

Challenges faced by grandparents caring for AIDS orphans in Koster, North West Province of South Africa

DELIWE R. PHETLHU¹ AND MADA WATSON²

¹*University of the Western Cape, South Africa. E-mail:dphetlhu@uwc.ac.za*

²*School of Nursing Science, North-West University, South Africa*

Abstract

Caring for orphans who have lost their parents due to AIDS, and some of whom are infected, is an enormous challenge. This immense responsibility often resides with the grandparents, who are in most cases sickly and not financially capable to undertake the task. The objectives of this study were to explore and describe challenges faced by such grandparents and their needs while caring for AIDS orphans in Koster, North West province, South Africa. Maslow's theory of human needs was used as a theoretical framework to guide the study. A qualitative approach with an explorative and descriptive design was used. Grandparents who cared for AIDS orphans and were assisted by non-governmental organisations were purposively selected. Semi-structured interviews were conducted with 15 participants and thematic analysis was done to interpret the data. The findings revealed that the grandparents faced biophysical, socio-economic and psychosocial challenges and these impacted on their emotions; however, they indicated different coping strategies which were available to them. The participants highlighted that their main priority, as a need, was assistance with food supply for themselves and the orphans. The study concluded that the focus in attempting to meet the grandparents' needs should not only be the basic order needs in Maslow's hierarchy but all the other orders, as they have a great impact on both the grandparent and the AIDS orphan.

Keywords: AIDS orphans, caring, grandparents, challenges.

How to cite this article:

Phetlhu, D.R. & Watson, M. (2014). Challenges faced by grandparents caring for AIDS orphans in Koster, North West Province of South Africa. *African Journal for Physical, Health Education, Recreation and Dance (AJPHERD)* October 2014 (Supplement 1:2), pp. 348-359.

Introduction

HIV/AIDS has devastated the social and economic fabric of African societies and made orphans of a whole new generation (Matshalanga & Powell, 2000). After the death of their parents orphans are followed by cycles of poverty, malnutrition, stigma, exploitation and psychological trauma. This occurs when parents who are supposed to raise their children die prematurely due to AIDS and leave them without support, parental love, guidance and resources. In many African communities the responsibility for the care of an orphan is placed on the immediate families, with the main expectation being placed on grandparents. Thus orphans have to rely on aging and often impoverished grandparents who are not financially, physically and emotionally ready for this new responsibility. This leaves the grandparents with challenges that they have to face despite their incapacity to do so, which often has detrimental effects on their health.

HelpAge report (UNAIDS, 2008) confirms that half of the world's 15 million orphans are currently being cared for solely by their grandparents, and these numbers will double again by 2015. These older people above the age of 60, many of whom are women, struggle to feed their grandchildren and nurse sick toddlers while being vulnerable to physical ailments such as backaches and chronic diseases (Weiten, 2007), complicating their situations further (UNAIDS, 2008). Nonetheless, because the grandmothers have always been seen as nurturers, the burden of AIDS has fallen mostly upon them (Kaizer Family Foundation, 2006).

Although studies have been done with regard to challenges of grandparents caring for AIDS orphans (Mudavanhu, Segalo & Fourie, 2008; Hlabyago & Ogunbanjo, 2009), none have been done in a rural setting of North West province in South Africa, which has its own unique dynamics, with Koster being one such setting. Koster is situated in the Bojanala region of North West province, and district statistics show that in 2008/2009 the employment figure for the area stood at 10 241 (25.5%) with most of the people working on farms. There is one health clinic and one hospital, and both offer voluntary counselling and testing for HIV.

The limited work opportunities and health care resources expose the community to problems such as poverty and associated health issues; hence the grandparents might be grappling with specific challenges related to their geographic location and economic status. Therefore lack of knowledge and understanding with regard to the specific contextual challenges faced by grandparents and their needs while caring for AIDS orphans is problematic, because generic assistance strategies by policy makers might not be what the grandparents need.

Methodology

A qualitative research approach using an exploratory and descriptive design was used. The population included grandparents who cared for AIDS orphans in Koster, North West province, South Africa, and linked to two non-governmental organisations (NGOs) that are involved in the care of AIDS orphans in that area by supplying them with food parcels. Purposive sampling (Burns & Grove, 2005) was used to select participants who met the specific selection criteria. Individuals working at the NGOs consented to select participants as they already had established trust relationships, but did not participate in the data collection process. This was also meant to ensure that no ethical protocols were compromised by giving the researchers the identity of these participants without their consent. The sample size was determined by data saturation, which was reached after 15 interviews were conducted.

The process of data collection started after permission to conduct the study was received from North-West University Ethics Committee and from the two participating NGOs. After the participants were recruited by the NGOs' staff, they were introduced to the researchers who explained the purpose of the study and the procedure which would be followed during the interviews.

A pilot test of the interview guide was conducted with three grandparents two weeks before the main data collection process, to ensure that the questions asked explored and described what they were intended to. The data from the pre-test were included in the main data collection as no changes were made to the questions. Data collection over five days commenced after consent was obtained from the participants. Semi-structured interviews were conducted in Setswana, the language used by participants and understood by a trained field worker.

The interviews were voice recorded, and field notes as indicated by De Vos, Strydom, Fouche and Delpont (2005) were taken immediately after each interview, and all ethical principles were adhered to ensure confidentiality, autonomy and justice. Data captured on the MP3 voice recorder as well as field notes were transcribed and translated into English for the purpose of organising and writing up the findings.

Thematic analysis was done to create themes, categories and sub-categories for ease of interpretation (Terre Blanche, Durrmer & Painter, 2006). An experienced researcher in qualitative research was appointed as independent coder and a discussion meeting followed in order to reach consensus on the categories which emerged from the data.

Results

Four themes emerged from the data pertaining to the challenges faced by the grandparents in caring for AIDS orphans. These were: 1) dimensional challenges; 2) impacts of the identified challenges; 3) mechanisms used by grandparents in coping with the challenges of caring for AIDS orphans; and 4) grandparents' identified needs. These were clustered into categories and further divided into sub-categories.

Dimensional challenges

The findings revealed that grandparents were faced with different dimensional challenges. The predominant challenges were mainly experienced in the biophysical, socio-economic, psychosocial and emotional dimensions.

Biophysical dimension

Biophysical challenges as reported by the grandparents included limited physical space due to overcrowding, burden of disease due to the orphans' and their own illness, and their challenges in caring for smaller children.

Limited physical space due to overcrowding: The grandparents clearly indicated that they had limited space for accommodation since the orphans joined their families, leading to overcrowding. One of the participants stated that she had no adequate space and as a result her husband slept on a dilapidated sofa inherited from her employers.

Burden of disease due to orphans' and own illnesses: Grandparents were more concerned about the illnesses of the orphans than their own illnesses. Most of them were diabetic and hypertensive, but have decided to prioritise the orphans' illnesses above their own. The grandparents had to visit the health facilities frequently to save the ailing orphans, and as such this caused a burden. The participants mentioned how they frequently utilised wheelbarrows in order to help the orphans when ambulances were not responding immediately. Another participant further indicated how she took her orphans to the clinic for voluntary testing in order for her to intervene timeously if they were found to be HIV positive.

Grandparents' physical challenges in caring for smaller children: One participant indicated that she was expected to bath the orphans and take them to the crèche even though she was a chronically ill patient. The participant highlighted that she was not supposed to touch water and to cook due to weakness, but she was bound because nobody could assist. The participants indicated how they were expected to walk long distances to the Social Development department to apply for social grants, even though they were old and did not have the physical strength.

Socio-economic dimension

Financial challenges in caring for AIDS orphans were highlighted as a major issue as most of what the grandparents need to do for their own survival and that of the orphans requires money. This category was further divided into sub-categories, namely provision of day-to-day basic needs and access to governmental assistance.

Provision of day-to-day basic needs: Grandparents were unable to meet basic needs like food and clothes for orphans. One participant mentioned that an orphan under her guardianship was supposed to go to school and she couldn't afford to pay school fees, while others struggled to purchase school uniforms.

The participants indicated that they had applied for social grants without success and resorted to selling small goods in order to provide the orphans with basic needs. Access to governmental assistance: Some grandparents were unable to access pension grants because they were below 60 years of age and as such do not qualify. Another participant indicated that she requested assistance from government in the form of groceries while waiting for the orphan's social grants, which were delayed due to poor service delivery at the Social Development department. According to the participants most orphans used to be on social grants before their parents died; after the death of their parents the government cancelled the grants, and the grandparents must reapply. It was also mentioned that even after applying for the grants the money takes time to be released. They mentioned that in the case of those who received social grants the money was meagre, and could not cover school fees, school uniform, food and transport. Most participants seemingly did not have information about foster care grants, and this aggravated the situation.

Psychosocial and emotional dimensions

The third category is divided into the grandparents' loss of their own children, the grandparents' lack of skills to deal with post-traumatic experiences of the orphans, and their' lack of skills to deal with the orphans' deviant behaviour.

Grandparents' loss of own children: The way in which the grandparents lost their children was traumatic and made it difficult for them to cope psychosocially. One participant reported how her daughter suffered and another participant indicated how AIDS robbed her of her daughter. Many of the grandparents saw their children dying and were still traumatised. The grandparents still grieved for their children and many reported that they were not coping emotionally. Another participant shed tears as she tried to explain what happened to the mother of the orphans.

Grandparents' lack of skills to deal with post-traumatic experiences of orphans: Grandparents lacked skills to deal with post-traumatic experiences of the orphans. The participants reported how they assisted their children before they died in front of the orphans, and the experiences were traumatic to the orphans. One participant indicated how her orphan behaved strangely by repeatedly attempting suicide, and had decided to keep her chronic medication with the neighbours lest the orphan take an overdose.

Grandparents' lack of skills to deal with orphan's deviant behaviour: One participant reported that she is afraid to rebuke the older orphan as she attempted suicide every time that was done. She further stated that the girl did as she wished, did not want to be reprimanded, misbehaved, and she had to still hold

her peace. Orphans were reported to have played truant, were disobedient and kept bad company, resulting in some becoming drop-outs.

Associated stigma: The grandparents still had a problem with stigma. One participant indicated that she felt ashamed wherever she went because people did not want to eat her food lest they contract HIV. A participant further described incidents where people stigmatised them and treated them differently as soon as they knew that their children died of AIDS. It was indicated that the people who were supposed to support them were now mocking, discouraging and discriminating against them.

Impacts of challenges faced by grandparents

This main theme had one sub-category, namely emotions caused by the challenges. **Emotions caused by the challenges:** Most participants reported having felt hopeless, shameful and frustrated, and they were not 'really' coping but surviving on a day-to-day basis. The participants not only reported being hopeless but were perceived as such by the researchers during the interviews.

Mechanisms used by grandparents in coping with challenges of caring for AIDS orphans

Different coping strategies were reported, which assisted the grandparents in the midst of their challenges. **Support from relatives:** The participants indicated that their relatives supported them with food, clothes and money. One indicated that her sister, who worked as a domestic worker, bought food and clothes for the orphans. Another participant stated that one of her siblings collected old clothes for the orphan from work, while another indicated that her son, who works, deposits money every month for the orphans, which makes life easier.

Support from employers: Many of the employed grandparents got support from their employers, although only a few of them were employed. One participant mentioned that her employer bought clothes for the orphans and also gave her money. Another indicated that her employer bought medication from the chemist when the orphan was sick and also paid the doctor for consultations. Another participant mentioned that her employer contributed towards the needs of the orphans.

Support from home-based carers: These caregivers assisted with bathing of small orphans and emotionally supporting the grandparents. According to the participants the caregivers had specific days to visit the grandparents, when they also assisted the HIV/AIDS-positive orphans with regard to taking their treatment and reminding them of their expected visits to the health facilities.

Odd jobs to augment income: Most of the grandparents sought odd jobs to augment their income. These included domestic work, cutting trees and selling Simba chips in order to make ends meet.

Cheap and second-hand goods: Grandparents resorted to using cheap and second-hand items in order to make ends meet. One participant mentioned that her siblings collect clothes from their place of employment for the orphans.

Grandparents' identified needs

Only one theme emerged here which showed where the grandparents in this context saw their solution to lie. Assistance with supply of food: Assistance with food in order to survive was a priority for these grandparents. One participant indicated that she was not receiving an old-age pension, the orphans under her care were not yet registered for social grants, and it would bring her joy to see them receiving groceries while waiting for the grants. Participants mentioned that they could not afford food since they were unemployed, and that some orphans had to go to school with empty stomachs. Sometimes they have to wait for three months to get groceries from government.

Discussion

Human beings are generally known to have different dimensions to them that make up a whole. These dimensional layers were identified in the interviews with the grandparents as the challenges that they experienced in different aspects of their existence. The implication is that when strategies are developed in an attempt to assist the grandparents in their new role as primary caretakers, all of the different elements have to be considered.

The biophysical challenges of grandparents pose a great threat to the well-being of these elderly folk as it touches the very core of the basic needs identified in the first and second levels of Maslow's theory of human needs (Slavin, 2009). According to Maslow (in Slavin, 2009), all human beings have to satisfy the basic needs before they can feel the need to try and accomplish or satisfy their higher order. The challenges that the grandparents raised validate the importance of the first two levels of human needs as described by Maslow's theory.

Other studies that looked at care of AIDS orphans indicated that limited physical space made it difficult for the grandparents to move around as freely as they would like, lowered their feelings of control and limited (if not took away) their privacy, thus impacting on their sense of security (Aronson, Wilson & Akert, 2005; World Health Organization, 2002). In this study this was depicted in the following excerpt by one participant: "Our two-roomed houses are small for three extra people ... hhh....so?"

Not only does overcrowding impact on the grandparents, but the burden of having young children at an age when physically they need to rest is a challenge. The assumption that grandparents have always taken care of the children in the past might not be plausible, as the conditions are completely different because in this case grandparents worry about the health status of the children in their care due to assumed HIV status. Therefore the costs are not only financial but highly emotional. The following statement sums up the experienced burden: "When they are sick, we carry them with wheelbarrows to the hospital because ambulances don't respond immediately and delay. We don't want them to complicate". According to Oluwagbemiga (2007) it is a strain on household resources and income to take care of orphans that are diagnosed with HIV, because grandparents can no longer work despite the mounting medical fees, pushing affected households into deeper poverty.

The grandparents are further challenged by their own physical health in caring for smaller children. Caring for orphans ranging from infants to teenagers can be physically challenging and exhausting for the grandparents, who have become 'mothers' again and are expected to assist the AIDS orphans despite their own physical abilities (Orb & Davey, 2005; Mudavanhu et al., 2008).

After the biophysical dimension, the challenges on the socio-economic dimension of the grandparent seemed to be a great challenge. The fact that most of the basic needs are dependent on money to be achieved shows the impact on this basic human need. This can also be associated with the first and the second order in Maslow's theory. Provision of day-to-day basic needs is a challenge that can only be resolved when adequate financial resources are available. The following quote from a participant indicates the plight that the grandparents find themselves in, in the absence of this resource: "My challenges are countless, lack of food and clothes ... because I am unemployed and have no money."

According to Orb and Davey's (2005) study, the most challenging hardship for grandparents is finances. Safman (2004) found that the dominant concerns of caregivers of orphaned children are the costs associated with child-rearing in an increasingly market-based society. It is quite evident that the provision of basic needs is taxing on the grandparents; moreover, they are in an environment where there are no opportunities for financial emancipation. Under the circumstances in this rural context, the grandparents' only hope is assistance from government. However, it is clear that accessing this assistance was not easy.

The fact that financial support can be terminated is of concern, as this causes more desperation for the caregivers, who in this case are old and not financially capable. An investigation by government might be necessary before this action is taken to ensure sustenance of the family while corrective measures are being put in place. Failure to do that result in statements like the following by the

grandparents: “I am asking for his money [social grant to be released]. Once I start receiving it, I will be able to pay for his school fees”. This challenge is real, as grandmothers relied on aid from NGOs. Those fortunate to be enlisted for governmental aid complained about delays and the fact that most often orphans do not have birth certificates (Mudavanhu et al., 2008), which creates a problem in accessing government assistance.

The third dimension which is associated with the upper three orders of Maslow’s theory was also highlighted. Grandparents are social beings and need to belong; their self-esteem needs to be boosted so that they can reach a state of calmness in their lives. The grandparents’ loss is often not highlighted, despite the fact that they are parents who hurt when they lose a child. Grandparents are expected to move on, and in the plans to assist them the challenges that impact on their own psychological well-being are never given much thought.

The majority of the grandparents still had fresh wounds that affected them psychologically and emotionally, hence intervention is relevant and appropriate. Grandparents’ grief is often ignored, and they are not given necessary support in their loneliest time. UNICEF (2002) explains that grief is a normal reaction of parents to loss of their children, and is usually intertwined with bereavement. According to Reuter (2009) the social workers, as members of the multidisciplinary team, should provide assistance in order for the grandparents to cope with psychosocial issues such as bereavement and stresses associated with financial worries and the loss of their child.

The grandparents’ lack of skills to deal with the post-traumatic experiences of orphans is also an area that is not often dealt with. An assumption is made that because they have raised children before, they will be able to pick up where they left off. However, the generational gap and associated changes are not considered. Therefore the issues of how the grandparent tends to deal with a child who has lost a parent are never highlighted, leading to frustration for both parties, as depicted by the following statement from the study: “The girl stresses me. After reprimanding her, I don’t move lest she will commit suicide...”.

According to Van Dyk (2008) children or orphans have to go through the same tasks of grieving as adults. In caring for the orphans, the grandparents should understand them and be skilled enough to assist them. Egan (2002) indicated that transferring skills to the grandparents helps them manage their problems in living more effectively and developing unused resources, and also becoming better at helping themselves in their everyday lives. Gouws, Kruger and Burger (2000) stated that it is a frightening fact that suicide among adolescents is increasing because they have been exposed to greater stress while environmental support has decreased, leaving the adolescents more vulnerable. The older orphans were

not an exception, in that they had suicidal tendencies and rebelled against the authority of the grandparents.

Even after decades of the existence of AIDS, stigma is still experienced in contexts like these. This quotation from this study indicates how stigma is still manifested: "... Besides I am mistreated here at the township as they heard that my daughter died of HIV/ AIDS." Van Dyk (2008) stated that AIDS-related stigma and discrimination remain the greatest obstacles to people living with HIV infection or AIDS, because fear, self-righteousness and cohesiveness can be so great in some communities that they regard the person with AIDS as having committed a crime, and infected people are perceived as guilty and denied the ordinary privileges of social life. The Koster community was not an exception because of how they mistreated the grandparents for no apparent reason.

The findings revealed that the dimensional challenges impacted on the grandparents immensely. Hopelessness, shame and frustration were emotions reported by grandparents in their quest to care for AIDS orphans. According to Jeffreys (2005) grandparents are in such despair that every word that proceeds from them is negative. Mudavanhu et al. (2008) indicated that the despair experienced by most of the grandparents emanated from the fact that events in their lives have taken a turn for the worst, in this regard having to care for the orphans with limited resources. The despair was also exacerbated by the feeling of shame created by how the community viewed the death of their child. Winston (2003) established that most grandmothers suffer due to death of their children from AIDS, which includes shame, guilt and anger. This resulted in frustration due to lack of appreciation of the grandparents.

However, the findings seemed to suggest that the grandparents had some coping mechanisms that assisted them in dealing with their situation. Support from different sources was the dominant coping strategy that was reported. The relatives, employers and home caregivers were appreciated by the grandmothers in this context. D'Cruz (2002) noted that caregivers' support from extended family is an important buffer. However, to achieve the fourth order in Maslow's theory, grandparents showed that they don't want to be dependents if there is an option for them to take any job they can get, thus increasing their self-esteem. In a study by Matshalanga and Powell (2000) some grandmothers resorted to selling home-made beer or fruit to generate income. Oluwagbemiga (2007) mentioned that grandparents had to change their lifestyle and were often forced to work more than they would have in order to cope with the needs of the orphans.

The findings in this study, although expected, were quite interesting as the participants unanimously called for assistance with food as a dire need. No other support for their needs was highlighted, even though different challenges were

reported. The participants did not even prioritise finance as a need; one would presume that when food is available the money is not seen as a need. However, it will be detrimental to make such an assumption, as the findings might be indicative that when grandparents are desperate, the basic need – which is food – becomes a priority. The other orders will be taken care of or properly thought of when both the grandparent and child in his/her care are satisfied in terms of basic needs.

Conclusion

The grandparents' plight in needing food in the rural context of Koster was highlighted. However it is important that the totality of the challenges should be examined when strategies are developed. It will be significant for the all of the role-players who intend to assist the grandparents who have AIDS orphans in their care to not only focus on the bottom order of Maslow's hierarchy of needs, but also to look at the other aspects like the psychological support and skills development needed by the grandparents. This could be helpful in helping them rear a positively supported AIDS orphan.

Acknowledgements

This study is in honour of the late Mr Jackson Makgatho, who worked tirelessly but was unfortunate not to see the fruits of his labour. Having worked with him for three years we certain that he would have appreciated this publication.

References

- Aronson, E., Wilson, T.D. & Akert, R.M. (2005). Population overcrowding: Texas boom (online), at <http://www.lotsofessays.com/viewpaper/1711144.html>. November 2010.
- Burns, N. & Grove, S.K. (2005). *The Practice of Nursing Research: Conduct, Critique and Utilization* (5th ed.) (pp. 56–57). St. Louis: Elsevier.
- D'Cruz, P. (2002). Caregivers' experiences of informal support in the context of HIV/AIDS. *The Qualitative Report*, 7(3), at <http://www.nova.edu/ssss/QR7-3/dcruz.html/> August 2010.
- De Vos, A.S., Strydom, H., Fouche, H.B. & Delport, C.S.L. (2005). *Research at Grass roots: For the Social Sciences and Human Service Professions* (3rd ed.) (pp. 193-333). Pretoria: Van Schaik.
- Egan, A. (2002). *The skilled Helper* (7th ed.). Pacific Grove, California: Wadsworth Group.
- Gouws, E., Kruger, N. & Burger, S. (2000). *The Adolescent* (2nd ed.). Sandown: Heinemann.
- Hlabyago, K.E. & Ogunbanjo, G.A. (2009). The experiences of family caregivers concerning their care of HIV/AIDS orphans. *South African Family Practice*, 51(6), 506-511.

- Jeffreys, J.S. (2005). *Helping Grieving People: When Tears Are Not Enough. A Handbook for Care Providers*. New York: Bruner-Routledge.
- Kaiser Family Foundation (2006). *The global impact of HIV/AIDS on grandmothers* (online), at www.kff.org November 2010.
- Matshalanga, N. & Powell, G. (2000). *Community based Orphan Care Program: Zimbabwe's Approach Theca*. New York: Institute for African Development, Cornell University.
- Mudavanhu, D., Segalo, P. & Fourie, E. (2008). Grandmothers caring for their grandchildren orphaned by HIV and AIDS (online), at www.unisa.ac.za/contents/faculties/hu. October 2010
- Oluwagbemiga, A.E. (2007). HIV/AIDS and family support systems; a situation analysis of people living with HIV/AIDS in Lagos State. *Journal of Social Aspects of HIV/AIDS*, 4(3), 668-677.
- Orb, A. & Davey, M. (2005). Grandparents parenting their grandchildren. *Australian Journal on Aging*, 21(3), 162-168.
- Reuter, H. (2009). *HIV/AIDS Management for Professional Nurses*. Pretoria: Foundation for Professional Development.
- Safman, R.M. (2004). Assessing the impact of orphan hood on Thai children affected by AIDS and their caregivers. *Aids Care*, 16(1), 11-19.
- Slavin, R.E. (2009). *Educational Psychology: Theory and Practice*. Boston: Pearson.
- Terre Blanche, M.T., Durrheim, K. & Painter, D. (2006). *Research in Practice: Applied methods for the Social Sciences* (pp. 1-34). Cape Town: University of Cape Town.
- UNAIDS (2008). Caregiving in the context of HIV/AIDS: Joint United Nations program on HIV/AIDS (online), at www.un.org/womenwatch/daw/egm/equalsh. November 2010.
- UNICEF (2002). *Manual for Training Community-based Counsellors*. Harare: UNICEF.
- Van Dyk, A. (2008). *HIV/AIDS Care and Counselling: A Multidisciplinary Approach* (2nd ed.) (pp. 344- 348). Cape Town: Pearson.
- Weiten, W. (2007). *Psychology Themes and Variations* (7th ed.). California: Wardsworth.
- Winston, A.C. (2006). African American grandmothers parenting AIDS orphans: Grieving and coping. *Qualitative Social Work*, 5(1), 33-43.
- World Health Organisation (2002). *Care for HIV/AIDS orphans* (online), at <http://www.who.org/media/media.html> . June 2009.