Stigma and Discrimination and HIV/AIDS: The Plight of Women and Children

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It is a great pleasure to be here with you this evening and I thank the organizers for inviting me. I will focus my talk on the interplay between stigma, discrimination and gender inequality and how both increase women and children’s vulnerability to infection and fuel stigma that leads to discrimination, violating the human rights of women and children.

According to the latest data released by UNAIDS, 19.2 million women and 3.2 million children were living with AIDS by the year 2002. Women accounted for 49% of new infections. The majority of these women live in sub-Saharan Africa, where women represent 60% of HIV-infected adults. Over 90% of HIV infections among children occur through mother to child transmission during pregnancy, at delivery or tragically through breastfeeding. In 2002, an estimated 800,000 children were infected. AIDS is an increasing cause of death among women resulting in increasing numbers of orphans estimated to be between 13 million and 15 million. Having decimated in Africa for three decades, with little hope of reversing the spread, the HIV/AIDS epidemic is spreading like wild fire to Asia, the Caribbean, Eastern Europe and Russia.

Women’s vulnerability stems from a combination of biological, social, and economic realities facing women in developing countries. Women and young girls, especially the girl-child, are emerging as the most vulnerable to HIV infection for a variety of reasons. Recent studies show that women, especially young girls, are physiologically more susceptible to infection than males.

In the worst affected countries in southern Africa, adolescent girls aged 15-19 are infected at rates four to seven times higher than boys of the same age. Girls are susceptible to sexual violence and abuse, as well as coercion from relatives, teachers and friends. They get lured into cross-generational sex i.e. sex with older men, a.k.a. sugar daddies. Recent evidence shows that cross
generational sex has increased in the worst affected countries with older men looking for younger girls who are expected to be uninfected by the virus. In some countries such as in South Africa, there is belief that sleeping with a virgin is supposed to be a cure for AIDS. Girls who are orphaned by or from AIDS affected families are lured into commercial sex and trade sex for survival for themselves and their orphaned siblings or to take care of ailing parents. In Asia and Eastern Europe young girls are increasingly being trafficked for sex trade. Sex workers typically have much higher HIV prevalence in many countries, which can be as high as 70%. Stigma against sex workers and the illegal nature of the trade makes it difficult for commercial sex workers to seek treatment, report abuses or negotiate safer sex.

The changing HIV patterns of infection mirror gender inequalities and inequities present in society. In developing countries women and girls are more vulnerable to HIV infection because they are often economically, culturally and socially disadvantaged and lack equal access to health-care, education, employment, resources, and decision-making powers on their own. Cultural beliefs and social attitudes about sexual relations have fueled stigma and discrimination against women and children. In many cultures, women are socialized to be submissive on matters related to sex and therefore lack the power to negotiate safe sex, negotiate condom use and withstand sexual abuse, coercion and violence. In many societies it is socially acceptable and expected for men to have multiple sexual partners and engage in commercial sex. This places wives, and female partners at greater risk of HIV infection and other sexually transmitted infections. The presence of sexually transmitted infections increases the risk of women getting infected. Unfortunately most women are often asymptomatic and may not even be aware that they have a sexually transmitted infection. Women are perceived as the transmitters of sexually transmitted infections. While men are excused for their sexual behaviors, women take the blame and shame for infecting their male partners and their children.

Furthermore, the two widely available and easy means of preventing HIV/AIDS transmission – male condoms and abstinence – are available to men independent of what women may want. They can only be practiced and used by women with male cooperation. Because of the acceptance of violence against women, women run the risk of being assaulted if they ask their husbands to use a condom. In many countries in Africa, men use condoms with other partners but not with their wives.
Stigma is particularly strong surrounding mother to child transmission. The phrase “mother to child” itself can cause stigma as all the responsibility of transmission is put on the mother and none on the father of the child. Mixed messages are given to women whether to breastfeed or use formula. In Zambia and Botswana, stigma around MTCT is quite strong. Pregnant women, whether HIV positive or not face a dilemma: if they do not breastfeed, they are assumed HIV-positive but at the same time if they do breastfeed, they are accused of killing the baby. As a result, many women just pretend and continue breastfeeding as if all is well. Mothers in this room can understand the pain of this dilemma. The strategy itself is flawed. Nevirapine prevents the transmission but without treatment of the mother she dies and leaves orphans behind.

The gender gap in basic education increases women and girl’s vulnerability. Uneducated girls, or illiterate women, are less likely to have the information and education on HIV/AIDS or reproductive health especially in cultures where such information is synonymous with promoting promiscuity and spoiling girls. They are less likely to have the life skills or social standing to negotiate safe sex. In AIDS affected families, girls are likely to be pulled out of school to care for ailing parents or assume responsibility for siblings when the parents die.

Unequal economic opportunity contributes to women’s risk of HIV infection. Women’s dependency on men stems from their lack of access to productive resources such as land property, other household assets, credit and livelihood skills. Lack of equal rights to inheritance of property has left many AIDS widows and orphans destitute and homeless, particularly in polygamous societies in Africa. When women are found to be infected, families and friends ostracize them as promiscuous and bad women. When women fall sick, it is often difficult and sometimes impossible to gain access to health care, treatment and support. Because of stigma and discrimination against AIDS widows and orphans, family members throw them out of their homes and disinherit them of their property. This leaves few options to the widows and adult children to turn to risky behaviors and sex for survival.

Women and children with HIV/AIDS face many different types of discrimination including refusal of services. In India, infected children have been turned away from school. Health providers discriminate women with HIV/AIDS by refusing to touch them, withholding treatment, performing
HIV tests without consent, and deny confidentiality, hospital facilities and appropriate medicines. Infected women may also feel anticipated discrimination or felt stigma, which limits their care seeking behaviors because they fear or suspect discrimination. This might explain the slow uptake of ARV treatment when offered in work places and close communities.

“There is an almost hysterical kind of fear – at all levels starting from the humblest, the sweeper, the ward maid, up to the heads of departments, which makes them pathologically scared of having to deal with an HIV positive patient. Whenever they have an HIV patient, the responses are shameful” A retired senior doctor from a public hospital in India who was discussing the impact HIV has had on the healthcare providers.

Wars and conflict has contributed to women and children’s vulnerability and risks to HIV infection. Displaced people and refugees, in general, have been populations exposed and vulnerable to HIV/AIDS, affecting both genders particularly young soldiers/men and women of all ages. The article by Save the Children (July 2002) states conflict as a root cause of the spread of HIV/AIDS; HIV and Conflict are a “Double Emergency”. In Sierra Leone, Rwanda and Democratic Republic of Congo, sexual violence and coercion was used as a deadly weapon against women and girls. It left many maimed and infected. It destroyed the health services that might have been able to educate the public, identify the diseases associated with HIV/AIDS or screen the blood transfusions that might transmit it. Generally, conflict fuels the spread of HIV due to the increased interaction among military/combatants and civilians, poverty and commercial sex for survival, decreased availability of STI/HIV and other health services information, the breakdown of law and order, and the disintegration of social and family structure in conflict and post conflict situations.

Gender inequalities and stigma and discrimination are fueling the epidemic in intertwining vicious cycles. Gender inequalities exacerbate the vulnerability and the risk to HIV/AIDS increasing the lack of access to information and services. Stigma and discrimination against women and HIV/AIDS leads to fear, fear of rejection, silence, and denial creating a deadly barrier that prevents women from using VCT services to find out their sero status and seeking care or treatment. Both vicious cycles condemn and sentence women and their children to painful and lonely deaths when they could receive treatment and prolong their lives. It reminds me if Gugu
Dlamini who was stoned and beaten to death by her neighbors in a township near Durban in South Africa after speaking out openly about her HIV status on World AIDS day in 1998.

How can we overcome stigma and discrimination? How can we change attitudes towards AIDS? First and foremost, to prevent the spread of HIV among women and address stigma and discrimination, gender issues must be addressed and mainstreamed into national multisectoral AIDS responses to promote the social, legal, economic and human rights of women. This is embodied in the declarations and pledges the world has made during international conferences i.e. the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (1979), the Fourth Conference on Women, ICPD (1994), the Beijing Platform for Action (1995), the Millennium Development Goals (MDGs) (2000), the Millennium Declaration and UNGASS on AIDS (2002). They all recognize the importance of gender equality and women’s empowerment as a core long-term strategy to reduce the vulnerability of women and the discrimination that follows.

Uganda can be sited as a best practice example and is among the few countries quite successful in this area, though it needs to do more. The Government of Uganda introduced policy and legal reforms to increase women’s participation and voice in government at the grassroots level and in local government structures (the resistance councils and village health committees, health facility management committees) and provided for a quota of women parliamentarians. Legal reforms changed the inheritance laws giving women property rights. Women’s groups were promoted and empowered to play an effective role in the process of development and the national HIV/AIDS strategy. Women’s groups were instrumental in strengthening the response to HIV/AIDS and protecting women’s interests, to the extent that women living with AIDS being represented as Members of Parliament. They are advocating for the protection of legal, civil, and human rights of women to ensure that women have the same access as men to information, treatment, counseling, and support. They also lobbied for better health education and public awareness and for the adoption of preventive strategies such as safer sex, monogamy, abstinence, and the use of safe blood products.

Good leadership involving civic society leaders, such as religious, traditional and professional and other associations, can help facilitate an open
discussion on stigma and discrimination issues and encourage changes in attitudes towards the HIV epidemic and particularly to people living with AIDS. Today at the World Bank, we listened to Reverend Byamugisha, a person living with AIDS from Uganda talking about the role religious leaders can play. He has played an enormous role in Uganda and globally in breaking the silence and promoting humanitarian and spiritual values of compassion for stigmatized people including women.

Numerous countries have enacted legislation to protect the rights and freedoms of people living with HIV/AIDS to safeguard them from discrimination. Much of this legislation has sought to ensure their right to employment, education, privacy and confidentiality as well as the right to access information, treatment and support.

Enforcing laws against discrimination is still a challenge. For the laws to work, women living with HIV/AIDS must be informed of their rights. Women need to be educated so that they are able to challenge the discrimination, stigma and denial that they meet in society. Human rights instruments (notably international conventions, treaties, covenants and national legislation) and other monitoring mechanisms can enforce the rights of people living with AIDS and provide a means of mitigating the worst effects of discrimination and stigma.

Building the capacity and confidence of people living with AIDS is key in the fight against stigma and discrimination. While working to improve the legal and customary instruments can be effective and are crucial to protect the rights of people living with HIV/AIDS, increasing the confidence of people living with this disease will help to minimize the fear, silence and denial associated with the illness and ultimately reduce the impact of the disease.

Health providers need to receive better training and more professional support. There is need to ensure that codes of ethics and professional conduct for health care services are in place and are enforced. Promoting VCT, treatment and care for health care workers can also help.

Mass media such as radio, TV, print and the Internet can unintentionally promote stigma, but they can also be powerful tools to help reduce it. Given their potential to shape attitudes, values and perceptions of large numbers of people, communicators have an important role to create clear messages
about HIV/AIDS and gender inequalities and to do so in a non-stigmatizing and non judgmental manner.

Programs for adolescents and young girls that promote life skills, education and counseling can help them cope with the vulnerability and assist infected and affected children cope with stigma. Peer-to-Peer programs and providing youth friendly reproductive health services and training in livelihood skills that open up employment opportunities is critical to addressing the vulnerabilities. The loveLife project in South Africa is an example of a successful intervention to address problems of young people especially young women.

Finally, gender is about both men and women and we must not forget or diminish the roles and responsibilities of men in the fight against HIV/AIDS, stigma and discrimination. Too often the acknowledgement of gender dynamics related to the epidemic result in the over emphasis on the risks and response strategies appropriate to women, like I have done in my talk overlooking the importance of male involvement, educating them to take responsibility for their wives and partners and encouraging greater responsibility in their sexual behaviors.

In conclusion, eliminating stigma and discrimination is an uphill task but it can be done. We are challenged to do much more to reduce gender inequalities, promoting hope and acceptance if we are to curb the spread of HIV/AIDS and death toll. Despite all the devastation the disease has caused, there remains hope that, one day, no one need ever again die of AIDS. Until then, let us do all we can to support those who are afflicted with the disease and work to prevent its further spread.