

# “INKALA IXINGE ETYENI: TRAPPED IN A DIFFICULT SITUATION”

## THE BURDEN OF CARE ON THE ELDERLY IN THE EASTERN CAPE, SOUTH AFRICA

Research conducted in South Africa and Kenya indicate that HIV/AIDS is placing a substantial burden of care on the elderly (Joubert et al. 2000; Joubert et al 2001a; Joubert et al 2001b; HSRC 2004; Juma et al. 2004). Building on this body of research, in 2004, the Medical Research Council, Age-in-Action, and the Horizons Program embarked on a study of elderly caregiving in the Eastern Cape in order to develop and test interventions to mitigate the effects of HIV/AIDS on the elderly as well as those they care for.

This summary focuses on the findings from the formative research, which examined the scope of caregiving by the elderly, and the social, psychological, and economic factors that facilitate and inhibit their ability to provide quality care.

### Methods

A total of 89 elderly people participated in 12 focus group discussions (FGDs) conducted in Xhosa. Six FGDs groups were conducted in Motherwell Township and Port Elizabeth. The other six FGDs were carried out in KwaNobuhle Township and Uitenhage. The interview schedule used for the FGDs was developed through a process of community participation. This included a workshop with 20 community health workers to elicit information about health and welfare issues in the study sites, the role of the elderly in caregiving, and perceptions about the impact of HIV/AIDS on the elderly.

The resulting schedule consisted of open-ended questions about the health status of participants, their access to healthcare, the types of care they provided, the impact of caregiving



*Elderly caregivers in the Eastern Cape.*



on them and their peers, and the factors that facilitate and inhibit their ability to provide quality care. A three-day workshop was held to train nine female community health workers to facilitate the FGDs.

The study participants were purposively selected and included elderly people, 60 years and older, who were known by the community health workers employed by Age-in-Action to be providing care for sick and dependent children and grandchildren. The South African Medical Association gave ethical approval for the study. The elderly were informed about the aims and purpose of the study in detail, and verbal consent was obtained at the time of the FGD.

The data were analyzed using Kwalitan, a qualitative data analysis package. The package allows for the data to be searched systematically, coded and segmented according to the themes that emerge. Three individuals reviewed themes and reached agreement on the results.

## Profile of Respondents

The vast majority of respondents were female (n = 82), with more than two-thirds being over 65 years old. More than half were widowed and 31 percent were married. Thirty-eight percent had never attended school. Of those who attended school, most had completed up to either lower or higher primary.

## Key findings

### **The elderly provide a variety of care services to a range of dependents.**

The respondents in this study live in extended families with their children and grandchildren, and sometimes with other dependents, such as the children and grandchildren of their siblings or other relatives, as well as abandoned children.

*“I am staying with my son and daughter and my daughters’ children who are already deceased, and another child who is just a relative; the father and the mother of this child passed away.”*

*Female, Motherwell*

Elderly caregivers are responsible for meeting the needs of their dependents by providing food, clothing, education, medical and emotional support. For sick children and grandchildren, they provide physical care, including bathing, washing clothes, and cleaning the house.

*“Preparing for the school children, putting water for my grandchildren, cooking porridge for them, after that, they going to school. After they left me in the house, I clean the house...after that I go outside.”*

*Female, Uitenhage*

They also provide monetary support for treatment and with administering medication.

*“...even the child when is sick the money must be involved and you have to take the child to the doctor, these are the daily encounters that we come across, that depend on you as the granny...”*

*Female, Motherwell*

### **Because of illness and death, the elderly must carry out multiple parenting roles.**

Study respondents continue to be parents to their children and have assumed the unexpected role of being mother and father (in addition to being grandparents) to their grandchildren, often being responsible for many dependents.

*“We never thought that it is going to be like that, we never even thought that there will be even those children, we raised ours now we have to raise the grandchildren.... I am starting at the beginning where I was supposed to be resting and the children are looking after me.”*

*Female, Motherwell*

Many respondents find themselves in situations where they are expected to care for their children who are at the height of their economically productive years, but unable to fulfill these responsibilities due to ill health, especially from HIV/AIDS. In some instances, the elderly report being frustrated that the roles are reversed and that they have to support their unemployed children.

*“My other son is staying (with me) with his children and he is not working.”*

*Female, Uitenhage*

### **Pensions and grants are vital sources of support for the elderly, although access is not always easy.**

The elderly in this study depend on their monthly pension grants to support the entire family and report that the amount is insufficient to cover basic needs of the household.

*“You do not have anything to add—you struggle in that pension money, there is nothing to add on the food.”*

*Female, Motherwell*

Many respondents also experienced difficulties accessing child or foster care grants because they could not trace dependents' living parents to obtain signatures on the required documents or lacked the necessary registration documents.

*“...because their mother passed away November last year, and I make the application for the foster care grant this year February, but I did not get it yet because they said I must go to the fathers of these children of which I do not know their whereabouts.”*

*Female, Motherwell*

A small number of elderly caregivers report being involved in income generating activities such as raising chickens, gardening, sewing, or selling drinks to further supplement the family income. Also, some belong to stokvels (rotating credit schemes), which provide periodic payments of small amounts of money. However, this does not appear to make much difference to their general financial situation.

### **Social and community activities are important sources of support for the elderly.**

Despite their commitments to their dependents and multiple responsibilities, respondents say that socializing and involving themselves in community activities are important to them. These include going to church, socializing with people of their own age, and being involved in community work. These activities give them a sense of normality and belonging, which helps them to relax.

*“We also have a club. This loneliness inside do get away. On Sunday I go to church. I do feel very much happy on Thursdays because you feel free to talk to the mothers there and you feel much relieved afterwards.”*

*Female, Motherwell*

Respondents also report providing psychological and emotional support to each other by talking about their problems. This appears to provide the elderly with the opportunity to identify with and relate similar experiences, although there are concerns about confidentiality.

*“I have my neighbor. When I have a problem I go to my neighbor, irrespective of what the problem is.... I don't share my problems with just anybody.”*

*Female, Uitenhage*

Support groups and prayer seem to be a source of comfort and strength.

*“And there is a need for the support group and these groups do pray a lot, that is the thing that I like about them, and I like them a lot because they support each other.”*

*Female, Uitenhage*

### **The elderly feel that they have little influence on the behavior of youth.**

In general, respondents express confusion and a sense of hopelessness with matters regarding youth.

*“We are really struggling with these children. You are raising them, but they come and go as much as we are trying as parents, they are just out of control.”*

*Female, Uitenhage*

*“The children that we are raising have no love at all, you will find out the child is very cheeky and not satisfied with all you are trying to do to satisfy them.”*

*Female, Motherwell*

They are concerned that young people, including their dependents, are consuming alcohol, using drugs, and engaging in unsafe sexual behaviors. Overall, respondents feel unable to influence their children's sexual behavior and worry about their risk of getting HIV or becoming pregnant. The majority perceive that the youth have an irresponsible attitude toward HIV/AIDS. Respondents singled out young females, in particular, saying that the girls are disrespectful to their bodies, are lazy, do not help with chores at home, and have relationships with men who will support them financially.

*“Now our children are infested with AIDS. They learn, we educate them, but day-in and day-out a child is going up and down with a boy.”*

*Female, Uitenhage*

*“She'll say that she comes from school, but she was with a boy. From there she'll wed that boy, stay with that boy. She doesn't want to abide by the rules at home. She comes back when there's a problem.”*

*Female, Uitenhage*

Another concern of the respondents is that many youth tend to hide the fact that they are HIV-positive from their caregivers until it is too late and they are dying from HIV/AIDS.

*“And she won't even tell you, instead she'll go around telling other people ‘have a disease’. They'll say to her. ‘Why don't you inform your Mother?’ then she'll say, ‘No, Mom will talk non-stop.’ She's your child, you'll forgive her when she has that disease.”*

*Female, Uitenhage*

## **Many elderly experience multiple losses but have no option but to continue with their responsibilities.**

Looking after their sick children is a painful, stressful, and traumatic experience for the elderly. A common complaint of respondents is that they have to endure the pain of losing a child or sometimes multiple children, without going through the process of bereavement because they have to be emotionally and physically strong to support and look after the dependent children left behind.

*“In 1997 my nerves started when my daughter passed away. The stress, it’s the child that I was depending on—that she will be able to bury me and do these things for me, you understand.”*

*Female, Motherwell*

*“Oh, the three passed away, it is only one daughter that is left, and she is married. I have this burden of looking after grandchildren. The fourth son passed away leaving behind my grandchild.”*

*Female, Motherwell*

## **Many elderly cope with poor health in addition to looking after dependents.**

The elderly in this study are affected by many physical ailments, including arthritis, high blood pressure, diabetes, and hearing, vision and mobility problems. This makes caregiving difficult and caregivers might compromise their own health needs to meet the needs of their dependents.

In addition many respondents find it difficult to access medical care and the health system. This includes transportation difficulties, unhelpful staff, and inaccessible services. There is also a common belief that they are getting poor and inappropriate treatment.

*“...in this money of the grant I have to put aside money to hire a car for going to the hospital. I just cannot go to the hospital on my own. I have to hire a car that will take me there.”*

*Female, Motherwell*

*“We are not satisfied, my child. It is even worse when you go to the hospital. You get the high blood pills and told that the ones for the bones are not available. When you say, ‘I have a headache’ you are told that there are no headache tablets and you are given three panados. That is all.”*

*Female, Motherwell*

## **Conclusions and Recommendations**

Historically, grandparents in South Africa have played a role raising their grandchildren when parents left rural communities to seek employment in the mines and big cities. The phenomenon of the elderly caring for grandchildren is not new or unusual. However what is new is for the elderly is to be solely responsible for the economic and psychological well-being of a large number of dependents. This is often because of the death or illness of their adult children, rather than them being absent for work-related reasons.

In this study, the elderly have clearly articulated their difficulties in providing care for dependents largely on their own. These include coping with issues of parenting, limited financial resources, and difficulty in accessing existing grants and support. Also, many respondents report being in ill health and having difficulties addressing their own health problems. In addition, emotional stress from multiple losses makes it more difficult for them to cope.

Recommendations drawing from this formative study include the need to quantify the extent of the burden of care on the elderly, as well as to prioritize which challenges and barriers are the most important to

address. Furthermore, as a result of the variety and range of challenges facing elderly caregivers, it is recommended that actors from different sectors, including health, social development, education, and community organizations be encouraged to work together to address to problems facing elderly caregivers.

Proposed interventions need to address structural needs, such as financial assistance, medical support, nursing care, transport support, safety, and food security. In addition interventions to increase access to community support, provide support for the elderly to cope with HIV/AIDS related concerns and intergenerational issues are needed.

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