Exploring the Spiritual Experiences of Parents on Care and Management of Children Living with Human Immunodeficiency Virus (HIV) in Chingola, Zambia: An Interpretive Phenomenological Study

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ABSTRACT

The family is the bedrock of the society and parents are at the center of the family in ensuring the physical, psychological and social wellbeing of their children. Being role models and the primary caregivers to their children, parents intrinsically influence their children's values and attitudes, which in turn affects the wider community. This means that well-balanced, well-rounded parents will produce well-rounded and balanced children and hence, the more stable the community will be. A strong family structure is vital for promoting healthy child development, adding to the stability and affluence of the society. Thus, the parents' state of being as they care for and manage their child is pivotal to the development of the child and ultimately the society at large. This study explored the spiritual experiences of parents in their management of children living with HIV (CLWH) in Chingola, Zambia. An interpretive phenomenological research design supported by qualitative approach was used. A sample of 10 parents- 9 female and 1 male, drawn from various socioeconomic contexts, and aged between 39 and 69 years were used. These were parents of children living with HIV and aged between 5 to 18 years. Qualitative data was collected through use of open-ended questionnaires and analysed using thematic analysis approach. The analysis involved coding data in order to establish emerging themes which were was conducted, interpreted and presented descriptively as findings. The findings revealed that parents faced various challenges in their care and management of CLWH ranging from stress to emotional burden over their children's condition. It was also found that parents were fearful and anxious concerning the uncertainty of the trajectory of the child's illness, burdened with routine hospital visits and refusal to take medicine, which spiritually impacted negatively on them. Further, it was found that the church was seen as being a source of strength by many parents. The spiritual support received from the church harnessed and improved upon their wellbeing, as most parents were receiving spiritual, moral, and material support from the church. It was also found that most of the parents had not disclosed their child's HIV status for fear of ostracization and stigma, which had a negative effect on them spiritually. Thus, the study recommends that church should come up with a deliberate programme that engages parents and helps them with specific spiritual, moral and material support. Further, the church should scale up HIV sensitisation because stigma and discrimination against people living with HIV (PLWH) which still rife in the church leading to fear of disclosure.

Key Words: Church, Spiritual experiences, parenting; HIV; ART; care and management

INTRODUCTION

As of 2022, there was an estimated 3.4 million children living with HIV worldwide (UNICEF, 2023). A report by UNAIDS (2023) shows that in Africa alone, there is a staggering 1.5 million children below the age of 15 living with HIV in Africa, and 89% of them live in Sub-Saharan Africa. Reports have confirmed that the Sub-Saharan region has the highest number of children and adolescents living with HIV, as it accounts for 84% of

children and adolescents living with HIV (ibid). There are various reasons as to why the numbers are so large, and some of them are; age disparity among parents, early marriages, and extreme poverty.

In Zambia, a Zambia Country Progress report done by the Global AIDS Monitoring team of 2020 reported an estimated 1.3 million people are living with HIV, with roughly 65,000 children and adolescents (Zambia Demographic Health Survey Report, 2022). A Sub-Saharan Africa Snapshot 2021 report showed that there were approximately 140,000 children aged between zero and 18 years living with HIV in Zambia. The high infection rates among children are attributed to vertical mother-to-child-transmission (MTCT) of HIV either at birth or during breastfeeding. Other infections among children have been attributed to unprotected sex, having multiple sexual partners, (USAID/Zambia, 2022), substance abuse and limited information on HIV/AIDS.

Although there have been drops in the rates of infection among children, from about 10,000 in 2010 to 6,000 in 2019, and a decline in deaths from 24,000 in 2010 to 19,000 in 2019, the numbers of children living with HIV have increased. These elevated numbers of children living with HIV (CLWH) can be credited to the introduction of antiretroviral medicine (ART). Munthali, Michelo, Mee & Todd (2020) reported that before ART was introduced, the majority of CLWH died before their second birthday.

In Chingola District, Copperbelt Province of Zambia, the Chingola District Health Office showed that there were an estimated 636 children aged zero to 14 years representing 0.7 per cent of the population and about 555 children aged between 15 to 23 years old representing 12.1 per cent of the population living with HIV in Chingola, as of June 2024.

These numbers are not mere statistics, but represent real people facing real challenges that come with living with a chronic health condition. This entails that parents who have to provide care for these children living with HIV because they do not have the ability to fully care for themselves. In a study conducted by Atanuriba et al (2021), it was shown caring for people living with HIV is highly burdensome, but the care of children living with HIV was much higher due to the fact that a child's dependency is totally on the parent or caregiver. This means that parents of CLWH face various challenges when it comes to providing care for their children.

Approximately 300,000 children were infected with HIV in 2021 (UNICEF), and in 2020 alone, AIDS related illness claimed the lives of about 120,000 children. The UNICEF report further shows that the majority of these deaths occurred in sub-Saharan Africa, which also accounts for 88% of children and adolescents living with HIV worldwide! That is, 88% of between 2 to 3.4 million children and adolescents and this raises questions as to the experiences and coping mechanisms parents employ as they care for and manage their children in this situation?

As a result of the presence of children and adolescents with HIV in families, parents and other caregivers increasingly found themselves caring for and managing such a condition. Since no parent would want their child to experience any kind of pain arising from chronic illness, a child or adolescent living with HIV becomes a source of concern to parents and caregivers in the families. Because of this position of the parents and caregivers in the process of caring and managing of children with HIV, they find themselves wanting to access spiritual, moral and materials support from the churches, and other religious individuals with a view of supporting their children living with HIV. It is against this background the study sought to explore the spiritual experiences of parents of children with HIV as they attempt to provide care and management of their children's condition from a spiritual perspective.

LITERATURE REVIEW

Religion has been acknowledged as having an impact on care, prevention, and management of PLWH in sub-Saharan Africa (WHO, 2016). It is believed to have a significant influence on how the public view children with HIV and their parents. This view has been supported by a study conducted by Azia, Nyembezi, Carelse, & Mukumbang (2019) in Kenya, where it was shown that some factions of faith-based organisations had made a negative impact by misinforming people on HIV and that this error had greatly affected ART adherence in clinics where such services were being offered. It is however, not clear as to how parents of children with HIV

in Zambia have been influenced by religious practices. A comprehensive study therefore became necessary with a view of establishing how religion played a part in parents' response to the condition of their children.

In a study on caregivers of children living with HIV conducted by van Deventer and Wright in 2017 in New York, it was discovered that most caregivers had a religiously inclined in that they mentioned "God" several times during the interviews, indicating that religion was central to their being. Although a portion of them attested that they were no longer able to congregate with others and worship due to their caregiving task, they did emphatically state that religion had been a comfort to them and had helped their faith to grow during their caregiving journey.

In another study conducted in Nigeria by Amaugo in 2019, the participants stated that their faith in God gave them strength to overcome the challenges that they faced in their care and management of their children living with HIV. They believed that it was God who healed their children whenever they fell sick and recovered. They further stated that they continually prayed because they understood that it was God who gave them strength to care for their children.

The World Health Organisation (WHO, 2016) also reported that parents have confidence in the healing power of God and so they were actively involved in church activities and that religion gave them hope and a sense of relief from their caregiving burdens faced as they cared for their CLWH. They stated that prayer was the tool they used to ask God for sustenance and help to deal with any challenge their children were in, no matter how difficult.

There were reports of some religious beliefs that negatively affected the parents and their children. This was seen in a study done by Azia, Nyembezi, Carelse & Mukumbang, (2023), where some religious leaders were cited as having told caregivers to stop taking administering ART to their children, as it went against their faith. However, it was noted that most of the parents chose to take both the religious and medical route as they cared for their children. They understood the consequences of defaulting and chose to stick to the treatment regimen, (MoH, 2017 Demographic Health Report). Some people did solely depend on prayer, believing they were miraculously healed and they stopped taking their medicine, ended up developing serious health conditions.

PROBLEM

People living with HIV (PLWH) face various challenges apart from dealing with their health, such as stigma, discrimination, financial and material challenges. Furthermore, parents of children living with HIV face even more challenges in that they have to ensure the holistic wellbeing of a young individual who is possibly facing stigma among other challenges that come with being HIV positive. In light of these, it is important to take note of the experiences of parents of CLWH and how they can be assisted. Over the last 15 years there has been a decline in AIDS-related deaths due to scale-ups in treatment (WHO, 2017), and the implication is there is a rise in the number of children that are living with HIV.

As of recent years, the burden of caring for a person with HIV is still quite high because the condition of a person living with HIV might develop into a serious sickness at any time. Caring for a child with HIV is even more burdensome because the child is usually totally dependent on the parent caregiver and unable to care for themselves. In a study conducted by Yiryuo et al (2024), it was shown that caregivers living with HIV, who are the primary carers of CLWH were often overtaken with challenges and did not have enough resources to utilize in the care of their child. Less, however, is known about the spiritual experiences of parents of children living with HIV as they cared and what they go through as they spiritually cared for and managed such children in Zambia. Hence, the aim of this study was to explore the spiritual experiences parents as they managed their children with such a condition. The objectives that guided the study were to:

1) explore the spiritual experiences of parents of children with HIV in their clinical care and management of the children in the site,

2) explore perceived consequences of parents' spiritual experiences in their clinical care and management of children with HIV in the study sites,

3) establish coping strategies parents of children with HIV employ with a view of addressing concerns arising from their spiritual experiences on clinical care and management of the children

Significance

It is hoped that the findings of this study would raise awareness concerning the experiences of parents caring for their children living with HIV and make their challenges apparent. It is also hoped that the awareness raised will help reduce stigma and discrimination against the families of parents and caregivers dealing with CLWH. Further, it is hoped that the results of this study will ensure a change in the way hospital appointments are handled to reduce on the time parents spend in queues waiting at the hospital. The researcher hopes that the study would contextualize parents' spiritual experiences as they care for children with HIV and that the local church should come up with a deliberate programme that engages parents and helps them with specific spiritual and material support because the church was mentioned several times by many as being a source of strength.

Further, it is hoped that the church will scale up HIV sensitisation because stigma and discrimination against PLWH are still quite prominent in the church, leading to fear of disclosure and living in isolation. Lastly, the researcher hopes this study will contribute to the existing literature on the experiences of parents of children with HIV in Chingola District, and motivate further research in the same area.

Theoretical Framework

The study was guided by two theories which are the Person-Centered Theory and the Uncertainty in Illness Theory. The Person-Centered Theory was coined by Carl Rogers in 1951 and expanded by Seligman (2006) and Corey (2012). It states that an individual helps oneself to cope with stress arising from workload when through experiences, one acquires and understand the situation. The theory stresses the need for self-actualization where Rodgers posits that all human beings and other living organisms have an innate need to grow, enhance themselves, and survive, (Hergenhan (1998) in Mafumbate, Ganga & Sekeni (2010)). The person-centered theory promotes autonomy and allows the client to decide without the therapist's interference or coercion. Thus, it entails that when they have the correct information, parents with children living with HIV have the ability to cope with pressure arising from challenges such as caring for a chronically ill child.

HIV is an incurable condition which is managed through rugs and a good balanced diet. This entails that it may develop into serious illness at any given time, and so one of the challenges faced by parents of CLWH is uncertainty of the child's medical stability. Merle Mishel developed the uncertainty in illness theory (UIT) in 1988 in order to address uncertainty during diagnosis or treatment phase of an illness, or an illness that is known to be incurable. The theory defined uncertainty as the inability to determine the meaning of illness-related events, occurring when the decision maker is unable to assign definite value to objects or events, or is unable to predict outcomes accurately. The focus of Mishel's theory was on cancer conditions but like cancer, HIV is incurable and has an uncertainty in its trajectory, but the healthcare provider can help reduce the patient's levels of uncertainty by providing them with enough information about the condition and exhibiting high levels of competence in dealing with the patient's condition.

Topographical Features of Study Site

This study was conducted in Chingola District of Copperbelt Province, Zambia, a mining town located north of Copperbelt's busiest town Kitwe, and south of Chililabombwe town which borders with neighbouring country Congo DR. Chingola District is an urbanized town with people of different ethnicities and nationalities, and according to the Zambia Demographic Health Survey Report of 2020, this contributes to the district being among those with high rates of HIV infections. The town has people of varying levels of economic status and this impacts on social life with a potential of increased people living with HIV (Zambia Demographic Health Survey Report, 2019, 2020; 2021).

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MATERIAL AND METHODS

In the quest to understand the lived spiritual experiences as parents of children living with HIV in the context of their spirituality, an interpretive research design supported by qualitative approaches was used in order to try and understand the parents' perception, perspectives and understanding of their situation in caring for their children. Kasonde-Ngandu (2013), defines a research design as the overall strategy that a researcher employs in seeking to integrate the different components of the study in a coherent and logical way, thus addressing the research problem effectively. This research design was ideal for the study because it emphasizes the ability to construct and interpret the unspoken, unconscious and hidden meaning that exists in the phenomenon under study (Patton, 2012; Creswell & Plano, 2012). In-depth interviews and open-ended questionnaires designed by the researcher were used to collect data in exploring the lived experiences of parents of children living with HIV. Mugenda and Mugenda (2009) state that open-ended questions require more depth and lengthier responses from parents and so they were designed to encourage meaningful answers from the participants' own experiences on caring and managing children with HIV.

FINDINGS

This section presents findings according to the objective of the spiritual experiences of parents on care and management of children with HIV in Chingola, Zambia. The study was conducted from 2022 to 2024.

Spiritual Experiences as Parents care and manage CWHI

Caregivers

The researcher interviewed ten (10) parents for the study, of which nine (9) were female and one (1) was male. All the parents interviewed had been the primary caregiver for a child for over a year, with the children being aged between 5 to 18 years old. The parents did confirm that they had faced various challenges with their child's health condition, and most of them had required help in one way or another.

In seeking insight into the spiritual experience of parents as they cared for their children living with HIV, the study sought to become familiar with the ways in which spirituality, faith and personal beliefs impact on a parent's caregiving, and the indispensable role that spirituality plays in preserving the parents' emotional and psychological wellbeing as they care for their children.

It was discovered that one's spiritual propensity determines the parent's capacity to cope with diagnosis, as they navigate uncertainty and find meaning and purpose amidst the challenges of caregiving. The study delved into themes of hope, resilience and transcendence.

Table 1 Parents' Spiritual Experiences as they cared for and managed CLWH

No.	Emerging Themes	Code or near codes
1	Hope	Inspiration from Sermons and Teachings Hope in the midst of Adversity Renewed hope
2	Disclosure and Encouragement	Disclosure to Spiritual Family Moral support
3	Fear of Discrimination	Concerns of being judged, ostracised or discriminated against
4	Emotional Support	Emotional support Spiritual support Pastoral care

		Comfort in prayer
5	Practical Support	Comfort in fellowship Material support
6	Community and Belonging	Sense of belonging Social connections
7.	No support	Lives in isolation

It was noted during interviews that the parents were all connected to a local church, but they were either regular or irregular members. Some of the parents were leaders in their local churches and others had not been in church for a long time, and the reason given was their caregiving duties. It was established that help was rendered from church for both regular and irregular members, depending on their level of need, that is, their financial status.

Raised Hope as they care for Children

The Oxford Advanced Learner's Dictionary (2010), defines hope as a feeling of wanting and expecting something to happen, or the desire for something and expectation that it will happen. All the parents interviewed, whether regular or irregular church-goers, stated that spirituality has been a source of hope for them as they cared for their children. They said they found hope in the fact that there is a God who cares. **EMF** an irregular church-goer stated:

> *I am a Christian, but I have not been to church in a very long time. Regardless of this, my religious beliefs have helped me immensely as I have been strengthened by the word of God. I know that despite there being sickness and suffering in the world, there is a God who loves and cares for all of us. And although my daughter is in this condition, I know God loves and cares for her and she is alive today because of Him. If not for God, I would not be here today.*

BNF, a leader in church had this to say:

> *I am a leader in our church and I have been finding myself in situations where I have had to counsel people in the same situation I am. This has forced me to take my own words and apply them to myself and I have been finding healing daily. Being a Christian has been a rock to me. I am often encouraged by teachings and in prayer meetings and this has helped me invest more and take better care of my daughter because I know her future is bright.*

BKF who rarely attended church due to work said that:

> *I am an irregular church member due to financial constraints, so I have to work on Sundays so that I can feed my dependents. I do understand that God loves us and I pray when I can. Being a Christian has given me hope that no matter how much we suffer, God has promised us eternal life. I take care of my grandson knowing that whatever he is going through, God already knew and has given me strength to cope.*

ASF a regular church-goer also stated that:

> *I am a regular attendant of church programmmes but I am not a leader. Christianity has been a fortress that gave me strength I never knew I had. Through preachings and teachings, I have been strengthened enough to even encourage other people in a similar situation despite my troubles.*

RCF a regular worshipper had similar words to say that:

I am a very regular church attendant. My beliefs have helped me to have faith in the healing power of God; that God heals through food, water, as well as medicine. I thank God that my granddaughter is not as sickly as she used to be and I have been strengthened by this healing. My faith gives me hope that tomorrow will be better than today.

BMF also echoed the words of the other participants when she said that:

I am a regular church goer. Teachings from the Bible have encouraged me to face my hardships with a prayerful stance. Prayer sessions have had a massive impact on my care of my niece, as I have developed a kind and caring attitude towards her.

Based on the findings, it can be seen that all the caregivers had faith in God and also found hope in the teachings they heard from the church. These helped then to spiritually cope with the situation of finding themselves living with children with HIV. Spiritual support became a source of strength in their care and management of their children living with such condition.

Disclosure and Encouragement

Many people living with HIV do not want to have their status public for fear of discrimination, and yet according to Shushtari *et. al.* (2014), one major benefit of disclosure is social support, and this is a crucial resource that enables one to cope with HIV infection. Certain participants confirmed having disclosed their child's status with the hope of receiving emotional support, and they did. The psychological wellbeing of an individual living with HIV becomes better with when one opens up to those they considered as trustworthy. This ensures they have someone to talk to and ask for help in challenging times. Some of the participants said that after they disclosed the HIV status of their child, they received spiritual support and encouragement from a sector of the church as can be seen:

EMF a 39-year-old widow shared that:

I have told my daughter's condition to only two people from church who have been encouraging me concerning her condition. They visit us and pray with us, and have been a source of strength. They have been very supportive and make me feel like we belong somewhere, and our lives matter.]

Perceived Consequences Arising from Parents' Spiritual Experiences

Fear of Discrimination

Disclosure helps with reduced risk of transmission of infection (Shushtari *et. al.,* 2014). However, due to society's cynical view of HIV and the stigma that follows, many people are afraid of disclosing their HIV-positive status. In this study, there were mixed responses from the participants, although were spiritually strong they feared discrimination as is evidenced below:

BNF a widow feared discrimination and she explained that:

I have not disclosed my situation to anyone from church because I fear they might sideline my daughter.

RCF felt she could not deal with people's questioning stares due to past experiences and she submitted that:

I have not disclosed my granddaughter's condition to anyone at church. I feel they speculate, since some of them knew my daughter and saw how she died. I just do not want to talk about it. I don't want my granddaughter to be discriminated against.

BMF did not want people to think she disclosed her niece's condition because she was not the biological mother. She shared that:

I have not disclosed the condition of my niece to anyone at church because I fear she might be discriminated against. I also do not want people to think I am gossiping about her only because she is not my biological daughter. I want her to feel secure enough to disclose her HIV status, if she chooses to.

It can be seen from the parents' reactions that some of the parents feared disclosing the HIV status of their child due to stigma and discrimination. Although in some cases their fears were well founded, it is clearly not an innate desire of the parent, but a forced one due to circumstances.

Lack of Emotional, and Material Support

When asked whether they had received any kind of support from their churches or spiritual family and how such support, or lack thereof impacted on their care and management of children living with HIV, most of the parents stated that the church had been quite helpful in this regard.

EMF shared that the church family encouraged her whenever they visited her family. She submitted that:

I have received emotional and spiritual support from my church family. They visit and pray for us and I am encouraged whenever we sit to study the Bible.

ASF a widow who received help consistently from the church said that:

Although I have not disclosed my son's condition to anyone from church, I have been receiving both spiritual and material support from them and this has helped lighten the financial burden of caring for my son. When they bring foodstuffs, it is usually the things he likes to eat, and I know for a while I will not have to worry about whether he will eat or not.

RCF a grandmother taking care of two CLWH and five other grandchildren also received help from the church. She submitted that:

I receive regular material assistance from the church in form of food, clothing and money because I am a grandparent taking care of seven (7) grandchildren. This help is not because I have disclosed the condition of my granddaughter but it has really helped lessen the mental burden. I stress less when church people visit us because I know I will not have to worry about food.

The church has been instrumental in offering help to people in the society not only because they are sick, but also because they are vulnerable or without help. The parents' statements attest to the fact that the church has been a great source of help in ensuring that these parents are not without assistance.

Limited social interactions

One of the participants said she had not received any help from the church and the reason may be because she had not disclosed her niece's condition to them. The caregiver taking care of a 16-year-old said since this was not her biological daughter, she did not want people to think she was slandering her niece. Further, she said she was weary of hearing people's negative views when it came to dealing with the topic of HIV, so she chose to be mute.

BMF aunt to a 16-year-old girl said that:

I have not received any help from the church with regard to my niece's condition, owing to the fact that I have not disclosed to any of them.

Parents caring for CLWH shared that they found some strengthen due to their spiritual inclination. Despite the challenges they faced as they cared for their children living with HIV. The parents stated that their faith helped them to overcome the difficulties they faced in providing care for their children living with HIV. Although some of them did not disclose their children's HIV status for fear of discrimination yet those who shared their children's status, their spiritual family were very supportive providing emotional, material and spiritual

support through prayers and fellowship. All in all, the spiritual experiences of parents caring for their CLWH highlight the importance of compassionate support, non-judgemental care and show that inclusivity in the community can uplift and empower these families.

DISCUSSION

Renewed Hope

It was seen that all the participants attributed their faith to Christianity, and most of the participants said they were receiving spiritual and material support from the church. Whereas some of the parents attended church regularly, others were leaders in their denominations, while others had not attended church in a long time. They stated that the sermons, prayers, and teachings received in church kept them afloat even during the most difficult times as they offered care and management to their children living with HIV. Their hope was renewed hope and they were grateful that their child was still alive up until now. The parents had found hope in the midst of adversity such as discrimination, stigma and emotional burden and that regardless of the challenges they faced each day, their faith in God has given them strength and resilience to soldier on. Their faith had become a beacon of hope that gave them comfort even during times when their hope was low and they felt like giving up even on their own lives. They stated that fellowship with others of the same faith enabled them to stay strong. These findings were contrary to the findings of Azia, Nyembezi, Carelse, & Mukumbang (2019) in Kenya, who showed that church leaders misinformed people on HIV ART and contributed non-adherence to ART. It has been determined that in Zambia, parents of children with HIV have chosen to adhere to medication and at the same time pray and believe God for healing. A comprehensive study of this nature therefore became necessary in order to establish how religion played a part in parents' response to their child's condition.

Disclosure and encouragement

Moral support

The study revealed that there were participants who had disclosed the HIV status of their child one or two people from church. According to them, disclosure felt like a weight had been lifted off their chest because they had someone who understood their struggles even as they shared the word in fellowship and prayed together. The church had offered to some parents because their condition was known. This made the parents feel emotionally supported and they felt a sense of belonging. The constant reassurance that they are not alone on this journey and that God is with them through all their struggles encouraged them to stand firm.

Fear of discrimination

There were sentiments from the parents of fear of discrimination and stigma from other church members, and they feared to disclose their child's condition, fearing ostracisation. Some parents said they had faced discrimination and stigma from church members before, and hence would not want to disclose for fear of a similar incident happening with their child. Despite the stigma, parents felt that religion was the source of comfort and that their faith in God had increased thus playing a significant role in their care and management of the child's condition and consequential illness. The study findings are in line with those of van Deventer & Wright (2017), who state that most of the caregivers of children with HIV have a religious inclination because they mentioned "God" several times during their interview sessions and it was observed that religion played an important role in their care for their children living with HIV.

Spiritual and Emotional Support

All the parents spoken to were members of a local church and whether leaders, regular members or irregular members the church had not neglected any of them but had continued offering them spiritual and emotional support. One caregiver had shared that although she had not been to church in a long time, and neither had she disclosed the HIV status of her grandson, the church had always been supportive by providing them food, school requirements and other material.

Those parents who had disclosed the condition of their child to some church members said they had been offered spiritual support through sharing of the word of God and prayers and these had helped them stay strong and trust that there was a God who was with them, and this somehow helped with their emotional stability. The church has offered a compassionate approach to caring for the families through provision of spiritual and emotional support to the parents and this has been a crucial aspect of their caregiving journey.

Pastoral Care

According to Femsa (1996) in Mafumbate, Gwitimah & Mutswanga (2010) there is need to offer pastoral care to parents and children living with HIV for encouragement in order for them to experience spiritual healing, sustenance, guidance, nurture and reconciliation, which at one time each one of us need not be only full givers, but recipients of this ministry and this is necessary in the care and management of such children. In the present study, parents saw pastoral care as being based on spiritual values outlined in the Bible, as shared and taught by Jesus Christ and the Apostles with a call to meeting the spiritual, moral and materials needs of those in need within and outside church family. Pastors, church leaders and lay ministers provide pastoral care through listening, encouraging, and praying for the parents and their children living with HIV from time to time and during difficult times, including periods of hospitalization. Such measures taken by the churches helped parents emotionally cope with the situation of looking after their children living with HIV. In the study site, it was evident that pastoral care was helping parents effectively care and manage their problems as they looked after their children living with HIV.

Comfort in prayer and fellowship

In the study, it was discovered that prayer was seen as prayer is a source of strength and solace through which the parents could express their concerns, hopes and fears, and find peace and reassurance. According to them, the participants said that prayer and fellowship helped them to cope with their situation because it offered them comfort knowing that there was a higher power at work in their lives. According to Pargamet *et. al.* (2004) in Utley and Wachholtz (2011), spirituality uniquely predicts health and wellbeing outcomes in PLWH such as improvement in life satisfaction, functional health status and health-related quality of life.

Practical Support

The study showed that most of the participants acknowledged that the church was very supportive materially, and church-members did not just visit and encourage them using the word of God and prayers, they also gave them foodstuffs and money and, in some cases, even their children were helped with school requirements such as uniforms, shoes, books and school bags in order to help cushion their financial and material needs. This support boosted the morale of the parents and urged them to keep hoping that all would be well with them.

Social connections and Sense of belonging

The participants who opened up to someone from church concerning their child's condition stated that the church had given them a sense of belonging and social connection. They said that because there was usually someone visiting and updating them, they did not feel left out as much as before. They affirmed that the visits from their fellow Christians helped them to gain a sense of self-worth and identity. The parents were sometimes asked to participate in church programmes such as cleaning or prison ministry which they gladly participated in because it gave them a chance to interact with more people than those they usually interacted with. This sense of belonging and self-worth helped break the cycle of self-pity and consolidated the fact that they were also much needed members of society.

Living in isolation

Based on the outcome of the study on social experiences of parents as they cared for and managed children with HIV, it was evident that some parents had not opened up to anyone from family or community concerning their child's condition in order to avoid living in social isolation. Due to their non-disclosure which stemmed from fear of stigma, rejection, and discrimination, some parents carried a burden of secrecy and lived in

isolation, not taking part in community activities, social gatherings, and being confined to their own world. This self-imposed isolation worsened their pain, leaving them emotionally drained, unsupported in their caregiving, and lonely. These findings have been also documented in several cases, out of fear that disclosure may actually facilitate social support, as evidenced in the work of Moraa *et. al*., (2023). Many parents spoken to stated that they received social support after they disclosed to someone thereby no longer lived in isolation.

CONCLUSION

This article explored the spiritual experiences of parents as they manage their CLWH. It was seen that the faith aspect of their lives was one that helped them navigate the uncertainty of their children's condition. Although there were some fears of stigma and discrimination among those who decided against disclosure of HIV status, it was generally found that those who had disclosed had gained hope, encouragement, emotional support, a sense of belonging, and practical support from the church family. According to them, their caregiving burden was made lighter because of the care and support they received from their local church. Among those who did not disclose, there were some who still received support from the church and they were very thankful for whatever material and spiritual support they received.

RECOMMENDATIONS

1. The church should come up with a deliberate program that engages parents and helps them with specific spiritual and material support.

2. The church should come up with programs to continually educate its members concerning HIV/AIDS to reduce on stigma and discrimination.

3. The church should consider training counsellors who will speak to such parents about their condition.

4. The church should partner with organisations that deal with HIV/AIDS-related issues in order to be better placed to help the parents as they care for

Conflict of Interest Statement

The authors declare no conflicts of interest.

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