



COLLEGE OF MEDICINE AND HEALTH SCIENCES

RESEARCH REPORT

**EXPERIENCES FACED BY CAREGIVERS OF CHILDREN LIVING
WITH HIV AND AIDS IN LIBERIA: THE CASE OF MARTHA TUBMAN
MEMORIAL HOSPITAL.**

By:

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**This dissertation was submitted in Partial Fulfilment of the requirements for
the master's degree in NURSING SCIENCES (PEDIATRIC) of the SCHOOL
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DECLARATION

I, AMELIA TINA VORKPOR; do hereby declare that this research report submitted in partial fulfillment of the requirements for a master’s degree in Nursing Sciences at the University of Rwanda, is my original work and has not previously been submitted elsewhere. Also, I do declare that a complete list of references is provided indicating all the sources of the information quoted or cited.

AMELIA TINA VORKPOR

Signature



AUTHORITY TO SUBMIT RESEARCH REPORT

We in our capacities as supervisors, do hereby authorize student Amelia Tina Vorkpor to submit the report “The experiences faced by caregivers of CLWHA in Liberia; The case of Martha Tubman Memorial Hospital”

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Signature... ..



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Signature...



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Signature



DEDICATION

I dedicate this work to my family members i.e. parents, brothers, and sisters for being supportive to me in the process of preparing this research dissertation.

ACKNOWLEDGMENT

The preparation of this research report is indebted to many individuals and organizations who gave me advice, encouragement, assistance, inspiration, and guidance from start to end.

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ABSTRACT

Introduction:

HIV and AIDS continue to have a catastrophic impact on both adults and children. In 2017, the World recorded 3 million children and adolescents aged 0-19 years LWHA, of which 1.9 million lived in Eastern and Southern Africa; 780,000 lived in West and Central Africa (prevalence rate was 2.2%, 2017) and 130,000 lived in South Asia, but study focus is on (Liberia- W /Africa) As of 2018, Liberia recorded 3700 children aged 0-14 years LWHA.

Greater efforts were made to provide care and support to CLWHA across the world including the provision of pediatric HIV care. E.g. The United against AIDS initiative was targeted in 2010 to provide either ARV treatment or co-trimoxazole or both to 80% of children in need. It was also aimed, to reduce the percentage of young PLWHA by 25% globally. However, only 52% of children aged 0-14 were receiving ARVs therapy across the world, with West and Central, recording only 26% of ART coverage among children aged 0-14 years. Of the 26%, only 18% of CLWHA in Liberia are receiving ARVs treatment. HIV first case in Liberia (1986) .MTMH (381 cases, record of 2021). After reviewing other literature worldwide, with topic under study, the researcher seeks to know the experiences of C/givers of CLWHA in Liberia at the MTMH.

Objectives: To explore experiences faced by the caregivers of CLWHA at the MTMH in Liberia.

Method: The study applied a phenomenological research design through which the researcher collected qualitative data by interviewing 8 primary C/givers of CLWHA at the MTMH.

Population: The researcher used family C/givers of children between 0-14yrs. Purposive sampling was used to select participants. Sample size (8) primary C/givers of CLWHA who meet the pre-set criteria. **Method of data collection:** Semi-structured interview guide was used to collect data from the primary C/givers of CLWHA.

Method of data analysis:

The researcher utilized a thematic analysis to analyze the data and also used the dropbox server for data safety. **Results** of this study show that these people are experiencing multiple challenges in Liberia: Extensive caring responsibilities, etc.

Conclusion: Holistic care and attention is needed to address their problems.

KEYWORDS: EXPERIENCE, CAREGIVERS, CHILDREN LIVING WITH HIV/AIDS.

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS;Acquired Immuno Deficiency Syndrome

ART;..... Antiretroviral therapy

ARVs;..... antiretrovirals

CLWHA;children living with HIV/AIDS

FCGs;..... Family caregivers

HIV;.....Human Immunodeficiency Virus

MTMH;Martha Tubman Memorial Hospital

PLWHA;..... People living with HIV/AIDS TABLE

CHAPTER ONE: BACKGROUND INFORMATION

1.1 Introduction

HIV and AIDS continue to have a catastrophic impact on both adults and children. [1] In 2017, the World recorded 3 million children and adolescents aged 0-19 years living with HIV/AIDS, of which 1.9 million lived in Eastern and Southern Africa; 780,000 lived in West and Central Africa, 130,000 lived in South Asia, 100,000 lived in Latin America and the Caribbean, 93,000 lived in East Asia and the Pacific, and 7,100 lived in the M/ East and N/ Africa. The location of study is in W/Africa (Liberia) reason study focus was on said location. [2] As of 2018, Liberia, a Sub-Saharan African state recorded 3700 children aged 0-14 years CLWHA ,reasons why study was carry out. The implication (s) is that if care is not taken we will lose our children to such disease, increasing family burden, depressions and reducing human resource for future [3]

The international community has made greater efforts to provide care and support to children living with HIV/AIDS across the world including the provision of pediatric HIV care. For instance, the Unite for Children, Unite against AIDS initiative was targeted in 2010 to provide either antiretroviral treatment or co-trimoxazole or both, to 80% of children in need. It was also aimed, to reduce the percentage of young PLWHA by 25% globally. On October 25,2005, UNICEF,UNAIDS, WHO and other partners around the world lunched 5-years global campaign to work with organizations who primary goal is to reduce the spread of HIV/AIDS, and other infections with focus on children and Aids, including youth to met SDG # 6) to stop the spread of HIV/AIDS, and other diseases, with focused on 4 key areas: PMTCT, provision of pediatrics treatments (either ARVs, or CTX,(cotrimoxazole), or both to 80% of children in need, prevent infections among adolescents and young people(with reduction in percentage by 25% globally), and protect and support children affected by AIDS (by 2010).[4] However, available data indicates that only 52% of children aged 0-14 were receiving antiretroviral treatment across the world, with West and Central Africa where Liberia belongs recording only 26% of ART coverage among children aged 0-14 years. Their objectives were met, although not 100% by then. [2] The current data indicates that only 18% of CLWHA in Liberia are receiving antiretroviral treatment. [3] The Misconceptions of ARVs amongst population and limited care from c/givers was contributing to death of these children before reaching the age of 2years (Survey done in MTMH 2013), despite local and intentional partners supports.

The government of Liberia in collaboration with other international organizations has made a greater effort in providing services geared toward preventing new HIV infections and providing HIV treatment, care, and support services, to all the people in the country including the children.[5] For several years the Liberian government has implemented a multisectoral decentralized HIV response with national coordination by National AIDS Commission through five mandates (Programs and Policy, Partnership, Decentralization, and Monitoring & Evaluation). Also, the Ministry of Justice has established an HIV and Human Rights Platform to advocate and coordinate stakeholders' response to HIV-related human rights issues and violations and creates a legal environment for enforcement [5]

In partnership with the government, the media in Liberia has significantly contributed to the national HIV response by covering key events as well as providing information, education, and communication on HIV prevention, treatment, care, and support. [5] Despite all the efforts by the government of Liberia and other stakeholders, care and support for children living with HIV and AIDS have remained a difficult task among caregivers of children living with HIV and AIDS.

In the global context, the literature provides a significant number of factors that explain the phenomena. For instance, a study conducted by Lundberg [6, 7] on caregiving to persons living with HIV/AIDS on experiences of the Vietnamese family members identified, cultural and religious factors associated with caregiving, keeping secrets to avoid stigma and discrimination, lack of knowledge about the disease and provision of care and fear, anxiety, and frustrations are the main experiences being faced by the primary caregivers of persons living with HIV/AIDS. On the other hand, Williams, Van Rooyen, and Ricks [8] identified service accessibility, staffing, stigma, fear of disclosure, and denial as the major experiences faced by the primary caregivers of CLWHA in South Africa. Also, Mafune, Lebeso, and Nemathaga during their study on a similar topic established that financial burdens to comply with follow-up dates, insufficient money to buy food and clothes for children in need of care, as well as stigmatization against children on ART by family members, represents the main experiences faced by caregivers in Mutale Municipality, Limpopo province. [9]

While a significant number of studies have been done globally to investigate the phenomena, little was known in the Liberian context, thus, the constraints and concerns expressed by C/givers in other parts of the world were the motivation for carrying out similar study in country at the

MTMH, G/GEDEH COUNTY to investigate their own experiences that they (caregivers) face in Liberia, with prevalence rate is 3.9%. The study aimed to use the double ABCX model to explain the experiences faced by caregivers of CLWHA in Liberia specifically from Grand Gedeh County.

1.2 Problem statement

Problem statement (base on the reviewed of other literature around the world with topic under study, the researcher seek to know the experiences of C/givers of CLWHA in Liberia at the MTMH).

Caregivers of CLWHA go through numerous experiences, some of which are psychosocial.

According to Lundberg, Doan, Dinh, Oach, and Hoang Le, [6, 7] C/givers should be given special attention and assistance that will ensure their better emotional and economic well-being. That way, they will be able to adequately attend to their children and wards for proper care. With a scheme in place that provides equal attention to C/givers of these children, they will grow to overcome their experiences and attain maximum potential in their life journeys. [6, 7,] at the MTMH, most of the care provided to CLWHA by C/givers is inadequate, given the fact that most of the C/givers are impoverished, have a knowledge deficit about disease, and are aged. (Quoting study participants). They also walk long distances to facility.

There are some international organizations such as Partners in Health, and UNHCR that have a program of support with food, clothes, etc for C/givers of CLWHA. Despite all efforts, there have been delays in-clinic appointments as the health care providers have been insisting on the importance of adherence to appointments, as attendance at the clinic is not coherent with appointment dates.

A significant number of studies have been carried out globally to explore the experience of CLWHA [6, 7, 8, 9, 10], but no study has been done in Liberia (from the Literature viewed) context where the prevalence rate is 3.9% (both children and adults). [3] Therefore the researcher seeks to answer the research question: What are the experiences faced by caregivers of CLWHA at MTMH in Liberia. In carrying out the study, the researcher used the double ABCX model(is a family stress model which in terms of crisis teaches family how to build positive resilience in the

mist of crisis), reasons why such was chosen to explain similar experiences faced by caregivers of CLWHA in Liberia specifically from Grand Gedeh County.

1.3 The general objective of the study

The general objective of this study was to explore the experiences faced by caregivers of CLWHA in Liberia.

1.3.1 Specific objectives

1. To garner personal experiences faced by caregivers of CLWHA at the Martha Tubman Memorial Hospital in Liberia.
2. To identify resource-related experiences (ABCX model) faced by caregivers of CLWHA at the Martha Tubman Memorial Hospital in Liberia.
3. To explore psychosocial experiences faced by caregivers of CLWHA at the Martha Tubman Memorial Hospital in Liberia.

1.3.2 Research questions

1. What are the personal experiences faced by caregivers of CLWHA at the Martha Tubman Memorial Hospital in Liberia?
2. What are the resource-related experience (ABCX model) faced by caregivers of CLWHA at the Martha Tubman Memorial Hospital in Liberia?
3. What are the psychosocial experiences faced by caregivers of CLWHA at the Martha Tubman Memorial Hospital in Liberia?

1.3.3 Significance of the study

The relevance of this study was constructed on the fact that no research on this design had been conducted in Grand Gedeh County in Liberia to explain the experiences faced by the caregivers of children living with HIV/AIDS. Therefore, this study was designed to fill this knowledge gap that is relevant for policymakers, health care practitioners, and the academic community in general on the subject. More specifically, the findings from this study enable the policymakers

and healthcare practitioners in Liberia to better understand the severity of experiences encountered by the caregivers of children living with HIV/AIDS in the country thus, come up with relevant interventions to address the identified experiences to boost the provision of quality care to CLWHA. Regarding the academic community, the findings from this study add knowledge among the researchers on the phenomena under investigation from the context of Liberia, thus ensuring external validity.

1.3.4 Organization of the Report

This report proceeded as follows; Chapter One: Background information;

Introduction, The general objective of the study, Specific objectives, Research questions, and Significance of the study.

Chapter two discussed concepts, a theoretical model which explained the experiences faced by FCGs of CLWHA, empirical studies, and research gap, whereby chapter three focused on the methodology such as the study design, study area, participants, sampling strategy, data collection instruments, data analysis plan, ethical consideration, limitation of the study and the timeframe, chapter four: Results presentation; 4.0 Introduction Section 4.1 provided the general socioeconomic and demographic characteristics of the sample population including the number of respondents who participated in this study, age, marital status, relations with the child they took care of, residence area, occupation, and so forth.

Section 4.2 presented the study findings on the personal experiences of C/givers of CLWHA who attend clinics at MTMH. Section 4.3 provided the findings on resource-related experiences of C/givers of CLWHA who attend the clinic at MTMH. Section 4.4 presented the results on the psychosocial experiences of C/givers of CLWHA who attend clinics at MTMH.

Chapter **five**: This chapter provides a summary of the study findings responding to the specific research objectives of this study, which aimed to understand the personal, resource-related, and psychosocial experiences of caregivers of CLWHA in Liberia.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Literature were reviewed from various sources, research questions developed base on objectives of study with the list of keywords, and 23 relevant articles were review and used.

This section covered sub-topics such as the definition of key terms, theoretical literature, empirical studies, research gap, and the conceptual framework which guided this study.

2.2 Definition of key terms

2.2.1 Caring

In this study, caring referred to the primary caregiver's role of looking after the children living with HIV/AIDS to ensure that the children's social, educational, financial, health, physical and emotional needs are met.[10]

2.2.2 Children

In this study, children referred to persons under the age of 0 to 14 years living with HIV/AIDS. [10]

2.2.3 Caregivers (family c/givers; parents, and extended relations)

In this study, a primary caregiver referred to an adult, living in the same household as the child in question, who is ordinarily responsible for supervising the care of the child in the home and for bringing the child to the hospital for his/her regular clinic visits. [10]

2.2.4 Experience

2.3 Theoretical literature

This study opted to utilize the double ABCX model of family stress and adaptation initially developed by Reuben Hill in 1965 to explain the experiences facing caregivers of children living with HIV and AIDS. Hill in his ABCX model identified three factors that explain the severity of the crisis, and they include (a) the hardships of the situation or the event itself, (b) the resource of the family, and (c) the family's definition of the event as threatening. According to Hill, these are the explanatory factors that determine the severity of the crisis, [11].

More than three decades later McCubbin and his colleagues reviewed this model on the ground that it did not provide social scientists with a complete understanding of the process of families under the stress. [11]

In 1982-83 McCubbin and his colleagues developed the double ABCX model of family stress and adaptation which redefined the precrisis variables and added the postcrisis variables, to describe (a) the additional life stressor and strains, before or following the crisis-producing event which results in a pile-up of demands; (b) the range of outcomes of family process in response to this pile-up of the stressor (maladaptation and bonadaptation); and (c) the intervening factors that shape the course of adaptation: family resources, coherence, and meaning. [12]

The Pile-Up (the aA Factor)

McCubbin and colleagues described the pile-up of demands as the cumulative impact of both pre and post-crisis stressors and strains. The authors pointed out that postcrisis stressors for instance required role changes, prior unresolved strains, and intrafamily boundary ambiguity, all may be demand for change and source of strain that the family faces while struggling with the major stressor event. [12]

Family adaptive resources (the bB factors)

Adaptive resources here include both the existing family resources and the additional resources developed or strengthened in response to the demands brought by the stressor. [9] These resources tend to act as mediators between the accumulated demands and family adaptation to the crisis. This means the resources have the potential to facilitate the family's adaptation to the change or to reduce the effects of the demands. These resources exist in three forms (a) personal resources-that is the attributes of a family member for instance self-esteem, knowledge, and skills which is available in the family when the family needs them, and (b) family system resources which include family cohesion, family adaptability, and supportive communication (c) Social support- such as community support and friendship support. [12]

Perception and coherence (cC factor)

This involves the general adaptation of the family to the overall situation. It reflects a sense of acceptance and understanding of the situation, a framework within which the definition of the situation is made and within which perceptions are judged.

The authors point out that, coherence at the family level is influenced by the family experiences from its internal environment, for instance, the family strength and the cumulative effects of the experiences whether positive or negative with the external environment.

The family experiences tend to shape the definition the family gives to the event or a situation, including the stressor, and the resources the family has to address the accumulated demands, in this way coherence acts as an intervening variable between the crisis and the capacity of that family to handle the crisis. Therefore it has the potential to facilitate or distort family efforts to address the situation. [12]

Family adaptation (xX factor)

Family adaptation is treated as the outcome of the family's processes to respond to a stressful event and additional demands. This variable runs from maladaptation to Bonadaptation. Maladaptation implies the continuing imbalance between the cumulative demands and the capacity of the family to address the demands. This can be characterized by deterioration of family integrity, family members' sense of wellbeing, and their physical and/or psychological health,[12] On the other hand, bonadaptation is the positive end of the family adaptation spectrum demonstrating a minimum discrepancy between the cumulative demands and the capacity of the family to address them. It is characterized both by the maintenance or strengthening of family integrity and by family members' sense of well-being. [12]

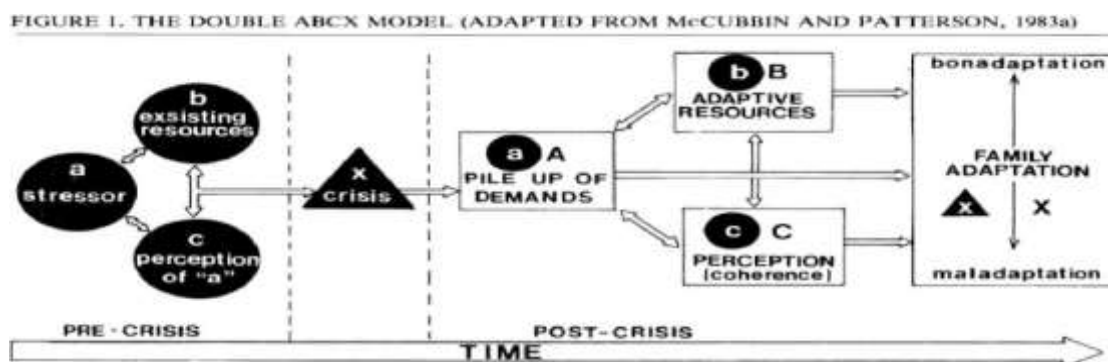


Figure1: The Double ABCX Model (Adapted from McCubbin and Petterson, 1983a)

2.4 Empirical literature

Kathuli-Ogola, Mugenda, and Kerre investigated challenges faced by family caregivers in dealing with people living with HIV/AIDS in Thika District, Kenya.

The researcher collected data from 177 primary FCGs of PLWHA, drawn from proportionate stratified random sampling from three divisions in the study area were used.

Data was collected through interviews and focus group discussions and analyzed qualitatively and quantitatively. The results indicate that financial, food provision, stress, and stigma are the main challenges faced by FCGs. [13]

Rutakumwa, Zalwango, Richards, and Seeley, explored the Care Relationship between Grandparents and Children Infected with HIV in South-Western Uganda: The researchers collected the data through semi-structured interviews, and the study found several challenges faced by caregivers including, “poor physical and psychosocial wellbeing; poverty and reliance on cultivation-based livelihoods; and inadequate support from family members. [14]

Bejane, Havenga, and Aswegen investigated the primary caregivers’ challenges related to caring for children living with HIV in a semi-rural area in South Africa. The researchers identified several challenges faced by the primary caregivers including not knowing the causes of the children’s frequent illnesses, coming to terms with the HIV-positive diagnosis, ensuring treatment adherence, as well as the prevention and management of episodes of illness. [10]

Rujumba, Mbasaalaki-Mwaka, and Ndeezi investigated the challenges faced by health workers in providing counseling services to HIV-positive children in Uganda. The researcher adopted a descriptive study design. The findings indicate that the knowledge gap in pediatric HIV and the lack of counseling skills, as well as health system-related constraints, were the main challenges faced by health workers in the provision of counseling services to children living with HIV/AIDS. [1]

Osafo investigated the experiences of caregivers of children living with HIV and AIDS in Uganda. The researcher adopted a qualitative study design. The findings indicate two major challenges faced by caregivers including the insecure provision of food and difficulties in accessing health care. [15]

Mafune and Lebeso explored and describe the challenges faced by caregivers of children on ART at Mutale Municipality, Vhembe District, Limpopo Province. The researchers adopted the qualitative, explorative, descriptive research design. The findings indicate that caregivers of children on ARTs face two main challenges; the financial burden and stigma. [9]

Nasuuna investigated challenges faced by caregivers of virally non-suppressed children in the intensive adherence counseling program in Uganda. The study adopted a qualitative study design.

The results of the study surfaced several challenges faced by caregivers including i) environmental (school activities, working away from home), ii) personal (nondisclosure, stigma), iii) psychological (guilt), iv) financial (lack of food and transport) and v) child-related (fatigue and peer influence). [16]

Williams, Van Rooyen, and Ricks conducted a study in South Africa and identified several challenges facing caregivers of children living with HIV/AIDS, including staffing, service accessibility, Stigma, and Fear of disclosure and denial. [17]

Kajubi explored the communication between HIV-infected children and their caregivers about HIV medicines in Uganda. The researchers adopted a cross-sectional study design. The findings indicate that communication about, and knowledge of, HIV medicines among children with HIV is low. [18]

Lentor investigated the psychosocial Challenges Associated with Caregiving in the Context of Pediatric HIV in Rural Eastern Cape. The researcher collected the data through interviews. The findings surfaced several challenges facing caregivers of children living with HIV/AIDS including, Poor Quality Social Conditions, Overcrowding (Density), Unemployment, Lack of Financial Resources and Support, Lack of Nutrition, stigma, Continuing Child Health Problems, and Caregiver Health Problems. [19]

2.5 Research gaps

It is clear from the literature that multiple studies had been carried out across the world to explore the experiences faced by caregivers of children living with HIV/AIDS.

However, in Liberia, no such type of study had been conducted to explore the caregiver's experiences faced during caring for CLWHA. Thus this study aimed to use the double ABCX model to explain the experiences faced by caregivers of children living with HIV/AIDS in Liberia specifically from Grand Gedeh County.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter explained how the study was carried out. It described sub-topics such as the study design, study area, participants, sampling strategy, data collection instruments, data analysis, ethical considerations, limitations of the study, and timeframe.

3.2 Study design

This research applied a phenomenological research design. This design entailed collecting qualitative data by interviewing the caregivers of CLWHA in the field. The researcher used six (6) weeks to collect data from the study participants i.e. from the second week of October to the third week of November 2021. This research design was adopted because it allowed the researcher to probe deeper understanding into the phenomenon under investigation given the fact that little was known about experiences faced by caregivers of CLWHA in Liberia; therefore, this design was an appropriate approach for this study as it focused more on the what, how and why of the research subject.

3.3 Study area

This study was carried out in Liberia, specifically at the Martha Tubman Memorial Hospital, which is located in Grand Gedeh County South East of Liberia, approximately 250 miles from Monrovia, Liberia's capital. The hospital was selected because it is the only public referral and teaching hospital in Zwedru City and Tchien District of Grand Gedeh County with a 100-bed capacity. The hospital has both inpatient and outpatient departments. The outpatient department includes maternal and child health clinics, an eye unit, an Antiretroviral Therapy clinic (ART), an immunization center, a tuberculosis center, and a laboratory department. The inpatient department comprises four wards namely; male, female, pediatric, obstetric wards, and the emergency department. The facility uses both electronic and hard copies of patient records. The hospital offers free health services which include; consultations and medication, also through Partners in Health (PIH) they are provided with nutritional support and clothes, especially to those disadvantaged groups of patients, it offers excellent care to HIV/AIDS-positive patients receiving ARV and other medications out-patient and in-patient departments.

3.4 Participants

The study participants included primary family caregivers (FCGs are parents and extended family members who are caring for CLWHA, with data collection for period of 6weeks (Oct-Nov.2021). However, only caregivers who had primarily given care to children living with HIV/AIDS for at least 6 months were recruited for the study. This was because the study believed that these caregivers could provide valid experiences since they had taken care of CLWHA for a substantial period. However, caregivers of CLWHA with seriously sick children and those who had cared for less than 6 months were excluded to participate in this study.

3.5 Sampling strategy

The study used purposive sampling strategies to select participants for the study. This may have some biases but which were minimize as study was done with all credibility intact (trustworthiness, transferability, dependability, and confirmability) [20], and as far as this research is concern, there is no conflict of interest. The researcher used this method to select participants from among the primary FCGs who bring their children to attend the ART clinic at the aforementioned hospital. The researcher opted to utilize a purposive sampling technique because the researcher was interested in gaining insight into experiences faced by caregivers of CLWHA in Liberia, so selecting the right population was key to the success of the study at hand. Through this strategy, the researcher targeted to select the sample size of 8 participants, base on saturation as there were no new themes emerging.

According to Sim et al,2015 saturation is the best metric to identify the right participants Also Malterud and Sandelowski.,[21,22] sample size should be large enough to answer research questions to achieve objectives. Weller proposes the use of saturation as a salience [22].According this tool sample size can be 10 units the purpose is to explore the most revalent ideas (as in the case of this study), or larger if aims are to explore broader ideas. The establishment of this sample size is based on several factors including the nature of the study itself (qualitative study) which after data collection requires the researcher to transcribe each participant's interview and analyze them to know whether all possible pieces of information related to the study have been covered. Other factors include available resources both human and financial resources, the number of questions in the interview guide, and the volume of data that the researcher seeks to record.

3.6. Data collection instrument (include interview guide and how data was collected).

The researcher developed and used the interview guide with semi-structured questions to collect primary data from the selected primary caregivers of CLWHA. The interview guide contained two sections; the first section captured information relating to the socioeconomic and demographic characteristics of participants whereby the second section captured information concerning experiences (personal, resource, and psychosocial) of caregivers of CLWHA. Before the actual collection of data from the field the researcher piloted the interview guide to see the level of understandability and confusion. All interviews were carried out in English.

The researcher held the interviews in English and all interviews took place in a specific private place within the Martha Tubman Memorial Hospital premises to assure participants' privacy. The researcher consulted the hospital management in advance to get a private place (room) within the hospital compound where interviews took place. During the interviews, the researcher, in addition, used a voice recorder to collect the data from among the participants; however, before the interview started the researcher clearly explained to the participants the need to record the interviews, and the decision to be recorded or not was left in the hands of respondents. In case respondents were willing to be recorded the researcher gave them a consent form to sign, and for those who did not want to be recorded the researcher took field notes. To ensure data management, the researcher used a drop box server for maintaining data to ensure that participants' data are secure.

The risks encountered in this study included holding interviews with people who were among the vulnerable groups who could have emotional and or trauma problems during the interviews. When this happened the researcher stopped the interview and referred them to a mental health professional to assist them as the researcher didn't have counseling skills. After counseling the researcher asked the respective respondents if they would like to proceed with the interview or not. For those who were not willing to proceed with the interview, the researcher had to recruit other informants to deal with such incomplete data till the saturation point was reached. To ensure data collected was of high quality the researcher adopted multiple strategies including involving participants checking after each interview to find out if what had been noted down is what they said, this provided them with an opportunity to confirm or clarify points that a researcher might have noted incorrectly. And where a voice recorder had been used to collect the

data the researcher assigned the two research assistants (triangulation of data analysts) to cross-check the transcription to ensure what is noted down reflects what participants said.

3.7 Data analysis plan

The researcher adopted a thematic analysis to analyze the data. The analysis focused on the responses around the experiences of providing care to CLWHA. The researcher began the analysis by gaining a sense of each transcript. The researcher achieved this by carefully digging into the transcripts and noting down initial thoughts about each respondent.

Initially, the researcher did a within-case analysis of each transcript and noted down the themes. Afterward, the researcher compared themes that emerged across all transcripts and then noted down themes that were relevant to the research questions. The researcher then established the linkage between the identified themes. After defining and categorizing each theme the analysis continued by discussing it in detail. In the end, the researcher selected fascinating quotes from the transcripts which represent key information for the selected themes and research questions. To ensure the validity of the study findings, all participants had the opportunity to read their transcripts and develop their codes.

3.8 Ethical considerations

The researcher obtained ethical approval from the University of Rwanda and clearance to conduct a study from the Martha Tubman Memorial Hospital. Also, the researcher informed respondents that participating in this study was voluntary and that any refusal to participate in this study had no negative impact on the treatment and care of their children from the clinic. To sensitively conduct interviews and handle the situation, for instance, psychological distress or emotional distress which was more likely to be observed when sensitive information was disclosed the two assistant researchers received training on how to handle these situations. Respondents that were observed to express a high degree of psychological or emotional distress were referred to a psychologist for consultation. To ensure anonymity, the respondent's identification numbers were kept privately. Patients confidentiality were ensure by keeping records of information in a secure place (available to only term members), as well as personal identifiable information were protected (e.g. medical information, names, etc).

Confidentiality, several measures were taken into consideration including obtaining signed nondisclosure documents, restricting access to participant's identification, revealing participants information only with written consent, and restricting access to data instruments where the participant is identified.

CHAPTER FOUR: RESULT PRESENTATION

4.0 Introduction

This chapter provides the major findings of the study. Section 4.1 provided the general socioeconomic and demographic characteristics of the sample population including the number of respondents who participated in this study. Section 4.2 presented the study findings on the personal experiences of caregivers of CLWHA who attend clinic at MTMH. Section 4.3 provided the findings on resource-related experiences of caregivers of CLWHA who attend the clinic at MTMH.

4.1 Socioeconomic and demographic characteristics of respondents

The socioeconomic, demographic, and clinical characteristics of respondents are presented in table 4.1, below.

Table 4.1: Socioeconomic, demographic and clinical characteristics of respondents

Variable	Frequency	Percent
Age of primary caregivers (years)		
18 – 35	1	12.5
36 – 50	5	62.5
51 and above	2	25
Age of HIV + Child (years)		
≤5	1	12.5
6 – 12	6	75
13 – 14	1	12.5
Marital status of a primary caregiver		
Married	2	25
Single	2	25
Divorced	4	50
The educational level of a primary caregiver		
Illiterate	1	12.5

Primary school level	4	50
Junior high school level	2	25
Senior high school and college level	1	12.5
Caregiver's relations to a child		
Mother	5	62.5
Grandmother (biologically related)	1	12.5
Others (unrelated i.e. step mums, aunts, etc.)	2	25
Residence area of a primary caregiver		
Urban	2	25
Rural	6	75
Occupation of a primary caregiver		
Employed	1	12.5
Unemployed	1	12.5
Self- employed	6	75
Monthly income of a primary caregiver		
Low	7	87.5
Moderate)	1	12.5
Member of any social security schemes		
Yes	1	12.5
No	7	87.5
Health insurance		
Yes	2	25
No	6	75
Distance to a health care facility (km)		
≤ 4	2	25
[5 – 7]	5	62.5
[8 – 10]	1	12.5

This study involved eight (8) caregivers of children living with HIV/AIDS who attend the ART clinic at the Martha Tubman Memorial Hospital. The caregivers' age ranged from 36 to 50 years and those of children living with HIV/AIDS ranged from 6 to 12 years.

The majority of caregivers was divorced and had attained a primary level of education. Most of the caregivers were biological mothers of children they cared for and a few were biologically unrelated to children they cared i.e., aunts, and grandfathers. The caregivers lived in rural settings where access to health care facilities was limited. They had to travel approximately 5 to 7km to Martha Tubman hospital to access health care services. Most of the caregivers worked as entrepreneurs either on their farms as peasants or in the mining sector as small miners. The caregivers did not have a stable income to support their life and that of the child they care for and most of them did not have health insurance.

4.2 Personal experiences

The purpose of this objective was to explore the personal experiences of primary caregivers of children living with HIV/AIDS who attend the ART clinic at Martha Tubman Memorial Hospital; Four emerging themes: extensive caring responsibilities, managing opportunistic diseases, coping of child's HIV/AIDS status, and inadequate social support.

4.2.1 Extensive caring responsibilities

The result of the current study indicates that most of the primary caregivers of children living with HIV and AIDS in Liberia are women family members i.e., mothers, aunts, or grandmothers. The caregivers pointed out that they were the sole providers of care and supported their children living with HIV. The caring responsibilities mentioned were rather extensive and challenging because this was done in a daily routine.

“Since he was born, I’m the only one doing everything for him. I work from people’s house, I wash clothes, cut grass for us to eat and survive, and from this earning, I save transport fair for our next visit to the clinic” (R3)

“I’m the only one who has been taking care of her since the passing of her mother in March 2012. She is 9 years old now and in the 2nd grade. My husband and I work in the goldmines for their survival. We don’t know where her father is located, we are everything to her”. (R7)

“My daughter cannot even crawl on her kneel but on her buttocks, she can do nothing, she is not talking, I’m alone when I don’t bath her, nobody can touch her, it is my responsibility to do everything for her” (R4) “Respondent (R4) explained during the interview that her daughters’ feet are too weak to the point that she cannot stand without holding something, every morning she tries to force her daughter to stand up by holding something”.

”I have been to the specialist to check her legs, the specialist said that her feet had no problem, and give medication for 3 months, and I return to base on instructions but was told he took a transfer to another hospital”. (R4)

4.2.2 Coping with opportunistic diseases.

The caregivers reported that they experienced difficulties coping with opportunistic diseases. This was narrated more by caregivers who did not have the skills to handle it. Opportunistic disease gave caregivers hard time given the limited resources they had in their family to handle it. Caregivers reported that an HIV-positive child could develop opportunistic diseases at any time and this would give the child a hard time. Opportunistic diseases also gave the primary caregivers hard time because most of the time it happens, they thought they were about to lose the child they took care of. When it happens, caregivers are forced to rush the child to the hospital. They mentioned that it is hard to adapt and manage opportunistic diseases.

“Sometimes fever can easily be on her, but the main thing that can easily give her a hard time is the cough, when she gets a serious cough like that, her eyes can turn red, like blood set in something, and she often gets a fever. (R1)

When it happens my husband and I can rush her to Martha Tubman hospital, where most of the time she receives blood because her blood dries in her body. (R7)

4.2.3 Digesting news of the child’s HIV/AIDS status

The caregivers narrated during the interview that they experienced difficulties adapting to the presence of an HIV-positive child in the family. This was because the grand majority of primary caregivers who took care of an HIV-positive child had little knowledge of the disease, and had neither the experience nor the skills to handle the situation especially when the HIV-positive child encountered opportunistic infections.

It was reported that before examination caregivers didn't know what their children were suffering from and so didn't take their children to the hospital for examination.

Even after the child was diagnosed with HIV, they still didn't understand how the child got the disease, especially in situations where all other family members tested negative.

“they examined her and discovered that she was HIV positive, I was also surprised, when tested negative upon doing the test, her father also tested negative too so, the question was, how did she get it. The other children in the house tested negative. (R5)”

Other caregivers received HIV/AIDS awareness education from health workers which helped them to understand how the disease could spread from one person to another, and how to prevent transmission of the HIV. The knowledge and skills obtained enabled caregivers to adapt to the situation by understanding the disease which in turn enabled them to take good care and support the child living with HIV/AIDS.

“the health worker explained everything to me and I understood, how one can get it, not by eating or touching one another, even by sleeping on the same bed as children, so from that day my heart was free and I was also free with her.

(R1)”

Also, inadequate resources in the family made it difficult for them to take well care of and support the child they cared for.

“All of us depend on the work my boyfriend is doing, I'm not working, I'm a house mother. Things are not easy but God is making a way, we are surviving from hand to mouth with no other support besides us. (R6)” Treatment adherence is another challenge experienced by primary caregivers of children living with HIV/AIDS in Liberia. Respondents mentioned that in the beginning, it was really hard to ensure that the HIV-positive child takes his/her ARV drugs every day and at the same time.

However, the knowledge they received from the ART clinic they regularly attended helped them to adapt to the situation and manage their adherence to ARV drug consumption.

“In the morning I give it to her at the same hour, then evening I give I to my older daughter who knows her status, to Please give her a table when out, the patient can also do it by herself, I always tell her when I go out/somewhere, (R1)”

4.2.4 Inadequate social support

The caregivers pointed out that they do not receive support from both government and community structures to support their service of caring for children living with HIV/AIDS. They added that in Liberia children living with HIV/AIDS and who live with their parents are not classified as children in need, and therefore they do not receive grants from the government. Caregivers also mentioned that the process of obtaining government services for orphans, the vulnerable children, and their guardians was difficult given the presence of uncooperative government officials and bureaucratic systems.

On the other side, caregivers pointed out that they are receiving inadequate support from family members. In most cases, the burden of caring for an HIV-positive child is often left to the mother of a child as sometimes the father tends to abandon his family after having learned that one of the family members is HIV positive.

“No other family member is helping me with her; you know when people heard about this sickness, they believe that the person will die one day. We are currently having money problems, the business is not doing well, and next month schools are opening (R6)

I’m the only one doing everything for 12years including hygiene I am tired. (R6)”

Destruction of family relationships is one of the obstacles mentioned that prevent caregivers from disclosing the child’s status within and outside of the family and thus making it difficult to access external support. Caregivers added that in most cases, the truth about the child’s status normally comes out only following the passing of his/her mother, before that no one in the family is aware of this.

However, caregivers pointed out that recently a few non-governmental organizations for instance Partner in Health have stepped in and had a program of support with food, clothes, and renovating housing for caregivers of children living with HIV/AIDS.

“from the onset, we were paying school fees from kingdom guarding, but Partners in Health came in from 1st or 2nd grade, and since then we stop paying school fees, we only look forward to copybooks and recess. With

God’s help he is in good hands. (R2)”

4.3 Insufficient finance

The caregivers pointed out during the interviews that they experienced financial hardships while caring for a child living with HIV and AIDS. It was revealed during this study that the primary caregivers do not have a reliable source of income as most of them are working in the informal sector as small-scale peasants or small entrepreneurs. Thus, they experienced difficulties to provide their dependents including the child living with HIV/AIDS with the basic needs such as nutritious food, and clothing but also finance to cover transport costs to and from the hospital to attend ART clinics and pay for medicine or hospital bills especially once the child develops the opportunistic infections/diseases. The situation is elaborated by respondents’ narrations below

Her father is not working, we depend on substance farming to send the other children to school, and even the food we eat at home comes from our farms. If we had had good money, we would have taken her to the city or tappita hospital for a proper checkup, but we don’t (R4)

I’m not working, I’m a housemother. Things are not easy but God is making a way, we are surviving from hand to mouth. Nobody is helping me to take care of her since I took her beside my boyfriend. He is helping us with both feeding and school necessities. You know it is not easy to feed one person apart from school that is expensive nowadays, (R6)”

The situation is even harder when the HIV positive child’s parents are no longer staying together, and when the burden of caring for a child living with HIV and AIDS has been left to one parent mostly women as the respondent narrates below

“his father and I are not together. I’m struggling, I can make bread and juice and carry it around to sell, but I do not have a reliable income, but it helps us, , I used the profit gained from the sale to enroll him in this school (R1)”

Caregivers said that insufficient finance has forced them to shift from consuming nutritious food they often ate during the favorable situations to consuming something else (non-nutritious food) that they could afford something which affects the health of an HIV-positive child.

‘‘we are not able to buy rice for 3days now, because the price has gone up (150) for a cup of rice because of the bad road, sellers have increased the price, we are only surviving on cassava, fufu (cassava flour), sometimes plantain, things are not easy, (R1)’’

Caregivers reported that the financial burden on the family has been intensified by the presence of an HIV-positive child because a large proportion of the household income is used to support caregiving needs which include medical costs, hospital bills, and transport to the clinic. The bad weather condition has fuelled the financial hardship in the family.

‘‘Now, there is no money especially during this rainy season, everywhere is water, roads are bad, the country is getting worse every day, life is getting harder, there is no money. it is hard to get Gold during the rainy season. Her constant sickness brings me down, but still, I thank God, (R4)’’

The financial difficulties experienced forced some caregivers to send their children to their relatives or other people in the community with the capacity to take care of them as the respondent explains below.

‘‘my daughter moved to gboleken village to stay with one of my sisters, she is studying there because I’m not having the capacity to send her to school, her father and I separated since the time we found that our daughter was positive. Even her brother doesn’t live with us; he is living with one nurse. (R5)’’

A few Non-governmental organizations have stepped in to help the children living with HIV and AIDS with school fees and other needs that matter which in one way or another lessens the financial hardship experienced by caregivers as the respondent narrates below.

‘‘for now, by the grace of God am doing my best as father and grandfather to provide for their needs, and NGOs are helping to pay his fees as I care for other needs, but if it is not the NGO help, it would be a big challenge. (R7)’’

4.3.1. Resource related challenges

The purpose of this objective was to explore the resource-related experiences of caregivers of children living with HIV and AIDS. Only one theme i.e., insufficient finance emerged from this objective.

4.4 Psychosocial experiences

The purpose of this objective was to explore the psychosocial experiences of caregivers of children living with HIV/AIDS in Liberia. Three themes i.e., stigma, fear of disclosure, and stress emerged from this objective.

4.4.1 Stigma

The caregivers reported during the interview that children are living with HIV/AIDS and (primary caregivers) experienced stigma from the individuals in the community surrounding them. Sometimes the stigma came from close family members. The HIV positive children experienced some level of stigma that ranged from not sharing basic things such as plates, spoons, and cups to being treated as if they are not human beings, as respondent 4 narrates

“they don’t feel comfortable with her because when she drinks in a cup they don’t want to drink with that cup when she eats with a spoon they don’t like to eat with that spoon. She gets her cup separate, nobody can drink in her cup, nobody can eat with her spoon, everybody is afraid of her. (R4)”

As mentioned earlier in this report, the knowledge of HIV among the community members including some of the caregivers in Liberia is still very low, especially in the peripherals. The low level of knowledge about the disease has fuelled the degree of stigma toward the HIV-positive individuals among the community members. HIV positive people in the community are considered unable to marry or get married and people who cannot make their own families as the following respondent narrates;

“ he will not be able to get married and get children if he tells a woman that he is positive unless he hides it. (R2)”

Caregivers of HIV positive children also experienced a high degree of stigma from close friends as the following respondent narrates:

“My close friends and people in the community stigmatize me because I’m the mother and I’m taking care of a child living with HIV and AIDS, they think I’m the one who infected the child, on top of that they also think it is wrong for me to take care of her. (R7)”

4.4.2 Fear of disclosure.

In this study, caregivers reported that in most cases husbands refused to accept to be responsible for bringing the HIV into the family, and instead they blamed their wives for bringing the HIV into the family the matter which in most cases led to disruption of the relationship and or HIV positive children being kicked out of the family. Thus, to maintain their relationship with their husbands’ women caregivers opt to not disclose the HIV status of their children, they keep it a secret between themselves and the HIV positive child, and sometimes the mother never discloses it to even the child as respondents narrated;

“I have not told her (father) about her, I can only tell him that she is not alright, but the main sickness I did not tell him, (R1)”

The challenge here now is I don’t know how to disclose the boy’s

Condition to his father, (R3)

“I do not want my boyfriend to know her status, if he knows he might kick her outside, I tell my daughter not to tell her father, only two of us know (R2)”

Inability to disclose the child's status has made it difficult for caregivers to manage the HIV positive child as the following respondents narrate: “I’m already thinking about how I will disclose it to her, I’m worried about how she is going to feel when she gets to know her health status I’m also afraid when she is playing with other children, she can get injured and spread the disease to other children. (R6)”

4.4.3 Stress

Caregivers reported that they often experienced stress while caring for a child living with HIV and AIDS. The source of anxiety was thinking hard about the child living with HIV and also the inability of caregivers to effectively help the child.

They experienced depression, anxiety, persistent headache, frustrations, and loss of appetite, and poor concentration which is all an indication of stress.

“Sometimes I think so much about how my child’s life is going to be? Taking medicine for a lifetime, how is he going to manage it after he grows? (R3)”

This response brought to the front the aspect of helplessness that some of the caregivers feel as they provide care to the children living with HIV and AIDS within a context of inadequate material and financial resources.

“I’m worried about my daughter, why is it only her that got the disease, her brother and sisters, me, and her father do not have the disease. I hear people say that when you get this sickliness, you can die anytime. So I’m expecting to lose my child anytime soon (R5) “

The narrations from this study indicate that the presence of a child living with HIV and AIDS in the family strain the physical and mental well-being of caregivers.

Caregivers are worried about the future of HIV-positive children.

“My biggest worry is that how this boy will just keep taking medicine throughout his life, and another thing is that he will not be able to get married and get children if he tells a woman that he is positive unless he hides it. He sometimes gets worried that if he misses the medicine he will die because I often tell him that his life depends on it. (R2)” Other caregivers were more stressed at the beginning before the child they took care of started to attend ART clinics but afterward the degree of stress went down as the respondent below narrates “Before I was worried about her frequent sickness. Most of the time I would talk to myself that the daughter of my sister is now in my hand and the way her mother died. (R6)”

CHAPTER FIVE: SUMMARY OF FINDINGS, DISCUSSIONS.

5.1 Introduction

This chapter provides a summary of the study findings responding to the specific research objectives of this study, which aimed to understand the personal, resource-related, and psychosocial experiences of caregivers of children living with HIV/AIDS in Liberia.

5.2 Summary and discussion of findings

The purpose of this study was to explore the experiences faced by caregivers of CLWHA in Liberia. This study was carried out in Liberia, specifically at the Martha Tubman Memorial Hospital. The study participants included eight (8) primary family caregivers (FCGs) of children living with HIV/AIDS. The results of this study are summarized based on the general characteristics of respondents, and specific research objectives. Regarding the general characteristics of respondents, the result indicates that the majority of primary caregivers were adults aged between 36 to 50 years. This indicates that caregivers of children living with HIV/AIDS are in the age period where they can leverage their energies on caring responsibility, however, if they do not get support from family and or other community members they are likely to use all their energies on caring demands hence leading to psychological problems and burnouts. Secondly, the low level of education among the caregivers of children living with HIV/AIDS (primary education) makes it difficult for them to access health information including adherence to ART. Thirdly, the fact that most caregivers are divorced is seriously disturbing and hampering the provision of quality care because the burden of caring for a child living with HIV/AIDS is left to only one parent (mother). The majority of caregivers lived in rural settings about 5 to 7 km away from the urban where Martha Tubman hospital is located, this hampered the provision of quality child care since most hospitals are concentrated in the urban setting than in rural areas, and since most of the caregivers are living in poverty they cannot afford to pay transport fare to and from the health care facility to access health care services.

The results of the present study are in line with several research reports for instance,

[12]

Regarding caring responsibilities, the results indicate that women caregivers' caring responsibilities are very extensive and hard.

Taking care of a child living with HIV and AIDS is a challenging task because the primary caregivers have to work hard to find basic resources for the caring activities, which include food, medication, and clothing, as well as transport to attend clinics, and so forth. Women caregivers are offering this service even though they are living with their children in severely deprived settings and abject poverty, in most cases; they all experienced a severe shortage of materials needed to provide good care. The present study results are in line with research conducted in rural Malawi, showing that women caregivers of HIV-positive children experienced extensive caring responsibilities.[16] Regarding adaptation to HIV/AIDS in the family the results indicate that women caregivers experienced difficulties adapting to the presence of an HIV/AIDS child in the family because the grand majority of primary caregivers had no or inadequate knowledge of the disease, and had neither the experience nor the skills to handle the situation especially when the HIV positive child developed the opportunistic disease.

Inadequate resources in the family also made adaptability harder.

Family social support be it financial or non-financial support is very crucial in ensuring the provision of quality care by caregivers to children living with HIV/AIDS. Family social support has the potential to facilitate the family's adaptation to the change or to reduce the effects of the demands. The support could be in terms of knowledge or skills on how to handle opportunistic infections or could be financed to support the primary caregiver with school fees, payment for drugs, and transportation to the health facilities. The presence of support lessens the emotional and physical effects that caregivers experience when they are left alone to care for a child living with HIV/AIDS. The present study indicates that caregivers of children living with HIV/AIDS are receiving inadequate support from family members, and therefore the burden of caring for an HIV positive child is often left to the mother of a child as sometimes the father tends to abandon his family after having learned that one of the family members is HIV positive. The present study results are in line with research conducted in Vhembe District, Limpopo Province, showing that primary caregivers of children living with HIV/AIDS experienced inadequate support from the government and community structures.[16]

Only one theme (insufficient finance) emerged under the resource-related experiences of caregivers of children living with HIV/AIDS in Liberia.

Financial resources are a very important resource as they provide caregivers with the capacity to access health care services by being able to attend clinics regularly and make payments for drugs, also purchase nutritious food for children which in one way or another prevents the occurrence of opportunistic diseases as well as making them able to consult medical specialists any time in case their children get opportunistic infections. The present results indicate that primary caregivers experienced financial hardships while caring for a child living with HIV and AIDS because the majority of them do not have a reliable source of income. They experience difficulties to provide their child living with HIV and AIDS with the basic needs such as nutritious food, and clothing but also finance to cover transport costs to and from the hospital to attend ART clinics and medicine bills. The present study results are in line with research conducted in the Thika District in Kenya [10] showing that the primary caregivers of children living with HIV/AIDS experienced insufficient finance to adequately care for the child

Regarding objective number three (psychosocial experiences) three themes (stigma, fear of disclosure, and stress emerged. Regarding stigma, the results indicate that both the children living with HIV/AIDS and (primary caregivers) experienced a high degree of stigma from the individuals in the community and sometimes from close family members. The present study results are in line with research conducted in the Thika District in Kenya by [10] showing that the primary caregivers of children living with HIV/AIDS experienced stigma from the community members.

Regarding fear of disclosure: The caregivers pointed out during the interview that they experienced difficulties disclosing the HIV status of their children to the family and community members. Several factors explain this, for instance, “anticipated disruption of relationship, fear of discrimination, concerns about employment benefits, the desire to protect oneself and others emotionally, protecting oneself from possible physical and verbal abuse, stigma concerns, concerns about confidentiality, timing, access to care; treatment and support, access to group therapy, and involvement in protection initiatives” [16]

The results indicate that primary caregivers experienced difficulties disclosing the HIV status of their children to both close family and community members because in most cases husbands refused to accept to be responsible for bringing the HIV into the family and instead, they blamed their wives for the matter which led to disruption of the relationship and or HIV positive children being kicked out of the family. The present study results are in line with research conducted in Uganda [13] showing that both parents and children experienced dilemmas in disclosing their HIV status.

Regarding stress, the results indicate that primary caregivers often experienced stress while caring for a child living with HIV and AIDS. The source of anxiety was thinking hard about the child living with HIV and also the inability of caregivers to effectively help the child. Caregivers experienced depression, anxiety, persistent headache, frustrations, loss of appetite, and poor concentration. The present study results are in line with research conducted in the Thika District in Kenya [13] showing that the primary caregivers of children living with HIV/AIDS experienced a high degree of stress while offering care to an HIV-positive child.

5.3 Conclusion

It is evident from the current study that primary caregivers are experiencing multiple challenges as they care for children living with HIV/AIDS in Liberia. The challenges experienced range from extensive caring responsibilities, financial burdens, and adaptation to HIV/AIDS, stigma, and fear of disclosure of the child's status, to stress. This, therefore, means that primary caregivers require targeted intervention strategies to counter the challenges.

5.4 Recommendations

The government in close collaboration with NGOs working in the sector should build community centers that will build capacity and empower primary caregivers to cope with the challenges encountered during their duties of caring for children living with HIV/AIDS.

The government needs to come up with sound policies and programs that will classify primary caregivers and children living with HIV/AIDS in the category of vulnerable groups that need direct support from the government, this will allow HIV positive children and their caregivers receive grants from the government structures in terms of food supplements, free medication, education, and other basic needs.

There is a need to involve men in the caregiving role, men and women in the family should share the caregiving responsibilities. This means that NGOs and other stakeholders should come up with initiatives that will increase male participation in providing care for children living with HIV/AIDS in the family, this will not only reduce the caring responsibilities of women rather it will also reduce the degree of stigmatization and negative attitude towards the HIV positive child.

There is a need for health care providers to include family and other community members in the health education programs concerning care and support of children living with HIV/AIDS so that they appreciate the care offered by women caregivers and hence begin to offer support.

The primary caregivers of children living with HIV/AIDS should be provided with all information concerning care and support because they are the ones looking after the HIV-positive children, providing them with complete information will make them able to improve their care.

5.5 Limitations of the study

The nature of the study (Qualitative Research) inclusion (have to care for 6months and above), sampling method (purposive) that only sick information from well-informed informants, and exclusion criteria (those caring for less than 6months and the very sick ones)

The study was conducted at Martha Tubman Memorial Hospital the only public referral hospital in Zwedru City and Tchien District of Grand Gedeh County. The results were limited in depicting the national picture due to geographical and cultural diversity among the different Counties available in Liberia. However, since Martha Tubman Memorial Hospital is a referral hospital the researcher tried to minimize this limitation by recruiting participants for the study from all counties of the country, as study took into considerations all crebdibilities as it relate to research, especially qualitative research.

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Appendix 1: Interview guide.

My name is Amelia Tina Vorkpor and I am currently studying for a Master's degree in nursing sciences (pediatric track) school of nursing and midwifery, college of medicine and health sciences at the University of Rwanda. As part of my Master's research thesis, I am conducting research that explores the experiences faced by caregivers of CLWHA in Liberia; the case of Martha Tubman hospital. There is no right or wrong answer in this study. Please answer that applies to you. Any information that has been gathered will only be used for research purposes and will remain confidential. I greatly appreciate the valuable time and effort that you will spend participating in this study.

Section A: socioeconomic and demographic characteristics of respondents

1. Age of a primary caregiver

18 – 35 years

36 – 50 years

51 and above

2. Age of HIV + child

≤10 years

11 – 14 years

3. Marital status of a primary caregiver

Married

Single

Divorced

Widow

4. The educational level of a primary caregiver

Illiterate

Primary school level

Junior high school level

Senior high school and college level

5. Caregiver's relations with a child

Farther

Mother

Grandmother (biologically related)

Others (unrelated i.e. step mums, aunts, etc.)

6. Residence area of a primary caregiver

Urban

Rural

7. Occupation of a primary caregiver

Employed

Unemployed

Self-employed

8. Monthly income of primary caregivers

Low (less than the minimum wage)

Moderate (equal to the minimum wage)

High (higher than the minimum wage)

9. Member of any social security schemes

Yes

No

10. Health Insurance

Yes

No

11. Distance between residence area and Martha Tubman hospital

≤ 4

[5 – 7]

[8 – 10]

≥ 11

12. The primary caregiver is physically fit to care for the HIV + child

Yes

No

Section B: The personal, resource, and psychological experiences of caregivers of HIV + children.

1. What resource challenges do you experience in caregiving for an HIV + child?
2. What personal challenges do you experience in caregiving for an HIV +child?
3. What psychological challenges do you experience in caring for an HIV + child?
4. What livelihood strategies do you use to organize the scarce resources to reduce the strain of caregiving?
5. What survival strategies do you use to cope with personal challenges you experience?
6. What strategies do you use to cope with the psychological challenges you experience?

Appendix 2: Informed Consent Form

The researcher invites you to participate in the study titled: experiences faced by caregivers of CLWHA at the Martha Tubman Hospital in Liberia. The study is being conducted by Amelia Tina Vorkpor who is currently studying for a Master's degree in Rwanda. The specific purpose of this study is to investigate the personal experiences, resource experiences, and psychological experiences faced by the primary caregivers of CLWHA in Liberia.

The study targets the caregivers of CLWHA who have primarily given care to children living with HIV&AIDS for at least 6 months and who attend ART clinics at Martha Tubman Hospital in Liberia. Data will be collected at Martha Tubman Hospital in Liberia from the second week of April-may, 2021 Monday to Friday. During data collection, the primary researcher and two data collector assistants will interview the primary caregivers of CLWHA attending ART clinics at Martha Tubman Hospital in Liberia. The interview will take 15 to 20 minutes.

There are no direct benefits to you for participating in this study however, your response will be beneficial in helping health stakeholders understand the severity of experiences faced by caregivers of CLWHA in Liberia, thus come up with relevant interventions to address the identified experiences to boost the provision of quality care to CLWH. There will also be no compensation (including monetary payment) to you for participating in this study. In the case of emotionally being affected following this interview, you will be referred to the counselor and get attended to. Upon resolving the situation, the decision to either continue or discontinue the interview will be left in your hand.

Any information that will be gathered during this study will only be used for research purposes and will remain confidential.

Please be aware that, your participation in this is completely voluntary. You may withdraw from participating in this study at any time and there will be no penalty or loss of benefits. You do not have to answer any question that you don't want to answer.

By signing below, you are indicating that you have read and understood this consent form and that you agree to participate in this study.

Study participant signature

.....

Dd/mm/yyDd/mm/yy

...../...../.....

Witness signature

.....

...../...../.....

Appendix3: Data collection permission letter



Republic of Liberia
Ministry of Health
Martha Tubman Memorial Hospital
GRAND GEDEH COUNTY HEALTH & SOCIAL WELFARE TEAM
Zwedru, Grand Gedeh County



July 20, 2021

PERMISSION TO CONDUCT RESEARCH

The above hospital hereby grants Ms. Amelia Vorkpor permission to conduct research titled: 'Experiences Faced by Caregivers of Children Living with HIV/AIDS IN LIBERIA', as a study requirement.

During the course of this research, all departments concerned are asked to give Ms. Vorkpor the fullest cooperation in collection of the data.

The principal Investigator is under obligation to observe patients confidentiality and that the data collected will be solely used for academic purposes.

Thanks,

Dr. Jude G. Whesse
Medical Director



Appendix4: Ethical clearance letter



UNIVERSITY of
RWANDA

COLLEGE OF MEDICINE AND HEALTH SCIENCES
DIRECTORATE OF RESEARCH & INNOVATION

CMHS INSTITUTIONAL REVIEW BOARD (IRB)

Kigali, 17th /08/2021
Ref: CMHS/IRB/270/2021

AMELIA VORKPOR
School of Nursing and Midwifery, CMHS, UR

Dear AMELIA VORKPOR

RE: ETHICAL CLEARANCE

Reference is made to your application for ethical clearance for the study entitled *"The Experiences Faced by Caregivers of Children Living with HIV and Aids in Liberia: The Case of Martha Tubman Memorial Hospital"*.

Having reviewed your application and been satisfied with your protocol, your study is hereby granted ethical clearance. The ethical clearance is valid for one year starting from the date it is issued and shall be renewed on request. You will be required to submit the progress report and any major changes made in the proposal during the implementation stage. In addition, at the end, the IRB shall need to be given the final report of your study.

We wish you success in this important study.

A handwritten signature in blue ink, appearing to read 'Stefan Jansen'.



Dr. Stefan JANSEN
Ag. Chairperson Institutional Review Board,
College of Medicine and Health Sciences, UR

Cc:

- Principal, College of Medicine and Health Sciences, UR
- University Director of Research and Postgraduate studies, UR