A QUALITATIVE STUDY OF THE KNOWLEDGE OF INFORMAL CAREGIVERS OF CHILDREN WITH HIV/AIDS ON ANTIRETROVIRAL THERAPY ADHERENCE

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ABSTRACT

The burden faced by informal caregivers in caring for a child diagnosed with HIV/AIDS, and placed on Antiretroviral Therapy (ART) is high due to the nature of the child's dependence on the caregiver for fulfilling the child's necessary needs. Evidence linking knowledge to the likelihood of performing the desired action exists. It is therefore crucial to explore caregivers' knowledge of ART, and how that influences their children's adherence to ART. The sought to explore the knowledge of informal caregivers on adherence to ART among their children with HIV/AIDS who received care at St. Joseph's Hospital, Jirapa, Ghana. A qualitative phenomenology design was used. Data were collected from 13 purposively chosen caregivers of children with HIV/AIDS on ART at a hospital, using a semi-structured in-depth interview guide. A reflexive thematic analysis approach was used for data analysis. Informal caregivers were knowledgeable in the regularity of visits to the HIV Testing and Counselling (HTC) Centre for ARTs, identifying ARTs, ARTs administration, ARTs side effects identification, HIV transmission, and the nutritional restrictions for ARTs. A few, however, had misconceptions about HIV transmission. Informal caregivers still need education in the area of HIV transmission. The findings will guide nurses to focus on areas of education for informal caregivers to improve upon their knowledge of ART and to ensure increased adherence among children living with HIV/AIDS under their care.

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INTRODUCTION

World Health Organization (WHO) stated that about 1.7 million children aged 0-14 years were living with HIV - 160 000 of them newly infected - at the end of 2018. HIV/AIDS is said to be a major global public health concern, having killed about 33 million people globally[1]. To avert this, 53% of children living with HIV/AIDS have been put on antiretroviral therapy in 2019, to control the virus and prevent onward transmission of the disease to others[1]. The author added that over 60% of the newly infected cases are women, infants, or young children. Surprisingly, 90% of babies that get the disease from their infected mothers are found in Sub-Saharan Africa. The estimated national prevalence of HIV in Ghana was 1.69% in 2018 with an estimated 334,713 persons living with HIV (PLHIV)[2]. Of these, 65% (217,515) are females in the reproductive age group of 15 to 49 years. The median HIV prevalence in women attending antenatal care in 2018 was 2.4%[3].

In 2018 in Ghana, 30,000 children between the ages of 10-14 years were infected with HIV and 0.4% and 1% of males and females, respectively, between the ages of 15-24 years were living with HIV/AIDS[4]. The number of deaths of children aged 0-14 is recorded as 2,441. New children infected with HIV/AIDS through mother-to-child transmission were also 2,971. The estimated prevalence of HIV/AIDS among people between the ages of 15-49 years in the Upper West Region of Ghana is 0.72%[5].

Antiretroviral drugs have great potential in preventing HIV transmission and acquisition, including through pre- and post-exposure prophylaxis, by preventing mother-to-child transmission, and through antiretroviral therapy that achieves viral suppression[6]. Interventions with ART have led to a significant improvement in the health and survival of children with HIV/AIDS. However, socio-economic factors such as the knowledge of informal caregivers and the psychological burden of taking care of a child with HIV continue to influence negatively the outcome of medications[7-10]. Findings from an Ethiopian study reveal that despite the good knowledge caregivers had regarding ARTs, knowledge of their curative nature was poor[8]. Further, some studies conducted in two African countries showed that the majority of caregivers had incorrect information about HIV transmission[9,10].

In its 2019 end-of-year review report, the St. Joseph Hospital, Jirapa, Ghana, reported that several children diagnosed with HIV/AIDS missed their appointment for ART[11]. In response to such problems of non-adherence, the global research agenda for pediatric HIV in the area of HIV treatment of children and infants set priorities for research to focus on strategies to monitor and improve adherence to ART[12]. This study, therefore, sought to explore the experiences of informal caregivers concerning their knowledge of adherence to ART among their children with HIV/AIDS who receive HTC services at the St. Joseph's Hospital of the Jirapa Municipality in the Upper West Region of Ghana.

MATERIALS AND METHODS

Study Design. A qualitative phenomenology design was used to collect information on the knowledge of informal caregivers of children living with HIV/AIDS based on their experiences concerning ensuring their children's adherence to ART. Phenomenology aims at gaining a deeper understanding of the nature of everyday experiences which aligns with the study's aim and objectives. This design was considered suitable for this study because there was inadequate recorded literature on exploring the knowledge of informal caregivers of children with HIV/AIDS on ART adherence.

Research Setting. The study was carried out at St. Joseph's Hospital, in the Jirapa Municipality of the Upper West Region of Ghana. According to the 2019 end-of-year review report of St. Joseph's Hospital, Jirapa, the hospital currently serves as the municipal hospital and a referral facility for eight health centers, fourteen Community-based Health Planning and Services (CHPS) Zones in the Municipality, and other facilities outside the municipality. It has a bed capacity of 206 and provides outpatient, diagnostic, HIVHTC, and in-patient services.

Target Population. The target population for this study was informal caregivers of children with HIV/AIDS on

ART who receive HTC services at the St. Joseph Hospital of Jirapa Municipality. Informal caregivers included parents, uncles, aunties, grandparents, and nonrelatives who were responsible for the care of children with HIV/AIDS. The population of children diagnosed with HIV and below the age of 18 years was 31, comprising 19 males and 12 females.

Sample Size and Sampling Technique. The sample size of the study was determined by data saturation, where no new information was obtained and redundancy was achieved[13,14]. Data saturation was realized after interviewing the 13th participant. Therefore, the sample size for this study was 13 caregivers, coming from diverse locations in the municipality. A purposive sampling technique was employed in this study. Purposive sampling is based on the belief that researchers' knowledge about the target population can be used to handpick sample members. Sampling in this subjective manner, however, provides no external, objective method for assessing the typicalness of the selected subjects[13]. Nevertheless, this method can be used to explore the knowledge of informal caregivers of children with HIV/AIDS who receive care at the HTC of the St. Joseph's Hospital in the Jirapa Municipality on ART adherence from the perspective of their lived experience.

Data Collection Instrument. A semi-structured in-depth interview guide was used as the main data-gathering instrument. It had open-ended items as they provide a high degree of flexibility to probe. The instrument was made up of an introduction to welcome respondents and explain what the study was about, and two other sections (A and B). Section A contained demographic characteristics (age, sex, marital status) of the respondents and Section B contained knowledge on ART. The in-depth interview guide was translated from English to the native language (Dagaare) for respondents who could not communicate in English. Pretesting of the research instruments (interview guide) was carried out at the HTC center of Nadowli District Hospital in the Upper West Region to validate the instrument before it was implemented in the study area.

Data Collection Procedure. The period of data collection spanned from April 2021 to May 2021. Two research assistants were recruited and given the training to assist in the data collection process. All participants who met the inclusion criteria were invited to the study. Caregivers who met the inclusion criteria were approached face-to-face and through phone calls. However, data collection was discontinued when data saturation was achieved in interviewing the 13th participant. Meetings were scheduled for those who consented to participate in the study. Respondents were given information about the study such as purpose, confidentiality, and anonymity, and these were discussed. Taking into consideration the convenience of the respondents, a meeting was scheduled for an interview. Respondents were reminded a day before the interview.

To maintain the confidentiality of the respondents, data collection meetings were scheduled during their routine visits to the HTC Centre for ART services and other check-ups. A private counseling room in the hospital was secured for the interviews. During the interviews, respondents were allowed to decide whether to participate or withdraw, evidenced by the provision of a signed/thumb-printed informed consent

form, which was made available to each respondent. Data were collected from the respondents using a semi-structured in-depth interview on a face-to-face basis. During the interview, the main open-ended question was that *"Please tell me all that you know about HIV/AIDS medications?"*. This was followed by probes such as: *"How often do you administer each of the antiretroviral medications?"; "Please tell me some of the side effects of the ARTs the child is currently on"; "What do you do when the child experiences any side effect of the ARTs?"; "What happens if you forget to give the child his/her ARTs?"*. These questions elicited rich data on the knowledge of informal caregivers of children with HIV/AIDS on medications and their adherence. Each interview recording lasted between 45 and 50 minutes. All interviews were audiotaped and field notes were taken.

Data Analysis. The authors had a theory-driven view where data were approached with specific research questions in mind that guided the study[15]. The study employed a reflexive thematic approach in the analysis of data[16], following the steps according to Braun and Clarke[16], and Xu and Zammit[17]. These steps include ***familiarizing with the data;*** transcribing data, reading and rereading the data, noting initial ideas, ***generating initial codes;*** coding interesting features of the data systematically across the entire data set, collating data relevant to each code, ***searching for themes;*** collating codes into potential themes, gathering all data relevant to each potential theme, ***reviewing themes;*** checking if the themes work in relation to the coded extracts and the entire data set, generating a thematic map, ***defining and naming themes;*** on-going analysis for refining the specifics of each theme and the overall story that the analysis tells, generating clear definitions and names for each theme, ***producing the report;*** the final opportunity for analysis, selection of vivid, compelling extract examples, final analysis of selected extracts, relating the analysis to the research question and literature, producing a report of the analysis.

Ethical Consideration. Ethical clearance for the study was obtained from the Institutional Review Board of the Navrongo Health Research Centre (NHRCIRB415). Permission for data collection was also obtained from St. Joseph's Hospital through the Regional Health Directorate of the Upper West Region. Before the commencement of the study, the researchers informed potential respondents about the purpose of the study, the nature of the data to be collected, how the data will be treated (publication), the estimated time required for the interview, and the risks and benefits of taking part in the study. Informed consent was obtained from respondents. Respondents were free to withdraw from the study without consequence during the collection of data. Additionally, the data were collected anonymously and strict confidentiality was ensured between the researchers and respondents. As such, each respondent was given a code, Rn, where R stands for the respondent and n represents the number assigned to each respondent, ranging from 1 to 13.

Methodological Rigor. To ensure the credibility of this study, the researchers explained the study in detail to the understanding of the respondents, and the response of each respondent was translated and transcribed into English in order not to lose any of the meaning of their narratives. Guaranteeing dependability, the researcher ensured that interviews were carried out

and analyzed till the data was saturated and there were no more known new themes that could be recognized. Confirmability of the data was ensured by ensuring that the personality of the researcher did not influence the responses of the respondents. In addition to interviews as a method of data collection, observations and taking of field notes ensured credibility. Moreover, to ensure the transferability of data, the researcher gave a proper description of the research design, and a thorough description of the research setting, and used the purposive sampling method to select respondents that met the inclusion criteria.

RESULTS

Thirteen (13) informal caregivers participated in this study. They had a mean age of 37.4 (SD± 9.0) years. Most were females (84.6%), married (84.6%), and farmers (92.3%). Close to half of them had no formal education (46.2%). Almost all caregivers (92.3%) were actual parents of the children living with HIV/AIDS. The children had ages ranging from 2 to 14 years, with a mean age of 8.6 (SD± 5.2) years. Over half of the children were males (61.5%). In terms of duration since the children started ART, the period ranged from 4 months to 14 years, with a mean duration of 4.5 (SD ± 4.3) years. This information is captured in Table 1.

Major Themes. Six major themes were generated from the study through reflexive thematic data analysis. The main themes and subthemes focused on exploring the knowledge of informal caregivers of children with HIV/AIDS on ART adherence. The six major themes generated were; knowledge of the regularity of visits to the HTC center, ART identification, ART administration, ART side effects, HIV transmission, and the nutritional restrictions of ART.

Table 1. **Demographic Characteristics of Respondents**

Demographic Characteristics	Frequency (n=13)	Percentage (%)
Caregivers gender		
Male	2	15.4
Female	11	84.6
Marital status of caregivers		
Married	11	84.6
Widowed	2	15.4
Occupation of caregivers		
Farmer	12	92.3
Weaver	1	7.7
Educational Status of caregivers		
No formal Education	6	46.2
Primary education	1	7.7
Junior High School	3	23.1
Senior High School	1	7.7
Vocational/Technical school	2	15.4
Caregivers relationship with the child		
Son/Daughter	12	92.3
Niece	1	7.7
Child gender		
Male	8	61.5
Female	5	38.5

Mean age of caregivers = 37.4 (SD± 9.0) years, Mean age of Children = 8.6 (SD± 5.2) years, and Mean duration since the start of ART by children = 4.5 (SD ± 4.3) years.
Source: In-depth Interview Data (2021)

Knowledge of regularity of visits to HTC center. One of the essential components necessary for informal caregivers to ensure the adherence of children to ART is the knowledge of how often to visit the HTC center. Respondents have different days to visit the HTC center ranging from monthly to every six months, but each of them is conscious of when to visit. Some respondents have indicated this as shown below:

"… we use to come every month, later they gave us three months, now they have given us every 6 months, my starting was every two weeks." **R2**

"They use to give us every month to come for the ART, but now they have given us every three months." **R6**

ART Identification. Identification of the different types of ARTs given to caregivers was seen as an important component of the knowledge necessary to ensure that children living with HIV/AIDS under their care adhere to treatment. Because most of the respondents did not have formal education, they did not know the names of ART given to them except Septrin. However, they have a way of using symbols to aid in identifying and differentiating them. The following were some of their expressions:

"They write on the containers…they make small zeros on the counter for the smaller one, they make a little bit bigger zero for the senior child and as for me they make the zero big and that is how am able to differentiate the drugs" **R1**

"They have asked me to buy Septrin syrup so after administering the tablet I will give that one too" **R13**

Knowledge of ART administration. Informal caregivers expressed knowledge of how to administer the ART to children with HIV/AIDS under their care, and their knowledge of the ART administration was expressed as shown in Figure 1, and they are dosage, the procedure of administration, and time of administration.

In ensuring adherence to ART among children, knowing the dosage, procedure, and time of administration is very vital. Informal caregivers demonstrated their knowledge in this regard as follows:

"All of us take the medicines every evening. But the small one takes the medicines morning and evenings." **R1**

"The medicines are two types; one is removing a full tablet and the other one I divide into two and put them together and give to the child ones every day in the evenings **R9**

Knowledge of side effects of ART. Informal caregivers mentioned many signs and symptoms which were side effects of ART administered to the children under their care. Knowing and reporting the side effects of ART is an essential component to ensure that children adhere to the medication regimen. Some of the side effects of ART as mentioned by the informal caregivers were dizziness, diarrhea, body shivering, rashes, sleeping after taking ART, vomiting after ART, intoxication, and hunger. All side effects experienced were reported and managed appropriately to ensure strict adherence to ART. Respondents demonstrated their experiences in the following statements:

"…when he started taking the medicines, he was having some skin rashes, but when he continued for some time the rashes disappeared. It was the medicines that brought about the rash." **R3**

"I use to have some shivering of my body when I take the ART. It will be like when you take alcohol and you are intoxicated, and that is what will happen to me until daybreak then I will be fine. When it happens like that, I use to feel hungry in the morning and needed to eat early" ***R7***

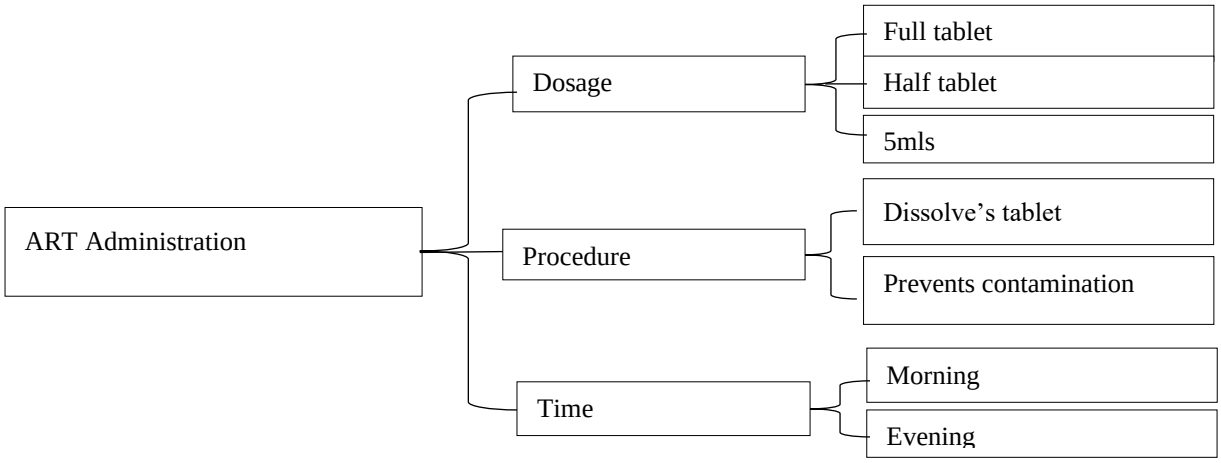

Figure 1. Thematic Map Showing Knowledge of ART Administration

Knowledge of HIV/AIDS transmission. Informal caregivers demonstrated knowledge of the transmission of HIV/AIDS. Knowing disease transmission can lead to better prevention. Figure 2 shows the knowledge generated on HIV transmission. Informal caregivers expressed their knowledge that a person could still transmit HIV when put on ART. They explained that the ART does not kill the virus, but rather makes it weak and hence suppresses its activity in the human body.

"*If someone is on the medication, the disease can still be transmitted to other persons because the disease organism is in me and not dead, but it cannot work like when I was not taking the medicine….*" **R5**

Some informal caregivers demonstrated accurate knowledge of HIV transmission. Some of the accurate knowledge expressed by the respondents was that HIV could be transmitted through transfusing infected blood, having unprotected sex, sharing blades, and from mother to child.

*"What I know is that if you are a woman and you have the disease and you come to collect the medicine, you can give birth to children who will not be infected because the medicines always protect the children if not the child will be infected…."***R6**

"If a person is on this medicine and you have an affair with the opposite sex without using a condom and your blood mix, you will get it, and using of the blade, maybe I have it and used a blade and my colleague who doesn't have also uses the same blade, it can cause her to have it" **R8**

However, while some demonstrated accurate knowledge of the mode of HIV transmission, some informal caregivers demonstrated inaccurate knowledge. Some of the informal caregivers, however, stated that HIV could be transmitted through sharing toothbrushes, breathing on a person, eating leftover food of HIV patients, having the same blood group, and sharing bath sponges.

"If you are taking the medicine, you can still spread the disease to someone if your blood and that of that person is similar or I eat something and give to that person or we breathe on each other" **R12**

"If you are taking the medicine and you share a sponge with somebody, you can still get it, or share a brush or you use a blade and someone also uses it, those people can get the disease" **R2**

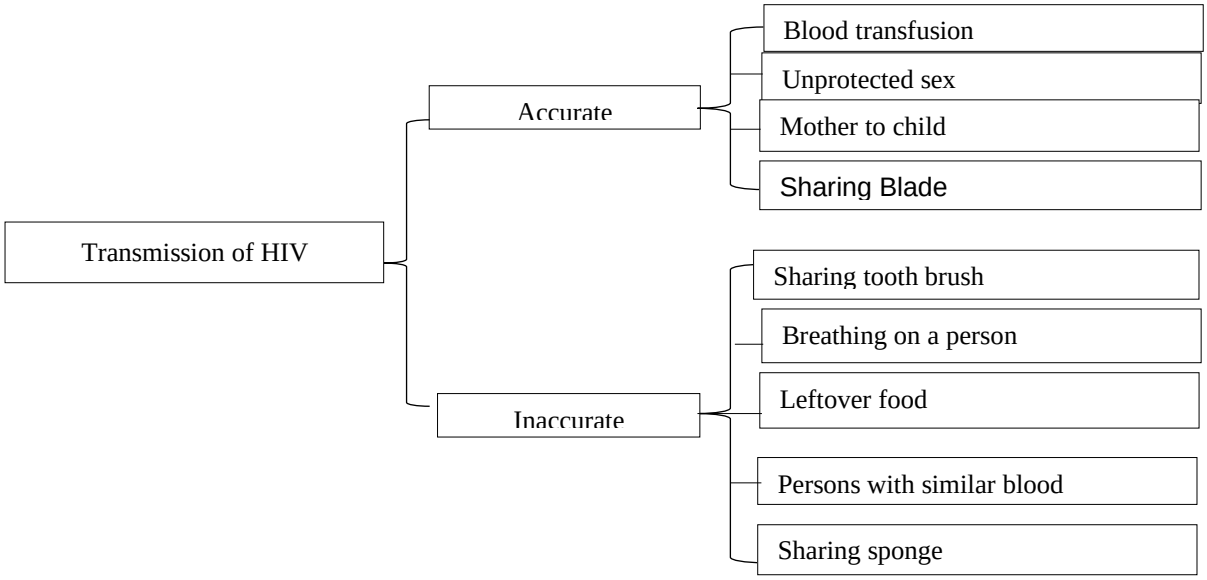

Figure 2. Thematic Map on Knowledge of Caregivers on HIV Transmission

Knowledge of nutritional restrictions of ART. Informal caregivers demonstrated knowledge of nutritional restrictions of ART based on the health education received at the HIV Testing and Counselling (HTC) Unit. Some of the nutritional restrictions mentioned are; alcohol, raw salt, pepper, local medicine, fresh meat, and oily food:

"They said when you are on the ART, you are not supposed to drink any form of alcohol, you are not to take fresh meat, you don't take pepper, you don't eat a lot of oily food, you don't also give some of the medicine to someone…." **R4**

"The medicine we come to collect has taboos, you don't take fresh meat, you don't drink alcohol, you don't take pepper, and it doesn't want promiscuity, befriending a man that is not your husband…." **R10**

"They told us that if you are on the ART, you don't take alcoholic drinks, you don't eat pepper, raw salt, fresh meat, you need to carry it where ever you are going because you might not be able to come back so that you can help yourself with it…you don't also give some to someone" **R11**

DISCUSSION

In exploring the knowledge of informal caregivers of children with HIV/AIDS on ART adherence, six major themes were generated and discussed as follows:

Knowledge of the regularity of visits to the HTC center. The findings of this study revealed that one of the essential components necessary for informal caregivers to ensure the adherence of children to ART is the knowledge of how regularly to visit the HTC center. Respondents have different days to visit the HTC center ranging from monthly to every six months, but each of them is conscious of when to visit. Similarly, in a cross-sectional study conducted to ascertain the factors that influence adherence in Dire Dawa realized that knowledge and practice of follow-up at the HTC center among HIV patients were associated with ART adherence[18]. The reason for adherence to ART could be that caregivers with the knowledge of follow-up will also ensure

there is enough ART available to be given to the child to ensure strict adherence. It could also be that people who follow up on their medications receive frequent education at the center that helps them to ensure strict adherence.

ART identification. Identification of the different types of ART given to caregivers was seen as an important component of the knowledge necessary to ensure that children living with HIV/AIDS under their care adhere to treatment. Because most of the respondents did not have formal education, they asserted that they did not know the names of ART given to them except Septrin. In the same vein, less than 5% of the study's respondents knew the names of their ART[19]. Although respondents could not mention the names of the ART may be because of a lack of formal education, they have a way of using symbols to identify and differentiate them, which is good for medication adherence.

Knowledge of ART administration. Informal caregivers expressed knowledge of how to administer ART to children with HIV/AIDS under their care, their knowledge of the ART administration was expressed in dosage, procedure, and time of administration. Most respondents of Raberahona et. al., similarly demonstrated good knowledge of dosage and when to take it when a cross-sectional study was conducted on the knowledge, attitudes, perception, and practices regarding ART[19]. However, just a few of them knew how to take the ART. Expressing sufficient knowledge among informal caregivers on the dosage, time, and administration of ART is essential to facilitate proper adherence. In ensuring adherence to ART among children, knowing the dosage, procedure, and time of administration is very vital.

Knowledge of ART side effects. Informal caregivers mentioned many signs and symptoms which were side effects of ART administered to the children under their care. Some of the side effects of ART as mentioned by the informal caregivers were dizziness, diarrhea, body shivering, rashes, sleeping after taking ART, vomiting after ART, intoxication, and hunger. All side effects experienced were reported and managed appropriately to ensure strict adherence to ART. Similar findings were revealed when respondents demonstrated knowledge of the side effects of ART and equally reported them when experienced to be addressed by their clinicians during cross-sectional studies conducted to ascertain the factors that influence adherence in Dire Dawa. Some of the side effects reported were anemia, vomiting, gastrointestinal intolerance, nausea, headache, depression, and rashes[18]. Knowing and reporting the side effects of ART is an essential component to ensure that children adhere to the medication regimen.

Knowledge of HIV transmission. Informal caregivers expressed their knowledge that a person could still transmit HIV when put on ART. They explained that the ART does not kill the virus, but makes it weak and hence suppresses its activity in the human body. Some of the accurate knowledge expressed by the respondents was that HIV could be transmitted through transfusing infected blood, having unprotected sex, sharing blades, and from mother to child. Similarly, it was said that HIV could be transmitted through the exchange of infected fluids such as blood, breast milk, semen, and vaginal secretions, through blood transfusion, unprotected sex, and breastfeeding[20-23]. It is well documented

that vertical transmission from women living with HIV accounts for more than 90% of pediatric HIV infections[22]. Parenteral exposure to blood and blood products via transfusion is the most highly efficient method of HIV transmission, as well as sharing infected needles by injection drug users[24]. Respondents with knowledge of HIV/AIDS transmission will have a good reason to adhere to the ART and live a life that will prevent them from spreading the HIV/AIDS infection. However, while some demonstrated accurate knowledge of the mode of HIV transmission, some informal caregivers demonstrated inaccurate knowledge. They stated that HIV could be transmitted through sharing toothbrushes, breathing on a person, eating leftover food of HIV patients, having the same blood group, and sharing bath sponges. Similarly, studies in Tanzania and Ghana found that most of the caregivers had inaccurate HIV transmission knowledge[9,10]. It shows that informal caregivers' knowledge is limited by continued misconceptions about the transmission of HIV/AIDS. This can influence adherence to ART negatively because people with HIV/AIDS may think that taking ART cannot help in the prevention of the spread.

Knowledge of nutritional restrictions of ART. Informal caregivers demonstrated knowledge of nutritional restrictions of ART based on the health education received at the HIV Testing and Counselling (HTC) Unit. Some of the nutritional restrictions mentioned were; alcohol, raw salt, pepper, local medicine, fresh meat, and oily food. Equally, an article on the role that diet and nutrition play in the life of people with HIV/AIDS advised that they should avoid salty foods, sugar, the unhealthy fat present in fresh meat, and palm oil and alcohol which can lead to depression immunity[25]. Informal caregivers of this study assimilating these nutritional restrictions will help to improve their immunity to facilitate the effectiveness of the ART.

CONCLUSION

Informal caregivers of children with HIV/AIDS in Jirapa in the Upper West Region of Ghana have demonstrated good knowledge of ART. They demonstrated that they knew their schedules for when to visit the HTC unit for ART and had more knowledge on how to manage HIV/AIDS. Although most of the respondents did not have formal education and did not know the names of the ART given to them, they demonstrated good knowledge of how to differentiate ART from symbols. They demonstrated good knowledge of ART administration in areas such as dosage, procedure, and time of administration. Caregivers were also knowledgeable in identifying and reporting the side effects of ART. They also expressed good knowledge of the nutritional restrictions of ART. Good knowledge was also shown among most of the informal caregivers in the area of HIV/AIDS transmission. The findings imply that informal caregivers who receive care at the Jirapa HTC unit are ensuring that children living with HIV/AIDS under their care adhere strictly to their ARTs to prolong their lives. However, some respondents still have misconceptions regarding HIV/AIDS transmission, hence the findings will also serve as a guide for nurses and health workers working at HTC to plan educational programs to insure ART adherence.

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CONFLICT OF INTEREST

The authors declare that there is no conflict of interest

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AUTHOR CONTRIBUTION

Lilian Yiryuo and Wahab Osman were involved in the conceptualization, methodology, and reviewing of literature. Lilian Yiyou and Stephen Kpekura undertook data collection, analysis, and drafting of the manuscript. Wahab Osman undertook critical revision for intellectual content, proofread, and approved the final manuscript for submission.

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