PERCEPTIONS OF EASTERN AFRICAN MUSLIMS ON HIV/AIDS STIGMA

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“Freedom from stigma and discrimination are human rights of HIV positive people as well as core components of an effective response.”

(Civil Society Coalition on Human Rights & Constitutional Law, 2012, p. 4)
BACKGROUND
UGANDA...

- Is a land-locked country in East Africa, with an area of 93,072 square miles.

- By 2010, it had a population of 33.4 million (USDS, 2012).

- It continues to experience a national health care crisis.

- Fertility rate is at 6.7 lifetime births per woman.

*Mesce and Foreman (2011)*
UGANDA

• About 1.2 million people (3.7% of the total population) are living with HIV.

• Of these 150,000 are children. Mesce and Foreman (2011).

• In 2009 about 64,000 people died from AIDS.

• 1.2 million children have been orphaned by the AIDS pandemic. (UNAIDS, 2010).
HIV Prevalence in Uganda
Current Status...

According to Uganda’s Ministry of Health (2011):

- HIV prevalence has risen from 6.4 to 7.3% between 2006 and 2011.

- A higher prevalence rate was reported for women aged 15 – 39 compared to men of the same age group.

- HIV prevalence increased with age;
  - Peaking at 12.1% for women aged 35-39 and
  - 11.3% for men aged 40-44.
Current Status

• Less than 1% of Ugandan children <5 years are HIV-positive.
  – HIV infection rates among children are nearly identical for boys and girls.

• 3.7% of the youth (aged 15-24) were HIV-positive.
  – HIV prevalence among female youth is higher than among male youth.
  – There is no gender difference among youth aged 15-17.

• There is an increase in HIV counseling and testing;
  – 66% of women and 45% of men aged 19-49 have ever been tested for HIV and received their results.
  – Only 13% women and 11% men had ever been tested in 2004-2005.
HIV Stigma in the Community
The Presentation:

This presentation is based on the results from:

- Focus Group Discussion among Muslim youth leaders in Uganda (2012).
- Literature review on HIV Stigma in Uganda (2012).
Findings are presented as:

• General findings.

• Findings from the United States setting.

• Findings from the Ugandan setting.

• Findings from the literature.
General Findings

The studies provided notable insights regarding the fight against HIV/AIDS stigma.

• Stigma was potent in both settings.

• Cultural norms and values as well as the socio-economic and political factors seem to undergird community attitudes towards HIV/AIDS and PLWHA.
The US setting (2008)...

• The EA immigrants in the Metro-Atlanta area reported that stigma was highly entrenched within their families and communities.

• Most participants believed that HIV/AIDS was transmitted through promiscuous acts.
  
  – Promiscuity, fornication, or adultery was a sin and taboo in most African communities.
  
  – These behaviors are condemned by the participants’ self-reported faiths (Islam and Christianity).
  
  – The onset of HIV/AIDS therefore, was regarded as a “punishment for these sins.”
  
  – Most African families were unclear about how to deal with teenage sex and pregnancy or spousal cheating to the extent that it was usually handled as a family secret.
The US setting

A sample of quotations from the study illustrate the range of responses on stigma:

• “Some people are too conservative; they think it (HIV) is a punishment from God” (Male).

• “Yes, that is what they believe, if you are HIV positive they kick your a**” (Male).

• “You can be abandoned and ashamed by the community because they do not have knowledge of the disease, they do not see the consequences” (Male).

• “I do not communicate with people who have it (HIV) or even have contact with them…I just pray for them…I feel sorry for them” (Female).
The Ugandan setting (2012)...

Just like the participants from the US setting, the Ugandan Muslim youths indicated that:

• Stigma was highly entrenched within their families and communities, and

• HIV/AIDS was transmitted largely through promiscuous acts.

Note: This finding was very disturbing given Uganda’s leading role in HIV prevention education. Moreover, these were university level youth.
The Ugandan setting

A sample of quotations from the study illustrate the range of responses on stigma:

• “Adults do so (stigmatize) to create a sense of fear among the youth and to protect their cultural values. Like if you go have sex before marriage you’ll get AIDS and you’ll be treated like this AIDS patient is being treated” (Female youth).

• “People are afraid of saying their status because they are afraid that the society will think negatively about them. That is to say having premarital sex and secondly, in cultural societies and religious societies it’s an abomination to have sex out of marriage and it’s not acceptable” (Male youth).

• “AIDS is associated with bad groups, having more than one partner, and bad moral behavior that’s why people shun from saying they are positive” (Female youth).

• “People fear to be marginalized and they also fear to lose friends and partners in case they reveal their status” (Female youth).
Findings from literature (2012)...

Literature results validated the above findings. Despite HIV prevention and education campaigns, stigma is still intense in Uganda.

• There was widespread discrimination, stigmatization, and denial (DSD) against and among PLWHA in Uganda. DSD was at the family level, community level, church level, NGO level as well as self-stigmatization. (Moniko et al, 2001).

• Faith Based Organizations were perceived to foster HIV/AIDS-related stigma and discrimination. This was attributed to “inadequate knowledge, moralistic perspectives, and fear relating to the sensitive issues surrounding sexuality and death” (Otolok-Tanga et al, 2007).
Findings from literature

• In the Amuria district of Eastern Uganda, parents were reported shunning to verify their children’s HIV status despite knowing their status due to self-stigma. (Odong, 2012).

• In the United States, Khaliq, et al. (2004) conducted a study among Somali communities in Minnesota and found a significant level of stigma in the community.

• This phenomenon was also reported by Rosenthal, et al. (2003) among African immigrants in the Texas area.

• Rajab (2008) stated that “the strong stigma exhibited by the participants, against the HIV/AIDS disease and its victims, may be a result of their socially constructed reality which has in turn been consolidated by the nature of their resettlement in close knit environments”.

LESSONS LEARNED
Positive Lessons...

The Islamic tradition and ethics stress empathy for the sick, no matter the type of illness.

According to the prophet of Islam (PBUH), one of the five rights a Muslim has over another Muslim is to visit the sick. Reported by Abu Hurayra

(Al-Nawawi, 1997)

“The Messenger of Allah, may Allah bless him and grant him peace, said ‘Allah, the Mighty and Exalted, will say on the Day of Rising, ‘Son of Adam, I was ill and you did not visit Me”. The man will say, “O Lord, how could I visit You when You are the Lord of the worlds? He will say, ‘Do you not know My slave was ill and you did not visit him? Do you know that if you had visited him, you would have found Me with him?’

Reported by Abu Hurayra

(Al-Nawawi, 1997)
Positive Lessons

• In Uganda community-initiated programs have been launched to fight against HIV/AIDS stigma.

• The message that HIV is not a death sentence is beginning to take hold.

• Patients are increasingly seeking treatment instead of hiding.

• More African governments are taking ownership of confronting the disease.

• Many NGOs, community groups, faith groups are involved in the fight.
Negative Lessons...

• Complacency - HIV infection rates are starting to climb in Uganda due to complacency.

• Ignorance - “There are so many people who still do not know anything about AIDS, people are still illiterate about this problem” (Male Youth).

• Access - “HIV/AIDS treatment is very limited due to cost, corruption, lack of infrastructure and other resources” (Female Youth).
Negative Lessons

• Stigma - stigma against the disease is still very potent
  – “Denial, even if one knows they have AIDS, they do not want to accept the fact, even if they know the truth, hence not wanting to go for testing” (Male Youth).

• Campaign - There is no significantly focused and sustained campaign against HIV/AIDS stigma.

• Policy - “Government activities on AIDS education is very limited and does not reach so many people including those who are deep in the villages” (Female Youth).
STRATEGIES TO ERADICATE STIGMA
Education on three major areas:

Outcomes from study participants and the literature suggested education targeting three major areas as possible strategies to combat HIV/AIDS stigma.

The three areas were:

- Culture
- Faith/religion
- Community
Education at cultural level

Muslim youths were concerned about some cultural practices; they stated that:

• “Ugandans unfortunately still believe in witchcraft and that if they get sick they are bewitched hence going to witchdoctors instead of medical doctors” (Male Youth).

• “It still goes back to sensitizing and educating cultural leaders and the society at large on sex education and AIDS in connection to their cultures” (Female Youth).
Education at faith/religion level

• According to Otolok-Tanga et al (2007), Uganda’s program continues to face challenges and faith based organizations (FBOs) are well-positioned to contribute to breaking the silence about HIV/AIDS.

• The AIDS UGANDA (n.d.) suggested to “Adopt harmonized non-stigmatizing, non-condemnatory approaches to HIV & AIDS sufferers across all faith communities…”

• On the other hand, study participants pointed out that, “Muslim leaders should be vigilant in teaching the youth about AIDS not just threatening them with the hell fire. They should also adopt modern ways of teaching the lesson of AIDS, taking both the religious perspective and use the ABC module as a solution” (Female Youth).

“Religious leaders should adopt the explanatory method of teaching than the threatening method like the holy prophet did when he was giving summons…” (Male Youth).
Education at community level

Moniko et al (2001) recommended the following:

• Government action to provide legal framework to address discrimination against PLWHA.
• Education and information about HIV/AIDS transmission.
• Protection for women, their property and social security.
• Encourage PLWHA to come out.

Focus group participants appealed to leaders and suggested that:

• “There should be vigilant and educative leaders in society, leaders should know how to teach the youth” (Female Youth).

• “Put more emphasis on raising awareness about AIDS by government officials, non government officials, parents and the community at large to everyone no matter what the age group and what the level of education because AIDS knows no body” (Female Youth).
ERADICATING STIGMA AT IUIU
Students at the Islamic University in Uganda (IUIU) started IUPEC in January 2009 with a membership of 20 under the leadership of Dr. Haruna Kigongo.

• The mission of the Club is:
  “to produce a students’ community that is AIDS sensitive and informed through creation of awareness, peer education, counseling, and guidance” (IUPEC Magazine 2012, p. 7).

• The objectives of the Club are:
  “a) to provide basic information on HIV/AIDS prevention and care to students;
  b) to enhance positive attitude in addressing HIV/AIDS issues among the University students and surrounding community; and
  c) to empower students with skills that will enhance positive behavior change” (IUPEC Magazine 2012, p. 7).
IUPEC

• The club activities include workshops, confidential HIV testing and counseling, World AIDS Day events, and community outreach programs.

• Because of the Club’s activities, stigmatization of HIV/AIDS and PLWHA has been greatly reduced on the University campus.

• The Club’s magazine published this year (2012) includes powerful testimonials from students living with HIV who felt comfortable to publicly share their stories in order to promote the mission and objectives of IUPEC.
IUIU Student Testimonial:

“I was born with HIV/AIDS. I have lived with the virus all my life. My father died of the disease when I was in senior four; my mother is still struggling with the virus...I have gone through thick and thin being at school as a person living with HIV/AIDS. No form of stigma have I not received, no amount of discrimination have not been poured unto me. Many times physical insult has been extended unto me, I wish I could fight back! I have changed schools a number of times I cannot surely tell...The longest I stayed in one secondary school was one year...Only at IUIU have I managed to stay for three solid years, but even then, I had to change rooms twice.”

CONCLUSIONS/RECOMMENDATIONS
Conclusions

• There seems to be sporadic and ad hoc programs that address stigma both among the African immigrant populations in the United States as well as the community in Uganda.

• Most of these programs, if any, are initiated by different groups at the community and individual levels. Some are government initiated.
Recommendations

For Uganda:

• A well planned, all-round, focused, and sustained national intervention to eradicate HIV/AIDS stigma must be initiated by the government in collaboration with other stakeholders.

• Such stakeholders should include advocates at the grassroots, national, and international levels including:
  – Youth leaders (the IUPEC model)
  – Women leaders
  – Cultural and religious leaders
  – Policy makers
  – Ugandan Ministry of Education (MOE)

• to design a comprehensive anti HIV/AIDS stigma curriculum.
“Persistent stigmatizing comments by high level religious leaders, government officials, and other policy makers that people who have HIV have “gone looking” for infection have most likely undermined the response in Uganda by creating exclusion and stigma in communities”

(Civil society coalition on human rights & constitutional law, 2012 p. 4)

And yet,
“Increasing evidence definitively demonstrates that investments in the HIV response can lead to clear reductions in discrimination and stigma, help people in accessing information and services to reduce their risk of HIV infection, and deliver the treatment, care, and support that will extend and improve the lives of people living with HIV”

(UNAIDS, 2010 p. 7).
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