

Research Article

# A Qualitative Study of Caregivers of Children Living with HIV/AIDS in Ghana: Diagnosis History, Health-seeking Behaviour, and Care Expectations

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## Abstract

Caregivers of Children Living with HIV/AIDS experience severe burdens in Africa amidst unmet needs while seeking care from hospitals. This study aimed to explore the diagnosis history, health-seeking behaviour, and care provided by hospitals and whether the services meet caregivers' expectations. We used a qualitative approach and conducted individual in-depth interviews among purposively sampled caregivers of children living with HIV/AIDS from three hospitals. We achieved data sufficiency after interviewing nine participants. Audio-recorded interviews were transcribed verbatim and thematically analyzed manually through Collaizi's steps. Four themes developed including; history of pregnancy and poor HIV testing, effective care for caregivers and CLWH, attitude of healthcare providers, and unmet expectations of care. Healthcare providers showed positive attitudes towards caregivers and provided services (counselling, dispensing Anti-retrovirals, health monitoring, and coordination of clinical care). Expectations bordered on financial support (for food, education, health care), and treatment for opportunistic infections. Findings indicate gaps in HIV voluntary testing for pregnant women, enrollment in Prevention of Mother to Child Transmission (PMTCT), and unmet needs. It is imperative to improve coverage of testing for pregnant women and efforts made to meet their needs. Financial support, provision of food security, and assistance for caregivers are essential for care.

## Introduction

Several decades after the Human Immune Virus/Acquire Immune Deficiency Syndrome (HIV/AIDS) was discovered it has continued to affect the health of many across the world. According to Tang, et al. [1], by 2017 globally 80% of pregnant women were receiving ART even though a substantial improvement in 2010 with 51%, about 180,000 children

were newly infected in the same year under review with half of these children infected during breastfeeding. Srivastava, et al. [2] elucidated gaps within the Prevention of Mother-to-Child Transmission (PMTCT) cascade and evidence suggests delivery models are not meeting families' needs and suggests a prompt re-consideration and evaluation of how PMTCT could be delivered. Evidence shows how PMTCT could avert children being infected with the virus. Countries in Sub-

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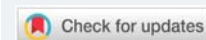
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**Keywords:** Caregivers; Children living with HIV/AIDS health-seeking behaviour; Hospital care unmet needs; Qualitative study

**Abbreviations:** HIV: Human Immune Virus; AIDS: Acquire Immune Deficiency Syndrome; PMTCT: Prevention of Mother-To-Child Transmission; CLWH: Children Living with HIV/AIDS; ARVs: Antiretroviral





Saharan Africa (SSA) are the heaviest hit accounting for about 69% of the world cases even though in this region Ghana's epidemic statistics remain one of the lowest [3]. By prudent management, Ghana has managed to slow the infection rates over the years [4]. With Anti-Retroviral Therapy (ART) sites, PMTCT, and HIV counselling sites across the country there is a need to consolidate these gains. In Ghana, HIV prevalence among ANC clients was 2.1% in 2017 [5] and evidence suggests proper adherence to ART care for children one year and older increases their survival rate by 85% and about 93% in their subsequent years of life. With PMTCT as a major pillar in the fight against HIV/AIDS, new infection among children (0 - 14 years) is expected to reduce by 2022, new infections among this age group will reduce by 29.05%, the paediatric HIV population reduce by 49.8% and HIV orphans reduce from 214,804 in 2013 to 118,527 due to the combined effects of ART and PMTCT [6]. However, the absolute number of children infected with HIV/AIDS is unreasonably and unacceptably high [2].

The United Nations Programme on HIV/AIDS (UNAIDS) in 2004 explained the deadly nature of the pandemic has created an orphan crisis in many heavily hit nations. They bemoaned the crisis has jeopardised the health of elderly women who assume the responsibility of caring for children orphaned by HIV/AIDS. Current pieces of evidence show a staggering 3.2 million Children Living with HIV/AIDS (CLWH) globally, unfortunately, there is an acute rise in HIV/AIDS-related mortality among the youth and parental-aged people in SSA [7]. High incidence rates among these age brackets who are often productive, have a high dependency, and have serious implications on social, and economic strain on nations [8]. Evidence suggests in low- and middle-income countries (LMICs) like Africa, 60-70% of caring happens in the homes by relatives and Lundberg, et al. [9] state that this caring process and burden poses mental and physical challenges to the health of the primary home caregivers. They are confronted with stigma, fear, and isolation, and most often some do not have adequate knowledge and education about their roles. It has also become evident that due to the stigma associated with HIV/AIDS, many PLWH and their caregivers find it difficult to get social support [10,11]. Due to misconceptions and myths about transmission, caregivers sometimes fear sharing utensils or living areas with PLWH [9].

Previous studies have recognized the unique role of primary caregivers in the life of CLWH in their quest to meet their needs [5,12]. Caregivers' expectations and level of satisfaction with healthcare provision for their vulnerable children are said to influence health utilization, and service usage and aid therapeutic relationships with healthcare providers (HCPs) [13]. There are also several factors linked to the inhibition of the usage of HIV interventions and utilization [4]. Healthcare providers' attitudes remain one of the most worrying barriers to HIV voluntary counselling, testing, and treatment in SSA which interferes with interaction and

communication during service provision in most health facilities [3,14]. For instance, in Ghana, Dapaa [3] explains that HCPs particularly nurses have been noted to be rude, and harsh to patients while patients known to them (HCPs) are given more immediate and quality care than others. Also Bo and Ob [15] in Nigeria where HCP showed discriminatory and unethical behaviours towards PLWH. It is therefore clear in these instances that poor HCPs' attitudes served as a barrier to healthcare utilization by PLWH.

Similarly, there is empiric knowledge of positive and professional conduct of HCPs in Ghana even though nurses had satisfactory knowledge of HIV/AIDS others held erroneous beliefs and misconceptions about its transmission, with fear of contracting the virus leading to the display of unprofessional conduct by some nurses [16]. It was worrying to also note high knowledge of universal precautions did not reflect actual practice and compliance by staff [16]. Globally, many health experts are beginning to view health care "through the patients' eyes" which has become ethically and professionally pivotal to health systems in helping care seekers achieve their desires and expectations [13]. According to Lundberg, et al. [9] in Vietnam where 104 caregivers were studied via a multi-method study, caregivers of both genders reported similar severity burden of care, cultural and religious factors influenced caregiving and the majority kept their status a secret to avoid stigma and discrimination. They further maintain a majority of the caregivers' lack of knowledge about the disease and provision of care. This could have effects on the quality of informal care and mare their expectations from the formal health care system. Since there is a paucity of knowledge on the satisfaction of HIV and non-HIV-related child health services in Africa, the few studies done on non-HIV-related services showed varying levels of satisfaction. The care provided to the caregivers measured against their expectations before their enrollment into ART care is a serious link missing to fully understand caregiver experiences and utilization of care services. Knowledge from previous studies presupposes that when expectations are met, healthcare utilization is more likely going to increase for CLWH [13].

Previous studies in Ethiopia [17], South Africa [18], and Vietnam [9] have cited financial difficulties, stigma and discrimination, and food insecurity among others as the challenges caregivers encountered while caring for CLWH. These challenges are overcome by the resilience of caregivers and the quest to see their children happy and live fulfilling lives. Caregivers expect the health care facilities to ameliorate their suffering with a range of care, counselling, and other physical support to meet their far-reaching needs. For the PLWH in the poor north of Ghana, their plight is worsened and that of caregivers of CLWH leaves less to be desired. Das, et al. [19] intimated for instance in West Bengal-India that CLWH and their respective caregivers face numerous challenges and have many unmet but relevant expectations. They further explained caregiver's role goes beyond the CLWH-caregiver



relationship and is interwoven with the local community and the healthcare and support system structures. The health care facilities, therefore, remain a major component of the caring process. By far there is no study in Ghana which had explored the care rendered for CLWH and the expectations of their caregivers regarding hospital services. A previous study by Atanuriba, et al. [5] explored caregivers' experiences and reported; changed family dynamics, diagnosis discovery, reaction to CLWH diagnosis, caregiving challenges and burden but not care expectations of these caregivers about hospitals. The current study explores care services provided from voluntary counselling and testing to their care expectations. To this end, the current study aimed to qualitatively explore the care and expectations of caregivers concerning HIV care. The research question was "What are the diagnosis history, health-seeking behaviour, and care expectations of caregivers of CLWH?"

## Methods

### Study design

A qualitative approach was used because less is known about the phenomena and its ability to explore the lived experiences of people [20,21]. We used The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist to guide the presentation of this report [22].

### Study setting and population

The authors conducted the study in three referral hospitals in the Northern Region of Ghana. These facilities were located in the Tamale Metropolis, the third fastest-growing urban region in Ghana. We purposively sampled home caregivers from the Sexually Transmitted Infection (STI) clinic/ ART units of the hospitals.

### Inclusion and exclusion criteria

The inclusion criteria were [1] primary informal home caregivers of CLWHA aged 2 years - 14 years [2], those who had actively, continuously undertaken care for six months, and [3] those who were aged 18 years or older. However, caregivers who did not consent were excluded from the study.

### Sampling and sample size

We purposively sampled home caregivers till data saturated at the 9<sup>th</sup> participant. Thus, a point in which interview information became repetitive and did not yield any new information. Also, data were analysed concurrently with data collection through all the facilities. Data saturation is a point in qualitative research when information becomes repetitive and redundant [20].

### Instrument and data collection

A semi-structured interview guide was developed based on our research objectives and published evidence. Individual in-depth interviews were conducted for each consented

participant. The tool was examined by the authors and piloted at one of the sites to ensure the tool's accuracy, consistency, and comprehension by the participants. Results from the pilot transcripts were not added to the final report because the guide was revised.

The participants were approached at the STI clinics/ ART units while they were waiting to be consulted from September to November 2019. They were introduced to the study by the research team and those who could read and write handed the participant information leaflet to read. Those who agreed voluntarily to participate in the study were taken through the consent process. For those who met the inclusion criteria, an appropriate time and place for the interviews were scheduled.

Only one participant was interviewed at home, the rest were interviewed in consulting rooms within the hospital premises. After their consultation, the participants were interviewed alone by a trained research assistant in Dagbani or the lead author in English. The interviews lasting 25 minutes - 50 minutes were audio-recorded and salient notes were taken for non-verbal communication. Due to the sensitive nature of the topic interviews were conducted with only the interviewer present. Meanwhile, focal counsellors were identified and informed of the study at each site to intervene when participants became traumatized. Probing questions were used to direct the interviews and further explore their narrations. After the data collection participants were debriefed and assessed for emotional stability.

### Data analysis and management

Immediately, after the interviews, the audiotapes were listened to severally and transcribed verbatim for English interviews. Dagbani interviews were transcribed verbatim and translated back to back to ensure meanings were not lost. These transcripts were stored on a Computer and an external hard drive protected with a password. We ensured identifiable details were omitted and all ethical principles were adhered to. We analysed data thematically, manually, and concurrently with data collection till saturation was achieved at the ninth (9<sup>th</sup>) participant.

Collaizi's steps were utilized to analyze the qualitative data gathered from individual in-depth interviews with caregivers of children living with HIV/AIDS. Following the transcription of audio-recorded interviews, the data underwent analysis through Collaizi's steps, involving familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the final report. This systematic approach facilitated the identification and development of four key themes: history of pregnancy and poor HIV testing, effective care for caregivers and children living with HIV/AIDS, attitudes of healthcare providers, and unmet expectations of care. Through this process, the study gained insights into the experiences and perspectives of caregivers, highlighting areas of improvement in HIV/AIDS care provision.



Findings were presented in themes and subthemes and emphasis was placed on caregivers' direct quotations. We conducted member checking as a final step of quality control by sending the final works to some participants for validation [21].

### Rigour/trustworthiness

We ensured rigour and quality by conducting; member checks, peer debriefs, and audit trails. The authors also, bracketed their knowledge of the phenomena to ensure that the descriptions given truly represented that of the participants. A pilot was conducted to ensure the work was sound and devoid of biases. Coding was done independently by two of the authors and the differences were amended. Two other authors then supervised the coding and themes and the differences were discussed and reconciled. We provided a detailed description of the study setting, design, and sample to allow for the transferability of the findings.

### Ethical considerations

This study is part of a major study titled the "Experiences of Caregivers of Children Living with HIV/AIDS in Tamale Metropolis Northern-Ghana" with ethical approval from the Committee on Human Rights, Publication and Ethics (CHRPE) of Kwame Nkrumah University of Science and Technology and Research Development Division of Ghana Health Services (GHS) (CHRPE/AP/407/19), and (GHS-ERC 051/05/19) respectively. We obtained administrative approvals from Tamale Teaching Hospital and Northern Regional Health Directorate-Tamale before data collection. Ethical principles such as written informed consent, minimal harm, fairness, and justice among others were adhered to. All participants gave written informed consent before they were added to the study.

## Results

### Characteristics of caregivers

A majority [7] of the participants were females who were all HIV-positive caring for their biological children. Five were Muslims and had an average age of 38 years in their productive years. Among the participants, three were unemployed and only two were engaged in employment that earned them regular incomes. Five of the children were orphaned by HIV/AIDS and even among the non-orphaned children only two lived with their two biological parents and were being cared for. The characteristics of caregivers are presented in Table 1.

### Main themes

Four main themes and seven sub-themes emerged from the analysis of data. These themes bothered the history of pregnancy and HIV testing, care rendered to caregivers and CLWH, and health care professionals' attitudes and expectations. Table 2 presents the main themes with corresponding sub-themes.

### History of pregnancy and poor HIV testing

This theme explores PMTCT of HIV and the history of pregnancy from the caregivers concerning HIV voluntary counselling and testing. This theme stems from the fact that the majority of CLWH is contracted from vertical transmission from the mother. Since the majority (7 of 9) of the caregivers of this study were biological female HIV mothers, the essence of this theme came with mixed feelings. Findings from history showed that many of the mothers did not undertake the test or failed to believe their positive status. Strangely, none of the mothers or caregivers intimated mothers enrolling in the PMTCT programme. It means they either did not report to the facility for Ante-Natal Clinic (ANC) or the care providers did not refer them to the appropriate facilities for testing and management. The theme explores the knowledge of HIV status and their health-seeking attitudes and behaviours following disclosure.

### Positive knowledge of the mother's status

This sub-theme explores the knowledge/history of the caregivers/mothers concerning their HIV status. Findings showed the majority of the caregivers knew of their HIV-positive status but did not enrol on PMTCT. While others who were referred to undertake the test refused, some also did not take the test at all but it's the impression most mothers refused to attend ANC in order to keep their status a secret.

Narrations such as those below show the mothers or caregivers in the known of their positive status at pregnancy.

*"(when I was pregnant) I was consulting in a private clinic and the doctor didn't test me (because) he said he had not seen those symptoms from me, I told him that he should do HIV test because I have been seeing on TV that they want to stop the transmission of from mother to child. Me too my mind wasn't on it, since he is a doctor and he says he has not seen those symptoms me too I took my mind off it and didn't do that test. Till I gave birth and the child was sick. So, it was at Korle-Bu that I did this test (for the child)" (Caregiver-6).*

*"When I was pregnant, I went to a clinic I started it at village A (a rural setting in northern Ghana). so it was just one day they ask me to go and test because every pregnant woman is testing so I called him (husband) and told him, and he said that no I should not go and test. By then it was left with some few days for me to deliver and whenever I go to the hospital, they are not telling me anything" (Caregiver-8).*

Other mothers intimated they were negative at the time of pregnancy

*"When I was pregnant .... Yes, they(facility) did and it was negative, I wasn't having it and when I delivered, I was negative" (Caregiver-9).*

*"Yes, I was not told (I had the virus), is the current girl that I got to know. It hurt me so much when I got home, I cried seriously" (Caregiver-4).*





**Table 1:** Characteristics of caregivers.

Pseudo name	Age	Sex	HIV Status	Religion	Caregiver Education	Caregiver Type	Occupation	Orphan Status of Child
Caregiver 1	24	F	+	Islam	SHS	Biological parent	Trader	Both parent alive
Caregiver-2	41	M	-	Christian	Tertiary	Uncle	Insurance Sales Manager	One parent died
Caregiver-3	40	F	+	Islam	Nil	Biological parent	Nil	One parent died
Caregiver-4	36	F	+	Islam	Nil	Biological parent	Nil	One parent died
Caregiver-5	26	M	-	Islam	Tertiary	Brother	Student and Rentals	One parent died
Caregiver-6	44	F	+	Christian	Tertiary	Biological parent	Teacher	Both parents alive
Caregiver-7	48	F	+	Christian	Nil	Biological parents	Laundry	Both parents alive
Caregiver-8	42	F	+	Christian	SHS	Biological parent	Seamstress	One parent died
Caregiver-9	37	F	+	Islam	Tertiary	Biological parent	Typist	Both parent alive

SHS: Senior High School, F: Female, M: Male

**Table 2:** Summary of themes and sub-themes.

Number	Main Themes	Sub-Themes
One	History of pregnancy and poor HIV testing	Positive knowledge of the mother’s status
		Poor health-seeking behavior
Two	Effective care rendered for caregivers and CLWH	Care and services
		Effective pre-testing and routine counselling
Three	Attitudes of healthcare providers	Positive professional conducts
		Satisfaction with care at the hospital
Four	Unmet expectations of care	

*“When I was pregnant, I went to the hospital, I did they did several tests but I was not told I was positive my first two children are negative” (Caregiver-7).*

*Poor health-seeking behaviour*

This sub-theme explains the narrations of the caregivers about mothers of CLWH health-seeking behaviours after knowing of their positive status. The majority of mothers refused to visit the hospital for PMTCT. While others continued to attend their ANC without any PMTCT care owing to refusal to test even though were HIV positive.

*“and when she went to give birth I learned the nurses were very hard on her because she was not coming for clinical (ANC), so I presumed that she was hiding something from the family, then when she herself finally started going for the retroviral drugs it was affecting her because she was not so religious taking the drugs” (Caregiver-2).*

And for a participant whose doctor did not test her for HIV continued to attend ANC without being put on PMCTCT. This participant attended a private facility and was not tested even though positive.

*“Me too my mind wasn’t on it, since he is a doctor and he says he has not seen those symptoms me too I took my mind off it and didn’t do that test, but was still attending ANC till I delivered” (Caregiver-6).*

Those who were told of negative status cultivated positive healthy health-seeking behaviours by attending ANC as shown in the following.

*“and I used to go for ANC, the day I was to even deliver it was*

*the same hospital they (health care provider) did not tell me anything” (Caregiver-8).*

*“Yes, I was coming for the hospital here (TTH), when I was pregnant for ANC and I wasn’t having it and when I delivered, I was negative” (Caregiver-9).*

**Effective care rendered for caregivers and CLWH**

This theme describes the care/services provided for caregivers for HIV-related and non-HIV-related care services while caring for the CLWH. This theme explores the major services provided by formal healthcare systems and HCPs. Particular attention is laid on the counselling component of care provision concentrating on how it was rendered and their impression of it.

**Care and services**

The sub-theme enumerates and describes the services provided by the Health Care Facilities (HCFs) during out and in-patient care paying particular attention to routine care received at STI Clinic/ ART Unit. These services and care include continual monitoring, dispensing of medication, health education, and coordination of clinical care for medical conditions.

*“We collect medicine only; first, they used to give us foodstuff long ago but they have stopped, they say the foodstuff is not there again” To the mainstream OPD and In-Patient Care she emphasized “They (staff at these places) don’t know her status so no bad experiences have been seen.... They give us our medications” (they treated just like other patients)” (Caregiver-3).*

Among the services given aside from the collection of antiretrovirals (ARVs) are: health education and monitoring of health status demonstrated by the following:

*“Because of the advice (health education) they gave me at the counselling unit I have taken extreme care so that he doesn’t even fall sick frequently. I can’t even remember the last time he was sick” (Caregiver-2).*

*“It came to a time when boils were disturbing us. When we come and I complain to them they will tell me when she is sick,*



*I should send her to hospital, and we should not sit at home and say we are doing local treatment” (Caregiver-4).*

While their health status was always monitored.

*“They always take care of our weight, blood pressure before they give us our medicine” (Caregiver-9).*

### Effective pre-testing and routine counselling

Counselling remains the backbone of HIV testing, management, and worthwhile intervention. The failure of this could message the gains of health interventions and policy on HIV care. This theme explores the narrations of caregivers concerning the counselling services provided by HCPs. It delves into the overwhelming effects on the mental toughness of the caregivers while caring for CLWH. Counselling was carried out before and after screening and continuously during routine visits. Caregivers were impressed by the tact with which it was carried out.

A caregiver who visited the unit willingly to undertake the service for a 9-year, male, CLWH, had this to say:

*“... they made me feel ok and welcomed me well... the counselling was very good which helped me emotionally” (Caregiver-2).*

*“I was counselled by the man at the unit but the pain was much and after I was counselled that day when the news of the child being positive...but I was guilty knowing the child too is sick because if it were to be me only it would have been better than the child too” (Caregiver-7).*

There was however an absence of counselling for some caregivers who were abruptly told of their children’s status even before counselling was given at the STI/ART unit. A caregiver, a student who brought the junior sister (Ayisha) suffered this, as he narrates;

*“No please, I was not counselled at the lab there. When they gave us the results, they said we should come back the next day and we did. And they referred us to this unit and counselled us... I was wondering if she was raped or something cut her (mother has not been screened yet)” (Caregiver-5).*

*“The Counseling it wasn’t ok, and I was not ok..... I was not actually counselled, I was just informed when she called me in and asked to do the test and it was after the test, they took us somewhere that they were counselling us (disclosure of husband’s positive status at Accra before she did hers and the child)” (Caregiver-8).*

### Attitudes of healthcare providers

This theme explains the attitudes and conduct of HCPs at the various HCFs STI Clinic/ART Units HCPs such as pharmacists, records officers, and laboratory professionals are among the HCPs, even though nurses remain the most visible component of HIV care. The attitudes of these people remain

important to the caregiver’s experiences. The attitudes of the HCPs were said to be commendable and ethically professional and were devoid of harsh attitudes, rudeness, stigma, and discrimination.

### Positive professional conducts

This theme explains and echoes the positive attitudes of the HCPs in this study. The following are narrations that exhibit this;

*“They take very good care of us if we come, they don’t maltreat us when I come with her, they play with her very nicely. Then she becomes happy, they never say anything that disturbs us” (Caregiver-7).*

Another caregiver maintains that the staff are accommodating even when they default and they take the pain to educate them.

*“The care is good, they do well. If I say anything bad, I will be lying, even when my date comes and I don’t come and I come they understand me and give me my medications” (Caregiver-4).*

### Satisfaction with care at the hospital

This theme explains the satisfaction caregivers have concerning the HCPs’ attitudes and services provided. The majority explained excellent satisfaction with the care rendered to them while seeking care for HIV and non-HIV related care services. Even though there exist unmet needs such as food provision and financial support caregivers expressed deep appreciation for the care rendered to them and their CLWH. Some emphasis includes;

*“I feel normal and feel happy and I don’t feel anything or shy anytime am coming here for the medicine because they take good care of us. The nurses are good to us every month we come, I will give them 10/10 because they never do anything that will make us bad” (Caregiver-1).*

*“As for .....(Hospital A), I think if am grading it, it should be the best in Tamale as compared to when I used to go to (hospital B). (Hospital B) is just chaos they don’t have time for the patients and don’t even know what it is about. Yes, this unit here is good because of that I have adapted Hospital A for him, and the handling there is good” (Caregiver-2).*

Some expressions of delight and quality services with a passion for caregivers are

*“Yes, good, here they do well (and take good care of us) (Caregiver-3).*

*“The care is good, they treat you (us) well, they respect us and every information that you are supposed to know they will give you” (Caregiver-5).*

*“They take good care of us and make sure we are comfortable” (Caregiver-9).*



## Unmet expectations of care

This final theme describes the expectations of caregivers regarding the services to be provided by the formal healthcare facilities regarding CLWH. The theme on expectations was descriptions of the activities and interventions caregivers expected to be carried out for them and/or their CLWH to help in care and support. It also explores the narrations of how they expected HCFs to provide services that would cushion their households against the shocks of the disease. It further explained their desires for the HCFs' provision of services that will help with their physical health, mental support, and wider socio-economic welfare. Among the numerous was the provision of food security, financial support, provision of health and vitality medication such as multivitamins, and iron preparation. The caregivers also expected their constant provision of ARVs without shortage as well as the availability of medications for the treatment of Opportunistic Infections (OI) such as co-trimoxazole which are often unavailable and demand they purchase them. These are expressed in the following;

*"I would have wished they give multivitamins or iron or drugs that will help the patient to eat well or keep us healthy. We buy such drugs, as I just came, I told the guy I don't have money to buy... And I see that when he, my son takes it he eats well. So, they could have been sharing it with us for free. When I was in Accra, they used to give us tom brown and other things but here they have never given us these but one time I learnt they were giving corn and other things but I never had some"* (Caregiver-6).

*"Some medicine like septrin first they used to give us, especially for abdominal pain but now they don't give, because its good. If you take it, it helps a lot but we are asked to buy it at the drug store ourselves. We ladies need to care for the child, I did not go to school and I don't have a job. Sometimes it may be one week, two weeks or three but I have not had work. Then it becomes a problem if we could be helped to get work, to get money to care for ourselves and the children or some money to start a small business, like selling ice water to support ourselves. And food for instance, if I don't eat no problem but for the child, if she does not eat taking the medicine will be a problem so we want food. If you don't eat and you take the medicine it will do you as if you are drunk, so that's the major concern because we don't do work"* (Caregiver-7).

They expressed willingness to join associations and institutions that were concerned with PLWH to share their pain and possibly get partners, which they believe the facilities could facilitate to enhance their usefulness.

*"...here no ... since we moved to Tamale 2008 up to now, I have not had anybody to discuss this with the person, those meetings were helpful and I wish they are done here too"* (Caregiver-6).

A single mother caregiver also reckoned,

*"With such an organisation, you can get someone positive and you will all know and live together; it is good that way. They could come from different places Kumasi, Accra among others for us to meet, it used to give us hope..... I may get a partner"* (Caregiver-7).

## Discussion

The study aimed to explore the diagnosis history, health-seeking behaviour, and care expectations of caregivers of children living with HIV/AIDS. Four main themes emerged including history of pregnancy and poor HIV testing, effective care rendered for caregivers and CLWH, attitudes of health care providers, and unmet expectations of care.

The majority of caregivers in this study were females who all happened to be HIV-positive consistent with a qualitative study conducted in Ghana [23] and Namibia [24]. Our findings, however, contrast [8] where caregivers were grandparents and elderly people. In this study, the number of orphan children was equally high however many of the caregivers were positive biological parents of the CLWH, and were widowed, separated, or divorced. The findings are a reflection of HIV/AIDS prevalence being high among females, its association with poverty, and increased chances of being infected during reproductive age [25,26]. Caregivers described their burden as severe in this study as against low -moderate in India [27]. This is attributable to the low economic power of the women and implies caregivers need financial or economic support.

In Ghana, voluntary HIV counselling and testing is a major aspect of care during ANC attendance for pregnant women [28]. HIV-positive pregnant women are enrolled in the PMTCT programme "Option B" and "Treat All policy" which was adopted by Ghana to ensure there is no transmission of the virus to the unborn child during pregnancy, birth, or breastfeeding. In China, due to the PMTCT programme, 1.4 million HIV infections in children have been prevented between the years 2010 and 2018 alone [2]. In this study, none of the biological mothers indicated their enrollment in the program while it's the impression children were exposed to the virus during this period (pre-natally exposed). This is because in this study at least seven of the biological parents of CLWH were positive for the virus. This finding is in contrast to the goals of the Ministry of Health (MoH) and its related agencies in health to reduce the MTCT of HIV/AIDS. The finding is consistent with the findings of [29] in a tertiary hospital in India and [30] in Nigeria where it was shown that 90% of CLWH acquired it through MTCT. However, [30] indicated about 45% - 90% of these CLWH die between 1 to 3 years of life. This explains how huge the number of children who continue to lose their lives to the virus. With risk associated with high maternal viral load, multiple pregnancies, and rupture of membranes more than four hours before labour, prolonged duration of





breastfeeding, mixed feeding and breast diseases, and non-adherence to PMTCT or enrollment may have accounted for the high prevalence in this study.

### History of pregnancy and poor HIV testing

The narrations showed a majority of the biological mothers tested negative or didn't know their status at the time of ANC registration. Some were not tested at 36 weeks before delivery for which time they may have tested positive. The finding is consistent with [31] where there were untested ANC attendants and even increased from 17 % in 2011 to 25 % in 2013 in the analysis of Ghanaian data. This increasing trend shows many more pregnant Ghanaian women are refusing to be tested, thereby exposing their children to unnecessary risk as may be the case in our current study. While those who attended health centres or Community-based Health Planning and Services (CHPS) compounds with no laboratory capacity to do retro-screen were left out thus, did not hide to HCPs advice to go for a test at referred facilities or pay to be done at private labs. These findings go on to verify the infrastructural problems encountered by the health system in Africa, as stated in a study in Ethiopia [32] and the extra expenditure incurred by health-seekers on insurance [33] in northern Ghana. It was surprising that the few who were aware of their positive diagnosis kept theirs a secret and did not enrol or become consistent with PMTCT care. The untested ANC registrants have an implication on MTCT as evidence in Ghana shows for instance per regions in 2013, Greater Accra (31%), Northern (27%), and Volta (48%) recorded high percentages of untested ANC pregnant women. Overall, HIV-positive pregnant women initiated onto ARVs remarkably increased from 57% (2011) to 82% (2013), yet about a third (33%) of them in the Volta and Northern regions did not receive ARVs or enrol on the PMTCT programme [31]. These further confirm the high levels of prenatally HIV/AIDS infection among children and call for drastic approaches to improve enrollment unto PMTCT.

### Effective care rendered for caregivers and CLWH

Services provided by the ART units and STI clinics were consistent with Adjetey, et al. [34] in a study conducted in Ghana on the fact that CLWH is given comprehensive health screening; checking of temperature, pulse, respiration, blood pressure, and weight before administration of ARVs. We observe this care provision to be crucial to clinical disease progress and proper management of PLWHA in Ghana. Similarly, evidence in this study affirms the coordination of care by ART Units in referral for nutritional management, counselling, supportive care, and treatment of other diseased conditions and ailments such as malaria, especially tuberculosis as revealed by [30] in Nigeria and Ghana [35]. We consider this service as pivotal to CLWH and their caregivers which ought to be maintained.

Caregivers were satisfied with the care rendered by

the ART units similar to views among 70% of Ethiopian PLWH [32]. The finding also corroborates with predictors of satisfaction such as; availability of services, interaction with HCPs, and privacy during examination but not for disclosure of status to immediate family [32]. The attitudes of the HCPs were also positive while providing care for the CLWH as affirmed in previous studies in Thailand [36], Kenya [37], and South Africa [38]. However, the findings are similar to Chamla, et al. [13] in Nigeria where the majority (63%) were satisfied with pediatric HIV care but differed in that study where 44.4% explained they could not speak in private with the HCPs, 56.9% said that queues to see HCPs were too long, and 89.9% opined that some HCPs did not treat PLWH with sufficient respect. An earlier study in Ghana by Dapaah [3] emphasized that a few HCPs showed positive attitudes and behaviours towards clients during clinical interaction by addressing clients with courtesy, advising clients on a wide range of issues, and even supporting clients financially. However, in Zambia, there are long queues and waiting hours for PLWH which marred the satisfaction and limited HCPs and PLWH interaction time base [39]. These complaints were not seen in this study because of the good scheduling nature of the ART clinics to ensure that many PLWH do not come on a specific day.

### Attitude of healthcare providers

Counselling was adequately done for caregivers during their routine visits in this study for which reason caregivers explained help in their mental toughness. These findings are not consistent with Owusu [40] who revealed poor linkage between HIV testing and HIV care and treatment services, lack of patient confidentiality, and a shortage of HIV/AIDS specialists in Vietnam. Proper and effective counselling in this setting could be attributed to the availability of adequately trained staff and counsellors manning the clinics. Also, because, all clinical and non-clinical staff at the ART clinics were given in-service training on counselling and HIV care. Mchenry, et al. [41] asserted counselling helped caregivers improve adherence to ARVs and increased HIV knowledge which helped in the resilience of the caregivers in their role in the lives of CLWH in Kenya. The evidence is typical in this study but on disclosure among caregivers, many did not show interest in disclosing status to other people. Peer sharing and counselling were not also seen in this study despite their importance in Western Uganda [42]. In Ghana, disclosure has often been attached to the loss of shelter and food security [43]. They postulated for the poor disclosure in this setting. The authors further explained disclosure is done purposively for support which often is not provided and prevented by stigma and recommended pre and post-testing counselling should dwell on cooperating disclosure benefits to ensure comprehensive care for which this study concord.

### Unmet expectations of care

There exist many unmet needs confronted by caregivers across the world but in Africa, such challenges/needs are





much more severe [38,44-48]. Among those challenges and needs cited include financial, and physical strain, emotional breakdown, stigma, and discrimination. In a similar study using people living with advanced prostate cancer and their caregivers in Ghana, physical strain, stigma, and unmet care needs were reported [49,50]. Asuquo, et al. [48] in studying the ameliorative measure in Calabar, Nigeria for reducing the caring impact on PLWH and their caregivers bemoaned little or no support in the form of financial assistance, paucity of information on practical and coping skills, emotional support, and lack of physical help with caregiving. Whereas evidence of a significant relationship between the availability of support and caregivers' burden has been opined [51]. According to Asuquo, et al. [48], national and international health institutions and stakeholders must develop and incorporate relief services into counselling services for PLWH and their caregivers. These beliefs sat well with caregivers of this study as many were frantic about their difficulties and of the view that the hospitals could help.

Owing to the struggling National Health Insurance Scheme (NHIS) in Ghana, many treatments are not covered by the scheme while even those covered are not available requiring out-of-pocket payments [33]. It appears to be the same among Vietnam PLWH seeking ART services where out-of-pocket payments were made for which caregivers and their PLWH could not often absorb [52]. On reflection, the expectations of caregivers in this study about the availability and accessibility of treatment for opportunistic infections and improvement of health are genuine concerns and must be tackled. According to Das, et al. [19] in India, we saw caregivers' concerns for the future of their children in terms of jobs, and discrimination and expected the facilities to help educate their children to be independent in the future. These are genuine concerns as caregivers of their children are disadvantaged and were realized in this study.

Even though family support was adequate in a study conducted by Rajan, et al. [53] in Karnataka-India, institutional support in the form of food and finances was expected. Yet, food insecurity has been well documented with adherence to ARVs, this unmet need of caregivers from the hospitals appears to be visible as some caregivers complained it sometimes causes poor adherence. On the contrary caregivers in this study did not mention the expectation of having parental caregiver support groups to serve as psychological support for pediatric HIV caregivers as in Canada [44] and the need for disclosure to CLWH [54]. We express concerns about measures to be taken to provide these to meet the needs of CHLH and their caregivers. This is because they don't know the ameliorating effects of such group therapy. Our findings showed employment and health were associated with the resilience of the home caregivers as such employment assistance and health services improve the resilience of caregivers of PLWH. They made a clarion call for concerted efforts from the public and private sectors and policymakers

to create sustained formal employment opportunities and intervention programs for PLWH and their caregivers. Even though caregivers in this study were not very concerned about their health, it is important to emphasize health screening of the caregivers which is more often than not neglected. Just as has been the case in South Africa [55] where there was the need for an increased level of personal and medical care it's an expectation that was not mentioned by caregivers in this study. Another study in Namibia states caregivers gravely expressed their expectations for financial and social support from the health facilities by indicating this support with their resilience in their role as caregivers [8].

### Limitations and strengths

We consider the absence of the narrations of staff of STI/ARTS clinics on this critical phenomenon and the high majority of female participants as weaknesses to the study. Yet the evidence provided here is worthwhile to improve care for PLWH especially children living with HIV/AIDS. Our study strength includes; adequate elucidation of an important aspect of HIV/AIDS care among home caregivers and reports critical but less researched knowledge on PMTCT, services provided by Ghanaian STI/ART units, staff attitudes, and unmet needs that impact caregivers and CLWH in northern Ghana.

### Conclusion

The study aimed to explore the diagnosis history, health-seeking behaviour, and care provided by hospitals compared to caregiver's expectations. Four themes emerged including; a history of pregnancy and poor HIV testing, effective care for caregivers and CLWH, positive healthcare provider's attitudes, and unmet expectations of care. Healthcare providers showed positive attitudes towards caregivers and provided services. Expectations bordered on financial support, employment, and treatment for opportunistic infections. The findings of the study highlight gaps in HIV voluntary testing for pregnant women, enrollment in PMTCT, and unmet needs. It is imperative to improve coverage of HIV testing for pregnant women and efforts made to meet needs. Financial support, provision of food security, and assistance for caregivers are essential.

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### Data availability

The transcripts used for the analysis of the study are available from the corresponding author upon reasonable request.

### Author contributions

GAA; conception and design, analysis and interpretation of data, and drafting of the original paper,



FA and TTL; conception and design, revising the manuscript critically for intellectual content

YS; design and revising the manuscript critically for intellectual content

CA; data collection, analysis, and revising manuscript critically for intellectual content

RSM and MAA; interpretation of data and revising manuscript critically for intellectual content

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