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How do caregivers of children living with HIV/AIDS cope, and where do they get support?: A qualitative study in Ghana

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Abstract

Background

Caring for children living with human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) is challenging and has a tremendous impact on the physical and psychological health of caregivers. Caregivers of children with HIV/AIDS need to adopt coping mechanisms to navigate these complexities as it influences the quality of care provided. The literature on coping strategies and support (formal and informal) available to caregivers of children living with HIV/AIDS is scant. This study aimed to explore the coping strategies and support systems for caregivers of children living with HIV/AIDS.

Methods

A phenomenological study design was adopted. A total of nine participants across three hospitals in the Tamale metropolis were interviewed using purposive sampling. The interviews were audio recorded, transcribed verbatim and analysed using Colaizzi's approach.

Results

Four main themes emerged from the analyses: (1) coping strategies, (2) types of support activities, (3) support from informal institutions and (4) support from formal institutions. The

caregivers navigated the caring process with much spiritual coping. The caregivers had little or no support from informal institutions such as immediate family, faith and community leaders. Non-governmental organizations were not visible in support, and there were no support groups for caregivers.

Conclusion

Support for caregivers and the active involvement of the immediate family in paediatric HIV care is imperative.

1 INTRODUCTION

Since the discovery of the human immunodeficiency virus and acquired immunodeficiency syndrome (HIV/AIDS) in the 1980s, it has become a global public health concern and is responsible for the death of 32 million people globally.¹ The worst hit is the Sub-Saharan African (SSA) region and other resource-limited countries. Globally, a total of about 1.8 million adults and 26,730 children under 15 years, respectively, are living with HIV. As of 2017, 180,000 new infections among children with a corresponding 90% of these children residing in SSA. Ghana's incidence of HIV as of 2018 was 0.62%, with projected new infections of 17,649 and 11,908 AIDS deaths while deaths amongst children from 0 to 14 years were projected to be 2,473 by the year 2022.²

Nonetheless, the development of antiretroviral therapy (ART) in 1988 by the U.S. Food and Drug Administration has been a breakthrough for people living with HIV/AIDS (PLWHA) and reduced significantly the number of HIV/AIDS-related morbidities and mortalities.³ Even though current medical technology has not achieved a cure, many more people are living longer with strict adherence to ART and the cultivation of healthy lifestyles. Disturbing episodes exist in low and middle-income countries. In Nigeria, about 70% of medications are said to be adulterated or fake,⁴ and in Ghana faith leaders are believed to be healing people from the virus.^{5,6} The devastating nature of the pandemic has affected nearly every household across the world directly and indirectly. Many children have been orphaned by the virus in a typical study in rural Lesotho.⁷ Evidence from the study suggests families are increasingly adapting to HIV-related orphans and bemoaned despite local ideas about kinship and care being of patrilineal social organization; in reality, maternal caregivers, sometimes grandmothers, are widely caring for orphaned children.

Owing to the increasing life expectancy of PLWHA, HIV/AIDS is now considered as a chronic disease.^{8,9} Caring for PLWHA, therefore, has seen a twist where home caregivers become pivotal to HIV care across many health systems. For children living with HIV/AIDS (CLWHA), the role of the caregivers becomes painstaking due to the likelihood of dependency of the children on activities daily.^{10,11} Evidence suggests HIV-associated neuro-developmental delays among

CLWHA.¹² Earlier studies have shown that caregivers experience severe burdens in Nigeria,¹³ rural Malawi,¹⁴ and Southern India.¹⁵ Even in areas where there are reported mild/moderate burdens such as in Calabar Nigeria¹⁶ and Malaysia,¹⁷ caregivers express concerns of caring having a toll on their finances and psychological and physical health.

It has been established that most caregivers of CLWHA are vulnerable poverty stricken females, support for these people is necessary for the welfare of the children they are caring for. Evidence suggests that Africa with its fragile social protection policies affects caregivers of CLWHA. According to a qualitative study conducted in South Africa, grandmother caregivers expressed among other challenges lack of social support, extreme difficulty in acquiring social grants, and financial difficulties.¹⁶ It is further explained that even though the caring role is divinely ordained, the rejection of orphans by their biological fathers was disheartening and painful. There is a need for caregivers to be supported not only to care for their CLWHA but to care for themselves. According to Refs. [18](#) and [19](#), there are different sources of support for caregivers: non-governmental organizations (NGOs)^{20, 21} and immediate family^{22, 23} among others.

Supportive interventions for caregivers have a synergic effect on the caregiver–patient relationship and are identified as telephone coaching, problem-solving skills, social support and stress management.²⁴ In the West African sub-region and wider African setting, there are reports of minimal support for caregivers.¹³ Amidst this daunting task, caregivers resolve to cope with the stress of the process through several behaviours and thought processes. Even though there exists positive coping among caregivers of CLWHA,^{25, 26} the majority of them cope negatively with the caregiving process and burden as reported elsewhere.^{24, 27, 28}

These negative copings include crying, guilt and fear, among others. Evidence suggests female caregivers have poor coping mechanisms than men.²⁹ According to Ref. [30](#) in Ghana, practices such as skipping entire daily meals (13%), reducing portions of meals (61.3%), harvesting immature crops (6.7 %), and begging (5.6%) were practised by households as means of coping with HIV/AIDS; whereas Ref. [31](#) has provided evidence that CLWHA and infected caregivers reported significantly lower levels of social support compared with AIDS-orphaned children, other-orphaned children and non-orphaned children.

There is a dearth of knowledge on the experiences of caregivers of PLWHA in Africa and much serious among minority groups such as children.^{14, 32} In a systematic review of the experiences of caregivers of minorities such as men who have sex with men and lesbians,³³ authors reported less research among these key populations and suggest extensive research on these areas will be beneficial. There exists little knowledge on the experiences of caregivers of CLWH in Ghana, to the best of our knowledge, there are no studies that have extensively looked at the coping strategies employed and support available for caregivers of CLWHA. This current study

explored the coping strategies and support of caregivers of CLWHA in three hospitals in the Northern Region, Ghana. The literature reviews highlighted gaps in caregivers' coping and support systems. Therefore, the research question was: What are the coping strategies and support systems for caregivers of CLWHA?

2 MATERIALS AND METHODS

The research team and reflexivity

The research team is composed of nurses in clinical practice settings and academia who are interested in maternal and child health as well as HIV/AIDS care. The study was supervised by FA, VMD, and ABBB who have vast experiences as clinical nurses and lecturers with their research focusing on HIV/AIDS and maternal and child health. AGA the lead author was a master's student and a registered nurse with experience in qualitative interviews. Seven interviews were conducted in English by AGA and two in Dagbani by a registered nurse with a bachelor's degree and prior experience in qualitative interviews. The latter was given training before the commencement of data collection.

Except for AGA who works in one of the facilities, none of the authors' works have a relationship with any of the facilities used for this study. All the authors did not know (professionally and personally) any of the participants recruited for this study.

Design, setting, population, sampling and sampling procedure

A descriptive phenomenological approach was used to undertake this study in the three largest public hospitals in Northern Region, Ghana. According to Refs. [34](#) and [35](#), the philosophical assumptions are not rigid empirical science approaches even though they also rely on philosophy but rather a broader dimension, suspending or bracketing all presuppositions about the phenomena as christened 'epouche' by Husserl, the intentionality of consciousness and refusal of subjectivity and objectivity differences since both play a part in describing the lived experiences of people are well inculcated in this study. This approach was chosen because it explores the lived experiences of heterogeneous people who are experiencing phenomena. It also seeks to subjectively enquire how individuals lived with phenomena and conclusively get objectivity of the common experiences of other people to the phenomena³⁶ and is useful in under-explored phenomena like this.³⁴

Through purposive sampling, nine caregivers of CLWHA were recruited. This number was determined by data saturation, the point at which data become repetitive, and no new information was obtained during qualitative data collection.³⁴ These three hospitals were selected because they have the highest OPD attendance and Sexually Transmitted Infections (STI) clinic and antiretroviral therapy (ART) units with the highest attendance in the Northern

part of the country.³⁷ The prospective participants were approached at the clinics while waiting for antiretrovirals (ARVs), and those who consented were interviewed in a consulting room in the hospital for 20–45 min. The interviews were conducted in Dagbani and English by the first author and trained research assistant with prior experience in conducting qualitative interviews, respectively.

Interview guide

A semi-structured interview guide was developed based on the specific objectives. The interview questions were informed by the outcome of the literature review and the practical experience of the research team. Through in-depth face-to-face interviews, data were collected after the instrument was reviewed and the pilot executed to improve it. The pilot allowed for accuracy, consistency and appropriate wording of the guide.

Data management

Audio-recorded interviews were transcribed verbatim for English interviews immediately by the researcher. Interviews in the Dagbani language were transcribed verbatim and translated back to back. Anonymity and confidentiality were ensured by not collecting identifiable data.

Analysis and rigour

Data were analysed manually through content analysis by the approach of Collaizi.³⁴ The analysis was done concurrently with data collection. All the transcripts were read many times to acquaint us with them. Re-reading of each transcript was done, and significant statements were extracted. The meaning of each significant statement was formulated about the phenomena. These earlier formulated meanings were well organized into clusters of themes after coding. The preliminary themes established were followed up in subsequent interviews and verified to develop all the themes. This ensured validation and help resolve discrepancies noted among or between the various themes and amend the same. At this stage, we ensured data/themes/information avoidance/ignoring does not happen. We then integrated all the findings into an exhaustive description of the phenomenon. Finally, an overwhelming description of the phenomena is made from the integrated description. Member checking was executed where transcripts were sent to some of the participants for validation. The findings are reported in themes and subthemes.

To ensure rigour, member checking was done. The data were first analysed by the first author independently and verified by the second, third and fourth authors to ensure the views of the participants were accurately and sufficiently represented. Differences were then discussed, and amends were made for further exploration in subsequent interviews. An audit trail was also carried out by independent researchers. The authors also bracketed their preconceived ideas

and opinions about the phenomena to ensure no biases were introduced. The study was conducted with a detailed description of the approach, tools and setting among others.

Ethical consideration

Ethical principles were followed concerning the conduct of research among human subjects. Participants consented to the study and were treated fairly. Ethical clearance was obtained from Committee on Human Rights, Publication and Ethics (CHRPE) of the Kwame Nkrumah University of Science and Technology (CHRPE/AP/407/19) and the Research Development Division of the Ghana Health Service (GHS) (GHS-ERC 051/05/19).

3 RESULTS

Demographic characteristics of participants

Most of the participants were still in their active years of life with about 55% of them being less than 40 years. Sadly, 78% of caregivers were HIV-positive females while caring for their biological children and 67% became family heads of their nuclear families suddenly. About 44% are either separated or divorced due to positive HIV status with 22% of them widowed by the disease. Their households are plunged into poor economic livelihoods as low as 22% of them have government jobs that provide sustainable jobs with regular incomes. Averagely, these caregivers assume the responsibility of caring for about three children and 33% could not manage any level of education and thus do not have employable skills. The demographic characteristics of the caregivers are presented in Table 1.

TABLE 1. Demographic characteristics of caregivers.

Characteristic	Division	Frequency	Percentage
Age	Less than 30 years	2	22
	31-40 years	3	33
	Above 40 years	4	45
Sex	Male	2	22
	Female	7	78
HIV status	Sero-positive	7	78
	Sero-negative	2	22

Characteristic	Division	Frequency	Percentage
Marital status	Married	2	22
	Divorced/separated	4	44
	Widowed	2	22
	Single	1	11
Religion	Muslim	5	56
	Christian	4	44

Abbreviations: CLWH, children living with HIV/AIDS; HIV, human immunodeficiency virus.

Themes and sub-themes

Four main themes emerged from the data collected from the caregivers concerning their coping and support while caring for children living with HIV/AIDS (CLWH). These include (1) coping strategies, (2) types of support activities, (3) support from informal institutions and (4) support from formal institutions. The main themes and subthemes are presented in Figure 1.

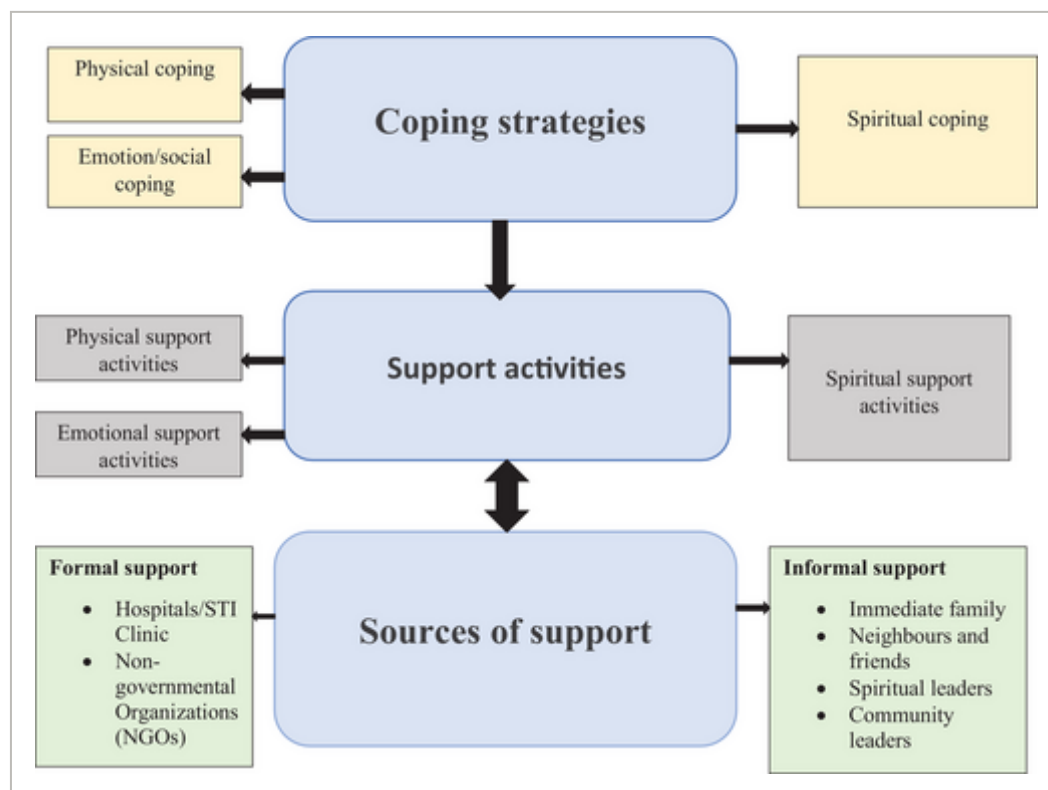


FIGURE 1

Summary of themes and subthemes. STI, sexually transmitted infections.

Coping strategies

This major theme explains the coping strategies caregivers of children living with HIV/AIDS (CLWH) use and is crucial in helping mitigate the stress of caring for children living with HIV/AIDS (CLWH). Caregivers used physical, social or emotional as well as spiritual coping strategies in caring for CLWH. Spiritual coping activities (such as praying, Qur'anic recitation and fasting) were however, most engaging.

3.3.1 Physical coping

This sub-theme explains physical activities which are used by caregivers to cope with the stress of caring. These are physical activities that were used by caregivers while experiencing the burden of caring for children living with HIV/AIDS. Under physical coping caregivers employed activities such as watching TV, taking evening walks and partaking in sporting activities among others.

Caregivers expressed this as below:

“ ...when I feel very bad sometimes and when I am disturbed and can't pray, I go to sit and watch TV, ... I cry and take my medications. (Participant-8, female, HIV+VE, single)

”

“ Physically I cope, yes that is why I belong to a keep fit club, so I exercise. (Participant-2, male, HIV-VE, married)

”

“ I do chat with the woman in the house, especially in the evening, if not her sometimes I can sleep in the room like that ahh, sometimes too I walk around with the child to the roadside. If I have a coin, I will take it then we will go and come. Use the coin to buy something outside. (Participant-7, female, HIV+VE, divorced)

”

3.3.2 Spiritual coping

Spiritual coping stems from the religious and faith activities in that caregivers were involved themselves. These include going to church and mosque, praying, and reading the Bible or

Quran among others. Spiritual coping was extensively used as it gave them hope in a Supernatural Being, and this was demonstrated in the following quotes:

“ We are Catholics, we say our prayer in the morning, and we agree that everything God is in control. (Participant-2, male, HIV+VE, married) ”

“ I always sleep and most often pray and make recitations from the Quran. (Participant-9, female, HIV+VE, married) ”

“ I pray to God that he knows and gave us this disease. He should support us as always. (Participant-7, female, HIV+VE, divorced) ”

3.3.3 Emotional/social coping

This sub-theme explains the activities of social networking and interactions between the caregivers and their immediate family, neighbours, friends and significantly others. Emotionally and socially, a few caregivers were having friends whom they shared their experiences to help during coping. They, however, engaged in chatting and conversation with others who do not know their status.

A caregiver opined: ‘... my uncles help me with talks (advice)’ (Participant-5, male, HIV+VE, student). While another caregiver narrated: ‘I chat with my co-tenant in the evenings sometimes ... I think of committing suicide, but the child will suffer if I die’ (Participant-7, female, HIV+VE, divorced). The hope for a cure to be found keeps them equally positive, and one participant expressed faith by saying, ‘One day we should just wake up and hear that there has been a cure for the disease so that we will be treated’ (Participant-6, female, HIV+VE, single).

Types of support activities

Caregivers and CLWH rely on support to complement their efforts to live with HIV/AIDS. This theme explains the kinds of support activities that were given to caregivers and their CLWH. The type of support activities was most often emotional and spiritual while financial and physical support was woefully inadequate.

3.4.1 Physical support activities

This support bordered on physical activities that were undertaken by others to mitigate the suffering of caregivers and expressed: 'They (family and friends) bring food when we are on admission' Participant-1 (female, HIV+VE, married) explained. While other caregivers said:

“ ...my uncles sometimes after harvesting they give foodstuff... and my grandmother help bath for her when am not home sometimes. (Participant-5, male, HIV-VE, student). ”

“ ...senior-most brother and my brother too is here, so I made them know where his record is so that when am in seminar and the next date is tomorrow or tomorrow next when am not there they can try and get it (ARVs) so that he does not skip. I just don't want him to skip. (Participant-2, male, HIV-VE, married) ”

3.4.2 Spiritual support activities

Caregivers were mostly given spiritual support in the form of offering prayers and leading them to believe in a Supreme Being which provided hope and faith to withstand the challenges of caring for CLWH.

“ When the child is sick and I'm at the hospital, they come to greet me and pray for me and console me. For the Imam he comes to pray for me, and sometimes prepare water pray over it for us or sometimes some concoctions as medicine in Islam for us to be drinking, for this, he has done well. (Participant-3, Female, HIV+VE, Widow). ”

“ When am sick he does not come home to pray for me unless I go to the church to request for prayers. (Participant-7, female, HIV+VE, divorced) ”

“ He (Pastor) does not support but I told him what is wrong with us. He has never even supported me, but he prays for me especially when we are having congregational prayer. (Participant-8, female, HIV+VE, widowed) ”

3.4.3 Emotional support activities

Advice and being talked to help and a caregiver whose father was deceased narrated:

“ My uncles advise me, and they are always praying for me to be able to care for the family since my father is late, ... my two close friends, help emotionally, motivate me and talk to me when my mother and sister's condition becomes serious and take me away from school. (Participant-5, male, HIV+VE, student)

”

Another participant narrated: ‘The only support we get from them is comforting, they will only come and talk to you’ (Participant 1, female, HIV+VE, married).

Support from formal institutions

This theme of support was described by caregivers to be the formal health system where professional healthcare providers rendered services to them at hospitals and NGOs. Formal caregiving was mentioned to have provided caregivers and CLWH much comfort; among these the continuous counselling they were given with the comforting attitudes of staff at the ART/STI clinics they visited.

3.5.1 Support from hospital /STI clinic

They also talked about the foodstuffs that used to be given but were not forthcoming again, was helpful and wished this could be continued. Institutions such as the ‘Model of Hope’ and the Association of PLWH, which served as support groups for People Living with HIV/AIDS (PLWH), were not much patronized and utilized even though many of them expressed the need to belong to them.

“ First, they use to give us maize, oil among others when it comes, we were happy because it helps us... I don't belong to any association, but I think is good. I want a partner and I think with such I can get one. (Participant-7, female, HIV+VE, divorced)

”

“ Way back in Accra we use to have groups and we meet and talk and sometimes we go for meetings and then nurses will come and educate us on the condition and other things. But since we moved to [Anonymised]in 2008 up to now, I have not had anybody to discuss this with. Those meetings were very helpful, and I wish they are done here too. (Participant-6, female, HIV+VE, single)

”

3.5.2 Support from non-governmental organizations

NGOs were invisible to PLWH and their caregivers at the clinical site. Caregivers explained they have not been engaged in any support from these not-for-profit organizations and other social welfare organization or groups.

“ I don't belong to any organization or institution that is a concern with PLWH, for NGOs I have not heard of any before. (Participant-1, female, HIV+VE, married)

“ No, I don't belong to any NGO or institution, that is concerned with PLWH. (Participant-2, male, HIV-VE, married)

Support from the informal system

Participants shared their views on the provision of support from the informal system such as immediate family, neighbours, friends and spiritual and community leaders. Most of the participants reported that due to the stigma associated with the disease, they were unable to disclose their diagnosis leading to inadequate provision of support by family, friends and community leaders.

3.6.1 Immediate family

The immediate family support ranged from little to nothing at all. Most caregivers lived in different places from their extended family which further worsened their support base. One caregiver narrated as below:

“ I don't have anyone except my husband. Sometimes you don't know how to tell the person, you may tell the person, the person will hear and will not help you. (Participant-4, female, HIV+VE, married)

A participant who was separated from her husband due to her status lamented:

“ ... the father does not offer any financial help but these days he can call and ask to talk to the girl. (Participant-7, female, HIV+VE, divorced)

“ No, they (family) don't come (when am are on admission to visit), they live at A and we live at B. Is only I who call, they have no time to call (to even call), is only when the child continuously asks the father that I will go and look for credit and call them for her to talk to them because I don't want her to feel bad. (Participant-3, female, HIV+VE, widow)

”

3.6.2 Neighbours and friends

Support provided by friends and neighbours was not significant, inconsistent and consisted of emotional support. Some of the participants explained that they did not receive any form of financial support:

“ Today while I was coming out one of them asked me, if she has not seen me for some time. So, they come to greet me but, gave something no, and they do pray for me as well. On the part of friends, she said: “I don't have friends ... Even partners I tried severally and failed.” (Participant-7, female, HIV+VE, divorced)

”

“ The only support we get is comforting, they (neighbours) will only come and talk to you. They don't give us anything, they don't give us money. (Participant-1, female, HIV+VE, married)

”

“ When am sick they (neighbours) come to visit me and pray for me, sometimes they bring food, but they don't offer money. (Participant-4, female, HIV+VE, married)

”

3.6.3 Spiritual leaders

“ When am sick he (pastor) does not come home to pray for me unless I go to the church to request for prayers. (Participant-7, female, HIV+VE, divorced)

”

Some of the participants indicated that spiritual leaders did not provide much physical or financial support. One participant disclosed, 'For the Imam, he only comes to pray for me and sometimes prepare water for me' (Participant-1, female, HIV+VE, married).

Another caregiver shared that 'He (pastor) does not support but I told him what is wrong with us, he has never supported me, but he prays for me especially when we are having congregational prayer' (Participant-8, female, HIV+VE, widowed).

3.6.4 Community leaders

A caregiver (Participant-8, female, HIV+VE, widowed) responded, 'I don't even know him'. Concerning a question on support from community leaders such as assemblymen or women, one participant responded, '... No please they (assemblyman and Imam) don't come. If you have an Imam who does not come to see, then you don't have one' (Participant 4, female, HIV+VE, married). A caregiver answered affirmatively regarding help offered by community leaders or Imams: '... for assemblyman, no I don't even know him...' (Participant-7, female, HIV+VE, divorced).

4 DISCUSSION

This study explored coping and support for caregivers of children living with HIV/AIDS and found they largely used spiritual coping while receiving little or no support from informal institutions such as immediate family, faith and community leaders. Our findings show caregivers engaged in physical, spiritual and emotional coping while caring for CLWHA and engaged more in spiritual coping. Support activities from significantly others such as immediate family, friends, faith, and community leaders bordered more on spiritual and social activities than financial and physical activities which largely help absorb their burden. Most caregivers did not have friends, and community leaders were invisible neither to talk about providing support. While hospitals provided emotional support and care, non-governmental organizations with an interest in providing HIV support were invisible. They provided little or no support to caregivers.

Findings from this study concur with a study in South Africa,³⁸ Uganda,³⁹ India,⁴⁰ and Ghana⁴¹ where the majority were females. For instance, according to Paintsil et al.,⁴¹ 80.5% were female and about 60% were HIV-positive in a quantitative study in a tertiary hospital in Kumasi, Ghana. Even in that study where 78% were self-employed with estimated low incomes for their households, in this study about 44% were unemployed with 33% self-employed. The evidence shows the plight of caregivers in this study is much worse as cultural practices influence how well an HIV orphan will be cared for.⁴²

Caring for CLWH is burdensome^{33, 39, 43, 44} and especially in resourced-constrained countries in SSA, where there exist serious income disparities the plight of caregivers is worsened by extreme poverty and gender issues.⁴³ Evidence from the study conducted in South Africa shows caregivers are confronted with physical/medical, social, material, financial, physiological/emotional, gender issues and instrumental needs. For low levels of disclosure in Africa,⁴⁵ caregivers are more likely to receive less support compared to those who disclose their status.

Caregivers in this study engaged in physical activities such as watching TV and taking an evening walk to divert their attention to cope physically. These findings contrast alcohol and drug use among women living with HIV/AIDS in South Africa and Ethiopia.^{47, 48} The psychological burden of caring for CLWH caused fear,⁴⁸ guilt,⁴⁹ shame and even suicidal ideation^{29, 50, 51} among caregivers. It affirms the results of a systematic review which showed about 39% of PLWH were depressed.²⁹

According to Larmar,⁵² support for PLWH and caregivers reduces stigma and increases hope and resilience. Another study in Ghana reported stigma among tuberculosis patients, a disease that is usually associated with HIV/AIDS, due to the immunosuppression that arises from it and that stigma could stifle a source of support.^{53, 54} In this study, support was invariable low for many caregivers and centred on emotional/social support and spirituality and consistent with a study conducted in eastern Uganda.⁵⁵ A spectacular example of supporting caregivers points to Ref. [56](#) in Nigeria where orphaned and vulnerable children caregivers were studied. With similar demographic characteristics, most caregivers being females and with low incomes, strangely evidence collaborates with this study as family support dwindled considerably or does not exist at all. They further espoused that little organized support came from NGOs and faith-based organizations for food security and school supplies which was evident in this study. Registered NGOs in the northern region of Ghana concerned with HIV/AIDS care were not visible to caregivers⁵⁷ as compared to those in South Africa²⁰ for children orphaned by HIV/AIDS.

CLWHs in this study were not given support for education even though they have poor school attendance and educational delays due to frequent hospital appointments and poor cognitive difficulties. A study in South Africa intimated schools served as support for adolescents living with HIV/AIDS which could be beneficial for CLWH not realized in this study as school authorities were not in the knowledge of the CLWH's predicament.⁵⁸ In Nigeria, caregivers' experiences are consistent with those in this study as limited support in the form of financial assistance, poor information on practical and coping skills, emotional support and lack of physical help with caregiving were cited. They posit a significant relationship between support and caregivers' burden and reflect a study conducted by Salifu et al.⁵⁹ On reflection, a major determinant of support for the caregivers was strongly tied to poor non-disclosure of status

since most caregivers kept their status a secret, and they are unable to get the needed support. This affirms the wider benefits of disclosure for caregivers and PLWH.^{60, 61}

Emotional and spiritual support was seen as the most frequent support offered to caregivers, this support, according to Ref. [1](#) social support from friends, neighbours and significantly others, is more likely to reduce anxiety, worry and suicide among PLWH. Physical support in the form of providing foodstuffs and visiting the hospital seen in this study is similar to a study conducted in rural Malawi.¹⁴ Even though this study's findings were similar to another in Ghana³⁰ on skipping meals and reducing portions, caregivers in this study did not resort to begging, harvesting immature crops and eating elsewhere. Since study findings saw siblings helping and supporting caregivers and CLWH, it was not consistent as much as has been seen in South Africa.⁶²

Caregivers' recognition and relationship with a Supreme Being has been well expatiated to become one that draws strength, hope and peace while living with the virus.⁶³ Reliance on spiritual coping speaks volumes of the confidence caregivers place in their faith in this study as Ref. [63](#) in a typical Muslim community like Tamale Metropolis. Spirituality emphasizes how women use 'religious coping' to their advantage. Caregivers in this study believed in their spiritual leaders, recitation of the Quran and developed a good relationship with their Maker in the face of fear, guilt, self-condemnation and poor/ lack of support.

According to Ellen,⁷ there are gains in the extended family system and social networks in absorbing AIDS orphans and CLWH in Africa; however, caregivers in this study reported poor support from family and social networks such as friends, neighbours, community and spiritual leaders. Similarly, poor informal support is worrisome and contrasts findings that explained that the extended family and its related social networks provided safety nets for CLWH and orphans in SSA.⁶⁴ Inadequate support in this study, therefore, comes as a surprise and contrasts with adequate support caregivers received from family and especially community leaders in rural Malawi.¹⁴ Just as caregivers have relied on spirituality to cope, the findings revealed spiritual leaders did not provide much physical and financial support to benefit caregivers and their children except for the spiritual activities carried out for them. Caregivers expressed their disappointment in them as they expected to receive cushioning in the form of foodstuff or financial support as most disclosed their status to them. Community/opinion leaders such as the assemblymen/women and unit committee members were invisible and did not provide any support. These findings are different from those from a study in rural Malawi¹⁴ and Uganda⁴³ where these people provided much support to PLWH.

5 CONCLUSIONS

Caregivers amidst their care developed maladaptive and adaptive physical, emotional, social and spiritual coping. Religious coping was utilized the most, and the most offered support was from informal people. Caregivers were guilty, cried and attempted suicide sometimes, and immediate family provided little or no support to caregivers. Many caregivers indicated they did not have friends to talk to about support. Spiritual leaders did not provide the physical or financial support they so much desired while community leaders and NGOs were not always present to support. Surprisingly, caregivers did not belong to any support groups through which they could be emotionally supported. The impression of support was seriously tied to disclosure such that secrecy of status by caregivers marred the support from others.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflict of interest.

Open Research



DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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