



Exploring the burden of care: challenges faced by caregivers of HIV-infected children in Limpopo Province, South Africa

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ABSTRACT

The number of new HIV cases worldwide has gradually declined; however, South African adolescent females and young women continue to account for the most infections. Although the availability and accessibility of antiretroviral drugs have improved the survival rates of women, some still transmit HIV to their children despite the availability of HIV prevention interventions, resulting in a dual responsibility for the care of themselves and their infected children. This study aims to explore the challenges experienced by caregivers of HIV-infected children in Limpopo Province. The study employed qualitative, exploratory, and descriptive designs, and data was collected from 12 caregivers through semi-structured interviews. Data were analysed using Tesch's eight steps of analysis. The study identified three challenges facing caregivers of HIV-positive children. Caregivers struggled with disclosure and stigma, finding it difficult to reveal the child's HIV status. The burden of care was significant, including the management of the child's unstable health, ensuring compliance with treatment, and attending frequent hospital visits. The unemployment rate posed a financial burden, particularly in arranging hospital travel costs and providing adequate nutrition to HIV-infected children. These challenges highlight the need for increased support for caregivers of HIV-infected children, including education and awareness campaigns to reduce stigma. Policymakers should consider providing financial support to caregivers. A holistic, multisectoral approach involving healthcare, education, social services, and policymakers is essential.

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Introduction

Globally, the number of people living with the Human Immunodeficiency Virus (PLWH) was estimated to be about 37.7 (30.2 - 45.1) million in the years 2021 and 2022 (Zhong et al., 2023). In the same period, South Africa had about 7.6 million PLWH, which was the highest number of people with HIV in a single country in the world (Elflein, 2023). Irrespective of the number, a global decline of 31% of new HIV infections among young women was observed (UNAIDS, 2021). Although there has been a decline, there are still, on average, 6,000 young women who are infected with HIV (Muthelo et al., 2020). In South Africa (SA), adolescent girls and young women have the highest rates of new HIV infections. Despite the infection rate, girls and women survive to adulthood due to the global commitment to improve services and access to antiretroviral therapy (ART) worldwide (Khan et al., 2023).

Some HIV-infected women fall pregnant and transmit HIV to their children despite the availability of antiretroviral prophylaxis, safe obstetric practices and breastfeeding habits (Astuti et al., 2021). The mother-to-child transmission (MTCT) of HIV bears the double burden of mothers caring for themselves and then also caring for their children who are infected with HIV (Moshoeshe & Madiba, 2021). The burden is brought about by the long-term management of HIV, which might be complex, making them clinically, socially and emotionally vulnerable (Bouabida et al., 2023). The vulnerability exposes them to different challenges related to their care and

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the care of their HIV-infected children. The study seeks to answer the question: “what are the challenges facing caregivers of HIV-infected children in Limpopo Province?”. Exploring the challenges faced by caregivers of HIV-infected children provides a basis for healthcare providers, social workers and policymakers to create effective support systems and interventions. Hence, the purpose of the study was to explore the challenges experienced by caregivers of HIV-infected children in Limpopo Province. This paper provides an initial introduction and background. The next section provides an overview of the literature, followed by the research methodology, outlining the research approach and design, process, and steps undertaken to collect and analyse the data. The last three sections present the results and discuss the findings and conclusions.

Literature Review

Caregivers of children living with HIV generally assume a disproportionate burden of care for their children, as children with HIV have significantly higher rates of disease and mortality compared to their counterparts, thus necessitating the administration of antiretroviral drugs and other medications to ensure their survival. Such circumstances impose a tremendous responsibility on the primary caregiver (Maddocks & Chetty, 2021). Caregivers bear a substantial burden and often have limited personal time while having to deal with challenges that add to their precarious economic situation, leading to a vicious cycle of disadvantage, including food insecurity and increased poverty (Fauk et al., 2023). Above all, caregivers find it challenging to meet the physical and mental needs of children mainly because of the negative perception and prejudice they face from the community. Studies identified several phases of challenges faced by caregivers of HIV-infected children, including stigma, discrimination and the lack of financial support (Bouabida et al., 2023; Robinson et al., 2023). The challenges affect caregiver’s mental health, which makes them doubt their ability to take care of the children (Ikefuna et al., 2020).

Stigma and discrimination

Stigma and discrimination in the context of HIV infection remain a significant challenge despite progress made in HIV treatment and prevention. The 2021 UNAIDS report revealed that over 25% of people between the ages of 15 and 49 years in 25 countries still stigmatise and discriminate against people living with HIV (UNAIDS, 2021). Hence, caregivers and their HIV-infected children continue to face discrimination and stigma due to the family and community’s misunderstanding of HIV infections, thus making it difficult for caregivers to disclose their status. Studies have shown that when caregivers disclose the status of their children, they often face rejection from their family and others in the community (Bouabida et al., 2023). Rejection and judgment from others add more burden to caregivers in addition to overseeing the well-being of the child. The burden has a negative effect on the mental and physiological outcomes of both the caregiver and the child (Ikefuna et al., 2020; Katana et al., 2020). The negative physiological outcomes appear to be related to non-compliance to treatment, which in some cases results from the inability to take medication in the company of other family members with fear of discrimination and stigma (Robinson et al., 2023).

The lack of disclosure causes caregivers to isolate children and not seek the assistance or support of family members and the community (Moshoeshoe & Madiba, 2021). In most cases, caregivers do not disclose the status to the infected children. In addition to perceived stigma, the reason for non-disclosure to the child is the perceived lack of understanding from the child, which is associated with the child’s age. Studies have found a low level of disclosure among children under 11 years of age compared to older children and among girls compared to boys (Atanuriba et al., 2021). Although some caregivers decide not to disclose, those who disclosed found the children more dedicated to protecting their health and following treatment and care protocols (Hlasoa, 2023).

Financial burden

Caregivers of HIV-infected children encounter significant financial challenges, which can further worsen their existing financial burdens. The financial expenses arise from the child’s frequent medical appointments, the need for specialised treatment, and the child’s specific dietary requirements. The expenses are sometimes too high, putting even more pressure on already limited funds and creating a debt and financial insecurity cycle for caregivers (Katana et al., 2020; Maddocks & Chetty, 2021). The financial insecurity makes it harder for both the child and the caregiver to get medical care and support services, which makes it harder to manage the child’s health and well-being. The inability to take good care of the child’s health will lead to an increase in opportunistic infections, resulting in the condition worsening to AIDS and eventually the child’s death (Fauk et al., 2023).

Psychological difficulties

Caregivers of HIV-infected children are faced with mental health challenges, which can worsen existing challenges. Some caregivers may experience high levels of anxiety and sadness because they are constantly stressed, afraid of being judged and worried about the health of their children (Murray et al., 2017). Caregivers are more likely to develop depression than the general population, requiring social and mental health support (Ikefuna et al., 2020; Katana et al., 2020). Social and psychological support, including counselling, is important for addressing the mental health challenges of the caregivers. It is also important to set up help that goes beyond medical care.

Empirical Review and Hypothesis Development

Based on the literature, caregivers of HIV-infected children face numerous challenges. These include stigma and discrimination, which lead to rejection from family and community, difficulties in disclosing HIV status, and isolation of children. Disclosure

challenges, particularly regarding when and how to inform the child and others about their HIV status, add another layer of complexity (Bouabida et al., 2023; Moshoeshoe & Madiba, 2021). Financial burdens are significant, with increased expenses for medical care, specialised treatments, and specific dietary requirements, often resulting in financial insecurity and limited access to necessary services (Katana et al., 2020; Maddocks & Chetty, 2021). Caregivers also experience psychological difficulties, including high levels of anxiety, depression, and constant stress (Murray et al., 2017). While these challenges are well-documented globally, there appears to be a knowledge gap regarding the specific experiences of caregivers in Limpopo Province, South Africa. The paper, therefore, hypothesises that "There are local cultural, social and economic factors challenges facing caregivers of HIV-infected children in Limpopo Province".

Research and Methodology

Design

A qualitative research approach using exploratory and descriptive designs was used to conduct the study, thus enabling the researcher to obtain a holistic overview of the natural situation (Gray & Grove, 2021). The researchers chose a qualitative research design as it is a scholarly and rigorous approach used to describe life experiences from the perspective of the mothers taking care of their HIV-infected children (Gray & Grove, 2021; Polit & Beck, 2021).

Study setting

The study was conducted at a Paediatric Medical Ward at a hospital in the Capricorn District, Limpopo Province, South Africa. The hospital offers antiretroviral treatment (ART), HIV counselling and testing (HCT), prevention of mother-to-child transmission (PMTCT) and other specialist services. There is a HOPE Clinic within the hospital dedicated only to the care of HIV/AIDS patients. Mothers of HIV-infected children lodge in the ward to look after their sick children who are admitted with HIV-related illnesses.

Population and sampling

The study population was caregivers of HIV-infected children admitted to the pediatric ward. About 10 HIV-infected children were admitted to the Paediatric Medical Ward with HIV-related illnesses monthly. Twelve (12) caregivers of children living with HIV were purposively sampled and interviewed. The sample size was determined by data saturation, where no new information emerged from the data (Brink & Van Rensburg, 2022). The selection criteria included caregivers of children between 1 and 12 years admitted to the pediatric ward. The caregivers should stay with the child when the child is not admitted to the hospital.

Recruitment

The researchers gained access to the participants through the operational manager of the pediatric unit after obtaining ethical clearance for the study. The participants were recruited following approval by the hospital's chief executive officer (CEO). Caregivers were approached while visiting the children admitted to the medical ward. The study was explained, and participation was requested.

Data collection

Data were collected in one of the offices allocated to the researcher by the operational manager of the Paediatric ward. The office was secure and offered privacy to the participants. At the same time, it offered little background noise that helped retain the quality of recordings and allowed open dialogue from participants. Semi-structured in-depth interviews were used to collect the required data. The interviews were guided by an interview guide, which the researcher developed after reviewing literature in the field. The interview guide was prepared in English and Sepedi (participants' language). Each interview lasted 30–45 minutes and was recorded with the respondents' permission.

Data analysis

The researcher transcribed the interviews verbatim in Sepedi, translated them into English and checked the transcripts for accuracy against the audio recordings. Data were analysed following Tesch's eight (8) steps of qualitative data analysis (Creswell & Poth, 2018). The researchers started by reading through all transcripts to make sense of the data. The shortest and most interesting transcripts with the most information were identified and thoroughly read to understand the underlying meanings. In completing the reading of the transcripts for all participants, the researcher listed topics. Similar topics were clustered, and columns were drawn for the most unique topics. The list was compared with codes documented next to the segment of each text. The researcher then reviewed the initial grouping to identify new categories and themes. The themes were turned into categories. More familiar concepts were categorised together, the themes were reduced, and the lines were drawn between sub-themes to show interrelationships. A final decision was taken on the abbreviation for each theme. The data material belonging to each theme was grouped to allow for preliminary analysis and to arrange themes in order of priority and not by alphabetical order for logical coherence. Finally, the themes were referred back to the original raw data to check whether any information that should be part of the themes was left out.

Measures to ensure trustworthiness

Trustworthiness pertains to the level of confidence researchers have in their data and analysis (Polit & Beck, 2021). Credibility was established by maintaining prolonged interaction with the participants and asking questions until data saturation was achieved. This

fostered trust and rapport, aiding the researchers in gathering precise and comprehensive information. Audio recordings were conducted during the interviews to ensure precise data transcription. Member checking was applied by seeking participants' feedback on the researchers' interpretation of the data before they left the interview session. To ensure confirmability, the researchers accurately represented the participants' voices, sentences and inquiry conditions without incorporating their biases, intentions or perspectives (Polit & Beck, 2021). All interviews were recorded to establish an audit trail of raw data. Transferability was ensured by providing detailed and comprehensive descriptions of the study's methodologies, participants and environment. Authenticity was maintained by documenting field notes to capture the emotions and atmosphere of nurse lecturers' experiences (Polit & Beck, 2021).

Ethical considerations

The study received Ethical clearance from the University of Limpopo Research Administration and Turfloop Research Ethics Committee (TREC/79/2016/PG). The permission to collect data was granted by authorities from the Limpopo Department of Health and the managers of the selected health facility. Participation in this study was voluntary, and informed consent was obtained from the participants before the interviews were conducted. The researcher maintained confidentiality and anonymity by not identifying participants by their real names but by using numbers. The interviews took place in a private room to ensure a confidential environment. The research posed minimum psychological risks to the participants, and none of the participants needed counselling due to the interview. However, a social worker was on standby for those participants needing counselling during interviews.

Findings and Discussions

Findings

Demographic characteristics of the participants

Twelve (12) caregivers of HIV-infected children admitted at a Pediatric Ward of a hospital in Limpopo Province participated in the study. All were females. Among the caregivers, nine (75%) were biological mothers, two (17%) were grandmothers, and one (8%) was a legal guardian. Caregivers' ages ranged from 33 to 72 years, with a mean of 44 years, and only three (25%) were employed. According to caregivers, 11 (92%) of children were diagnosed at birth and one (8%) at two months of age. The children's ages ranged from three to 11 years, and the mean age was eight (8) years. Table 1 displays the demographic characteristics of participants.

Table 1: Demographic characteristics of participants

No	Relation to child		Caregivers' age years	Marital status	Employment status	Child age at diagnosis	Child's age in years
1	Legal Guardian	Female	38	Single	Employed	At birth	10
2	Mother		36	Widow	Unemployed	At birth	9
3	Mother		41	Married	Employed	At birth	8
4	Grandmother		72	Widow	Pensioner	At birth	7
5	Mother		34	Single	Unemployed	At birth	11
6	Mother		38	Married	Unemployed	At birth	11
7	Mother		41	Single	Employed	At birth	8
8	Mother		45	Single	Unemployed	At birth	10
9	Grandmother		68	Widow	Pensioner	2 months	7
10	Mother		40	Single	Unemployed	At birth	3
11	Mother		33	Single	Unemployed	At birth	6
12	Mother		36	Single	Unemployed	At birth	5

Emergent themes

Three main themes with four subthemes emerged from the analysis of the interviews. The themes were: (1) Disclosure and stigma related to the HIV-positive status, (2) the burden of taking care of an HIV-infected child challenge and (3) Financial burden (see Table 2).

Table 2: Themes and sub-themes

Theme	Subthemes
1. Disclosure and stigma related to the HIV-positive status	1.1. Disclosure of HIV-positive status to the child 1.2. Isolation of the child due to anticipated stigma 1.3. Stigmatising the HIV infected children
2. Burden caring for an HIV-infected child	2.1. Unstable health status 2.2. Challenges with treatment compliance 2.3. The demands of regular hospital visits
3. Financial burden	3.1. Challenges with hospital travelling costs 3.2. Demands of daily maintenance of an HIV-infected child

Theme 1: Disclosure and stigma related to the HIV-positive status

The participants expressed challenges regarding the disclosure of the HIV-positive status to the child, isolation of the child due to anticipated stigma and Stigmatising the HIV-infected children.

Disclosure of HIV-positive status to the child

The study found that participants faced difficulties when it came to revealing their children's HIV-positive status to them. They delayed informing the children about their HIV status, even though they kept providing ARVs to them. Some participants said they were not adequately prepared to deal with the potential repercussions of informing their children about their HIV status. They expressed a need for medical professionals or counsellors to help them share this information with the youngsters:

I was unsure how to tell him about his HIV status because some people have mental and emotional issues after realising they have it. I was told to tell him about his HIV when he was 12, but I could tell he was ready at 11, so I sat down with him and told him everything. I was glad we never had issues. Okay! (P6)

Telling him he has HIV at 10 years is hard. He won't understand. Doctors or trained professionals should talk to children until they understand their conditions. So when he starts dating, he can safeguard himself and his partner. We don't know how he'll react when we talk to him about it as parents. (P8)

I was assisted by the doctor to tell him about his status. He asked him if he knew why he was taking the medication and continued to explain to him the purpose of the medication and his HIV status. (P12).

Isolation due to anticipated stigma

Most participants expressed concern about their HIV-infected children's reluctance to engage with peers of the same age group. One participant stated that her child always wanted to spend time alone with her, afraid of being stigmatised by other people. In addition to the child's self-isolation, some participants expressed that they would not allow their children to visit family members without them being there to watch over them and make sure they followed their treatment schedule:

"What I've noticed is that he lives close to me." I've noticed that the child doesn't play with other kids or do things with other kids, like going to see relatives. (P8)

He feels very alone some days. You can tell he's lonely just by looking at him. Mmmh! He'd look sad. He does nothing but sit there. (P10)

Stigmatising the HIV infected children

The participants expressed challenges in disclosing their children's HIV-infected status to teachers at school because they feared that others would discriminate against their children. Some were confronted by the teachers' inquiries about the children's frequent school absences. The participants believed that the teachers were interested in obtaining confidential information regarding the specific illness the children had been diagnosed with:

I'm afraid that we haven't told his teachers at school about his condition because the teachers are not the same (coughing). You may tell some and end up treating the child badly. On the other hand, you could ask other teachers and find out that they are fine. (P6)

The other problem has to do with school. The teacher questions the child at school. They ask the child difficult questions, and the child gets frustrated because the teacher wants to know why he went to the hospital, seeking out private information. Sometimes, I think this troubles the child at school. (P8)

One participant who disclosed the child's need for consistent medical check-ups to the teachers found the disclosure beneficial as it assisted with planning appointments and the child's assessment schedule at school.

The teachers never caused me any trouble. He just completed the form at the beginning of the year, indicating that he is not well and going for checking over and over. They check when he consults with the doctor and know when he goes to the doctor. When he talks to the doctor, they know he did go to the doctor. The problem is when you keep it a secret and do not complete the form confirming that the child is sick. (P1)

One of the participants further acknowledged that caregivers sometimes discriminate against the infected child from other children in the family.

Parents who do not accept and acknowledge [that their children are HIV positive] will find that they have children who are all right and not infected with HIV and only one child who is infected with the virus. I look at other parents with empathy as I am already a grandmother myself. There's always a temptation to discriminate against children who are HIV-infected because you love those who are well, as if you blame the HIV-infected child that got infected because of the child. That's how I see it (P6)

Theme 2: Burden of caring for an HIV-infected child

The study found that caring for an HIV-infected child was a burden to caregivers due to the children's unstable health status, challenges with treatment compliance and the demands of regular hospital visits.

Unstable health status

Most participants explicitly said that the health of children with HIV is not stable because they are prone to opportunistic illnesses compared to HIV-negative children. The following sentiments were expressed:

He was in the intensive care unit (ICU) for months, participant 5 said. I just said yes! What do I say? HIV was the reason, together with other diseases, was the reason for his admission to the ICU. He also had TB just after birth. (P5)

"As a parent of an HIV-infected child, I know that he got TB, the type affecting the lungs and also bronchitis. He was on medication after that, and he got better. Now he has bronchopneumonia" (P7)

Challenges with treatment compliance

Most participants reported that a common difficulty they faced was children forgetting to take their medication as they grew older, particularly when parents were not around. Some participants expressed that their children occasionally refused to adhere to the therapy routine:

"The only problem is that he is getting older and street-savvy. Some days, he doesn't take his medicine, and when I ask him about it, he says he's sick of it" (P3).

"The only trouble is when he doesn't want to take his medicine. I get stressed out because he gets stubborn. I would have to chase him around first. That's the trouble I am having" (P12)

The demands of regular hospital visits

Some participants found the regular hospital visits for monthly check-ups and prescription collection for their children to be burdensome and difficult. In addition to the inconvenience of travelling, this monthly schedule required children to skip school and caregivers to be absent from work to accompany their children to the hospital:

"Being a parent of an HIV-infected child is hard for me because I have to go to the hospital a lot. The child has to miss school when he goes to the hospital for check-ups, and I have to take time off from work". (P2)

"I only stay with the two children, this one and his brother. Only the three of us are at home. So, when the child is sick, I must travel a long way. I told myself to accept things as they are. I do not ask for assistance because people would make fun of me and treat me badly if I told them we have HIV because they are afraid of it" (P4)

Theme 3: Financial burden

Caring for an HIV-infected child poses a financial burden to the caregivers as they have challenges with hospital travelling costs and meeting the demands of daily maintenance of an HIV-infected child.

Challenges with hospital travelling costs

Some participants faced financial difficulties due to a lack of regular income, making it hard for them to afford transport for their children to and from the hospital:

"The hardest thing for me is running out of money. Because of this, I struggle. The small amount of money I get as a social grant comes from their late father and is not enough to cover things like getting to the hospital and other costs" (P3).

"I have another child too. The other one does not have HIV. Mms! My only problem is that I don't have a job. I do have trouble finding the money to come get his medication and bring him to the hospital. Mms!!!" (P7)

Demands for daily maintenance of an HIV-infected child

The participants highlighted the importance of ensuring that the children have a good and balanced diet as a difficult aspect of their care. The problem is that the diet is expensive, and women, particularly those without a stable income, had to rely on social grants to buy the required food, which was inadequate to last the entire month:

"The child support grant is not enough. Sometimes you get a debit order from the bank and are having a hard time because these kids need to eat and expect to eat healthy, balanced food. It is a struggle; they eat spinach every day". (P6)

"He needs to be taken care of by making sure he eats when he wakes up; he needs to eat well." But the money can be hard sometimes" (P10)

Discussion

The study sought to understand the challenges experienced by caregivers of HIV-infected children, with the majority being single and unemployed. These findings are consistent with similar studies conducted in Africa, which revealed that females are mostly primary caregivers, unmarried and unemployed (Maddocks & Chetty, 2021). The caregiver's challenges include disclosure of the HIV-positive status, the burden of caring for an HIV-infected child and the financial burden. Most caregivers found it difficult to disclose the HIV status to the child. The non-disclosure was due to the presumed inability of the child to deal with the condition due to immaturity, young age and caregivers' perceived lack of ability to explain the condition and deal with possible reactions from the child. The finding concurs with that of Nathaniel et al. (2024), who found that some caregivers were not prepared to answer possible questions and needed the assistance of the nurses; hence, in the current study, some disclosed alone, others with the help of the medical practitioners while others did not. The practice of non-disclosure due to young age was reported in similar studies conducted in Ghana and Ethiopia (Atanuriba et al., 2021; Shallo & Tassew, 2020).

Disclosing the HIV status of the child appeared to have resulted in the self-isolation of children from their peers, which is a sign of self-stigmatisation. Self-stigmatisation results from awareness of negative stereotypes about HIV-infected individuals and agreement with those judgments (Bouabida et al., 2023; Rich et al., 2022). Self-stigma and fear of discrimination appear to be evident in many HIV-infected people and are one of the main reasons for non-disclosure (Chime et al., 2019; Rich et al., 2022). Furthermore, the fear of discrimination and stigma also affected the disclosure of the child's HIV status to the teachers. Schools are viewed as areas that facilitate gossip and social exclusion of HIV-infected children (Bouabida et al., 2023; Rich et al., 2022). The view about school is indeed true in other settings, as the study in Ghana revealed that HIV-infected children were often labelled or given names at school that were associated with how they looked due to their sickliness (Atanuriba et al., 2021).

It is important to acknowledge that the non-disclosure of HIV status might prevent caregivers from initiating the necessary conversations to seek social support (Moshoeshoe & Madiba, 2021), while disclosure poses a potential risk of financial loss, partnership dissolution and abuse (Jia et al., 2022). As a result, caregivers and their children tend to disengage and distance themselves from their friends, relatives and social events (Rich et al., 2022). In contrast, some caregivers in the study disclosed the child's status to the teachers. The disclosure made it easy for teachers to understand the child's needs and develop catchup plans for lessons missed during medical follow-up care. Correspondingly, studies discovered that HIV disclosure was associated with numerous favourable outcomes, including greater social support, diminished psychological distress and enhanced happiness (Jia et al., 2022; Khan et al., 2023).

The interesting finding in the study is that some caregivers were somehow tempted to discriminate against their HIV-infected children by transferring the anger from their partners who are believed to have infected them with HIV to the children. Consequently, treating the HIV-infected child differently from other children in the home. In contrast, a previous study found that caregivers become harsh on the kids due to the stress that is caused by the burden of care, not anger (Murray et al., 2017).

Caregivers in the study were faced with the burden of caring for an HIV-infected child due to their unstable health status. The children were consistently having lung infections like bronchitis and TB and subsequently requiring medical care and, at times, even admission to the hospital. The findings are consistent with other studies in sub-Saharan Africa, which revealed that HIV-infected children have weaker immune systems as compared to their peers, leading to frequent opportunistic infections placing a heavy burden on caregivers and local health facilities (Hlasoa, 2023; Mujjuzi et al., 2021).

HIV treatment requires lifelong treatment with antiretrovirals, which requires regular medical consultation and follow-up (Buell et al., 2016). While HIV treatment is important for suppressing the viral load and maintaining the health status of the children, our study found non-compliance with treatment by some of the children. The non-compliance might be due to a lack of understanding of the disease due to non-disclosure. In accordance with the present study, a similar study in Lesotho found that children miss doses intentionally because they are tired of the treatment. However, the same study found that children who knew their status showed improved compliance with treatment (Hlasoa, 2023). Non-compliance exacerbates their low immunity, making them more vulnerable to infections.

The vulnerability to infection causes sickliness, requiring frequent medical visits rather than the usual follow-up visits (Katana et al., 2020; Mujjuzi et al., 2021). The visits cause the children to often be absent from school, missing important lessons. Missing school affects the child's potential to complete basic education, consequently threatening the children's and the family's economic outcomes (Zinyemba et al., 2020). Furthermore, frequent medical visits come with travelling costs (Katana et al., 2020; Mujjuzi et al., 2021). The travelling costs present a financial burden on caregivers of people living with HIV and can lead to poor adherence and reduced retention of treatment (Katana et al., 2020; Maddocks & Chetty, 2021).

In addition to the travelling costs, caregivers found it challenging to meet the daily demands of the HIV-infected children. They acknowledged the need to provide a nutritious diet. However, it was challenging as most were unemployed and dependent on social grants. They found the grant to be insufficient to cover their financial needs. The present findings seem to be consistent with other studies in sub-Saharan Africa, which showed that caregivers, mainly women, have lower social and economic status while also assuming the primary care role of the family (Katana et al., 2020; Maddocks & Chetty, 2021).

The low economic status results in food insecurity, which is linked with decreased antiretroviral therapy adherence, resulting in poor suppression of viral replication and thus reducing treatment outcomes (Fauk et al., 2023). The challenges might make it difficult for the country to meet the 90-90-90 strategy, which aims to ensure that 90% of people know their HIV status, 90% are on ARVs, and 90% are virally suppressed by 2020 (Marinda et al., 2020). Therefore, increasing the support for caregivers of HIV-infected children is necessary to reduce and increase treatment adherence.

The support should be aimed at increasing food security and access to health care (Maddocks & Chetty, 2021). In Tanzania, food and cash incentives increased the number of people living with HIV in care and adherence to treatment (Uwishema et al., 2022). Psychological support for both caregivers and children is important to cope with the disease burden and deal with self-stigmatisation. Studies found that caregivers of HIV-infected children are at an even higher risk of depression and other psychiatric problems. The fear of HIV risk situations, social isolation and traumatisation have been reported to heighten the caregiver's feelings of guilt (Ikefuna et al., 2020; Katana et al., 2020). The study it cannot be generalised to the entire province because it was conducted in a single health facility with a limited sample, however, it provides essential information regarding the challenges faced by caregivers of HIV-infected children.

Conclusions

It is evident from the current study that caregivers of HIV-infected children in the South African context carry a high burden of care that has the potential to affect their health and treatment outcomes, highlighting the need for comprehensive support interventions. Education and awareness campaigns in schools and communities are necessary to reduce stigma, mainly self-stigmatisation. Health services must strengthen psychosocial support by providing regular counselling services and helping caregivers develop support groups to share experiences and coping strategies. Furthermore, policymakers must consider increasing social and financial support for caregivers based on their economic status, as is evident from the current study and similar studies that the social grant is not sufficient to meet the family and care needs of HIV-infected children. Social support may include developing food assistance programmes and education on affordable, nutritious diets. Financial support includes increasing social grants for caregivers of HIV-positive children. Overall, it is necessary to adopt a holistic and multisectoral approach, including health care, education, social services, and policymakers, to effectively support caregivers and HIV-positive children.

Comparative studies investigating caregiver experiences in different contexts may provide more information on challenges and coping strategies. Furthermore, longitudinal studies investigating the long-term mental impacts of caring for an HIV-infected child may further expand the knowledge base to improve support for caregivers.

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