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AIDS, STIGMA AND POVERTY

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A number of workshops addressed the stigma that still surrounds HIV/AIDS, and the ways that discrimination, behaviour and poverty compound its effects.

Prior to the Gathering, many of the African grandmothers requested a workshop to provide an overview of the impact of AIDS in Africa. This was facilitated by Dr. Alan Whiteside from the University of KwaZulu-Natal in South Africa.

We heard from Alan that the world is still learning about the AIDS pandemic and its many complexities as a disease — and as a force affecting sub-Saharan Africa specifically. What we know for sure is that the pandemic will get worse before it gets noticeably better, because the death toll has yet to reach its peak. Just a sampling of the devastating statistics he quoted:

- In Kenya, 1.5 million people have died of AIDS to date, and 1.5 million orphans carry the virus; mortality rates are steadily growing, and by 2010 there will be an estimated 1.9 million orphans in Kenya alone;
- In Swaziland, there is now only a 28%

chance that a 15-year old boy will live to age 50, and a 22% chance that a girl will live that long. Prior to the epidemic, the likelihood was 92% for boys and 97% for girls.

- In some countries, 25 % of children will be orphaned children. “The number of orphans carrying the AIDS virus is a ticking time bomb,” Alan told us.
- In South Africa, a woman between 25 and 35 years old is 3.5 times more likely to die during those years than those of comparable age in 1985. This statistic struck an especially familiar chord for the African grandmothers, who discussed the unprecedented phenomenon of a middle generation being wiped out, leaving children and grandparents or no caregivers at all.

Many of the African grandmothers talked of the shame and stigma that entered their lives along with the disease. One woman felt that she “was finished” when she learned that her daughter was HIV-positive. When her family found out, they did not want to share household items such as dishes, sheets or soap with her. Group discussions unleashed an

avalanche of similarly painful anecdotes about the stigma associated with death from AIDS.

“A child, after losing her parents to HIV, she too [may be] HIV-positive. It is very difficult and often grannies do not tell the child because of the stigma she will receive at school.”

A Kenyan grandmother told us there is often a kind of ‘veil’ blocking communication between grandchild and grandmother. The child knows something is wrong, and the grandmother knows the child’s status is positive, but neither can bring themselves to disclose their terrible knowledge to the other.

A South African grandmother of an HIV-positive 10-year-old girl feared that if the child knew her status, she would let it slip and then experience stigma, or she might become convinced that she would die as her mother had. When she finally told the child, the girl revealed that not only had she known (or suspected) for some time, but she had not shared her suspicions because she wanted to spare her grandmother the burden of sadness and worry.

The fear of stigma is not without grounds. Often the result of a positive diagnosis is abandonment followed by isolation and solitary grief. Many of the African grandmothers had stories to tell about family members who had kept their status secret from others — spouses, parents, children, grandmothers — either because of the fear of reprisal, or out of shame, or both.

Grandmothers’ groups at the Gathering shared their strategies for bringing reluctant new members into their groups, often by inviting them to social or informational events where AIDS is not explicitly mentioned and stigma can be avoided. Other groups were struggling with the need to break through the stigma by being transparent and open about their HIV/AIDS focus, while at the same time wanting to protect the privacy, safety and accessibility of the people who attend their programmes and clinics. In the words of researcher Alan

Whiteside, “In Africa, studies show that HIV/AIDS increases poverty. We are expecting the poor to care for the destitute.” The burden of caring and paying for ill family members, and the loss of young income-earning people, is economically disastrous for households that have always lived in, or on the brink of, absolute poverty. Alongside parents, the loss of teachers, health professionals, civil servants — an entire young adult and middle-aged generation — has placed untenable strains on African health systems and economies, causing families, cultures and societies to unravel.

Throughout the workshops, grandmothers discussed some key factors contributing to the spread of HIV and the continued silence and stigma in so many communities:

A long period of denial by politicians, in tandem with an international community that provided too little and too late, has translated into millions of unnecessary deaths. Access to adequate health care, proper nutrition, medications for opportunistic infections, and AIDS treatment, is woefully inadequate across the spectrum of those infected, and even more egregiously absent for impoverished grandmothers and children.

Stigma and the taboos that surround inter-generational discussions of sex, sexuality and sexually transmitted diseases, in almost all cultures in the world, feed a cycle of ignorance and transmission — and interfere with the effectiveness and pervasiveness of prevention programmes. There has been a marked improvement in these areas over the last few years, but much more must be done to make future generations safe.

Underlying the pandemic is the low social status of women. Gender inequality, on every front, creates a breeding ground for HIV. Women who are unable to realize their sexual rights — to end cultural acceptance of polygamy, female genital mutilation, early marriage and forced pregnancy — are naturally at risk.

Without autonomy, economic independence or political power, women remain desperately vulnerable. Marital rape is not acknowledged as a possibility in most countries, and weak legislation and enforcement make women targets for intimate partner violence and rape. “If we continue to allow cultures to go on as they are, that is, as long as women have to sleep with men without being able to talk about AIDS, the prevalence will remain high,” said one African grandmother angrily.

Religious leadership was cited, by many of the grandmothers, as an obstacle. An indignant African grandmother told us that “the religious leaders are often shaming and blaming rather than using their power in the pulpit effectively.” Another told us, that in her experience, churches mislead people by saying that their faith will be enough to protect them.

From a number of workshops, we heard that the combination of stigma, religion, fear and blame creates a powerful force impeding effective work on AIDS. A Rwandan grandmother described how sexual domination of women led to the use of rape as a weapon of war during the 1994 genocide in her country. Mothers, daughters and children tested positive for HIV as a result of sexual

assaults suffered during the 100-day massacre. “The guards would separate the men from the women, and then again the women from their daughters, and would rape again and again. It is very difficult to talk to the children and women about the infection,” she said, “because of the horrible indignity of the rape itself.”

HOPE FOR THE FUTURE

Prevention was discussed, particularly in the contexts of caring for the dying, and worrying about raising children together, when some are HIV-positive and others are not. Alan stressed that without prevention, all attempts to deal with this epidemic will be futile. Treating the sick with ARVs, without also preventing more people from becoming infected, he said, “is like leaving the tap running and just mopping the floor.”

Many of the grandmothers discussed working through their projects to raise awareness of how the virus is transmitted, to debunk myths, and to promote safer sex. Everyone was hopeful that treatment and care would break the back of the pandemic, and at the same time, there was an overwhelming awareness that drugs were not widely available and were still often prohibitively expensive. Alan gave an example of this, “The aver-

GRANNIES’ STORIES

Maria Virgilio

Kukumbi – Organization for Rural Development, Kukumbi, Mozambique

Maria speaks: “I have 14 children who are orphans. I am a member of a grandmother group supporting other 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.”

Ten of the children in her care have been orphaned, and four have a mother who is too ill to take care of them, so Maria has stepped in. She herself had eight children, four of whom died of AIDS.

Maria’s small grandmothers’ group has a little land where they grow vegetables to sell. Some of the proceeds are

saved for the group and the rest of the funds go to the needs of the children.

“The money is not enough; some days we don’t have lunch or dinner, and the children go to sleep without eating anything. There is not enough for school uniforms.”

Maria gets up early every morning to go to the market to sell vegetables and when she returns, she prepares lunch for the children, if there is food. Some of the children can go to school, but she has difficulty affording the mandatory uniforms. When those who go to school return home, Maria prepares dinner. She told us that she receives two dollars a month from her community to support her. The space she lives in is not big enough, so some of the children sleep on the floor.

age spending per year is \$7 per person. The estimated cost of treatment — at the lowest price available — is \$150 per person for one year. That is for the drugs alone. We all know that it takes more than drugs: laboratory tests, ancillary work, doctors and infrastructure.”

He also underscored that it is critical to increase the understanding of the importance of a healthy lifestyle and diet for people living with HIV, along with making care and drugs universally affordable and accessible.

There was consensus amongst all the grandmothers and project coordinators that keeping children in school was essential. For children who are not infected, the longer they stay in school, the less likely they are to become HIV-positive, since education, empowerment and awareness are strong elements of prevention. The grandmothers felt that educators needed to be made more intensely aware of all the issues surrounding the virus, since schools are, after all, community centres for children and youth.

Canadian grandmothers spoke about their current and future roles in beating the AIDS pandemic. They discussed lobbying governments to fulfill their obligations by providing support to African

countries. They understood that international pressure plays an important role, not only by affecting the levels of assistance that flow to Africa, but also by influencing the responses of African governments. The world needs to send a loud and clear message that the situation is intolerable; what is being done is negligible given the cost in human lives.

The African grandmothers confirmed that every grassroots initiative with which they are involved knows what needs to be done, can rely upon legions of volunteers from the community, and has innovative and effective strategies. But their reach is simply not long enough because the lack of funding lessens their impact at every turn. Whether it's school fees, money for food, shelter, awareness-raising and treatment literacy campaigns, orphan care, home-based care, support and bereavement groups, or voluntary counselling and testing and provision of treatment, the money available is nowhere near what is needed.

They were intensely hopeful that the Gathering would raise awareness and inspire people to give, and to recognize the expertise of Africans themselves (and particularly the grandmothers) in dealing with the pandemic in their communities.

Akidi Balbina Okot

TII KI KOMI Women's Group, Gulu, Uganda

Akidi says, “I am Akidi Balbina Okot, aged 64, from northern Uganda. I have 10 children. Four have died and left me with 13 grandchildren. My husband is alive, but cannot walk as he was hit by a speeding vehicle last year. I earn my living as a peasant farmer growing food crops, part of which I keep for food (it's never enough) and part of which I sell for fees. Every morning I wake up, and with a hoe on my shoulder go to the garden to dig up to mid-day. After digging, I have to pick up some greens from the garden to make sausages and then some firewood which is carried on the head. On reaching home, I go back to collect water for cooking. The greatest challenges are food, paying school fees, clothing, bedding, medical treatment and transport.”

Margaret (Maggie) Njobvu

Children in Distress (CINDI), Kitwe, Zambia

Margaret speaks: “I am 61 years old with seven children. Six of them have passed away. Ten grandchildren are in my care; two of them are HIV-positive and quite ill. Two of my own children are also critically ill. I started suffering in 1999; I am a woman who knew nothing about HIV/AIDS. My husband became sick with TB and in 2000, I became sick with TB. After eight months of TB treatment, I became sick again. I found out then that I was HIV-positive. My husband was a truck driver and had been sick for a long time. He was taking medication for a number of years, but he did not tell me of his illness. He said he didn't tell me because he thought I would divorce him, though he had deserted the home for six months to be with another woman. In 2000, I started taking ARVs.”