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

Fatima and Jeanette

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.[1] 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 Katherine Willson, a former intern at Positive Muslims, notes in an unpublished thesis that *"faith seems to be a big part of the [support group] participant's strategy to cope with HIV/AIDS"*.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.[2] As 'insiders' we won't make that mistake.

Another advantage of addressing the issue of HIV as Muslims is the awareness on the importance Muslims attach to their religious leaders, and how they contribute to the shaping of values. As Muslims we have an inside knowledge of 'the chain of command' in Muslim communities. This gives us an advantage in getting the message through.

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."*[3] 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

of creation, *"Indeed, my mercy overcomes my anger"*. Such compassion, we believe, must be accompanied by a critique of, and challenge to, a society that marginalizes people.

The formulation of this theology of compassion can largely be ascribed to Professor Farid Esack, a pioneer in the formation of Positive Muslims. Esack is a key figure within progressive Islam, which shares much with liberation theology[4] in its emphasis on social justice and insistence of keeping a close link between text and context. According to Katherine Willson, it is this *"unique relationship between discourse and practice in Positive Muslims' approach that distinguishes it from other faith-based organizations."* This means the theology of compassion underpins all our activities, making non-judgmentalism a core value of our practice. That is why we never ask anyone, approaching us for help, how they got infected.

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 and deepen awareness of HIV and AIDS among Muslims. Furthermore, advocacy and lobbying the relevant structures is a priority of Positive Muslims. Eradication of stigma and discrimination towards people living with HIV is the thread running through all our activities.

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.

Mymoena's case

The case of Mymoena, a 59-year-old grandmother from Cape Town, illustrates how Positive Muslims assists and supports persons feeling marginalized and alone as a consequence of HIV and AIDS-related stigma.

When Mymoena tested positive for HIV in 2004, she thought it was a death sentence. The family of her sexual partner told her that she was going to die when they came to warn her about the consequences of sleeping with this man. Mymoena believed them as she had no knowledge of HIV and AIDS. Fearing rejection, Mymoena did not reveal her status to anyone at first, but later disclosed to her family. She literally burst out her secret to her husband, who had the habit of insulting an HIV-positive woman in a TV series, calling her dirty. *"She can't hear you, but I can, and I am also HIV positive!"* she exclaimed. Mymoena has been brave in confronting people who speak ill of her. It is her experience that, when people hear from her that she is HIV positive and what that means, they stop insulting PLWH and become supportive.

Though Mymoena had a strong spirit, she struggled with feelings of despair and loneliness. A friend introduced her to a Positive Muslims support group, where she was welcomed. Mymoena is a regular in, and a great asset to this group, which meets every two weeks. In addition she has individual sessions of counselling with Chanbi, her counsellor, and talks warmly about what her support means to her: *"After meeting Chanbi, I feel better… sometimes she phones me, just to ask how I am… it's like she knows when I need to talk."* Besides the backing she gets from Chanbi, Mymoena found a

Mymoena

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 goooood"*, 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."*[5] This is the approach we are striving for and advising other faith-based organizations to adopt. ■

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://www.positivemuslims.org.za

1. S. Charnley, *Speaking up: Muslim views on HIV & AIDS. An in-depth study from the Asian Muslim Action Network*, 2007, http://www.arf-asia.org/aman_hiv_act_pub.php
2. *Appreciating assets: The contribution of religion to universal access in Africa*. African Religious Health Assets Programme & World Health Organization, 2006, http://www.arhap.uct.ac.za/publications.php
3. *What religious leaders can do about HIV/AIDS. Action for children and young people*. UNICEF, World Conference of Religions for Peace & UNAIDS, 2003, http://www.unicef.org/publications/index_19024.html
4. Liberation theology is a social movement within Christian theology that arose in Latin America in the 1960s and preaches 'God's preferential option for the poor'.
5. F. Esack, *Muslims responding to AIDS. Mapping Muslim organizational and religious responses*. UNAIDS, 2007, http://www.e-alliance.ch/media/media-6859.pdf

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.

http://www.icrw.org/docs/2006_SVRI-Manual.pdf

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.

http://www.tarsc.org/publications/documents/stigma%20guidelines%20final.pdf