The Positive Muslims’ approach to stigma, HIV, AIDS and PLWH

A theology of compassion translated into non-judgmental support for HIV-positive Muslims in South Africa

Jeanette Westh & Fatima Noordien

The South African organization Positive Muslims, based in Cape Town, resulted from one of the founding members' experience of being stigmatized. When Faghmeda Miller discovered her HIV-positive status, she noted that there were no support structures for Muslims living with HIV in South Africa. On the contrary, stigma surrounds infected and affected persons in Muslim communities. Since HIV is associated with pre- and extramarital sex and drug usage, the widespread conception is that ‘good Muslims’ are above contracting the virus as they are not supposed to indulge in these activities. A survey on Asian Muslims’ opinions on HIV and AIDS, conducted by the Asian Muslim Action Network, found that approximately half of the respondents viewed AIDS as God’s vengeance on immorality. An almost similar percentage considered AIDS a ‘disease of sinners’ and almost as many regarded people living with HIV (PLWH) as ‘devoid of morality’. Although the study focused on South East Asia there is valid reason to presume similar tendencies in South African Muslim attitudes towards AIDS and PLWH.

Faghmeda’s initial reaction, when she tested HIV positive, was that of shame. She kept the information to herself, assuming death was approaching. She did not die and instead overcame her shame and disclosed her status through a community radio station. Faghmeda was the first and only Muslim woman in South Africa to disclose in public until recently. In the absence of a Muslim support group Faghmeda had joined a Christian one. However, she longed to be with other HIV-positive Muslims, knowing that she was not the only one. Faghmeda with other founding members of Positive Muslims then initiated a support group committed to addressing HIV and AIDS in a Muslim context, thus revealing the secret: that HIV also infects and affects Muslims. The organization was formally founded in 2000.

The importance of addressing the problem from ‘the inside’

Why is it important that we are Positive Muslims? Simply because the people we work with are Muslim PLWH, and interpret their life and illness within the framework of Islam. Katherine Willson, a former intern at Positive Muslims, notes in an unpublished thesis that “faith seems to be a big part of the [support group] participant’s strategy to cope with HIV/AIDS”. A report on religious health assets from the African Religious Health Assets Programme at the University of Cape Town and the World Health Organization concludes that the impact of religion in (especially African) people’s health-seeking strategies is generally greatly underestimated by western policymakers. As ‘insiders’ we won’t make that mistake.

We know that in order to really influence people’s thoughts and behaviours, you have to respect the authority of the local imam. Getting him on board interventions against HIV-related stigma is an added advantage. In a publication by UNICEF, titled What Religious Leaders can do about HIV/AIDS, it is noted that “As trusted and respected members of society, religious leaders are listened to. Their actions set an example. This can be especially instrumental in eradicating the stigma and discrimination against people living with HIV and AIDS.”

This is supported by the case of Uganda, where mosques and churches openly discussed HIV internally, with a reduction in new infection rates as a result.

Promoting a theology of compassion

Stigma reduction forms the core of all Positive Muslims’ work in the target communities in Cape Town. We operate within a context of ignorance and prejudice regarding HIV and PLWH. In any strong traditional or religious community such prejudice is prevalent. Positive Muslims strives to create an enabling environment for Muslims infected and affected by HIV, based on a theology of compassion, a theology neither silent nor judgmental about HIV issues. Positive Muslims’ mission statement defines the theology of compassion as a way of reading the Quran and understanding the Sunnah [the path of Prophet Muhammad] that focuses on Allah as a God who cares deeply about all creation. The God who, according to the Hadith [prophetic tradition], said at the time...
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Lessons learned
- Stigmatization is grounded in ignorance and fear of the unknown; consequently the first step to eradicate stigma is to ‘demystify’ HIV, by educating people on HIV and what it means to be HIV positive.
- Getting diagnosed with a serious illness can be a very lonely experience, upon which support from people in a similar situation is invaluable.
- The most valuable help counsellors and peers can offer, is to empower PLWH to cope with their HIV-positive status, but also the associated stigma.

What we do
We support Muslims infected or affected by HIV through individual counselling, group therapy, empowerment projects, home-based care and assistance to access treatment. Positive Muslims also conducts research on the relationship between HIV and Islam and the prevalence of the disease in Muslim communities. We conduct workshops and presentations at mosques, schools, workplaces and prisons to create social network of peers in the support group. Chanbi confirms that Mymoena has grown a lot since she met her, and characterizes her as a ‘real fighter’ and a role model to others. Recently Mymoena told her story to a local newspaper. When asked if she worried about the consequences of going public, she answered: “They can shout at me… I am not afraid anymore!”

As a result of the publicity, Mymoena got positive responses from people who read about her. Some of her neighbours were even upset that the article did not mention which area of Cape Town she was from. An empathetic reader gives her food monthly. Mymoena subsequently shared her story with South African parliamentarians and staff. She came back from parliament bursting with newfound self-esteem, telling about how she had not cried and how people afterwards came to hug her and offer her money and gifts. “I was gooood”, she said with a big smile lighting up her face. Mymoena has clearly found a way to deal with stigma.

Lessons learned
Though every person’s life story is unique, there are some fundamental lessons to be drawn from Mymoena’s case. Her experience confirms that stigmatization is grounded in ignorance and fear of the unknown. Consequently the first step to eradicate stigma is to ‘demystify’ HIV, by educating people on HIV and what it means to be HIV positive. Mymoena’s case shows that there can be change of attitude if the infected person educates those surrounding...
her/him. Both Faghmeda and Mymoena needed help to cope when learning of their HIV-positive status. Lesson number two is that we all need peers in times of trouble. Getting diagnosed with a serious illness can be a very lonely experience, upon which support from people in a similar situation is invaluable. ‘Outsiders’ can be of great importance for PLWH as counsellors. It takes a trained and dedicated therapist to know “when I need to talk”, as Mymoena said, Chanbi does. The challenge of counselling PLWH should not be underestimated! Noteworthy, everybody carries their illness alone. Therefore the most valuable help counsellors and peers can offer, is to empower PLWH to cope. The importance of focusing on empowerment is the third lesson to be drawn from the case of Mymoena, who had the strength to handle, not only her HIV-positive status, but also the associated stigma, and even to challenge the stigmatizers, thereby changing their attitudes towards her.

Dealing with stigma in a comprehensive and effective way is a process demanding time, effort, an open mind to learn new things, a preparedness to grow and grapple with all of life’s challenges, as well as willingness to embrace change and lastly to act in a responsible and accountable way at all times. Mymoena’s case highlights that when one takes the step to disclose, help is forthcoming, often from unexpected sources, and former stigmatizers become supporters. It is possible for communities to eradicate stigma!

**Our main aim: a comprehensive approach**

Though Positive Muslims is a ‘faith-based organization’, we do not advocate solely for a ‘return-to-faith’ solution to the AIDS epidemic, since such an approach in isolation often enhances stigma. Instead we aim for a more comprehensive approach. Although commendable, ‘pulling babies out of the river’, as Farid Esack has put it, is not enough, we must go up the river, and find out who is throwing the babies in the river, and why, and stop them from doing so. In other words: we need to address the structural injustices causing the epidemic’s continuous growth among the poorest of the world. As faith-based organizations we are obliged to. As Esack suggested in a research of Muslim responses to HIV, conducted on behalf of Positive Muslims for UNAIDS last year, “Only a multifaceted approach… that incorporates both personal transformation and socio-economic justice – including the religious dimension to both of these – will offer humankind some hope in the face of this crisis and such future crises. This is the approach we are striving for and advising other faith-based organizations to adopt.”

**Resources on stigma and its reduction**

**HIV & AIDS-stigma and violence reduction intervention manual**

N. Duvvury, N. Prasad, & N. Kishore, ICRW, 2006 (130 p.)

The HIV & AIDS-stigma and violence reduction intervention manual is a guide for community-based organizations to facilitate a community-led and -owned process that addresses stigma and gender-based violence in HIV prevention efforts.


**Guidelines for reducing stigma & discrimination and enhancing care and support for people living with HIV and AIDS**

N. Khan & R. Loewenson, Training and Research Support Centre (Zimbabwe), 2005 (29 p.)

This document aims to provide guidelines on HIV and AIDS stigma reduction strategies for use by non-governmental organizations and the communities that they work with. They cover four thematic areas: 1) stigma and the family; 2) stigma in faith-based organizations; 3) stigma in the workplace; and 4) stigma and the media/communication. The guidelines were developed by reviewing good practices on stigma and discrimination in sub-Saharan Africa with the objective of providing a format which may be utilized by partners to plan intervention programmes to suit their various environments.


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**Jeanette Westh**

Intern from Denmark, currently doing her MA in Theology

**Fatima Noordien**

Director of Positive Muslims

Correspondence:

Fatima Noordien

15 Mars Road, Wynberg 7800

Cape Town, South Africa

Tel: +27 21 761 2249 / 81

Fax: +27 21 761 2284

E-mail: info@positivemuslims.org.za

Web: http://wwwPOSITIVEMUSLIMS.ORG.ZA

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[ Challenging stigma ]