

## Research Article

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# Caring for Children Living with HIV/AIDS: Family Caregivers Experiences at the Princess Marie Louise Hospital, Ghana

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## Abstract

**Introduction:** Family caregivers remain the pillar of support for children living with HIV/AIDS. Appreciating their roles and experiences is a significant aspect of family-centered care and has implications for improved care outcomes. This study therefore aimed at exploring the care related experiences of Ghanaian family caregivers of children living with HIV.

**Methods:** A descriptive qualitative study was conducted among family caregivers of children living with HIV accessing healthcare at the Princess Marie Louise Hospital, Accra. A total of 15 one-on-one interviews had been conducted by the time saturation of data was reached. Thematic content analysis was employed to unravel the data.

**Results:** Almost all (n=14, 93.3%) of the caregivers were women, less than two thirds (n=10, 66.6%) of the caregivers were below forty years and (n=7, 46.7%) being the non-biological parent(s). Emergent themes were: social experiences (financial constraints, good family support, social isolation/secrecy); spiritual experience (Inner strength derived from increased faith in God); psychological experiences (inner satisfaction in performing caregiver roles; and anxiety over their children's future); physical experiences (care being demanding); altered quality of life (mainly adverse changes); and health care related experiences (supportive staff a key motivator fostering caregiver role).

**Conclusion:** The study found both positive and negative family caregiver experiences with regards to the care of their HIV-infected children. Healthcare providers must capitalize on the positive experiences to provide strength-based care, which involves incorporating the clients' own strengths and capabilities as well as wider support network in the planning and delivering of services for children and adolescents living with HIV. Available social support from government and non-governmental organizations should also be sustained.

**Keywords:** Children Living with HIV/AIDS; Family Caregivers; Experiences

**Abbreviations:** AIDS: Acquired Immune Deficiency Syndrome

ARVs: Antiretroviral drugs

ART: Antiretroviral Therapy

**ChilHIV:** Children living with HIV/AIDS

**GAC:** Ghana AIDS Commission

**HAART:** Highly Active Antiretroviral Therapy

**HCPs:** Health Care Providers

**HIV:** Human Immunodeficiency Virus

**NACP:** National AIDS/STI Control Programme

**PLHIV:** Persons living with HIV

**UNICEF:** The United Nations Children Fund

**WHO:** World Health Organization

## Introduction

HIV continues to be a significant public health issue. The Sub-Saharan African (SSA) Region remains the most affected, accounting for almost two-thirds of the global new HIV infections [1]. Globally, children and adolescents constitute a significant number of persons affected by HIV/AIDS. As at 2017 there were 1.8 million children living with HIV/AIDS (<15 years) out of which nearly 90 percent lived in SSA. There were also 180,000 new infections recorded among children [2,3]. In Ghana, about 28,000 children 0-14 and 19,000 adolescents 10-19 years were living with HIV at 2017[4]. These figures suggest that there is a possible corresponding number of parents or guardians who are overseeing the care of these children. With the increased survival rates due to the accessibility and usage of Highly Active Antiretroviral Therapy (HAART), the condition has assumed a chronic status and parents are likely to live with these children for years. Globally reports of parental experiences in the care of children with HIV/AIDS are largely about the negative experiences, which include mental illness, financial difficulties, physical health challenges mainly due to parental HIV positivity status [5,6]. The situation is not different in Africa. Demmer explored the experiences of caregivers of children affected by HIV/AIDS in Kwazulu-Natal, South Africa and found mostly negative experiences of psychosocial stresses associated with stigma, lack of money, and delayed treatment. These experiences affected their quality of life in terms of happiness, emotional stability with implications for their social, psychological and physical health [7]. In a similar study carried out in Ghana, Mwinituo and Mill, also reported mainly negative experiences. The caregivers in that study experienced social isolation, lived in secrecy and were not willing to share information with family members concerning the condition of their children [8].

These negative experiences which are widely reported suggest that parenting a child with HIV/AIDS is associated with many negative experiences. As such, not much attention has been paid to positive experiences [9]. Although most studies focused on the negative experiences, it is likely that there may be positive experiences that family caregivers might have gained in the course of caring for their children, which may be useful to the society, the health providers, researchers, and policymakers. An exploration of the positive experiences and not only the negative ones may bring to fore useful information that could also be shared with others whose children have been newly diagnosed with HIV/AIDS. Just as the health needs of children with HIV/AIDS is necessary, the family caregivers must also be in an optimum state of health to

enable them to participate meaningfully in the care of their children. Understanding their experiences is an entry point to planning and implementing relevant support services aimed at improving their quality of life to facilitate provision of optimum chronic care to their children. With regards to especially the positive caregiver experiences, not much is known about the Ghanaian situation and how these can impact on the care of these children. There is also little known about how the varied socio-cultural context of Ghana, specifically, influences these experiences. Additionally, not much is documented about the evaluation of how well current services provided for Persons Living with HIV (PLHIV) meet the needs of these family caregivers. Hence, the need to explore the Ghanaian situation, and to generate the needed evidence that can inform programming for such population, where gaps are identified.

## Materials and Methods

### Design, population, and settings

Qualitative research design, using the descriptive approach was conducted among 15 family caregivers of children (less than 18 years) living with HIV/AIDS and who access routine HIV Clinic and ART Services at Princess Marie Louise (PML) Hospital, popularly called the Children's Hospital, in Accra-Ghana.

### Sample size and sampling

Family caregivers who have lived and cared for children with HIV/AIDS for at least six months were purposively sampled and interviewed until data saturation was attained at a sample size of 15.

### Data collection process

Data were collected from May to June 2018. A one-on-one in-depth interview (using an interview guide) was conducted at an identified counselling room at the HIV/ART Clinic site. Signed (written) informed consent was obtained before the commencement of each interview. The interviews were conducted by the Principal Investigator (PI) assisted by a research assistant fluent in English, Ga, and Akan, and audiotaped. During the interview process, the PI kept field notes on the participants' verbal and non-verbal expressions and the entire interactions. The sequence of events throughout the research process was also noted in a research diary. The recorded data were transcribed verbatim from the audiotapes and translated into English by a second research assistant proficient in English and the two local languages (Akan and Ga). Back translation was conducted to ensure that the meaning of the data was not lost during translation.

### Data analysis

Interviews were analysed using Nvivo; a qualitative data analysis software. The approach used was thematic content analysis. The interview transcripts were read and re-read several times

to identify the key concepts and codes. Codes were developed to describe identified key concepts. The responses of the participants were coded. The similar coded statements were then clustered into themes. These themes were examined for interconnection theme. Member-checking was also conducted by revisiting the participants with the transcripts and the findings to ensure that their thoughts and experiences were well represented by the themes.

## Results

### Socio-demographics

Almost all caregivers were females (n=14, 93.3%) and Christians (n=14, 93.3%). Majority (n=10, 66.6%) and (n=8, 53.4 %) were respectively less than forty years and the biological parents of the children. The years of experience taking care of these children ranged from one to twelve years (Table 1).

| Variables                       | n (%)      |
|---------------------------------|------------|
| <b>Gender:</b>                  |            |
| Females                         | 14 (93.3%) |
| Male                            | 1(6.7%)    |
| <b>Age group:</b>               |            |
| 20- 30                          | 5 (33.3%)  |
| 31 – 40                         | 5 (33.3%)  |
| 41 -50                          | 2 (13.3%)  |
| 51-60                           | 3 (20.0%)  |
| <b>Type of Family Caregiver</b> |            |
| Biological parent               | 8 (53.3%)  |
| Non-biological parent           | 7 (46.7%)  |

| Duration of care for the child |            |
|--------------------------------|------------|
| <1 year                        | 0 (0%)     |
| 1-5 years                      | 5 (33.3%)  |
| 6-10 years                     | 6 (40%)    |
| >10 years                      | 4 (26.7%)  |
| Educational Background         |            |
| Primary                        | 5 (33.3%)  |
| Secondary                      | 10 (66.7%) |
| Tertiary                       | 0 (0%)     |
| Employment Status              |            |
| Employed                       | 12 (80%)   |
| Unemployed                     | 3 (20%)    |
| Religion                       |            |
| Christianity                   | 14 (93.3%) |
| Islam                          | 1 (6.7%)   |
| Traditionalist                 | 0 (0%)     |
| Other                          | 0 (0%)     |

**Table 1:** Socio-Demographics of Family Caregivers (N=15).

### Emergent themes

The study aimed to explore the experiences of family caregivers caring for children living with HIV/AIDS under social, physical, psychological, spiritual, treatment and quality of life domains. The narratives of the family caregivers revealed varied positive and negative experiences while caring for their children or wards diagnosed with HIV. For each of the domains, both negative and positive experiences are presented in (Table 2), followed by the narration.

| Themes  | 1<br>M | 2<br>G | 3<br>M | 4<br>M | 5<br>M | 6<br>M | 7<br>G | 8<br>M | 9<br>M | 10<br>A | 11<br>M | 12<br>F | 13<br>S | 14<br>A | 15<br>G |
|---|--------|--------|--------|--------|--------|--------|--------|--------|--------|---------|---------|---------|---------|---------|---------|
| <b>1. Social Experiences</b>                    |        |        |        |        |        |        |        |        |        |         |         |         |         |         |         |
| • Financial constraint                          | X      | X      |        | X      | X      | X      |        |        | X      | X       |         | X       | X       | X       | X       |
| • Social isolation and secrecy                  | X      |        | X      | X      | X      | X      |        |        | X      | X       |         | X       | X       |         | X       |
| • Family support                                |        | X      |        |        |        | X      | X      | X      |        |         | X       |         |         | X       | X       |
| <b>2. Spiritual Experience</b>                  | X      | X      | X      | X      | X      |        | X      |        | X      | X       | X       |         | X       | X       | X       |
| • Increased belief in God                       |        |        |        |        |        |        |        |        |        |         |         |         |         |         |         |
| <b>3. Psychological Experience</b>              |        |        |        |        |        |        |        |        |        |         |         |         |         |         |         |
| • Anxiety about the child's future              | X      |        | X      | X      | X      | X      |        | X      |        |         | X       | X       | X       | X       | X       |
| • Satisfaction of rendering service to humanity |        | X      |        |        |        |        | X      |        |        | X       |         |         | X       | X       | X       |
| <b>4. Physical Experience</b>                   |        |        |        |        |        |        |        |        |        |         |         |         |         |         |         |
| • Physically demanding                          | X      |        |        |        |        |        |        |        | X      |         |         | X       | X       |         | X       |

|   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 5. Altered Quality of Life                                  | X |   | X | X | X | X | X |   | X | X |   | X | X |   | X |
| • Negative changes in lifestyle                             |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| 6. Healthcare Experience                                    |   |   |   |   |   |   |   |   |   |   |   |   |   |   |   |
| • Supportive staff a key motivator fostering caregiver role | X | X | X | X | X | X | X | X | X | X | X | X | X | X | X |

Key: M - Mother; F - Father; G - Grandmother; S - Sister; and A - Aunty

**Table 2:** Emergent Themes from Interviews with Family Caregivers.

### Theme One: Social Experiences (Negative and Positive)

#### Negative experiences

##### Financial constraint

Although seeking care was not expensive, the majority (eleven) of the family caregivers reported experiencing financial difficulties that were associated with caring for the 'sick' child. The demanding nature of paediatric HIV care which includes frequent hospital appointments, physical presence during sick episodes resulted in loss of working hours that impacted their work output and consequently, the incomes of those who were self-employed.

"Six years ago, I was financially better, but since the onset of the condition I have not been to the market." (P01, a mother)

"I was working, and I stopped because of the child's condition, and I spent all the money on hospital bills. I started selling gari and sugar (a local Ghanaian food item), but profit is not enough" (P05, a mother).

The financial constraints usually resulted in the need for dependency on the benevolence of other family members and friends. Some participants, therefore, reported the feeling of inadequacy.

"The father of the child used to send some money, but for a year now he has refused to send money, so I rely on the little that I get and from friends and some family members" (P02, a grandmother)

These feelings of dependence, inadequacy and financial instability associated with caring for a child with HIV affected the state of mind of the family caregivers and invariably the care experience. Despite these feelings, the financial support garnered from family members and some friends were reassuring and helpful.

#### Social isolation and secrecy

The fear of stigmatization associated with an HIV diagnosis reportedly resulted in social isolation of some family caregivers. Most (ten) of the family caregivers (seven of which were the biological parents) consciously lived in secrecy and were not willing to share information with family members concerning the condition of their children. Because most of them were the

biological parents of the child, they were cautious about whom to tell about the child's condition, chiefly for fear of negative reaction.

"I have not told anyone of my condition and that of my child's, but most of my family members want to know because she (child) used to get sick when she was not on treatment. I usually do not attend family gathering because I want to keep it as a secret" (P03, mother)

"I made a promise to my wife, before she died, that I will not tell anyone of the child's sickness. So, I will stick to that promise. Apart from the staff at the special clinic, no one knows about the child's condition, not even her siblings because I am afraid of what will happen next" (P12, father)

This fear of stigma affected the life choices of some participants, employing stringent measures such as relocation of their residence.

"I have not informed my husband or any family member yet because I am afraid of stigma...I have relocated with my daughter to distance myself from family members and friends because of the condition." (Shed tears) (P04 mother)

The burden of secrecy and nondisclosure accounted for the limited family and social support experienced by most of the participants.

#### Positive experiences

##### Family support

A positive social experience in the form of having family support (both material and non- material) was cited among seven of the participants. In addition to financial support received, siblings and other family members care for the affected children in their absence, as well as assisting in performing activities of daily living as observed in the following quotes.

"Her siblings assist me in caring for the child even though they do not have the condition. When I go to the market they take turns in ensuring that the child has eaten, bathed, goes to school and if she accidentally gets hurt, they know how to manage her" (P08, mother).

"Her father supports us financially even though it is only me and my daughter who have the condition and we do not live together" (P11, mother)

This support lightened the caregivers' burden and was very much appreciated.

### **Empathy/Sympathy**

Despite the difficult circumstances, non-biological parents or guardians, who took up the responsibility of being primary family caregivers, reported the feeling of empathy and sympathy underscoring their decision to care for the infected children;

"When I went and saw the child, she was ill, and the father was not taking good care of her. I felt pity for him and brought him to Accra even though the extended family was against it. They say I am not married and should not take the child, but I know I can take care of him, so I did"(P10, auntie).

The client being a child and a victim was cited as stimulating the feeling of sympathy. "I was with the child, and some family members called a meeting saying I should give up my grandchild, and if I don't I will be infected with HIV/AIDS, but I refused because the child was sick and has not done anything wrong "(P02, grandmother).

One key observation common to these different experiences narrated is a feeling of sympathy/empathy towards the child's plight and innocence of the situation. This finding also suggests that the extended family members' attitude can significantly influence the caregiver's role of such children and that it takes determination for non-biological parents to care for such children.

## **Theme Two: Spiritual Experiences (Positive)**

### **Increased faith in God**

The proximity to suffering and the chronicity of the HIV infected child was cited as stimulating the faith of family caregivers. Almost all (twelve) caregivers expressed a strong belief in God and were expectant of a miracle of a sort. The non-biological parents cited that the spiritual belief urged them to take care of the child and not to give up,

"Well, I know, I am doing the work of God. It is God's creation, and I cannot throw him away."(P02, grandmother)

"I believe I am doing what every Christian should do. There is always a blessing in taking care of others, especially orphans"(P14, auntie)

Most of the biological parents expressed their optimism about the children's future because they had hope in God - that God can influence the course of their predicament positively, as evident in a participant's quote

"I believe God would listen to my prayers one day and heal my child for me so that she will be free from this sickness because I want to see my daughter grow to become an adult" (P9, mother)

Religious activities such as prayers, faith for healing, increased faith in God were reportedly established during the sick periods. Most caregivers' strong belief in God supports the notion that Ghanaians are highly religious. HCPs can capitalize on this coping strategy to enhance the strength-based approach in providing care to such clients. Strength-based approach as applied in this context involves incorporating the clients' own strengths and capabilities as well as wider support network in the planning and delivering of services for children and adolescents living with HIV. Family caregivers should also be given the opportunity to exercise their belief appropriately to help them cope well with the treatment and care of the child.

## **Theme Three: Psychological Experiences**

### **Negative experience: Anxiety**

The psychological experiences of the family caregivers manifested as anxiety or worries. Worrying has a psychological effect and can lead to a significant anxiety disorder. Eleven of the family caregivers' worrying were expressed as a feeling of guilt, grief, blame, and fear of the child dying.

"I feel guilty for infecting this innocent child with this condition and look at the way this small child is suffering taking drugs every day also I think about it sometimes and blame myself I wish God would add my child's sickness to my own, so she can be free" (shed tears) (P05, mother)

The maternal instinct of protection was usually reported when the child felt sick. This resulted in self-blame, fear, and self-reproach.

"I am afraid my child would not grow up to become an adult, looking at the way he gets sick when he was not on treatment, and I am sad for him to experience this at his age" (P11, mother)

These findings suggest a greater psychological toll of a child's HIV positivity status on family caregivers and suggest a need for HCPs to strengthen the supportive interventions. Employing the services of clinical psychologists to routinely attend to these caregivers is very crucial.

### **Positive experience**

#### **Satisfaction**

The non-biological caregivers expressed satisfaction derived from caring for the children. They reported that in discharging their duties as family caregivers, they felt complete and satisfied. They believed that they had played their role well as expected of them.

"I become happy for taking care of my grandson despite her mother's unruly behavior before she died. I treat him as a special child, and he is very co-operative, and I derive satisfaction from it.

Because of him, I am a grandma now" (P15, grandmother)

This satisfaction is heightened when the children are healthy and emotional bonds are formed between the caregivers and their wards.

"I am always excited to take care of this child because he is fun to be with. I do not see him as a sick child because he does everything as a normal child does. I am always happy when he is around me, we eat together, bath together and play together. He calls me mummy, and because of him I have learned a lot about caring for children, since I do not have one of my own." (P10, auntie).

## Theme Four: Physical Health Experiences (Negative)

### Demanding nature of the care

The family caregivers ensure that the children living with HIV/AIDS are comfortable, as such, much effort, time and attention is required.

"I have to monitor his activities daily so he did not get hurt and even if I have to travel, I go with him because we are living alone, and I am the only person who can give him his medication. I always leave from work early to take care of him and cannot go to work during his clinic day, so it affects my work" (P09, mother).

For those family caregivers who were not parents themselves, the parenting role in addition to the hassles of caring for a child living with HIV was reportedly demanding. This assertion is highlighted in a narrative below:

"I have to assume a parental role and sometimes I have to close my shop to bring him to the clinic..." (P10, auntie).

Sick episodes, repeated hospitalization as well as standing hospital appointments were cited contributing to the heightened sense of strain experienced by the family caregivers.

"Caring for this child has taken all my time. I cannot go to the market to sell anymore. She always gets sick and we have been on admission for three times and I cannot even take of my personal need anymore" (P15, grandmother).

## Theme Five: Healthcare Facility Experiences

### Supportive staff

It emerged that all participants seemed to have accepted to continue the care due to the good interpersonal skills exhibited by the staff at the clinic and on the wards. Aside from feeling comfortable at the facility, a good relationship facilitated adherence to the child's treatment.

Comments highlighting the supportive staff include:

"The first day I heard about my status, I decided to commit suicide. At that time, I was pregnant in 2017. So, a Nurse at Maamobi Polyclinic, called me to her office just as you called me into the office. While sitting there, she said, "looking at your situation. I think it is worrying you, so you cry, after that, I will talk to you. After that, she told me that the condition is manageable. There are medicines to manage it and, in the future, medicines will be available to cure it. So that should not be a bother. When I came to the children's hospital after giving birth, the staff at the clinic were very nice to me, and so I am always happy when I bring my child here for treatment. (P06, mother)"

"I like the staff here because they are so caring and nice. They have taught me many things I did not know about the condition and even if we are at home and there is a problem with the child and I call them they help to address the problem. (P12, father)"

"The workers in this hospital are very nice, and I like the way they counsel me. It gives me hope to continue caring for the child" (P13, sister)

## Theme Six: Altered Quality of Life

### Negative changes in lifestyle

The impact of the family caregivers' responsibilities on their quality of life was explored. Abandonment by spouse upon disclosure of the child's condition had resulted in depression and financial constraints of a participant.

"The child's father has abandoned me, and my child and I have worked hard to provide for my child. I sometimes feel depressed because of the changes in my routines in caring for the child" (P01, mother).

Financial difficulty, feeling of self-neglect and being overwhelmed were cited. Consequently, a participant felt she had to sacrifice her marriage to care for the child. She said:

"Apart from occasional financial difficulties, I feel I have no social life.... I have to postpone marriage and settling down till he is old and strong enough". (P13, sister)

This challenge is a great concern because of the poor quality of life on the part of the caregivers would affect their care. It is essential to address this situation on an individual basis through counselling and guidance sessions.

## Discussion

In this study, the majority of the interviewees were women. This finding is in agreement with other related studies [10,11]. This pattern is suggestive of the likelihood of more women willing to care for children living with HIV/AIDS. This appears to support real-world situations, where women tend to bear the responsibilities of caring for children. This is particularly so in African settings,

supported by the traditional distribution of societal responsibilities of keeping households and raising children, assigned to women. However, recent trends which are in contrast with the study seem to suggest that men are gradually participating in the care of children, although not significantly [10,11].

In terms of relations, most of the caregivers were biological parents of the children, while other family caregivers constituted grandparents, aunties, and siblings of the child. The non-biological parentage was mainly as a result of either parent's death or neglect of the child, as also reported elsewhere [10]. Most of the family caregivers being self-employed and engaged in trading activities suggest that they may have time to care for the children as they can regulate time according to their situation. However, it may affect the hours left to make sales and invariably the amount of money made to support the care of the child.

From the social domain experiences, financial constraint and social isolation/living in secrecy were the two negative experiences observed for most of the caregivers. The financial constraint was reported as a significant factor that hindered the care process and was expressed as insufficient funds for feeding, treatment, and transport to the clinic. The findings were similar to the observation made in South Africa by Demmer, who reported financial constraints as one of the experiences of persons caring for children affected by HIV/AIDS in Africa [7]. Financial constraints may limit the quality of nutrition for such families, with negative implications for the growth and development of these children [10].

On the other hand, a positive social experience of having good family support was cited among seven of the participants. In addition to financial support received, siblings and other family members care for the affected children in their absence, as well as assisting in performing activities of daily living such as bathing, grooming, and feeding. This support lightened the caregivers' burden and was very much appreciated. Although social support is an important resource for family caregivers of PLHIV, some caregivers may not experience this, due to varied reasons including the desire not to trouble others and a feeling of shame to be dependent [12]. As observed in this study, a plausible reason for caregivers not receiving family support could be family caregivers living in secrecy, social isolation and non-disclosure of the HIV positivity status to the other family members. Although the disclosure is associated with negative experiences, the act can result in family/social support for PLHIV when family and friends react positively to the news of the diagnosis [13,14].

Ten of the family caregivers experienced social isolation and were living in secrecy. They were cautious of whom to tell about the condition of their child, because they did not know how the reaction could be. In a similar study, Wattradul and Sriyaporn, reported family caregivers' hesitance to disclose the HIV/AIDS status of their children due to fear of discrimination in their

community [15]. Similarly, in the Ghanaian context, the above explanation accounted for negative parental experiences of social isolation, living in secrecy and unwillingness to share information with family members concerning the condition of their children [8]. Failure to involve other family members due to fear of stigma and the negative societal reaction has many negative implications: In an instance where the family caregiver is not in a position to provide basic needs or send the child to the hospital to seek treatment, the treatment and care may be compromised [13,14]. Conversely, involving key family members is suitable for social integration. Persons who value the family system and are willing to perpetuate it, are likely to receive some form of family support [13,14]. The extended family system may serve as a shock absorber in times of distress for family caregivers. Hence, in situations where the biological parents are not able to provide the care due to illness or material constraints, credible extended family members should be given an opportunity to partake in the care of the child.

The dynamics of caregiver spiritual perspectives/beliefs, as observed in this study, seems to serve as an impetus to the care of children living with HIV/AIDS among the participants. Five of the non-biological parents were of the strong conviction that taking care of such children was a godly duty which when done well will attract many blessings. In a similar study carried out among persons caring for children in an institutional setting elsewhere in Ghana, most participants expressed the motive for doing that job as doing the work of God because they believe children belong to God [16]. Furthermore, almost all the participants reported gaining inner strength from their increased belief and trust in God and his supernatural powers. Some expressed that what propelled them to this far in the care of their children was God, who has the ability to positively influence the course of their predicament.

Spirituality/religiosity has been identified as an important resource for coping in relation to caregivers of patients confronted with chronic diseases [11,17]. Chang and colleagues also reported that caregivers who used spiritual or religious beliefs as a coping strategy for caregiving, had a better relationship with care recipients, which was associated with lower levels of depression and role submersion [18]. Spirituality as a way of coping focuses on a person's internalized resource that flows from the belief of an intimate relationship with a higher power or supreme being [19]. The belief in the supreme being to overcome the limitations of all human efforts provides the assurance that human sufferings can be lessened by the power of the supreme being. This power seems to be activated in time of difficulties through prayers, for the supreme being to come to their aid to reduce or stop their sufferings.

Given that spirituality can sustain the desire by the caregivers to continue their caregiving role, this should be viewed as a great resource. This, according to Hobfoll [17], adds to the repertoire of resources available to the individuals concerned and collectively provide a backbone for their well-being. In this study, most

caregivers' strong belief in God supports the notion that Ghanaians are highly religious. Hence HCPs can capitalize on this coping strategy to enhance the strength-based approach in providing care to such clients. Family caregivers should be given the opportunity to exercise their belief in an appropriate manner to help them cope well with the treatment and care of the child.

Closely linked to the spiritual experience is non-biological parents' expression of inner satisfaction with their caregiver role of caring for these children. Although a few of the family caregivers viewed this role as demanding, physically and financially, five non-biologic parents expressed that being able to provide help to someone in need, was very satisfying to them. Caregiver satisfaction of being involved in the care of their children living with HIV is also linked to their spiritual beliefs among other factors [16,19]. With regards to the psychological experiences, different forms of anxiety were observed among eleven of the participants. The caregivers cited being worried about the outcome of their child's condition and the fear of the child dying. The gloomy nature of living with HIV and the fear of the unknown contributes greatly to the heightened tension and worries among family caregivers of children living with HIV [20]. Family caregivers should, therefore, be encouraged to express their fears and concerns and receive adequate feedback from their HCPs. The findings also heighten the need for Healthcare Providers (HCPs) to provide adequate information concerning the health of the child, as well as routine psychological assessment, counseling and other support to the family caregivers.

Information on the demanding nature of the caregiving role was provided by five respondents. They expressed that they must spend more time caring for the child, especially with the bouts of illness states or when they accompany them to their routine HIV clinic attendance. Aside from the need to make an adjustment in their lifestyle, this experience limits their economic activities which in the end affect their finances. Experiences of altered quality of life due to changes in lifestyle after the onset of the care were mentioned by eleven of the participants. The change was largely negative and the psychological and social wellbeing were impacted greatly. Financial challenges, social isolation, persistent worries, or anxiety as already discussed, might have denied them happiness and pleasant moment, and contributed to the poor quality of life. Altered quality of life among family caregivers of children living with HIV/AIDS has been widely reported [11, 21].

All participants seemed to have accepted to continue the care due to the good interpersonal relation of the staff at the HIV/AIDS Clinic. Some cited the psychosocial support received whilst others mentioned empowerment via education on how to cater for the children. Good healthcare attitudes and practices in HIV/AIDS is integral in treatment, care, and support services and has been widely reported as an impetus for treatment adherence of infected clients.

## Conclusions

The study showed that family caregivers have both positive and negative experiences with regards to the care of their HIV children. Healthcare providers and other stakeholders must capitalize on positive experiences such as spirituality and family support to provide strength- based care for these clients. Available treatment, care and psychosocial support from government and non-governmental organizations should also be sustained.

## Ethical Considerations

Ethical approval was obtained from the Ghana Health Service Ethical Review Committee. Permission was also sought from Princess Marie Louise Hospital, following the ethical approval. Contact with participants was made possible through a special clinic after receiving an approval letter from the facility. Informed consent was sought from every participant prior to recruitment.

## Authors' Contributions

HA and AHB: contributed to the conception of the research idea, designing the study, data collection and analysis, and the drafting of the manuscript. PSD: Participant's recruitment and data collection. SAA & EA: contributed to the data analysis and provided a critical revision of the manuscript. All authors contributed to the final revision of the manuscript.

## Competing Interest

The authors declare that they have no competing interest.

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