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Missed Opportunities for Religious Organizations to Support People Living with HIV/AIDS: Findings from Tanzania

Melissa H. Watt, Ph.D.,[1] Suzanne Maman, Ph.D.,[2] Mark Jacobson, M.D.,[3] John Laiser,[3] and Muze John[3]

Abstract

Religious beliefs play an important role in the lives of Tanzanians, but little is known about the influence of religion for people living with HIV/AIDS (PLWHA). This study shares perspectives of PLWHA and identifies opportunities for religious organizations to support the psychological well-being of this group. Data were collected in 2006 and 2007 through semistructured interviews with 36 clients (8 Muslims and 28 Christians) receiving free antiretrovirals (ARVs) in Arusha, Tanzania. Swahili-speaking interviewers asked about participation in religion, change in religious engagement since HIV diagnosis, and what role faith plays in living with HIV and taking ARVs. Interviews were audiotaped, transcribed, translated, and analyzed using Atlas t.i. The findings revealed that patients' personal faith positively influenced their experiences living with HIV, but that religious organizations had neutral or negative influences. On the positive side, prayer gave hope to live with HIV, and religious faith increased after diagnosis. Some respondents said that prayer supported their adherence to medications. On the other hand, few disclosed their HIV status in their religious communities, expressing fear of stigma. Most had heard that prayer can cure HIV, and two expected to be cured. While it was common to hear messages about HIV prevention from churches or mosques, few had heard messages about living with HIV. The findings point to missed opportunities by religious organizations to support PLWHA, particularly the need to ensure that messages about HIV are not stigmatizing; share information about HIV treatment; introduce role models of PLWHA; and emphasize that prayers and medical care go hand-in-hand.

Introduction

Religion plays an important role in the lives of people in Tanzania, where approximately two thirds are Christians and one third are Muslim.[1] With 1.3 million adults (7% of the adult population) living with HIV in Tanzania,[2] every religious community is likely to have HIV-positive members. Religious organizations are important both as social organizations and sources of influence on people's beliefs and behaviors, and therefore have an important role to play in providing care and support for people living with HIV/AIDS (PLWHA). This study sought to understand the role of religion of people living with HIV in Tanzania, and to use this information to draw lessons for religious organizations.

Evidence demonstrates that religious engagement holds important potential for improving physical and psychological health and well-being of PLWHA.[3–5] In particular, holding religious beliefs may reduce depression and increase optimism.[6,7] An HIV diagnosis may in fact strengthen religious convictions, as people look for solace and meaning to deal with a difficult life transition.[8,9] In a study among African American women in the United States, religious involvement was associated with less psychological distress, in part because of the social support and coping mechanisms that benefited those who were religiously involved.[10]

At the same time, high perceptions of stigma have been documented in religious communities, usually related to associations between HIV infection and "sinful" sexual behavior.[11] Religious-based stigma may be internalized or enacted,[12,13] and can have a negative influence on uptake and adherence to HIV care.[14] Additionally, stigma may both reduce PLWHA's involvement in religious organizations, and prevent religious organizations from mobilizing a compassionate response to PLWHA.

In Tanzania, faith-based organizations, particularly the Lutheran Church,[15] play an essential role in the provision of

[1]Duke Global Health Institute, Duke University, Durham, North Carolina.
[2]Department of Health Behavior and Health Education, University of North Carolina School of Public Health, Chapel Hill, North Carolina.
[3]Selian Lutheran Hospital, Arusha, Republic of Tanzania.

health care throughout the country,[16,17] and churches and mosques play a central role in shaping social communities and personal belief systems. However, no studies have been conducted on the role that religion and religious organizations play in the lives of HIV-positive Tanzanians. In other parts of East Africa, it has been documented that religious organizations may contribute to HIV-related stigma and therefore undermine national efforts for care and treatment,[18] but at the same time that religious organizations offer an important outlet for people to deal positively with traumatic events,[19] which may be applied to dealing with an HIV diagnosis. We assumed that a similar dichotomy of the negative and positive influences of religion may be found in the Tanzanian setting.

The purpose of this study was to understand how religion influences the lives of people who are living with HIV and taking antiretroviral therapy (ARVs) in Arusha, Tanzania. Understanding the influence of religion can provide insight into the cultural context in which patients are taking ARVs and help to identify missed opportunities for religious organizations to support people living with HIV in this setting.

Methods

The study was part of a larger mixed-method investigation of patients' experiences taking ARVs. The data presented in this paper include in-depth interviews conducted between October 2006 and February 2007 with 36 patients receiving free ARVs from a single clinic in Arusha, Tanzania. Patients were eligible to participate in the study if they had been taking ARVs for at least 1 month at the study clinic, were at least 18 years of age, and could give informed consent. We used maximum variation sampling with quotas[20] to ensure that we included both men and women who had been taking ARVs for various lengths of time (<6 months, 6–12 months, >12 months).

Trained Tanzanian researchers conducted the individual in-depth interviews with respondents in Kiswahili. Interviews took approximately 60 minutes and followed a semi-structured interview guide. Religion was not the primary focus of the interviews, but a preliminary analysis of the interviews after 18 respondents revealed that religion had an important influence on people's experiences living with HIV and taking ARVs. We therefore added questions and probes to explore religion as an area of interest, in particular asking respondents about changes in religiosity since HIV diagnosis and how religion influences both living with HIV and taking ARVs. Because of the evolving nature of the interview guide and the narrative methods applied, the depth and richness of discussion about religion was not consistent across interviews.

The research staff audio-recorded the interviews, transcribed them into Kiswahili and translated them into English. Transcription and translation occurred immediately after the interview. Translated, transcribed interviews were coded and analyzed using Atlas.ti (Atlas ti, ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). The study received ethical approval from the Institutional Review Board at the University of North Carolina's School of Public Health and the Tanzanian National Institute for Medical Research. All respondents who participated in the interviews received 5,000 Tanzanian shillings (approximately US $4.00).

Results

Sample demographics

The sample of respondents included 19 females and 17 males. Approximately three quarters of the sample (28/36) were Christian, while the remaining were Muslim. The average age of respondents was 41.6 years, with male respondents being older than female respondents (45.9 years versus 37.7 years). Only 14% of respondents had received education beyond primary school and only 19% of respondents had formal employment. Respondents had been taking ARVs for a mean of 9.8 months.

The interviews with PLWHA highlighted that religion had both positive and negative influences on respondents' experiences living with HIV and taking ARVs.

Positive influences of personal faith

The positive influences of religion that emerged related primarily to people's individual and personal faith, more than their active participation in religious organizations.

Respondents' faith gave them hope and encouragement. Most respondents (20/36) said that they turned to God for support after receiving their HIV status, and that their belief in God relieved them of worry and gave them confidence to live with hope. This woman spoke about how her faith led her to accept her status.

> I: How did you respond to the HIV results? What did you do?
>
> R: Really I just accepted it. I was not surprised and not worried, because I am Christian and I know God and I know that all diseases are below God's will, I mean they are under God. So I was not worried. (Female, age 36)

As illustrated in the quote above, faith was often associated with a sense of fatalism, an acceptance that hardship and misfortune were part of "God's will." Many said that their faith alleviated their fear of death, which so often accompanies getting a positive HIV status.

> I: How has religion helped you more?
>
> R: It helps me because to be close to God takes out my worries, I have no fear.
>
> I: What was the cause of your fear?
>
> R: I was worried that I am going to die soon. But God did miracles to me. I no longer have that worry . . . I must go on living and working on my plans. And what made me think like that is religion. (Female, age 40)

Because HIV is a stigmatized disease, and people fear disclosing their HIV status in their social network, the ability to confide in God and have an open relationship with God provided people with social support that they were not getting elsewhere.

> It helps me because I have the light of God. Because the word of God said, "You shall remember your God and tell him your problems." Therefore you get lessons that encourage you. (Male, age 55)

Ten of the respondents we interviewed told us that after they were diagnosed with HIV, their commitment to their faith deepened. These were all Christian respondents, and four of them reported being "saved" or "born again" after being diagnosed. People found or renewed a commitment to God out of a desire for emotional comfort. This is illustrated

by a female respondent who said that after getting diagnosed she decided to become "saved":

> I: How is your participation in religion?
> R: I am participating well and I was saved after getting this problem. I have received Jesus as the Lord and savior of my life.
> I: So you became saved after getting this problem?
> R: Yes, after getting the problem.
> I: What made you decide to be saved?
> R: I saw the Lord as the one to run to, because if you get this disease you expect to die. So I had nothing to depend on but my Lord. It's a place for hope and I am happy now. I don't have any fear of death! Prayers give us energy and hope, and since the day I got saved I am confident. (Female, age 40)

Religious practices supported adherence. For most respondents we spoke with, religious convictions and ARVs played complementary roles in living positively with HIV. While religion provided spiritual and emotional sustenance to respondents, it also helped to provide the context for respondents to take ARVs as they were supposed to. The following man attributed his ability to remember to take his drugs to God's constant presence in his life.

> First I accepted the drugs, second I stand for God that I use the medicine, and even my ability to remember depends on God. Sometimes I may forget, but then something comes to my mind to remind me to take the drugs. (Male, age 38)

Two respondents expressed that taking the pills is itself something they do in God's name.

> As I've told you, when I'm using anything I'm using it by the power of God, and I pray for it to do a certain function in my body . . . I'm sure if I take the pills and pray with faith then God can help me. He always helps me in my problems. (Male, age 56)

The routine and discipline of praying also provided reminders to two respondents to take their pills, as illustrated by this quote:

> I: Do you have any strategies you're using to use your pills effectively?
> R: Someone to alert me?
> I: Strategies to help you remember.
> R: To my side it's mostly prayers. When I finish praying I turn on the radio, then take my pills. After that I'm waiting for my tea and go to work. (Male, age 60)

Neutral or negative influences of religious organizations

While respondents drew upon their personal faith to find strength and support in living with HIV and taking ARVs, the influences of formal religious organizations (churches and mosques) was primarily neutral or negative.

Respondents feared disclosing in their religious communities due to stigma. Only three respondents said that they disclosed their status to religious leaders or church members. For most, the reason to not disclose in religious communities was reflective of respondents' larger decisions to disclose very selectively in their social environments.

> We didn't disclose to the church, so they don't help us. So we appear in the church just like the negative ones. If the family knows nothing, how can the church know about our status? (Female, age 40)

However, the same respondent also gave some indication that it might be particularly difficult to disclose in a religious community, because of a fear of blame and being judged.

> I: So what have you heard in your church about HIV?
> R: I tried to find out how the church sees this problem. I found out that they take it as people who have done sin, so that is why we get this infection. That's why we isolate ourselves from them, because they see us as we are not good people and we were not following the commandment of God.
> I: How do you feel when you hear these things?
> R: That's why I tell you that you can't be free to tell other people your problem, that I have this problem when you have already grouped us as sinners. (Female, age 40)

Fear of blame and judgment from the religious community was echoed by other respondents. The following man said that he had heard people in his church speak derogatorily about people living with HIV, which made it difficult for him to disclose.

> They talk about it, but it will reach a moment you'll be angry because the perceive that anyone who is positive committed a sin, you're a "muasherati" (promiscuous person) and you went away from religion. (Male, age 55)

Disclosure was easier if there were others in the church who were open with their HIV status. For example, one respondent said that one of the workers at the church was HIV positive, which seemed to make him to feel more free to disclose to his congregation.

> I: Do all the people at your church know?
> R: They all know. When we went on Saturday, the pastor and church workers who are there help us. One among the workers is HIV positive. (Male, age 60)

For some, participation in religious organizations decreased. Even though, as mentioned earlier, most respondents reported experiencing an increase in religious conviction after diagnosis, this was not necessarily accompanied by an increase in participation in religious organizations. For four respondents (three of them Muslim), religious participation decreased because a sense of shame or a fear of disclosure. In particular, respondents who were still suffering from visible illnesses did not feel comfortable being in a public environment of the church because they either felt embarrassed about their appearance or feared inadvertently disclosing their status to others.

> I: Can you tell me about your involvement in religion. For example, are you involved in any groups at church?
> R: I haven't gone to church for a long time now, since I was divorced from my wife. I used to go before I got a skin rash all over my body, because I was feeling ashamed of my body. I just decided to pray inside [the house]. (Male, age 40)

Community beliefs about religious cures for HIV were common. Of the 21 people we talked to about the idea of religious cures, 10 said they had heard other people say that it was possible to be cured from HIV through prayer, and 4 (all Christians) said that they themselves expected to be cured. The following woman was 1 of the 4 respondents who said she believed that she believed she would be cured of HIV through intervention from God.

I: Have you ever seen anyone who has been cured?

R: So many!

I: Mmh! And how would you know that you are cured? What ways can use to know "I am cured."

R: I can come for a test! There are so many people who have been cured. It's not just one, two, or three, there are so many. They went for a re-test, even here two of them who used to take ARVs with us have been cured and they went for a test more than two times. (Female, age 36)

The woman was so confident that she would be cured through prayer that she was anticipating the day when she would stand before her congregation to witness to her cure by God's hands.

I know the day will come when God will take away this problem! All diseases are evil spirits. That's why we are suffering with HIV all over the world. Yes! And I believe that this disease will leave me . . . If I am cured, for example if I go for a (HIV) test now and find that I am cured, I will come to the hospital and take all the diagnostic certificates and I will stand before people and witness, because I will have all that to prove (that I was cured). (Female, age 36)

Religious organizations talked about prevention, but not about living with HIV. When we asked people what they heard discussed about HIV and ARVs in their religious organizations, 12 respondents had heard HIV prevention talked about in their church or mosque, but no one said anything about living with HIV or taking ARVs. This man illustrates:

I: What do they say about HIV there in the mosque?

R: They are not talking much, because Muslims were only talking about it to be safe, but not like Christians.

I: How about medicine. Do they say anything about these drugs?

R: They only say that people must be safe from this disease because it is a bad disease. (Male, age 32)

The HIV prevention messages that people received in their religious organizations often focused on the association between HIV acquisition and immoral behavior. While the intention may have been to reduce risky behaviors among the HIV negative, the effect was to reinforce perceived stigma and discourage disclosure among the HIV positive.

Discussion

The findings presented here demonstrate that people living with HIV in this setting seek solace and support in their religious faith, which helps them to live positively with the virus. Even though very few respondents were disclosing their HIV status in their religious organizations, respondents' religious beliefs nevertheless gave them hope and provided them with courage to face their condition. The psychological benefits of religious beliefs for PLWHA has been documented in other settings,[3,9] and has also been associated with improvements in disease progression.[4] Many respondents said that their religious convictions increased after their diagnosis, a phenomenon that has been observed elsewhere and has been attributed to a search for meaning and comfort.[8,9] At the same time, however, participation in religious organizations decreased for some because of a fear of involuntary disclosure and resulting stigma.

For the most part, religion played a complementary role with clinical care in respondents' lives. The fact that respondents saw ARVs as a gift from God meant that religious and medical practices and beliefs were not mutually exclusive. In addition, religious beliefs and practices facilitated adherence to medication, as respondents reported anchoring the routine of medication-taking to prayer. It has elsewhere been shown that religious practices (such as regular church attendance) may positively influence adherence,[14] and having a consistent daily routine, as one that revolves around regular prayer and religious activity, can make it easier to remember to take medication on time.[21–23]

The positive influence of religion on people's lives came through an individual relationship with God and prayer, and not through the institutional structures of the church or mosque. In fact, respondents revealed that these institutional structures sometimes exerted negative influences by expressing judgmental attitudes about people living with HIV. Stigmatizing attitudes have been documented in religious settings, in large part because of the associations between HIV and "immoral" sexual behavior.[11] Perceptions of stigma, even if stigma is never experienced directly, can make it difficult for patients to disclose their status and participate freely in their religious communities.

Expressed beliefs about the ability to be cured from HIV through prayer is concerning. Although only two respondents believed that spiritual cures were possible, almost all respondents said they had heard of such beliefs. It is unclear to what extent these "cures" may account for dropout from ARV programs,[24] but a small investigation in Uganda suggests that it may play an important, but underrecognized, role.[25]

While religious-based health facilities play an important role in meeting the clinical needs of people living with HIV in Tanzania,[15] churches and mosques appear to be falling short in meeting the psychological needs of HIV positives. While many respondents in our study reported hearing HIV prevention messages in their church or mosque, none said they had heard messages about living with HIV. This echoes findings in other parts of Africa that religious organizations are failing as institutions to provide support and care to people living with HIV,[26,27] even though people may get individualized support from pastors or congregation members.[28,29] The institutionalized programs that do exist[30,31] should be examined for their impact and disseminated to other settings.

The study's findings highlight opportunities for the religious communities in this setting to provide spiritual support and guidance for people living with HIV. First, in order to avoid negative influences of religion, leaders should review messages and sermons about HIV to ensure that they do not to stigmatize people living with HIV. Prevention messages that equate immoral behavior with HIV may inadvertently enforce discrimination against PLWHA.[11] Instead, religious leaders should take care to create an environment in which PLWHA feel comfortable to disclose, by making it clear that they will be accepted unconditionally and without judgment. This environment may be strengthened by inviting PLWHA to speak at religious meetings, in order to introduce role models for positive living and disclosure. The act of making public the stories of HIV positive people can be an important step for religious organizations to mobilize an appropriate and compassionate response to PLWHA.[30]

Religious organizations have an important role to play in sharing knowledge and dispelling misconceptions about HIV. Religious leaders should encourage people to seek out testing

and care, and provide information about where services might be accessed. They should responsibly address myths about prayer as a cure for HIV, and emphasize that prayer and medical care go hand-in-hand for PLWHA.

Finally, religious organizations should see themselves as an important source of social support for PLWHA. In addition to providing support through their normal ministry, they could organize venues for PLWHA to come together to discuss their situations, pray together, and share information and ideas. By reaching out to governmental or nongovernmental bodies, religious organizations could become a venue for providing financial or food support to PLWHA.

The results presented here must be viewed in light of the study's limitations. The themes reported in this paper are limited to the issues that individual respondents chose to discuss during the interviews. While the interview guide included several broad questions and probes about religion, it was not the only topic explored in the interviews, and the depth of discussion on religion was not standard across the interviews. The lack of a common denominator across the themes made it impossible to provide proportions who agreed with statements or ideas. The small number of respondents, and limited discussion of religious influences among Muslim respondents, made it difficult to compare the experiences of Christians and Muslims. Finally, as applies to any qualitative study, the results are not meant to be statistically generalizable to a larger population, but to illuminate aspects of experience and context that may be shared by others.

Despite the limitations of the study, the results provide some important insight into the influence of religion for PLWHA in this setting. The findings highlight the positive role that religious beliefs play in the lives of PLWHA, and point to specific areas where religious organizations may build on this role to better support PLWHA.

Author Disclosure Statement

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Address reprint requests to:
Melissa H. Watt, Ph.D.
Duke Global Health Institute
Duke University
235 Trent Hall
Durham, NC 27708

E-mail: melissa.watt@duke.edu