



Grandmothers: the heart of the response to AIDS in Africa

For a quarter century, HIV/AIDS has devastated the African continent, tearing the social fabric and forever altering the supports that hold communities together. The numbers are staggering – in 2007, sub-Saharan Africa had 22.5 million people living with the virus, 61 per cent of them women. In some of the worst-affected countries, AIDS has dramatically lowered life expectancy, crippled health systems, and stunted economic growth – the impact of AIDS will be felt for many years to come.

Since the first AIDS diagnosis, more than 25 million people have died, leaving millions of children in their wake – as many as 13 million children have been orphaned by AIDS in sub-Saharan Africa.ⁱ As governments struggle to cope with the impact of the pandemic, it is grandmothers who are shouldering the burden of caring for the next generation; they are burying their adult children and immediately stepping in to raise the orphaned children. With little to no support, these heroic women have become the heart of the response to the AIDS pandemic in Africa.

HIV/AIDS: ‘The Grandmothers’ Disease’

Although older women do not account for a large number of people infected with HIV, “they are often the most deeply affected by its social and economic implications,” says researcher Christine Oppong. “They are the ones who must ultimately care for the sick, prime-age adults and the children left behind.”ⁱⁱ For this reason, in many villages throughout rural Africa, HIV/AIDS is referred to as ‘the grandmothers’ disease.’ⁱⁱⁱ As the guardians of children who represent the future and hope of Africa, it is clear that a special intervention is needed on their behalf.

The burden of care

It is estimated that 70 to 80 per cent of all those who are ill and dying of AIDS are cared for by older parents or relatives.^{iv} As the sick return to their parents’ homes to live out their final days, it is the elderly women who are often forced to work longer hours or to give up paid work to care for their relatives, and to sell personal items and other household assets to buy necessities.^v

“Because of the poverty, and the economic situation in Africa, very few people save for old age; the only thing you are saving for old age is your children, so that when you’re old and you don’t have money, they will look after you,” says Winstone Zulu, a prominent Zambian AIDS activist. “Now with AIDS, that has changed, because you have the children that have reached 30 [or] 33 years of age, then they die and they leave the children. So, you lose your investment, which is your children, who are supposed to look after you afterwards, but also they leave you with a burden – their children. So, it’s a double tragedy in many ways.”

These women have lost everything: traumatized by the magnitude of loss and suffering; pressed into parenting again in old age; and robbed of income-earners, elderly heads of household scrape together money – for funerals, for school fees, for food, for medicine. But this financial burden is often more than most can bear: a study in four provinces of South Africa showed that households with an AIDS-related death in the previous year spent an average of one-third of their income on funerals alone.^{vi}

“A grandmother buries her own children, weeps for the loss, and then picks up and looks after the grandchildren, as if it was the most normal thing in the world to do,” says Stephen Lewis. He recounts the concerns voiced at meetings with grandmothers across the continent: “They stand up and they say, ‘We buried three children, we have seven grandchildren. We need food. [The children] can’t go to school because we can’t afford the uniforms.’ And the next one stands up and says, ‘I buried two children. My husband has died. I’m all alone. I have seven grandchildren



and I'm looking after them as best I can, but I need food.' Everyone needs food. *Everyone* needs food. Everyone is hungry, bar none."

In South Africa and Lesotho, many grandmother-headed households rely on meagre old-age pensions to cover food, medical care, and supplies for HIV and AIDS-infected family members. Grandmothers stretch their pensions as far as they can, but it can be very difficult to support a large household on a small stipend. South Africa has a number of child-support grants, although many grandmothers are unable to access them, particularly when the children's fathers are still alive but are not involved in raising them. Elsewhere on the continent, people over 60, including those caring for orphaned children, can expect no social grants at all.

Counting the caregivers

Few global AIDS statistics are compiled for people over 49 — as a result, data on the pandemic's effect on grandmothers is scarce. But we do know that grandparents, especially grandmothers, are caring for some 40 per cent of all orphans in Tanzania, 45 per cent in Uganda, more than 50 per cent in Kenya, and around 60 per cent in Namibia, Zimbabwe^{vii} and South Africa.^{viii}

In Swaziland, where 31.3% of all children have been orphaned or made vulnerable by AIDS, most of the care is provided by grandparents or other elderly relatives.^{ix} HIV/AIDS is crippling the ability of families and communities to cope – vulnerability assessments indicate that 43.4% of all Swazi households are now caring for orphans, and it appears that the crisis has not yet reached its peak.^x

"The impact today is shocking," says researcher Alan Whiteside in a 2007 report on Swaziland. "Grandparents are masking the true extent of the [orphans and vulnerable children] problem. In the long-term, the death of grandparents will leave thousands of children with no support structure." Discussions with grandmothers reveal that they worry about the future and what will happen to their grandchildren when they die: "what happens when I go to sleep and do not wake up?" asks Joyce, a Kenyan grandmother. "You look at them now – beautiful, nice, innocent kids – but you are afraid for their tomorrow."

Emotional toll

Research is starting to show the emotional toll AIDS is taking on grandmothers — their feelings of fear, helplessness, isolation and despair. The emotional stress on grandmothers is compounded by the stigma surrounding HIV/AIDS. Many caregivers face discrimination, which makes them reluctant to talk openly with their neighbours and their grandchildren, get tested for HIV or gain access to support.

For the grandmothers, the agony of watching their children suffer and die is matched only by their grief and worry for their grandchildren. "I watched my daughter die every day for months, without soap to bathe her, all of us in one room, hearing her whimpers at night and wishing that I was the one who would perish so she could stay and raise her babies," says one African grandmother. "The children were so afraid, but their mother would not let me tell them what was happening or that she would die. At her funeral they got so upset when they realized she was going to be put in the ground. I was too sad to help them."^{xi}

Accessing resources

For the most part, older people are invisible when it comes to allocating resources to fight HIV/AIDS. The majority of grandmothers do not have access to any form of counselling or psychosocial support, and the incredible emotional stresses on them are not often publicly recognized. "I have 14 children who are orphans," says one grandmother. "I am a member of a



grandmother group supporting vulnerable children in the community. [I depend on agriculture: vegetables, cassava – this is how I survive.] In my community there are so many other grandmothers who are not receiving any assistance.”

Many older people lack information on HIV/AIDS and have difficulties gaining access to social and health services available in their communities. Even those who do have access to information and services report feeling frustrated because they find it difficult to talk with younger generations about sex. “I am talking about my kids – I take them to the clinic; I take home condoms. But they don’t listen, they are still taking risks. I suspect my son has it. But how am I supposed to help if he won’t get tested?” asks a South African grandmother who is supporting nine children and grandchildren.

Grandmothers as community leaders

In the absence of targeted government programmes for grandmothers, many communities have created initiatives for themselves. They start and run community gardens, home-based care initiatives, drop-in centres, income-generating projects, and a range of activities that communities have come to depend on: “As grandmothers, we decided to start something instead of just asking from people... we try to sell the stuff that the [Busy Bees grandmothers’ group] knits and the money that we get, we use it to help ourselves and we use it to help each other,” says Matilda, a Zambian grandmother.

Many grandmothers have joined formal and informal support groups to help each other deal with their grief and to share their concerns. A grandmother from Cape Town, South Africa, described her experience: “I started attending the *Gogo* [granny] support group in 2002 whereby the group helped me to deal with the loss of my two children with support I got from other grannies. While I was attending the group, I realized I was not alone thinking that raising orphans was hard, especially when you’re as old as I am. I have to help [my granddaughter] to cope with the loss of her mother. In 2003, I had a stroke and I lost my job, but still I continued to attend the support group because of its importance.”^{xii}

Grandmothers’ needs: In their own words

At the **Grandmothers’ Gathering**, a conference hosted by the Stephen Lewis Foundation in Toronto on the eve of the XVI International AIDS Conference in August 2006, 100 African grandmothers from 11 countries shared their stories with 200 grandmothers from across Canada. The Gathering was the first international forum where grandmothers from across the continent had the opportunity to speak openly about HIV/AIDS and to share their concerns, their hopes and their experiences raising orphaned grandchildren. Over three days, the African grannies shared their stories and outlined their needs, which were captured in the Gathering’s outcome document, the *Toronto Statement*:

In the short term, we do not need a great deal, but we do need enough: enough to safeguard the health of our grandchildren and ourselves; enough to put food in their mouths, roofs over their heads and clothes on their backs; enough to place them in school and keep them there long enough to secure their futures. For ourselves, we need training, because the skills we learned while raising our children did not prepare us for parenting grandchildren who are bereaved, impoverished, confused and extremely vulnerable. We need the assurance that when help is sent, it goes beyond the cities and reaches the villages where we live. In the long term, we need security. We need regular incomes and economic independence in order to erase forever our constant worry about how or whether our families will survive.



We grandmothers deserve hope. Our children like all children, deserve a future. We will not raise children for the grave.

Canadian grandmothers responded with their own clarion call:

We recognize that our African friends are consumed each day with the business of surviving, and so we have offered – and they have accepted – the loan of our voices. We pledge to act as their ambassadors, raising the volume on their long-suppressed stories until they are heard, understood and acted upon. We promise to apply pressure on governments, on religious leaders, and on the international community. We are committed to mobilizing funds, and recruiting more ambassadors among our sisters in Canada. We are dedicated to finding ways to make it clear that Africa's grandmothers hold a place in our hearts and in our thoughts not just today, but each day. We are acutely conscious of the enormous debt owed to a generation of women who spent their youth freeing Africa, their middle age reviving it, and their older lives sustaining it. We will not rest until they can rest.

Stephen Lewis Foundation: Support for grandmothers

Since the Stephen Lewis Foundation (SLF) launched the Grandmothers to Grandmothers Campaign in March 2006, it has become a national movement of more than 5,000 grandmothers. To date, \$3 million has been raised and sent to Africa through the Stephen Lewis Foundation and some 200 grandmother groups have formed across Canada in support of the Campaign. Funds are used to provide for grandmothers' immediate needs – food, transportation, medical care, adequate housing and more – as well as the needs of the orphans in their care, such as school fees, uniforms and supplies. SLF also supports initiatives that will sustain grandmothers in the long term by providing micro-credit grants, HIV awareness training, parenting and business skills workshops, bereavement counselling, and grandmother support groups.

Further reading:

- Landsberg-Lewis, I. *Grandmothers to Grandmothers: the Dawn of a New Movement*. Report from the Grandmothers' Gathering. Toronto: Stephen Lewis Foundation, Mar. 2007.

ⁱ Based on a range of 10.5 million – 14.6 million, as listed in UNAIDS' *2007 AIDS Epidemic Update*, p.8.

ⁱⁱ Opong, C. "Familial roles and Social Transformations: Older Men and Women in Sub-Saharan Africa." *Research on Aging*. Volume 28, Number 6. November 2006, p.654.

ⁱⁱⁱ "The grandmothers' disease – the impact of AIDS on Africa's older women." *Age and Aging*. Volume 30, 2001, p.10.

^{iv} International HIV/AIDS Alliance & HelpAge International. *Building Blocks: Supporting older carers*. Brighton, UK: International HIV/AIDS Alliance. Updated December 2005, p.3.

^v UNICEF. *State of the World's Children 2007: Women and Children: the Double Dividend of Gender Equality*. NY: UNICEF, 2006, p.30

^{vi} UNICEF. *State of the World's Children 2007*. NY: UNICEF, 2006, p.30.

^{vii} UNICEF. *State of the World's Children 2007*. NY: UNICEF, 2006, p.30. HelpAge International. "Helping carers claim." *Ageing and Development*. Issue 20, August 2006, p.9.

^{viii} HelpAge International. "Helping carers claim." *Ageing and Development*. Issue 20, August 2006, p.9.

^{ix} Whiteside, A. & Whalley, A. *Reviewing 'Emergencies' for Swaziland: Shifting the Paradigm in a New Era*. Scott Naysmith, ed. Report prepared by HEARD / NERCHA. November 2007; 2.3.5.

^x Whiteside, A. & Whalley, A. *Reviewing 'Emergencies' for Swaziland*. November 2007; 2.3.5.

^{xi} Testimonial from a workshop at the Grandmothers' Gathering. Source: Landsberg-Lewis, Ilana. *Grandmothers to Grandmothers: The Dawn of a New Movement*. Report from the Grandmothers' Gathering. Toronto: Stephen Lewis Foundation, March 2007, p.23.

^{xii} Testimonial from a workshop at the Grandmothers' Gathering. Source: Landsberg-Lewis, Ilana. *Grandmothers to Grandmothers: The Dawn of a New Movement*. Toronto: Stephen Lewis Foundation, March 2007.