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# GRIEF AND HARDSHIP

“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. 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.”

One workshop at the Gathering asked African and Canadian grandmothers the question, “What is grief?” Their answers:

Loss, shock, pain, emptiness, sadness, anger,  
loneliness, change, depression, self-blame, guilt, survivor  
guilt, fear, inertia, sorrow, love, denial, numbness,  
acting out, loss of meaning, disbelief,  
helplessness, loss of faith, broken heart



**M**any of the workshops at the Gathering addressed grief, and tried to capture the enormity of the loss to be dealt with by every grandmother who has been touched by the pandemic (those at the Gathering, and the hundreds of thousands in Africa they were there to ‘represent’). In these workshops, Canadian and African grandmothers shared their most profound experiences of personal loss and sadness. We felt the presence of so many deceased loved ones in the rooms where their names were invoked, in sadness, with intensity and love, as a backdrop to the discussions that unfolded around grief and how to cope with it.

In one workshop, participants were asked to take an object from a pile in the middle of the room and explain why they had chosen it and the loss it represented. The common experience of sadness in loss was apparent:

*“I chose this red shoe because Nanny was a great dresser. Even in later years when she couldn’t speak, she always wanted to look great. Even with five years of ALS (Lou Gehrig’s disease) she never complained. Taking care of her husband and her children, I never had a chance to grieve.”*

*“My husband and I were together for 23 years. I am infected with AIDS, too. My second son doesn’t accept that his father gave me the infection. He doesn’t phone me or talk to me... Helping others gives me energy. It gives me life.”*

*“I picked this children’s puzzle for my sister...she died of AIDS...when I see this I think of her asking me to teach her children.”*

*“It’s been four months since my sister passed away. There isn’t a day I don’t think of her — there isn’t a day I don’t think of the Residential Schools and what it did to us.”*

*“I chose this jar of Vaseline because when my children were young, I used it after their baths...now with my grandchildren, I have come back to doing what I did with my children so many years ago.”*

Workshop participants found that culture and geography do not distinguish experiences of loss and sorrow. But for the Canadian grandmothers, recalling their own

sorrows gave shocking context to the losses suffered by African grandmothers, losses multiplied by poverty, hunger, fear, stigma, illness, and the overwhelming burden of caring for so many dependent children and their own struggle to survive. One Canadian grandmother said of her personal loss that it was “the deepest pit of sorrow — but I don’t have to worry about sending my grandchildren to school in Canada. I can’t imagine it.”

*“Our systems of support in Africa have always been the family — they have been our safety net — but what do we do when our family of 25 becomes two through so many deaths?”*

### EXPERIENCES WITH GRIEF

This section records the part of the Gathering during which the African grandmothers explored their grief — compounded by hardship — and described the different ways they struggle to cope, and some of the strategies they have found most helpful.

Many grandmothers talked about the anger and frustration they felt as they tended to their dying children. They described feeling helpless as they watched their daughters and sons waste away — most often in agony, and without adequate medication, soap, salves or bedding. They told of their children’s children watching as their parents’ health deteriorated, and of the desperation of wanting to care for everyone and being unable to do so. The grandmothers spoke openly of the bewilderment, ignorance and denial surrounding AIDS, and the fact that their own knowledge of the disease had, in many cases, been vague or non-existent at the time, leaving them unaware of how to protect themselves during caregiving, and often fearful of the stigma and retribution that would come if anyone found out that AIDS had struck their homes. Many talked with great pain about children who had left

home to seek work, only to return to die or be buried. “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 I was the one who would perish so she could stay and raise her babies,” recalled one 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.”

*“Our homes have become graveyards.”*

Participants described how, in the throes of mourning, they suddenly had anywhere from two to 20 children to care for. We heard, again and again, about the hardship of losing a second child while still reeling from the first loss. The African grandmothers talked about the terrible loneliness, isolation, abandonment and grief they felt with the loss of each child. Each woman who spoke acknowledged — and others nodded in agreement — that they had never been able to grieve properly in the midst of everyone else’s sadness and confusion and the immediate needs of their grandchildren. All still felt overwhelmed by the responsibility for the material needs of their grandchildren, but also by the difficulty of dealing with the children’s losses on top of their own. Many of the grandmothers talked about the pain of having to share the burden of care amongst family and friends, so that their grandchildren lost first their parents and then their siblings as the community did what it could to cope.

*“I have six children, inherited six orphans — their parents died, and I discovered I should have used gloves to care for them, and now I am sick — I had to accept that I’m positive. I have 19 children under my care, without the shoes, clothing or shelter I need for them.”*

Worry about how to subsist was also a constant theme among the grandmothers, many of whom are poor enough that

## Grieving orphans

Many workshops addressed a pressing concern for the grandmothers in dealing with grieving grandchildren, and learning how to provide the support they need to heal and eventually lead happy and fulfilling lives.

We heard from grandmothers who were confused but desperate to understand their grandchildren's behaviour and grief in order to better support them. Projects working with children orphaned by AIDS were strongly represented at the Gathering; the Foundation recognized the necessity of involving the grandmother-caregivers in the children's healing processes.

The grandmothers and project coordinators held intense workshops to explore this worrisome issue.

Participants discussed obstacles to their healing, beginning with denial — first by the dying (overwhelmingly it was a daughter whose husband or partner had long since died or left), and also by the grandmothers themselves. They described their denial as being motivated by fear of reprisals (if community members found out), by shame, and by an unrealistic hope that if they refused to acknowledge the inevitability of their children's death, their grandchildren would somehow be spared the agony. As one grandmother put it, "In our culture there is a lot of denial. Our pain is so great we do not want to put the children through it. We think if we don't talk about it, it will be easier for them."

Workshop leaders explained that while avoiding the topic of illness or death is common, even when grandchildren raise the topic, it can be very damaging, suggesting to the child that she or he should repress feelings and pretend that nothing is happening. It might also cause the child to feel responsible for taking care of the grandmother.

There was consensus amongst participants that breaking the silence is critical for bewildered and frightened children to understand what is happening and begin to deal with it. Grandmothers exhorted one another to tell the truth; to repeat the facts of what is happening clearly and openly and to admit when there are unknowns; to keep the child physically close and comforted; to be as supportive and predictable as possible; to show emotions and be a role model for the child so that he or she will also feel entitled to grief and  
(cont'd on p.28)

ensuring adequate food, clothing and shelter for their families are daily challenges. Some said they felt that their grief would never abate, partly because of the extent of the death and infection all around them.

Several participants revealed ongoing disbelief at the turn their lives had taken:

*"At 53 I can't prepare my own destiny, I can't rest and I can't die. There are too many demands; many more are dying, bringing more and more children..."*

*"We are nearing the end of our journey...we need help because in the back of our minds, we know that we will die, and some of the children have HIV and will die — how do we cope?"*

*"I had 15 brothers and sisters. Now there are only four left. All [the rest] of them are dead from AIDS. I had ten children of my own and have lost eight. I care for all of the orphans in a four-room house, and they are walking almost naked. There is never enough food."*

*"I am so tired, it is difficult to feed the children and take care of them the way their mother did."*

*"I look young, but I am ill — I cannot work, my [CD4] counts are low, and I cannot get aid because I am only 53 years old. I have a two-room house, without adequate food, shelter, clothing for the kids — it is very, very painful."*

*"I too, as I sit here in front of you am HIV-positive. My youngest grandchild is also HIV-positive. My biggest concern and worry are the living and sleeping conditions in my home. The children don't own any beds. The few blankets that they have are ripped. They also don't have much to wear. They wear ripped clothes because they have nothing else. And then our house collapsed on one side during the last rains. We only have two rooms left."*

*“I started attending the Gogos’ 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 is 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.”*

At times it seemed that the grandmothers were at a loss to describe how the devastation of their loss was multiplied many times over by the fact that they and their grandchildren lack the basics of mere survival: food, clothing, shelter and education. But there were other hardships touched upon as well — subjects that could have been the topics of entire workshops in themselves:

**LAND RIGHTS:** We heard that the lack of inheritance rights for women put grandmothers in terrible jeopardy. The stigma around HIV/AIDS often meant that, although grandmothers may have been staying in a relative’s home and caring for the orphaned children left behind (their daughter’s, son-in-law’s, sister’s, etc.), it was not uncommon for a male family member to swoop in and take possession of the land and the dwelling. In some instances, the grandmother was defined legally as a squatter without any rights, and could be jailed for staying in the home to care for her grandchildren.

**ELDER ABUSE:** We heard shocking stories of abuse of older women by angry community and family members because of their relationship to the person who died of AIDS. We also heard of angry, uncontrollable older orphaned children who — furious at the world and at the loss of their parents, and unable to get the help they needed — were sometimes verbally or even physically abusive to



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their grandmothers. We also heard of an alarming increase, in some areas, in the sexual assault of older women by men who, it is said, erroneously believed that all older women are free from infection.

**PARENTING:** Participants became keenly aware that Africa’s grandmothers are parenting in a situation that has no parallels and therefore no models. Only the exchange of experiences with other grandmothers and experienced counselors can assist these caregivers as they learn to observe their grandchildren more closely, learn how to interpret behaviour, and help the children understand what has transpired and move on from their losses. One grandmother recounted, with bewilderment, that her granddaughter had asked to leave a mirror at her mother’s graveside so that when she emerged from the grave, she would see her daughter’s face. The grandmother was at a loss about how to interpret this sad request and comfort her granddaughter.

## Grieving orphans (continued from p.26)

anger. The grandmothers talked about anticipating different reactions from the children as they were being told of their mothers' status or, indeed, of their own. We heard that it is quite common for a child to appear not to be listening, as this is one way of coping with the pain. We also heard that the children may ask the same questions over and over again, and fill in details that they don't know. Since imagined details are usually distorted and inaccurate, and can sometimes be more horrifying than the actual details, such misperceptions can interfere with the healing process.

There was discussion of the fact that a child may feel terrible guilt because he or she is still alive. We heard stories of children who only understood that their mothers or fathers had died when they attended the funeral or were later taken to the graveside.

The grandmothers who related their experiences found this set of workshops especially painful. They proved very difficult, as well, for the Canadian grandmothers who listened but everyone found them cathartic, sharing tears along with much singing and comforting.

It doesn't help, we heard, that orphans can often behave in terribly challenging ways – acting out physically and emotionally, running away, becoming withdrawn, having nightmares, or railing against their grandmothers. Grandmothers discussed their struggles to cope, and to provide love, and participants heard about the importance of creating environments that allow bereaved children to talk about their pain. Project coordinators talked about the need to have orphaned children tested. Although the majority are not HIV-positive, those who are will have special needs, including heightened attention to nutrition and antiretrovirals (ARVs) and other medications introduced at the appropriate times.

Some grandmothers spoke of their fear about losing their homes. Others were anxious about being able to keep their grandchildren in school, still others were afraid of losing them to AIDS, and some spoke with dread of losing children to the streets and to the 'survival sex' that too many impoverished, hungry and hopeless youth succumb to as a last resort. The projects, working with orphaned children, described how they tried to help grandmothers with the ongoing challenge of talking to their grandchildren, and tried to allay the fears felt by both generations.

**DEPRESSION:** The depths of despair had provoked suicidal thoughts among many, and the grandmothers who spoke of their depression also described the hope and succour they receive by linking up with projects that bring them together with other grandmothers and provide them with emotional and financial support.

**SEXUALITY:** In several boisterous exchanges, grandmothers from Africa talked about their fears around sex and sexuality. Some said how difficult it had been to educate themselves about HIV and AIDS and discuss such issues with their grandchildren — but they had done so to stop the cycle of infection and death. For the grandmothers themselves, we heard that the fear of contracting the virus put a strain on their sexual relationships with their spouses, and for some, the combination of a lack of power to say no to unprotected or unwanted sex, and cultural norms that make it difficult to raise the subject of condoms with their husbands, leave them in a constant state of worry.

**HIV+ GRANDMOTHERS:** There was ample evidence of a lack of targeted assistance and counselling for HIV-positive grandmothers everywhere. Many of the grandmothers are in remote areas, caring for many children, and have neither the money nor the time to visit far-away clinics. Many told stories of contracting the virus while tending to their dying children, unaware of the precautions required. The grandmothers, who are HIV-positive, have the added burden of being constantly tired and sick as they push themselves beyond what they can manage physically to care for the children. Several project coordinators expressed concern that because so many grandmother-headed households were without adequate food, many grandmothers were starving themselves in order to feed the children on a regular basis. This caused the coordinators

particular alarm when the grandmother was HIV-positive and the need for good nutrition was even more urgent.

**DIGNITY IN DEATH:** A great many grandmothers spoke of the emotional devastation they felt because they lacked the money to pay for funerals or proper burial ceremonies and graves for their daughters and sons. They spoke of the stress and sadness it caused them, as they nursed their children to their graves, to know that they would not be able to avail them of dignity in death. One grandmother told of a “sea of graves” in her front yard and her guilt because there had been no proper burials, no religious figures and no flowers at the funerals of her family members.

Each personal account of loss and continued deprivation made one thing abundantly clear to all present: there is nowhere near the support to meet even these grandmothers’ needs, let alone the countless additional caregivers who need help. Many project coordinators said that they were only just beginning to reach more of the grandmothers through their home-based care programmes, orphan-care programmes, etc., and to realize how much, much more was needed. Grandmothers in remote and rural areas, they said, are particularly isolated.

#### **STRATEGIES FOR COPING: PROGRAMMES THAT OFFER HOPE IN HARDSHIP**

African grandmothers were unanimous in their conviction that group support, counselling, and a space to cry, talk, laugh, dance and sing with other caregivers are absolutely essential for coping with the burdens and the devastation of HIV/AIDS. They expressed the unqualified belief that projects which provide emotional and, sometimes financial support, are sustaining and fortifying them.

Several strategies and advice were common among the grassroots projects:

- Help grannies identify the pain of loss due to HIV/AIDS;
- Help grannies appreciate the usefulness of grief counselling, and acquire the skills to help and support one another, since unexpressed grief does not go away, but manifests itself as physical and emotional difficulties;
- Facilitate meeting with other grandmothers who are talking about challenges, grief and grandchildren, as these encounters alleviate loneliness, and can often help when dealing with difficult situations;
- Provide support and relief for grandmothers through moments of laughter, enjoyment, and respite;
- Create a safe space to talk about the difficult work of caring for sad, angry and bewildered children, in order to discuss the challenges they present without fear of stigma, judgement or recrimination;
- Offer grandmothers who have given up hope, or who are feeling overwhelmed by their circumstances, a forum in



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which they can develop skills as community leaders, have their courage and resilience recognized by others, and find avenues to self-esteem and healing;

- Provide a venue in which groups of grandmothers can discuss and educate themselves about land rights, elder abuse, HIV/AIDS transmission and prevention, parenting skills, nutrition, access to pensions and other topics;
- Allow for advocacy to support grassroots organizations, but also to gain financial help and skills training for caregivers from governments, in addition to education for children at no cost.

As one grandmother who runs a non-governmental organization (NGO) working with widows, grandmothers and orphans remarked, “You don’t sow seeds of hope if you cannot justify that hope.”

#### GRANDMOTHERS GALVANIZING: LOOKING BEYOND GRIEF AND INTO THE FUTURE

Grief, poverty, hunger, vulnerability and fear about the future dominated discussions at the Gathering. And yet, by the

time they left, both Canadian and African grandmothers spoke with exaltation about the joy, hope and inspiration they felt.

For the African grandmothers, despair was initially supplanted by hope and purpose when they formed or joined their own groups; the Gathering added to that solidarity, organizing a much wider circle of support, a chance to unburden themselves and a commitment to improve the quality of their lives, however modestly.

There were projects that first tapped this supportive resource within caregivers — whether the groups were founded by grandmothers, or the grandmothers found one another through other community AIDS efforts such as orphan care, home-based care or organizations of people living with HIV and AIDS. Each group has given its grandmothers emotional and material support, hope for the future and the sense of empowerment that comes from having one’s voice heard.

Many of the project coordinators, who attended with the grandmothers (many of whom are grandmothers themselves), talked about an increasing awareness

## GRANNIES’ STORIES

### Karmela Kasule

#### Reach Out Mbuya, Kampala, Uganda

Karmela speaks: “I am an HIV-positive grandmother living in one of the communities designated to accommodate people displaced by war in northern Uganda. I am taking care of over 28 dependants. I do beadwork and work in a stone quarry.”

Karmela is 51, and cares for a family made up predominantly of orphaned children, who range from infants to young adults. Karmela raised five children, three of whom have died of AIDS. “I prayed that God would take me instead of my children,” she says. The sorrow of watching the lives of her children snatched away and the memory of throwing dirt on their caskets still causes Karmela to fall silent. She says that she has not had time to properly mourn her losses. More relatives died in recent years — her sister, her brother — and there were too

many children who needed her care. “They have no parents and nowhere to go, and they are my family. I used to think to myself that I was being punished by God when new children were brought to my household. But even though I had no money or room for them, I would have never considered turning them away.” Her tiny house has no electricity or water and the children sleep in rows. “I managed to rent an extra room with our neighbour to add a little more space to our two-room house, but the children still have to sleep on the floor.”

Karmela has pinned her hopes on the children’s education. Her husband of 35 years sleeps outside the house to make room for the many smaller children, the youngest of whom is three months old.

of the need to include grandmothers in all their 'formal' HIV/AIDS activities. We learned that a lot of these projects had not started off with a focus on grandmothers. But, they soon realized either that such groups were needed or that they were forming spontaneously, and that grandmothers formed the sustainable centres of community care. Many community groups dealing with orphaned children have come to realize that children cannot flourish — even with their assistance — if a grandmother is at home, unwell emotionally and desperately impoverished, because the children are likely to stay home to help her manage.

Naturally, projects established to work with grandmothers had much to share about their successes, and what they had learned in the course of their work. But, in every instance, the relationship grandmothers forged with one another under the auspices of grassroots projects in their communities had lifted them out of despair, helped them to deal with their grief and depression, and given them the strength to cope with their difficult lives.

Common themes emerged about what is truly helpful for the African grandmothers in their communities— primarily self-sufficiency and independence.

We heard that one-time handouts are not the answer. Grandmothers said they would much prefer to be trained in practical ways so that they could support themselves. Some had begun to do so, making and selling crafts, creating community gardens, and engaging in other money-making activities. Those organized to earn money in groups appreciated being able to rely on others in times of difficulty. It was acknowledged that no one model was universally successful — different cultural norms and circumstances (rural groups vs. urban, for instance, or countries where drought makes planting impossible) would necessitate different models.

The importance of connections resonated with the Canadian grandmothers, who agreed that they play an essential role in building self-esteem, a sense of purpose and appreciation for the skills they contribute in their communities. All participants spoke with a feeling of 'empowerment', self-determination and

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Karmela dreams that when the children grow up, they will be able to get jobs and help the younger ones get through school. She realizes that it is a tenuous hope, however, because in Uganda, the cost of school fees, uniforms and supplies are prohibitive. Grandson Jimmy is now eligible for university, and dreams of being a lawyer, but paying tuition is out of the question. As it is, Karmela struggles to find the money to send her five youngest school-age children to primary school. "I can't afford the school fees, so they must stay at home every day."

Karmela works at a stone quarry together with hundreds of other residents from her area. She goes to work every morning and returns at night, after spending hours in the burning sun in a cloud of red dust, her hands torn up from the work of hammering large rocks into smaller pieces. The work at the quarry provides the family with the equivalent of US \$11 every two weeks. A 50kg bag of maize meal, the amount she needs

to feed her family porridge for two weeks, costs \$24. When the older children are not in school, they come to the quarry to increase the family's yield of crushed stone. "I know it is bad for my health, but what can I do? I have to bring food to my children, even if I know this work can worsen my condition." Karmela feels sure that she contracted HIV while nursing her late son through the worst of his illness. "He had so many wounds. I would come home from the quarry with wounds on my hands and tend to his wounds. I wasn't aware that HIV is transmitted through such contact."

Like the other grandmothers, Karmela worries about what will happen to the children after she dies. "Who will take care of them if I fall sick, and make sure they are not orphans again?" Fortunately, her husband has tested negative, and Karmela tells us they are extremely careful to avoid transmission. "I am grateful he can take care of me should I fall sick."

independence. Project coordinators and grandmothers alike talked about the importance of listening as grandmothers identify their own needs, and of involving the grandmothers in decisions taken to assist them. Several grandmothers raised the issue of empowerment through political involvement at the community and national levels, whether advocating for pensions, inheritance rights, respect for their wisdom, recognition of the roles they play in their communities and societies, legislation benefiting and protecting older persons, access to government grants or working to end the stigma around HIV/AIDS.

Finally, several grandmothers talked about the peace of mind they experienced working with projects to create memory books with their dying children, or to write their own wills. These preparations for death have helped them manage some of the inevitable loss their grandchildren experience, by preserving loving memories of the deceased, and allowing grandmothers to leave something behind for their grandchildren.

Here are just a few examples of the many activities we heard described that

have given the African grannies support and pride:

- Grandmothers with the Kenya Widows and Orphans Support Programme (KWOSP) have come together to sew school uniforms for orphans, do beadwork for sale, and have taken up mechanics' vocational training and dressmaking;
- Grandmothers affiliated with CINDI (Children in Distress) in Zambia have helped mobilize their communities to offer support for orphans and provide care to child-headed households;
- The Busy Bees cooperative, a grandmothers' group affiliated with PALS in Zambia, has become self-sustaining by making and selling crafts and school uniforms. They prepare food for sale, and are now working on a vegetable garden to feed orphaned children. [This group talked about its need for sewing machines at the Gathering, and has since received funding from the SLF for additional machines from funds sent in by Canadian grandmothers groups.];
- The Gogo Grannies from South Africa,

## GRANNIES' STORIES

### Zodwa Hilda Ndlovu

#### Treatment Action Campaign (TAC), Durban, South Africa

Zodwa speaks, "I will die one day; maybe next year, my CD4 counts will go down [an indication that the immune system is failing]. But I know what I will have died of, and I know that I am using my time right now to do what I can. I lost everything." She draws her eyes tightly shut. "We are going forward, we are going to fight the stigma, we are going to fight the discrimination, we are going to fight the virus itself. I tell people I am HIV+ and there is life on the other side for the people who are positive. Even if you are positive, come out from the shed so you can get help!"

Of her work at TAC, Zodwa told the group, "The organization does give me power, and it does give me strength to

be an activist. It also gives me power to know that when I lost all my kids, [I wasn't alone]."

Zodwa's daughter gave birth to an HIV-positive baby before realizing that she herself was infected. Zodwa, who was then 55 years old, and her husband decided to care for their granddaughter to allow their daughter to continue her education. When the granddaughter was still quite small, the daughter fell ill. A trained nurse, Zodwa travelled back and forth to care for her daughter. The journeys took a toll on Zodwa and forced her eventually to resign her paid nursing position. Her daughter passed away, and Zodwa learned that she, too, had contracted HIV. At the time, ways to prevent transmission



said that although for the first three months, their meetings were “just sitting there crying, going to funerals, and singing.” Since then, activities for grandmothers have expanded;

- At Cotlands, “we do singing and praying. We do our jobs — some do sewing and some make necklaces — they give us food, and we talk — just talk, laugh and be nice.”

### COMMUNITY OF SUPPORT

The African grandmothers talked about the power of group discussion and bereavement counselling in many workshops. Having a forum gave them a voice in which to discuss their problems, feelings and needs — and an active role in problem-solving for themselves and for their peers. This helps to ameliorate their sense of helplessness, and many of the grandmothers talked about moving from solitude and a feeling of powerlessness to becoming community leaders and healers.

weren't well understood, particularly in rural areas.

Shortly afterwards, Zodwa's only remaining child discovered that he was HIV-positive. Upon learning this, he doused himself with gasoline and set himself alight. He died instantly. His suicide note revealed that he did not want his mother to re-live witnessing the agonizing death that his sister had endured. He didn't realize that Zodwa was also HIV-positive.

The granddaughter's paternal grandmother made a claim to take the granddaughter away, citing customary law that grants the father's family the right to retain custody of orphaned children. Zodwa agreed to give up the child because she was fearful of leaving the child without a caregiver after her own death.

Zodwa began referring to herself as a mother in the past tense, “I was a mother.” With her family gone, she turned her efforts to supporting other orphaned grandchildren in her neighbourhood in Durban, South Africa. Each morning,

she runs a small soup kitchen for orphaned children to visit on their way to school. Often the children will return at other meal times, asking for food and seeking company. In this way, she sustains a small legion of children who see her as their grandmother. “They call me Mama Darling, because I tell them they are all my darlings,” she laughs. Zodwa is a TAC volunteer; she conducts training sessions in the community, looks after sick people and is a founder of a support group. “I am not the only mother that is positive, there are other mothers that are positive hiding out there...I must try and do something for them,” she says.

Zodwa tells the story of how she learned of her HIV-positive status: “The reason that made me go for testing...I was not sick, I am a community worker...and I started a group of home-based care workers [volunteers who look after sick people]. I went because I wanted to tell the truth

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### GRANNIES' STORIES

The isolation, loneliness and feeling of abandonment by society was immobilizing for the grannies, in every instance, and even dangerous to their health. Many had felt suicidal or depressed and unable to function until they joined a group of other grannies and were able to talk, comfort others and receive help themselves.

One woman said that when she lost her daughter, she wanted to die, and then she was invited to a social gathering to make crafts. “What is the connection between my broken heart and making crafts? While making the crafts, they talk and talk and talk, and they are not alone.” GAPA’s project coordinator added that when the isolation is broken, the despair begins to be more manageable.

Breaking the silence about HIV/AIDS in the grandmothers’ groups is a powerful starting point for healing. One project coordinator put it this way: “HIV can be turned down. We have turned the face of HIV sadness to smiles in the community because we, as the community, picked up and went and started helping our brothers and sisters...we have seen a change in the face of HIV and the stigma.”

Another says, “I have sisters here... I can cope with everything now. I feel strong about everything. Before I was feeling that I could also die. I was asking every year, why me? My heart was opened when [my granny support group] opened. I would have died long ago.”

And still another says, “As grandmothers, we decided to start something instead of just asking from people... we try to sell the stuff that we knit and the money that we get, we use it to help ourselves, and we use it to help each other. We do home visitation amongst ourselves, and if one of us doesn’t have anything, we help that person to get food.”

## LACK OF TIME

Repeatedly, we heard about the lack of time for grandmothers — to grieve, to reflect, to invest in training and income generation — all the while caring for dying children and orphaned grandchildren. GAPA started a preschool programme in order to afford the grannies in their groups more time to work and network.

### GRANNIES’ STORIES (cont’d from page 33)

[about her children’s deaths] to the people. I did not think that I would be positive. I was just telling people [the home-based care volunteers] that if you are going to the community you must talk to them and tell the community that you know your status. If you are free from the virus, you must learn to stay free. Don’t ever become positive. Stay negative. So I went to the clinic...when I get there, I know the people that are working [there], some of the nurses I worked with and the small girl that is a counsellor. She knows me because I used to come to the same clinic to educate the patients. She asked, ‘Ma’am, you want to be tested?’ I said, ‘Yes, how can I not be? Because I am a community worker. I don’t want to tell lies to people.’ She did a little bit of pre-counselling and then I went for testing and I was supposed to come for post-counselling. When I came for post-counselling, she looked at me...I also looked

at her. She said, ‘I’m sorry.’ I said, ‘Why are you sorry?’ ‘I’m sorry ma’am, you are HIV-positive.’ I said, ‘What!? How can that be?’ Just imagine, a person who is a community worker...a person who is an activist, an HIV-activist... being told she is HIV-positive. I say, ‘Why? How did it happen?’ And the counsellor said to me, ‘I don’t know how to do the post-counselling with you, Ma’am, because you are the person who is doing that job for other people.’ She gave me my results and I took them and put them in my bag. I went home but the first question that came into my mind was, ‘What is my husband going to say? How am I going to tell my husband this thing? How did it happen?’ I went home. I did not tell my husband. I stayed for two months not telling that I had such a thing. After two months, I went to another clinic because it came to my mind that I am supposed to go back to the clinic after two months. I went to the other

We also heard that grandmothers, caring for many children and trying to eke out a living, did not have the luxury of 'quality time' with individual grandchildren, or even enough one-on-one time to get to know much about them. The grandmothers were pained by this lack of time and felt it as a real hardship, knowing that the children in their care are enduring extreme hardship and could benefit so much from more emotional support and individual attention.

We have cited just a few examples of the activities that groups undertake in their work with grandmothers. At the end of this report, there is a listing of all the groups that attended and what they do. For each group that attended, there are yet hundreds more across the continent of Africa who are providing vital life-sustaining support to grandmothers and the orphans in their care. The work continues.



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## GRANNIES' STORIES

clinic and when I went ...I did not tell them I had tested. So they tested me. The results came positive. When the counsellor [started to talk to me] I said, 'Thank you, baby, I do understand. I came here knowing very well that I am positive but I was not trusting the results.' So, it ended there on that day that I told my husband. He is negative.

I want to share all that there is in life. If you are HIV-positive, you think you are going to die, but you must try to give information to others. You must also keep in touch with other people. You are a grandmother, you go and share with other grandmothers...There is nothing that is specific for grandmothers (currently within TAC), so I will take the idea of grandmothers to the groups back home."

*Story compiled with notes from Gillian Hewitt.*

### **Akello Santina**

#### **TII KI KOMI Women's Group Gulu, Uganda**

Akello, age 71, speaks: "I am Akello Santina from northern Uganda. I am married with nine children. Four have died of AIDS and left me with 20 grandchildren. In my home, we measure seven cups of beans to be enough for a meal, and so we eat only once in a day because of lack of food. My husband, although alive, cannot walk; he just crawls on his buttocks and cannot do anything. So the burden of the family is on me and the grandchildren and widows. We have no money. Some grandfathers are irresponsible, and drink what they earn."