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Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

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ABSTRACT

Background: Family caregivers of children living with HIV/AIDS in most cases they are found to be overwhelmed and under resourced, yet they are believed to be the primary source of support for children living with HIV/AIDS. Family caregivers experience different challenges that affect the children's Antiretroviral Therapy (ART) adherence.

Aim: The aim of this study was to explore the lived experiences of family care givers of children living with HIV/AIDS who sought ART Services for these Children at the St. Joseph's Hospital of Jirapa, Ghana.

Method: Using a qualitative phenomenology design and a semi-structured in-depth interview guide, data was gathered from thirteen family caregivers of children with HIV/AIDS receiving ART treatment at St. Joseph's Hospital-Jirapa. All interviews were tape-recorded and transcribed verbatim. The reflexive thematic analysis method was used to analyse the transcribed data.

Findings: Family caregivers of children living with HIV/AIDS experienced financial challenges, human-related challenges, challenges at HIV Testing and Counselling (HTC) centres, challenges with transportation, and challenges in disclosing children HIV status to them. Support was received at the HTC and from their family members.

Conclusion: Health care providers should explain policy regarding disclosure of HIV/AIDS status of children to their caregivers and enhance their capacity to reduce time spent at the centre by family care givers. Furthermore, they should limit access to the centre by people who have no business there. Family care givers need support from government agencies and Non-Governmental Organizations (NGOs) in terms of skills acquisition that will give them work to reduce their financial challenges. ART should be sent to clinics closer to family care givers to get rid of the

challenges related to distance and transportation. Support received by family care givers had contributed to enhancing ART adherence among HIV/AIDS children under their care.

Key words: Experiences**,** Caregiver, Children, HIV/AIDS, Adherence, Antiretroviral therapy.

ARTICLE SUMMARY

Strengths and Limitations

- The study allowed for the collection of information from family care givers of children living with HIV/AIDS who have a shared experience to better understand their views on ensuring children adhere to ART.
- The study gives a thorough grasp of the difficulties that family care givers face when caring for HIV/AIDS-infected children.
- The researchers' background as nurses who understand the nature and dynamics of HIV/AIDS in children may have influenced their interpretation of the data.
- Although the small sample size and use of only one hospital limited the generalizability of the findings, saturation was achieved during the interview.

INTRODUCTION

One point seven (1.7) million children aged 0 to 14 were infected with HIV worldwide. Furthermore, of the 1.7 million children sick 160 000 were newly infected by the end of 2018.[1] About 2.5 million people age below 15 years are infected with HIV/AIDS globally, with newborns and young children accounting for more than 60% of newly infected cases.[2] HIV/AIDS has killed around 33 million individuals worldwide, making it a public health hazard.[1] According to the author, 90% of babies that contract the disease from infected moms are found in Sub-Saharan Africa. According to a World Health Organization (WHO) assessment, more than thirty-three

million individuals, including 4.4 million children, are infected with HIV/AIDS worldwide, with 90% of those infected living in developing countries such as Ghana, resulting in the deaths of 3.2 million children.[2]

Furthermore, the authors estimate that 2.5 million and 1.9 million children under the age of 15 are infected with HIV/AIDS in the world and Sub-Sahara Africa, respectively.[2] In Ghana, 30,000 children aged 10 to 14 years were reported to be HIV-positive, with 2,441 children dying from the disease in 2018.[3] The prevalence of HIV/AIDS is 0.72% among people aged 15 to 49 in Ghana's Upper West Region.[4] An estimated 100,000 children died of AIDS-related illnesses in 2018 and that fifty percent (50%) of HIV-infected children will not live up to two years and 80% will die before the age of five due to a lack of access and poor adherence to ART.[1]

In Ghana, the problem of poor adherence among the few children taking ART drugs exists. In its drive to end the pandemic by 2020, the Joint United Nations Programme on HIV/AIDS (UNAIDS) stipulates that 90% of persons living with HIV/AIDS should be diagnosed, 90% of those diagnosed should be treated, and 90% of those on treatment should have their viral load suppressed.[5] However, the number of children receiving antiretroviral therapy falls significantly short of the target. In 2019, for example, 53% of children living with HIV/AIDS were started on antiretroviral medication to manage the virus and prevent illness transmission to others.[1] Early access to antiretroviral medication and strong adherence are crucial in improving the health of persons living with HIV/AIDS and preventing the disease's spread.[6] Also, adherence to antiretroviral therapy of 95% or above is essential for a favourable outcome.[7] The scientists went on to say that poor adherence due to a lack of support can result in insufficient viral suppression, the establishment of resistant virus strains, and treatment failure. This will result in an increase in morbidity and mortality. However, the few who are put on ART struggle with adherence. The adherence rate

among infected toddlers residing in Ghana was 62%.[8] Adherence to long-term therapy is defined by the World Health Organization as the amount to which a person's behaviour - taking medication, following a diet, and/or implementing lifestyle modifications - aligns with agreed-upon recommendations from a health-care practitioner.[9]

Family care givers have critical roles in increasing children's adherence to ART. Family care givers are typically family members or close relatives who provide partial or full unpaid care to a dependent person who is unable to care for themselves, facilitating their well-being and assisting in various tasks and activities related to the person's health such as medication adherence, wound treatment, and equipment monitoring.[10] According to studies, these informal carers bear more pressures due to the nature of children's reliance on them to meet their basic needs, and they are frequently overloaded and under-resourced.[11 12]

There has not been much study done on how the problems that family care givers face, as well as the presence of a support structure, affect adherence to ART among HIV/AIDS children. The purpose of this study is to investigate the challenges and support systems as experienced by family care givers of children with HIV who seek HIV care for their children at St. Joseph's Hospital in Jirapa Municipality, Upper West Region of Ghana, and how these challenges and support systems influence adherence to ART among children with HIV/AIDS.

METHODS

Design.

The study made used of a qualitative phenomenology design. The design is considered appropriate for the study because of insufficient data on the lived experiences of seeking ART services for children living with HIV among their family care givers in Ghana. Is the believe of the researchers

that exploring the experiences of family care givers of children living with HIV/AIDS will bring to bare their challenges and availability of support systems that influence adherence to ART among the children. Knowing their experiences will help the researchers recommend suitable interventions to alleviate their burden that will ensure adherence to ART among children living with HIV/AIDS.

Setting and participants

St. Joseph's Hospital which is located at the Jirapa Municipality is the setting for this study. Currently, St. Joseph's Hospital serves as the municipal hospital as well as a referral institution for eight health centres, fourteen Community-Based Health Planning and Services (CHPS) Zones inside the municipality, and additional facilities located outside of the municipality. It has 206 beds and offers outpatient, diagnostic, HTC, and in-patient care.[13] The study targets family care givers of children suffering from HIV/AIDS and on ART who receive services at the HIV/AIDS Treatment Center (HTC) at the St. Joseph Hospital of Jirapa Municipality.

Sampling and data collection

The researchers chose study participants using the purposeful sampling technique. Participants who satisfied the inclusion criteria were contacted both physically and by phone to clarify the purpose of the study and to organize a meeting with the participants at a convenient location. They were subsequently handed over an information sheet and a consent sheet to sign when they agreed to take part in the study. The researchers translated the interview guide, information sheet, and informed consent into Dagaare, the municipality's local language. Participants were informed that they could withdraw from the study at any moment without penalty. On the participants' days of visit to the HTC of St. Joseph's Hospital, interview sections were organized in a provided private

room within the hospital premises. During the face-to-face interview, the semi-structured in-depth interview guide was used whilst observing the protocols guiding COVID 19 prevention. Using participants own dialect allowed for open ended questions to be asked and further probes of interested issues and it allowed the participants to share their experiences at ease with the researchers. Each interview lasted 20-30 minutes and recorded using digital recorder. Semi-structured interview guide was used to collect data. It contains open-ended questions and probes to produce reach data (see supplemental file 1 online). Thirteen (13) family caregivers of children living with HIV/AIDS and receiving care at the HTC of the St. Joseph's Hospital in the Jirapa Municipality were interviewed during the study. This sample size of thirteen was arrived at by data saturation where the participants did not produce any added information.[14 15] Study data were collected from the month of April 2021 to May 2021. Data collected from this study was stored in a computer with a password to prevent unauthorized access.

Trustworthiness and rigour

The study was credible in the sense that the researcher explained the goal of the study to the understanding of the participants, and they were free to ask questions for clarity. The researcher repeated some of the participants' comments to ensure that they were accurate reflections of their experiences, and she used a variety of data gathering methods, including interviews, observations, and field notes. Ensuring dependability, interviews were continued and analysed until saturation where participants responses did not produce new responses. Confirmability of data was ensured by ensuring that coded data were categorized into subcategories and themes. The study was piloted for validity and reliability. For transferability, the researchers gave details on the research design, setting and how purposive sampling was employed to choose participants who met the inclusion

criteria. Standard for reporting qualitative study check list by O'Brien was used as a guide in presenting this paper.[16]

Data analysis

Reflexive thematic approach was used in the analysis of data.[13 17] The theoretical framework for the analysis of the data was the constructionist perspective which holds that people's senses and experiences are socially constructed and changed but are not innate to them. Hence the researchers theorized the sociocultural and structural context that pushed the phenomenon under study. A theory-driven view was considered by the researchers where data was looked at with precise research questions in mind that steered the study.[12 18] Researchers followed the six steps in data analysis.[13 14 17 19] It embraces data familiarization, transcription of data, identifying initial ideas and generating initial codes across the entire data set through reading and repeated reading of the data, and collating data relevant to each code. The researcher searched for themes and collated the codes into probable themes, gathered all data appropriate to each potential theme and reviewed them examining if the themes work in accordance with the coded extracts and the entire data set. Thematic maps were generated, defining and naming themes. The researchers during the final analysis produced the report. There was also analysis and selection of vivid, convincing extract examples. The researchers related the analysis to the research question, producing a report of the analysis.

Patient and public involvement

There was no patient or public involvement as far as the construction of the study design, or conducting the study, reporting or dissemination of the research findings are concern.

RESULTS

Demographic characteristics

Table 1 presents the summary of demographic data of thirteen (13) respondents who participated in the study. The table shows that majority of respondents were females (11), married (11), farmers (12), and did not have formal education (6). Most of them (12) were actual parents of the children. Most of the HIV/AIDS children were males (8). With duration of treatment for the children, they have been on ART for 4 to 14 months (mean 4.5years, SD 4.3). Additionally, family care givers were between the ages of 20 and 50 years (mean 37.4 years, SD 9.0) and that of HIV/AIDS children were from 2 to 14 years (mean 8.6 years, SD 5,2).

Table 1: Socio-demographic characteristics of respondents.

Socio-Demographic Characteristics	Frequency (n =13)	Percentage (%)
Caregivers gender		
Male	2	15.4
Female	11	84.6
Caregivers' marital status		
Married	11	84.6
Widowed	2	15.4
Caregivers' occupation		
Farmer	12	92.3
Weaver	1	7.7
Caregivers' educational level		
No formal education	6	46.2
Primary School	1	7.7
Junior High School	3	23.1
Senior High School	1	7.7
Technical School/Vocational	2	15.4
Caregivers' relationship with child		
Child	12	92.3
Niece	1	7.7
Child's gender		
Male	8	61.5
Female	5	38.5

Source In-depth Interview Data (2021).

Themes

Family care givers of children living with HIV/AIDS shared their experiences in ensuring ART adherence among the children as full of challenges and a little support. The analysis of transcript data generated six themes: financial challenges, human-related challenges, challenges at HTC centres, challenges with transportation, challenges in disclosing HIV status to child, and forms of support. These themes are further explained in the following narratives.

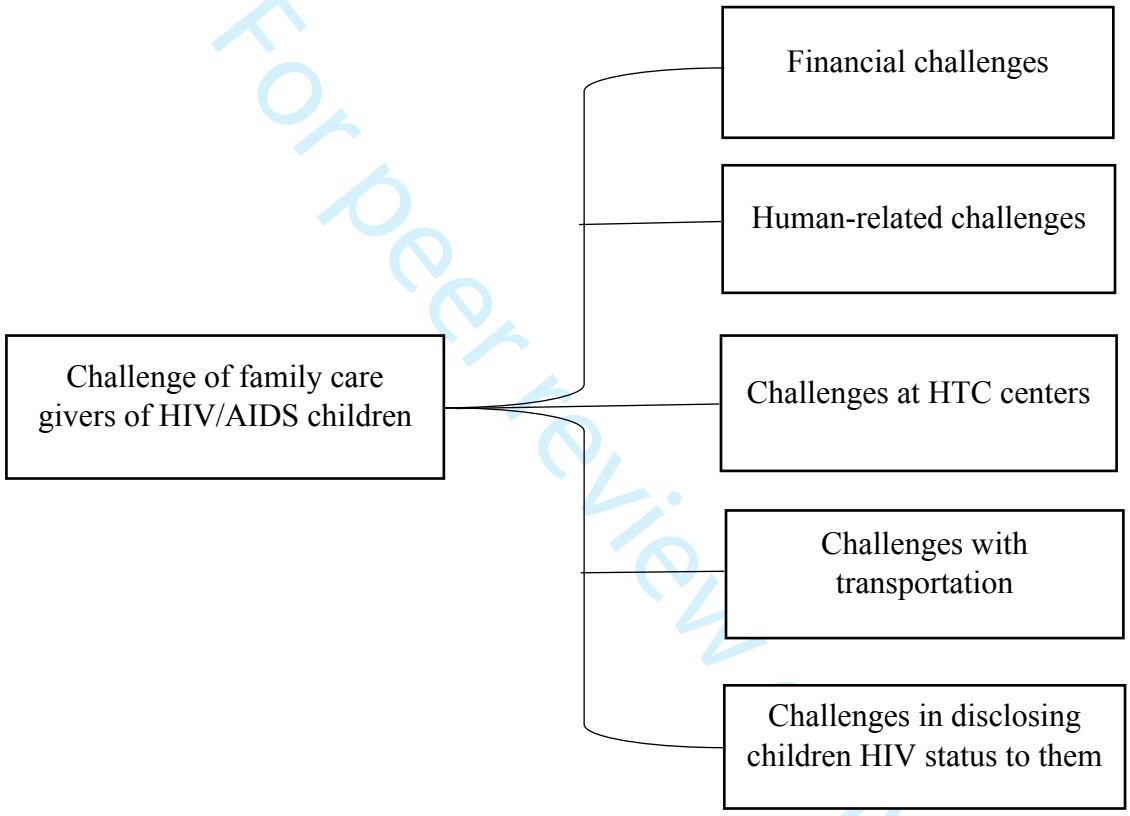

Figure 1: Thematic map on family care givers' challenges in ensuring HIV/AIDS children adheres to ART.

Financial difficulty

Participants narrated their challenges in connection with finances. Some said they did not have money to take transport to collect their ART, meeting the demands of their children at the HCT unit, such as buying food and other things for the child when hungry, buying Septrin which is part of the ART, and buying food stuff to feed themselves and the children. They complained that one

need to eat well if on ART, but they did not have money to buy food. This is what they have to say.

> *"Because I don't have money for car fare to come, the medicines can finish about three weeks or month before we come for the medicine…."* **R1**
>
> *"…may be is time for you to come and collect your medicine and If you get motor you have to buy fuel but sometimes you don't have the money… because of that the day will pass…."* **R10**
>
> *"…you know he will be hungry and suppose to eat and if you do not have money, it becomes a worry to you…."* **R4**
>
> *"…the only problem is the absent of Septrin here that we are asked to buy but if you don't have money, you can't, the Septrin is helpful if you are able to buy and take your body becomes strong, but if they don't give you and you don't have money to buy you will take this one and your body will still be disorganized. It will be good if they make it available…."* **R12**
>
> *"…we have challenge in feeding, because we don't have any proper job, it will help us to manage our disease, if you get the food stuff and you don't even have money you will also try to get herrings and 'dawadawa' which will help you to be better because it will help the medicine to suppress the disease…"* **R9.**

Human-related challenges.

Human-related challenges in ensuring that HIV/AIDS children adhere to ART were identified as an important challenge by informal care givers. Three subcategories generated under this main one as shown in Figure 1 were child related difficulties in adherence, caregiver related difficulties in adherence and society related difficulty in adherence. Child related challenges were expressed by respondents as due to the bitterness and tablet nature of ART, child not knowing the importance, and its swallowing been monotonous. The follow is what they have to say.

> *"I give him the medicine, if you give him the tablet, he will not swallow…"* **R1.**

> *"… because is bitter when you are giving it to the child, he doesn't want to drink you have to force him….when you take medicine every day like that; it will get to a time when you will not want to take the medicine again…it is compulsory but because you know it importance but he is a child and doesn't know anything"* **R4**

Society related stigma was spoken of as causing dissatisfaction regarding and against them. This does not give them the peace of mind to go to the HTC unit to manage children living with HIV/AIDS. Below are some expressions reported.

> *"… if you have an issue with someone and the person knows that you are in this situation collecting the medication and sees you somewhere outside the hospital, he/she will be making mockery of you…sometimes they call to ask where I am, I tell them am somewhere, I don't tell them am here and I don't like it"* **R5**

Some family care givers expressed their challenges for not been able to ensure children adheres strictly to ART as due to forgetfulness, some due to feared of the unknown specially when they miss a dose, some also complained of busy schedule, and finally some said they are not always present at home to administer ART. The following were some of their statements.

> *"Sometimes I forget but when is too late we cannot take it again like if you forget and sleep or roam till is 10pm there is always fears whether to take or not…Missing doses of medicines happen when am not at home"* **R3.**

> *"Sometimes I forget to give the medicine to the child because when I come from work, and I have to cook and sometimes before you realize she is sleeping but when I forget I try to give the following day…."* **R5**

Difficulty at HTC centre

Family care givers of this study experienced difficulties at the HTC centre which affect strict adherence negatively. They complained of delaying to get treatment at the centre and meeting familiar people who talk ill about them. The following were said by participants.

"…at the hospital you cannot get the medicines early like that…" **R3.**

"Because of that fear of people seeing me come here for the medicine, sometimes I feel like not coming but I think again that if I don't come it means that is the child that I want to die so whatever it is I try to come" **R5.**

Difficulties with transportation

Informal care givers also complained that non availability of transportation from their places of residence to the HTC centre and had to trek a distance was having a negative toll on ensuring strict adherence to the ART. Because of this, some informal care givers advocated that some of the ART be sent to clinics closer to their places of stay. This is what they said.

"…there used to be public transport to Jirapa…but now it doesn't come again…I will wish they are able to send some of the medicines to the clinic at our place so that our journey will be short" **R7.**

"…when I decided to come, I did not get means…vehicles that pass there to Jirapa no more pass there but different route to Wa' **R10**

"If you don't get someone to pick you and the child to the hospital for the treatment, you have to back the child and walk a distance to the hospital" R3.

Difficulties in disclosing HIV status to child

Participants feel that if children get to know their HIV status it will help them to adhere strictly to the ART. However, participants expressed their challenges in disclosing to the child of his or her HIV status. The following were said:

"…she asked me that what medicine have we been collecting and the woman said we should not miss any dose, so I told her that there is a disease in our body that is why we have to take this medicine without missing doses and that she supposed to take it all the time…the child upon hearing this became moody which also affected my mood and is paining me…." R7

"…It is a worry how to disclose it to him because he is a child if you tell him, he has AIDS he will be thinking because he has also heard that AIDS is a bad disease and is a worry…when he gets to certain age, we will tell him, and he will understand" R12

Support for family care givers

Support for informal care givers is very necessary to ensure that children LWHIV/AIDS adheres strictly to ART. Family care givers received support from both nuclear and extended families and HTC centre as indicated on Figure 2. Support from their families were in the form of food stuff, finances, and support in ART administration. The following were their expressions.

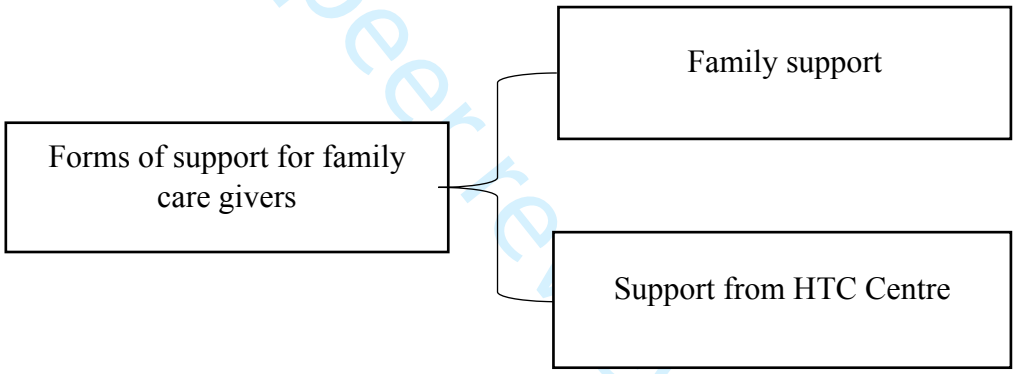

Figure 2: Thematic map for forms of support for family care givers in ensuring HIV/AIDS children adheres to ART.

"When am not around is the father that gives the medicine to the child and if the father is not around, I break it into two and give to the grandmother though I cannot tell her what medication it is, and tell her when time is up, she should give to the child" **R2.**

"Is only my husband that supports me, when we are coming for the medicine, he gives us money in case the child wants food I can buy for him or if they talk about money I can pay" R5.

"The money we get from my brother in-law helps a lot…for food stuff he farms for us to put down for the feeding, so the money he gives is for buying soup ingredients and grinding the flour" R8.

Assistance received from HTC centre by family care givers was explained in relation to receiving food stuff from nurses, psychological support from colleagues and free ART from the HTC centre. These were explained as follows.

> *"For help is, one nurse who ever helped me, she gave me rice, oil and other things to prepare for the child"* R13.
>
> *"We used to come here for a meeting every Saturday ...you can come and hear something and when you get home all your worries will be thrown away. It was helpful...."* R11
>
> *"The support we get from the hospital is when we come, and our doctors and nurse are able to give us the medication well for us to take home and the government trying to always get the medicine for us for free"* R6.

DISCUSSION

The researchers after the analysis of the interview scripts asserted that; family care givers of children living with HIV/AIDS related their experiences in six themes; financial challenges, human-related challenges, challenges at HTC centres, challenges with transportation, challenges in disclosing HIV status to child, and forms of support.

Family care givers of children with HIV/AIDS complained they did not have money to take transport to collect their ART, meeting the demands of their children at the HCT unit such as buying food and other things for the child when hungry, buying Septrin which is part of the ART, and buying food stuff to feed themselves and the children. They complained that one need to eat well if on ART, but they did not have money to buy food. According to the family care givers, these challenges negatively affect their efforts to ensure children under their care adheres to the ART. Similarly, the majority of studies conducted in Sub-Saharan Africa and even in other third-world countries recognized financial stress as a daily difficulty faced while seeking ART services, such as transportation fees during follow-up visits and insufficient money for meals.[12] These difficulties have a deleterious impact on adherence to ART. Out-of-pocket payments and the high

cost of ART were noted in a review article showing the detrimental impact of adherence to ART.[20] Inadequate money for transport, buying food stuff and Septrin are factors that could lead to non-adherence to ART by informal care givers and children under their care.

Human-related challenges in ensuring that HIV/AIDS children adhere to ART was identified as an important challenge by informal care givers. Child related challenges were expressed by respondents as due to the bitterness and tablet nature of ART, child not knowing the importance, and its swallowing been monotonous. Findings of the current study is in consonance with a longitudinal observational cohort study where medication regimen such as using tablet formulation is a negative influencing factor to adherence to ART.[21] The taste, formulation and child's knowledge on ART importance influence adherence to ART. Respondents did not adhere to ART because of its tablet formulation and bitterness.[22] Making available injectable or sweeten syrup ART and explaining its importance will take away some challenges to ensure strict adherence to ART among children LWHIV/AIDS.

Society related stigma was spoken of as causing dissatisfaction regarding and against them. This does not give them the peace of mind to go to the HTC unit to manage the children living with HIV/AIDS. Stigma discourages people from seeking health services hence public education is needed on the cause, management, and prognosis of the disease HIV.[23] Stigmatisation is one of the challenges care givers face mostly ensuring strict adherence to ART by the children under their care.

Some family care givers expressed their challenges for not been able to ensure children adheres strictly to ART as due to forgetfulness, some due to feared of the unknown specially when they miss a dose, some also complained of busy schedule, and finally some said they are not always

present at home to administer ART. A cross sectional study revealed that PLWHIV/AIDS sometimes do forget to take their ART hence affecting adherence negatively.[24] They further explained that their respondents forget to take their ART because they were too busy and far from home. The afore mentioned factors were recorded by Neupane and others as the main cause of non-adherence to ART.[25] These challenges influenced ART adherence among children LWHIV/AIDS negatively, hence family care givers need family support to ensure strict adherence to the ART among children LWHIV/AIDS under their care.

Family care givers experienced difficulties at the HTC centre which affect strict adherence negatively. They complained of delaying to get treatment at the centre and meeting familiar people who talk ill about them. Too much waiting time affect adherence to ART negatively.[20] Furthermore, the authors stated that care providers at the centre must reschedule their activities to shorten the waiting time for clients to ensure adherence to ART. The study further revealed that family care givers see people who do not take HIV medications to be a source of stigma and for that matter do not wish to see them most especially at the HTC centre. If informal care givers continue to be seen at HTC centre and stigmatised, they are likely to be discouraged from seeking HIV care.[23] Care providers at the centre are to be encouraged to limit unnecessary visits by people who are not HIV positive and hence do not take ART from the unit.

Family care givers also complained that non availability of transportation from their places of residence to the HTC centre and had to trek a distance was having a negative toll on ensuring strict adherence to the ART. If a child is found to be living with HIV the child and caregiver will have to travel a distance to access care and treatment which already constitute a barrier to service utilization and retention in care.[26] Far distances to HTC centres and lack of transport are seen by informal care givers as challenges to ensuring that children LWHIV/AIDS under their care adheres

strictly with ART. Because of this, family care givers of this study advocated that some of the ART be sent to clinics closer to their places of stay.

Participants feel that if children get to know their HIV status it will help them to adhere strictly to the ART. However, participants expressed their challenges in disclosing to the child of his or her HIV status with the reason that child will feel bad upon hearing this news. Likewise, studies conducted in Africa has shown that nondisclosure of children HIV status by care givers has influenced ART adherence among children negatively.[26 27 28] Hence family care givers have complained of children refusal to take ART because, in a longitudinal observational cohort study, a child's awareness on his/her HIV status is an influencing factor to adherence to ART.[21] Children with information of their HIV status adhere to ART better than children without knowledge of their HIV status. The National AIDS/STI Control Programme and Ghana Health Service has recommended 8 – 10 years at which full disclosure of HIV/AIDS status should be made known to the child in a helpful and supportive approach and environment.[29]

Forms of family support for informal care givers are very necessary to ensure that children LWHIV/AIDS adheres strictly to ART. Informal care givers received different forms of support from family members; they were provision of food stuff, financial support and administering ART to the child. These forms of support were received from extended family members of informal care givers such as grandparents, mothers, in-laws, and sisters. They were also received from nuclear family members of informal care givers such as daughters and partners. Most informal care givers had support from both extended and nuclear family members in administering ART to children under their care. Informal care givers of children LWHIV/AIDS received financial support from both extended and nuclear family members. This support assisted them in many ways to ensure strict adherence of the children to ART.

Support for family care givers is very necessary to ensure that children LWHIV/AIDS adheres strictly to ART. They receive support from their families both external and internal in the form of food stuff, finances, and support in ART administration. Care givers who had family support were more likely to adhere strictly to ART than the one who had no family support. They further explained that though some infected persons do forget to take the ART, with family and friends support, they are able to adhere strictly.[24 25] Likewise, the Joint United Nations Programme on HIV/AIDS postulates that care and support services should be complete in nature to include medical, psychosocial, physical, socioeconomic, nutritional and legal support.[30] They further said that these forms of support are so crucial to the well-being and existence of PLWHIV/AIDS and their caregivers. Family support is therefore essential for family care givers to ensure strict adherence to ART among children LWHIV/AIDS.

The study reveals that assistance received from HTC centre by family care givers was explained in relation to receiving food stuff from nurses, psychological support from colleagues and free ART from the HTC centre. Support received by children LWHIV/AIDS and their care givers at the HTC centre make them feel supported hence they believing in a better future.[31] Psychological support for people living with HIV/AIDS influences adherence positively.[20] A longitudinal observational cohort study stated that social support as received by caregivers and their children at the HTC centre is a buffer against stressful environment which enhance adherence to ART.[21] It is therefore encouraged for people LWHIV/AIDS to get together often to know one another and share their problems and encourage one another. Care providers are supposed to empower them psychologically through the health education giving at the centre. Availability and accessibility of antiretroviral medications at the HTC centres influence positively the adherence to ART.[20] Support

received from HTC centre such as counselling, food stuff and medications facilitate adherence to ART among children LWHIV/AIDS.

STRENGTHS AND LIMITATIONS OF THIS STUDY.

This is the first research to explore the experiences of family care givers of HIV/AIDS children in the setting and has provided rich information on their challenges and support system. This information provided by this study will bridge the knowledge gap in this area and provide a resource for policy review, clinical practice, and development of interventions that will aim at reducing the challenges faced by family care givers of children suffering from HIV/AIDS. However, the study is limited by some factors. A small sample size and the usage of one municipal hospital limited the generality of the findings, interviewing more family care givers from different settings may have produced more richer experience.

Conclusion and implication for practice and policy

This study concluded that family care givers faced challenges such as financial challenges, human-related challenges, challenges at HTC centres, challenges with transportation, challenges in disclosing HIV status to child, and they also experienced some forms of support. These challenges prevent family care givers from ensuring that children under their care adhere strictly to ART. The support received by family care givers had contributed to enhancing ART adherence. Despite these challenges of the informal givers, there are no targeted interventions that addresses their plight. Health care providers should explain policy regarding disclosure of HIV/AIDS status of children to their caregivers and enhance their capacity to reduce time spent at the centre by family care givers. Furthermore, they should limit access to the centre by people who have no business there. Family care givers need support from government agencies and NGOs in terms of skills acquisition

that will give them work to reduce their financial challenges. ART be sent to clinics closer to family care givers to get rid of the challenges related to distance and transportation. There should be revision of existing policies that takes into consideration the challenges of family care givers of children living with HIV/AIDS.

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Authors Contributions

All authors were involved in the conceptualization, methodology, and review of the study. Data collection, analysis and drafting of the manuscript were done by authors 1, 2, 5, 6 and 7. Authors 3 and 4 undertook critical revision for intellectual content, proofread, and approved the final manuscript for submission.

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Competing Interest

It is declared unanimously by all authors that there is no existence of conflict of interest.

Data Availability Statement

The in-depth interview guide is uploaded as a supplementary file. However, audio-taped recordings of the interview cannot be shared with third party because of the confidentially agreement signed by participants.

Patient and public involvement

Neither patient nor public participated in the design, conduct, reporting, or dissemination of this research.

Ethical approval

Ethical clearance was obtained from the Institutional Review Board of the Navrongo Health Research Centre (NHRCIRB415). At the site, the researchers were granted permission by the HTC centre of the St. Joseph's Hospital in Jirapa Municipality. Participants signed/thumb printed the consent form after going through it and the information sheet. The letter 'R' representing participants with a number attached were assigned to family care givers to ensure anonymity.

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In-depth interview guide

Research Article Tittle: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

Introduction: The purpose of this study is to investigate the challenges and support systems as experienced by family care givers of children with HIV who seek HIV care for their children at St. Joseph's Hospital in Jirapa Municipality, Upper West Region of Ghana, and how these challenges and support systems influence adherence to ART among children with HIV/AIDS. It will be appreciated if you could respond appropriately to all the questions that will be asked in this interview. You are assured of confidentiality of any information shared. Thank you for agreeing to take part in this interview.

Section A: Socio-demographic characteristics of participants

Can you please introduce yourself and your child? I want to know you better.

Possible probes.

1. Please how old are you?
2. What is your marital status?
3. What is your occupation?
4. What is your level of formal education?
5. How are you related to the child?
6. What is the age of your child?
7. How long has your child been on ART?

Section B: Family Care givers of HIV/ADIS children challenges when seeking ART services

Please tell me some of the challenges that you go through as caregiver of a child with HIV/AIDS in ensuring the adherence to antiretroviral therapy.

Possible probes.

1. Tell me the challenges you encounter ensuring strict adherence to the antiretroviral therapy?

2. Tell me how these challenges mentioned above influence the adherences of your child to the antiretroviral therapy?

3. How easy is it for you accessing the HIV/AIDS medications?

Thank you so much for sharing that with me, and I appreciate it. Now, I like to talk with you about the available support systems for you and the child.

Section C: Support toward adherence

Please tell me the support you get from others and how it helps you to ensure the child adheres to the ART.

Possible probes.

1. Describe to me the forms or sources of support you get?

2. Explain to me how the sources of support play a role in the child's adherence to medications?

3. How does your family support you in ensuring that the child takes the medications well?

4. What kind of support do you get from the health sector/hospital to ensure that the child stays on the ARTs?

5. What role do your friends play in supporting you to ensure that the child stays on the ARTs as ordered?

6. How easy is it for you getting these supports?

Thank you for spending time to take part in this interview. We appreciate every bit of information provided.

Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

Standard for Reporting Qualitative Research by O'Brien et al., (2014)

No	Topic	Item	Checked
Title and abstract			
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	√
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	√
Introduction			
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	√
S4	Purpose or research question	Purpose of the study and specific objectives or questions	√
Methods			
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	√
S6	Research characteristics and reflexibility	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	√
S7	Context	Setting/site and salient contextual factors; rationale	√
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale	√

Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	√
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	√
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	√
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	√
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	√
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	√
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	√
Results/findings			
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	√
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	√
Discussion			

Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field.	√
S19	Limitations	Trustworthiness and limitations of findings	√
Others			
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	√
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	√

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Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study at the Jirapa St. Joseph's Hospital in Ghana.

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Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study at the Jirapa St. Joseph's Hospital in Ghana.

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ABSTRACT

Background: Family care givers of children living with HIV/AIDS in most cases are found to be overwhelmed and under resourced, yet they are believed to be the primary source of support for children living with HIV/AIDS. Family care givers experience different challenges that affect the children's Antiretroviral Therapy (ART) adherence.

Aim: The aim of this study was to explore the lived experiences of family care givers of children living with HIV/AIDS who sought ART Services for these Children at the St. Joseph's Hospital of Jirapa, Ghana.

Method: Using a qualitative phenomenology design and a semi-structured in-depth interview guide, applying purposeful sampling, data was gathered from thirteen family care givers of children with HIV/AIDS receiving ART treatment at St. Joseph's Hospital-Jirapa at saturation after receiving ethical clearance. All interviews were tape-recorded and transcribed verbatim. The reflexive thematic analysis method was used to analyse the transcribed data. Methodological rigor was ensured through credibility, dependability, confirmability, and transferability.

Findings: Family care givers of children living with HIV/AIDS experienced financial challenges, human-related challenges, challenges at HIV Testing and Counselling (HTC) centres, challenges with transportation, and challenges in disclosing children HIV status to them. Support was received at the HTC and from their family members.

Conclusion: Health care providers should explain to the care givers of children living with HIV/AIDS the policy regarding disclosure of HIV/AIDS status of children. Health professionals working at the HTC should enhance their own capacity to help reduce time spent at the centre by family care givers. Furthermore, they should limit access to the centre by people who have no business there. Family care givers need support from government agencies and Non-Governmental

Organizations (NGOs) in terms of skills acquisition that will give them work to reduce their financial challenges. ART should be sent to clinics closer to family care givers to get rid of the challenges related to distance and transportation. Support received by family care givers had contributed to enhancing ART adherence among HIV/AIDS children under their care.

Key words: Experiences**,** Care giver, Children, HIV/AIDS, Adherence, Antiretroviral therapy.

ARTICLE SUMMARY

Strengths and Limitations

- The study allowed for the collection of information from family care givers of children living with HIV/AIDS who have a shared experience to better understand their views on ensuring children adhere to ART.
- The study gives a thorough grasp of the difficulties that family care givers face when caring for HIV/AIDS-infected children.
- The researchers failed to seek the views of children living with HIV/AIDS which could have enriched the data on challenges of living with HIV/AIDS with diverse views.
- The study could not determine the HIV/AIDS status of the family care givers, this could have enriched the study further in understanding the experiences of family care givers who are infected with HIV/AIDS as compared to those who are not.

INTRODUCTION

One point five (1.5) million children aged 0 to 14 were infected with HIV worldwide. Furthermore, of the 1.5 million children sick ,130 000 were infected in 2022 [1]. About 2.58 million people aged 0-19 years are infected with HIV/AIDS globally in 2022, with children aged 0-9 accounting for almost 50% of newly infected cases [2]. HIV/AIDS has killed 630,000 individuals worldwide in

2022, making it a public health hazard [1]. According to the author, 90% of babies that contract the disease from infected moms are found in Sub-Saharan Africa. According to a World Health Organization (WHO) assessment, more than thirty-three million individuals, including 4.4 million children are infected with HIV/AIDS worldwide, with 90% of those infected living in developing countries such as Ghana, resulting in the deaths of 3.2 million children [2].

Furthermore, 2.5 million and 1.9 million children under the ages of 15 are infected with HIV/AIDS in the world and Sub-Sahara Africa, respectively [2]. In Ghana, 25,000 children aged 0 to 14 years were reported to be HIV-positive, with 2900 newly infected and 2,200 children dying from the disease in 2022 [3]. The prevalence of HIV/AIDS is 0.72% among people aged 15 to 49 in Ghana's Upper West Region [4]. Fifty percent (50%) of HIV-infected children will not live up to two years and 80% will die before the age of five due to a lack of access and poor adherence to ART [5].

In Ghana, the problem of poor adherence among the few children taking ART drugs exists. In its drive to end the pandemic by 2020, the Joint United Nations Programme on HIV/AIDS (UNAIDS) stipulates that 90% of persons living with HIV/AIDS should be diagnosed, 90% of those diagnosed should be treated, and 90% of those on treatment should have their viral load suppressed [6]. However, the number of children receiving antiretroviral therapy falls significantly short of the target. In 2022, for example, 44% of children living with HIV/AIDS were receiving antiretroviral medication to manage the virus and prevent illness transmission to others [3].

Early access to antiretroviral medication and strong adherence are crucial in improving the health of persons living with HIV/AIDS and preventing the disease's spread [7]. Also, adherence to antiretroviral therapy of 95% or above is essential for a favourable outcome [8]. The scientists went on to say that poor adherence due to a lack of support can result in insufficient viral

suppression, the establishment of resistant virus strains, and treatment failure. This will result in an increase in morbidity and mortality. However, the few who are put on ART struggle with adherence. The adherence rate among infected toddlers residing in Ghana was 62% [9]. Adherence to long-term therapy is defined by the World Health Organization as the amount to which a person's behaviour - taking medication, following a diet, and/or implementing lifestyle modifications - aligns with agreed-upon recommendations from a health-care practitioner [10].

Family care givers have critical roles in increasing children's adherence to ART. Family care givers are typically family members or close relatives who provide partial or full unpaid care to a dependent person who is unable to care for themselves, facilitating their well-being and assisting in various tasks and activities related to the person's health such as medication adherence, wound treatment, and equipment monitoring [11]. According to studies, these informal carers bear more pressures due to the nature of children's reliance on them to meet their basic needs, and they are frequently overloaded and under-resourced [12, 13].

Studies have been carried out in Ghana to explore the experiences of family care givers on several topics. For example, studies exploring the knowledge of family care givers on ART for children, and the beliefs of family care givers on adhering to ART for children [14-16]. No study was found by the researchers that directly explored how the problems that family care givers face, as well as the presence of a support structure, affect adherence to ART among HIV/AIDS children in the Jirapa municipality. The purpose of this study is to investigate the challenges and support systems as experienced by family care givers of children with HIV who seek HIV care for their children at St. Joseph's Hospital in Jirapa Municipality, Upper West Region of Ghana, and how these challenges and support systems influence adherence to ART among children with HIV/AIDS.

METHODS

Research team and reflexivity.

The research team is made up of nurses and lectures in both clinical and academic fields. They all have interest in paediatric care and the management of HIV/AIDS. The lead author, LY who is a nurse was a student for a membership program who has interest and experience in qualitative studies. This work was supervised by OW. The supervisor is a nurse and lecturer who has in-depth knowledge in the conduct of qualitative research with focus in HIV/AIDS and child health. The interviews were conducted by the lead author and SK. All the other authors have at least first degree in nursing and underwent training before the commencement of their roles in this study. Though the lead author works in the facility, she has no business with the HIV/AIDS unit in the facility. The work of the authors has no bearing with the facility used for the studies and therefore did not know any of the participants either personally or professionally.

Design.

The study made used of an interpretative phenomenology design [17]. The design is considered appropriate for the study because of insufficient data on the lived experiences of seeking ART services for children living with HIV among their family care givers in the Upper West Region of Ghana. It's the believe of the researchers that exploring the experiences of family care givers of children living with HIV/AIDS will bring to bear their challenges and availability of support systems that influence adherence to ART among the children. Knowing their experiences will help the researchers recommend suitable interventions to alleviate their burden that will ensure adherence to ART among children living with HIV/AIDS.

Setting and participants

St. Joseph's Hospital which is located at the Jirapa Municipality was the setting for this study. Currently, St. Joseph's Hospital serves as the municipal hospital as well as a referral institution for eight health centres, fourteen Community-Based Health Planning and Services (CHPS) Zones in the municipality, and additional facilities located outside the municipality. It has 206 beds and offers outpatient, diagnostic, HTC, and in-patient care**.** The study targets family care givers of children suffering from HIV/AIDS and on ART who receive services at the HIV/AIDS Treatment Centre (HTC) at the St. Joseph Hospital of Jirapa Municipality [18].

Sampling and data collection

The researchers chose study participants using the purposeful sampling technique. The researchers translated the interview guide, information sheet, and informed consent from English into Dagaare, which is the municipality's local language. Participants who satisfied the inclusion criteria were first contacted physically and subsequently by phone to clarify the purpose of the study and to organize a meeting with the participants at a convenient location for both participants and the researcher. Participants were subsequently handed over an information sheet and a consent sheet to sign when they agreed to take part in the study. Participants were informed that they could withdraw from the study at any moment without penalty. Study data were collected from the month of April 2021 to May 2021. On the participants' days of visit to the HTC of St. Joseph's Hospital, interview sessions were organized in a provided private room within the hospital premises. During the face-to-face interview, the semi-structured in-depth interview guide was used whilst observing the protocols guiding COVID 19 prevention. The guide contains open-ended questions and probes to produce rich data (see supplemental file 1 online). Participants own dialect, dagaare was used for the interview which allowed for open ended questions to be asked and further probes of

interested issues and it allowed the participants to share their experiences at ease with the researchers. Each interview lasted 20-30 minutes and recorded using digital recorder. Thirteen (13) family care givers of children living with HIV/AIDS and receiving care at the HTC of the St. Joseph's Hospital in the Jirapa Municipality were interviewed during the study. This sample size of thirteen was arrived at by data saturation where the participants did not produce any added information [17, 19]. Data collected from this study was stored in a computer with a password to prevent unauthorized access.

Rigour

The quality of this study was ensured by using the approach of Lincoln and Guba (1985) by ensuring credibility, dependability, transferability, and confirmability [20]. The study was credible in the sense that the researcher explained the goal of the study to the understanding of the participants, and they were free to ask questions for clarity. The researcher repeated some of the participants' comments to ensure that they were accurate reflections of their experiences, and she used a variety of data gathering methods, including interviews, observations, and field notes. Ensuring dependability, interviews were continued and analysed until saturation where participants responses did not produce new responses. Confirmability of data was ensured by ensuring that coded data were categorized into subcategories and themes. The study was piloted for validity and reliability. For transferability, the researchers gave details on the research design, setting and how purposive sampling was employed to choose participants who met the inclusion criteria. Standard for reporting qualitative study check list by O'Brien was used as a guide in presenting this paper [21].

Data Analysis

The interview recordings were transcript in Dagaare and translated into English by a person that has proficiency in both Dagaare and English. Data were analysed manually. The researchers employed interpretative phenomenology in this study using the reflexive thematic approach according to Braun and Clarke [17, 22-24]. The theoretical framework for the analysis of the data was the constructionist perspective which holds that people's senses and experiences are socially constructed and changed but are not innate to them. Hence the researchers theorized the sociocultural and structural context that pushed the phenomenon under study. A theory-driven view was considered by the researchers where data was looked at with precise research questions in mind that steered the study. Researchers followed the six steps in data analysis by Braun and Clarke as described below [22-24].

1. Data familiarization and writing familiarization notes: Two researchers carefully read through the transcript data to familiarise themselves. Each made an initial note which was discussed together, each then put their notes into a visual map with some conceptual definitions.
2. Systematic data coding: the first author in consultation with co-authors started identifying initial ideas and generating initial codes across the entire data set through reading and repeated reading of the data, and collating data relevant to each code. The codes helped to organize the data.
3. Generating initial themes from coded and collated data; The researcher searched for themes and collated the codes into probable themes, gathered all data appropriate to each potential theme and reviewed them examining if the themes work in accordance with the coded extracts and the entire data set.

4. Developing and reviewing themes. Then, themes were continuously developed into meaningful patterns. Through literature review and comparing with the source data, researchers developed and reviewed the themes.
5. Refining, defining, and naming themes; the authors discussed extensively the meaning of the patterns to refine the existing patterns.
6. Writing the report: The researchers during the final analysis produced the report. There was also analysis and selection of vivid, convincing extract examples. The researchers related the analysis to the research question, producing a report of the analysis. Thematic maps were used to indicate the themes and subthemes.

Patient and public involvement

There was no patient or public involvement as far as the construction of the study design, or conducting the study, reporting or dissemination of the research findings are concern.

RESULTS

Demographic characteristics

Table 1 presents the summary of demographic data of thirteen (13) respondents who participated in the study. The table shows that majority of respondents were females (11), married (11), farmers (12), and did not have formal education (6). Most of them (12) were actual parents of the children. Most of the HIV/AIDS children were males (8). With duration of treatment for the children, they have been on ART for 4 months (0.33years) to 14 years (mean 4.5years, SD 4.4). Additionally, family care givers were between the ages of 20 and 50 years (mean 37.4 years, SD 9.0) and that of HIV/AIDS children were from 2 to 14 years (mean 8.6 years, SD 5,3).

Table 1: Socio-demographic characteristics of respondents.

Socio-Demographic Characteristics	Frequency (n =13)	Percentage (%)
Care givers gender		
Male	2	15.4
Female	11	84.6
Care givers' marital status		
Married	11	84.6
Widowed	2	15.4
Care givers' occupation		
Farmer	12	92.3
Weaver	1	7.7
Care givers' educational level		
No formal education	6	46.2
Primary School	1	7.7
Junior High School	3	23.1
Senior High School	1	7.7
Technical School/Vocational	2	15.4
Care givers' relationship with child		
Child	12	92.3
Niece	1	7.7
Child's gender		
Male	8	61.5
Female	5	38.5

Source In-depth Interview Data (2021).

Themes

Family care givers of children living with HIV/AIDS shared their experiences in ensuring ART adherence among the children as full of challenges and a little support. The analysis of transcript data generated six themes: financial challenges, human-related challenges, challenges at HTC centres, challenges with transportation, challenges in disclosing HIV status to child, and forms of support. These themes are further explained in the following narratives.

Financial Challenges

Participants narrated their challenges in connection with finances. Some said they did not have money to take transport to collect their ART, meeting the demands of their children at the HCT

unit, such as buying food and other things for the children when hungry, buying Septrin which is part of the ART, and buying food stuff to feed themselves and the children. They complained that one needs to eat well if on ART, but they did not have money to buy food. This is what they have to say.

> *"Because I don't have money for car fare to come, the medicines can finish about three weeks or month before we come for the medicine…."* **R1**
>
> *"…maybe it's time for you to come and collect your medicine and If you get motor you have to buy fuel but sometimes you don't have the money… because of that the day will pass…."* **R10**
>
> *"…you know he will be hungry and suppose to eat and if you do not have money, it becomes a worry to you…."* **R4**
>
> *"…the only problem is the absent of Septrin here that we are asked to buy but if you don't have money, you can't, the Septrin is helpful if you are able to buy and take, your body becomes strong, but if they don't give you and you don't have money to buy you will take this one and your body will still be disorganized. It will be good if they make it available…."* **R12**
>
> *"…we have challenge in feeding, because we don't have any proper job, it will help us to manage our disease, if you get the food stuff and you don't even have money you will also try to get herrings and 'dawadawa' which will help you to be better because it will help the medicine to suppress the disease…"* **R9.**

Human-related challenges.

Human-related challenges in ensuring that HIV/AIDS children adhere to ART were identified as an important challenge by informal care givers. Three subcategories generated under this main one as shown in Figure 1 were child related difficulties in adherence, care giver related difficulties in adherence and society related difficulty in adherence. Child related challenges were expressed by respondents as due to the bitterness and tablet nature of ART, child not knowing the importance, and its swallowing been monotonous. The following is what they have to say.

"I give him the medicine, if you give him the tablet, he will not swallow…" **R1.**

"… because is bitter when you are giving it to the child, he doesn't want to drink you have to force him…. when you take medicine every day like that; it will get to a time when you will not want to take the medicine again…it is compulsory but because you know its importance but he is a child and doesn't know anything" **R4**

Society related stigma was spoken of as causing dissatisfaction regarding and against them. This does not give them the peace of mind to go to the HTC unit to manage children living with HIV/AIDS. Below are some expressions reported.

"… if you have an issue with someone and the person knows that you are in this situation collecting the medication and sees you somewhere outside the hospital, he or she will be making mockery of you…sometimes they call to ask where I am, I tell them I'm somewhere, I don't tell them I'm here and I don't like it" **R5.**

Some family care givers expressed their challenges for not being able to ensure children adheres strictly to ART as due to forgetfulness, some due to fear of the unknown specially when they miss a dose, some also complained of busy schedule, and finally some said they are not always present at home to administer ART. The following were some of their statements.

"Sometimes I forget but when it is too late we cannot take it again like if you forget and sleep or roam till is 10pm there is always fears whether to take or not…Missing doses of medicines happen when I'm not at home" **R3.**

"Sometimes I forget to give the medicine to the child because when I come from work, and I have to cook and sometimes before you realize she is sleeping but when I forget I try to give the following day…." **R5**

Challenges at HTC centre

Family care givers of this study experienced difficulties at the HTC centre which affect strict adherence negatively. They complained of delaying getting treatment at the centre and meeting familiar people who talk ill about them. The following were said by participants.

"…at the hospital you cannot get the medicines early like that…" **R3.**

"Because of that fear of people seeing me come here for the medicine, sometimes I feel like not coming but I think again that if I don't come it means that is the child that I want him/her to die so whatever it is I try to come" **R5.**

Challenges with transportation

Informal care givers also complained that non availability of transportation from their places of residence to the HTC centre and had to trek a distance was having a negative toll on ensuring strict adherence to the ART. Because of this, some informal care givers advocated that some of the ART be sent to clinics closer to their places of stay. This is what they said.

"…there used to be public transport to Jirapa…but now it doesn't come again…I will wish they are able to send some of the medicines to the clinic at our place so that our journey will be short" **R7.**

"…when I decided to come, I did not get means…vehicles that pass there to Jirapa no more pass there but different route to Wa' **R10**

"If you don't get someone to pick you and the child to the hospital for the treatment, you have to back the child and walk a distance to the hospital" R3.

Challenges in disclosing HIV status to child.

Participants feel that if children get to know their HIV status it will help them to adhere strictly to the ART. However, participants expressed their challenges in disclosing to the child of his or her HIV status. The following were said:

"…she asked me that what medicine have we been collecting and the woman said we should not miss any dose, so I told her that there is a disease in our body that is why we have to take this medicine without missing doses and that she supposed to take it all the time…the child upon hearing this became moody which also affected my mood and is paining me…." R7

"…It is a worry how to disclose it to him because he is a child if you tell him, he has AIDS he will be thinking because he has also heard that AIDS is a bad disease and is a worry…when he gets to certain age, we will tell him, and he will understand" R12.

Support for family care givers.

Support for informal care givers is very necessary to ensure that children LWHIV/AIDS adheres strictly to ART. Family care givers received support from both nuclear and extended families and HTC centre as indicated on Figure 2. Support from their families were in the form of food stuff, finances, and support in ART administration. The following were their expressions.

"When am not around is the father that gives the medicine to the child and if the father is not around, I break it into two and give to the grandmother though I cannot tell her what medication it is, and tell her when time is up, she should give to the child" **R2.**

"Is only my husband that supports me, when we are coming for the medicine, he gives us money in case the child wants food I can buy for him or if they talk about money I can pay" R5.

"The money we get from my brother in-law helps a lot…for food stuff he farms for us to put down for the feeding, so the money he gives is for buying soup ingredients and grinding the flour" R8.

Assistance received from HTC centre by family care givers was explained in relation to receiving food stuff from nurses, psychological support from colleagues and free ART from the HTC centre. These were explained as follows.

"For help is, one nurse who ever helped me, she gave me rice, oil and other things to prepare for the child" R13.

"We used to come here for a meeting every Saturday …you can come and hear something and when you get home all your worries will be thrown away. It was helpful…" R11

"The support we get from the hospital is when we come, and our doctors and nurse are able to give us the medication well for us to take home and the government trying to always get the medicine for us for free" R6.

DISCUSSION

The researchers after the analysis of the interview scripts asserted that; family care givers of children living with HIV/AIDS related their experiences in six themes; financial challenges, human-related challenges, challenges at HTC centres, challenges with transportation, challenges in disclosing HIV status to child, and forms of support.

Family care givers of children with HIV/AIDS complained they did not have money to take transport to collect their ART, meeting the demands of their children at the HCT unit such as buying food and other things for the child when hungry, buying Septrin which is part of the ART, and buying food stuff to feed themselves and the children. They complained that one needs to eat well if on ART, but they did not have money to buy food. According to the family care givers, these challenges negatively affect their efforts to ensure children under their care adheres to the ART. Similarly, studies conducted in Sub-Saharan Africa and even in other third-world countries recognized financial stress as a daily difficulty faced while seeking ART services, such as transportation fees during follow-up visits and insufficient money for meals [13]. These difficulties have a deleterious impact on adherence to ART. Out-of-pocket payments and the high cost of ART were noted in a review article showing the detrimental impact of adherence to ART [25]. Inadequate money for transport, buying food stuff and Septrin are factors that could lead to non-adherence to ART by informal care givers and children under their care.

Human-related challenges in ensuring that HIV/AIDS children adhere to ART was identified as an important challenge by informal care givers. Child related challenges were expressed by respondents as due to the bitterness and tablet nature of ART, child not knowing the importance, and its swallowing being monotonous. Findings of the current study is in consonance with a longitudinal observational cohort study where medication regimen such as using tablet formulation

has negatively influenced adherence to ART [26]. The taste, formulation, and child's knowledge on ART importance influence adherence to ART. Respondents did not adhere to ART because of its tablet formulation and bitterness [27]. Making available injectable or sweeten syrup ART and explaining its importance will take away some challenges to ensure strict adherence to ART among children LWHIV/AIDS.

Society related stigma was spoken of as causing dissatisfaction regarding and against them. This does not give them the peace of mind to go to the HTC unit to manage the children living with HIV/AIDS. Stigma discourages people from seeking health services hence public education is needed on the cause, management, and prognosis of the disease HIV [28]. Stigmatisation is one of the challenges care givers face mostly ensuring strict adherence to ART by the children under their care.

Some family care givers expressed their challenges for not been able to ensure children adheres strictly to ART as due to forgetfulness, some due to feared of the unknown specially when they miss a dose, some also complained of busy schedule, and finally some said they are not always present at home to administer ART. A cross sectional study revealed that PLWHIV/AIDS sometimes do forget to take their ART hence affecting adherence negatively [29]. They further explained that their respondents forget to take their ART because they were too busy and far from home. The afore mentioned factors were recorded by Neupane and others as the main cause of non-adherence to ART [30]. These challenges influenced ART adherence among children LWHIV/AIDS negatively, hence family care givers need family support to ensure strict adherence to the ART among children LWHIV/AIDS under their care.

Family care givers experienced challenges at the HTC centre which affect strict adherence negatively. They complained of delaying getting treatment at the centre and meeting familiar people who talk ill about them. Too much waiting time affects adherence to ART negatively [25]. Furthermore, the authors stated that care providers at the centre must reschedule their activities to shorten the waiting time for clients to ensure adherence to ART. The study further revealed that family care givers see people who do not take HIV medications to be a source of stigma and for that matter do not wish to see them most especially at the HTC centre. If informal care givers continue to be seen at HTC centre and stigmatised, they are likely to be discouraged from seeking HIV care [28]. Care providers at the centre are to be encouraged to limit unnecessary visits by people who are not HIV positive and hence do not take ART from the unit.

Family care givers also complained that non availability of transportation from their places of residence to the HTC centre and had to trek a distance was having a negative toll on ensuring strict adherence to the ART. If a child is found to be living with HIV, the child and the care giver will have to travel a distance to access care and treatment which already constitute a barrier to service utilization and retention in care [31]. Far distances to HTC centres and lack of transport are seen by informal care givers as challenges to ensuring that children LWHIV/AIDS under their care adheres strictly with ART. Due to this, family care givers of this study advocated that some of the ART be sent to clinics closer to their places of stay.

Participants feel that if children get to know their HIV status it will help them to adhere strictly to the ART. However, participants expressed their challenges in disclosing to the child of his or her HIV status with the reason that child will feel bad upon hearing this news. Care givers feel it is an issue because the children were too young to understand, whilst others think older children have heard that HIV/AIDS is a bad disease and telling them will make them feel bad. Likewise, studies

conducted in Africa has shown that nondisclosure of children HIV status by care givers has influenced ART adherence among children negatively [31-33]. Hence family care givers have complained of children refusal to take ART because, in a longitudinal observational cohort study, a child's awareness on his/her HIV status is an influencing factor to adherence to ART [26]. Children with information of their HIV status adhere to ART better than children without knowledge of their HIV status. The National AIDS/STI Control Programme and Ghana Health Service has recommended 8 – 10 years at which full disclosure of HIV/AIDS status should be made known to the child in a helpful and supportive approach and environment [34].

Forms of family support for informal care givers are very necessary to ensure that children LWHIV/AIDS adheres strictly to ART. Informal care givers received different forms of support from family members; they were provision of food stuff, financial support and administering ART to the child. These forms of support were received from extended family members of informal care givers such as grandparents, mothers, in-laws, and sisters. They were also received from nuclear family members of informal care givers such as daughters and partners. Most informal care givers had support from both extended and nuclear family members in administering ART to children under their care. Informal care givers of children LWHIV/AIDS received financial support from both extended and nuclear family members. This support assisted them in many ways to ensure strict adherence of the children to ART.

Support for family care givers is very necessary to ensure that children LWHIV/AIDS adheres strictly to ART. They receive support from their families both external and internal in the form of food stuff, finances, and support in ART administration. Care givers who had family support were more likely to adhere strictly to ART than the one who had no family support. They further explained that though some infected persons do forget to take the ART, with family and friends

support, they are able to adhere strictly [29, 30]. Likewise, the Joint United Nations Programme on HIV/AIDS postulates that care and support services should be complete in nature to include medical, psychosocial, physical, socioeconomic, nutritional, and legal support [35]. They further said that these forms of support are so crucial to the well-being and existence of PLWHIV/AIDS and their care givers. Family support is therefore essential for family care givers to ensure strict adherence to ART among children LWHIV/AIDS.

The study reveals that assistance received from HTC centre by family care givers was explained in relation to receiving food stuff from nurses, psychological support from colleagues and free ART from the HTC centre. Support received by children LWHIV/AIDS and their care givers at the HTC centre make them feel supported hence they believe in a better future [36]. Psychological support for people living with HIV/AIDS influences adherence positively [25]. A longitudinal observational cohort study stated that social support as received by care givers and their children at the HTC centre is a buffer against stressful environment which enhance adherence to ART [26]. It is therefore encouraged for people LWHIV/AIDS to get together often to know one another and share their problems and encourage one another. Care providers are supposed to empower them psychologically through the health education giving at the centre. Availability and accessibility of antiretroviral medications at the HTC centres influence positively the adherence to ART [25]. Support received from HTC centre such as counselling, food stuff and medications facilitate adherence to ART among children LWHIV/AIDS.

STRENGTHS AND LIMITATIONS OF THIS STUDY.

This is the first research to explore the experiences of family care givers of HIV/AIDS children in the setting and has provided rich information on their challenges and support system. This

information provided by this study will bridge the knowledge gap in this area and provide a resource for policy review, clinical practice, and development of interventions that will aim at reducing the challenges faced by family care givers of children suffering from HIV/AIDS. However, the study is limited by some factors. A small sample size and the usage of one municipal hospital limited the generality of the findings, interviewing more family care givers from different settings may have produced more richer experience.

Conclusion, implication for practice and policy, and recommendations.

This study concluded that family care givers faced challenges such as financial challenges, human-related challenges, challenges at HTC centres, challenges with transportation, challenges in disclosing HIV status to child, and they also experienced some forms of support. These challenges prevent family care givers from ensuring that children under their care adhere strictly to ART. The support received by family care givers had contributed to enhancing ART adherence. Despite these challenges of the informal care givers, there are no targeted interventions that addresses their plight. Health care providers should explain to the care givers of children living with HIV/AIDS the policy regarding disclosure of HIV/AIDS status of children. Health professionals working at the HTC should enhance their own capacity to help reduce time spent at the centre by family care givers. Furthermore, they should limit access to the centre by people who have no business there. Family care givers need support from government agencies and NGOs in terms of skills acquisition that will give them work to reduce their financial challenges. ART be sent to clinics closer to family care givers to get rid of the challenges related to distance and transportation. There should be revision of existing policies that takes into consideration the challenges of family care givers of children living with HIV/AIDS.

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Authors Contributions

LY: involved in conception and study design; data collection; analysis and interpretation; critical revision for intellectual content; approved final manuscript for submission. SK: involved in conception and study design; data collection; analysis and interpretation; drafting of manuscript; critical revision for intellectual content; approved final manuscript for submission. WO: contributed to conception and study design; supervision, analysis, and interpretation; critical revision for intellectual content; approved final manuscript for submission. MWK: contributed to conception and study design, analysis, and interpretation; revision of the study; approved final manuscript submission. NDM: contributed to conception and study design; analysis and interpretation; revision of the study; approved final manuscript submission. MMW: contributed to conception and study design; analysis and interpretation; revision of the study; approved final manuscript submission. AN: contributed to conception and study design; analysis and interpretation; revision of the study; approved final manuscript submission.

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Competing Interest

It is declared unanimously by all authors that there is no existence of conflict of interest.

Data Availability Statement

The in-depth interview guide is uploaded as a supplementary file. However, audio-taped recordings of the interview cannot be shared with third party because of the confidentially agreement signed by participants.

Patient and public involvement

Neither patient nor public participated in the design, conduct, reporting, or dissemination of this research.

Ethical approval

Ethical clearance was obtained from the Institutional Review Board of the Navrongo Health Research Centre (NHRCIRB415). This study is part of a bigger study that was undertaken. At the site, the researchers were granted permission by the HTC centre of the St. Joseph's Hospital in Jirapa Municipality. Participants were protected against minimal harm such as physical and/or psychological by allowing them to relax and express emotional concerns about the study and interviewing participants in safe and private environments. Additionally, participants were taken through the consent process effectively to communicate what the study entailed to allow participants to make their decision of taking part or not. They were assured of confidentiality. Researchers collected only relevant information from participants and data collected could not be linked to participants. Participants signed/thumb printed the consent form after going through it and the information sheet. The letter 'R' representing participants with a number attached were assigned to family care givers to ensure anonymity.

Figure 1: Thematic map on family care givers' challenges in ensuring HIV/AIDS children adheres to ART.

Figure 2: Thematic map for forms of support for family care givers in ensuring HIV/AIDS children adheres to ART.

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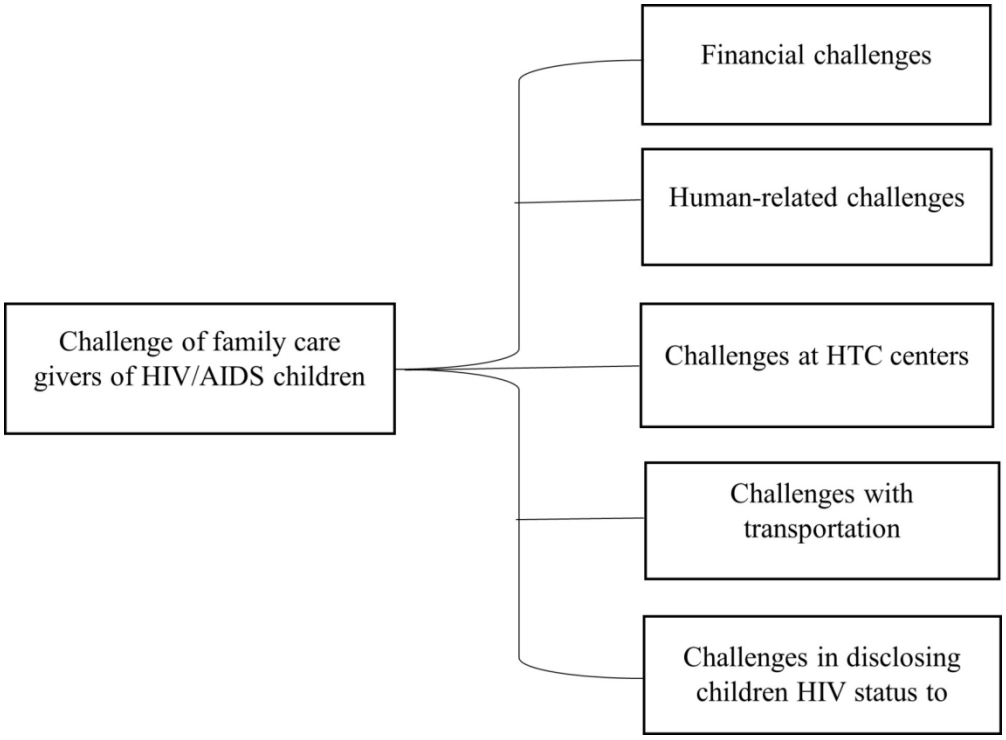
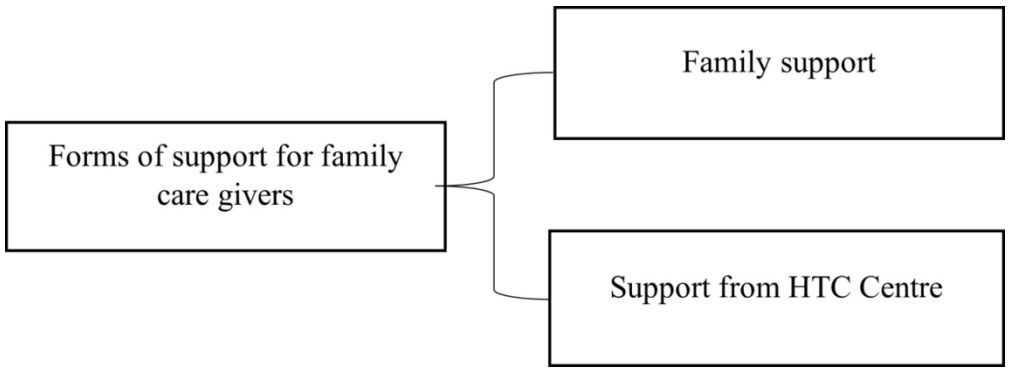


Thematic map on family care givers' challenges in ensuring HIV/AIDS children adheres to ART.

148x108mm (300 x 300 DPI)



Thematic map for forms of support for family care givers in ensuring HIV/AIDS children adheres to ART.

133x48mm (300 x 300 DPI)

In-depth interview guide

Research Article Tittle: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

Introduction: The purpose of this study is to investigate the challenges and support systems as experienced by family care givers of children with HIV who seek HIV care for their children at St. Joseph's Hospital in Jirapa Municipality, Upper West Region of Ghana, and how these challenges and support systems influence adherence to ART among children with HIV/AIDS. It will be appreciated if you could respond appropriately to all the questions that will be asked in this interview. You are assured of confidentiality of any information shared. Thank you for agreeing to take part in this interview.

Section A: Socio-demographic characteristics of participants

Can you please introduce yourself and your child? I want to know you better.

Possible probes.

1. Please how old are you?
2. What is your marital status?
3. What is your occupation?
4. What is your level of formal education?
5. How are you related to the child?
6. What is the age of your child?
7. How long has your child been on ART?

Section B: Family Care givers of HIV/ADIS children challenges when seeking ART services

Please tell me some of the challenges that you go through as caregiver of a child with HIV/AIDS in ensuring the adherence to antiretroviral therapy.

Possible probes.

1. Tell me the challenges you encounter ensuring strict adherence to the antiretroviral therapy?

2. Tell me how these challenges mentioned above influence the adherences of your child to the antiretroviral therapy?

3. How easy is it for you accessing the HIV/AIDS medications?

Thank you so much for sharing that with me, and I appreciate it. Now, I like to talk with you about the available support systems for you and the child.

Section C: Support toward adherence

Please tell me the support you get from others and how it helps you to ensure the child adheres to the ART.

Possible probes.

1. Describe to me the forms or sources of support you get?

2. Explain to me how the sources of support play a role in the child's adherence to medications?

3. How does your family support you in ensuring that the child takes the medications well?

4. What kind of support do you get from the health sector/hospital to ensure that the child stays on the ARTs?

5. What role do your friends play in supporting you to ensure that the child stays on the ARTs as ordered?

6. How easy is it for you getting these supports?

Thank you for spending time to take part in this interview. We appreciate every bit of information provided.

Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

Standard for Reporting Qualitative Research by O'Brien et al., (2014)

No	Topic	Item	Checked
Title and abstract			
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	√ Page 1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	√ Page 2 &3
Introduction			
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	√ Page 4 & 5 line 16-32 under introduction
S4	Purpose or research question	Purpose of the study and specific objectives or questions	√ Line 6-9 of last paragraph under introduction
Methods			
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	√ Page 6 line 1 under study design
S6	Research characteristics and reflexibility	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	√ Page 6 under methodology
S7	Context	Setting/site and salient contextual factors; rationale	√ Page 7. Line 1-7
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was	√ Page 7 & 8. Line 1-21 under sampling and data collection

Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

		necessary (e.g., sampling saturation); rationale	
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	√ Page 23-line 1-12
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	√ Page 7 & 8. Line 1-21 under sampling and data collection
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection, if/how the instrument(s) changed over the course of the study	√ Page 7 & 8. Line 1-21 under sampling and data collection
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	√ Page 7. Line 1-7 & page 11
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	√ Page 9 & 10. Line 1-31 under data analysis
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	√ Page 9 & 10. Line 1-31 under data analysis
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	√ Page 8 line 1-12 under rigour
Results/findings			
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	√ Page 10 -20
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	√ Page 10 -20

Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

Discussion			
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field.	√ Page 16-20, 21.
S19	Limitations	Trustworthiness and limitations of findings	√ Page 8 line 1-12 under rigour. Page 20, 21
Others			
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	√ Page 22
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	√ Page 22

BMJ Open

Challenges and Support Experienced by Family Caregivers Seeking Anti-Retroviral Therapy Services for Children Living with HIV/AIDS: A phenomenological study in Ghana.

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Article Title: Challenges and Support Experienced by Family Caregivers Seeking Anti-Retroviral Therapy Services for Children Living with HIV/AIDS: A phenomenological study in Ghana.

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ABSTRACT

Background: Family caregivers of children living with HIV/AIDS in most cases are found to be overwhelmed and under-resourced, yet they are believed to be the primary source of support for children living with HIV/AIDS. Family caregivers experience different challenges that affect their children's Antiretroviral Therapy (ART) adherence.

Aim: This study explored the lived experiences of family caregivers of children living with HIV/AIDS who sought ART Services for these Children at the St. Joseph's Hospital of Jirapa, Ghana.

Method: Using a qualitative phenomenology design and a semi-structured in-depth interview guide and using purposive sampling, data was gathered from 13 family caregivers of children living with HIV/AIDS receiving ART treatment at St. Joseph's Hospital-Jirapa following ethical approval. All interviews were audio-taped and transcribed verbatim. The reflexive thematic analysis method was used to analyze the transcribed data.

Findings: Six (6) themes were generated; 5 challenges; and 1 support. Family caregivers of children living with HIV/AIDS experienced: 1. financial challenges, 2. human-related challenges, 3. challenges at HIV Testing and Counselling (HTC) centers, 4. challenges with transportation, 5. challenges in disclosing children's HIV status to them, and 6. support received from HTC and their family members.

Conclusion and Recommendation: Family caregivers of children living with HIV/AIDS experience daunting challenges in their quest to care for their children. Governmental and non-governmental HIV/AIDS programs support should include small business skills training and acquisition including capital to help set up small scale businesses for such caregivers to reduce their financial challenges. Access to ART at clinics closer to caregivers is also key to promoting adherence. Family and community support has been recognized as key to enhancing ART adherence. Education of caregivers on policy regarding disclosure of the HIV/AIDS status of children, the need to work to reduce the time spent by caregivers at HTC, and ensuring privacy by limiting access to HTCs to only caregivers and their children are important to enhancing adherence.

Key words: Antiretroviral therapy; Children; Family caregiver; Lived experience; HIV/AIDS; Therapy adherence.

ARTICLE SUMMARY

Strengths and Limitations

1. Using the phenomenological method, the study was able to acquire enough evidence and understanding of the lived experiences of informal caregivers.
2. The enthusiasm and willingness of the informal caregivers during the study was an advantage for the collection of in-depth data.
3. The researchers were unable to seek the views of children living with HIV/AIDS which could have enriched the data on challenges of living with HIV/AIDS with diverse views.
4. The study could not determine the HIV/AIDS status of the caregivers; this could have enriched the study further in understanding the experiences of caregivers who are infected with HIV/AIDS themselves as compared to those who are not.

INTRODUCTION

One point five (1.5) million children aged 0 to 14 were infected with HIV worldwide. Furthermore, of the 1.5 million children sick, 130,000 were infected in 2022 [1]. About 2.58 million people aged 0-19 years are infected with HIV/AIDS globally in 2022, with children aged 0-9 accounting for almost 50% of newly infected cases [2]. HIV/AIDS has killed 630,000 individuals worldwide in 2022, making it a public health hazard [1]. According to the World Health Organization, 90% of babies that contract the disease from infected mothers are found in Sub-Saharan Africa [1]. According to a World Health Organization (WHO) assessment, more than thirty-three million individuals, including 4.4 million children are living with HIV/AIDS worldwide, with 90% of those infected living in developing countries such as Ghana, resulting in the deaths of 3.2 million children [2].

Furthermore, 2.5 million and 1.9 million children under the age of 15 are living with HIV/AIDS in the world and Sub-Saharan Africa, respectively [2]. In Ghana, 25,000 children aged 0 to 14 years were reported to be HIV-positive, with 2900 newly infected and 2,200 children dying from the disease in 2022 [3]. The prevalence of HIV/AIDS is 0.72% among people aged 15 to 49 in Ghana's Upper West Region [4]. Fifty percent (50%) of HIV-infected children will not live up to two years and 80% will die before the age of five due to a lack of access and poor adherence to ART [5].

In Ghana, the problem of poor adherence among the few children taking ART drugs exists. In its drive to end the pandemic by 2020, the Joint United Nations Programme on HIV/AIDS (UNAIDS) stipulates that 90% of persons living with HIV/AIDS should be diagnosed, 90% of those diagnosed should be treated, and 90% of those on treatment should have their viral load suppressed [6]. However, the number of children receiving antiretroviral therapy falls significantly short of the target. In 2022, for example, 44% of children living with HIV/AIDS were receiving antiretroviral medication to manage the virus and prevent illness transmission to others [3].

Early access to antiretroviral medication and strong adherence are crucial in improving the health of persons living with HIV/AIDS and preventing the disease's spread [7]. Also, adherence to antiretroviral therapy of 95% or above is essential for a favorable outcome [8]. The scientists went on to say that poor adherence due to a lack of support can result in insufficient viral suppression, the establishment of resistant virus strains, and treatment failure. This will increase morbidity and

mortality. However, the few who are put on ART struggle with adherence. The adherence rate among infected toddlers residing in Ghana was 62% [9]. Adherence to long-term therapy is defined by the World Health Organization as the amount to which a person's behavior - taking medication, following a diet, and/or implementing lifestyle modifications - aligns with agreed-upon recommendations from a healthcare practitioner [10].

Family caregivers have critical roles in increasing children's adherence to ART. Family caregivers are typically family members or close relatives who provide partial or full unpaid care to a dependent person who is unable to care for themselves, facilitating their well-being and assisting in various tasks and activities related to the person's health such as medication adherence, wound treatment, and equipment monitoring [11]. According to studies, these informal carers bear more pressure due to the nature of children's reliance on them to meet their basic needs, and they are frequently overloaded and under-resourced [12, 13].

Studies have been carried out in Ghana to explore the experiences of family caregivers on several topics. For example, studies exploring the knowledge of family caregivers' ART for children, and the beliefs of family caregivers adhering to ART for children [14-16]. No study was found by the researchers that directly explored how the problems that family caregivers face, as well as the presence of a support structure, affect adherence to ART among children living with HIV/AIDS in the Jirapa municipality. The purpose of this study is to investigate the challenges and support systems experienced by family caregivers of children with HIV who seek HIV care for their children at St. Joseph's Hospital in Jirapa Municipality, Upper West Region of Ghana, and how these challenges and support systems influence adherence to ART among children living with HIV/AIDS.

METHODS

Research team and reflexivity.

The research team is made up of nurses and lecturers in both clinical and academic fields in nursing and healthcare. They all have an interest in pediatric care and the management of HIV/AIDS. The lead author, LY, is a pediatric nurse specialist and has experience in qualitative studies. The author, OW, is a clinical nurse, a fellow of pediatric nursing and a lecturer who has in-depth knowledge of the conduct of qualitative research with a focus on HIV/AIDS and child health. The interviews were conducted by the lead author and SK. All the other authors have at least a first degree in

nursing and underwent training before the commencement of their roles in this study. Though the lead author works in the facility, she has no business with the HIV/AIDS unit in the facility. The work of the authors has no bearing on the facility used for the studies and therefore did not know any of the participants either personally or professionally. Despite of all these experiences and previous work, the researchers bracketed their emotions and personal experiences and ensured that it did not influence their interviewing or analysis.

Study design.

An interpretative phenomenology design [17] was adopted for this study. This design was used because we wanted to understand the lived experiences of caregivers about challenges and support in that impact ART adherence among their children living with HIV/AIDS in the study setting. This allowed us to extract as much detail as possible from how people describe their experiences. The design is considered appropriate for the study because of insufficient data on the subject in the setting. In-country cultural and societal differences result in context nuances that impact health. As such, the researchers wanted to explore how these caregivers make sense of their experiences [17]. The researchers believe that exploring these experiences will bring to bear the challenges faced by these caregivers and the availability of support systems that influence adherence to ART among the children. Further, reporting in this manuscript follows the "standards for reporting qualitative research (SRQR)" guidelines by O'Brien et al. [18].

Setting and participants

The Jirapa Municipality is in the northwestern corner of the Upper West Region of Ghana. The total population of the Jirapa municipality is 88,402 distributed across all age groups and sexes, 53% of them being females and 47% males. It shares borders to the north with Lambussie-Karni District, to the east with Sissala East and West Districts, to the south with Nadowli District and the West with Lawra District [19].

St. Joseph's Hospital which is located at the Jirapa Municipality the setting for this study. It serves as the municipal hospital as well as a referral institution for eight health centers, fourteen Community-Based Health Planning and Services (CHPS) Zones in the municipality, and additional facilities located outside the municipality. It has 206 beds and offers outpatient, diagnostic, HTC, and in-patient care**.** The total adult population (18 years and above) of people

living with HIV is 458, with 70% being females and 30% males. The study targets family caregivers of children living with HIV/AIDS and on ART who receive services at the HIV/AIDS Treatment Centre (HTC) at the St. Joseph Hospital of Jirapa Municipality. The children population of HIV cases below the age of 18 years is 31, comprising 19 males and 12 females. The unit was managed by three registered general nurses, one orderly, one statistician, and one medical doctor who visits there occasionally [20].

Sampling and data collection

Thirteen (13) family caregivers of children living with HIV/AIDS and receiving care at the HTC of the St. Joseph's Hospital in the Jirapa Municipality were interviewed during the study. This sample size of thirteen was arrived at by data saturation where the participants did not produce any added information [17, 21].

The researchers chose study participants using the purposive sampling technique. The researchers translated the interview guide, information sheet, and informed consent from English into Dagaare, which is the municipality's local language. Family caregivers who met the following inclusion criteria in the study: (1) Family caregivers who cared for children living with HIV/AIDS (2-14 years) continuously for at least 3 months and (2) Caregivers 18 years and above. Family caregivers, who (1) have other health disorders such as relating to mental, language, visual, and hearing that may affect the outcome of the study, and (2) could neither speak English nor Dagaare were excluded from the studies.

Participants who satisfied the inclusion criteria were first contacted physically and subsequently by phone to clarify the purpose of the study and to organize a meeting with the participants at a convenient location for both participants and the researcher. Participants were subsequently given information and consent sheets to sign or thumbprint when they agreed to take part in the study. The interview guide was developed with the specific study objectives in mind. Based on the findings of the literature review, the interview guide's content-specific questions were developed. Participants were informed that they could withdraw from the study at any moment without penalty. Study data were collected from April 2021 to May 2021. On the participants' days of visit to the HTC of St. Joseph's Hospital, interview sessions were organized in a provided private room

within the hospital premises. During the face-to-face interview, the semi-structured in-depth interview guide was used whilst observing the protocols guiding COVID-19 prevention.

The guide contains open-ended questions and probes to produce rich data (see supplemental file 1 online). Participants own dialect, Dagaare was used for the interview which allowed for open-ended questions to be asked and further probes of interesting issues and it allowed the participants to share their experiences at ease with the researchers. Each interview lasted 20-30 minutes and was recorded using a digital recorder. Data collected for this study was stored in a computer with a password to prevent unauthorized access.

Methodological Rigor

The quality of this study was achieved through actions that ensured credibility, dependability, transferability, and confirmability [22]. The study was credible in the sense that the researcher explained the goal of the study to the understanding of the participants, and they were free to ask questions for clarity. The researcher repeated some of the participants' comments to ensure that they were accurate reflections of their experiences, and variety of data gathering methods were used including interviews, observations, and field notes. Ensuring dependability, interviews were continued and analyzed until saturation where participants' responses did not produce new responses. Confirmability of data was ensured by ensuring that coded data were categorized into subcategories and themes. The interview guide was piloted for validity and reliability. For transferability, the researchers gave details on the research design, setting, and how purposive sampling was employed to choose participants who met the inclusion criteria.

Data Analysis

The interview recordings were transcribed in Dagaare and translated into English by a person who has proficiency in both Dagaare and English. Data was analyzed manually. The researchers employed interpretative phenomenology in this study using the reflexive thematic approach according to Braun and Clarke [17, 23-25] and guided by interpretative phenomenological approaches. The researchers did not start with predetermined categories or themes in mind. Instead, the themes were identified through an iterative process during data analysis. The researchers aimed to understand the meanings that individuals attach to their experiences.

The theoretical framework for the analysis of the data was the constructionist perspective which holds that people's senses and experiences are socially constructed and changed but are not innate to them. Hence the researchers theorized the sociocultural and structural context that pushed the phenomenon under study. A theory-driven view was considered by the researchers where data was looked at with precise research questions in mind that steered the study. Researchers followed the six steps in data analysis by Braun and Clarke as described below [23-25]:

1. Data familiarization and writing familiarization notes: Two researchers carefully read through the transcript data to familiarize themselves. Each made an initial note which was discussed together, and each then put their notes into a visual map with some conceptual definitions.
2. Systematic data coding: the first author in consultation with co-authors started identifying initial ideas and generating initial codes across the entire data set through reading and repeated reading of the data, and collating data relevant to each code. The codes helped to organize the data.
3. Generating initial themes from coded and collated data; The researcher searched for themes and collated the codes into probable themes, gathered all data appropriate to each potential theme, and reviewed them examining if the themes worked by the coded extracts and the entire data set.
4. Developing and reviewing themes. Then, themes were continuously developed into meaningful patterns. Through literature review and comparing with the source data, researchers developed and reviewed the themes.
5. Refining, defining, and naming themes; the authors discussed extensively the meaning of the patterns to refine the existing patterns.
6. Writing the report: The researchers during the final analysis produced the report. There was also an analysis and selection of vivid, convincing extract examples. The researchers related the analysis to the research question, producing a report on the analysis. Thematic maps were used to indicate the themes and subthemes.

RESULTS

Demographic characteristics

Table 1 presents the summary of demographic data of thirteen (13) respondents who participated in the study. The table shows that most respondents were females (11), married (11), farmers (12),

and did not have formal education (6). Most of them (12) were actual parents of the children. Most of the children living with HIV/AIDS were males (8). With duration of treatment for the children, they have been on ART for 4 months (0.33 years) to 14 years (mean 4.5 years, SD 4.4). Additionally, family caregivers were between the ages of 20 and 50 years (mean 37.4 years, SD 9.0) and children living with HIV/AIDS were from 2 to 14 years (mean 8.6 years, SD 5,3).

Table 1: Socio-demographic characteristics of respondents.

Socio-Demographic Characteristics	Frequency (n =13)	Percentage (%)
Caregivers gender		
Male	2	15.4
Female	11	84.6
Caregivers' marital status		
Married	11	84.6
Widowed	2	15.4
Caregivers' occupation		
Farmer	12	92.3
Weaver	1	7.7
Caregivers' educational level		
No formal education	6	46.2
Primary School	1	7.7
Junior High School	3	23.1
Senior High School	1	7.7
Technical School/Vocational	2	15.4
Caregivers' relationship with child		
Biological child	12	92.3
Niece	1	7.7
Child's gender		
Male	8	61.5
Female	5	38.5

Source: In-depth Interview Data (2021)

THEMES

For purposes of anonymity, Family caregivers of children living with HIV/AIDS, who shared their experiences, admitted numerous challenges to ART adherence among the children. The analysis of transcript data generated six (6) themes: 1. financial challenges, 2. human-related challenges, 3. challenges at HTC centers, 4. challenges with transportation, 5. challenges in disclosing HIV status to children, and 6. forms of support. These themes are further explained in the ensuing sections.

Financial Challenges

Participants narrated their challenges in connection with finances. Some said they did not have money to take transport to collect their ART, meet the demands of their children at the HCT unit, such as buying food and other things for the children when hungry, buying Septrin which is part of the ART, and buying foodstuff to feed themselves and the children. They complained that one needs to eat well if on ART, but they did not have money to buy food. This is what they have to say.

> *"Because I don't have money for car fare to come, the medicines can finish about three weeks or month before we come for the medicine…."* **R1**
>
> *"...maybe it's time for you to come and collect your medicine and If you get* a *motor you have to buy fuel but sometimes you don't have the money… because of that the day will pass…."* **R10**
>
> *"...you know he will be hungry and* supposed *to eat and if you do not have money, it becomes a worry to you…."* **R4**
>
> *"...the only problem is the* absence *of Septrin here that we are asked to buy but if you don't have money, you can't, the Septrin is helpful if you* can *buy and take, your body becomes strong, but if they don't give you and you don't have money to buy you will take this one and your body will still be disorganized. It will be good if they make it available…."* **R12**
>
> *"...we have challenge in feeding because we don't have any proper job, it will help us to manage our disease, if you get the* foodstuff *and you don't even have* the *money you will also try to get herrings and '*Dawa Dawa*' which will help you to be better because it will help the medicine to suppress the disease..."* **R9.**

Human-related challenges

Human-related challenges in ensuring that children living with HIV/AIDS adhere to ART were identified as an important challenge by family caregivers. Three subcategories generated under this main one as shown in Figure 1 were child-related difficulties in adherence, caregiver-related difficulties in adherence, and society-related difficulty in adherence. Child-related challenges were expressed by respondents as due to the bitterness and tablet nature of ART, a child not knowing the importance, and its swallowing being monotonous. The following is what they had to say.

> *"I give him the medicine, if you give him the tablet, he will not swallow…"* **R1.**
>
> *"… because is bitter when you are giving it to the child, he doesn't want to drink you have to force him…. when you take medicine every day like that; it will get to a time when you will not want to take the medicine again…it is compulsory but because you know its importance but he is a child and doesn't know anything"* **R4**

Society-related stigma was spoken of as causing dissatisfaction regarding and against them. This does not give them the peace of mind to go to the HTC unit to manage children living with HIV/AIDS. Below are some expressions reported.

> *"… if you have an issue with someone and the person knows that you are in this situation collecting the medication and sees you somewhere outside the hospital, he or she will be making* a *mockery of you…sometimes they call to ask where I am, I tell them I'm somewhere, I don't tell them I'm here and I don't like it"* **R5.**

Some family caregivers expressed their challenges for not being able to ensure children adhere strictly to ART due to forgetfulness, some due to fear of the unknown especially when they miss a dose, some also complained of a busy schedule, and finally, some said they are not always present at home to administer ART. The following were some of their statements.

> *"Sometimes I forget but when it is too late we cannot take it again like if you forget and sleep or roam till* 10 pm *there* are *always fears* about *whether to take* it *or not…Missing doses of medicines happen when I'm not at home"* **R3.**
>
> *"Sometimes I forget to give the medicine to the child because when I come from work, and I have to cook and sometimes before you realize she is sleeping but when I forget I try to give the following day….'* **R5**

Challenges at HTC Centre

Family caregivers of this study experienced difficulties at the HTC center which affected strict adherence negatively. They complained about delaying getting treatment at the center and meeting familiar people not on ART who talk ill about them. The following were said by participants.

> *"…at the hospital, you cannot get the medicines early like that…"* **R3.**

"Because of that fear of people seeing me come here for the medicine, sometimes I feel like not coming but I think again that if I don't come it means that is the child that I want him/her to die so whatever it is I try to come" **R5.**

Challenges with transportation

Family caregivers also complained that the nonavailability of transportation from their places of residence to the HTC center and having to trek a distance was taking a negative toll on ensuring strict adherence to the ART. Because of this, some family caregivers advocated that some of the ART be sent to clinics closer to their places of stay. This is what they said.

"...there used to be public transport to Jirapa…but now it doesn't come again…I wish they were *able to send some of the medicines to the clinic at our place so that our journey will be short"* **R7.**

"...when I decided to come, I did not get means…vehicles that pass there to Jirapa no more pass but different route to Wa' **R10**

"If you don't get someone to pick you and the child to the hospital for the treatment, you have to back the child and walk a distance to the hospital" **R3.**

Challenges in disclosing HIV status to the child.

Participants feel that if children get to know their HIV status it will help them to adhere strictly to the ART. However, participants expressed their challenges in disclosing to the child his or her HIV status. The following were said:

"...she asked me what medicine have we been collecting and the woman said we should not miss any dose, so I told her that there is a disease in our body that is why we have to take this medicine without missing doses, and that she supposed to take it all the time…the child upon hearing this became moody which also affected my mood and is paining me…." **R7**

"...It is a worry how to disclose it to him because he is a child if you tell him, he has AIDS he will be thinking because he has also heard that AIDS is a bad disease and is a worry…when he gets to a *certain age, we will tell him, and he will understand"* **R12.**

Support for family caregivers.

Support for family caregivers is very necessary to ensure that children living with HIV/AIDS adhere strictly to ART. Family caregivers received support from both nuclear and extended families and HTC centers as indicated in Figure 2. Support from their families was in the form of foodstuff, finances, and support in ART administration. The following were their expressions.

> *"When am not around is the father that gives the medicine to the child and if the father is not around, I break it into two and give* it *to the grandmother though I cannot tell her what medication it is, and tell her when* the *time is up, she should give to the child"* **R2.**

> *"Is only my husband that supports me, when we are coming for the medicine, he gives us money in case the child wants food I can buy for him or if they talk about money I can pay"* **R5.**

> *"The money we get from my* brother-in-law *helps a lot…for* foodstuff, *he farms for us to put down for the feeding, so the money he gives is for buying soup ingredients and grinding the flour"* **R8.**

Assistance received from the HTC center by family caregivers was explained about receiving foodstuff from nurses, psychological support from colleagues, and free ART from the HTC center. These were explained as follows.

> *"For help is, one nurse who ever helped me, she gave me rice, oil, and other things to prepare for the child"* **R13.**

> *"We used to come here for a meeting every Saturday …you can come and hear something and when you get home all your worries will be thrown away. It was helpful…"* **R11.**

> *"The support we get from the hospital is when we come, and our doctors and nurse* can *give us the medication well for us to take home and the government trying to always get the medicine for us for free"* **R6.**

DISCUSSION

Following data analysis, family caregivers' experiences in relation to their children adherence to ART were captured in six (6) themes; financial challenges, human-related challenges, challenges at HTC centers, challenges with transportation, challenges in disclosing HIV status to the child, and forms of support.

Family caregivers of children living with HIV/AIDS complained they did not have money to take transport to collect their ART, meet the demands of their children at the HCT unit such as buying food and other things for the child when hungry, buying Septrin which is part of the ART, and buying foodstuff to feed themselves and the children. They complained that one needs to eat well if on ART, but they did not have money to buy food. According to the family caregivers, these challenges negatively affect their efforts to ensure children under their care adhere to the ART. Similarly, studies conducted in Sub-Saharan Africa and even in other third-world countries recognized financial stress as a daily difficulty faced while seeking ART services, such as transportation fees during follow-up visits and insufficient money for meals [13]. These difficulties have a deleterious impact on adherence to ART. Out-of-pocket payments and the high cost of ART were noted in a review article showing the detrimental impact of adherence to ART [26]. Inadequate money for transport, buying foodstuff, and Septrin are factors that could lead to non-adherence to ART by family caregivers and children under their care.

Human-related challenges in ensuring that children living with HIV/AIDS adhere to ART were identified as an important challenge by family caregivers. Child-related challenges were expressed by respondents as due to the bitterness and tablet nature of ART, a child not knowing the importance, and its swallowing being monotonous. The findings of the current study are in consonance with a longitudinal observational cohort study where medication regimens such as tablet formulation have negatively influenced adherence to ART [27]. The taste, formulation, and child's knowledge of ART's importance influences adherence to ART. Respondents did not adhere to ART because of its tablet formulation and bitterness [28]. Making available injectable or sweetened syrup ART and explaining its importance will take away some challenges to ensure strict adherence to ART among children living with HIV/AIDS.

Society-related stigma was spoken of as causing dissatisfaction regarding and against them. This does not give them the peace of mind to go to the HTC unit to manage the children living with HIV/AIDS. Stigma discourages people from seeking health services hence public education is needed on the cause, management, and prognosis of the disease HIV [29]. Stigmatization is one of the challenges caregivers face mostly ensuring strict adherence to ART by the children under their care.

Some family caregivers expressed their challenges for not being able to ensure children adhere strictly to ART due to forgetfulness, some due to fear of the unknown especially when they miss a dose, some also complained of a busy schedule, and finally, some said they are not always present at home to administer ART. A cross-sectional study revealed that PLWHIV/AIDS sometimes forget to take their ART hence affecting adherence negatively [30]. They further explained that their respondents forgot to take their ART because they were too busy and far from home. The aforementioned factors were recorded by Neupane and others as the main cause of non-adherence to ART [31]. These challenges influenced ART adherence among children living with HIV/AIDS negatively, family caregivers need family support to ensure strict adherence to ART among children living with HIV/AIDS under their care.

Family caregivers experienced challenges at the HTC center which affected strict adherence negatively. They complained of delaying getting treatment at the center and meeting familiar people who talk ill about them. Too much waiting time affects adherence to ART negatively [26]. Furthermore, the authors stated that care providers at the center must reschedule their activities to shorten the waiting time for clients to ensure adherence to ART. The study further revealed that family caregivers see people who do not take HIV medications to be a source of stigma and for that matter do not wish to see them, especially at the HTC center. If family caregivers continue to be seen by people who do not take ART at the HTC center and are stigmatized, they are likely to be discouraged from seeking HIV care [29]. Care providers at the center are to be encouraged to limit unnecessary visits by people who are not HIV positive and hence do not take ART from the unit.

Family caregivers also complained that the nonavailability of transportation from their places of residence to the HTC center and having to trek a distance was taking a negative toll on ensuring

strict adherence to the ART. If a child is found to be living with HIV, the child and the caregiver will have to travel a distance to access care and treatment which already constitutes a barrier to service utilization and retention in care [32]. Far distances to HTC centers and lack of transport are seen by family caregivers as challenges to ensuring that children living with HIV/AIDS under their care adhere strictly to ART. Due to this, family caregivers of this study advocated that some of the ART be sent to clinics closer to their places of stay.

Participants feel that if children get to know their HIV status it will help them to adhere strictly to the ART. However, participants expressed their challenges in disclosing to the child his or her HIV status with the reason that the child will feel bad upon hearing this news. Caregivers feel it is an issue because the children were too young to understand, whilst others think older children have heard that HIV/AIDS is a bad disease and telling them will make them feel bad. Likewise, studies conducted in Africa have shown that nondisclosure of children's HIV status by caregivers has influenced ART adherence among children negatively [32-34]. Hence family caregivers have complained of children's refusal to take ART because, in a longitudinal observational cohort study, a child's awareness of his/her HIV status is an influencing factor in adherence to ART [27]. Children with information about their HIV status adhere to ART better than children without knowledge of their HIV status. The National AIDS/STI Control Program and Ghana Health Service have recommended 8 – 10 years at which full disclosure of HIV/AIDS status should be made known to the child in a helpful and supportive approach and environment [35].

Forms of support for family caregivers are very necessary to ensure that children living with HIV/AIDS adhere strictly to ART. Family caregivers received different forms of support from family members; they were provision of foodstuff, financial support, and administering ART to the child. These forms of support were received from extended family members of family caregivers such as grandparents, mothers, in-laws, and sisters. Supports were also received from nuclear family members or family caregivers such as daughters and partners. Most family caregivers had support from both extended and nuclear family members in administering ART to children under their care. Family caregivers of children living with HIV/AIDS received financial support from both extended and nuclear family members. This support assisted them in many ways to ensure strict adherence of the children to ART.

Support for family caregivers is very necessary to ensure that children living with HIV/AIDS adhere strictly to ART. They receive support from their families both external and internal in the form of foodstuff, finances, and support in ART administration. Caregivers who had family support were more likely to adhere strictly to ART than those who had no family support. They further explained that though some infected persons do forget to take the ART, with family and friends' support, they can adhere strictly [30, 31]. Likewise, the Joint United Nations Programme on HIV/AIDS postulates that care and support services should be complete to include medical, psychosocial, physical, socioeconomic, nutritional, and legal support [36]. They further said that these forms of support are so crucial to the well-being and existence of people living with HIV/AIDS and their caregivers. Family support is therefore essential for family caregivers to ensure strict adherence to ART among children living with HIV/AIDS.

The study reveals that assistance received from the HTC center by family caregivers included receiving foodstuff from nurses, psychological support from colleagues, and free ART from the HTC center. Support received by children living with HIV/AIDS and their caregivers at the HTC center makes them feel supported hence they believe in a better future [37]. Psychological support for people living with HIV/AIDS influences adherence positively [26]. A longitudinal observational cohort study stated that social support as received by caregivers and their children at the HTC center is a buffer against a stressful environment which enhances adherence to ART [27]. It is therefore encouraged for people living with HIV/AIDS to get together often to know one another, share their problems and encourage one another. Care providers are supposed to empower them psychologically through the health education given at the center. Availability and accessibility of antiretroviral medications at the HTC centers influence positively adherence to ART [26]. Support received from the HTC center such as counseling, foodstuff, and medications facilitate adherence to ART among children living with HIV/AIDS.

Strengths and Limitations of the Study

This is the first research to explore the experiences of family caregivers of children living with HIV/AIDS in the chosen setting and has provided rich information on their lived challenges and support systems. The information provided by this study bridges the knowledge gap in this area and provide a resource for policy review, clinical practice, and development of interventions that aims to reducing the challenges faced by family caregivers and enhance ART adherence among

children. However, the study is limited by some factors; most respondents were females, hence the findings could be skewed to that direction. The usage of one municipal hospital limits generalizability of the findings and interviewing more family caregivers from different settings may have produced a richer experience.

Conclusion, Implication for Practice, Policy, and Recommendations

This study concludes that family caregivers faced financial challenges, human-related challenges, challenges at HTC centers, challenges with transportation, and challenges in disclosing HIV status to children, and they also experienced some forms of support. These challenges prevent family caregivers from ensuring that children under their care adhere strictly to ART. The support received by family caregivers contributed to enhancing ART adherence. Despite these challenges of family caregivers, there are no targeted interventions that address their plight. Healthcare providers should explain to the caregivers of children living with HIV/AIDS the policy regarding disclosure of the HIV/AIDS status of children. Health professionals working at the HTC center should enhance their own capacity to help reduce time spent at the center by family caregivers. Furthermore, they should limit access to the center by people who have no business there. Family caregivers need support from government agencies and NGOs in terms of skills acquisition and capital to set up small-scale businesses that will give them work to reduce their financial challenges. Bringing ART services closer to family caregivers will solve the challenges related to distance and transportation. There should be a revision of existing policies that take into consideration the challenges of family caregivers of children living with HIV/AIDS.

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Authors Contributions

LY: involved in the conception and study design; data collection; analysis and interpretation; critical revision for intellectual content; and approved final manuscript for submission. SK: involved in the conception and study design; data collection; analysis and interpretation; drafting of the manuscript; critical revision for intellectual content; and approved final manuscript for submission. WO: contributed to conception and study design; supervision, analysis, and

interpretation; critical revision for intellectual content; and approved final manuscript for submission. MWK: contributed to conception and study design, analysis, and interpretation; revision of the study; approved final manuscript submission. NDM: contributed to conception and study design; analysis and interpretation; revision of the study; and approved final manuscript submission. MMW: contributed to conception and study design; analysis and interpretation; revision of the study; and approved final manuscript submission. AD: contributed to conception and study design; analysis and interpretation; revision of the study; and approved final manuscript submission.

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Competing Interest

It is declared unanimously by all authors that there is no existence of a conflict of interest.

Data Availability Statement

The in-depth interview guide is uploaded as a supplementary file. However, audio-taped recordings of the interview cannot be shared with third parties because of the confidential agreement signed by the participants.

Patient and Public Involvement

Neither patients nor the public were involved in the design, conduct, reporting, or dissemination of this research.

Ethical approval

Ethical approval was obtained from the Institutional Review Board of the Navrongo Health Research Centre (NHRCIRB415). This study is part of a bigger study that was undertaken. At the site, the researchers were granted permission by the HTC center. Participants who got emotional during the interviews were allowed to express emotional concerns and relax before the interview was continued. The interviews were conducted in safe and private environments. Additionally, participants were taken through the consent process effectively to communicate what the study entailed to allow participants to make their decision of taking part or not. They were assured of

confidentiality. Researchers collected only relevant information from participants and data collected could not be linked to participants. Participants signed/thumb-printed the consent form after going through it and the information sheet. The letter 'R' representing participants with a number attached was assigned to family caregivers to ensure anonymity.

Figure Legend

Figure 1: Thematic map on family caregivers' challenges in ensuring children living with HIV/AIDS adhere to ART.

Figure 2: Thematic map for forms of support for family caregivers in ensuring children living with HIV/AIDS adhere to ART.

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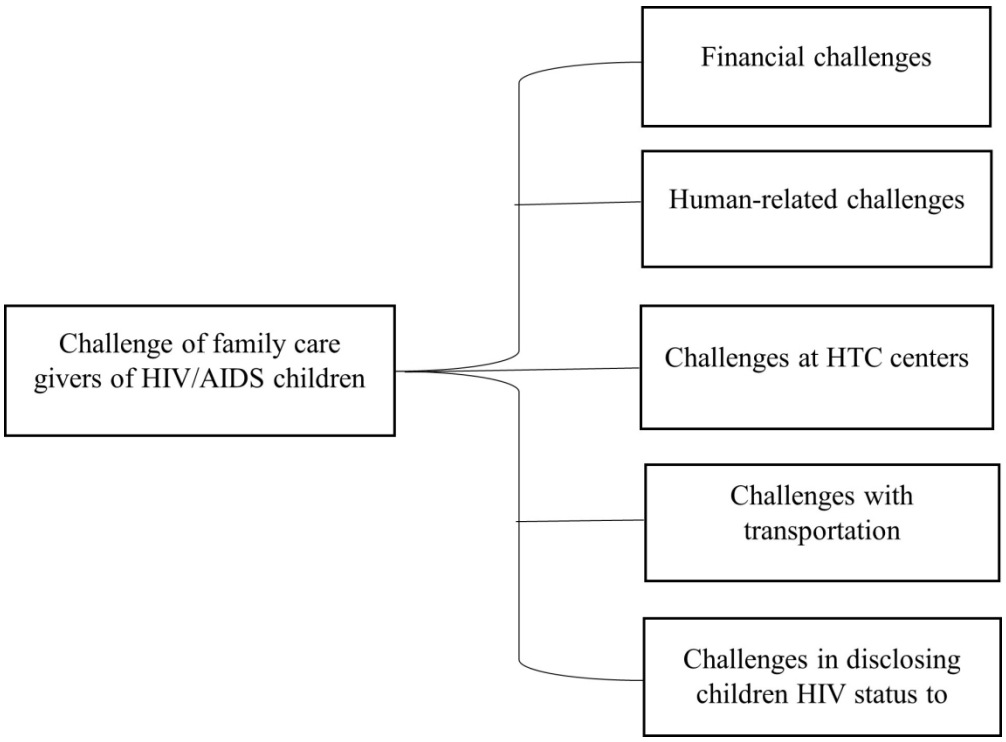
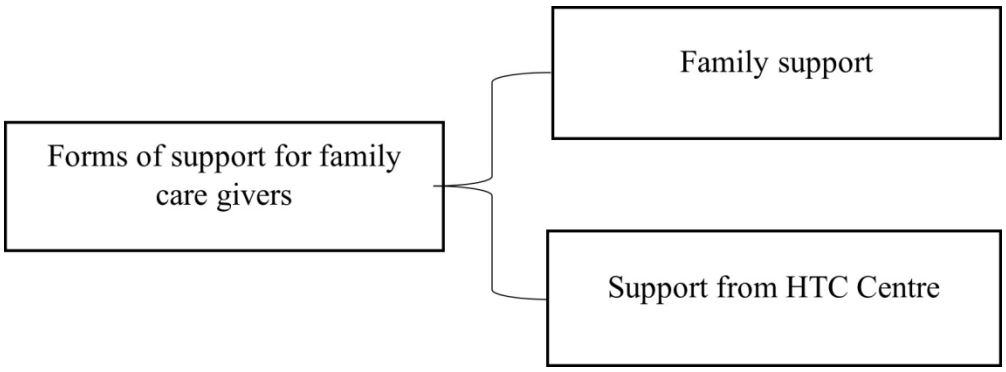


Thematic map on family caregivers' challenges in ensuring children living with HIV/AIDS adhere to ART.

148x108mm (330 x 330 DPI)



Thematic map for forms of support for family caregivers in ensuring children living with HIV/AIDS adhere to ART.

133x48mm (330 x 330 DPI)

In-depth interview guide

Research Article Tittle: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

Introduction: The purpose of this study is to investigate the challenges and support systems as experienced by family care givers of children with HIV who seek HIV care for their children at St. Joseph's Hospital in Jirapa Municipality, Upper West Region of Ghana, and how these challenges and support systems influence adherence to ART among children with HIV/AIDS. It will be appreciated if you could respond appropriately to all the questions that will be asked in this interview. You are assured of confidentiality of any information shared. Thank you for agreeing to take part in this interview.

Section A: Socio-demographic characteristics of participants

Can you please introduce yourself and your child? I want to know you better.

Possible probes.

1. Please how old are you?
2. What is your marital status?
3. What is your occupation?
4. What is your level of formal education?
5. How are you related to the child?
6. What is the age of your child?
7. How long has your child been on ART?

Section B: Family Care givers of HIV/ADIS children challenges when seeking ART services

Please tell me some of the challenges that you go through as caregiver of a child with HIV/AIDS in ensuring the adherence to antiretroviral therapy.

Possible probes.

1. Tell me the challenges you encounter ensuring strict adherence to the antiretroviral therapy?

2. Tell me how these challenges mentioned above influence the adherences of your child to the antiretroviral therapy?

3. How easy is it for you accessing the HIV/AIDS medications?

Thank you so much for sharing that with me, and I appreciate it. Now, I like to talk with you about the available support systems for you and the child.

Section C: Support toward adherence

Please tell me the support you get from others and how it helps you to ensure the child adheres to the ART.

Possible probes.

1. Describe to me the forms or sources of support you get?

2. Explain to me how the sources of support play a role in the child's adherence to medications?

3. How does your family support you in ensuring that the child takes the medications well?

4. What kind of support do you get from the health sector/hospital to ensure that the child stays on the ARTs?

5. What role do your friends play in supporting you to ensure that the child stays on the ARTs as ordered?

6. How easy is it for you getting these supports?

Thank you for spending time to take part in this interview. We appreciate every bit of information provided.

Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

Standard for Reporting Qualitative Research by O'Brien et al., (2014)

No	Topic	Item	Checked
Title and abstract			
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	√ Page 1
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	√ Page 2
Introduction			
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	√ Page 4 & 5 line 17-33 under introduction
S4	Purpose or research question	Purpose of the study and specific objectives or questions	√ Line 6-9 of last paragraph under introduction
Methods			
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale	√ Page 6 line 1 under study design
S6	Research characteristics and reflexibility	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	√ Page 5 under methodology
S7	Context	Setting/site and salient contextual factors; rationale	√ Page 6. Line 1-7 under setting and participants
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was	√

Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

		necessary (e.g., sampling saturation); rationale	Page 7 & 8. Line 1-21 under sampling and data collection
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	√ Page 20 & 21 -line 1-12 under ethical approval
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	√ Page 7 & 8. Line 1-21 under sampling and data collection
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection, if/how the instrument(s) changed over the course of the study	√ Page 7 & 8. Line 1-21 under sampling and data collection
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	√ Page 6 & 8. under setting and participants & page 9 & 10 under demographic characteristics
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	√ Page 8 & 9. Line 1-31 under data analysis
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	√ Page 8 & 9. Line 1-31 under data analysis
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	√ Page 8 line 1-12 under rigour
Results/findings			
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	√ Page 10 -19

Article Title: Challenges and Support Experienced by Family Care Givers Seeking ART Services for Children Living with HIV/AIDS: A phenomenological study.

S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	√ Page 15 -19
Discussion			
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field.	√ Page 15-19.
S19	Limitations	Trustworthiness and limitations of findings	√ Page 8 line 1-12 under rigour. Page 18, 19
Others			
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	√ Page 20
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	√ Page 20