

CARE OF HIV-POSITIVE ORPHANS BY ELDERLY PEOPLE IN SWAZILAND

The elderly are often the only remaining carers for children orphaned in the HIV pandemic.

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HIV/AIDS has had devastating effects in southern Africa, from which Swaziland is not spared. This has left a trail of orphans, most of whom are taken care of by their grandparents. Swaziland, with its HIV prevalence currently pegged at 26.6% among the 15 - 49 age group,¹ is facing not only the task of reversing the growth of the epidemic, but also the huge challenge of mitigating its impact on the nation's children. There are currently almost 70 000 children orphaned by HIV/AIDS and the United Nations Children's Fund (UNICEF) predicted that there would be 120 000 orphaned children by 2010, a staggering 13% of the country's population. Besides being burdened with the task of taking care of these orphans, the country is also grappling with the responsibility of taking care of its more than 16 000 children currently living with HIV. To date, the government has only managed to place about 2 800 of the 16 000 HIV-positive children on antiretroviral treatment.²

The participants reported that the HIV-positive orphans were initially very sick, requiring a great deal of attention, thus placing a heavy burden on the elderly caregivers and interrupting their normal life.

Most of the 2 800 HIV-positive children on the antiretroviral programme are orphans under the guardianship of their grandparents who live in poverty, experience ill health and lack adequate knowledge, skills and resources to cope with this responsibility.³ This article gives the results of a study on the experiences of the elderly caring for HIV-positive orphans who are on antiretroviral treatment in Swaziland. It covers the challenges that they face in providing such a crucial service, as well as the strategies they employ to deal with the situation and the support systems available to them.

Aim of the study

The purpose of the study was to describe the experiences of elderly caregivers of HIV-positive orphans on antiretroviral treatment in Swaziland.

Research design and methodology

We conducted an exploratory, descriptive and contextual qualitative study based on a phenomenological approach. Data were collected by means of semi-structured interviews with 12 elderly people who were selected at Mbabane Government Hospital's antiretroviral treatment clinic. Qualitative data analysis was conducted. Tronto's⁴ ethics-of-care framework was used to analyse the process of caregiving and as a visionary to evaluate the experiences of caring.

Table I. Biographical information of participants

Participant	Age	Marital status	Area of resident	Level of education
A	62	Divorced	Peri-urban	Primary
B	70	Widowed	Rural	Primary
C	63	Married	Rural	Primary
D	64	Widowed	Peri-urban	No education
E	62	Widowed	Rural	Primary
F	63	Married	Urban	Secondary
G	61	Widowed	Rural	No education
H	68	Widowed	Rural	Primary
I	60	Married	Rural	Primary
J	65	Married	Peri-urban	Primary
K	67	Married	Rural	Secondary
L	64	Widowed	Rural	Primary

Findings

Biographical profile of the elderly caregivers

Table I provides the biographical information of the 12 participants in the study.

The elderly people we interviewed were all non-professional women with mainly a primary level of education who live in rural areas under conditions of extreme poverty.

Categories and themes

Table II depicts the experiences, challenges, coping strategies and support systems of the elderly caregivers. It serves to summarise the findings of the study and reveal areas for intervention strategies.

Experiences in caring before the initiation of antiretroviral treatment

The findings of the study revealed that the elderly caregivers took over the care of very young HIV-positive orphans as a response to a crisis because the child's parents were dead. Children who had contracted HIV vertically often become very ill early in life.

The participants reported that the HIV-positive orphans were initially very sick, requiring a great deal of attention, thus placing a heavy burden on the elderly caregivers and interrupting their normal life. These caregivers were not sure of what was wrong with the children until the latter were eventually tested and consequently started on antiretroviral treatment.

The children were needy, dependent and functionally inadequate (Tronto's ethics-of-care framework) and the responsibility for their care fell on the shoulders of the elderly people, who had to respond to these needs with no significant external support.

The turning point in the lives of both the elderly caregivers and the sick children occurred when antiretroviral treatment was initiated.

Experiences in caring after the initiation of antiretroviral treatment

The turning point in the lives of both the elderly caregivers and the sick children occurred when antiretroviral treatment was initiated. The intervention brought a new set of experiences. The participants reported a marked improvement in the health status of the children and a considerable increase in appetite, which alleviated the child's suffering, and lifted some of the burden of caring from the caregivers – emotionally and physically. The elderly caregiver also experienced some financial relief, because the child was healthier, but increased appetite meant that food security became more of an issue. The children were functionally more adequate, more independent and required less attention, meaning a reduced need for 'care receiving', which enabled the elderly caregivers to concentrate on other activities such as income generation and acquiring resources for 'caring about'. According to Tronto's ethics-

Table II. Categories and themes

Categories	Themes/sub-themes
Experiences in caring before initiation of antiretroviral treatment	Caring due to crisis Caring for very sick children <ul style="list-style-type: none"> • Persistent ill health • Not knowing what was wrong
Experiences in caring after initiation of antiretroviral treatment	Beneficial effects of antiretroviral treatment <ul style="list-style-type: none"> • Improvement in health status • Reduced burden of caring for the sick financially, emotionally and physically • Marked increase in appetite More responsibility to monitor treatment <ul style="list-style-type: none"> • Treatment administration • Ensuring adherence
Challenges experienced during the caring process	Excessive responsibility <ul style="list-style-type: none"> • Caring for more than one sick orphan • Caring for other adult family members Economic constraints <ul style="list-style-type: none"> • Poverty Food insecurity <ul style="list-style-type: none"> • Lack of adequate food • Inability to meet nutritional requirements Poor infrastructure <ul style="list-style-type: none"> • Transport problems • Few centres for treatment collection • Poorly equipped health centres • Shortage of drugs for opportunistic diseases • Lack of protective clothing Physical constraints <ul style="list-style-type: none"> • Chronic ill health • Lack of strength Psychological constraints <ul style="list-style-type: none"> • Panic at having contracted the disease • Stress and depression Social constraints <ul style="list-style-type: none"> • Abuse by husbands • Lack of time for friends, family and social events • Fear of stigma and discrimination
Coping strategies	Income-generating activities <ul style="list-style-type: none"> • Buying and selling • Borrowing from money lenders and relatives • Part-time employment Activities to boost food security <ul style="list-style-type: none"> • Small-scale farming • Backyard orchards
Support systems	Type of assistance required <ul style="list-style-type: none"> • Basic necessities • Resources for income generation Government assistance <ul style="list-style-type: none"> • Grants are not enough • Food hampers selectively distributed • Orphan and vulnerable child grants ill defined Non-government and faith-based organisations <ul style="list-style-type: none"> • International organisations • Local churches • Volunteers Community and extended family <ul style="list-style-type: none"> • Extended family • Community members

of-care framework, 'caring about' involves the mobilisation of resources as the caregiver interacts with the care receiver.

The introduction of antiretroviral treatment had such a huge impact on the lives of the caregivers that they were very grateful, although it was accompanied by the extra responsibility of daily administration of medication and close monitoring to ensure adherence. The elderly carers did not experience any difficulties with giving the medication and the older children were able to take their medication themselves, emphasising the importance of involving the children in their treatment. The children did not experience many side-effects, which could have compromised adherence.

The findings imply that involving the children in the antiretroviral treatment and care plan shifts some of the responsibility of ensuring adherence to medication from the caregiver. This improves adherence and the success of the intervention. Adherence to antiretroviral treatment in children also increases if the general context of caring for a child with HIV improves.⁵ This context involves the level of household income, social and family support, and the availability and accessibility of the health care provider. The participants did not experience any difficulties in administering the medication because they were receiving education and support from the health care providers, even though support from the community and family members was not adequate.

Challenges experienced during the caring process

It also emerged from the study that the caring capacity of the elderly people was compromised by the daily challenges they dealt with, for which they received little support. They also found it hard to develop adequate coping strategies. They were often faced with caring for more than one child on antiretroviral treatment, which was demanding. Some were also looking after other adult members of the family who were either ill or too old to care for themselves. These enormous demands meant that the elderly people were carrying great responsibility, which affected their ability to be attentive and responsive to the children's needs. This compromised their competency as caregivers.

Poverty was a major problem in the elderly-headed households, resulting in a lack of basic necessities. The elderly were economically inactive and were unable to engage in any income-generating activities, while the illness in the family drove them deeper into poverty.⁶ This shows that the elderly were giving care in a context of reduced power, underprivilege and inadequacy, with few resources at their disposal for mobilisation to provide holistic care.⁴ These findings also have important implications for development in general and the Millennium Development Goals (MDGs) in particular. The MDGs commit the world to eradicate extreme poverty and hunger; hence, targeting these impoverished elderly people could go a long way towards achieving that goal.

There were long queues at the clinics, resulting in lengthy waiting times.

Food insecurity was also reported as a challenge, resulting in lack of sufficient and nutritionally adequate food necessary for the quick recovery of the sick children. Assisting the elderly to boost their household food security would enable them to improve the children's nutritional status and their response to the antiretroviral treatment, thereby reducing child mortality caused by opportunistic infections and illnesses related to malnutrition. Specific targeting of elderly people with support and information on nutrition could greatly help to reduce infant and child mortality, which is the aim of the MDGs.⁴ Nutrition is important in HIV-positive children; therefore the elderly need support to meet the nutritional demands of the sick children.

The findings of the study also revealed that efforts by the elderly caregivers to ensure that the children receive their medication were frustrated by the poor road network in Swaziland, lack of money for transport, and the fact that only a few centres offer paediatric antiretroviral treatment. There were long queues at the clinics, resulting in lengthy waiting times. Shortages of drugs for opportunistic infections and malfunctioning equipment for investigations were also cited as major problems experienced by the caregivers at the clinics. The travelling and the queuing presented a burden to these

elderly people because of their age, physical frailty and chronic ill health.

The elderly caregivers were living in persistent fear of being infected with the virus because they were exposing themselves to bodily fluids without protective clothing, such as gloves. The caregiving role was also very stressful because of its demands and the fact that there was no support and assistance. The stress they experienced resulted in aggravation of their own chronic ill health. This was worsened by social isolation, abuse from their husbands and fear of stigma and discrimination. These findings imply that the elderly caregivers are vulnerable to burnout.

The challenges faced by the elderly caregivers negatively affect their responsibility and competency as care providers.⁷

Coping strategies

The challenges of poverty were addressed in many different ways. The elderly took up buying and selling on a small scale to boost the family income, which brought in small amounts of money. Some supplemented their income by borrowing from money lenders, friends and relatives; however, they faced problems when it was time to pay back the loans. Some took up part-time employment.

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Food insecurity led to small-scale farming in the form of gardening and backyard orchards. The produce was sufficient for domestic consumption and there was a little surplus for sale. The major problems with this were the lack of labour, implements and fertilisers and the time required for caring for the children. Often, no assistance was available as the children were young and other family and community members were concentrating on their own concerns. All these compromised the production of food.

These elderly women require economic empowerment to help with their income-

generating activities, which goes against the norm of providing this for the younger members of a community. These neglected elderly need to be a target for support in the face of the HIV pandemic.

The corruption and nepotism that characterised what aid was available was another concern.

Support systems

The elderly caregivers needed a lot of support to meet their basic needs and those of the orphans under their care. However, little was available from government, NGOs, faith-based organisations, the extended family and the community. The elderly lacked information on aid organisations and were often left out when aid was distributed. The corruption and nepotism that characterised what aid was available was another concern.

The elderly people were often afraid to ask for help and some eventually decided that begging for assistance was a waste of time and continued to struggle on alone.

Conclusion

The elderly were the main caregivers of HIV-positive orphans on antiretroviral treatment. They were doing so under compulsion with very little support from the government, the community and other organisations. Their caregiving capacity was compromised by many challenges. They were employing a number of coping strategies to counteract the difficulties they were facing. The elderly people were at the centre of the survival of the sick orphans and if supported with sufficient resources from the government, aid organisations and the community, they could be mobilised and play a very crucial role in meeting the MDG of reducing child mortality.

References available at www.cmej.org.za

IN A NUTSHELL

- The human immunodeficiency virus has left a number of HIV-positive orphans in Swaziland.
- Elderly people are the main caregivers for these orphans.
- The caregivers are mainly non-professional women residing in rural areas under conditions of extreme poverty.
- They are caregivers as a result of a crisis.
- A number of challenges compromise their caregiving abilities.
- The caregivers employ a number of coping strategies.
- There is insufficient support for these caregivers.
- The elderly are crucial for the survival of HIV-positive orphans on antiretroviral treatment.

SINGLE SUTURE

Drugs overdone

Prescriptions for antipsychotic drugs have more than doubled in the USA over the past 15 years, often administered for conditions for which there is scant evidence that they work.

Expensive antipsychotic drugs were originally approved to treat schizophrenia. They are now also prescribed for conditions including anxiety disorders and dementia, even though the Food and Drug Administration has not approved these off-label uses. The side-effects of such drugs can include diabetes, weight gain and an increased risk of heart disease.

Caleb Alexander and colleagues at the University of Chicago analysed the results of a survey of visits to doctors between 1995 and 2008. In the sample population, the prescriptions of antipsychotics increased from 6.2 million in 1995 to 16.7 million in 2006 and fell to 14.3 million in 2008. Off-label prescriptions also doubled during this time.

Alexander points the way to combat the trend, such as reducing heavy drug marketing and raising awareness of off-label prescribing.

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