



EXPERIENCES OF PARENTS ON CLINICAL CARE AND MANAGEMENT OF CHILDREN WITH HIV IN CHINGOLA, ZAMBIA

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Abstract:

Raising a child is a challenging experience, more so for a child living with HIV. The nature of the condition of a child goes with its complexities, including those which, from time to time, require clinical care and management. The complexities often put parents to the test of how to care for and manage such children. The study explored the experiences of parents of children with HIV as they clinically care for and manage the children in Chingola, Zambia. An interpretive phenomenological framework supported by qualitative approaches was used in the study. The parent participants were selected using a non-probability, homogeneous sampling purposive procedure. The sample was 10 parents of children with HIV drawn from various geographical locations in the study district. Qualitative data was collected using in-depth interviews and was analysed using a thematic analyses approach. The study revealed that parents were central in securing clinical services for their children. These involved HIV testing, access to ART clinic Support, observing hospital appointments, and receiving medical, education and training support on care for their children. As a result, parents found themselves dealing with child's constant sicknesses and regularly soliciting medical support for the children. It was also found that parents faced challenges arising from initial reactions to the child's condition, centering on failure to accept the child's condition, feeling emotionally burdened and increasing desire to get the child get treatment. Additionally, the study revealed that parents were using various coping strategies in dealing with experiences, these involved collaboration with stakeholders like other parents, medical staff and counsellors. These provided clinical, moral and emotional support to parents as they cared for and managed their children on clinical-related issues. as well as regularly

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receiving education on how to care for children with HIV. Further, parents were working with faith-based groups in areas transporting the child to the hospital, meeting the cost of supplementary medication and receiving regular moral and emotional support, especially when children were hospitalized. However, it was evident from the study that parents required more support when dealing with hospital cases of their children from families, medical personnel and well-wishers, especially in meeting transportation costs, counselling, and supplementary feeding during hospitalization. The study recommends individual, family and group support in various aspects of clinical care of children, including counselling to minimize negative clinical, emotional and psychological challenges encountered as they deal with clinical issues surrounding their children.

Keywords: parenting; clinical experiences; HIV; ART; care and management

1. Introduction

Parenting a child with a chronic condition can be a huge challenge, especially when that condition is incurable. Parents who care for children living with HIV face a variety of challenges, such as adherence to antiretroviral therapy (ART), management of opportunistic infections, and the psychological impact these challenges bring on the child and require high levels of parental vigilance. UN General Assembly Report on AIDS of 2015 notes that, besides managing the child's health, a parent also has to deal with their own emotional stress and anxiety as they care for such a child. Atanuriba et al. (2021) observe that globally, the burden of caring for people living with HIV was relatively high in developing countries. It was, however, observed that caring for children with HIV was a burden and required various support. The study believed that parents faced a greater as a result of challenges encountered, including accessing clinical services for their children.

In a report by UNICEF (2023), it was indicated that approximately 3.4 million children were living with HIV under the age of 19 globally. The report further notes that this was out of the estimated 39.9 million people living with HIV in the world, and 31.5 million of them being adults. In Africa alone, UNAIDS (2023) reports an estimated 1.5 million children under the age of 15 living with HIV, with 89% of them living in sub-Saharan Africa. Arising from the report, it appears that the Sub-Saharan Africa region is the most affected by having children living with HIV in that it accounts for 84% of children and adolescents living with HIV. There are several reasons for the high number of HIV cases in Sub-Saharan Africa. These range from age disparity among parents, limited sensitization and advocacy of HIV, too many being orphaned through HIV, increased vertical transmission, and extreme poverty failing to access condoms, thus limiting chances of self-protection from HIV.

A Zambia Country Progress report done by the Global AIDS Monitoring team of 2020 indicated a population of 1.3 million people with HIV. Zambia is, therefore, one of the most affected countries in Africa. In the context of children and adolescents living

with HIV, the Zambia Demographic Health Survey Report of 2022 estimated children and adolescents living with HIV to be between 58,000 and 65,000, with a prevalence rate of 10.8% in people between the ages of 15 and 49. The report further indicates that 88% of the children were on ART. In the USAID/Zambia report of 2022, vertical Mother to Child Transmission (MTCT) of HIV was seen to be relatively high. It was estimated to be at 95%, meaning that the majority of child HIV infections were a result of MTCT. This indicates that children often find themselves with HIV at birth or acquired it through breastfeeding. At a global level, Liamputtong (2023) accounts for MTCT to be 90%, meaning children access the conditions through mainly mothers. However, other factors, although accounting for just about 40% of HIV infections, especially among children and adolescents in Zambia, have been associated with inappropriate sexual behaviour, usually taking the form of unprotected sex, early sexual debut, and sex with multiple partners (USAID/Zambia, 2022). It has also been associated with increasing substance abuse among adolescents, poverty in homes and resource constraints, lack of information on HIV and gender-unequal beliefs, which often puts girl children and adolescents at risk of contracting HIV.

However, USAID/Zambia (2022) does acknowledge efforts being made in Zambia to reduce the new pediatric infections and the increasing population of pregnant women who are accessing antiretroviral drugs. For example, between 2010 and 2021, the number of new pediatric infections dropped from 8,800 to 3,800 which was a significant change in children's infections. The Zambia Demographic Health Survey of 2022 reports that the number of pregnant women accessing antiretroviral drugs moved from 71% to 97% indicating a significant increase in the number of pregnant mothers under protection, thus contributing to a reduced infection or MTCT in Zambia. UNAIDS (2023) report explains the improvements in several initiatives: Empowerment of Children and Adolescents on HIV through advocacy and sensitization and peer-to-peer education. Siula (2024) believes that initiatives taken have significantly played a role in informing adolescents and putting them in a state where making informed decisions is possible.

As a result of the presence of children and adolescents with HIV in families, parents and other caregivers have 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 context of clinical care and management of children with HIV, they find themselves wanting to access medical services with a view of supporting their children living with HIV. This is in line with Siula (2024) observation that when medical personnel make every effort to enlighten parents or caregivers on clinical care and management of children with HIV, including the availability of health care services, children with such a condition are able to live a better and more meaningful life thus parents strive for such. It is against this background the study sought to explore the lived experiences of parents of children with HIV as they attempt to provide care and management of their children's condition from a clinical perspective.

2. Review of Related Literature

The study conducted by Smith & Kaye (2012) showed that parents of children living with chronic health conditions often find them to be burdensome to parents in that they require from time-to-time comprehensive therapy. Liamputtong (2023) states that using a biopsychosocial lens helps researchers understand the problems that parents and families encounter as they deal with chronic illnesses. This view was shared by Nostlinger et al. (2004), who also report that parents may face various challenges during their parenthood, including coping with their children's HIV diagnoses, disease progression, emotions, and complex adherence issues. It was further observed that psychological problems such as feelings of guilt and concerns towards the future of their children place a significant challenge on them as parents. Parents, for example, face stigma from society and extended family members arising from their children's condition. It is for this reason that parents are being targeted in the present study in order to understand and appreciate their lived experiences as they clinically care for and manage their children living with HIV.

In another study by Atanuriba et al. (2021) in Australia, it was found that children with HIV depended on their families to offer psychological care while struggling to access clinical care. The families were responsible for ensuring that the child met hospital appointments, adhered to medication and received supplementary food regularly. In another study conducted by Muscara et al. (2017), which was longitudinal in nature and done from 2015 to 2017, it was found that the severity and extent of HIV demographic factors such as parent age, gender and ethnicity influenced parents' perceptions on clinical support. While the middle-aged parents appeared to value clinical support, the younger and elderly parents or caregivers valued interactions with clinical staff over the condition of the children. It was further observed that the status of parent's mental health, family functioning and structure appeared to influence how they received and valued clinical support. The study did stress a child's HIV diagnosis and progression to AIDS as being highly distressed on a parent. It was found that parents, due to the potential of the child's condition being potentially life-threatening, regularly sought clinical support in the hope of the child being better. It was evident, however, that the Muscara et al. (2021) study focussed on the role of clinical staff in the clinical care of children with HIV and not necessarily the experiences of parents as they clinically care and manage such children, hence the call for the present study.

In another study conducted by Gumede-Moyo et al. (2019) in Zimbabwe, it was found that there was an increase in the number of pregnant women accessing prevention of mother-to-child transmission (PMTCT) because of the frequent sensitization and education of HIV through clinical interventions. The services aimed to enhance the chances of reducing mother-to-child transmission (MTCT) among pregnant women. As a result of such provisions, the study reported a significant drop in transmission rates in East and Southern parts of Zimbabwe, from about 15% in 2010 to 6% in 2015. In another study conducted by Fauk et al. (2023) on coping strategies employed by mothers of

children living with HIV on how to deal with clinical and economic challenges as they cared for children with HIV, it was found that the awareness of a mother's on child's HIV status, family support, strong religious inclinations, in most cases helped parents to have a desire to take HIV tests, attend clinics, interact with clinical staff with a view making it possible for the child to live a more meaningful life. The study, however, was quantitative with a focus on using SmartCare, a database system; thus, data collected to support the study might not be quite comprehensive. However, although the approach was quite informative, the design of the study, in a way, made it difficult to establish the inner feelings of parents of children living with HIV as they go through various experiences in the clinical care of such children. The study, therefore, did not quite bring out the inner feelings and experiences of parents; thus, there is a need to have a better understanding through a study of this nature. It was, thus, necessary to conduct a study in order to establish what parents go through as they clinically care for and manage children with HIV from a Zambia perspective, hence the current study.

3. Problem

In the World Health Organization (WHO, 2022) report, it has been observed that there has been a significant decline in the number of deaths among children resulting from HIV/AIDS. This development has been due to scale-ups in testing and treatment of children living with HIV. Equally, Atanuriba et al. (2021), in Australia, observed that in the past 15 years, the country had registered a decline in the number of HIV cases, especially among children and health complications due to the availability of drugs as well as improvement in accessing medications. The caregivers, for example, who were mainly women, were believed to encounter challenges such as meeting the cost of hospital visitations and supplementary medication, accessing information on a child's HIV, and, in isolated cases, accessing ARTs for children. Similarly, Yiryuo et al. (2024) reported that parents living with HIV, who were at the same time the primary source of support for their children living with HIV, found themselves overwhelmed with hospital visitations, high cost to hospitals and under-resourced to meet the cost of optimistic infections, a situation which might be similar to what parents of children with HIV in Zambia might be going through.

Less, however, is known about the experiences of parents of children living with HIV regarding care and what they go through as they clinically care for and manage such children in Zambia. For this reason, the study attempts to understand the experiences of parents of children living with HIV as they clinically care for and manage the children. This is important in that such understanding can lead to appropriate interventions and support for parents, which in turn has the potential of bettering the lives of children with HIV. Arising from this view, the present study sought to address the knowledge gap on the experiences of parents of children living with HIV as they clinically care for and manage such children from the Zambian context with a focus on the Chingola district in Zambia. The following objectives guided the study to:

- 1) explore the 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' 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 experiences on clinical care and management of the children.

4. Significance

In this study, the researchers believed that the outcome of the study would uncover the experiences of parents of children with HIV as they clinically caring and manage their children. It was also hoped that the study outcomes would give a clearer understanding of their experiences, challenges and opportunities for much improved clinical care for children with HIV. Additionally, the study believed that results would help inform various stakeholders on what parents go through from a clinical perspective in the health sector and what parents of children with HIV go through as they source clinical services on behalf of their children. It was further hoped that the results would bring out a change in the manner in which parents accessed clinical services on behalf of children with HIV. Lastly, the study hoped that it would contribute knowledge to the existing literature on the experiences of parents about clinical care and management of children living with HIV. It is also envisaged that this study would raise awareness and motivate other scholars to explore further issues surrounding parents or caregivers and children with HIV in other parts of Zambia.

5. Theoretical Framework

Mishel's (1988) theory of uncertainty in illness (UIT) guided the study. The theory itself is a nursing theory that explains how people interpret uncertainty about an illness and how to cope with the uncertainties surrounding illness. The theory believes that uncertainty in illness can be a significant source of psychosocial stress for people with an illness as well as nursing patients such as parents or caregivers. It was developed by Merle Mishel in 1988 to address uncertainty during an illness's diagnosis or treatment phase with a determined downward trajectory. In theory, uncertainty in illness has been defined as the inability to determine the meaning of illness and related events occurring when the decision maker cannot assign definite value to objects or events or cannot accurately predict outcomes of the illness. It explains how people who are ill or who are caring for the terminally ill construct the meaning of illness from events the patient or caregiver is going through. It provides a guide on addressing uncertainty during diagnostic and treatment stages. It, for example, explains the antecedents of uncertainty, appraisal of uncertainty and coping strategies available to deal with uncertainty in illness. The present study, therefore, saw it as a relevant theory to guide the study in order to

understand and appreciate what parents of children with HIV experience as they deal with clinical issues of their children.

6. Topographical Features of Study Site

The study was conducted in Chingola District in the Copperbelt Province of Zambia. The study district is located between Copperbelt's busiest town, Kitwe, and the border town of Chililabombwe bordering with neighbouring country Congo DR. It is a mining town with economic activities, mainly mining and its related activities. It has a total area of 1,744 km² and is highly urbanized, with a population density of 172.4/km² (Zamstat, 2022). The district has a good number of social amenities, resulting in high levels of social interactions among its population and involving people of different genders and nationalities. The nature and economic activities are believed to have in some way impacted social life and increased the chances or potential of people living with HIV in the district (Zambia Demographic Health Survey Report, 2020). In terms of health facilities, the study site has one large government-owned hospital supported by several clinics, some of them receiving support from the mining firm and located in several compounds to serve a population of 300,651 people. Its annual growth rate of change was 2022 estimated to be 2.8% (ZamStat, 2022; Brinkhoff, 2023).

As a country, Zambia has been reported to have over 1.3 million people living with HIV, and the condition has been viewed as one of the leading causes of death, especially among adolescents. In the USA/Zambia Country Report of 2022, it has been reported that over 45,000 new HIV infections per year are recorded in Zambia. The District AIDS Task Force (DATF) HIV/AIDS in the study district- Chingola, however, reported in 2021 over 1,700 new HIV infections between January and June 2015, with most of them being children and adolescents aged below 18, which was significantly higher and explains why it was worth studying the district. This was quite a high rate as compared to the other towns in the same Copperbelt province, whose HIV cases per year have been reported to be below 1,200. The USA/Zambia Country Report of 2022 and the Zambia Daily Mail, report of 22 December 2015 have attributed the increased cases of HIV cases in the study district to several factors, including being a border town with Congo D.R. resulting in high interaction of people through trade or transit which might have led to increased cases of prostitution; poverty in the area as well as sexual exploitation which are likely to push up cases of HIV infections. It is out of this situation that some parents and caregivers find themselves taking clinical care and managing children living with HIV in the study site.

6. Material and Methods

The study used constructivism as a research philosophy supported by interpretivism as a paradigm. The research design was interpretive phenomenology supported by qualitative approaches. It was believed the research design chosen would help drive

accurately the desire to seek to understand parents' experiences as clinically cared for and manage their children living with HIV (Patton, 2012). The research design used emphasized the ability of a researcher to construct and interpret the unspoken, unconscious words of participants to get the hidden meaning of the phenomenon under study, such as the experiences of parents as they clinically care for and manage their children living with HIV (Creswell & Plano, 2012). The sample was 10 parents or carers of children with HIV, and the selection criterion was having cared for such a child for more than one year. Parents or caregivers who cared for such children for one or more years were considered to have had sufficient experience to contribute positively to the study. The participants were selected using a non-probability, homogeneous sampling purposive procedure. At the same time, qualitative data was collected through in-depth interviews and analysed using thematic data analyses approaches. The analysed data was interpreted and has been presented descriptively as indicated

7. Findings

In this section are presented the findings of the study, which was conducted from 2022 to 2024, on the experiences of parents on clinical care and management of children with HIV in Chingola, Zambia. The results are presented according to the objectives which guided the study.

7.1 Clinical Experiences

In this section, the study presents the results of the first objective on the experiences of parents in clinically caring for and managing children living with HIV. It was clear, from the results, that parents registered in the majority of cases similar experiences on what they went through and how they dealt with experiences as they clinically cared for and managed children with HIV. It was evident that parents often found themselves dealing with children who frequently became sick and needed hospital care. Parents were usually subjected to routine hospital visits, were exposed to separate days for blood tests, had to meet hospital appointments and, in some cases, had children who were hospitalized for a long time. Parents frequently escorted their children to hospitals for testing and blood accounts and to deal with several opportunistic diseases. Parents however reported that in most cases, their children were treated well by medical staff.

7.1.1 Constant Sickness

On the issue of constant sickness leading to frequent hospital visitation, it was found that some parents faced lengthy periods of sickness of their children, causing them to worry about the children. Parent-participants cited for example, ailments such as inexplicable weight-loss, cold, cough, fever and diarrhoea led to children looking quite weak. Some parent-participants reported their children being constantly sick right from birth, leading to being exposed to long periods of nursing their children in the hospital for a long time. The study also revealed that parents were quite uncomfortable with long periods of

hospitalization due to the sickness of their children, as was evidenced by an observation made by one parent-participants, EMF, a mother of a 15-year-old girl, had this to say:

Excerpt 1:

"She was very sick when she was a baby, and I was constantly seeking medical attention. She had constant coughs, colds and fevers. Sometimes, she would have a long cough, diarrhea in which case, we would be admitted for long periods. I was not quite comfortable with the long stay in hospital."

In support of the results on the constant sickness of children with HIV and the long hospitalization experienced as they cared for and managed them clinically, one parent-participant, RCF, a grandmother aged 67, observed:

Excerpt 2:

"My daughter was constantly sick, and this prompted us to request an HIV test only to discover the child had HIV. Afterwards, she was placed on ART. At one time, she was so sick that we were hospitalized for a week. She has been frequently hospitalized after that incident and is now quite weak physically."

Contributing on the same issue, one parent-participant, MCF, a mother aged 39 and of a boy aged 11, had this to say:

Excerpt 3:

"I found out about my daughter's condition when she was 4 months old. She was constantly sick, and so she was tested for HIV in the hospital, and ART was initiated. We are now made to go to hospital from time to time, thereby abandoning other family responsibilities."

Based on these results, it was evident that 7 out of 10 parent-participants had worries about frequent sickness of the children and long periods of hospitalization while the remaining 3 were not. The worries were as a result of parents not having sufficient information about the child's condition, medical staff not being quite helpful and not knowing how to manage the constant sicknesses surrounding their children.

7.1.2 Access to Medication

Another theme that emerged regarding the parents' clinical experiences was access to medication. The study observed that although in the majority of cases, the drugs are mostly available in hospitals and clinics in Zambia and children with HIV were able to access them on a daily basis, there were also concerns about the general management of child's medication. There were instances of long hospital waits or appointments to access services, issues of delayed Testing for HIV, delays in starting ART and long queues at clinics to access the medication. It was noted that during interviews, the parents became

tearful when they narrated their struggles in gaining access to medication and related services for their children. Parents, in some cases, attributed the failures of the child's access medication to increasing numbers of patients. There were also issues of children refusing to adhere to prescriptions. Some parents became discouraged because of long waits at hospitals to receive medication and treatment for opportunistic infections, as lamented by one parent-participant ASF, a 49-year widowed mother of a 15-year-old boy had this to say:

Excerpt 4:

"He has been on ART for about 13 years, but it has not always been easy to access such medication. There have been times when we have to visit hospitals several times to access them, and at times, children are forced to skip taking the drugs simply because parents are still struggling to access them from the health facilities. We have sometimes faced these difficulties in getting medicines for our children."

In support of these views, another parent-participant, MSF, a mother aged 49 and having a 15-year-old girl, had this to say:

"She was tested and placed on ART at 5 months old, though, at times, she had difficulties in getting the drugs. The hospital staff, however, were quite supportive and helped us by referring us to other health facilities to access medicine that was not available at the regular health facilities. At the time medication was available, but there was a problem of the long queues to access it."

However, there were some parents who had positive views on the manner in which hospitals facilitated access to medication. Appointments were observed, at times, followed parents' home and ensured all was well and did not take long to have medication for their children, as evidenced in the sentiments made by one parent, MBF, a 51-year-old mother to a 16-year-old girl observed:

Excerpt 5:

"I have no complaints concerning access to medicine. The hospital staff here are very helpful and friendly. They even call when you do not come to pick up your medicine sometimes, they even follow us home."

7.1.3 Long Hospital Waits

It was also found that, at times, parents were subjected to hospital waits. Parents lamented long hospital waits to access medicine, thereby interfering with their daily routine and productivity. Parents felt that something could be done differently to ensure that they did not have to wait for so long at the hospital to be served. Four out of 10 were of the view that some improvements be made to reduce long waits as they go to collect medication for their children- four to six hours was just too long, as evidenced in the

statement made by one of the parent-participant, AS F, a widow and single parent aged 47 who said:

Excerpt 6:

"We have no trouble getting medicine, except that we sometimes have to wait for a long time in queues and end up spending too much time here. Sometimes, even if we come early, we still end up spending too much time here."

Contributing on the same, another parent-participant, BMF, a mother aged 69 of a boy aged 14, said:

Excerpt 7:

"Sometimes, we are here for over four hours and that means that day will be unproductive in other areas. I think we should spend as little time here as possible."

During the interview, one parent-participant BKF, a grandmother aged 65 of a girl aged 15, observed:

Excerpt 8:

"The time we spend here should be shortened because if I go home late, then the other children won't have food to eat that day because I did not work."

Contributing to the discussion another parent-participant, MBF, a grandmother aged 61 of a boy aged 11 observed:

Excerpt 9:

"The queues are often long and we sometimes wait for a long to be attended to. We have other children to take care of at home, and even house chores which we leave need to be done. How can you be sweeping at 10 hours?"

Based on the results, 6 parents out of 10, did not have complaints about access to medication, while 4 parents had contrary views about access to medication. Those who had contrary cited shortages of drugs, uncomfortable being frequently referred to other health facilities to get medication and complaints of long distances to health facilities, which sometimes made children fail to adhere to prescriptions on medication.

7.2 Perceived Consequences

Regarding perceived consequences arising from parents' clinic experiences, parent-participants were asked what they thought were some of the perceived consequences of their experiences. The parent-participants acknowledged having developed adverse initial reactions, primarily upon receipt of the news of their children being HIV; at times, they experienced emotional burdens and developed a desire to have their children

treated. Through the information collected from fieldwork, parent-participants shared their experiences on how the initial medical staff gave them the news about the child's condition, developed negative emotions and worked with medical staff to ease their emotions.

7.2.1 Initial Reactions

On the issue of how parent-participants felt when medical staff shared the medical status of their children, 8 out of 10 parents reported that their initial reactions were quite negative. The parent cited having felt very bad upon receiving stressful news about their child's HIV status from the medical personnel and found themselves in seclusion and crying. It was also reported that in most cases, medical staff, relatives and friends were on hand to help them accept the status on their children. They provided counsel at a time when they needed help. Others also reported being frequently anxious, feeling lost on news of HIV and being not too sure what to do next until medical staff stepped in to help them understand the situation, thus starting to deal with issues of self-denial. The study revealed that initially, it was difficult to accept the news that the child had HIV, and the news made them feel worried about the child's frequent sickness and what would follow and not sure how helpful hospital staff would be as they went through the caring and managing situations. In support of these findings, one parent-participant, EMF, aged 39, mother of a girl child aged 16 years old, had this to say:

Excerpt 10:

"The news of her HIV status was stressful because I did not know how we would care for her."

In support of the same results, another parent-participant, CMF, a 48-year-old mother of his 18-year-old daughter, also shared her sentiments:

Excerpt 11:

"I was not prepared to be told that I was also HIV positive, so it was a huge blow. I was distraught at the information because it meant that we both had to be on ART. It is still difficult to come to terms with, but I have to be strong for her sake and that of her siblings. It has not been easy."

These results were also supported by what a parent-participant, RCM, a father aged 45 of a 14-year-old boy shared:

Excerpt 12:

"The news was a huge blow because we did not want him to encounter the same things we had encountered as adults. He was too young and innocent. I feared she would be ostracized, and her life would not be normal."

In her submission, parent-participant, PCF, a mother aged 48 of a 14-year daughter while shedding tears, also narrated:

Excerpt 13:

"The news was very difficult to accept. I refused to eat and was bordering on depression because I had struggled to accept my own HIV status and had refused to start taking medication. I feared for my daughter's life and wondered if he would cope with his status."

In short, 8 out of 10 parent-participants experienced adverse initial reactions upon receiving information about their children's HIV status. There were times when the news about children's status put them in a stressful situation because of the worrying news about child's HIV status. At times, they found themselves in seclusion and crying over the child's condition only to receive help from medical staff through education and counselling, which made them accept the child's situation.

7.2.2 Emotionally Burdened

In order to establish how parent-participants emotionally felt about the children's condition and regular visitations to hospitals and clinics, it was reported that parents often felt the situation was stressful, led to anxiety and made parents develop a sense of fear over the children's condition. In supporting these views, one parent-participant, BKF, a mother of a 5-year-old boy, shared:

Excerpt 14:

"I felt burdened at having to take over care of a small child, myself having grown children, but I knew there was nothing I could do because there was no one else willing to care for him."

These views were supported by those of one parent-participant, BNF, a mother aged 39 of an 8-year girl who shared:

"The news tore me apart. I felt like I had failed as a mother because my daughter had been so sickly for a long time, and yet I had never taken the step to take her for an HIV test. Looking back, I realise that it was a result of fear and denial. I failed to tell her the news, so I engaged one of the nurses to speak to her."

Another parent-participant, MBF, a mother of 45 years with a girl aged reported:

Excerpt 15:

"I think I had always known in my heart when I noticed the poor health of my child, but I did not want to come to terms with it. Regardless of this, I was afraid of the future when the doctor told me her HIV status because all I could think of was that she would be sick all the time. Whenever she was asleep, I would go to a secluded place to cry."

In support of the views of other participants in the study, one parent-participant, RCF, said, with a forlorn look on her face:

Excerpt 16:

“The news was a huge blow because we did not want her to encounter the same things we had encountered as adults. She was too young and innocent. I feared she would be ostracized, and her life would not be normal.

It was evident from the results on emotional burdens of the parents that some parents tended to feel stressed, have fears about the child’s future, became anxious and at times became worried about the child’s HIV news. Parents became emotionally burdened because of the child’s status and frequent hospitalizations because of the child’s condition. The worries also were a result of the negative impact of the child’s condition on the economies of the family, partially due to the cost of hospital appointments and medication.

7.3 Coping Strategies

On the issue of how parents were coping with their experiences in clinical care and managing their children living with HIV, they narrated several strategies centered on how to deal with emotions and acceptance by families, friends and medical staff over their children’s conditions. The study indicated various approaches parents were using, ranging from accepting moral and emotional support from family, friends and medical support, accepting a child’s condition to participating in education and training on how to care for children with HIV clinically. The participants cited several strategies, including:

7.3.1 Accepting Support Moral and Emotional Support

The study noted that moral and emotional support from family members generally helped them accept the child’s condition and their clinical experiences. Families were often found to provide emotional and moral support during clinical care, especially when the children were sick and hospitalized. Additionally, friends provided viable encouragement and counsel, which helped them emotionally to deal with negative experiences. They sometimes organize support group meetings so that parents are not left alone and feel isolated. Through such meetings, they could interact and share their experiences on how they clinically cared for and managed their children. A sense of being connected to others, especially during critical times when children were sick or hospitalized, assured the children, as evidenced in the statement made by one parent-participant CMM, a father to an 18-year-old daughter had this to say:

Excerpt 17:

"The news of her HIV status was stressful because I did not know how we would care for her, but my family and friends have been supportive through the years until now my daughter is a young lady."

In support of this view, one parent-participant, ASF, a mother aged 39 and of a girl aged 14 said:

Excerpt 18:

"I have told my family members about my child's condition, and they offer moral and emotional support by visiting and encouraging us. I have friends in the neighbourhood whom I have told about this condition, too, and they have been very supportive."

Contributing on the same issue, another parent-participant, MBF, a grandmother aged 67 and of a girl aged 12, indicated:

Excerpt 19:

"I have parents I talk to when I am here at the hospital. We have each other's numbers, and I call them when I need someone surrounding my child's illness to talk to."

In agreement with her sentiments, another parent-participant, BNF of an 8-year boy, observed:

Excerpt 20:

"Interacting with people in the community has really helped me a lot. Sometimes, I am too busy to sit and worry because of them. A long time ago, I would sit alone and cry, but now I have realized there are many people in my situation, and I get to meet them during clinic days."

It was evident that some parents used moral and emotional support from family and friends to overcome their loneliness, accept their situation and reduce on fear of the worst happening to the child. Parents were being helped to gain the required self-confidence and encouragement to deal with negative experiences as they cared for their children. Their support enabled parents to receive assurance and develop self-confidence and self-esteem in their dealing with clinical issues surrounding their children with HIV.

7.3.2 Support from Clinical Staff

It was also found that parent-participants were receiving support in various ways from medical staff on how to deal with the clinical issues of their children. Parents were at times educated and trained on how to care for and manage their children with HIV. They were supported materially and emotionally on how to deal with challenging situations such as the hospitalization of the children. For example, they were taught how to manage

tantrums and calm their children. It was also found that hospitals provided counsellors where possible who were helpful to the parents when they were emotionally low, especially when the child was hospitalized. This helped parents not to worry much because of the clinical demands surrounding their children. They always felt someone else was there to support them, as evidenced in the sentiments of one parent-participant, BNF, a mother aged 45 and of an 8-year girl who said:

Excerpt 21:

"We are afraid when she gets upset because she is difficult to console. When she is upset, everyone in the house is aware, and is quiet. I am grateful for the counsellors who talk with her because her behaviour has remarkably improved."

The experience cited above was in line with the thoughts of one parent-participant, MSF, 47-year-old mother of a 15-year-old girl observed:

Excerpt 22:

"It was not easy for me to come to terms with seeing my daughter take medicine every single day, but the hospital staff counselled me many times until I was able to learn how to help a child regularly take medication."

In support of these findings, another parent-participant, MBF, a 51-year-old mother to a 16-year-old girl, reported:

Excerpt 23:

"The hospital staff here are very helpful and friendly. There were times when, in my heart, I felt like giving up, but they even called to check on us. They call when I do not show up to pick up our medicine, and sometimes they even follow us home. Their care helped me through a lot."

7.3.3 Support from Churches and Non-governmental Organizations

On whether parents were supported by other people besides family, friends and medical staff, it was found that 7 out of 10 parent-participants acknowledged being supported by either churches or non-governmental organizations (NGOs) as they dealt with clinical issues of the children. Parents reported having received moral, emotional, material and financial support from churches and Lion's and Rotary International clubs with a view of easing the burdens of clinically caring for children. The support ranged from transportation of children to hospitals, provision of food supplements, sensitization on children's condition, to moral and emotional support. The assistance received helped them care for children with ease despite frequent hospitalization. The organisations and churches often brought foodstuffs, basic school requirements, and at times provided funds for transporting children to the hospitals as one parent, BNF, a widow and the mother of a 15-year-old girl, acknowledged:

Excerpt 24:

“An NGO has been sponsoring my daughter living with HIV for almost a year now. When she passed her exam, I was happy, but I did not know how I was going to pay hospital transportation and for uniforms and books and none of my family members were willing to help. The organization took over everything and lightened my load.”

From the results shared, it was clear that parents regularly received help from family, friends, and medical staff, including counsellors, churches and NGOs. Moral, emotional, material and financial support rendered helped parents to manage negative experiences which characterized the clinical care of parents of their children.

8. Discussion

We now present the discussion of the findings. The first objective was aimed at gaining knowledge of the experiences of parents as they clinically cared for their children living with HIV. In this study, clinical care was believed to have to do with the health-related services that are made available to help parents manage their child’s HIV infections and prevent or manage opportunistic infections. It was found that parents had to ensure that their child underwent the required medical routine, which included hospital appointments, tests and dealing with opportunistic infectious diseases to ensure the child was healthy. Parents also found themselves in a situation where they were required to ensure that their children adhered to the prescribed medicine, monitoring them regularly. Further, it was found that parents were actively involved in the collection of samples, such as urine, blood, and phlegm, to test for diseases and infections. Since HIV is a virus that targets and destroys the immune system of the human body, impairing its ability to fight disease and infection (World Health Organization, 2022), children required to have regular tests to ensure their health and wellbeing.

These findings were in line with the UN General Assembly of 2015, which reported that children do not have a fully developed immune system, making them prone to opportunistic infections, thereby making them become severely ill from paediatric infections at times. Since a child with HIV was more susceptible to disease and mortality (Yiryuo et al., 2024), parents found themselves striving to ensure that the child was kept safe from situations where their health became compromised.

Routine medical check-ups were conducted to ensure the optimum health of the child (World Health Organization (WHO), 2022). Parents for example, had to make sure that the children were always at the hospital in good time, on the dates designated for tests and appointments. It was evident from the results that parents were often stressed out due to the constant sicknesses of the child and the many medical appointments they had to meet.

With regards to constant sicknesses, it was found that parents interviewed reported the children as having been through bouts of sickness, that necessitated taking the tests that revealed a positive HIV result. It is safer to say children regularly

experienced serious bouts of sickness at a point in their parents' caregiving journey. These results were in line with the report of Stanford Medicine Children's Health (2024), which indicated that a child with HIV has several symptoms, including delayed physical and developmental growth, poor weight gain and bone growth associated with constant sicknesses of such children.

On the issue of routine hospital visits, it was found that parents with children living with HIV often found themselves expected to visit the hospital nearly every month for prescription refills and receiving antiretroviral medicines. These results were supported by the observations made by Nichols et al. (2021), who observed that parents were made to visit the hospitals regularly in order to access ART drugs for their children. From about 2016 in Zambia, parents of such children found themselves visiting the hospital at 3-month intervals for the purpose of collecting ART medicine. The 6-month dispensing policy was disregarded, a situation which made parents start feeling the clinical care of the children was putting too much pressure on them and impacted negatively on other socio-economic responsibilities. Such actions increased the burden encountered by parents through the healthcare system. For example, they were required to visit the hospital every so often, a situation which worsened in that they had to wait for long with the increasing numbers of ART patients to access the same services.

Notably, it was evident from the results on access to medication that there were mixed views among parent-participants. While some parents did not have complaints concerning access to medication and reported that drugs were always available and on time, other parents had contrary views about the availability of required drugs. They reported, for example, shortages of essential drugs and those dealing with opportunistic infections were not comfortable with being frequently referred to other health facilities to get drugs not in stock, as well as the idea of long distances to referred health facilities. Because of these situations, there were times when children could miss their prescriptions. It was also noted that there were times when they were subjected to long queues and waits to get medication. These results somehow, did not seem to agree with the 2022 USAID/Zambia report, which reported essential drugs being available in clinics and hospitals. The report indicated that in Zambia, ARTs, for example, were readily in clinics and that the country had continued to improve access to HIV medication and treatment over time.

On the second objective, which was on the consequence of lived experiences on clinical matters involving parents of children with HIV, it was found that parents did acknowledge the existence of several challenges in their attempts to provide clinical care for the children. It was found that parents had challenges which were either physical, emotional or financial in nature and led to worry about the children's condition and future. The challenges ranged from access to transport to meet hospital appointments, to failure to provide adequate meals to sick children, resulting in them worrying most of the time. Parents found themselves experiencing emotional burdens, stress and anxiety most of the time because of unresolved problems surrounding children's clinical care. The results agree with those of Nostlinger et al. (2004), who observed that, caregivers of

persons living with HIV encountered several challenges ranging from accepting outcomes of HIV diagnoses to complexities on adherence to medication and psychosocial-related problems. For example, having feelings of guilt and constant concerns for the child's future. Parents also found themselves faced with stigma from extended family members, community, which made them worried at times. However, there was also a positive front; for example, parents were able to learn from one another, especially during hospital visitations. The medical staff played a key role in easing some of the concerns of parents more so how to clinically care for them.

The study also revealed that parents fear for the future of their children with HIV conditions. Parents were afraid of the uncertainties surrounding the children. Parents were plagued with the thoughts of the uncertain future for the children living with HIV. They feared children dying at any time and not making it to adulthood. Parents were often worried or feared constant illness, making them always have negative thoughts about their children's future. Fear of the future can affect the way one makes decisions in that one may refuse to even plan for the child's future, believing they would die any time. Parents felt a child with a chronic condition is always calling for constant attention and, in the process, remains distressful. Parents constantly have to monitor the health and diet of the child and manage treatment and side effects of the condition. Parents are responsible for ensuring adherence and keeping every hospital appointment, which sometimes becomes stressful. These results were in line with a mixed-method study conducted by Sabin et al. (2020) in Hanoi, Vietnam, on the experiences of caregivers in caring for adolescents living with HIV. Sabin et al. (2020) found that caregivers were, in most cases, engaged in regularly taking adolescents living with HIV to hospitals, ensuring they had the right types of food and as well as making sure they adhered to the prescription. Madiba & Mokgatle (2017) also observed that most caregivers ensured access to medicines was available. Adolescents adhered to prescriptions but in some cases, parents feared disclosing their status to their children because parents felt children were either too young to understand the implications or would not quite keep the diagnosis a secret. The study reported that, at times, parents told children that the drugs they were taking were to ensure that they had sufficient blood or enough 'good' blood to grow well instead of the actual condition the child was in. The present study also revealed a similar situation in that parents feared disclosing to their children the actual status in the context of HIV.

On the third study objective, which was on strategies parents used to manage some of their clinical experiences as they cared for their children living with HIV, it was evident that parents used various approaches in addressing some of the negative encounters related to their children's clinical needs. They were able to receive emotional support from family, friends, medical personnel and non-governmental organizations (NGOs), including churches. It was evident that in some cases, family and friends were able to provide emotional and moral support, especially during critical times when the child had opportunistic diseases and was hospitalized. They provided moral, emotional as well as spiritual support, which helped the parent to gain confidence as they cared for

and managed the child during critical moments, hence reducing isolation and self-pity over the child's condition. It was also found that through hospital visitations, it was easier for parents through parent-parent groups to interact, exchange experiences, encourage each other, and, in the process, learn from each other. This went a long way in improving their clinical care of children. It allowed parents to develop a sense of being connected to others and being assured that other parents were available to support them when the situation became difficult.

On whether parents received support in one form or another outside family, friends and hospital setups on clinical issues surrounding children with HIV, it was found that some non-governmental organizations (NGOs), among them churches, Lion's Club and Rotary International, did provide support in the form of transport to hospitals, food supplements as well as sensitization, education and training on how to care and manage such children in home settings. In line with these results, Siula (2024), reports that with increased awareness, regular education and training on the plight of a child with HIV, charitable organizations such as Lions's clubs and churches stepped in to assist mothers meet the basic needs of children with HIV. Such actions had a positive impact on how mothers clinically cared for and managed their children. It was found that having a strong religious inclination helped mothers build a positive relationship with other parents as well as other stakeholders in the clinical care for children living with HIV.

9. Conclusion

Given the results of the present study, though they may not be generalizable, it is fair to state that parents of children living with HIV have a significant portion of positive and negative experiences regarding the clinical lives of their children. It was evident from the study that parents of children with HIV experienced a life which was full of uncertainty in the illness of the children and at times, quite worrisome about what would come of the future of the children. Indeed, regularly taking children for medication and, in some cases, being hospitalized for a long time had its toll on the parents. It was evident from the results parents often had to deal with the constant sickness of children, limited access to healthcare, frequent emotional bumps, difficulties in dealing with initial and follow-up reactions arising from the child's conditions and long hospitalization. It was also clear from the results parents had hidden fears about their children's future. These were further compounded by frequent shortages of medication and long queues when accessing medication. The study, however, showed that periodically, parents were able to receive support in the form of moral, emotional, psychosocial, material and financial from families, friends, medical staff, churches and, in some cases, non-governmental organizations (NGOS). It is particularly revealing that parents with diverse experiences in clinical care and managing children with HIV adopted different strategies to help cope with the pressure of caring for such children. Arising from these results, the following recommendations are made.

9.1 Recommendations

- 1) Health facilities should ensure that parents have regular access to individual and family counselling to help them deal with emotional and psychological challenges associated with improving negative clinical experiences encountered in the process.
- 2) Through health facilities, parents should be exposed to the option of group counselling, where they meet with other parents and share their experiences under professional counsellors.
- 3) Parent to parent Support groups should be strengthened and guided to help parents share their clinical, moral and emotional, experiences as care is given to their children.
- 4) Parents in dire need of clinical support, psychosocial, material and financial assistance should be helped from time to time through families, community, churches and stakeholder non-governmental organizations.
- 5) Healthcare providers should continue to orient, educate, train and encourage parents on how to provide clinical care and manage their children with HIV in order to ease the lives of children.

Conflict of Interest Statement

The authors declare no conflicts of interest.

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