



Has the impact of HIV and AIDS affected the lives of rural 'Gogos'?

Organisation: Lawyers For Human Rights (LHR) – HIV and AIDS Project
Documented and presented by: Urvasi Rajcoomar
Edited by: Margaret Roper

JOHAP The Joint Oxfam HIV/AIDS Program in South Africa seeks to strengthen the civil society response to HIV/AIDS through supporting integrated community-based services for HIV prevention and care, including a focus on gender and sexuality and the rights of people living with, and affected by, HIV/AIDS.



JOHAP OBJECTIVE 3:

Create a more enabling environment for HIV/AIDS programming, with a particular focus on the rights of people living with and affected by HIV and AIDS.

Acknowledgements

The authors would like to thank the staff, volunteers and the beneficiaries of Lawyers for Human Rights (LHR) for their contribution to the case studies. Without their generous support and cooperation these stories could not be shared with others.

Thanks also to the editor Margaret Roper for her contribution.

Thanks to the photographer Matthew Willman whose outstanding images show those involved in the projects.

Thanks are also extended to the staff of the Joint Oxfam HIV/AIDS Program (JOHAP) for their sponsorship and support of this research.

The opinions of authors or participants in this document do not necessarily reflect those of Oxfam Australia, Oxfam Affiliates, JOHAP or its staff.

The various case studies presented in this series were written by different people. As much as possible we have tried to maintain their style of writing to preserve authenticity and accuracy.

This document is one of a number of publications highlighting learning during the second phase of JOHAP (April 2002-March 2005). If you wish to read these please go to the following web address; http://www.oxfam.org.au/world/africa/south_africa/articles.html

One of the strategies employed by JOHAP to strengthen the quality of the civil society response to HIV and AIDS is to strengthen partner organisation's capacity to document and share their work with other. This case study and others in the series are a result of some of this work.

Photos

Front cover: A portrait of one of the unemployed women who attended a LHR meeting. Matthew Willman/OxfamAUS

Left: In the training room of the LHR offices. Matthew Willman/OxfamAUS

Acknowledgements	
Summary	4
Part 1: Program profile	6
Lawyers for human rights	6
Part 2: Interviews	6
Lucy Zuma	9
Reginah Pikizile Msimango	9
The LHR intervention	9
Part 3: Discussion on the impact of HIV and AIDS on rural grandmothers	10
Part 4: Conclusion and recommendations for action	14
References	15

Summary

For some, growing old has been seen as a process of slowly withdrawing from the hardships of daily life and taking time out to relax and enjoy the rigours of parenthood and child care from a distance. For others though, this has been a time where, traditionally, some forms of childcare have been the norm. The sometimes idealistic picture of quietude in old age is, for many, now being shattered by the pandemic. A complete reversal of roles has occurred, where the elderly now care for the sick and dying members in their family and rear their orphaned and vulnerable grandchildren. For the majority of the elderly a future where they are cared for by their family in their old age is virtually non-existent.

The devastating effects of the AIDS pandemic continues to wreak havoc and create pandemonium in all sectors of Government and Civil Society. As the number of adults dying of AIDS steadily increases over the next decade, the phenomenon of orphan-hood and child headed households¹ will reach catastrophic numbers in Africa and South Africa. It is said that in African countries the AIDS epidemic is churning out orphans so quickly that family structures as well as communities can no longer cope. According to statistics² an estimated 15 million children orphaned by HIV and AIDS exist globally, shockingly 80% (12.3 million) of the total number live in Sub-Saharan Africa. It is becoming blatantly evident that the productive labour force, that is individuals between the ages of 18 to 40 years, are disintegrating, and leaving behind a

generation of children to be raised by their grandparents or left to fend for themselves in child-headed households. More often than not it is the older women in these instances that bear the brunt of the AIDS epidemic as increased care-giving responsibilities befall them. Kofi Annan, Secretary General to the United Nations aptly stated that, "In Africa, AIDS has a women's face."³

Some of the problems that elderly women face have been documented and include chronic poverty, diminished physical and emotional health, loss of support from family and last but not least, the barriers that impede access to social assistance and health care. "In Africa, older persons tend to be marginalised in society and policy and de-prioritised in health care and resource allocation in general. In addition, deep gender divides in typically patriarchal societies disadvantage women in virtually all arenas of social, economic and political life. As a consequence of a life time of hardship and deprivation, the majority of older persons also suffer debilitating health conditions."⁴

LHR became aware of the plight of these grandmothers when a 64-year-old grandmother, who is the primary care giver of her four orphaned grandchildren, entered our office. Upon further investigation it became evident that the plight of this grandmother was not an isolated case as we uncovered several other cases that bore similar resemblance to the plight of our "Gogo's" (grandmothers). This prompted

us to seek out these grandmothers that are experiencing difficulties and assist them where possible. Alternatively if we were not able to assist them, then we would ensure that they would receive the desired assistance from the relevant body.

At the prompting of the Joint Oxfam HIV/AIDS Program (JOHAP), LHR saw the two cases of Lucy Zuma and Reginah Msimango as an ideal opportunity to evaluate its impact in creating an enabling environment, as well as documenting the plight of grandmothers who were looking after their orphaned grandchildren or vulnerable children from the community.

LHR decided to conduct interviews with Lucy Zuma and Reginah Msimango respectively. The interviews were to be carried out with the assistance of an interpreter who would translate the questions into isiZulu. The questions as well as the responses were recorded. Both grandmothers consented to being part of the interviews, as well as having their stories published. The interviews examined the new care responsibilities, coping strategies employed by the grandmothers to the losses that had befallen them, care difficulties experienced, lack of food and financial resources, lack of family support, orphaned grandchildren, community reaction, stigma and discrimination, schooling of the children, health of the children, lack of services and awareness of grants, difficulties experienced, their health and fears about the future.



It should be borne in mind that the progress of these two case studies is at different levels. Gogo Zuma's case is very near finalisation whereas Gogo Msimango's case is at its initial stages. This case study evaluates the intervention of the HIV and AIDS project in assisting these grandmothers.

It is also important to outline the parameters under which the project operates so that our role is more clearly defined. From our organisational profile below it is evident that we do not operate as a litigator. In fact our function centres around advocating and lobbying government on issues relating to HIV and AIDS;

creating awareness on the rights people infected and affected by HIV and AIDS are entitled to; and ensuring that those rights are realised.

Photo: Ladies listening intently to what is being said. Each woman is here learning how best to access Government Grants for their children. Paul Weinberg/OxfamAUS

¹ A household that is maintained by children when their parents have died or are too ill to maintain the household themselves

² <http://www.advert.org/aidSORPHANS.html>

³ March 2005 press statement

⁴ Ferreira, M. Older Caregivers in African Households affected by HIV and AIDS: supporting the caregivers and promoting family well-being www.uaps.org/confageing/monica%20ferreira.pdf

Organisational and program profile

Lawyers for Human Rights (LHR) is a non-governmental and non-profit organisation that was founded in 1976. The vision of the organisation is to be a leading, effective human rights and constitutional watch dog and advocate. LHR strives to promote awareness, protection and enforcement of legal and Human Rights through the creation of a human rights culture. The mission of LHR is to create an enabling environment, which promotes and protects the Rights of People infected and affected with HIV and AIDS.

The HIV and AIDS Project was founded in 1993 as a result of a growing recognition that discrimination against people living with HIV and AIDS was becoming one of the key human rights issues facing the country. The project is national and is situated in Pietermaritzburg. The staff component comprises of a National Coordinator, Assistant Coordinator and an Administration Officer.

For the funding period 2004/2005, the project is focusing on promoting and protecting the Rights of women and children infected and affected by HIV and AIDS.

LHR had been mandated by JOHAP to undertake the following activities:

- Develop capacity, through workshops and training of trainers within children's rights organisations and other stakeholders, to better understand HIV and AIDS and the law, in so far as it relates to children, so that they may be in a position to identify violations and have knowledge of appropriate referral mechanisms, in order to realise the rights of children affected and infected with HIV and AIDS.



- Examine the rights and interest relating to HIV and AIDS of children in pre-schools and crèches and where necessary, consider the development and/or promotion of policies and other documents to better protect the rights and interests of such children.
- To embark on a three year collaborative and consultative process, with key service providers working with children and HIV and AIDS to develop a more cohesive and structured advocacy and lobbying role within KwaZulu-Natal (KZN).
- To monitor and evaluate the governments' policy and implementation of the provision of post exposure prophylaxis (PEP) to women and children who have been sexually assaulted.
- Women and children may lack self-sufficiency and require mechanisms to assist in economic empowerment, particularly where the partner may have died of AIDS or been abusive as a result

of the woman of child's HIV and AIDS status. Therefore, an examination of mechanisms to assist in attaining socio-economic empowerment will be undertaken by the project.

From the design of our programs, it is evident that our project was also privy to the trap that many Non-Government Organisation's (NGOs), as well as government departments found themselves in. We had concentrated all our efforts and awareness campaigns on youth and young women leaving behind a generation of vulnerable grandparents who are rearing orphaned grandchildren.

Photo: Two ladies at a meeting at the Offices of Lawyers for Human Rights. Paul Weinberg/OxfamAUS

Two rural grandmothers in KwaZulu-Natal

On 1 December 2003 an elderly and frail woman in her early sixties walked into our offices in dire need of our help. She identified herself as Lucy Zuma residing in Tamboville, an informal settlement in Eastwood, KwaZulu-Natal. Upon consultation she revealed that she was a widow who was caring for her four orphaned grandchildren, three of these between the ages of six and twelve, and one a teenager (three female, one male).

She was financially destitute, as she could no longer support herself and her grandchildren with her pension, which amounted to R740-00 (USD121-00) per month. She was also deeply concerned about her four year-old granddaughter who was HIV positive and critically ill.

She revealed that her two children had died leaving her with their grandchildren. All her hopes were lost when her application for a Care Dependency Grant (disability grant for children) was rejected on the basis that her four year-old HIV positive granddaughter was not sick enough to receive the grant.

Lucy Zuma

Selected verbatim excerpts from the recorded interview with Lucy Zuma on the 14 December 2004:⁵

Personal information

I did not go to school. I cannot read and write.

When I first visited Lawyers for Human Rights my house was terrible. It was a half blockhouse and the other half of the house had no wall. I covered that half with a sail (tent)

I am not working because I am looking after my grandchildren.

Lack of food and financial resources

I got a pension grant of R740.00 (US121-00). I usually buy food and that food will never last a month.

If the food ran out I go to the field and find something like Imifino (wild herbs) and go home. Sometimes it happens that there is no pap (ground maize) to eat together with the Imifino and when the children ask "Gogo how are we going to eat this food," then I tell them if we got nothing then there is nothing we can do. We can survive on this until the pension comes.

Towards the end of the month we used to go to bed hungry.

Lack of family support

I had a son but he is living with his family and my relationship between him and his in-laws is not good.

Sometimes when we are hungry and there is nothing to eat I go to my son and maybe he will give me R50.00 (USD8-00 or R20.00 (USD3-00) but in most months I do not go to him because I know when I go there I

cause trouble between my son and his wife. I end up suffering until the pension comes.

I live alone with my four orphaned grandchildren. I look after them myself. No one helps me look after them.

Caring for the sick and the death of children

My children they are dead. My daughter (fifteen year old and eight year old grandchildren's mother) she go to work, she had a sleep in job. I got a report from the factory that she had a severe headache and her eyes changed red. The supervisor told her to go to her room. Someone go and check up for her and they found her dead without me knowing of any disease or what was wrong with her.

My other daughter, the mother of the other two children (the eleven year old and the four year olds mother) was HIV positive. The only thing I don't like about my daughter is that she was breast feeding her baby (the four year old child) although she was told by everyone, the doctors, nurses and even myself not to breast feed this baby while she was ill and she carried on breast feeding the baby.⁶

She was living in the squatter camp (informal settlement) at Mkhondeni. When I heard she was sick I go to her to take her home but she did not want to come with me.

I used to go there to look after her until I got the message from neighbours that she died. She died severely because the neighbours said she was in her house and she hasn't come out of her house for three days. After three days one of the neighbours goes to the house to check and knocks and there was no answer until they heard a little bit of a noise a children's voice.

⁵ The interview was translated from isiZulu into English

⁶ Lucy was latter on a participant in a HIV and not necessarily transmitted the virus via breast feeding

They broke the door down and it looked like she did not die that day or the day before, maybe two days ago. The baby was still on the dead mothers' chest.

Orphaned grandchildren

I don't know their fathers (the fifteen year old and the eight year old). I don't know if they are sharing the same father. Their mother was too secretive.

The other two grandchildren (the eleven year old and the four year old). They share the same father. I hear that their father died first before my daughter.

Community reaction, stigma and discrimination

The community, some of the members advised me not to take these children because they are HIV positive. They said that this child will spread the disease to the other children so they asked me to take these children to Edendale. Where can I leave them if they do not live with me?

I decided to make a complaint at the community structures. They told the community to accept the children. Even now the community is not happy about the child. I do not let the children go out and play because I know (granddaughter who is HIV positive) that she might be hurt by the comments the other children make.

The neighbour's children do come to my house to play but I notice their mothers call them when they are busy playing. They say to their children "can you come here please" and then their children leave.

I know that they do that because of my granddaughter who is having HIV.

My soul was very painful about what they were saying about this child.

Schooling for the children

Only the fifteen year old and the eight year old grandchildren were in school.

The eleven year old was not at school because their mother was not doing anything for them. They were not even immunized and they had no documents (birth certificates, clinic cards).

Health of the children

They are healthy now but before I came to LHR (Lawyers for Human Rights) that's the time when we had no food.

One day some of the people of the public asked me to go to Glenwood clinic. I went there with my HIV positive granddaughter and the clinic sisters said that they cannot help me because the child was not immunized and that no one can help me.

The doctor told me to take the eight year old one to a relative for a short time so that I can concentrate on the child who was HIV positive because the way she was critical.

Difficulties experienced

I was having a problem even when I had to take the child to hospital. I got no money to take the child to the hospital.

I wake up early in the morning like three or four (am) so that I can manage the queue at Grey's hospital

I got no money so I take the child on my back from Glenwood to Grey's Hospital (about five kilometres). When I am on the way I see some people coming and I am so scared because they might be the people that hate me and the child. I hid in the long grass and wait for these people to go away and then carry on walking.

When anyone would build in the community I would ask them if I could do the mudding⁷

of the house. They would pay me R25-00 (USD4-00) for the whole house. I take this sick child with me and I tie her on my back while I work on the mudding of the house.

Lack of services and awareness of grants

In all my terrible journey I have not met anyone who can help me except Varshi (Lawyers for Human Rights)

I got nothing in my mind about my rights. No one told me anything until one day I made a rope to commit suicide because I did not think that I could be helped in anyway in this world.

Lawyers for human rights intervention

The way I was neglected in my community and by my own people I did not believe the way Varshi (LHR) helped me and on top of that she was not Black and was not associated in my culture.

Varshi (LHR) referred me to relevant departments and because I can't read and write LHR wrote a letter telling me where to go. Sometimes I misunderstand and go without finding that place. Varshi would then send the Assistant Coordinator, Philani Dzanibe to go with me.

They (LHR) told those people about my situation and when I used to go there they know I am coming and then they would help me and I don't have to wait for a long time.

They helped me get the Foster Care grant for my grandchildren and the Care Dependency grant for my sick granddaughter.

Because of the grants I get R2800 –00 (USD410-00) per month now.

Photo: Urvashi Rajcoomar from LHR talking with Lucy Zama in their offices. Matthew Willman/OxfamAUS

Life change after LHR intervention

Before I was having a house of half block as well as sail on the other side and now I have a house.

Sometimes I lived without food and the children go to bed without food and now I have food for the whole month.

Even if you look at me now I am healthier than before. I am no longer an old granny but now I am an old wife

What do you understand by HIV and AIDS?

A person who is HIV positive dies badly because my daughter was having a very red mouth and when I asked her she said

she got TB problems. Even that time I was approached by the neighbours because I was not aware that she was positive and having symptoms of AIDS.

The neighbours told me that I mustn't allow my daughter to come and visit because when she visits home she will bring the disease and come.

Caring for an HIV positive child

The doctor told me to use gloves when I am caring for the child the way she was critical and I must avoid contamination with the other children but I must not show this to the child (HIV positive grandchild), as this will be discrimination.

They gave me gloves and when the gloves run out then I use plastic bags. But most of the times I forgot to use all those things and just touch the baby.

Plans for the future

I am not well. I have got Diabetes, BP (High blood pressure) and arthritis and I am scared about the future for these children.

I have a son but he has his own family. I only think that he is the one who can look after these children but I don't know

I know that when I die all the grants will stop but I don't know how to deal with that situation.



⁷ Rendering the othside walls of indigenous houses.

On the 24 November 2004 Reginah Phikizile Msimango, a 70 year old grandmother came to our office for help. She advised us that she was the sole caregiver of her three orphaned grandchildren. She and her grandchildren reside at France, an informal settlement on the outskirts of Pietermaritzburg. Her story mimicked that of Gogo Zuma. She expressed a feeling of helplessness when she discovered that her youngest granddaughter was HIV positive. Like Gogo Zuma she too had applied for a Care Dependency and a Child Support Grant. Both these applications are pending for almost a year without any positive feedback from the Department of Social Welfare and Population Development.

Reginah Pikizile Msimango

Selected verbatim excerpts from the recorded interview with Reginah Pikizile Msimango on the 12 January 2005:

Personal information

No, I never go to school but I can read and write (Signature only)

I live in France that is an RDP (Redistribution Program) township on Richmond Road near Thornville. My house is two rooms and is block. I have two beds and we all manage to sleep in the two beds.

I live with orphaned grandchildren and one great grandchild.

I do not work, as nobody wants to hire an old lady.

Lack of food and financial resources

I support my five grand children and myself with my old age pension of R740 (USD121). I also get a child support grant (R170 (USD28 per month) for my one grandchild.

The money does not last the month and when the food and money runs out then some people told me that if I go to the shops and people on the streets on a Thursday then they will give me something.

I visit the shops in town to ask for food. Some give me 20c (USD 3c), or bread, it depends.

When there is still not enough then I ask for loans from people in the community and pay back with interest when the pension comes.

Lack of family support

I deal with all this myself. I got no counselling and I support the children

Caring for the sick and the death of children

My first daughter she disclosed her HIV status to me. She died in 2003. She was

very ill, in and out of hospital. I was taking care of her.

My second daughter died in Johannesburg. I heard from the neighbours and friends that it didn't took her long time. She was having a flu (influenza) and she died in hospital in 1998

My son he was very ill too. He was in and out of hospital. He died of an AIDS related illness.

My children they were living in town and I was staying in the rural area. When they got sick they come to me in the rural area

Orphaned grandchildren

They have no one to look after them. Their parents are all dead. I am the only one to take care of them.

Although it is not easy to look after them but I always think to myself that there is no one else to care for them and that they are my own children.

Community reaction, stigma and discrimination

I did not tell the people in my community that my grandchild is HIV positive.

At the Hospital they told me that this information is confidential and also I am not a person who always chat with the neighbours. I always stay at home.

The community is not the same. Some they do accept and some don't accept e.g. they pass remarks to HIV positive people. They don't want to visit and even to go to their funerals.

Photo: Lawyer Urvashi Rajcoomar and translator Senzeni Kunene talking with a group of women gathered at the LHR offices. Matthew Willman/OxfamAUS

Schooling for the children

Three of my grandchildren are in school (eighteen, twelve and five years old). The other two are not schooling. My granddaughter, the one that is HIV positive, she attended school last year but because she got sick she did not finish the year. The other grandchild is too young to go to school.

It is hard for school fees. I have to borrow money from the loans people to pay for the school fees and then pay them back from the pension. I am not left with much pension money at the end of the month.

Health of the children

The health of the grandchildren is fine except for the one that is HIV positive. She was sexually abused when she was two years old. Her parents that time they were still alive reported the case to the police but the perpetrator was not found.

I have not taken the other children for an HIV test. I always think about that although I have not taken the steps.

Difficulties experienced

I am having problems with school fees, to look after my HIV positive grandchild and my house is not in good condition.

I want LHR to help me get the Grants I applied for so that I can be able to pay for school fees, because all school reports for my grandchildren were withheld by the principal because I owe them money.

One of my children's had a funeral plan but the others were having no funeral plans. I tried to bury them on my own. Borrowing money from other people. This situation abused me and I lost a lot of weight.

I paid the funeral costs in terms and borrowed the rest. I now pay it back of my pension.

I still owe my sister-in-law R900 (USD148) for the funeral costs.

Lack of services and awareness of grants

I went to the welfare office to apply for a grant. They made me wait for a long time for the grant. I applied for another grant last year and when I went back they told me to reapply for the grant.

Lawyers for human rights intervention

My neighbour who is in the same Church as me, she receive help from LHR in the past. She asked me to raise money for taxi fare for her and myself, so that she would accompany me to the offices of LHR.

I came to the LHR offices who helped me.

What do you understand by HIV and AIDS?

It means that, that person has AIDS.



* A Taxi is a mini bus which holds up to 20 passengers when full

The LHR intervention

In 2003 the HIV and AIDS Project, upon hearing the plight of Gogo Zuma decided to intervene. When she had come to us, her application for a Care Dependency Grant from government was refused on the basis that the child was not sick enough. In other words, the child was not in the latter stages of HIV. The children were not in school as she could not afford to pay school fees and uniforms, and her HIV positive granddaughter was extremely ill. We realized that Gogo Zuma did not have all the documentation needed to access the Foster Care Grant and the Care Dependency Grant for her HIV positive granddaughter. Hence, our first task was to get birth certificates for the children that were not registered at birth.

The referral network that our project developed with key service providers within the greater Pietermaritzburg and Durban areas was vital to aiding Gogo Zuma. Through this network we referred her to the Pietermaritzburg Child and Family Welfare Society where the social worker assisted Gogo with the application for birth certificates. Upon our request they also assisted Gogo with the application of a Foster Care Grant. Our next task was to attend to the rejection of the Care Dependency Grant. Here again we solicited the assistance of our networking partner, Black Sash⁹, who lodged an appeal on behalf of Gogo Zuma.

The next step was for us to get all the children of school going age admitted into school. After several letters to the Principals of the respective schools, the children were admitted into school for 2004 without the

payment of school fees. The Principal of one of the schools was extremely accommodating and upon our request allowed the children to be admitted into school without the required school uniforms.

In the interim we took Gogo Zuma to an organisation that was handing out food parcels. It was here that she would receive the food parcels when she ran out of food.

After having adhered to all the requirements for the grants, we decided to wait for three months as advised by the Department of Social Welfare and Population Development. After three months and numerous telephone calls and correspondence, without any response from the Department of Social Welfare, we decided that the delays in processing the grant were unnecessary and unreasonable. It was at this stage that we decided to litigate on this matter. After consultation with The Legal Resource Centre (another networking partner) our office issued a letter of demand to the Department of Social Welfare requesting them to process the grant within seven days failing which we would institute action against the Department.

Within the seven-day period we received correspondence from the Department advising that they were investigating the matter. Eventually, the matter was resolved and Gogo Zuma's application was approved with R12,000 (USD1,967) in back pay.

With regard to the Care Dependency Grant, Gogo Zuma received a date for the appeal. Despite numerous requests to the Department of Social Welfare, we were unable to represent Gogo Zuma at the

appeal hearing, which was scheduled for 8 October 2004. We decided to collect all information needed for the hearing such as medical records etc. We explained to her the process and coached her for the hearing. The hearing was successful as a social worker advised Gogo Zuma that she qualified to receive the grant from January 2005.

Gogo Msimango's case is still in the initial stages as we have already issued letters to the Department of Social Welfare requesting a reason for the delay in processing the grant. We have also admitted all the children into school for 2005.

Identifying that there was a lack of knowledge on HIV and AIDS, accessing grants and the rights of caring for orphaned children infected and affected by HIV and AIDS; we decided to host a workshop for grandmothers. This workshop in January 2005 covered issues relating to HIV and AIDS and the Law, home based care, information on grants and school fees, positive thinking and healthy living and assisting those grandmothers that enduring lengthy delays for their grants to be approved.

This is the first of a series of workshops and it is envisaged that workshops of this nature will be hosted nationally.

*Photo: A Gogo coming down the stairs to the offices of LHR.
Matthew Willman/OxfamAUS*



⁹ Black Sash is a South African NGO that works through non-violent action to ensure human rights for all (www.blacksash.org.za)

Discussion on the impact of HIV and AIDS on rural grandmothers

“From being provided for; to providers.”

This, to say the least, describes the predicament that many of the elderly face today. A good starting point would be the way we in society have viewed the elderly in the past. This view has since been altered by the AIDS pandemic. The elderly are no longer the recipients but the providers of care and financial support for their adult children. Although HIV and AIDS is a concern for all age groups, it is the elderly that are now bearing the brunt of the pandemic and to be more specific; the elderly women. It would appear that in our haste to know more about the disease and embark on awareness and prevention campaigns, we forgot a whole generation that plays a vital role in the pandemic. The two case studies in this booklet reinforce this finding.

These are but two of many Gogo's in South Africa that are in dire need of help. From the interview with the Gogo's the overall factors which were found to impede their ability to render better care for their grandchildren infected and affected by HIV and AIDS were poverty, schooling for the grandchildren, and coping with caring for their sick children ,and then those children that succumb to the illness.

Poverty is essentially living without the basic necessities of life. Poverty can also be translated into a state of political, social and economic disempowerment. According to Cahn¹⁰, poverty is also isolation, lack of resources, and support systems. “Poverty is also powerlessness: being trapped; relegated to a status from which one cannot escape; impotent to change

circumstances that effect ones fate; and unable to alter the conduct of others that impacts adversely on oneself, ones family, ones neighbourhood.”

Poverty, or a lack of money or insufficient money, radically reduced these two grandmother's access to resources needed in care giving, such a health care, food, transport to a health facility and the payment of school fees. Both the Gogo's were not accessing all the grants even though they knew they had a right to receive them. In the absence of money, Gogo Msimango resorted to begging on the streets on a Thursday and when that was not enough, she found herself caught in the trap of moneylenders. Apart from the costs required to care for their orphaned grandchildren, grandmothers are also attending to the debts left behind by their deceased children. The payment of funeral costs is a burden befallen on the shoulders of the older people. Gogo Msimango had to pay for the funeral costs of her two daughters. Every month a chunk of her pension money is taken out to settle that debt. This drives many elderly people to solicit the aid of moneylenders who pray on their vulnerability and ignorance and lend them money at extremely high interest rates.

The rearing of children in this modern era requires a great deal of effort and financial resources. School fees have been and will continue to be an issue in South Africa. Both grandmothers expressed their distress around the issue of school fees. In Gogo Zuma's case her daughter neglected to enrol her child into school. Hence, this child, even after the mothers' death,

remained at home whilst the other children went to school. When there was no money for school fees and uniforms the children were excluded from attending school. This trend is not unique to South Africa; in other African countries when there was no money for school fees it was the female grandchild that was prevented from attending school. Subsequently, they were asked to assist their grandmothers with household chores and in certain instances seek employment to generate an income.

One can assume that stigma and discrimination around HIV and AIDS is being eradicated. However, the Gogo's responses have proved otherwise. Stigma and discrimination is at its ugliest in the rural areas. Gogo Zuma experienced this first hand and had to approach the community structures such as the chiefs to assist her with the communities' reaction to her HIV positive grandchild living with her. Gogo Msimango on the other hand has not divulged this information to her community. This could be attributed to her observing the way PLWHA are being treated in the community.

Caring for sick children has proved to be a stressful task for the grandmothers both financially and emotionally. Many adults who are sick with AIDS related illnesses return to their parent's homes when they are no longer able to manage by themselves.



It is at this time that the older people shoulder the responsibility of caring for the children and providing them with emotional and economic support. “The greater the care needs, the less time available for older people to participate in income generating opportunities. At the same time, older people, because of their ignorance about the disease, will run from one traditional healer to another trying to find a cure. They will sell all their wealth, possessions and strip themselves economically naked. At the end their reward is the burden they face in caring for the orphans - fending for them, providing food, clothing and school fees.”¹¹ This pattern is unbroken even in this case study as the grandmother's children migrated from their urban areas to receive care and support from their ailing parents and at a time when their parents financial resources are decreasing rapidly.

Another area, which LHR has found to be astounding, is the lack of or no family support and grief counselling received by the grandmothers. The drafting of policy and implementation of service delivery mechanisms have overlooked these important areas. Grandmothers have to endure the death of not only one child but also several of their children without grief counselling. They are forced to cope with these traumas without the intervention of family and coping mechanisms. Similarly, they too are unable to console and provide emotional support to their grandchildren after the loss of parents. The extended family and the dynamics of extensive and unconditional family support used to be the pride of many cultures, but this too is fading away with the increased financial burden mounting. This is evident in the case studies as Gogo Zuma stressed that she was void of family support and that her

requests for financial support from her surviving son caused a rift in his family. Therefore, Gogo Zuma refrained from seeking his help.

Lack of knowledge and information on HIV and AIDS increases grandmother's vulnerability of being infected when caring for their sick children or grandchildren. It appears that they have not absorbed the seriousness of the disease and the need to comply with necessary precautions such the use of gloves etc. Both the Gogo's during the interviews revealed that they knew very little about the disease and expressed a desire to learn more about the disease.

Photo: Women listening to Urvashi speaking about Government grants. Matthew Willman/OxfamAUS

¹⁰ E.Cahn, Reinventing Poverty Law 103 Yale L.J. 2133, 2134(1994)

¹¹ Nhongo T. Paper presented at the 2002 East Southern Africa Conference on Children affected by HIV and AIDS, Namibia 2002.

Conclusion and recommendations for action

In order for LHR, civil society and government, to effectively assist grandmothers the following needs to happen:-

- 1. Recognise the impact of HIV and AIDS on older people.** There is a need to recognise the fact that older people are caring for the increasing numbers of children and they should be incorporated into all HIV and AIDS strategies to be undertaken.
- 2. Review and revise national HIV and AIDS and orphan care policies.** All policies dealing with orphan care and vulnerable children should equitably address the role that older people play. They should also revisit policies and laws such as the Social Assistance Act, which inhibits or acts as a stumbling block for grandmothers to access the grants for their orphaned grandchildren. Unnecessary and unreasonable delays should not be tolerated at any level. Service delivery by government and civil society should be effective and should be monitored regularly.
- 3. Inclusion of older people in the fight against HIV and AIDS.** "There is a need for an integrated, intergenerational approach to prevention, treatment and support to mitigate the impact of HIV and AIDS on families, communities and society a whole. Governments, NGO's and local communities need to work together to meet the needs of the whole community. In doing so, they need to include older people in policy development and Program planning."¹²

- 4. Support older people caring for people living with HIV and AIDS (PLWHA), orphans and other vulnerable children.** There is a need to provide the elderly with support for caring for the sick and orphaned children and skills that will help them cope with the challenges in rearing these orphaned children. This could be undertaken by community based programs and initiatives. There is also a need to empower and create awareness on the rights of the elderly caregivers. However, we should also be mindful of the fact that many elderly caregivers are illiterate; hence we need to devise novel mechanisms to empower them.
- 5. Target older people in HIV and AIDS awareness campaigns.** The elderly should be targeted in HIV and AIDS awareness campaigns so that they can:
 - Reduce their own risk of infection
 - Provide care more effectively for PLWHA
 - Provide orphans and other vulnerable children with accurate information about HIV and AIDS.
- 6. Interim relief for grandmothers awaiting grants.** The Social Relief of Distress Grant is available to all persons who are in need of support whilst awaiting the approval of a grant. However, there seems to be little awareness on the availability of this grant amongst the elderly caregivers. It is submitted that the government should develop policy that will enable every grandparent caring for orphaned children automatic access to the Social Relief of Distress Grant whilst they are awaiting approval of their grants.

Sadly, these two case studies will not be the only stories about the plight of grandmothers in South Africa in the future. Admittedly, the paradigm has shifted whereby the elderly are no longer being provided for but instead are the providers. LHR believes that these elderly grandparents who are looking after their orphaned grandchildren are unspoken heroes in our society. Despite the many adversities they face daily, they overcome them for their survival and the survival of their orphaned grandchildren. However, their fight for survival should not be a fight to be endured alone. We as a civil society, sectors of government, communities, family members, Non Government Organisations (NGO's) and Community Based Organisations (CBO's) should shoulder some of the burden that has befallen on the elderly, so that we can create an enabling environment for those children infected and affected by HIV and AIDS.

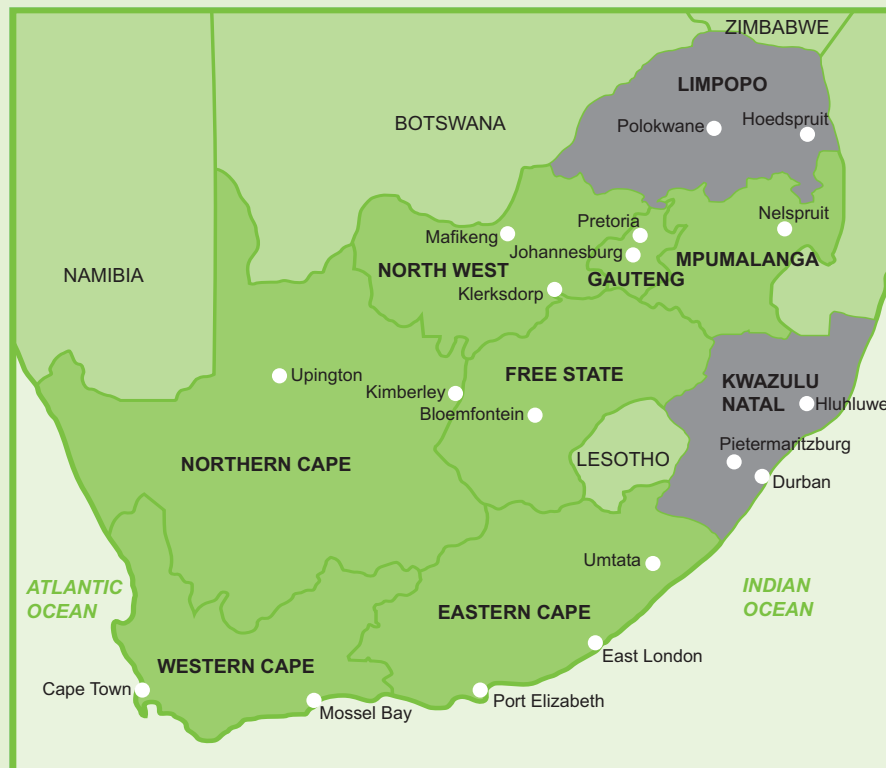
Documenting these case studies has been a heart wrenching and enlightening experience for LHR. We often hear people proudly say that society has evolved over the centuries with modern equipment and technologies. But then one is lead to question the nature of a society where the elderly are left to fend for themselves.

*Photo: A portrait of a Gogo waiting.
Matthew Willman/OxfamAUS*



References / contact details

The JOHAP program currently operates in two provinces; Limpopo and KwaZulu-Natal.



1. Ferreira, M, Older Caregivers in African Households affected by HIV and AIDS: Supporting the Caregivers and promoting family well being. www.uaps.org/confageing/monica%20ferreira/pdf
2. James kakooza, HIV and AIDS AND THE CHANGING ROLE OF THE AGED. Understanding the Role, Constraints and Consequences for the elderly as Providers of Education to children Orphaned by HIV and AIDS.
3. jkakooza@akesu.org
4. Nhongo. M. Tavengwa, The Changing Role of Older People in African Households and the impact of Ageing on African Family Structures. <http://www.uaps.org/confageing/tavengwa.pdf>
5. Mathangani. P, Elderly Carry the Burden of AIDS. <http://www.globalaging.org/health/world/kenya.htm>

Contact details: Lawyers for Human Rights HIV/AIDS Project

Contact person: Urvashi Rajcoomar

Address: Physical: 4th Floor, ABSA Building, 30 Timber Street, Pietermaritzburg

Postal address: Postal: P.O Box 388, Pietermaritzburg, 3201

Phone: +27 (0)33 – 3421130/80

Facsimile: +27 (0)33 – 3949522

Email: varshi@mail.ngo.za

Website: www.lhr.co.za

Photos

Right: One of the Gogo's listening to what is being said by LHR.

Paul Weinberg/OxfamAUS

Back cover: Having a tea break during the meeting at the offices of the LHR. The meeting was attended also by Nurses who spoke with the ladies on hygiene and health care. Matthew Willman/OxfamAUS

Oxfam Australia, 156 George Street,
Fitzroy Victoria, Australia 3065
Telephone +61 3 9289 9444
www.oxfam.org.au

