

WOMEN AND AIDS –CHALLENGES AND HOPES FOR AFFECTED COMMUNITIES

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Introduction:

It is a great honour for me to share this space with a panel of such distinguished persons; thank you for inviting me.

I would like dedicate my reflections to our absent friends: the Millions of men, women and children who we have lost to the AIDS pandemic.

I will premise my reflections in my experience as an African woman widowed by AIDS, a mother of five daughters and foster parent to fourteen young people.

As a survivor of this pandemic I have walked a long journey of mixed emotions these last eighteen years:

Anger, survival guilt, loss, excitement, frustration, envy, hope... But I have never allowed myself to lose hope

I am here today to re-ignite our collective hope as a global community to overcome HIV/AIDS .

Hope based on amplified action on those areas where we know what works and keeping our eyes wide open on the ongoing challenges posed by this pandemic.

Women, girls, children and AIDS

Thirty years ago the global community had not even heard about AIDS. Today we are faced with a global pandemic which is threatening the very core of our human existence: our mothers; sisters and our children.

- 50% of the 14,000 new infections occurring daily during 2003 being women
- 50% of these being among 15-24 year olds
- Average infection rates 2-5 times higher in teenage girls than boys in Sub-Saharan Africa.-and yet in Africa women do 80% of subsistence agricultural work and are the primary care givers in the homes. Young girls leave school to care for parents.
- Mothers die, children are infected, others are orphaned
- Grandmothers are becoming parents all over again

Living with AIDS in the family:

Seventeen years ago my husband Christopher died within a year of his AIDS diagnosis. The pain and indignity of his illness coupled with the stigma we suffered as a family made me so very angry!!

It was anger which propelled me to the frontline of the AIDS battlefield, to fight stigma and to restore hope among affected families.

. I was enraged at the lack of care and compassion for people who were being diagnosed with AIDS in my country. Uganda.
But I came pretty quickly to the conclusion that the anger I felt could be channeled into positive action to restore hope and dignity of people with AIDS and their families.

I sought out people with AIDS It was not difficult to find them; you just had to look for someone on the medical wards who had no relatives by their bedside and who was receiving no care from medical staff!!!

We formed a support group and named it TASO (The AIDS Support Organization). We so desperately wanted to break the silence surrounding this disease that we chose to have “AIDS” appear clearly in our name.
We adopted as our slogan “living positively and dying with dignity” and focused on counseling, family and community education on HIV/AIDS, as well as palliative care. Throughout this time I battled with intense feelings of guilt as many of my friends succumbed to AIDS and died

Today TASO is a nation-wide movement with a philosophy which has influenced Regional and global care programs. The voice, face and experiences of infected and affected people became the center piece of TASO’s advocacy message and was soon to become a key pillar in Uganda’s relative success in curbing the spread of HIV/AIDS.

We have come a long way – But we have a longer way to go!

The global community has come a long way in identifying what actions make a difference but we have also come to the conclusion that these actions are sadly not enough:

Leadership for example is very important,
But for political leaders to just talk openly about HIV/AIDS is simply not enough. They must accompany their words with resource commitments from National budgets.

Global leadership is also required (including from religious leaders) on difficult and sensitive issues such as needle exchange programs among injecting drug users, innovative programming among minority groups cross-border travel for HIV+ people and condom education in schools.

Information is not enough!!!

As a counselor and survivor of this pandemic I have listened to heart breaking stories of young positive women and have come to the same conclusion as many of you that information is simply not enough.

- Girls do not sleep with older men because they think it is safe. They do so to pay school fees or to replace a father figure who they lost in early childhood..
- Sex workers do not agree to have sex without condoms because they do not know the risk. They do so because they get paid five times as much.
- HIV+ women do not breastfeed their babies because they do not know the risk they do so because they are afraid of being stigmatized if they don’t or because they cannot afford to use breast milk substitutes safely.

Women and girls need more than information They need education and practical solutions: jobs, property , safety from fear of violence.

Having been one of the key promoters of the ABC (**Abstinence, Being Faithful and Condomize**) strategy to which much of the success in Uganda is owed I find it hard but must admit that it simply misses the point for the majority of women and girls in many cultures and situations:

- Girls are married off in their teens or they exchange sex for survival – often before they are biologically mature. These girls are not taking risks, they are simply vulnerable.
- Many married men continue to have multiple sexual relationships- even if the majority of married women remain monogamously faithful; the message of faithfulness becomes a mockery in this situation.
- Male condoms are more available- many men refuse to use them. Female condoms are more expensive, women cannot afford them

Treatment using combination drugs has turned the HIV/AIDS pandemic into a chronic but manageable illness in the more resourced parts of our planet while the rest of the world continues to struggle with heavy death rates and a growing orphan crisis.

- Even with current global efforts (led by WHO) to roll out treatment to an additional 3 million resource poor people, women, girls and children are likely to be the very last to access treatment- many have no bus fare to take them to treatment centers; many more will be too busy caring for others and will need special support to access care for self..
- And yet we know that treating women will directly reduce the orphan burden and that healthy women will take better care of their families.
- We also know that treating pregnant women will prevent babies being born with HIV.

The way forward

For the last eight years I have been working on a slightly different frontline, with the Joint UN program on HIV/AIDS secretariat in Geneva.

We UNAIDS staff consider ourselves frontline workers because UNAIDS is the catalytic mover of the UN family and the global community on critical action on HIV/AIDS.

In keeping with this mandate UNAIDS has recently initiated “The global Coalition on Women and AIDS” aimed at galvanizing and focusing action to reduce vulnerability and to mitigate the impact of HIV/AIDS on women girls and children.

Seven intervention areas have been selected. These are all areas where diverse partners are already active. But all are in agreement that action in these areas has to be amplified.

- **preventing** HIV infection among girls and young women
- **reducing** violence against women
- **protecting** the property and inheritance rights of women and girls
- **ensuring equal access** by women and girls to care and treatment
- **supporting** improved community-based care, with a special focus on women and girls
- **promoting** access to new prevention options for women, including microbicides
- **supporting on-going** efforts towards universal education for girls

The coalition is exactly what it says it is: a “global movement of diverse actors at different levels, all united by the same vision”.

Its actions will be guided and advised by a small steering committee of eminent persons, from different disciplines all committed to ensuring that women and girls survive the HIV/AIDS pandemic. (More information on the Coalition is available on request).

I will share two final reflections:

The first is that I know for a fact that had I not had a good education at the time I lost my husband my life would have taken a completely different direction.

If there are two, (just two !) actions we could individually and collectively take to make an immediate impact on the situation of families living with AIDS those actions would be :

- Ensure that children, especially girls go to school and remain in school for as long as it takes for them to mature biologically and to acquire the survival skills they need.
- Provide treatment to positive women and provide support to all women who are caring for their loved ones at home.

We could start right now here in this room, by committing to sponsor a girl child through school, or by financing treatment for one positive woman. There are many programs doing just that and we could channel our support through them. More strategically we should re-ignite our anger and collectively refuse to succumb to despair. We should exert influence through the programs we support and all the work we do to ensure positive discrimination towards women and girls for treatment and support. And when we do that we should not apologize.

Thank you.