


Caregivers' Experiences with Caring for a Child Living with HIV/AIDS: A Qualitative Study in Northern Ghana

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Abstract

With the advent of Anti-Retroviral Therapy, Human Immune Virus, and Acquire Immuno-Deficiency Syndrome is increasingly becoming a chronic disease as life expectancy among People Living With HIV/AIDS has increased. For Children Living With HIV/AIDS the role of the caregivers becomes essential as caregivers' decisions affect CLWH health. However, the experiences of these caregivers are often unnoticed while all interventions are directed at PLWH. This study aimed at exploring the experiences of caregivers of CLWH in some selected hospitals in northern Ghana. This study employed a qualitative descriptive phenomenological approach. Purposive sampling technique was used to recruit 9 participants from 3 public hospitals in the Tamale Metropolis of Ghana. Data was manually analyzed using the approach of Collaizi and the findings were presented in themes and sub-themes. We conducted individual face to face interviews in English and Dagbani from September to November 2019. These interviews were conducted at the convenience of the participants in hospitals and at their homes. They were introduced to the study while awaiting to take antivirals for their CLWH. Five themes emerged: changed family dynamics, discovery of diagnosis, reaction to diagnosis, disclosure, stigma and discrimination, and burden and challenges of care. Caregivers were severely impacted by caring for CLWH and traumatized by changed family dynamics which exposed them to many difficulties. Stigma was widely perpetrated by immediate family members and majority reacted badly to their children HIV-positive status with fear, shame, guilt and even suicidal ideation.

Keywords

experiences, caregivers, HIV/AIDS, CLWH

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Introduction

Human Immune Virus (HIV) and Acquire Immuno-Deficiency Syndrome (AIDS) remains one of the most serious public health concerns health systems have been confronted with in history.¹ The virus has affected many lives and households across the world with its peak in Low and Middle-Income Countries (LMICs).² Worthwhile interventions such as prevention of mother to child transmission, the discovery of Anti-Retroviral Therapy (ART), and empiric paediatric care has decreased new infections and improve the life expectancy of Children Living With HIV/AIDS (CLWH).

These interventions have led to the chronicity of HIV/AIDS and have influences on their daily lives. Likewise,

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has implications on the social relationships and interaction in the home, community participation such as sports, play, and school readiness, which influences not only educational but also social development.³⁻⁵

According to World Health Organization(WHO)⁶ globally about 36.9 million people are living with HIV, with about 1.8 million being children under the age of 15 years. Sub-Saharan Africa (SSA) alone accounts for 69% of all People Living With HIV (PLWH) worldwide.⁷ The Ghana National and Sub-National HIV and AIDS Estimates and Projections Report, 2017 reveals prevalence for 2017 is 1.67% translating into 313063 PLWH of which 28203 are CLWH. For the same year incidence rate at 0.68%, (19 101 new infections) comprising (82.1% adults, 17.9% children) and 15 694 AIDS deaths. A staggering AIDS death amongst children, 0 to 14 years is estimated to be 2902.

Informal caring of the sick in the African context has been well documented and crucial for people living with chronic diseases.⁸ Caregivers of CLWH are crucial to the welfare of these vulnerable children. Studies show that many PLWH rely on their families and caregivers for psychological care,^{2,9,10} physical and spiritual health.¹¹ The active role of caregivers is noted to be burdensome and include among others, ART clinic visits and administration, food, shelter and psychological care.⁵ Experiences of caregivers of PLWH has been established to be tiresome, in a qualitative study in Vietnam caregivers explain the role is confronted with cultural, social and religious issues associated with caregiving, having to keep a secret to avoid stigma and discrimination, lack of knowledge about disease and provision of care, and fear, anxiety, and frustration.¹²

This study is necessitated in Northern Ghana due to the varied socio-cultural characteristic of the populace, especially in Northern Ghana where health and living standard indicators are often bad.^{13,14} The aim of this study is to explore the experiences of home primary caregivers of CLWH. This evidence ensures health care providers understand the deep-seated experiences of caregivers and help meet their needs. It also provides knowledge on the subject in northern Ghana.

Methods

Design

A descriptive phenomenological approach was used to explore this phenomenon. This approach was used because it was suitable to explore the lived experiences

of heterogeneous people about a phenomenon with little or no attempt to interpret them.¹⁵

Setting and Site

Our study was conducted in 3 selected hospitals in the Tamale Metropolis of the Northern Region of Ghana. The metropolis is considered the capital of the now 5 regions of the north. The metropolis has a total of 116 communities for which 41 (35%) are urban, 15 (13%) peri-urban and 60 (52%) of them being rural. About 80.8% of the population live in urban areas than 19% of rural nature with a total population of 233 252.¹⁶

Participants were recruited from the largest referral public health facilities in the northern region. The first was Tamale Teaching Hospital, the only tertiary hospital in the northern belt, serving the 5 region and even the neighboring countries. The second was Tamale Regional Hospital. Finally, the Tamale West Hospital also located in the central business district of the region is a referral facility.

Population

The population of interest was primary informal caregivers of CLWH (2-14 years) in the 3 selected hospitals in the Northern Region of Ghana.

Inclusion and Exclusion Criteria

Caregivers who have actively cared for CLWH (2-14) continuously in the past 6 months and those 18 to 80 years were included in the study. Caregivers who were; (1) passive secondary caregivers, (2) those not in continuous care for 6 months, (3) those who could not speak Dagbani and English, (4) caregivers of newly diagnosed CLWH, and (5) caregivers less than 18 and above 80 years were excluded.

Sample Size and Sampling

Purposive sampling was used to recruit caregivers till data saturation was achieved at the 9th participant. According to Lowe et al¹⁷ data saturation occurs when there is repetition of ideas from participants and information becomes redundant. It is used to determine sample size in qualitative research.

Instrument

Semi-structured interview guide was used to collect the data. This guide was developed based on the

objectives of the study and literature on the subject. It comprised 2 sections; part on the biographic data (age, sex, relationship with the child, HIV status among others) and main questions with probes on the discovery of child status, reaction to the diagnosis, challenges among others.

Data Collection Procedure

Data was collected from September to November 2019 in a quiet place within the hospital's premises and client's homes. Face to face individual in-depth interviews were conducted in English by the researcher and Dagbani by an experienced research assistant after informed consent was signed by prospective participants. Individual face to face interviews was used due to the heterogeneity of the study participants. Nonverbal expressions were recorded and a series of events recorded in a book.

Data Analysis

English audios were transcribed verbatim immediately after the interviews while the Dagbani interviews were transcribed by a research assistant proficient in Dagbani and English before translation into English. To ensure meanings are not lost or changed, back translation was conducted by a second research assistant.

The data were analyzed manually using content analysis simultaneously with data. The Collaizi 7 stepped approach for analysis of descriptive phenomenology was used which include among others transcription, identification major statement, getting meanings of these statements, organizing the meanings into clusters of themes (from codes, grouping of similar ones for themes and sub-themes), integration of meanings, getting exhaustive descriptions of the phenomena and validating same with respondents via member checking.¹⁷⁻¹⁹ Before this, we bracketed our ideas and then followed the steps as;

- I. Transcribe, read, re-read and immerse self to with the verbatim transcribed data and become close to the information collected
- II. Identify and delineate meaning units or relevant significant statement in the transcripts
- III. Formulate and create meanings from the significant statements

- IV. The formulated meanings were then organized into central themes and clusters. Measures were made not to ignore some data.
- V. An integrated, comprehensive and exhaustive descriptions and meanings of the phenomena was then made.
- VI. Definite and unequivocal statements are made for proper understanding, providing the textual meaning and structural description of caregiving in the settings
- VII. We then sent back the final ideas for member checking from the participants. At this stage, discrepancies are cleared and additional information elicited was duly added to the final work.

Rigor

The study quality was ensured by applying Lincoln and Guba (1985) approach; credibility, dependability, transferable, and confirmability.^{15,20} The data collection tool was developed and vetted by the authors and a pilot conducted to ensure comprehension, accuracy and consistency. The research assistants for the Dagbani interviews were given 2 days of training on qualitative interviews, the study protocols and principles of ethical research. Member checks, bracketing, audit trail and peer debriefs were done to ensure the trustworthiness of the study. During interviews, minimal or no interruptions were made and the audio records were made clear to prevent problems with transcription. The authors also ensured a detailed explanation of the research approach settings and conduct of the study was done for transferability. Data analyses and coding were done differently and amends made for the differences.

Ethical Consideration

Ethical approval was obtained from the Committee on Human Research, Publication and Ethics (CHRPE) of Kwame Nkrumah University of Science and Technology (CHRPE/AP/407/19) and Research Development Division of Ghana Health Service (GHS) (GHS-ERC 051/05/19). Administrative approvals from Tamale Teaching Hospital and Northern Regional Health Directorate-Tamale and the various hospital management and unit heads were written to (Tamale Teaching Hospital, Tamale West Hospital, and Tamale Central/Regional Hospital) for permission before data collection was undertaken.

Results

Demographics of Participants

Pseudo name	Age	Sex	HIV status	Tribe	Religion	No of children cared for	Level of education	Relationship with child	Occupation	Head of family
Bintah	24	F	+	Dagomba	Islam	2	SSS	Daughter	Trader	Husband
Suhuyini	41	M	-	Kessina	Christian	7	Tertiary	Uncle	Insurance sales manager	Participant
Halima	40	F	+	Gonja	Islam	4	Nil	Daughter	Nil	Elder Daughter
Ruskatu	36	F	+	Dagomba	Islam	4	Nil	Son	Nil	Father-in-law
Adam	26	M	-	Dagomba	Islam	3	Tertiary	Junior sister	Student and rentals	Participant
Chentiweni	44	F	+	Kessina	Christian	2	Tertiary	Son	Teacher	Participant
Mendiaya	48	F	+	Frafra	Christian	3	Nil	Daughter	Laundry	Participant
Timtooni	42	F	+	Gonja	Christian	2	SSS	Daughter	Seamstress	Participant
Hajara	37	F	+	Dagomba	Islam	1	Tertiary	Daughter	Typist	Participant

A total of 9 participants were interviewed. This included 7 women and 2 men between the ages of 24 and 48. All female participants were HIV seropositive and were caring for their biological children while the males were negative, 1 cared for his nephew and the other cared for his junior sister. Three of them never had formal education, 2 with second cycle and 4 tertiary education. Three of the caregivers were unemployed with the others employed. The majority (6) of caregivers were head and breadwinners of their families with husband, father-in-law and elder sibling also playing these roles. The highest number of dependents/children cared for by a caregiver in this study was 7 and lowest being 1 while on average each caregiver cared for 3 children or dependents in addition to the child living with the virus.

Major themes	Sub-themes
Changed family dynamics with the diagnosis	
Discovery of diagnosis	Parental diagnosis or death Severe sickness of the child
Reaction to diagnosis	Caregiver prior knowledge New infection
Disclosure, discrimination, and stigma	Among family Outside family circles
Daily care and challenges	Daily care burden Challenges with the care of CLWH

Core Themes

The caregiver narrations bordered on seated aspects of their roles for caring for CLWH. Five core themes emerged from their narrations and are shown as below.

Theme 1: Changed Family Dynamics with HIV/AIDS Diagnosis

The stigma and misconception surrounding HIV/AIDS led to lots of family uproar and problems with diagnosis. Caregivers, families and households were hit with acrimony and this affected the family cohesion and structure. The normal dynamism of who becomes the head, decision-maker, breadwinner and others were severely affected. It brought about undue suffering on female caregivers in particular who were the majority and had to shoulder the responsibilities of caring for their children in precarious situations under little or no income generating ventures. Some of these were evident in the following statements of participants.

"We live in an extended family but I now live at a rented place at Vitting due to family quarrels and argument. And I don't want quarrels; I want peace so that I can care for my children. The children's father is not there (passed on) so when I live in the family house every day there are quarrels. That's why I went and rented a room" (Ruskatu, Female, HIV +VE, Widowed).

Another participant climaxed her emotions with this heartbreaking statement;

"His father said I should go with my child, he said am a big funeral and the child is a small funeral. . . so, they collected the other child and sacked us" (Mendiaya, Female, HIV +VE, Divorced)

Theme 2: Discovery of Diagnosis

The journey to the diagnosis of CLWH has been insidious and often occurs after a prolonged sickness of

children. They are often diagnosed when either of the parents has been diagnosed or died out of HIV/AIDS.

Sub-theme 1: Parental diagnosis or death. Participant narrations of parental diagnosis or death due to HIV/AIDS prior to CLWH diagnosis are;

“It was only the father who was tested and then I was told it was positive so I encouraged him to ask the wife to go and test, so after she also went and tested, she didn’t want to come out clear as to whether she was positive or not. . . after the mother also died, I carried him to the Central Hospital and they asked me to go for blood test and I went for the blood test and the woman told me that, I did well by bringing the child, he is positive. . . . Meanwhile, he was having sores all over the body which will not heal” (Suhuyini, Male, HIV-VE, Married)

I was once staying with the father, and the father was a worker, he goes from place to place to work, so we were staying together and he told me he was going to Accra. Then when he went, he came and visited us December but when he went back his condition was not good. And his parents called me to come through that when I went, I stayed there to take care of him. He told me that we should go home, not knowing he had this condition but he never told me and me too I didn’t know (Halima, Female, HIV+VE, Widow).

Sub-theme 2: Severe sickness of child. On the sub-theme on severe sickness of CLWH prior to diagnosis

“They told us from the hospital where she was admitted and they gave us this thing (lab request for retro-screen) to go for lab test, when we went and did it was positive I am also positive. . . .” (Bintah, Female, HIV+VE, Married)

“Small she will fall sick, it will go and come, and then the serious one happened to her. And I went to the hospital with her it was then that they ask me to go and test maybe I may also be a carrier. I just took a little time and went and tested and I took the small girl too and they said we all are carriers so since then they said they will put me and her on the treatment. By then the father had died of the disease” (Timtooni, Female, HIV+VE, Widow).

Theme 3: Reaction to Diagnosis

After the diagnosis caregivers often reacted negatively: suicidal thoughts, crying, devastated and most often failed to come into terms with the status. Since most caregivers were positive at the time of their children being tested positive, they had adjusted to the condition and were generally calm but still showed emotional instability. This theme is discussed under 2 sub-themes: caregiver prior knowledge and new infections.

Sub-theme 1: New infections. Typically, of the sub-theme of those who just discovered their own diagnosis or their children, painfully caregivers expressed;

“I planned to kill myself. Because I was thinking only me how can I cater for the child and myself, so I bought poison to drink. I kept the poison under my bed and my sister in-law saw it and ask me severally why I kept those smelling poison under the bed. I confided in her and inform her of the diagnosis when I came to the hospital” (Ruskatu, Female, HIV +VE, Married).

“I was looking at everything as if I was dreaming. I nearly killed myself it was a pastor and the wife who talked to me and then the nurse who took care of us was also advising me” (Timtooni, Female, HIV+VE, Widow).

One participant painfully lamented;

“I was scared and I was down. I was devastated, I thought my whole world had ended then, I was afraid that the child will even die” (Chentiweni, Female, HIV+VE, Single).

Sub-theme 2: Caregiver prior knowledge. Other caregivers who were positive or anticipated their children’s diagnosis and had prior knowledge on possible positive outcomes of their children were calm but disappointed. These were expressed their reactions as;

“I take it normal; my husband too took it normal because I am also positive so we all took it normal” (Bintah, Female, HIV+VE, Married).

“I was calm. . . . because the parents were positive” (Suhuyini, Male, HIV-VE, Married).

Theme 4: Disclosure, Discrimination, and Stigma

Even though there has been widespread of actual discrimination against PLWH, it was minimal among caregivers and their children in urban Tamale Metropolis. It largely bordered on perception but no reported narrations except subtle ones in the immediate family. This theme is subdivided into among the immediate family and the wider social circles (workplace, school, and community).

The theme also explains the kind of people and reasons for disclosure. The theme also describes reasons for non-disclosure among CLWH and other significant others. Caring of CLWH comes with huge fear and burden of disclosure. They largely confided their status to trusted people and those who can help them primarily. Among those disclosures were: spouses, spiritual

leaders and immediate family members and gave several reasons for this.

A participant, for instance, stated his views as;

“My grandmother is the only one that knows about her sickness because I don’t know how others will take the news, especially my mother who is not in a good frame of mind. If I break that news to them, I don’t know how they will react, how they will feel towards the child and they will look at her”. And for the other family member’s non-disclosure, *“I don’t trust them and they will go around and telling people* (Adam, Male, HIV-VE, Student).

“Only my pastor and his wife knows me here but at my hometown, everybody knew about my HIV status that is the reason why I travelled here” (Mendiaya, Female, HIV+VE, Divorced).

While one of the participants said;

“I told my sisters, the point I reached I thought I was going to die and I don’t want to die without telling them the truth because if I don’t tell them and later, they get to know my son may be deserted so I have to tell them that this is what is wrong with me and my son” (Chentiweni, Female, HIV+VE, Single).

Non-disclosure to CLWH was difficult for caregivers as they say they are immature and were praying for the day of disclosure not to even come; stigma and discrimination were among the other problems bordering disclosure.

“When such questions are asked it hurts me because I don’t know what to tell him and I feel sad and I also pity him because is my fault, hmmm I didn’t also know. So, when it happens like that I just move somewhere and cry. I pray to God that he should make a way for my son” (Chentiweni, Female, HIV+VE, Single).

Sub Theme 1: Disclosures, discrimination, and stigma in the social circles. One participant was emphatic that there was no discrimination when she said;

“There is no discrimination because I have not told anybody” (Bintah, Female, HIV+VE, Married).

Even though this participant emphasized that there was no discrimination, one cannot be sure here because the HIV status of the patient was not disclosed and so one will not know if there will be discrimination when the disclosure is made.

Another caregiver conceded;

“I don’t really ask him of discrimination because if I hear them it will hurt me, especially at school so I don’t ask, but

he has not reported of being discriminated at school or home” (Ruskatu, Female, HIV+VE, Married).

Again, a participant asserted that there was no stigma and discrimination against her but this was because the condition was not made known to people. This is what she said;

“There was no discrimination against me because many people don’t know she is with this condition” (Hajara, Female, HIV+VE, Married)

One participant narrated that at school the child is called *“chingiliny”*, *“yiateyiate”* (Twi word that means someone is too small or thin) and many other names due to his sickliness (did not find this word in the dictionary so consider using sickness) but not necessarily his HIV status (Chentiweni, Female, HIV+VE, Single).

Sub Theme 2: Disclosures, discrimination, and stigma among immediate family members. Continuous perpetration of stigma and discrimination came from the immediate family members. This was demonstrated in the following ways;

“Until she was diagnosed and I told my grandmother, she used to eat with the other siblings but I remember one day when I got home. She complained that her grandmother does not want her to eat with her siblings again and request she eats alone” (Adam, Male, HIV-VE, Student).

“She went to school and one of the younger uncle’s child small girl told her she should be careful and think of herself, HIV killed her father and that they can’t play and eat with her again” (Halima, Female, HIV+VE, Widow).

“When I was on admission and left, my son with the aunty, because of the vomiting problem they use not to take good care of him . . .they use to be insulting him” (Chentiweni, Female, HIV+VE, Single).

Caregivers were selective in their disclosures and only disclosed their status and that of their CLWH to only trusted people and those who can support them. While stigma was posited to be one of the reasons for non-disclosures.

“Only the doctor and for my family, no, only my husband, I never wish to tell anybody, because people are not to be trusted” (Bintah, Female, HIV+VE, Married).

“I think if I will like to share, it may be if I have friends who are medically oriented and I will tell them, to see whether there will be a better health care for the boy but the way society is, even my extended family in the village I will not like to discuss with them, because they will even think that

the rest of the family are HIV” (Suhuyini, Male, HIV -VE, Married).

“Husbands family, pastor, only my aunty I told, she is a midwife so when it all happened it was her, I called she told me that we should come back to North then I will come and be taking the drugs. My aunt took care of me since childhood so many things that disturb me, she is the one I tell” (Halima, Female, HIV+VE, Widow).

Caregivers did not inform their children because they felt they were small to understand the disease.

“I don’t know how he will handle it because he does not know why he takes the medications and he may tell his friends. Don’t you know am like this and then before you realize it has spread. And his friends may like to be with him but the parents can say no” (Suhuyini, Male, HIV-VE, Married).

Theme 5: Daily Care and Challenges

This theme looks at the daily routine care, caregivers provided for their children. It examines the burden and also identify the challenges they encounter on daily bases regarding their roles as caregivers. The activities involved in caring for CLWH were described as burdensome and hectic by caregivers and were expressed in physical, emotional and financial terms. Most women caregivers were isolated and lonely with no gainful employment to support them.

Sub-theme 1: Daily care burden. This sub-theme borders on caregivers’ burden and was expressed by the participants in these forms. A participant who cared for Ayisha explained that the mother had ‘*Arinze*’ (a sickness in the Dagbani language that makes the person delirious and unstable) and the grandmother who is a dependent. As such he is overwhelmed with caring and meeting the daily needs of the child and other dependents,

“Hmm, sometimes I have to skip lectures and bring her to the hospital, and my mother to the Imam for prayers for my mother” (Adam, Male, HIV-VE, Student).

“Hmm sometimes when they come and complain the meal is not sweet (delicious), I beg them to eat” (Ruskatu, Female, HIV+VE, Married).

While Issah (10-year, male, CLWH) requires extra care for the performance of activities of daily living, his mother intimates;

“Sometimes it is hectic . . . when you tell him to go and bath, he will be moving slowly, even his teeth he will not

brush. Everything you have to tell him, everything do this, wear your clothes, hmmm then tell him to do almost everything. I am always late to work because of him but for the junior sister (who is HIV negative) she does things fast, I will not even tell her, she will prepare herself and be waiting for us” (Chentiweni, Female, HIV+VE, Single).

Sub-theme 2: Challenges with care of CLWH. In caring for CLWH, these caregivers encountered problems such as absenteeism, with schooling due to frequent sickness at home and school and frequent visits to the hospitals due to ill health and collection of ARTs. Financial burden, disruption of caregiver job and economic activities, difficulty to disclose to people and particularly the children and inadequate support for caregivers.

This is how one of the participants puts it;

“Many people disturb me and ask, why is it that she falls sick so often” (Hajara, Female, HIV+VE, Married).

While difficulty to disclose to children leads to them asking questions, a mother expressed;

“The family does not help when am sick or the girl . . . If we are sick and I don’t have money, we lie down like that. . . She was then small, she said she was going home; this medicine that we collect all the time since she was small, she has taken this medicine like that ahh from the water one to the tablets. I told her it was malaria and she said no, so she said since she was a child and the malaria is not going, she will not take the medicine again” Mendiaya (Female, HIVE+VE, Single).

Discussion

Demographic characteristics of the study affirm previous studies that associate HIV with poverty, illiteracy, and females.^{3,21,22} This similarity is because these studies were conducted in an African setting where caregiving is often the reserve of females. Majority caregivers were not engaged in regular income-generating activities that will provide cushioning for their households. This robbed them of living a dignified life and ability to get basic necessities such as food, shelter and proper healthcare. Just as collaborated by Can²³ HIV is a disease of poverty and greatly affect the females who are vulnerable and exacerbated in Africa where social interventions are infrequent. The realization of two male caregivers in this study provides light with unpaid caring as the dynamics are changing and contradict African setting studies^{3,7,21} where only females were realized. This gradually shows globalization and the active participation of males in unpaid caring of close family members just as paid caring has garnered more participation in Africa over the

past decade. The finding also, however, contradict earlier studies in Namibia where 60% of caregivers were aged and grandmothers,²⁴ in Uganda where the majority were grandparents,²⁵ and South Africa.^{21,26} The difference is because these studies were conducted in a rural setting unlike this study in an urban setting.

Unfortunately, all caregivers had serious family dynamic changes with HIV+ status diagnosis in this study. This led to major problems for the caregivers and their dependents.²¹ In a qualitative study conducted in South Africa, reported that myths surrounding the disease led to grandmothers taking up the care of their infected grandchildren. As they experienced financial constraints, food insecurities among others that plunge them into fear, depression and even suicidal thoughts due to discrimination and stigma. These findings well collaborate in this study as female caregivers had to leave their family houses to rent new places due to bad cohesion with their extended families. Most female caregivers were divorced, widowed or single mothers and had assumed the role of breadwinners and family heads of their family with little or no support. These findings are similar to Matthews²⁷ in Singapore where family dynamics of caregivers were severely affected by HIV because the disease has been associated with irresponsibility, promiscuity, homosexuality, and morality. This similarity explains the long-held myths and misconceptions that have often surrounded HIV/AIDS in many cultures across the world.

In this study, there was a high prevalence of stigma from immediate family and lead to many caregivers living in isolation while caring for CLWH. The findings concur with the evidence of an ethnographic-anthropological study in Ghana by Van der Geest et al²⁸ where PLWH have a remarkable shift from care from the immediate family to outsiders/strangers thus, fellow PLW, health professionals, and volunteers. The move should not be credited to globalization but a complex change in societal and cultural values and family structure. Caregivers in this study cited a high prevalence of family stigma as a cause for PLWH hiding their diagnosis from their family members. This shows that in Ghana immediate and extended family members are more likely going to stigmatize PLWH than others and calls for measures to end the stigmatization of HIV. This has ramification for home care of HIV/AIDS in Ghana and amplifies the suffering of PLWH. In similar lamentations as in this study, Ethiopian caregivers explained they find themselves separated mentally and physically from their families and that their family become broken, desperate and smeared by disastrous family restrictions due to family stigma.²⁹ This poses a challenge for caring for PLWH and affect the quality of caring in this study.

Globally, there is an established averagely higher burden of care for PLWH,³⁰ for caregivers of CLWH the odds are higher among them^{3,30} and they posit occurrence is much higher in Sub-Saharan Africa (SSA) where living conditions are already poor. There is a higher burden among caregivers of CLWH because these children are dependent and may not be able to undertake basic activities of daily living like their uninfected counterparts. In a qualitative study conducted among caregivers of CLWH in Ethiopia, caregivers explained they were worried for their children whether they were home, school or wherever they are.²⁹ Similar evidence of mental and physical burden has been reflected in this study. This is because there are no support persons at school to provide care for children just as seen in this current study. For instance, none of the teachers of CLWH was told of the children status in this study even though school connectedness is seen to be important for CLWH in South Africa.³¹ In Asuquo et al⁷ another study in Nigeria also showed higher caregiver burden with minimal support for CLWH which is consistent with this study. This is because support for caregivers in Nigeria like Ghana is inadequate. These findings are different from results from India where 35% of caregivers of CLWH explained their burden as mild-moderate and only 10% as severe even though evidence showed their quality of life not severely affected by the caring process.³² Improved social interventions and family support are the reasons for the low severity of care in India compared to this study. Description of caregiving as severe is not surprising as many caregivers, especially females live in very poor standards with little or no support.^{33,34}

Discovery of the status of their children was explained by the caregivers as traumatic and accompanied by serious dilemmas. This was achieved by either severe illness of the child or parental death on account of HIV or prior diagnosis. Findings in this study surprisingly showed serious gaps in mother to child transmission of HIV/AIDS as the majority (8 out of 9) of the CLWH in this study had at least one parental diagnosis of HIV+. Even though evidence suggests Prevention of Mother to Child Transmission of HIV/AIDS (PMTCT) and ART programmes has reduced HIV infections by 42% among children across the world, countries in Africa still suffer severely for higher rates of MTCT with a staggering 380 000 by this route in 2017 for Nigeria alone.³⁵ The findings reflect in this study as at least one of the parents were diagnosed with the virus prior to children status being known. This may be accounted for by stigma, lack of understanding by many HIV positive pregnant women about PMTCT management as well as poor follow up by the health care system. The study finding is consistent with earlier studies where at least one of the biological parents of the children were had been

diagnosed.³⁶⁻³⁸ Before diagnosis all CLWH in this study had been reported seriously sick and had visited the hospital several times in the past one year and precipitated the health care personnel to request for the test. These journey of discovery of child diagnosis has been illuminated by prior studies.^{29,33,39} This is because the conditions weaken the immune system of the children and expose them to opportunistic infections.

Childbearing is culturally valued in Africa and tied to one's lineage existence and prided among Africans.⁴⁰ The realization that one heir has a chronic disease is problematic and alters parents or caregiver's life forever. Reactions to the caregiver's child status were tied to the discovery of diagnosis and prior knowledge of the parental diagnosis. The findings are consistent with earlier studies that revealed anxiety and sadness in Zimbabwe,⁴¹ isolation and even suicidal ideation in South Africa²¹ and among others^{3,22,42} in Africa where especially female caregivers intimated guilt, shame, crying among others as their reactions. This similarity is because of the importance and love attached to having a child, especially in African culture. Surprisingly, in this study caregivers who had prior knowledge of parental diagnosis were calm and did not react negatively to their children status. Even though some were disappointed they could not have a negative status child.

Stigma and discrimination according to Zhang et al⁴³ is the major stumbling block in HIV care and prevention in the world and high in SSA. In this study stigma and discrimination was not high among the caregivers as reported in Mchenry et al⁴⁴ Kenyan, where stigma and discrimination were high and related to poor knowledge and perceptions of associating the disease to immorality, low social and economic support. It was realized in this study, stigma and discrimination were associated with non-adherence, disclosures to CLWH or others and increased likelihood of psychological problems among caregivers of CLWH. The low stigma and discrimination contradict studies in Ghana,²⁸ and in Canada⁴⁵ where stigma and discriminations are perpetrated against PLWH seeking health care. This low stigma could be accounted for in this study by the high mass media with vast information on the stigmatization of HIV/AIDS and the urban nature of the setting. The urban nature makes it difficult for people to know each other very well to know their status. Interestingly, in this study stigma and discrimination were perceived much more than perpetrated and highly perpetrated by close family members than outsiders. This resonates with Mukherjee et al⁴⁶ where the majority of stigma were perpetrated in socio-familial context and perception of being stigmatized was much higher compared with those who actually faced stigma (69.2% vs 27.5%; $P < .01$) in India. The reasons for low stigma and discrimination from people outside

the family could be associated to low disclosure, high media penetration and high literacy rate as well as the urban nature of the study setting as these has been cited to be related to low stigma and discrimination.⁴⁷

Undoubtedly, caring for PLWH is confronted with numerous challenges and for CLWH caregivers remained pivotal in the role of caring.^{29,37,38} The findings are consistent with challenges identified in Mafune et al³⁷ where caregivers cited they experienced financial problems due to transport costs needed to adhere to follow-up to date appointment and insufficient money for food items, clothing, pocket money for school and time lost while waiting for consultations. Caregivers described some level of stigmatization against children on ART by family members, and secondary caregivers are problems they face. The findings saw many primary and secondary caregivers giving up on seeking support from government and community structures. In a systematic review in East Africa, studies showed widespread financial problems with caring for PLWH³⁴ and even with children, additional responsibilities exist for their inability to carry out some activities of daily living. The study concurs with findings from a study in Ghana where low rates of disclosure(23%) among caregivers and cited as one of the serious challenges of the caring process.⁴⁸ Low rates of disclosure are due to stigma and discrimination.⁴⁹ State food insecurity as a major challenge that was experienced by caregivers in that study but none of the caregivers cited fear of contracting the disease and lack of skill of caring as a challenge in this study. Reason for this is most of the caregivers has adequate knowledge on the HIV/AIDS.

Strengths and Limitations of the Study

Using the phenomenological approach, the study was able to gain enough evidence and insights on the experiences of caregivers. The zeal and cooperativeness of the participants in the study provided huge advantage to study. Also, because most of the participants were positive female mothers helped unravel many toils of these vulnerable people in society. However, the study did not explore the views of CLWH who may have unique views of living with HIV/AIDS. Most of the participants were PLWH and may have taken away the views of non-infected HIV caregivers.

Conclusion

In this study, findings showed there exists severe burden for caregivers of CLWH and exacerbated by poor financial status, discrimination, stigma and psychological troubles. Female caregivers were overwhelmed with care for their children amidst spiral acrimony, mistrust and

lack of family cohesion following HIV+ status discovery. The collapse of family dynamics leads to little or no support for caregivers. Reactions to the diagnosis are often accompanied by guilt, self-blame, shame and sometimes suicidal ideations. The findings have implications on the success of interventions geared toward CLWH. Recognition of the role of caregivers is crucial to overwhelming comprehensive care of CLWH while consolidating and incorporating the needs of caregivers. It is important to understand the welfare of caregivers in areas of physical and mental health affect that of CLWH.

Author Contributions

GAA: contributed to conception and design; contributed to acquisition, analysis, and interpretation; drafted manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy; FA: contributed to conception and design; contributed to acquisition, analysis, and interpretation; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy; ABBB: contributed to design; contributed to analysis and interpretation; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy; VMD: contributed to design; contributed to analysis and interpretation; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy; RAA: contributed to conception and design; contributed to analysis and interpretation; drafted manuscript; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy; TG: contributed to design; contributed to interpretation; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy; JKK: contributed to design; contributed to analysis; drafted manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy; PAA: contributed to design; contributed to analysis and interpretation; critically revised manuscript; gave final approval; agrees to be accountable for all aspects of work ensuring integrity and accuracy.

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