

The experiences of family caregivers concerning their care of HIV/AIDS orphans

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Keywords: HIV/AIDS; orphans; caregivers; South Africa

Abstract

SA Fam Pract 2009;51(6):506-511

Introduction: The HIV/AIDS pandemic is reducing life expectancy and raising mortality. An increasing orphan population is perhaps the most tragic and long-term legacy of the HIV/AIDS pandemic. By 2010 sub-Saharan Africa is expected to have an estimated 50 million orphans and it will be staggered by this challenge. By the middle of 2006, 1.5 million children under the age of 18 years were maternal orphans in South Africa, and 66% of these children had been orphaned as a result of HIV/AIDS. Although government and non-government organisations have responded by building orphanages, most of Africa's orphans have been absorbed into extended family networks. Many of these extended family caregivers are ageing and often impoverished grandparents.

Methods: This was a descriptive, qualitative study using the free attitude interview technique. All family caregivers who consulted at the Hoekfontein Clinic, North West Province, South Africa between March and June 2006 formed the study population. A total of nine one-on-one interviews had been conducted by the time saturation of data was reached.

Results: All nine caregivers were women, mostly grandmothers (67%), and the orphans were between the ages of 5 and 20 years. Emergent themes were: poverty and lack of money; bureaucratic difficulties and lack of assistance from the social support services; lack of support (financial, physical and emotional) from other family members; frustrations of coping with rebellious orphans; pain of caring for the terminally ill family members; feelings of despondency (hopelessness); conflicts in the family; and the rejection of orphans by their fathers.

Conclusions: The study showed that the family caregivers experienced a lack of welfare and family/emotional support in their care of HIV/AIDS orphans. It is recommended that health care workers, including social workers and home-based caregivers be trained on available social support from government and non-governmental organisations for caregivers of HIV/AIDS orphans.

Peer reviewed. (Submitted:2008-11-13, Accepted:2009-02-06). © SAAFP

Introduction

Children orphaned by Acquired Immune Deficiency Syndrome (AIDS) are entitled to non-discrimination; consideration of their best interests; and have survival and development rights, including education, health, social security and appropriate alternative care.¹ Caregiving takes a huge toll on the caregiver physically and emotionally; in some cases it can even lead to depression and burnout. According to Gale Ure, clinical director of the Talisman Foundation (a psychosocial rehabilitation institution in Gauteng, South Africa) – “caregivers are often expected to be all-enduring martyrs to the cause of caring, whether it is relatively short-term caring or long-term”.²

Sub-Saharan Africa remains the region most severely affected by the HIV/AIDS pandemic. It is a tragedy of epic proportion that is restructuring the African population.² In 2007, an estimated 22.5 million people were living with HIV/AIDS in sub-Saharan Africa, with South Africa being the country with the largest number of HIV infections in the world. By 2007, the number of global AIDS deaths was 2.1 million: 1.7 million adults and 330 000 children under 15 years of age.³

The increasing orphan population is perhaps the most tragic and long-term legacy of the HIV/AIDS pandemic. In sub-Saharan Africa the proportion of orphans has increased by over 50% since 1990. By 2010, sub-Saharan Africa will be home to an estimated 50 million orphaned children, more than a third of whom will have lost one or both parents to AIDS.⁴ In 2006 South Africa had over 1.5 million maternal orphans under the age of 18 years, and 66% of these children were orphaned as a result of HIV/AIDS.⁵

The principal researcher observed a growing number of caregivers (mainly grandmothers) who had requested state grants for their orphaned grandchildren over the past few years at the Hoekfontein Clinic, North West Province, South Africa. In applying one of the principles of family medicine – “The family physician seeks to understand the context of the illness”,⁶ – the researcher realised that these grandchildren were HIV/AIDS orphans. All the caregivers did not know their rights, or those of the orphans as far as the state grants were concerned. Some did not have the necessary documents to apply for state grants and also did not know how to obtain these documents. This problem created great distress among the caregivers.

The aim of this study was to explore the experiences of family caregivers seen at the Hoekfontein Clinic, North West Province, South Africa, concerning their care of HIV/AIDS orphans.

Methods

This was a descriptive, qualitative study, using the free attitude one-on-one interview technique in which family caregivers of HIV/AIDS orphans were interviewed about their experiences of taking care of their orphans. The exploratory question was: *“Would you please tell me your experiences as a family caregiver concerning your care of the orphans?”* A purposeful sample of nine caregivers was taken from family caregivers seen at the Hoekfontein Clinic, North West Province, South Africa. All interviews were conducted in Setswana by a research assistant fluent in English and Setswana, and audiotaped. All interviews were conducted at the homes of the participants. A signed informed consent was obtained before commencement of each interview. Data were collected from March to June 2006.

During the interview process the principal researcher kept field notes on the expressions of the participants, their attitudes, interactions, and non-verbal communication. In addition, the principal researcher kept a research diary to note the sequence of events throughout the research process. The recorded data were transcribed verbatim from the audiotapes and translated into English by a second research assistant proficient in English and Setswana. In addition, demographic characteristics of the participants were collected to link them to the data.

The data were analysed manually using the “Thematic Analysis” method, where themes are generated from the interpretation and exploration of various statements and situations.⁷ Colour coding and the “cut and paste” method were used to analyse each interview and the field notes. Emergent themes from the field notes were incorporated in the analysis of individual interviews and a list of combined themes was developed. Finally, a model was developed from the combined themes to show their inter-relatedness. Triangulation, that is, using more than one method of data collection, was done through audiotaping the interviews, compiling field notes and a research diary, to ensure confirmation and completeness of data.

Results

By the time saturation of data was reached, nine family caregivers had been interviewed. All nine caregivers were women: six were grandmothers (67%), two were aunts (22%), and one was a sister to the orphans (11%). Table I shows the demographic characteristics of the participants and Table II shows a summary of the emergent themes from the interviews. Each interview had a brief participant profile, and themes and supporting evidence from the transcripts.

Poverty and lack of money

This emerged from interviews with seven of the nine participants. Caregiver 4's house was old and dilapidated. She was the sole breadwinner and struggled financially, as indicated by the following quote: *“...we survive on this R190 child grant, and I add it to my old age pension grant”*. Caregiver 7 was also struggling financially and expressed the following: *“...my mother was struck by stroke and she is receiving old age pension grant and we try by all means to spend this*

Table I: Demographic characteristics of the participants

Participants	Race	Age (years)	Relationship to orphan(s)	Occupation	Ages of orphans (years)
1	Black African	76	Grandmother	Pensioner	13, 14 and 15
2	Black African	56	Grandmother	Unemployed	13
3	Black African	77	Grandmother	Pensioner	12, 14 and 18
4	Black African	74	Aunt	Pensioner	12
5	Black African	57	Grandmother	Unemployed	5, 16 and 17
6	Black African	53	Grandmother	Unemployed	6 and 8
7	Black African	50	Aunt	Unemployed	15 and 20
8	Black African	69	Grandmother	Pensioner	13
9	Black African	18	Sister	Unemployed	9 (twins) and 14

Table II: Emergent themes emerging from interviews with caregivers

Themes	Caregivers								
	1	2	3	4	5	6	7	8	9
1. Poverty and lack of money	X	X	X	X		X	X		X
2. Bureaucratic difficulties and lack of assistance from the social support services	X	X	X	X	X	X	X	X	X
3. Lack of support from family members (emotional, financial or physical)	X	X	X	X		X	X		X
4. Frustrations of coping with rebellious orphans	X	X	X			X	X		X
5. Pain of caring for the sick	X	X	X			X	X		X
6. Despondency (hopelessness)	X	X	X			X	X		X
7. Conflict in the family				X	X		X		
8. Rejection of orphans by their fathers					X				X

money on her special needs and the remaining one we use on other items in the house. The thing is these children they actually need care and support seriously. At times we end up having to go to sleep without food and right now is winter and the season is almost ending and we did not buy them anything warm, because I cannot afford to buy them anything”. Caregivers 5 and 8 did not reveal poverty and lack of money as a theme; their relatives supported them financially.

Bureaucratic difficulties and lack of assistance from the South African social support services

This emerged from all nine interviews. Seven of the participants indicated a lack of money to care for the orphans. Caregiver 2 expressed a lack of knowledge, and frustration, regarding how to apply for a foster care grant, and that it takes a long time to process such grant: *“I do not know how to go about applying for the orphan grant; I did go to Moshate (tribal authority), I went there and one woman there advised me that I should start with this child grant first because the one of orphans (foster care grant) takes time before you can start receiving it. It is hard because*

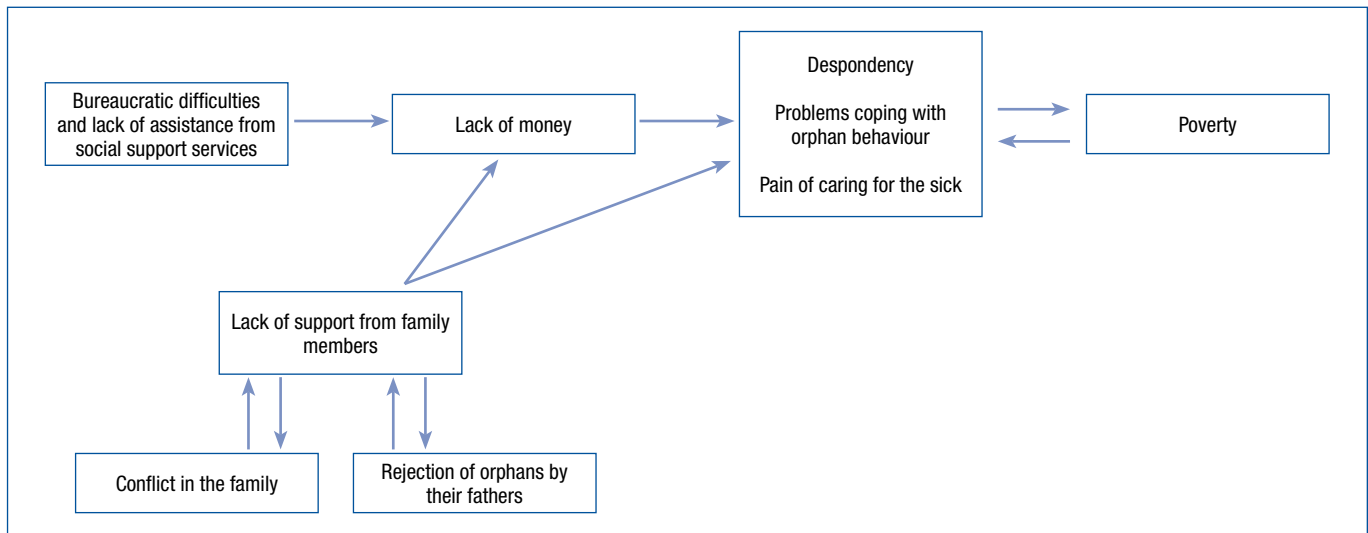


Figure 1: Relationship between emergent themes (model)

I am always going to Zone 5 (Department of Social Welfare offices) to ask about the money, and they always tell me that it is not available, and they always tell me that I should come next month; it is always next month and next month. Till today I have not yet received it, I truly do not know what to do because for me to go to Zone 5 it costs me money and when you get there you wait in long queues." Caregiver 4 indicated that the social workers and tribal office people were too slow to help with foster care grants: *"I got the heart to help this child by applying for this orphan grant. I am still waiting for the money because it is not yet released. I sent the documents a long time ago. The social worker has since told me that they will send someone at home and I am still waiting. I wish that money can come so that I can save some for him (the orphan) because I am old – anytime I can die, you see"*. Caregivers 5 and 8 were able to care for the orphans financially (they were financially supported by their family members) but they also experienced bureaucratic difficulties.

Lack of support from family members (financial, physical and emotional support)

This theme emerged from seven interviews. Caregiver 3 reported that she did not get help from other family members in taking care of the orphans, when she said: *"I am the one taking care of these children and I have since been the one who is taking care of them, I have struggled to take care of them."* Caregiver 6 shared that her husband did not support her emotionally when their children were terminally ill: *"The day Johanna died he came and found me struggling with her, he came into the room and walked out, and when he came back again the child was already dead. He is not cooperative in the house, but I just wish God to grant me the strength to care for these young ones until they are old enough to care for themselves"*.

Frustrations of coping with rebellious orphans

This theme emerged from six interviews. Caregiver 6 expressed difficulty in coping with teenage rebellion and that it was frustrating: *"... now that they are here we have seen that these two are so problematic, they do not want to do anything and when you punish them it is like you do not like them, you end up feeling guilty. I have observed that they think there is no one who can take care of them like their mother. This elder one is no longer going to school; he has just lost interest in school. You cannot talk*

to him; once you try and talk to him he becomes all argumentative. This other one, Thato, his school called us to tell us that he is not performing as he used to and he is a clever boy. At times I end up telling myself that maybe these people need counselling".

Caregiver 9 reported that it was hurtful dealing with her younger sisters' and brother's behaviour change: *"... since her death (their mother) things have changed and they are no longer like before. The first one to change is Maria, she was such a bright kid from primary school till now, and this other young girl has changed as well, hence she failed grade 2, it is only the boy who have passed, and now they are even naughty. They were not like this, and they do not listen when you talk to them, and my granny is not that strong, it hurts and I wish my mother was around."* Caregivers 4, 5 and 8 did not experience rebellion from the orphans.

Pain of caring for the terminally ill family members

This theme emerged from six of the nine interviews. Caregiver 1 expressed the pain of caring for the orphans and her terminally ill children at home: *"... the first one to die was their brother then later followed by his sisters. I nursed all my children when they were sick, all three of them (she cried and the interviewer allowed her to ventilate). This sickness kills a person horribly; it sucks all his blood out. I was so hurt – I nearly died. I had some terrible pains on the back of my neck, but I managed to come out of that and called upon God to carry me. I cried my heart out – I had to cry"*. Caregiver 6 also expressed the pain of caring for her late children, her HIV grandson and her immune-compromised granddaughter through this following quote: *"... after burying these children I was sick, because I nursed them throughout their illness until I realised that there is nothing that I can do. I took Tumi (her grandson) to the doctor because he was ill, he is HIV positive. I make sure that every month I take this child to the doctor. I hope they find a cure for AIDS soon. Tumi and this other girl (her granddaughter) are very weak and they are a bit slow. I think this girl might be infected by the virus as well"*.

Caregivers 4, 5 and 8 did not experience pain of caring for the sick. Caregiver 4 did not care for the orphan's late mother and she did not have an ailing person at home. Caregiver 5 was helped by her husband to care for the orphan's late mother and caregiver 8 was supported by her children to care for the orphan's late mother.

Feelings of despondency (hopelessness)

This theme was extracted from six interviews (caregivers 1, 2, 3, 6, 7 and 9). Caregivers 7 and 9 reported that conditions at home were overwhelming and they felt helpless and hopeless. Caregiver 7 said: *"It is difficult because I feel that all this is taking place within a very short space of time. It is overwhelming for me because it is my mother, my sister and the orphans, and these have made me not to consider my personal problems. I do not have enough time, to an extent that at times I just become so stressed and end up saying, hey! Things will work themselves out when the time is ready"*.

Caregiver 9 also said: *"... today this is very difficult and these children are growing up not knowing their father and now their mother is gone. At times I look at them, there is nothing that I can do, they are my mother's children and if I could help I would, and unfortunately there is nothing that I can do for them"*. Caregivers 5 and 8 had the support of their family members and there was no lack of money in their households. Caregiver 4 was comfortable with the decision she made to care for the orphan.

Conflicts in the family

This theme emerged from only three interviews (caregivers 4, 5 and 7). The conflict between caregiver 4 and her sister (the orphan's biological grandmother) was that caregiver 4 had decided to care for the child without negotiating this with her sister, and she was the one receiving the childcare grant. She said: *"... this child has a grandmother and because of my knowledge that she would not care for this child properly I decided to take him in and care for him. I think that she (the orphan's biological grandmother) is thinking that because I am receiving this child's orphan grant, she is not sending anything for this child who is basically her responsibility"*. With caregiver 5 the conflict between her and the orphan's grandmother was that there was no formal agreement of who should take care of the orphan, who was the caregiver's niece.

Caregiver 5 reported that: *"... the Friday after we buried her (the orphan's) mother she came to me with her things. She said she wanted to stay with me because she cannot stand her other aunt. I told her she can stay for the weekend and I will give her money on Monday to go back home because I was avoiding conflicts. On Monday when she arrived home, her aunt attacked her and she ended up not going to school. The same afternoon I heard someone knocking at my door, when I opened it was the orphan's grandmother. She said to me I have brought back the child – I said to her how could you? – I did not mean that I am taking this child permanently. I was just allowing her to heal for a while. I then told her (the orphan's grandmother) that I returned the child to you based on your funny stories and you return the child back to me. Okay, I will take child in, just as her late mother used to come and stay with me when you ill-treated her"*. The conflict between caregiver 7 and the orphan's uncle was that she (the caregiver) was the one receiving the childcare grant.

Rejection of orphans by their fathers

Four interviews did not provide information about the whereabouts of the orphans' fathers. Rejection of orphans by their fathers emerged from two interviews (caregivers 5 and 9). In three interviews, fathers to orphans were already dead at the time of the interviews. Caregiver 5 reported that the orphan's biological father does not contribute to the care of the child: *"Thapelo's father rejected him while he was a baby. He (Thapelo's*

father) is ailing, but he is still able to do other activities. Something very sad is that he is married to another woman who is sick in that sense (HIV/AIDS). I am not receiving anything from him".

Caregiver 9 also reported that her biological father as well as her stepfather rejected her, her brother and her twin half sisters: *"Our father is alive and married to another wife and he does not care about us, even when we go to him and tell him what we needed; he would at times swear at us so we stopped going to him. The twins' father left my mother when she was pregnant with them, we do not know where he is. It hurts and I wish my mother was around because I know that she would be able to do some thing"*.

Discussion

The results of this study were derived from the data collected. The interpretations and conceptualisations were those of the researchers. The research question was adequately answered by the participants. Much information was obtained about the experiences of family caregivers in their care of HIV/AIDS orphans. Although it was noted that some experiences were cited more than others by the participants, no attempt was made to look for consensus. In qualitative research consensus does not always mean that the correct answer has been found, as there is danger in deriving collective ignorance rather than wisdom.⁸ However, for the sake of conceptualising common trends, numerical representation were used to describe the themes.

Poverty was observed in seven participants' households. These participants cited lack of money to address the orphans' basic needs (food, clothing, shelter and education). The two participants (caregivers 5 and 8) who were financially comfortable were supported by family members. All seven caregivers' houses were dilapidated, unkempt and overcrowded. Other members in these families who were not caregivers and could be employed were unemployed. Poverty from joblessness remains unusually high in South Africa compared to other middle-income developing countries.⁹ In 2005/6, a major South African government study of income and expenditure found that half of all households, with between three to four persons in the average household, lived on less than R600 per person per month. The poorest 20% of households lived on less than R1000 a month and the richest 10% had over R15000 a month. High levels of poverty go hand-in-hand with deep inequalities. It was also found that, under apartheid, black people were pushed into the least developed parts of the country, that is, the former homelands, and were deprived of assets and education.⁹

According to Shisana and Louw, although orphans more frequently live in female-headed households, grandparents were found to be the main caretakers for almost half of the orphans.¹⁰ The economic status of the fostering household is important for child welfare as it increases school participation, which enhances orphans' overall wellbeing. According to Fleck many households have become poorer owing to the HIV/AIDS pandemic.¹¹ Increasing numbers of orphans are exerting tremendous pressure on fragile economies, and existing social and health services of the developing world.¹² Capacity and resources are stretched to breaking points, and those (persons) providing the necessary care are in many cases already impoverished, often elderly, and might themselves have depended financially and physically on the support of the very son or daughter who has died.¹³

Schonteich notes that families that foster children in Kenya usually live below the poverty line, and that orphan households in Tanzania have more children, are larger, and have less favourable dependency ratios than non-orphan households.¹³ Freeman and Nkomo note that in Botswana the 'orphan crisis' is impoverishing even working households, and caregivers lack sufficient resources to provide basic needs.¹⁴

All nine caregivers reported frustrations in accessing social grants for the orphans due to delays, misinformation by social service workers, or lack of necessary documents required to obtain these grants. According to the 2004 Health Systems Trust Report, the child welfare system has left many AIDS orphans stranded because of the increasing number of children orphaned by HIV/AIDS seeking foster care and the HIV/AIDS pandemic is placing enormous pressure on South Africa's child welfare system.¹⁵ Social workers are grappling with heavy caseloads, while caregivers applying for foster care grants have sometimes waited for as long as two years for their submissions to be processed. The poorest households rely on social grants and households that are unable to access these grants are the poorest of the poor. The latter is consistent with the experiences of family caregivers in this study.

Nicoli reports that an estimated 12 million South Africans living in poverty receive no social assistance.¹⁶ The roots of the South African system extend back to 'the apartheid days' when whites were the only ones eligible for government grants and were (for the most part) fully employed. This meant that there was only a need to support people who were too sick, too old or too young to work. Now the South African government's policies support everyone, regardless of race, but our welfare system is failing. This is because it has not adapted to the reality of high unemployment and our high HIV prevalence rate.

Lack of support (financial support, emotional support or physical support) from family members was experienced by seven of the nine caregivers. D'Cruz states that social support (formal and informal) is an important buffer for family caregivers of people living with HIV/AIDS. He found that caregiver perceptions of their experiences with the informal support from extended family varied along a continuum of satisfaction to dissatisfaction.¹⁷ Caregivers were inhibited from requesting help from their relatives by a desire not to trouble others and a feeling of shame to be dependent. Research on extended family support of family caregivers of HIV/AIDS orphans is sparse.

Experience of frustrations in dealing with rebellious behaviour of orphans was mentioned by six of the nine participants. Of the three participants who did not experience frustrations, one of them (caregiver 8) had the support (emotional, physical and financial) of other family members. Caregiver 5, who was financially supported by her husband, experienced feelings of acceptance and compassion for the orphans because of her increased trust in God to take care of the orphans. Caregiver 4 had made a decision to care for the orphan (who was her sister's grandchild) and had developed good communication with the child.

A study carried out by The Nelson Mandela Children's Fund found that South African AIDS orphans suffered emotionally, as a result of deprivation of parental guidance, emotional trauma as a result of loss, and the problem of having to cope with adult responsibility prematurely.¹³ The South African Department of Health, which looks at the impact of health in South Africa, predicts that children orphaned because of AIDS could be

at the risk of engaging in delinquent behaviour. As children under stress grow up without adequate parenting and support, they are at greater risk of developing antisocial behaviour and of being less productive members of society.¹³

HIV/AIDS orphans drop out of school to provide the necessary care for dying parents, and this almost guarantees that they face limited futures.¹⁸ In the Third World, education is the key in rescuing children from the vicious cycle of poverty. If these orphans attend school during a parent's illness, the emotional stress often manifests itself as a lack of attendance and inappropriate behaviour. These findings are consistent with the experiences of six of the caregivers in this study.

Six of the nine caregivers experienced the pain of caring for the orphans' terminally ill parents before they died. Five participants had lost more than one child to AIDS. They were burdened with taking care of the terminally ill at the same time that they were taking care of the orphans. Providing care to an ill family member is a stressful experience for the entire family.^{17,19} The progressive, long-drawn and terminal nature of HIV/AIDS compounds the stress engendered by the caregiving role but the stigmatising nature of the virus keeps caregivers from seeking and receiving much needed support.¹⁷ Cullen and Barlow report that parents of children with disabilities assume the primary burden of care, balancing time-consuming and complex treatment regimens with other aspects of family life and work commitments.²⁰ The greatest burden of care typically falls upon mothers, who are at greater risk of psychosocial distress compared with mothers of children without disability.

Only two of the nine participants reported that the orphans' fathers abandoned them. Three caregivers reported that the orphans' fathers died of HIV/AIDS-related illnesses and the remaining four caregivers did not provide information on the whereabouts of the orphans' fathers. Denis and Ntsimane, in their study on men and fatherhood in South Africa, established that among the poor a very high and growing proportion of children do not live in households with their fathers.²¹ Single mothers raise most children and their biological fathers play a marginal role in their lives. These men do not see the benefit of establishing permanent relationships with the mothers of their children, and even if they wish to form a stable couple, their life circumstances and the scarcity of jobs make it difficult for them to reach that goal.

In their study, Desmond and Desmond established that, in South Africa, fathers were present in the same household as their children in only 48% of cases, compared to mothers who were resident in 80% of the cases.²² This study reveals (once again) that the burden of care and responsibility for children falls largely on the women. They do state that this is only an observation, not a judgement. Furthermore "*there is no data available on the reasons for the absence of fathers*". But it is likely that in many cases it is circumstances rather than choice that lead to the separation of men from their children.

Information on conflict in the family was provided by three participants. Frankel et al, in a study of caregivers of patients with Alzheimer's disease, report that negative emotional responses by extended family members towards the family caregiver are highly predictive of caregiver depression.²³ Hence family variables such as negative expressed emotions strongly influence the health and well-being of both identified patients and family caregivers. In this study the conflicts were more due to financial conflicts.

Six participants (caregivers 1, 2, 3, 6, 7 and 9) experienced feelings of hopelessness about their caregiving roles. These caregivers were poor and did not receive support (financial, physical, emotional) from other family members. According to Baggaley and Needham, in Africa, AIDS has meant that childhood is lost for many children, who have prematurely taken on adult roles of caregiver and guardian.¹⁸ These children are often too young to understand what is happening and they feel angry with their “inadequate” parents for shifting the burden to them. Townsend and Dawes report that conditions of extreme poverty might result in endemic chronic stress; affectively distant, punitive and inconsistent parenting; and negative emotional states such as helplessness, decreasing self-esteem, depression and anxiety.²⁴ This is consistent with the experiences of six of the caregivers who were the subjects of this study.

Conclusions

The study showed that the family caregivers experience lack of welfare and family/emotional support in their care of HIV/AIDS orphans. It is recommended that health care workers, including social workers, and home-based caregivers be trained, on an ongoing basis, on available social support from government and non-governmental organisations for to caregivers of HIV/AIDS orphans.

Ethical considerations

The research protocol was approved by the Research Ethics and Publication Committee (REPC) of the University of Limpopo (Medunsa Campus) – clearance certificate no MP 03/2006.

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