

# **PRIMARY CAREGIVERS' CHALLENGES RELATED TO CARING FOR CHILDREN LIVING WITH HIV IN A SEMI-RURAL AREA IN SOUTH AFRICA**

**S.M. Bejane**, M Cur  
University of Limpopo (Medunsa Campus)  
Department of Nursing Science  
Corresponding author: Mmatsatsibejane@yahoo.com

**Y. Havenga**, D Cur  
Tshwane University of Technology  
Department of Nursing

**E. van Aswegen**, D Litt et Phil  
University of Limpopo (Medunsa Campus)  
Department of Nursing Science

## **ABSTRACT**

The increased number of orphans due to HIV, as well as the increased number of children living with HIV, increases the burden for primary caregivers in the community. This study focussed on the experiences of primary caregivers of children living with HIV in a semi-rural area of South Africa. The aim of this article was to describe the challenges experienced by the primary caregivers.

A qualitative study with eight purposively sampled primary caregivers was done. Data were collected by conducting unstructured individual interviews and analysed using Tesch's method. The identified challenges included not knowing the causes of the children's frequent illnesses, coming to terms with the HIV positive diagnosis, ensuring treatment adherence, as well as the prevention and management of episodes of illness. Additional challenges included the prevention of infection of family members and of the primary caregivers and financial challenges. A holistic comprehensive health service, addressing primary caregivers' challenges, is required.

**KEYWORDS:** caring for children with HIV, children living with HIV, HIV/AIDS challenges in South Africa, primary caregiver of children living with HIV

## **INTRODUCTION AND BACKGROUND INFORMATION**

HIV is one of the main health challenges facing South Africa with its large number of persons living with HIV and its paediatric HIV pandemic. During 2009, an estimated 5.21 million people were living with HIV in South Africa, of whom 280 000 were

children under fifteen years of age (Eley, 2010:41). HIV is a medical condition with psychosocial consequences positioned within the larger social framework of injustice and developmental crises. HIV has no cure, and given the number of AIDS orphans, HIV results in social, cultural and spiritual crises that lead to problems in families and in communities (Parry, 2008:25).

The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2008:3) estimated that 1.8 million people have died from AIDS-related diseases in South Africa since the start of the epidemic. The aftermath of HIV/AIDS-related deaths is a large number of orphans (Parry, 2008:25).

Some of these orphans may themselves be infected with HIV (Boon, Ruiter, James, Van Den Borne, Williams & Reddy, 2009:374; Ssengonzi, 2009:309). Due to the chronic nature of the disease, children living with HIV need to be on long-term antiretroviral treatment (ART). The success achieved by the use of ART enables children to reach adolescence. However, the children also require long-term psycho-social care and support which can be rendered with the assistance of their primary caregivers (Moody, Morgello, Gerits & Byrd, 2009:344).

In most Sub-Saharan African (SSA) countries, and also within a large part of the South African population, orphans are traditionally taken care of by their extended families. Studies in several South African districts revealed that most orphans, including those living with HIV, were cared for by their grandparents and family members, or lived alone (South African National AIDS Council, 2007:34). These primary caregivers are often elderly women who take care of the children after the death of their parents (Wacharasin & Homchampa, 2008:385).

## **STATEMENT OF THE RESEARCH PROBLEM**

According to the literature review, caregivers could experience problems while providing care for people living with HIV. Such problems include the caregivers' lack of knowledge, the caregivers' own physical burdens, sleep deprivation, anxiety, depression, stress, feelings of inferiority, hopelessness, restricted freedom, rejection, a loss of income, as well as stigma and discrimination. The caregivers might also have inadequate financial resources (Boon et al., 2009:374; Pallangyo & Mayers, 2009:482,490). In addition, children need special care, depending on their developmental stages (Mendez-Luck, Kennedy & Wallace, 2009:228).

There is a need for caregiver-focused research that explores the experiences, challenges, parenting behaviours, mental wellbeing, family support, social networking and coping mechanisms in their daily living contexts (Parry, 2008:35; Thomas, Nyamathi & Swamithan, 2009:994). Research should enable the development of social policies to

assist and support primary caregivers' roles. The mental health of caregivers needs to be fostered, as this will in turn lead to effective and efficient care of children living with HIV, without compromising the physical and mental health of the primary caregivers themselves (Hejoaka, 2009:874; Mendez-Luck et al., 2009:233).

The research question was thus: "What experiences are encountered while caring for children living with HIV by primary caregivers who attend a specific wellness clinic in a semi-rural area in South Africa?"

## **PURPOSE AND OBJECTIVE**

The purpose of the study was to promote the mental health of primary caregivers caring for children living with HIV by exploring and describing their caregiving experiences and making recommendations to assist them.

The objective of the article is to discuss primary caregivers' experiences of caring for children living with HIV, specifically related to their caregiving challenges.

### ***Operational definition of key concepts***

- Caring in this study refers to the primary caregivers' role of looking after the children living with HIV in order to ensure that the children's social, educational, financial, health, physical and emotional needs are met.
- Children refer to persons under the age of 18 years (Children's Act, no 38, 2005) living with HIV aged 7 to 12.
- Challenges refer to difficulties in caring for children living with HIV.
- Living with HIV refers to children who tested positive for the HI virus.
- Primary caregiver, for the purpose of this study, refers to any person who cares for and lives with a child living with HIV on a fulltime basis. This could include either biological parents, guardians or other persons who have taken on primary caregiver roles.

## **THEORETICAL FRAMEWORK**

The Theory for Health Promotion in Nursing (THPN) (University of Johannesburg, Department of Nursing Science, 2009) was the theoretical framework for this study. This theory views both the primary caregiver and the child living with HIV as whole persons with body, mind and spirit in interaction with their external environment comprising physical, social and spiritual dimensions.

## RESEARCH METHOD

A qualitative, explorative, descriptive and contextual research design was used (Polit & Beck, 2012:505). The setting was a wellness clinic providing HIV-related services, to both adults and children living with HIV, in a semi-rural area of South Africa. The population included all primary caregivers who brought their children to the wellness clinic. Eight primary caregivers were purposively selected until data saturation was reached (Polit & Beck, 2012:521). The inclusion criteria were adults, at least eighteen years old, who lived with the HIV positive children aged 7 to 12. The caregiver took care of the child in accordance with the operational definition of 'caring' and 'primary caregiver' roles, as defined by this study.

Data were collected from July to October 2010 by means of conducting individual unstructured interviews in Setswana, the participants' mother tongue. The interviews were audio-recorded and field notes were kept. Interviews lasted 45–60 minutes to ensure prolonged engagement and persistent observation. At the end of each interview, a summary was presented to the interviewee to enhance the credibility of the findings through member checking (Polit & Beck, 2012:591).

All interviews were transcribed verbatim and translated into English. Thereafter, translations were checked by an independent translator. The data were analysed using Tesch's method of data analysis (in Creswell, 2009:186) by both the researcher and an independent coder who reached consensus on the identified themes. This enhanced the credibility and confirmability of the findings. The findings included verbatim quotes to increase the credibility and authenticity of the research. Thick descriptions of the methodology and findings enhanced the transferability of the study's findings (Polit & Beck, 2012:588, 595). After the findings were described, a literature control was included in the discussion of these findings.

Ethical approval was obtained before the study commenced from the Medunsa Research Ethics Committee of the University of Limpopo, the Regional Health Ethics Committee and the Chief Executive Officer of the wellness clinic. The primary caregivers signed informed consent forms for participation in the study and for audio-recording of the interviews. Participation was voluntary and caregivers were free to withdraw from the study at any time. The interviews were conducted privately, in the absence of the child, to minimise psychological harm and to allow the primary caregivers to share their experiences freely. Psychological support was available if participants experienced emotional distress. Codes were used to ensure the anonymity and confidentiality of the participating primary caregivers. All audio-recordings would be kept safely locked up for five years to ensure that an audit trail is available (Polit & Beck, 2012:591).

## FINDINGS

The biographic information will be presented first, followed by a discussion of the challenges encountered by caregivers of children living with HIV.

### Biographic information

Out of the eight interviewed primary caregivers, seven were females. The primary caregivers' ages ranged from 25 to 79. One was a young adult, two were middle-aged adults, and five were older adults. Of the eight children living with HIV, seven were cared for by non-biological primary caregivers (aunts or grandparents). These seven children were orphans: two double orphans and five maternal orphans.

The level of education of the primary caregivers ranged from no formal education to Grade 12: two primary caregivers had no schooling, three had primary schooling and three had secondary schooling. Only one primary caregiver was employed as a part-time domestic worker, three were unemployed and four were pensioners. Social grants were the main sources of the families' incomes. Only one primary caregiver received financial support from the child's grandparents, who were gainfully employed.

### Themes

In the exploration of caregivers' experiences of caring for children living with HIV, the following five themes, representing the challenges caregivers experienced, were revealed as indicated in Table 1.

**Table 1:** Challenges experienced by caregivers related to caring for children living with HIV

<b>Challenges related to:</b>	
Theme 1	Not knowing the cause of the child's illness and coming to terms with the diagnosis
Theme 2	Dealing with treatment adherence
Theme 3	The prevention and treatment of illness
Theme 4	Protecting themselves and others from HIV infection
Theme 5	Finances required for meeting the needs of children

## **Not knowing the cause of the child's illness and coming to terms with the diagnosis**

Initially the primary caregivers explained that they did not know that the children were HIV positive. They were therefore at their wits' end with the children's frequent illnesses and failure to respond to the treatment. Finally, healthcare workers suggested that the children should be tested for HIV. A primary caregiver reported:

*“Three years after his mother died, he started having problems. One morning he had a high temperature, he was weak, and was not able to do anything. I tried everything in vain. I then took him to the clinic ... they said I should take him to have a blood test ... they said he is [HIV] positive.*

Some grandparents experienced the HIV positive test results as shocks, not only for their grandchildren, but also because they realised for the first time that their children had died from AIDS. One participant, who was the child's biological mother, had to come to terms with the knowledge that she was HIV positive herself, after receiving her child's HIV positive test results, and stated:

*“In the beginning, I was not aware that he was this way ... I realised in 2000 that I have HIV when my child was sick”.*

Caregivers' lack of knowledge about children's HIV status concurred with the findings from a study on caregiving for Thai children with HIV infection by Thampanichawat (2008:203–204) and a study by Wacharasin and Homchampa (2008:392) on a Thai family caregiving model. These studies also confirmed that primary caregivers wanted to know the truth about the diagnosis of children living with HIV, in order to remove the stress and anxiety caused by not knowing what was wrong with their child.

Thampanichawat (2008:203–204) and Wacharasin and Homchampa (2008:393) also found that the confirmation of the child's HIV positive status came as a shock to the caregivers, participating in their studies, and that they initially denied the HIV positive diagnosis. As was the case in this study, Wiener, Havens and Ng (2003:374–375) pointed out that the biological mother of a child living with HIV, might learn about her own HIV status when her child's HIV positive diagnosis has been made.

## **Dealing with treatment adherence**

After the initial shock of the diagnosis, primary caregivers said that they were relieved when the children commenced with anti-retroviral treatment (ART), because their physical symptoms improved. However, for some the symptoms became worse when the ART commenced and the primary caregivers did not know what to do, as stated:

*“We were not sure that these tablets will be effective. A lot of people were not yet taking this treatment ... that time we did not know what made her sick, whether it was the tablets or what was actually happening ... we were surprised that she was sick even when taking the tablets [referring to ARVs]. So it was what frightened us. Is it the treatment, illness, will she survive?”*

The effectiveness of the treatment depended on near perfect adherence. This posed a serious challenge to the primary caregivers, as it meant that the children would require constant supervision to make sure that they took the treatment as prescribed. Some children received support from family members, but many caregivers felt they could not trust other people with the children’s treatment. This dedication to the children’s treatment, prevented some primary caregivers from participating in family and social activities that would take them away from home. One primary caregiver explained:

*“His father is still alive ... one day he asked to take him to his place ... I let him go for two days. When the child came back he was not given his medication ... they [health personnel] explained that there should be no mistakes.”*

Another challenge was that some children had to be forced to take their medicines regularly, causing frustrations for the primary caregivers, as stated by one caregiver:

*“At times when I speak with him he listens, but other times when he refuses to take medication I become irritated and ask him: ‘do you know what this thing [HIV] is?’ ... he says ‘I will stop taking this treatment’. I say to him ‘you will die’, even if I know that I use a wrong thing to threaten him.”*

Another challenge related to adhering to the exact ART time schedule. Primary caregivers implemented different methods as reminders, such as cell phones and alarm clocks and cues such as the end of a daily television programme, to remind them that it was time to administer the medication to the children. Seven day pill containers were also used as a caregiver explained:

*“When I arrive home I have containers. I put in tablets for seven days every Sunday night ... Sunday night all containers are supposed to be empty. If I open the containers and find that they are not empty and I was not home, I will ask them, why are there tablets remaining?”*

As was the case for some primary caregivers in this study, McComsey and Leonard (in UNAIDS, 2006:166) reported that caregivers did not stop worrying after the children’s HIV status had been confirmed. This was the case as the side effects associated with the ART were severe and the caregivers were unable to distinguish between the complications of the disease and ART side effects.

Caregivers' distrust of others to ensure that the child takes the medication is supported in a study by Hejoaka (2009:891). Concerns about adhering to the time of taking the treatment caused primary caregivers to schedule their days to fit in with the children's times of taking medications, as they did not want to leave the children in the care of other people.

The challenges experienced by caregivers in this study, to ensure that children took ART as prescribed, were supported by Thampanichawat (2008:207) and Wacharasin and Homchampa (2008:391). These authors suggested that although children took their treatment voluntarily, the primary caregivers explained that it was important for them to supervise the children to prevent children from throwing away the treatment.

### **The prevention and treatment of illnesses**

In addition to treatment adherence, primary caregivers stated that they encountered challenges to prevent the children from getting ill. They had to take special measures to maintain clean environments and to ensure that the children ate balanced diets and appropriate food before administering treatment. Caregivers insisted that children should avoid eating cold food, as according to the caregivers, cold food caused illnesses. A caregiver said:

*"I prefer to be here [to] cook for her, and give her food to eat. When we do not have 'mealiemeal', I borrow from my neighbours, cook for her so that she can eat. I am happy when she eats, because she is sick, and when she does not eat I become upset ... I do not allow her to clean the floor or to use cold water."*

The children living with HIV suffered from opportunistic infections at times. The primary caregivers reported that they had sleepless nights when this occurred. They had to deal with diarrhoea, vomiting, oral thrush, pyrexia, tuberculosis and convulsions. Daily visits to the clinic and numerous consultations, involving various health care providers, were some of the challenges that the primary caregivers had to face. Furthermore, some caregivers explained that they did not know what HIV was and did not understand the child's symptoms and frequent opportunistic infections, as became apparent when one caregiver explained:

*"We only found out when this child was two years old. He did not gain weight, [was] coughing and he was sick. I took him to the doctor time and again. I did not have knowledge about this disease as we never experienced it at home. I did not know what was happening if the child was that way. Traditionally we think that the child's problem is "tlhogwana" [gastroenteritis]. You take the child to a healer, and they will give him an enema, he will have diarrhoea then you will end up not knowing what to do ..."*

Two studies (UNAIDS, 2006:170; Wacharasin & Homchampa, 2008:391) concurred with the findings of the current study about the importance of good nutrition for children living with HIV. These studies reported that caregivers of children living with HIV, realised the importance of providing balanced diets to these children. The primary caregivers realised that good nutrition would assist the maintenance of the children's immune systems and help to keep these children active and healthy.

### **Protecting themselves and others from HIV infection**

It was not only important to keep the children healthy, but the families also needed to be protected from becoming infected when taking care of children living with HIV:

*“... I tell her [the child living with HIV] that if you have sores don't, or if you are bleeding, do not touch the dishes it is just that here in the hospital they warned us that if she can get injured, do not allow her to touch anything because you will all become sick ...”*

Another challenge for caregivers was protecting themselves and other family members from infection without showing discrimination. They felt that using protective clothes, such as gloves, might cause the children to feel that they were treated differently from others. The primary caregivers were also afraid that other members of the family or community, who did not know the children's HIV status, would start asking questions if they noticed the use of protective clothing. Thampanichawat's (2008:206) study also reported that the primary caregivers did not wear gloves when washing the children living with HIV. To the caregivers in the same study, giving their children living with HIV loving care was their first priority and this overrode all their fears of getting infected with HIV.

The findings in this study, namely that the primary caregivers avoided the risk of exposure to the HI virus, are supported by a study by Hejoaka (2009:872), in which the primary caregivers stated that they were careful when they carried out their caregiving tasks to avoid getting infected with the HI virus.

### **Finances required for meeting the needs of the children**

Primary caregivers were challenged to meet the basic needs of the whole family and the children living with HIV. For primary caregivers, this problem was compounded by the fact that the children living with HIV had special needs in order to acquire and maintain the health status that would enable them to be asymptomatic. These special needs include adequate nutrition, taking meals before administering medication and frequent trips to the healthcare facilities. The elderly primary caregivers were using

their old age grants of R1 080.00 per month (South African Social Security Agency [SASSA], 2010). An elderly caregiver said:

*“I have two children and two grandchildren; they are four ... when I include this one [child living with HIV] they are five. They are all attending school. I get the pension grant of R1000.00. I use it to pay funeral societies, school fees”.*

Caregivers also supplemented their finances with the foster care grant of R710.00 per month per child living with HIV in their care (SASSA, 2010). However, they expressed various challenges related to accessing these social grants. The suspension of the previous foster care grants paid to all children in their care, without prior notification, caused financial hardships for some caregivers, as explained:

*“Their foster care grants. It has been suspended for long ... They suspended it in February. They said that they were going to renew it. I last got it in February, till today ... I went there three times and asked them”.*

Primary caregivers found the slow procedure to process the grant applications challenging. They were not conversant with the documents required and were sent from one office to another. At times they had to resubmit the applications as they were told that their papers had been lost and this meant longer waiting periods:

*“When I go to the social worker they say that they have forgotten, they have lost my papers. I went there three times and asked them ... they searched all over ... They told me to go home and they will call me so that I can go to court ... I am still waiting”.*

Literature, cited in a study by Tshililo and Davhana-Maselesele (2009:141), supported the findings of this study, namely that the family members were frustrated because the social workers delayed processing their applications for social grants. During this period of waiting, the primary caregivers had to make ends meet with their old age grants or some had to ask their older children for assistance. This, however, was not always possible and at times they had to manage without essentials such as electricity.

The primary caregivers further expressed their dismay with the children's biological fathers who often failed to provide financial support:

*“His father is still alive, but after the funeral, [of the mother of the child living with HIV] he never came again ... he came this year and the child is already ten years ... he gave the child R10 and said that he will come back during the weekend, he never did ...”*

For most primary caregivers, the sources of financial support were social grants. These findings concurred with those reported by the South African National AIDS Council (SANAC, 2007:33) indicating that the older women's unemployment status caused

them to be poor and to depend on social grants to care for a number of children in their households. The caregiving role also limited the primary caregivers' opportunities of improving their education and of becoming gainfully employed (Pallangyo & Mayers, 2009:488; UNAIDS, 2006:90). A study by Defilippi (2003:614) on dealing with poverty in South Africa and a study by Thampanichawat (2008:207) suggested that money was needed to care for the sick children, as well as to take these children to healthcare facilities that were sometimes far from their homes.

## **CONCLUSIONS**

Exploring the experiences of primary caregivers who cared for children living with HIV highlighted some of their challenges, pertaining to the diagnosis and its implications, such as dealing with frequent illnesses; challenges from a prevention and treatment perspective and financial challenges. These challenges need to be considered within the context of the advanced age of many caregivers and the many responsibilities and commitments of these often poor elderly women who might have to sacrifice their own social responsibilities to care for children living with HIV.

These challenges emphasise the importance of effective management of the social grant system, as well as the provision of a comprehensive holistic service to children living with HIV, including the wellbeing of the primary caregivers.

## **RECOMMENDATIONS**

Holistic health services should include services addressing the health of primary caregivers, a 24-hour government sponsored telephonic support line where primary caregivers can access information (for example on dealing with diarrhoea or the side effects of ART). The process of accessing grants should be improved. In addition, the structures and processes to enforce financial responsibility by parents (specifically fathers) should be a government priority.

## **LIMITATIONS**

A limitation of the current study is the small sample of primary caregivers who participated in the study. Future research should include more participants and could focus specifically on the experiences of biological mothers, as their realities might be different from those of other caregivers.

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