication since families from far deep Eastern Cape cannot travel easily to reach clinics. Additionally, poor telecommunications presented a challenge in delays to make procurement of ARVs leading to a flawed efficacy of the PMTCT program. The presence of such barriers leads to poor drug adherence as care givers would be discouraged to travel long distances to attain medical refills for the child hence leading to drug resistance in the child.

2.2.2. Related Case Study

A study which looked into the challenges faced by caregivers of children on antiretroviral therapy at Mutale Municipality selected healthcare facilities, Vhembe District, Limpopo Province showed that participants, that is, caregivers of children on ART, experienced financial burdens because of transport costs needed to comply with follow up dates and insufficient of money for food and clothing the child in need of care. Participants reported some level of stigmatisation against children on ART by family members, especially the husbands or in-laws of the secondary caregivers. Many primary and secondary caregivers seemed to have given up seeking support from government and community structures. The study concluded that caregivers hardly receive any support from family members or the community. Fear of disclosing the HIV-positive status of children resulted in the delay of financial support from the government, thus leading to serious financial burden on the caregivers. It can be evidenced from the case study that stigma and financial incapacity are the major problems being encountered in the management of children living with HIV & AIDs.

2.3. Zimbabwean Context

HIV and AIDS has been the worst chronic disease of the 21st century. Since the discovery of the virus that causes AIDS in 1983, the chronic disease has no cure and it continuous to threaten human life (UNAIDS 2010). International Journal of MCH and AIDS (2012), highlighted that, HIV and AIDS has caused untold suffering in the rural communities of Sub-

Saharan Africa with children being the most affected. About 95% of the infected populations in the world currently live in developing countries, particularly in Sub-Saharan Africa. Zimbabwe is one of the Sub-Saharan African countries burdened by high HIV infection prevalence. The country's population is estimated at about 13 million people with about 1.1 million HIV positive people, of which 151,749 are children below the age of 14. By the year 2010, only 326,241 people in Zimbabwe were estimated to be receiving antiretroviral therapy (ART).

In a study that was taken in Brunapeg area of Mangwe district, Zimbabwe, which aimed at determining the factors and challenges facing children on antiretroviral therapy, it was found that, despite the increasing introduction of antiretroviral therapy, many children, particularly in the rural communities of Zimbabwe remain vulnerable. They are impacted by non-adherence ART regimen due to several factors. WHO (2016) articulated that, the factors include inadequate access to food and nutrition which can be shown by the unbalanced diet and the number of meals they get per day, transportation problems, and long distance commute to hospitals, infrequent visits by the home based care givers (HBCs) and the prevalence of widespread stigma and discrimination.

From the study, a number of challenges emerged as barriers to the success of antiretroviral therapy for children. Primary care givers were less informed about HIV and AIDS issues for people having direct impact on the success of antiretroviral therapy in children whilst some were found to be taking the antiretroviral drugs meant for the children. It also emerged that some primary care givers were either too young or too old to care for the children while others had failed to disclose to the children why they frequently visited the Opportunistic Infections (OI) clinic. Most primary care givers were not the biological parents of the affected children. Other challenges included inadequate access to health services, inadequate food and nutrition and lack of access to clean water, good hygiene and sanitation. The lack of community support and stigma and discrimination affected their school attendance and hospital visits. All these factors contributed to non-adherence to antiretroviral drugs. These are some of the challenges that emerge within the management of children on ART.

Martin *et.al* (2007), postulate that, despite the increasing introduction of antiretroviral therapy, many children, particularly in the rural communities of Zimbabwe remain vulnerable. They are impacted by non-adherence to the ART regimen due to a number of factors. This includes inadequate access to food and nutrition which can be shown by the

unbalanced diet and the number of meals they get per day, transportation problems, and long distance commute to hospitals, infrequent visits by the home based care givers (HBCs) and the prevalence of widespread stigma and discrimination. Thus, this relates to the theory of needs by Abraham Maslow which states that there are certain needs which need to be met first in order to fulfil other needs. Failure to meet the nutritional requirements of the child relates to the basic physiological human needs such as food hence by so doing the child shows signs of stunted growth which also affects the proper function of the drugs, hence the management of children on ART is not only affected by drug resistance but also the failure to meet some nutritional requirements required by the child on ART.

Paterson *et.al* (2000), pointed out that, antiretroviral therapy is an integral component in the quest to improve the well-being and health of children living with HIV and AIDS. Its success is determined by factors that occur concurrently to the patients' health and social life during therapy. The social life of children living with HIV in Zimbabwe is rather lonely and stigmatised as caregivers of the children usually hide their HIV status as well as their children hence, they fail to acquire support from other family members as well as community members. Mullen *et.al* (2002), postulate that, antiretroviral therapy involves continual interaction between health staff and patients through on-going medical check-ups, prescription or drug refills, monitoring and adherence support. Due to the stigma related to HIV in the Zimbabwean community, especially the rural areas, it is almost difficult for the caregivers of children living with HIV to frequently visit the hospital for check-ups and medical refill hence most of the children and their caregivers as well face adherence issues.

2.4 CHALLENGES BEING FACED IN THE MANAGEMENT OF CHILDREN ON ART

The challenges in the management of children on ART are characterised as psychosocial and economic challenges. Thus these challenges are found to be common in the HIV context despite geographical boundaries thus they can be said to be a part and parcel of the HIV epidemic.

2.4.1 Poor resources

WHO (2017) articulated that, significant obstacles remain to scaling up paediatric care, including limited screening for HIV, a lack of affordable, simple diagnostic testing technologies for children less than 18 months of age, a lack of human resources with the

capacity to provide the care that is required, insufficient advocacy and understanding that ART is efficacious in children, limited experience with simplified, standardized treatment guidelines, and limited availability of affordable and practical paediatric ARV formulations.

2.4.2 Stigmatization

A study conducted by Nachega, Morroni, Zuniga, Sherer, Beyrer& Solomon, (2012) identified that there was a misconception relating to use of kitchen utensils as it is said that these utensils should not be shared with HIV-positive individuals for fear of infection. Demmer, (2011) postulates that, it is these stigmatising attitudes that have prompted some caregivers to keep their children's sickness a secret and sometimes ignore symptoms or treatment. Such stigma hinders the management of children on ART as caregivers end up boycotting hospital visits for check-ups and drug refills. Zhao, (2009) is of the view that caregivers often experience extended grieving, psychological trauma, fears, anxiety of neglect and discrimination from family, peers and neighbours.

2.4.3 Lack of Financial support

In a study by Mangwiro, (2014) it was concluded from the findings that community home based caregivers faced challenges of food, CHBC kits, gloves, cotton, soaps and money for transport to go for reviews and other essentials or even money to cater for their needs. Hence it can be argued that the time spent on the care-giving roles makes it difficult for the caregivers to involve themselves into income generating activities hence they fail to attain their basic needs.

In a study by Ahosi, Tawab, Geibel, Kalibala, Okal, Mane, (2014) it was argued that caregivers hardly receive any support from family members or the community. Fear of disclosing the HIV-positive status of children resulted in the delay of financial support from the government, thus leading to serious financial burden on the caregivers. Thus care givers would be ashamed to ask for assistance for their children due to the fear of being stigmatized after disclosing the child's status. Lack of financial support leads to financial incapacitation which then results in the failure of caregivers to secure a nutritional diet for the child which leads to malnutrition.

Mangwiro, (2014) expressed in a study on the effectiveness of community home-based care programmes in mitigating the effects of HIV and AIDs in rural areas in Zimbabwe that all these challenges become a barrier to the full recovery of many patients under CHBC

programmes. Thus taking for example a poor balanced diet will slow down the effectiveness of the ARV drugs and this would lead to high viral load within the patients as the body would be further weakened from malnourishment. This affects the management of children on ART as the patients would turn to be drug resistance and also high viral load.

2.4.4 Impact of age of primary care giver

In a study by, Macherera, Moyo, Ncube, Gumbi, (2012) on Social, Cultural and Environmental Challenges Faced by Children on Antiretroviral Therapy in Zimbabwe it was noted that other primary care givers are either too young or too old to take care of the children on ART such that they have problems adhering to hospital dates and times or monitoring the children on ART during their drug administration for correct dosages. This poses a huge challenge on the management of children on ART as the child will certainly develop drug resistance making it difficult to attain a suppressed viral load.

2.4.5 Lack of Knowledge from care givers

In a study by Macherera *et.*al (2012) primary care givers had inadequate knowledge on issues regarding HIV/AIDS and this affected the care they delivered to the children on ART, particularly with drug administration, providing adequate care and food and nutrition. Mothers lack the knowledge of when and where they can bring their child for follow up visits. Some of the mothers give birth at home and never bother going to the clinic earlier rather they go to the clinic to seek medical attention when the child is seriously ill hence it becomes a challenge to the management of children on ART.

2.4.6 Poor Policies focused on PLWH

According to MOCHW (2010), there is lack of a national strategy or policy addressing food and nutrition insecurity in vulnerable households with PLHIV. This shows that despite the availability of ART the HIV patients will remain vulnerable to malnutrition which will slow down the recovery rate of the infected children.

2.4.7 Intolerable ARV Drug Regimen

Mellins, Brackis-Cott, Dolezal, Richards & Abrams, (2002) expressed that ARV drugs require frequent dosing and are mostly supplied in formulations that may be difficult for children to tolerate, such as large pills, bitter tasting liquids and gritty powders. Thus the currently available ARV regimens are not quite tolerable to children as they are described as

large pills that can be difficult to swallow hence the children find it difficult to adhere to such drugs.

2.5 POSSIBLE INTERVENION TO IMPROVE THE MANAGEMENT OF CHILDREN ON ART

2.5.1 Prevention of mother to child transmission

Gahagan, Rehman, Barbour, McWilliam, (2007) articulate that, there is need to scale up the PMTCT programme to prevent new HIV infections resulting from mother to child transmission. Thus, big hospitals in the rural areas need to have mobile outreach clinics and satellite clinics within its catchment area providing PMTCT services through the voluntary counselling and testing services. Henceforth, with the PMTCT programme being implemented there will be a reduced number of children being born with HIV hence the management process become bearable requiring lesser resources to manage small numbers of children with HIV.

2.5.2 Voluntary Counselling & Testing services

UNAID's (2016), outlined that, voluntary counselling and testing helps in early diagnosis and treatment of HIV in patients. Voluntary counselling and testing help in identifying HIV positive pregnant mothers and by so doing efforts are made through PMTCT programme to protect the unborn child. Through the PMTCT programme, the HIV exposed infant (HEI) is closely monitored and is initiated on cotrimoxazole prophylaxis which is a form of ARV that protects the child from contracting HIV through breastfeeding.

2.5.3 Promote male involvement into antenatal healthcare

Kakaire, (2011) articulated that, male involvement during labour and delivery is significant for they provide emotional support. Thus, if males are also involved in antenatal care with their pregnant wife's it can be diagnosed quickly if a couple is positive hence lesser stressful to one partner rather they give each other emotional support if males are involved into antenatal health care. They are taught on safer sex practices that protect the unborn child from contracting HIV from the parents. Cultural norms particularly in patriarchal societies like Zimbabwe, converse the decision-making responsibility on the use of reproductive health services to men, but they are however rarely involved in antenatal care services.

2.5.4 Experienced staff

PEPFAR (2020) outlined that training medical staff in use of national standardised registers and patient records management for HEI can help clinic staff in implementing quality improvement activities and identify exposed and infected children at each point of contact with health services.

2.5.5 Introduction of new ARV regimens

WHO (2017), outlined that there is need for new ARV regimens for infants, children and adolescents and updated guidance on early infant diagnosis. This helps in promoting drug adherence as some of the available ARV's are not well compatible for children, hence the production of new antiretroviral regimen will result in favourable ARV's compatible for children.

2.5.6 Build linkages between EID databases

- PEPFAR (2020) outlined that there is need to build linkages between EID databases (health facility or laboratory-based) and PMTCT and paediatric ART programs to facilitate tracking of HEI and ensure all HEI received a definitive diagnosis after cessation of breastfeeding and infected infants-initiated ART promptly.

2.6 STRATEGIES TO ADDRESS CHALLENGES IN THE MANAGEMENT OF CHILDREN WITH ART

- In a study by, Mafune, Lebese & Nemathaga, (2017) on 'Challenges faced by caregivers of children on antiretroviral therapy at Mutale Municipality health facility', it emerged that the multidisciplinary team of heath care workers in collaboration with social workers and community peer mentors should provide to new mothers who move to their home or village after delivery clear information on what is an HIV exposed infant, how to reduce the risk of HIV transmission to the infant from the mother after birth and also available options for paediatric HIV care and treatment, and where these services are offered in the community where she lives.

- Mafune*et.al.* (2017) noted that, it is recommended that all caregivers be motivated to participate in community projects to generate income and alleviate poverty. Thus, to promote self-sustainability in caregivers through self-help project for example empowering the care givers with capital for small projects such as poultry which do

not require a lot of labour and costs. This can also be done through raising awareness, thus making the caregivers aware of the resources within their community that they can utilise for economic independence for examples in areas where there are dams and rivers caregivers can have gardens there. This will help the caregivers in attaining economic sustainability as well as good nutritional balance for the child from the produces from the garden.

- Graaff (2004) postulates that, Social workers by their profession's principles, ethics and values are expected to assist in restoring, maintaining and enhancing the social functioning of individuals and the greater society. Thus social workers have to play the role of an educator on issues that affects paediatric treatment through awareness campaign, there is need to endorse public awareness programmes and HIV specific support groups which improve adherence by minimising stigma and discrimination and increasing communal and social support for the affected children.

2.7 Chapter conclusion

The chapter related the topic in study to literature that had been already disclosed by other scholars as well as exploration of the theory guiding the study, which is Maslow's human needs theory. The experiences being faced in the management of children on ART were also outlined with challenges being faced by different third parties such as caregivers also outlined as well as possible interventions to address the challenges and better the management of children on ART.

CHAPTER 3

RESEARCH METHODOLOGY

3.0. Introduction

The main aim of this study was to explore the experiences being faced in the management of children on ART and also to figure out possible interventions to improve the management process of children on ART in Mhangura (ward 2) in Makonde district. This chapter outlines the research methodology used in the research, the data collection methods, ethical considerations, the research design, sample size, sampling technique, study site, target population and also data collection procedure.

3.1. Methodology

According to Khothari (2009), a methodology is an agreement that seeks to govern, regulate and guide any given discipline through a systemised set of methods. This is just a systematic theoretical analysis of the methods that are applied to a field of study. It is not set out to provide solutions.

3.2 Study Site

The research was conducted in Zimbabwe Mashonaland west in Mhangura; a former mining town in Makonde district ward 2. The majority of the population relies on subsistence farming and illegal gold mining. Mhangura was once a mining town hence this makes it perfect for the study since mining towns are mostly characterised by high rates of sexually transmitted diseases. Thus the mining activities of both legal and illegal miners attract commercial sex workers hence the prolonged spread of the HIV virus in adults which is later on transmitted to infants during gestation period, resulting from poor drug adherence.

3.3 Research design

Khothari, (2009) characterised research design as a blue print of extensive arrangement on how the study will be completed, picking information of concern pertinent to the investigation, choosing information to be utilised that will go about as a foundation for testing theory and dissecting discoveries. In this manner, a research design is an essential arrangement that controls the information assortment and investigation periods of the study undertaking and it gives the structure that determines the kind of data to be gathered, its

sources and assortment strategy. This investigation utilised the case study analysis research plan. Khothari, (2004) argued that a case study is basically a strategy for conducting a research which encompasses actual and practical investigation of a specific phenomenon. Case studies can assist with producing new thoughts and in this examination it is significant in making original thoughts on the best way to better the management process of children on ART. The study utilised an exploratory research design to get an insight into the experiences in the management of children on ART. The research was applicable for it does not focus on providing final and conclusive answers to the research questions but merely explores the research topic from varying objectives.

The research used the qualitative methodology in gathering and examining information. Qualitative methodology understands a phenomenon in open settings where it isn't controlled by the specialist (Creswell, 2014). Walliman (2011) adds on and noticed that discoveries are not reached at through arithmetical strategies or evaluation however rather discoveries are reached at from certifiable settings where a phenomenon unfurls normally. A qualitative research design produces leads and thoughts which can be utilised to define a practical and testable speculation. For instance, in this exploration, the researcher needed to discover the encounters behind the management of children on ART, so the researcher made interview guides for guardians and for the medical personnel at Makonde Christian Hospital, who are the nurses and the primary counsellors, requesting for their opinion and insights into the management of children on ART. Qualitative strategies are regularly firmly connected with interviews and focus group discussions, (Creswell 2014). The researcher chose the qualitative research design for it requires a little financial plan and it is likewise less one-sided.

3.4 Target population

According to, Silverman (2013), target population alludes to the total amount of elements from which the analyst needs to create an inference and the outcomes can be generalised. The exploration focused on children on ART, guardians of children on ART, attendants and essential instructors as the critical sources of the investigation. Punch (2011) defines population as the theoretically specified aggregation of study elements and therefore target population as the aggregation of element from which the sample is selected. Thus a target population can be depicted as individuals who can give significant data required during the study.

3.5 Sample size

Lavrakas, (2008) is of the view that, a sample size most typically refers to the number of units that are chosen from the population, from which data is gathered. The total sample size was 30 participants (3 nurses and 3 primary counsellors from Makonde Christian hospital, 12 care givers at home-based care level, 12 children living with HIV).

3.6 Sampling and sampling methods

Troicham (2008) regards sampling as a process that is used to select units, for example, people from a population of interest such that when the sample is under study, results may be generalised fairly back to the same population from which they were chosen. It refers to the technique or the procedure the researcher would adopt in selecting items for the sample. The researcher used Snowball and purposive sampling techniques which are all non-probability sampling techniques.

3.6.1 Purposive Sampling Technique

Creswell and Clark (2011), asserted that purposive sampling is a non-probability sampling method which refers a situation where the researcher uses the previous knowledge to select a sample of participants. Purposive sampling is a non-probability sampling technique which could be judgmental sampling or Quota sampling. In this study the researcher used the Judgmental technique to select 6 key informants. Through this technique the researcher used his judgment to select respondents who are good prospects for accurate information. Hence 3 nurses and 3 primary counsellors from the opportunistic infection (OI) department were selected through purposive sampling as key informants.

3.6.1 Snowball Sampling Technique

Creswell (2014) articulates that snowball sampling is whereby the researcher starts by identifying a few respondents who match the criteria for the inclusion in the study. The researcher used key informants selected through the purposive technique to identify caregivers and children on ART through snowballing were the key informants (nurses and counsellors) identified other participants who could be suitable and willing to comply to the study.

3.7 Data Collection methods

Creswell (2014) notes that data collection richly capitalises on instruments which enable the researcher to extract information from the participants. Research instruments are just tools that are used for measurement designed to obtain data on a certain topic of interest. Therefore, in this study, the researcher made use of the following data collection methods:

3.7.1 Unstructured Interviews

Edwards and Hollard (2013) note that the use of this tool allows the researcher to read non-verbal responses as well probing for more information in order to ensure an in depth understanding of the questions at hand. Here, the interviewer does not generate any specific set of standardised questions for research; rather he asks different questions in line with the context and purpose of the systematic investigation. Interviews were used for collecting data from the participants. 30 participants were interviewed in the counselling room to ensure privacy, with each interview taking about 20 to 30 minutes in session. The interviews were guided by certain questions which helped the interviewer and the interviewees not to deviate from the topic at study.

3.7.2 Data Collection Tools

Data collection tools refer to the instruments used to gather data from the research participants. The study used an interview guide to collect data from the participants which was guided by the objectives of the study.

3.7.2.1Interview guide

According to Etikan (2017), an interview guide refers to a list of structured questions prepared and serving as a lead for researcher and interviewers in collection of information on data on a specific topic or issue. The researcher uses the interview guide on collecting data. This helped the researcher in directing the conversations towards the experiences being encountered in the management of children on ART. The guide helped the researcher to keep in track with the topic at study; it acts as a sailing trail such that both the researcher and the respondents wouldn't get carried away from the topic. The researcher made use of structured

interviews. Data gathered through a structured interview is more objective and easier to analyse. The researcher interviewed 30 respondents. The interviews were held in a time interval of 20 to 30 minutes.

3.7.2 Data Collection Procedure

The researcher requested for permission from the Bindura University of Science Education to proceed with data collection. The researcher also sought for permission from Makonde Christian Hospital to carry out data collection for the experiences being encountered in the management of children on ART. For protection reasons, consent forms were created for and given to respondents. The researcher further explained to the respondents the research aim sand objectives. The researcher also made use of recording and taking notes after seeking consent from the respondents. All the parties involved granted their permission to the researcher to carry on with the research.

3.8 Data Analysis and Presentations

According to Donvos, (2002) in Kiteley and Stogdon, (2014) data analysis is referred to as the process of bringing order, structure and meaning to the mass of the collected data. Bryman (2012) data analysis aims to describe, discuss and explain the context of generated data in the study. Qualitative data is used in this study was analysed thematically to provide feasibility to the study. Clarke (2012) explains that thematic analysis is usually applied to a set of texts such as interview transcripts and it also allows the researcher to closely examine the data to identify common. Thematic analysis is a method of analysing qualitative data which is usually applied to a set of texts, such as interview transcripts. The researcher used this thematic analysis because when data has been collected there is need to analyse and interpret it. When conducting this thematic analysis, there are various steps to follow which are, familiarisation, coding, generating themes, reviewing themes, defining and naming themes then writing up.

3.8.1 Familiarisation

According to Clarke (2012) this stage entails familiarising with one's entire body of data or data corpus before going any further. The researcher familiarised with the information gathered, comprehended the activities and the responses as they were introduced by the respondents. The researcher recorded highlights, recording every one of the remarks that he

got from the respondents during the interviews and the conversations. The researcher wrote down the impressions by the respondents during the conversations.

3.8.2Coding

Clarke (2012) outlined that, codes are identified by developing coding groups and selection of useful data from less useful data. This stage is the point at which the researcher gathers translated or recorded information into significant information. The researcher gathered all the data that he got from the respondents into various classifications. The researcher gathered all the information into pertinent classes like social challenges and financial challenges. The researcher coded each section of information that was applicable to or that caught something interesting about the research questions.

3.8.3 Generating themes

Clarke (2012) outlined that on this stage; the researcher investigates the codes made from the previous stage, identifies the patterns among them and creates themes. The researcher created subjects to the codes from the past stage and connected them to the goals of the examination. Difficulties being faced in the management of children on ART were recognised and possible intervention systems to address the challenges were identified.

3.8.4 Reviewing themes

On this fourth stage, the researcher ensured that the subjects were valuable and delivered precise presentations of the data. Maguire& Delahunt (2017) argues that, on this stage modification and development of the preliminary themes that were identified in Step 3 takes place. The themes were compared against the information and checked if the subjects were truly present in the information and perhaps what could be changed to improve the themes.

3.8.5 Defining and naming themes

Braun & Clarke, (2006) argue that, this is the final refinement of the themes and the aim is to ‘identify the ‘essence’ of what each theme is about. The researcher checks the final list of themes, then names and defines each one of them. Defining these themes entailed deciding precisely what each theme meant and how it aids in the comprehension of the data. The method of naming themes entailed coming up with a simple name for each one. The researcher then double-checks the data to ensure that each piece of information was accurate.

3.8.6 Writing up

As stated by Clarke (2012), a report produced should be able to convince the reader of the validity and reliability of the data analysis. The data was analysed and presented in a report by the researcher.

3.9 Ethical Considerations

During the course of the study, the researcher took into consideration some ethical issues such as informed consent, confidentiality, gaining permission to access and right to self-determination during his time in carrying out the research. According to the British Psychological Society (2010) research ethics is a form of enquiry aimed at contributing to body of knowledge. Research ethics therefore relate to questions about how researchers formulate and clarify their research topics, design research and gain access, collect data, process and store data, analyse the data and write up the research findings in a moral and responsible way. Ethics are norms that distinguish between acceptable and unacceptable behaviours.

3.9.1 Informed consent

According to the British Psychological Society (2010) researchers should ensure that every person from whom data is gathered should freely agree to contribute to the research understudy. Participants were made aware of the purpose of the research and prior to their participation. This was clearly explained to all the respondents (caregivers, children living with HIV & medical personals) so that they would decide whether to participate or not. The researcher also got the permission from the chief of the area to carry out the research. Respondents were made aware that they can withdraw anytime they wished, if it happened that they changed their mind during the study

3.9.2Confidentiality

Leedy and Ormond (2010) define confidentiality as the ethical protection of those who are being studied by holding research data in confidence or keeping them a secret from the public; not releasing information in a way that permits linking specific responses to specific participants. Taking into consideration the topic at study, confidentiality should be upheld at all cost as people living with HIV attract more stigma from the society, hence in the event of

disclosing information for academic use anonymous names should be used. False names were used in the study so as to uphold confidentiality.

3.9.3 Voluntary participation

Babbie, (2011), notes that the notion of voluntary participation must be communicated to the participants in which taking part in the study will be voluntary and they can withdraw from the research at any time without any repercussions. To uphold voluntary participation from caregivers and children living with HIV the researcher outlined all the necessary information about the study thus, the objectives and the purpose of the study. The researcher also told the respondents how the study could benefit their society and the researcher then for the respondents who wished to participate. The respondents were not forced to participate during the process rather participation was voluntary. Respondents were also allowed to withdraw during the process if they were not comfortable with the discussions. This goes in line with the principles of respect for autonomy and dignity for all respondents during the process.

3.9.4 Avoidance of Harm

Clarke (2012) postulates that avoidance of harm is a principle where the researcher seeks to guard and protect the participants against any form of psychological, emotional or even physical danger that negatively affects their wellbeing. The researcher made sure that the information shared to him was kept confidential and was used for research purposes only to avoid stigma from the society which would bring psychological harm to the respondents.

3.10 Feasibility of the Study

The study was feasible as the intended research respondents agreed to participate in the study as it was beneficial to the community at large. The researcher was granted permission from Makonde Christian hospital to proceed with data collection hence it was feasible.

3.10.1 Credibility

Clark, (2012) articulate that, credibility is the extent to which the researcher proves that the results are believable. The researcher used the needs theory by Abraham Maslow as the theoretical framework which helped explain the experiences within the management of children on ART.

3.10.2 Transferability

Clark, (2012) expressed that; transferability is the extent to which the results of qualitative research can be generalised or transferred to other contexts. The research was conducted after getting concern from Makonde Christian hospital thus the research provided valid and inclusive results, promoting transferability.

3.10.3 Conformability

As articulated by Clarke, (2012) conformability refers to the extent to which the results of the study can be confirmed according to the degree of neutrality in the research study's findings. The data analysis included taking notes and recording. The researcher took note of the entire verbal and none verbal quos during the research. The researcher used non probability sampling method which promoted neutrality in selecting the results.

3.11Delimitations

The researcher chose Mhangura Township which is in Makonde district in Mashonaland West province because the area is characterised by mining activities which makes it a hotspot for STI's. The area is also close to where the researcher stays making it less expensive to travel. The study was focusing on the experiences in the managing of children on ART.

3.12 Limitations

The researcher encountered a few problems in the field. This research was associated with a sensitive issue of children living with HIV hence the care givers were not willing to open up to the researcher as the researcher was a total stranger to them. However, the researcher managed to overcome this challenge by explaining to the participants the principle of confidentiality and assured them privacy.

3.13 Chapter conclusion

This chapter outlined the methodology adopted for the study, and comprised the research design, target population, sampling methods, data collection methods, data collection instruments, data analysis and limitations and delimitations of the study. The chapter also focused on the ethics that the researcher was faithful to during the data collection and feasibility of the study.

CHAPTER 4

DATA ANALYSIS, PRESENTATION & DISCUSSION OF FINDINGS

4.1 Introduction

This chapter analyses and presents the qualitative data that was collected in Mhangura Town in Mashonaland West on the experiences in the management of children on ART. The results were derived from the interviews with the respondents from Makonde Christian hospital. The data is presented in form of tables and descriptions for the clear illustration of the themes that came out from the study. The main themes include: the experiences in the management of children on ART by caregivers and different related bodies, challenges being faced by children on ART, caregivers, and different health related boards in management of children on ART, coping mechanism being used in the management of children on ART by, children on ART, caregivers, and different health related boards in the management of children on ART and measures that can be implemented to improve the management of children on ART.

4.2 Demographic Information of Respondents

The section presents the demographic profile of the participants. The demographic profile of respondents is important in research study because it assists in data analysis and in constructing conclusions on data findings.

4.2.1 Demographics of the total respondents

Table 4.1

Respondents	Sex		Intended	Actual total
	Male	Female		
Caregivers	2	10	12	12
Children	6	6	12	12
Key informants (nurses, counsellors)	2	4	6	6
Total	10	20	30	30

Table 4.1 above, reveals that 12 caregivers participated in the study which included 2 males and 10 females. The table further shows that 12 children participated in the research with 6 females and 6 males. The table also shows that 6 key informants (nurses & counsellors) also participated in the study with 2 being males and 4 being females. The respondents included both males and females since the experiences in the management of children on ART affects them both. However, as shown by table 4.1, the respondents were mostly females, this shows that women are mostly relegated to care-giving duties due to matriarchy.

4.3 Qualitative Data Presentation

The research study aimed at exploring the experiences in the management of children on ART in Makonde District ward 2. In order to get the required information, the researcher conducted interviews with 6 key informants (nurses & counsellors), 12 care givers and 12 children on ART from Mhangura town. The researcher got the information from the respondents through interviews. The data was coded into different themes as illustrated below.

4.4 Experiences in the management of children on ART

This section explores the various experiences in the management of children on ART as articulated by caregivers, nurses, counsellors and children on ART. The experience of managing children on ART as articulated by the respondents was characterised by food shortages, loneliness, and shortage of drugs, stigma and discrimination.

All the key informants (6) pointed out that they experienced drug shortages in the hospital. One key informant further elucidated that there were times they gave patients medications which could only last for 2 weeks and this was said to be costly for the caregivers who needed transport to get to the hospital. This was strengthened by some care-givers (6) who explained that there were times when they were given a short supply of drugs which was costly for them as they faced transportation challenges. The caregiver explained that:

> "*panedzimwenguvadzatinombopuwamushongamushomausingakwanisekupedzamwedziizvizvinoitakutitiendekuchipatarakaviripamwedzizvinovazvinotidhurira*"
>
> "*there are times when we are given small drug quantities at the hospital which forces us to visit the hospital twice a month, this poses extra transport charges on us"*

Some key informants (3) further alluded that there was also lack of cooperation from the caregivers as they at times boycotted follow up visits. The respondent noted that some caregivers only come for drug refills but do not go with the child for review and monitoring to see if the drugs were responding well to the child. One of the respondents said that:

> *"some caregivers do not come with the children for viral load check-up and this is dangerous as the child can be drug resistant to the drug regime, which will result in a high viral load and it is dangerous"*

This shows that there should be cooperation of effort from both the caregiver and the nurse to ensure that the experience of managing children on ART is bearable for both the care-givers and the key informants.

Most of the caregivers (8) responded concerning the experience in the management of children on ART as a lonely and stressful experience as they went on to say that they were experiencing mental health distress such as anxiety and depression. Some of the care givers explained that they experience family disintegration because of the HIV virus living some of the care-givers as single mothers left alone playing the care-giving role, homemaker, household head and breadwinner.

> *"kubvapandakaberekamwanawanguainehutachiwanahweHIVhamahadzichandishanyire, kana iyemurumewangu baba vemwanauyuvakangoenda Havana kuonekananhasimwanaakurahavazivikanwekutivarikupi, sakadzimwenguvazvinondiremeranekutindinenge ndiri1 kutinditsvagechikafutiwanekudyapamba, zvinondidyapfungwakutisakaimhakayangu here kutiininemwanawangutinoraramanehutachionahweHIV"*
>
> *"*ever since I gave birth to my HIV positive child, family members have stopped visiting me. Even my husband, the father of my child just disappeared. Sometimes it's hard for me to provide food for me and my child and take care of her at the same time, I end up being stressed because of our health status*"*

This was said to be stressing and led to physical health deterioration.

Other caregivers (4) pointed out that they managed to get psychosocial support from family members as one caregiver argued that her in-laws were very supportive to her and her son since her husband died. She explained that her in-laws provided care and support that she

does not worry about anything as she was always free to go to them for help. The care-giver mentioned that:

> *"vatezvaravanguvanotipachibagemwedziwegawegavachititiwanekudyanemuzukuruwavo, amaivanouyawonedovirekubikiravana porridge kuitirahutanohwavo, naizvozvozvinondirerukirawopakuchengetamwanawangu"*
>
> "my father in-law gives us maize on a monthly basis for food, claiming it was for his grandchild's upkeep, and so does my mother in-law give us peanut butter as well, this makes it easy for me to take care of the child"

Children living with ART often complained that they were not getting enough food. This strengthens the findings from the caregivers who observed that they experienced food shortages in the management of children on ART as they could do some times without meals. This is because the caregivers will be confined to the house, providing care to the children infected by HIV, hence, not having enough time to be involved in income generating activities. Another child pointed out that there are days when they could survive on the lenience of well-wishers who would at times offer them meals however that would only sustain for a day.

> *"kanamumbamusinachikafundinoendakunodyakwagogondozodzokamanheruasimhamhavanengevasinakudyadzimwenguvagogovanombondipakutindivigiremhamha" (7 year old)*
>
> *"sometimes when there is no food in the house I go to grandma's house and feed sometimes she even give me some food to go and give my mother"*

The person being referred to as "gogo" by the child is not closely related to the child but is just a community member who is compassionate to the child for she understands her situation hence when she can, she assists the child by giving her meals here and there. The child also stated that "gogo" gives her some food to take to her mother at times.

4.5 Challenges in the management of Children on ART

This section explores the challenges faced in the management of children on ART by caregiver's, children on ART and key informants (nurses & counsellors). The findings expressed that financial challenges, disclosure challenges, drug administration challenges, poor resources, stigma and ill health are the main challenges experienced.

4.5.1 Poor Resources

In an interview with the key informants (3 nurses) they alluded that they faced challenges in human resources as they went on to say that they were understaffed in the OI department. Nurses alluded that it becomes tiring working 7 days a week hence at times they end up making mistakes in children's hospital cards which at times leads to wrong drug refill dates. As was confessed by one of the respondents that:

> *"one caregiver once returned for drug refill earlier than the date which was written for her because the drugs could not sustain to that date, if it wasn't for the caregiver the child would have deferred medication."*

Some caregivers (5) further strengthened this by alluding that the hospital is usually crowded with a lot of patients due to poor nurse to patient ratios, as the hospital is said to have a big catchment area hence in need of more human resource. Another respondent said that:

> *"chipatarachedu chine manusremashomaizvizvinoitakutitinonokekubetserwapatinengetauyakumushonga kana kuzorapwa"*
>
> *"our hospital has fewer nurses and this delays service delivery"*

Another key informant (1) (counsellor) articulated that the hospital lacks the technological capacity to perform HIV DNA-PCR for early HIV diagnosis in infants. The respondent said that blood samples are taken from the baby and are transported to Chinhoyi hospital for testing. The respondent was quoted saying:

> *"the turn-around time from the day blood samples are collected to the day the results are returned could take up to a week or even more hence delaying the child treatment if to be found HIV positive"*

This was further strengthened by another key informant (nurse) who articulated that transportation of blood samples for viral load and other tests like HIV DNA-PCR was a challenge as there are a few cars that are road-worthy at the hospital, hence samples are collected and at times stored at the hospital before being taken for testing this was said to be due to lack of transportation.

4.5.2 Drug Administration challenges

Some care-givers (7) noted that they faced challenges in administering the drugs to the children as they claimed that they were not clearly taught on the doses to give to the children at the hospital, as the nurses are always under pressure and also they were not able to read what was written on the prescription. One elderly caregiver explained that she was not able to read the prescription and administered 2 doses per day instead of one:

> *"kuverengakwavekundishupandakambopamwanamushongawemwedziwesemumavhiki maviriapondakadzokerakuchipatarakunotoraumwemushongamazuvaokudzokaasatiak wanandopandakazonyatsotsanangurirwakutimwanaaifanakupuwamushongasei"*

> *"reading is now a challenge to me as I'm now too old there was a time I gave the child wrong doses and the medication that was supposed to last for a month only lasted for 2 weeks only to be told when I returned to the hospital that I gave the medication incorrectly"*

This narrative shows that the age of the caregiver also affects the management of children on ART as the caregiver could be too old to read or administer drugs. This was strengthened by other respondents who explained that nurses were very busy at the hospital when the child was first initiated into ART and they did not explain thoroughly on how the drugs were to be administered. The caregiver said she used to give the child his medication without food and the child started feeling drowsy and sleepy sometimes. When the care-giver took the child to the clinic she was told to feed the chid first for the drugs were powerful and needed the patient to feed first.

This was strengthened by some key informants (4) who expressed that during the first days of initiation caregivers tended to have administration challenges as they sometimes forgot to give the children their medication and some would even double the doses. One key informant said that:

> *"there is one caregiver who once administered the ARV drugs to the child as if she was administering flue tablets as she gave the child the drugs three times a day"*

4.5.3 Drug Adherence Challenges

The key informants (6) all agreed that they faced adherence challenges as caregivers' boy courted drug refills soon after the date of initiation. The key informants pointed out that these

were lost to follow up clients and they were easily abandoned since tracking and re-initiating them into ART was said to be very costly. This was further strengthened by some caregivers (3) who explained that they faced adherence challenges when it comes to keeping the same time every day as one of the caregivers went on to express that:

"panenguvadzandinodzokakubasanguvayemwanayekutiamwemushonga wake yadarikaiyehaakwanisikuzivanguvaegakutiazvinwiresakazvinondinetsakuchengetedzanguvas akanaizvozvondinongoticheromwanandaupamushonga wake"

Most caregivers (8) articulated that the distance to the hospital was too long, such that at times they failed to go to the hospital for drug refills. This led to poor drug adherence as caregivers boycotted. This is further strengthened by some key informants (4) who explained that they faced challenges of high viral load in children on ART as a result of caregivers not adhering to ARV drug requirements.

> *"viral loads in children living with HIV are alarmingly high. This is mostly being caused by the failure of the caregivers to adhere to certain ART requirements such as time adherence and good nutrition"*

One caregiver complained that the writing which was used by the nurses at the hospital when writing the hospital cards was not clear enough, thus the caregiver went on to express that he once delayed returning for drug refill because he misread the returning date and by so doing the child skipped three days of therapy.

4.5.4 Financial Challenges

Financial instability was a common challenge amongst the care-givers, especially single mothers who were neglected by their husbands. The financial challenges were said to be emanating from transport costs, money for food and money for the children's school fees. This was strengthened by three key informants who expressed that the caregivers could sometimes walk to the hospital on foot as they claimed they had no money for transportation.

The time spent on care-giving made it difficult to spend more time on income -generating activities resulting in the caregivers being relieved of their duties from the farms they work in leaving the care-givers with no source of income. This led to little food in the house as was explained by one caregiver who said she was once employed as a sales lady on a farm, but when the child was consistently ill she started absconding from work and by the time the

child recovered she was told her services were no longer needed because she was not reliable. Thus being cut-off from her only source of income resulted in her relying on piece jobs:

> *Resp: "handiendekubasa, ndakasiyiswabasamazuvaarwaramwana, kubasavakanditindakangendavekunyanyakurovhasakazvinhuzvandaitengesazvakange zvoora (tomatoes, vegetables) sakavaidamunhuaikwanisakuuyakubasamazuvaose, sakamazuvanondavekungobatabatawohandingazongogarainindiriinimusorowemba. Dzimwenguvatinombosweranenzara"*
>
> *"I'm no-longer employed as I was sacked from my job because of inconsistence due to my child's sick health, whom I needed to take care of all the time"*

The reality of this narrative is a loss of job. This came as a result of the care-giver trying to juggle her care-giving duties with the daily demands of her job, hence it cost her, her job. It is clear that the care-giver losing her job affects the child receiving care as there will be no money for food.

In another related scenario, a care-giver said he lost his source of income as a result of the **COVID-19** pandemic as his kiosk was demolished in a bid to avoid people from gathering in market places:

> *Resp:"mazuvanozvinhuhazvinakumiramushe,murambatsvinawakaparadzapataishandi ratichitengesa,sakamazuvanokutizviitendinomboendakuchikorokozakutitikwanisekuw anakudyapamba"*
>
> *"these days things are even tougher since murambatsvina demolished my kiosk, I now rely on illegal gold mining"*

This shows that due to the need to curb the spread of the **corona virus** many were affected, mainly in the lower class, as they were left with no other source of living. Their kiosks were demolished. Kiosks are usually made from wood or light metal and are most commonly used by the lower class for business and at times for shelter. Hence the loss of his business did not only bring hunger to his house but emotionally he was affected as he was left desperate. The respondent explained that sometimes he would go for day's even weeks without returning were he would be illegally mining for gold so that he could earn the family a living. In some situations, it showed that care-giving was a team work between the father and the mother:

"dzimwenguva baba vachopavanoendakubasakunokorokozahavadzokekwemazuvamasangoanengearimate ma, zvinondiomerawoinikunokumbakutivanandovapeyi"

"there are times when my husband goes for work and takes long to returning, I will be left burdened on what I will feed the children"

This shows that in this partnership the father provides the raw materials for care-giving as the breadwinner, whereas the mother is the primary care-giver as she processes the raw materials for the direct benefit of the child. This means that if the provisions are cut off from the father the pressure imposed on the mother would be unbearable as she would be desperate on where to get the daily needs for the family meaning they would sometimes starve.

Some caregivers (4) expressed that due to poor financial status, it was hard for them to afford three meals a day. Some indicated that they aimed at one meal a day and if they managed to get a meal it was unbalanced in-terms of nutrition. This was strengthened by two key informants (nurses) who explained that some of the children on ART experienced stunted growth as a result of malnutrition. One caregiver said that:

"we only manage a meal a day so that me and my son can have our ARV drugs. It is almost difficult for me to go and seek employment because I have to be home taking care of my son most of the time. My health status has also deteriorated as I'm stressed psychologically because I'm always under pressure to feed my child as well as myself"

This is a typical case of double agony where a care-giver has to deal with her hunger and medical therapy simultaneously with that of her child who is even more vulnerable than her. The mental state of the caregiver could be comprehended from her narration that sometimes she cries out of desperation regarding what to do.

Some children (6) articulated that they faced financial problems as they could not afford money for school fees and stationery. The children (6) were of school going age but they spent all their time playing and helping in household chores as their caregivers had no source of income. One child went on to say that:

"I wish my mother had money for school fees so that I can go and learn and become a doctor one day, it's frustrating to be home every day as I watch my age mates go to school"

Five caregivers articulated that they faced financial problems for they could not afford to buy the children clothes so that they could wear. The caregivers said that they relied on good Samaritans who at times gave the children clothes and food.

4.5.5 Stigma from the Community

Findings from this study revealed that caregivers and children on ART were being stigmatised and neglected by family members after family members discovered that they were positive. This entails that caregivers were left alone to fend for themselves and their HIV positive children. One caregiver alluded that sometimes she feels ashamed by her HIV status and her child's as well:

"ndinopamwanamushonga wake chinyararirepasinaanoziva, nekutivanhuvanotaurisa"

"I give my child medication in secrete, because people are too talkative"

The truth of this narrative is that the caregiver was afraid that if people in the community knew that her child was HIV positive they would stigmatise the child as she has experienced before. Other respondents strengthened this by saying that they were left out in food aid programmes:

"mwedziwogawogakunouyachibagechemachembere, asiisuvanhukadzivanoramamanehutachionahweHIVhakunachinombouyadaivaizivakutizvinhuhazvinakutimiriramushemudzimbaumu"

"every month old people receive social grants, but us (PLWHIV) are left out in such programmes"

This narration shows that the care-giver felt left out in the society as they felt vulnerable and that no one was there for them. Given to them that old people where on grants they felt the need to be also included in food aid programmes on care-givers grants as it will help them.

Eight children expressed that they were stigmatised in the community as they were labelled and excluded by their age mates. Thus, this affects the children on ART as they internalise these and label themselves as different to others.

> *"vanhuvanondisvororodzavachitindirimwanawehure, zvinovazvinondishungurudzanguvazhinjindoswerapambahandichafarirekutambanekutindinozosekwa"*
>
> *"people in the community tease me saying that my mother is a prostitute that's why I have HIV and AIDs, I end up being ashamed of myself such that I can't even go and play"*

This shows that people view HIV as a disease acquired due to promiscuity thus people are so one sided to the extent that they oversee other ways in which HIV can be transmitted thus resulting in people attaching a lot of stigma to HIV and AIDs.

4.5.6 Disclosure challenges.

From the findings, it was noted that caregivers and children on ART faced disclosure challenges as the caregivers did not know how exactly to tell the children how they get infected by HIV on the other hand those children who knew about their statuses were not able to disclose to their peers as was the caregivers.

Other caregivers (9) strengthened this by alluding that they did not know how to tell the children about their status as they feared how these children would respond. This shows that the caregivers faced disclosure challenges as was observed from another responded:

> *"zvakanditoreranguvakutindizoudzamwanawangukutianehutachionahweHIV, ndaisimunyeperakutianwemushonga wake, ndakamuudzakutiasaudzavanhukutindomuraramirowedu"*
>
> *"it took me long to tell my child that he is HIV positive, however at some point I had to tell him but I told him never to tell anyone"*

This narrative shows that the caregiver was afraid to tell the child that he was born HIV positive which shows the amount of guilt the caregiver lays on herself for giving birth to her positive son. The caregiver admitted of telling her son not to tell people about their HIV status, this shows that the caregiver was not ready to let people to know about their status. On

top of that, she puts a lot of questions on the child why they kept it secret from other people. Not disclosing their HIV status could affect the child psychologically as he would think maybe he is different from other children. Some respondents argued that due to disclosure challenges, it came a time it was difficult to keep the child on his drugs for the children thought that it was unnecessary to keep taking drugs every day for they did not feel sick. This shows that the children receiving care were now resisting the drugs because they were not aware on why they were taking medication.

> *"dzimwenguvamwanaanorambakunwamushonga wake achitihandisikurwarazvekutindozosvikapakumumanikidzirakutianweizvizvinovazvino mushungurudzanekutianengeachitihandirwari"*
>
> *"there are times the child refuses to take her medication claiming she is not sick I then force her to take the medication"*

This narrative shows that some of the children on ART were now resisting medication for they were not aware on the reasons why they were taking the medication. There are possibilities that when the child was forced to take medication she could have been hiding the drugs pretending to be taking her drugs. Care-givers further alluded that disclosing the child's status to the child was one of the greatest challenges they faced in the management of children on ART as they claim they did not know how to tell the children. This was highlighted mostly by single mothers who said due to the fact that the child did not know their father, which made it worse for them to find ways how to will tell their children that they were born HIV positive.

Six children indicated that they faced disclosure challenges from their caregivers as they continued to take medication without the knowledge of why they were taking the drugs and also for how long they were going to be taking the drugs. This shows that the children on ART were given ARV drugs secretly until they became curious to know why they took drugs every day.

> *"ndakazozivakutiseindichinwamushonga everyday mushuremekungendarwarandaendeswakuchipatarandopandakazotsanangurirwa nana chirembakutindaivenehutachiwanahweHIV, zvakandiremeranokudakwekutiamaihavanakumbobviravandiudzavaingotitoramushonga wakomwananguukurewakasimba" (resp: 8 years old)*

"I realised why I took the medication every day after I was taken to the doctor it was difficult for me since my mother never told me"

This narrative shows that children living on ART came to know about their HIV status when they were a bit older due to curiosity regarding why and when they were going to stop taking their medication. Other children (5) also pointed out that they were scared to disclose their HIV status to their friends for they were afraid that their friends would not want to play with them anymore. Children on ART were distressed about their lifestyle for they were scared to disclose their status to friends because they were told not to by their caregivers. This caused distress to the child as they would be living a fake life were they would be lying about their status.

Four key informants conveyed that children on ART and their caregivers experienced disclosure challenges as the key informants' further articulated that caregivers had to come with the children to the hospital such that the primary counsellors would help disclose the HIV status to the child.

4.6Coping mechanisms used in the management of paediatric ART.

This subsection focuses on the coping mechanisms being implemented to overcome challenges in the management of children on ART. Respondents were asked on the ways they used to cope with their challenges and the results were presented below.

In a bid to address the challenges they face in the management of children on ART, the nurses in collaboration with ZACH came up with community peer mentors (CPMs) who are responsible for motivating caregivers to adhere to drugs as they would be responsible for most of the follow up visits during the first days of treatment. These CPMs are given assignments to track down defaulting clients and they report back to the hospital with information about the whereabouts of the client.

"the community peer mentors track down defaulting clients and those who will be in denial of their HIV status and they summon them to the hospital where the clients will receive counselling on adherence such that they carry on with their medication, however there are circumstance they do not succeed as some patients can be hostile due to the fear of stigma"

This narration shows that CPMs succeed in tracking and bringing defaulters back on ART but to some extent however failed on other clients who would probably be in denial. Other key informants indicated that they formed community ART refill groups (CARGs) which encouraged patients to adhere to their medication as they were grouped as community members on ART. This also helped in addressing stigma as another responded explained that through these CARGs confidence is built in the caregivers and children on ART. Murphy (1995), expressed that group work enhance the social functioning of people and communities hence these ART refill groups helps the caregivers and the children on ART to regain their social functioning as they would feel like they are not the only ones facing such challenges.

> *"vaberekivazhinji vane vanavanoraramanehutachionahweHIVvakapedzisiravonyarakuuyakuchipataranaizvo zvotakaonazvakakodzerakutitivagadziriremaCARGSayoanotimunhumumwechetepagr oupanokwanisakuuyaachitoramushongawevamwevachingopananamajanaasidzimwen guvatinombovadakutivesevauyenevanakuchipatara"*
>
> *"most of the caregivers ended up shying to come and collect their children's drugs hence CARGs were formed such that one group member could come and collect all other group members drugs however there are times we need to see the children for review at the hospital"*

This narrative shows that the CARGs are effective in addressing a lot of challenges being faced in the management of children on ART by both the caregivers and the key informants. It can also be noted that hospital visits for ART refills are reduced for caregivers and this gives them time to take on income generating activities so as to meet their basic needs requirements.

The findings on the coping mechanisms implemented by caregivers highlight that caregivers relied on piece jobs for income, in the farms they lived in as most of these caregivers lived in farm compounds. Other caregivers went on to say that these piece jobs were not reliable as they would only be employed during the rainy season hence for the rest of the year they would be struggling to make ends meet:

> *"kanairinguvayekunayatinombosunungukanekutimabasaanowanikahatizoshayisisech ekubatahazvizofananinedzimwenguva"*

"during the rainy season we rejoice as there would be many piece jobs which means more income for us"

Other respondents revealed that they relied on illegal mining for income such that they attain to get their needs met. This was effective as one of the respondents further explained that he could sometimes bring resources that could sustain the family for a month.

"ndinoendakuchikorokoza kana isiringuvayekunaya, zvinombobhadharawomamwemazuvaasimunongozivawomariyemusangokutihazviziika nwidzimwenguvazvinombodhakwazvekutindinopedzakaavhikimbirindirimusangopasin achabuda"

"during the dry seasons I go for illegal mining were sometimes it pays out and sometimes it doesn't"

This narrative shows that even if the caregiver managed to meet his family's basic needs, his ways of getting income were not sustainable as he mentioned that sometimes he could spend some time away from his family. Other respondents pointed out that they relied on social grants to address their challenges; this was explained by one elderly caregiver who articulated that she managed to meet her physiological needs and those of her grandchild through the old people's grants she received monthly:

"daiisirihurumendeinotivigirachikafuchamachemberemwedzinomwedzihandizivikutiti ngadaitichiraramaseinemuzukuruwangu, amaivakevakangomusiyahavasativadzokapavanemakorematatuvamusiya kana munyuzvavohavanditumire, ndinoitenda chose hurumendeyedudaiikarambayakadaro"

"if it wasn't for our government that gives us old people's grants I don't know how I could have managed with my grandchild, I appreciate our government so much."

This narrative shows that the elderly caregiver had no other source from which to earn a living if it wasn't for the old people's grants. The narrative again shows that the mother of the child being taken care of completely abandoned her child with no intention of coming back. Other respondents eluded that they shared household chores with the children on ART so as to reduce the burden of care giving on the caregiver alone and this was said to also motivate

the children on ART to build resilience as they felt useful just like their HIV negative counterparts.

The findings revealed that children on ART relied on their caregivers to address their challenges as they were too young to address some of the challenges themselves. Other child respondent eluded that she kept going to school despite the stigma she faced from her peers at school and she articulated that she was even better at school than most of the children who were HIV negative:

> *"vamwevaindisekakuchikorovachitindairwararauyeamaivanguipfambiasihandinakud akuoramoyondakarmbandichingoendakuchikoro, kudzamaravanhuvasisandisekemwakawakaperandakaita number 3 muclassmandodzidza"*
>
> *"my classmates used to laugh at me saying that I was always sick and my mother was a prostitute but that did not stop me, last term I came out in third place in my class"*

This narrative shows a unique case of resilience in a child who did not let the stigma from peers and society get to her as she pursued her dream in education.

4.7 Measures that can be implemented to improve the management of children on ART

The findings from the study showed that in a bid to improve the management of children on ART there should be following up visits to the chid living with HIV to monitor if the child is responding well to treatment. Key informants noted that these follow up visits should be drafted in a diminishing manner. This was strengthened by another key informant who explained that there was need to scale up voluntary counselling and testing through mobile outreach clinics which would reach out to those remote communities. This could help in index case findings for children living with HIV who could not be on treatment.

Furthermore, the current facility-based care model in the country that is essentially the provision of drug refills, counselling and peer activities, should be expanded to include direct supply of necessities such as food to vulnerable families, some caregivers eluded that the government should empower caregivers of children on ART with self-help projects that can enable them to be financially stable allowing them to meet their basic needs. Projects such as poultry and nutritional gardens were caregivers can manage to get a nutritional diet for the

child as HIV and nutrition are intimately connected. Thus through these projects the care givers will be self-sustainable.

The findings from the study eluded that there was need to address community structures to support people living with HIV through raising awareness on stigma related to HIV and how it could affect the community at large.

4.8 Discussion of findings

The researcher managed to understand all his 4 objectives from the findings presented above. The main aim of the study was to get an insight into the experiences of managing children on ART in Makonde district. The study was guided by Maslow's theory of needs. The theory assisted the researcher in understanding how the absence of the basic needs and the desire to attain the basic needs can influence the management of children on ART.

From the findings the researcher noted that women are the ones usually relegated to care-giving roles in the management of children on ART as most of the husbands neglect their families due to the HIV virus, hence women as primary caregivers are the ones who are mostly burdened in the management process of children on ART. It has also been noted from the findings that households affected by HIV are characterised by food shortages as the caregiver is mostly the breadwinner of the house hence much time of the caregiver is spent on care-giving hence no time for income generating activities leading to food shortages in the house. This corresponds to the findings by Mangwiro (2014) who expressed that households affected by HIV experienced food shortages which were exacerbated by bad weather patterns which made food production a problem.

From the findings, it was noted that nurses and primary counsellors faced challenges in human resources as they were understaffed. This collaborates with the findings from a study on the challenges faced in paediatric care and treatment in South Africa by Meyers (2007) whose findings explained that clinical capacity needed to perform HIV DNA PCR testing on infants at health care services, particularly outside of the major cities, is limited. Facilities are poorly staffed, and individuals with the skills required for paediatric venipuncture are scarce. This collaborates with the findings from the current study as both findings reveal that hospital facilities in the rural areas are understaffed. This causes problems in the management of children on ART as patient to nurse ratio will be unbalanced hence pressure is exerted on the nurses leading to mistakes in writing prescriptions for drugs as was evidenced in the findings

from the current study. Thus mistakes on drug prescription may result it wrong doses which will trigger drug resistance in the patients.

Dijk (2009) reported in his study that households of children infected with HIV have a low socio-economic. This concurs with finding from this study which expresses that, caregivers faced financial challenges as they failed to attain food commodities which are an essential in the management of children on ART as the ARV's are reinforced by a nutritional diet. The financial challenges emanated from money for medical bills, transportation cost for taking the child to the hospital and money food stuffs. The findings collaborates with the findings by Mafune (2017), which revealed that caring for children on ARV medication often resulted in caregivers borrowing money, accumulating and living in debt, footing or hiking for lifts to get access to the health facilities for follow-up. This also concurs to the findings by Mangwiro (2014) who expressed that, patients complain that they need food, CHBC kits, gloves, cotton, soaps and money for transport to go for reviews and other essentials or even money to cater for their needs. This also relates to another study by Zhao (2009) who articulates that caregivers often experience extended grieving, psychological trauma, fears, anxiety of neglect and discrimination from family, peers and neighbours. This also corresponds to the findings by Osafo (2017) who articulated that the caregivers of children on ART were insecurely employed as they spent most of their time in care-giving roles. This shows that care-givers of children on ART experience financial challenges in a bid to take care of the children on ART.

Findings from a study by Osafo (2017) conveyed that caregivers managed scarce resources by liquidating surplus from the farm produce, this shows that the caregivers where in a better position where they could harvest. Whereas in the current study care-givers expressed that they relied on grants for basic needs since they had no land to farm due to the fact that the area was once a mining town and the majority of the population were former employees from the mine with no agricultural land. This also goes hand in hand with the findings from a study by Osafo (2017) where some care-givers expressed that they relied on sponsors for food and school fees for the child. This also concurs to the findings by Mangwiro (2014) who expressed that some of the caregivers relied on aid and borrowing to meet their basic needs.

Findings from the study expresses that care-givers relied on piece jobs so that they could address food shortage challenges this corresponds to the findings from the study by Osafo (2017) where one caregiver articulated that he relied on his motor cycle for generating

income for food. This also concurs to the findings by Mangwiro (2014) who articulated that caregivers relied on piece jobs such as ploughing for others for money. Thus the similar studies show that care-givers of children on ART are not permanently employed but goes with whatever is available so that they put food on the table for the family, this can be due to the reason that the time spent on care-giving affects the daily routine of the care-givers such that they fail to get permanent employment for most of their time will be spent on care-giving hence affecting their working schedule.

Furthermore, it was shown from the findings of the study that follow up visits should be consistent in the management of children on ART such that nurses and social workers can monitor the progress and effectiveness of the drugs on the children. It can also be noted from the study that inclusion of the basic needs such as food in the provision of drugs to people living with HIV could also help in the management of children of ART as the children should be guaranteed of a meal every day. This corresponds to the study by Osafo (2017) who expressed that there was need for direct social intervention programs from government (in terms of daily provisions such as food) to resource-limited care-giving families of HIV patients was urgently required if informal home-based care for HIV should be a viable alternative.

4.9 Chapter Conclusion

The chapter has specified the research findings. The researcher managed to get an insight into the experiences of managing children on ART, understanding the challenges being faced in the management of children on ART by different third parties, strategies being employed by caregivers, nurses and counsellors to address the challenges in the management of children on ART and methods being implemented by different health bodies to better the management of children on ART.

CHAPTER 5

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

This chapter summarises the study findings on investigating the experiences in the management of children on ART in Zimbabwe a case study of Makonde district with reference to the research objectives and the data presented in Chapter Four. Moreover, it outlines the key recommendations and also the conclusion of the study.

5.1Summary of findings

The study sought to investigate the experiences in the management of children on ART in Makonde district. The research study was guided by the following objectives: to explore the experiences in the management of children on ART by caregivers and different related bodies; to identify the challenges faced by children on ART, caregivers, and different health related boards in management of children on ART; to find the coping mechanism being used in the management of children on ART by, children on ART, caregivers, and different health related boards in the management of children on ART; to identify measures that can be implemented to improve paediatric ART. The study utilised the needs theory by Abraham Maslow as its theoretical framework, which explained the experiences in the management of children on ART. The caregivers (12) and children on ART (12) were recommended by the key informants (3 nurses & 3 primary counsellors) who were sampled using purposive sampling technique. The qualitative methodology was used to present and analyse the research data.

5.1.2 The experiences in the management of children on ART

Findings from the study alluded that most of the respondents were experiencing food shortages, loneliness, and shortage of drugs, stigma and discrimination. These experiences are posing challenges in the management of children on ART as they affect the effectiveness of the drugs in children as the key informants expressed there is a high prevalence of high viral load in children. These experiences are affecting drug adherence in children on ART as older children are being affected by the stigma from the society.

5.1.3 The challenges in the management of Children on ART

In relation to the needs theory by Maslow, the time spent on care-giving activities means that there won't be much time for the caregivers to participate in income generating activities that can ensure their financial dependency such that they attain basic needs such as food. The findings from the study indicated that the challenges being faced in the management of children on ART includes, financial challenges, disclosure challenges, drug administration challenges, poor resources, stigma and ill health. These challenges are leading to the poor management of children on ART as they affect drug adherence, drug compatibility as ARV's require good nutritional support to be effective to the patient. The financial challenges were said to be emanating from transport costs to visit the hospital, money for food and school fees for the child being cared for. In relation to the needs theory, the lack of physiological needs such as food affects the management of children on ART as poverty further exposes the HIV infected house hold to social insecurities being perpetuated by stigma and discrimination.

5.1.4 Coping Mechanism being used in the management of children on ART

In relation to the theory of needs by Abraham Maslow, that states that if a human being fails to attain certain needs he or she find ways to try and meet those needs for example physiological needs (food), an individual cannot survive without food hence he/she is forced to search for food thus through working. The findings on the coping mechanisms being implemented to overcome challenges in the management of children on ART indicated that care-givers resorted to piece jobs in farms and illegal mining to meet their basic needs such as food and shelter amongst others presented. The findings indicated that community based ART refill groups that reported to Makonde Christian health facility were created which were there to help fight stigma and discrimination and reduce transport costs from hospital visits. Community peer mentors were established by ZACH an NGO that operates within Makonde Christian hospital, they were to help support adherence in HIV patients making child patients a priority.

5.1.5 Measures that can be implemented to improve the management of children on ART

Findings from the study indicated that there is need to scale up HIV testing and counselling through mobile outreach clinics that offers VCT and there should be follow up visits by health workers to child patients in the first months of medication to ensure that the child is responding well to medication. Findings indicated that the government of Zimbabwe and

other NGOs that have an HIV focused scope should connect with community based organisations in empowering economic independence in HIV affected households through self-help projects such as nutritional gardens and poultry which are sustainable projects that are income generating and at the same time providing the household with good nutrition.

5.2 Conclusion

In conclusion, the experience of managing children on ART in Makonde district ward 2 is characterised with loneliness in caregivers, food shortages, stigma and discrimination. These experiences are hindering the management of children on ART as majority of the child patients are said to have high viral load.

The study concluded that, financial challenges, disclosure challenges, drug administration challenges, poor resources, stigma and ill health are amongst the challenges that are faced in managing children on ART. These challenges have led to poor drug adherence and ill health in the child patients. The study concludes that caregivers of children on ART are physically and mentally worn out due to the double burden of performing double duties of care-giving and income generating.

The study expresses that CPMs, CARGs and FARGs were created for support purposes to HIV patients so as to promote adherence and fight stigma and discrimination. The study highlights that caregivers of children on ART relied on piece jobs and illegal mining for income such that they earn a living. This shows that the sources of income caregivers are relying on are not sustainable meaning that they are constantly exposed to poverty. The study concludes that mobile outreach clinics be engaged in a bid to scale up HIV diagnosis. The study also concludes that the government of Zimbabwe and befitting NGOs should empower HIV affected house-holds with self-help projects to empower economic independence and sustainability.

5.3 Recommendations

The study focused on the experiences in the management of children on ART in Zimbabwe a case study of Makonde district, ward 2. After an analysis of the findings the researcher came up with recommendations that can improve the management of children on ART. The recommendations are:

- The study recommends to NGOs like ZACH and the government of Zimbabwe, that HIV affected households in the rural areas be assisted financially, especially where the patients are children, the caregivers should be given care-givers grants.
- The study also recommends increasing health care facilities in remote areas, such as rural areas that are staffed with personals that are able to manage paediatric HIV, as well as knowledgeable about antenatal health care.
- The study also recommend that sound polices be put in place that have a bottom up approach so that they clearly address the challenges in the management of children on ART making the experience more manageable.
- There is need for more research to be carried on, in as much as paediatric ART literature is concerned so as to fully understand the concept of paediatric ART and find more ways to improve the management process.
- There is need for the invention of new ARV regimens specifically for children that would be tolerable to children, promoting drug adherence.
- The study recommends that social workers be employed in hospitals such that they can be case managers and help improve the management of children on ART.
- Implementation of socio-economic policies that provide caregivers with grants and empowers economic independence in the caregivers through self-help projects like poultry, goat farming and many other income generating projects.

5.4 Chapter Summary

The preceding provided a summary of findings, conclusion and recommendations to better the management of children on ART. It was highlighted in this chapter the challenges in the management of children on ART. The recommendations included more research to be carried out on the topic of children on ART and more policies to be formulated that cater for the socio-economic wellbeing of the house-holds affected by HIV.

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LIST OF APPENDICIES

Appendices (i)

Interview guide for nurses, caregivers, children on ART, primary counsellors from ZACH

My name is Zvikomborero Maushe a fourth-year student at Bindura University of Science Education, currently studying for a Bachelor Honours Degree in Social Work. As part of the requirements for the degree programme, a student should carry out a research on a preferred topic. My topic is entitled, **"An investigation on the experiences in the management of children on ART in Makonde district ward 2.** This study is strictly for educational purposes only hence forth l kindly asks for your support through participating in the interview to be carried out using this guide. The research will be carried out on the basis of informed consent, which means that you are given all the necessary information which will guide you through the research process as well as the freedom of choice in terms of participation and freedom to withdraw from participating. All the information you will share with me during the study will be kept confidential which means it will never be shared to any other individuals; hence you will be protected from any sort of societal stigma. Please if you agree sign in the gaps provided in the consent form below.

I……..consent to take part in this research under the above-mentioned terms. I confirm my willingness with the signature below.

Interviewee's signature: ……. Date: ……/……. /…….

Interviewer's signature: ……. Date: ……/……. /…….

Research Objectives

- To explore the experiences in the management of children on ART by caregivers and different related bodies.
- To identify the challenges faced by children on ART, caregivers, and different health related boards in management of children on ART.
- To find the coping mechanisms being used in the management of children on ART by, children on ART, caregivers, and different health related boards in the management of children on ART.
- To identify measures that can be implemented to improve paediatric ART.

Research Question

The main key questions to be addressed by this research are:

I. What experiences exist among care givers and different health related boards pertaining to the management of children on ART?

II. What challenges are being faced in the management of children on ART?

III. What coping mechanisms do you use in the management of paediatric ART?

IV. What strategies do you think can be implemented to better the management of children on ART?

V.

Appendices (ii)

Interview Guide for nurses and primary counsellors (ZACH) working at Makonde Christian hospital

SECTION A: **Demographic Information. (**Fill in the gaps)

1. How old are you? …….
2. Sex ……..
3. Occupational post……

Section B: To find out the experiences in the management of children on ART

1. How long have you been involved in pediatric ART treatment?
2. How can you describe your relationship with caregivers?
3. How do caregivers of children on ART respond to pediatric ART?

Section C: To identify challenges in the management of children on ART

1. What challenges do you face as nurses and at facility level in managing pediatric ART?
2. What challenges do you face as primary counsellors and at organizational level in the management of children on ART?

Section D: To identify copying mechanisms used in the management of paediatric ART

1. What strategies do you use to overcome those challenges in the management of children on ART as nurses?
2. What strategies do you use to overcome challenges in the management of children on ART as an organization (ZACH)?
3. How effective are these strategies in addressing these challenges?

Section E: To find out strategies that can be implemented to better the management of children on ART

1. What strategies do you think can be implemented to better the management of children on ART?
2. What strategies do you think the government should implement to better the management of children on ART?
3. What strategies are you implementing to improve the management of children on ART?

THE END…….. THANK YOU

Appendices (iii)

Interview Guide for caregivers of children on ART

SECTION A: **Demographic Information. (**Fill in the gaps)

4. How old are you? …….

5. Sex ……..
6. Occupational post……

Section B: To find out the experiences in the management of children on ART

1. How do the children on ART cope up with their lifestyle?

Section C: To identify challenges in the management of children on ART

1. Which challenges do you face in the management of children on ART?
2. From the challenges you mentioned earlier which challenge can you say to be most troublesome?

Section D: To find the copying mechanisms used in the management of children on ART

1. What copying mechanisms do you use to overcome challenges in the management of children on ART?
2. How effective are these copying mechanisms in addressing your challenges?

Section E: To find out strategies that can be implemented to better the management of children on ART

1. Which strategies do you think can be used to better the management of children on ART?
2. What do you think the government must do to better the management of children on ART?

THE END…….. THANK YOU

Appendices (iv)

Interview Guide for children on ART

SECTION A: **Demographic Information. (**Fill in the gaps)

1. How old are you? …….

2. Sex ……..

Section B: To find out the experiences in the management of children on ART.

1. Who do you live with?
2. Do you have friends?

Section C: To identify challenges in the management of children on ART.

1. What challenges do you face as children in the management of children on ART?
2. How do people treat you in the community?

Section D: To identify copying mechanisms used in the management of paediatric ART?

1. How do you address your challenges?
2. How effective are the methods you use to address your challenges?
3. Do family members give you assistance?

Section E: To find out strategies that can be implemented to better the management of children on ART.

1. What do you think should be done to help improve the management of children on ART by the government and NGO's?

THE END…….. THANK YOU

Appendices (v)

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BINDURA UNIVERSITY OF SCIENCE EDUCATION

Date .....

HEALTH SERVICES ADMINISTRATOR
MAKONDE CHRISTIAN HOSPITAL
11 JUN 2021
P.O. BOX 193, MHANGURA
TEL: 067-214 5948

TO WHOM IT MAY CONCERN

Dear Sir/Madam

REQUEST TO UNDER TAKE RESEARCH PROJECT IN YOUR ORGANISATION

This serves to advise that MAUSHE ZVIKOMBOREDO Registration No.

B 174 96 98 is a BACHELOR OF SCIENCE HONOURS

DEGREE IN SOCIAL WORK student at Bindura University of Science Education who is conducting a research project.

May you please assist the student to access data relevant to the study and where possible conduct interviews as part of the data collection process.

BINDURA UNIVERSITY OF SCIENCE EDUCATION
SOCIAL WORK DEPARTMENT
23 FEB 2021
FACULTY OF SCIENCE EDUCATION
PRIVATE BAG 1020, BINDURA, ZIMBABWE

HEALTH SERVICES ADMINISTRATOR
MAKONDE CHRISTIAN HOSPITAL
11 JUN 2021
P.O. BOX 193, MHANGURA
TEL: 067-214 5948

Yours faithfully

Maushe

Mr F. Maushe
CHAIRPERSON – DEPARTMENT OF SOCIAL WORK