

Community Perception, Misconception, and Discord Regarding Prevention and Treatment of Infection with Human Immunodeficiency Virus in Addis Ababa, Ethiopia

Ramin Asgary,* Sheila Antony, Zoya Grigoryan, and Jane Aronson

Department of Medicine, New York University School of Medicine, New York, New York; Department of Medicine, Yale New Haven Hospital, New Haven, Connecticut; Hunter College, City University of New York, New York, New York; The Worldwide Orphan Foundation, Maplewood, New Jersey

Abstract. Approximately one million persons infected with human immunodeficiency virus (HIV) live in Ethiopia. Socio-cultural factors influence prevention and treatment adherence. We applied a qualitative descriptive approach to evaluate community perception, knowledge, and the role of spiritual factors in regard to HIV. We conducted 14 focus groups with sampling of HIV+ and HIV– participants (n = 52) by using open-ended questions. We coded and analyzed data for major themes. There are misconceptions, including transmission via casual contact, and pervasive beliefs of holy water as a cure. Many HIV– participants believe treatment is ineffective or incompatible with holy water. Most HIV+ participants believe treatment and holy water can be taken together, but experienced either pressure to stop treatment or stigma when taking medications. Participants emphasized the role of spiritual leaders in directing and shaping community perspectives on HIV. Ongoing community education via local initiatives, nation-wide structural and environmental strategies, and efforts tailored toward Ethiopian society to reconcile treatment with faith are crucial.

INTRODUCTION

Despite the relatively high prevalence of human immunodeficiency virus (HIV) in urban Ethiopia (more than 7%), there are wide variations in knowledge about the disease, and in how people living with HIV and acquired immunodeficiency syndrome (AIDS) (PLWHA) are treated by the community.^{1–7} Although disparity in access to treatment is undoubtedly a well-documented barrier to treatment, misconceptions and lack of knowledge only compound the problem.^{1,2,5,8,9} Limited research from eastern Africa and Ethiopia has suggested that a belief in alternate cures might conflict with adherence to medically necessary treatments.^{10–13} Reasons for default from antiretroviral (ARV) programs in Ethiopia include community pressure and misconception about treatment.^{10,12}

Improving community knowledge about prevention strategies and medical treatment options, and more interaction with PLWHA, are associated with lower levels of stigma against PLWHA.^{2,4,14} Little information exists regarding which approaches reach communities most effectively or, most importantly, which ones translate into individual behavior change.¹⁵ It is important to explore knowledge and perceptions about HIV, conflicting traditional beliefs, and sources of information, as well as to attempt to identify strategies that could improve community awareness without alienating traditional and cultural belief systems. Qualitative research is useful in opening such discussions from the community perspective and reaching under-served populations.¹⁶ Specifically, focus groups offer the advantage of a protected forum, as well as the opportunity to explore and clarify complex topics through participants' conversation and interaction.^{17–19} There is very little, if any, qualitative data about community perception on HIV within urban Ethiopia. Using a qualitative descriptive research design, we explored community perceptions and knowledge about prevention, treatment, belief in alternative cures, and the potential role of spiritual leaders in health education with regard to HIV in Addis Ababa.

METHODS

With the assistance of local community health workers, we recruited participants (n = 52) by using prospective purposive sampling, non-probability snow-ball sampling, and criteria sampling techniques (Table 1). Criteria sampling was used to assure inclusion of HIV-positive and HIV-negative/unknown status, and a range of persons who have and have not had regular interaction with HIV+ persons, with varying educational background and inclusion of community leaders. In addition, we ensured representative samples by including different age groups, marital status, and other characteristics to the extent that it was possible. Snow-ball sampling was used for key informants and community leaders. A total of 14 focus groups (3–4 participants in each) were conducted, including 5 groups with HIV-negative or unknown status community members, 4 with non-health personnel of the health facility and school staff, and 5 with all HIV-positive patients. Sessions were held separately for HIV-positive and HIV-negative participants. Participants were ≥ 18 years of age. Focus groups were held at the local clinic and schools, and were conducted in Amharic (the most commonly used language in Addis Ababa) by using trained interpreters.

In addition to focus group discussions, further interviews were conducted with numerous key informants, which in our method were defined as persons positioned such as to possess knowledge of particular relevance to the research themes, including health workers, medical providers, and community leaders who were working or living in catchment areas for this study.

Because of the sensitive nature of discussing HIV and stigma, we chose to conduct focus groups in small numbers (3–4 participants at a time) to facilitate a more comfortable, and candid environment where participants could feel safe to discuss their fears and opinions freely. The decision to choose focus groups over individual interviews was based on input from community leaders and local informants. We took into account the social setting and participants' cultural background, and the social and education differences between interviewers and participants, and concluded that participants would be more likely to freely express their views in a focus group, as opposed to semi-structured individual interview.

*Address correspondence to Ramin Asgary, Department of Medicine, New York University School of Medicine, 227 E 30th Street, New York, NY 10016. E-mail: ramin.asgary@caa.columbia.edu

TABLE 1
Participant demographics, Ethiopia*

Characteristic	No.
No. participants	52
Male	9
Female	43
Average age (range 18–61), years	32
Education	
No schooling	9
Average of 8 grades	33
High school diploma	7
Bachelor of Arts degree	3
HIV status	
Positive	18
Negative or unknown	34
Focus groups	
Total	14
HIV positive	5
HIV negative/unknown non-staff	5
HIV negative/unknown staff	4

*HIV = human immunodeficiency virus.

Grouping HIV-positive participants together also helped them feel empowered to discuss issues affecting the HIV-positive community. Likewise, the focus group setting was also beneficial for HIV-negative and unknown status participants.

In focus groups, participants were asked a series of 12 mostly open-ended questions, with subsequent probes and follow-up questions when needed. Our pilot evaluation and discussion with local key informants for local discourse consistently brought up the issue of the belief in holy water as an alternative way of treating HIV/AIDS. Therefore, we decided to seek participants' opinion and thoughts on holy water. Other questions were regarding knowledge and perception of HIV transmission, treatment options for HIV and their effectiveness, sources of information about HIV, opinion on acceptance of HIV medication in the community, and (for HIV-positive participants) the opinion and experience of taking HIV medication in public. Informed consent was obtained orally. Active discussion and interaction among participants was encouraged. HIV status was based on self-report during recruiting, and participants were kept in their assigned groups. We clarified that participation would not affect participants in any negative way, and they could retract their participation or answers at any time during and/or after participation. The sessions were audio-recorded, transcribed verbatim, translated into English, and checked for interpreter accuracy when applicable. There was more than 90% accuracy in transcription. Non-verbal communication was noted. Transcripts were then coded and analyzed for major themes. In each focus group, participants were asked a series of characterization questions to assess education, employment, and level of interaction with PLWHA.

We applied a qualitative descriptive approach. Data were analyzed by two authors by using content analysis to identify core knowledge and understanding and perceptions about HIV and related issues. More than 200 pages of transcribed data were analyzed. During content analysis, we developed preliminary coding based on priority codes derived from theoretical framework and conceptual model guiding the study. We performed critical deliberation about initial coding and reviewed coding for similarities and variations among coders' output. Initial discrepancies were discussed, and a high level of agreement was achieved, suggesting that the coding scheme

used was appropriate. Two authors (RA and ZG) independently reviewed all codes; then met and reviewed codes; discussed the specific categories; used independent inputs as needed; and finally characterized, described, and agreed upon major important themes.

Coding of transcripts was done by using Excel (Microsoft, Redmond, WA) and through open, axial, and selective coding. Codes fell into distinct but overarching categories. Patterns in responses and codes were analyzed to explore and develop relevant themes. The codes from responses were referenced back to the subject characterization questions to stratify the data based on HIV status and interaction with HIV-positive persons. Emerging themes were analyzed and compared across cases to elucidate commonality and variability of themes. Observational data including setting and nonverbal communication were collected and noted to enhance analysis.

Our participants were mostly women because men in the community were largely unavailable during the day, and as per input from the community leaders, they were less likely to be interested in participating in such a discussion. We also believed that because of cultural norms, women were more likely to recognize the value of, and more likely to join, the focus groups. As per community leaders' input, women were more interested in discussing community knowledge and perceptions, elaborating on social issues during discussion sessions, and suggesting potential venues and strategies to improve awareness and advocacy.

The World Wide Orphans Foundation (WWO) clinic provides, among other community medical services, care to HIV-positive persons and orphans in urban poor areas of Addis Ababa, Ethiopia. The WWO is a non-for-profit organization with a relationship with local communities in Addis Ababa. This study received institutional review board approval from the Mount Sinai School of Medicine and the Addis Ababa Health Bureau.

RESULTS

Of the 52 original participants, 43 were women. The average age of the participants was 33 years (range = 18–61 years). Focus group participants were of varying occupation (including homemakers, laborers, teachers, community health workers), level of education, socioeconomic status, and level of interaction with PLWHA. Nine participants had no schooling, 33 had an average eighth grade schooling, seven had a high school diploma, and three participants had completed a bachelor's degree. Most participants were from urban areas, but many were in frequent contact with rural areas, visiting their families or returning home.

The range of responses showed overarching themes on transmission, prevention, treatment, alternative cures, efficacy of medication, HIV education, the role of holy water, and community acceptance (Table 2). As was addressed in the Methods section, our respondents were predominantly female. However, no apparent differences emerged between discussions with male and female participants.

Beliefs and constructs about transmission and prevention. Most participants discussed sex, childbirth (transmission of HIV from infected mother to child), "unsterilized materials like needles" (focus group [FG] 3, staff, HIV-/unknown status), and drug use as sources of transmission. Participants acknowledged

TABLE 2
Additional quotes from participants, Ethiopia*

Beliefs and constructs about transmission and prevention
HIV comes from God
“God will not let this to happen to his children, rather, these things happen because of our misbehavior.” (FG1, staff, HIV-/Unknown)
“It is just of gift of God. Some kind of sin. They think that way in the countryside.” (FG4, staff, HIV- /Unknown)
“In rural areas people think that HIV is God’s punishment and those PLWHA are under the punishment of God.” (FG4, staff, HIV-/Unknown)
“This disease is comes from the Gods without any reason.” (FG4, staff, HIV-/Unknown)
“Spouses may be tested for HIV and negative, but because of ‘curse’ one of them may get HIV and it happened to me like that.” (FG8, non-staff, HIV+)
HIV and other transmission
“Those who do not care about themselves and experience bad habits like ‘chewing chat,’ drinking alcohol, smoking.” (FG5, non-staff, HIV-/Unknown)
“They think that the condom can transmit [disease] in some cases.” (FG3, staff, HIV-/Unknown)
“The youth do not control themselves. However, HIV does not discriminate among Muslim and Christian. Youth and Old. Nowadays the youths are seen in the street. It is the workforce that is victim. The prostitutes do use condoms. But the husbands, especially the drivers, bring HIV to their spouse.” (FG12, non-staff, HIV+)
Community pressures and stigma about treatment and community knowledge and perceptions about treatment and cures
Stigma and isolation
“People afraid of stigma. Because of that, they do not want to take the medicine.” (FG2, staff, HIV- /Unknown)
“Because of fear of stigma, people do not want to tell their [HIV] status to their family or spouse, and it is difficult to take the treatment daily hiding from your family [when] you are living together.” (FG2, staff, HIV-/Unknown)
“We are hiding our selves. If they know our status, our relation with our friends will be broken and you will be hurt. . . It happened to me, my family doesn’t want me and I am lonely and I have to hide myself.” (FG8, non-staff, HIV+)
“We were told by our parents that we shouldn’t touch anything used by [my brother] and he was sleeping and eating alone because we [thought] the disease might be transmitted through breathing. . . now I am changed and I know . . . ways of transmission. . . and I regret for what we did to my brother.” (FG2, staff, HIV-/Unknown)
Repercussions to taking medication/disclosure
“One of the daughters of the owner of the house saw me while I was taking my medicine and she told her parents and they kicked me off their house.” (FG8, non-staff, HIV+)
“Even if you are healthy you may not get job opportunity because of your status.” (FG9, non-staff, HIV+)
“People living in rented house do face problems. Those who live in public house lead better life. When we get food aid from kebele and take it home they say ‘Leave our home.’ They think if we touch the water tap and the like, HIV can be transmitted. [This] can [cause] difficulty to get rental house.” (FG12, non-staff, HIV+)
Holy water: treatment vs. cure
“The basic thing is your internal faith on God. I know people who get cured by holy water. They were tested 3–4 times and they become negative.” (FG14, non-staff, HIV+)
“I heard the treatment helps to live healthy and longer, only it is not curative but the holy water can cure HIV.” (FG2, staff, HIV-/Unknown)
“If you want to use holy water just the holy water only – we learn it from spiritual fathers at church.” (FG11, non-staff, HIV-/Unknown)
“If you believe [in holy water] you will be cured. I know many people cured who were using holy water.” (FG1, staff, HIV-/Unknown)
“Because they asked God to cure them [if taking only holy water, they can get cured.]” (FG11, non-staff, HIV-/Unknown)
“I heard it through media/newsletter that religious fathers have allowed people to take treatment with holy water.” (FG9, non-staff, HIV+)
“Yes, they tell us to take the medication with Holy Water and tell us even the treatment is given by God.” (FG9, non-staff, HIV+)
Sources of information about HIV
Church and religious leaders
“Religion is one of the ways of prevention of HIV transmission. Now many young people are becoming religious and this is good opportunity to teach them about HIV. So spiritual institutions are playing great role in prevention of HIV.” (FG5, non-staff, HIV-/Unknown)
“Spiritual fathers are medicine. Like physicians they can give advice and help you to understand things that you don’t know and this restores your life.” (FG14, non-staff, HIV+)
Community programs
“Through media, at kebele community conversation programs, and training. . . Media, meetings, radio, and TV.” (FG12, non-staff, HIV+)
“Mainly the media and also through kebele and local associations, community based. In the early time, the messages delivered through media were fearful, but now it is changed. They teach us how to live positively with HIV.” (FG14, non-staff, HIV+)

*HIV = human immunodeficiency virus; FG = focus group; PLWHA = people living with HIV/acquired immunodeficiency syndrome.

that this understanding is more characteristic of urban knowledge, and that beliefs are likely to vary greatly “*in rural areas [where] people think that HIV is God’s punishment and those [people with HIV] are under the punishment of God*” (FG4, staff, HIV-/unknown).

They also elaborated on beliefs held widely in their community that eating or drinking, or other casual interaction with HIV-positive persons lead to transmission. “*The community think many things. They think HIV can be transmitted by eating. In Ethiopia there are many people [who] believe that if they eat, drink or share any utensils with a person living with HIV, they will get HIV*” (FG8 HIV+). Some participants told us that HIV can be caused by condoms, casual interaction, “*curse*”, or the “*will of God*.” Young people were said to be educated about condoms, but sometimes negligent about

their use. A few participants told us about a common phrase among young people: “*there is no AIDS after 6 pm*” (FG7 HIV-/unknown, FG12 HIV+). Almost all participants attributed alcohol and tobacco use to a greater risk for contracting HIV. “*What exposes one to HIV most is alcohol drinking and drugs*” (FG12 HIV+).

Our participants discussed safer practices such as condom use, monogamy, abstinence, and use of clean instruments as potential methods of prevention. “*Using condoms and avoid blood contact*” (FG10 HIV-/unknown). A few emphasized that educating the public about transmission is also an act of prevention, and pointed to the religious community as a potential vehicle of information. In particular, they emphasized that religious leaders should discuss monogamy as a method of preventing HIV, but they explained that condoms

are not discussed in the church. *"People think that married people should not use condoms, but sex workers can use them"* (FG10 HIV-/unknown). They noted that condoms suggest multiple sexual partners, which is incompatible with the church's message. *"Females who do not trust their husband... use [condoms]"* (FG11 HIV-/unknown). Other miscellaneous prevention methods cited were giving up smoking and/or alcohol, and avoiding the company of HIV-positive persons, especially during mealtime.

Participants consistently discussed women (especially housewives) as particularly vulnerable because of their husbands' infidelity, risk of rape, coercion into unprotected sex, and the general lack of education about HIV transmission. *"There are girls who face forced sex by men [and get HIV]"* (FG12 HIV+). *"In our culture women are not open or strong enough to say no for unsafe sex"* (FG7 HIV-/unknown). *"Street children, commercial sex workers, housekeepers raped by their employers [are the people most at risk for HIV]"* (FG9 HIV+). The general consensus was that sex workers are more likely to be educated about transmission and condom use than others, but are *"highly exposed"* and *"they are also forced to have sex without condom"* (FG10 HIV-/unknown).

Community knowledge and perceptions about treatment and cures. When discussing treatment, participants were aware to some extent of ARV medication, its importance in helping HIV-positive persons to maintain a productive and healthy life, and the importance of adhering to regular treatment. However, they simultaneously expressed confidence in prayer and holy water as a separate and possibly more effective option: *"Holy water is for cure. HIV treatment is for longer life not cure"* (FG7 HIV-/unknown). When probed regarding its perceived efficacy, the commonly shared belief is that *"it depends on [one's] faith. If you have faith you can be cured"* (FG2, staff, HIV-/unknown). *"People believe Holy Water can cure any disease... if you pray with faith you can get whatever you ask from God"* (FG11 HIV-/unknown). Every participant either knew someone or had heard of someone in their community who was *"cured"* by holy water. *"I saw in my eyes the couple who were cured by using holy water only"* (FG6 HIV-/unknown).

Notably, alternative cures and ARV treatment have in the past been established as mutually exclusive by religious authorities. In recent years, *"people were not allowed to take the HIV treatment while they are taking the holy water"* (FG1, staff, HIV-/unknown). Our participants overwhelmingly told us that people feel they must choose one option or another. *"We cannot mix the treatment and holy water. You have to stop taking treatment and take the holy water"* (FG8 HIV+). Reasons for this dichotomy included pressure from religious leaders and the community that *"if you are faithful, [you will use as treatment] only the holy water"* (FG11 HIV-/unknown). *"The problem is if you are suspicious – not fully trust[ing] God [if you take treatment along with holy water]"* (FG5 HIV-/unknown). HIV treatment itself is also sometimes seen with suspicion, but holy water is not associated with any danger or repercussions.

Some participants told us that they had experienced holy water helping them with other miscellaneous ailments, and that therefore they believed it could cure HIV. *"People believe Holy Water can cure any disease"* (FG11 HIV-/unknown). Information from health workers is sometimes dismissed in favor of information *"from friends"* (FG1, staff, HIV-/

unknown). Radio programs, word of mouth, and both secular and religious magazines reinforce these beliefs, recounting stories of people being cured by holy water.

Participants told us they feel that views are starting to change in urban centers, but are slow to catch up in rural areas. *"I think in the rural areas they don't have [access to] any awareness about [HIV], so they don't want even to see [an infected person]. Because they don't have awareness, they don't get any knowledge for this kind of condition"* (FG3, staff, HIV-/unknown). In rural areas, physical contact with known infected persons is still seen as taboo, but participants see a potential for change. *"I don't think [taking medication] is accepted in the rural community... but if they get the information [about it] they will be convinced or accept it"* (FG11 HIV-/unknown).

Taking medication: community pressures and stigma about treatment. Half of HIV-positive participants indicated that it was not acceptable in the community to take medication. Some also elaborated that it depends on the education level and status of persons in the community. Follow-up questions were asked to explore HIV-positive participants' experiences with taking medication in public. Most indicated some level of fear, and more than half of participants elaborated that they had been afraid to take medication in front of family or persons they knew. *"My family didn't know that I am taking an HIV medication. Even I don't want to tell my child"* (FG14 HIV+). A few participants said they were afraid to take medication in front of anyone at all. *"Yes, I fear... When we take our treatment we are afraid of people that they may see us"* (FG14 HIV+). In addition, most of the HIV-positive participants indicated that they felt pressured by other persons to give up their medication in favor of holy water. Some admitted to having stopped treatment at various intervals after being told to take holy water exclusively. *"I tell people my experience and many people advise me to go to holy places and stop medication"* (FG12 HIV+).

Notably, taking medication in front of persons is of particular concern to those who rent a room or a house from someone else. A recurring apprehension was the risk of losing one's home after being seen taking medication. *"When we take our treatment, we are afraid... people may see us... may get rid of you from their house. So I hide myself and live normal life with them"* (FG14 HIV+). At least two participants told us they had personally lost their homes after the owners/landlords discovered they were HIV-positive.

Some participants pointed out that spiritual leaders are starting to allow ARV treatment and holy water to be used at the same time, which is helping HIV-positive persons reconcile their faith and their ARV regimen. *"Now... spiritual leaders are encouraging people to take their treatment"* (FG1, staff, HIV-/unknown). This is still gaining acceptance throughout the community, and many still believe that taking treatment compromises one's faith.

Sources of information about HIV. Major sources of information included mass media, *"kebele"* community groups (FG 1, 2, 7, 8, 10, 12, and 14), neighbors and friends, churches and community workers. *"At kebele... they have discussion sessions about HIV... and these people have better awareness"* (FG12 HIV+). In addition, approximately half of the HIV-positive participants got information *"from the clinic"* (FG9 HIV+), health centers, and hospitals. Some of the HIV-negative participants received their information from some form of training,

school, or course on the subject. “From [organizations] who give training and education” (FG7 HIV-/unknown).

The role of the church and religious leaders was acknowledged as influential in spreading information. “Spiritual fathers are highly accepted and trusted by the community. What they believe is always true” (FG1, staff, HIV-/unknown). Religious leaders are respected, and given authority over health issues. “They are in a higher position to teach the community. There are spiritual fathers” (FG14 HIV+).

Although the primary source for HIV-positive participants can be identified as the health center, no such primary source can be identified for HIV-negative participants. Several HIV-positive participants explained that before their diagnosis they were ignorant about the disease, and discriminated against relatives or friends who were HIV positive. “Some years back, I have lost my sister by HIV. . . we were not well aware of HIV. We have isolated her in separate room.. that was due to lack of awareness and knowledge” (FG9 HIV+).

Participants elaborated that education about HIV transmission and treatment is improving, and attributed this to media efforts and church influence. Media such as radio spots contribute to greater awareness and encourage young persons to practice safe sex. Some said that this was helping to change attitudes and behavior in young people, but there are still people who “think that the condom can transmit [HIV] in some cases” (FG3 HIV-/unknown).

DISCUSSION

Rates of HIV infection in urban areas of Ethiopia are alarming, and multiple barriers hinder effective prevention and management of the disease, including misconceptions about transmission and treatment of HIV, and stigma against PLWHA.^{1,3,5-7,20} In our study population, a range of important issues were raised, including distrust of medical treatment and condoms, pressure to rely solely on advice from spiritual leaders for treatment or not to adhere to ARV in favor of holy water, difficulty taking medication in front of others, and discriminatory behaviors resulting in serious consequences.¹⁰

In Ethiopia, there are widely held beliefs in the curative effect of holy water taken orally or topically in a spiritual setting.²¹ Data regarding the prevalence of its use is rather scarce, but previous studies have explored reliance on holy water for treating mental illness, HIV, and other ailments.^{13,21} However, there is still need for a systematic evaluation of the use of alternative HIV treatment, along with the personal conflict created when having to choose between holy water and treatment, and the alienation caused by community pressure. There appears to be underlying conflict between spiritual messages and medical approaches.²¹ The prevailing belief that faith determines whether holy water will cure their affliction puts the onus entirely on the infected person. Thus, failure to be rid of the disease is simply a reflection of the strength or weakness of one’s faith, creating an environment of blame towards afflicted people. Furthermore, HIV-positive participants are often pressured by the community to rely solely on prayer and holy water, facing discrimination and repercussions when openly taking medication.^{3,21}

Our discussions showed that even if persons believe that medication can effectively help manage HIV, holy water is still believed to be a better alternative, offering a definitive end to the illness. Similarly, other studies have suggested the

use of holy water as a reason for non-adherence to treatment.^{10,11,13} HIV-positive participants continue to endorse staying on treatment, in contrast with HIV-negative community members, who for the most part saw no logical reason to stay on treatment with a cure available (in the form of holy water).

The fact that most of our HIV-positive participants expressed strong fear about taking medication (publicly) and experienced such pressure to give up their ARV medication is worrisome.¹⁰ Adhering to medically necessary, lifesaving treatment can mean severing oneself from the community and sometimes losing one’s home and job.⁹ Such low acceptance of taking HIV medication is a serious form of stigma, and a significant barrier to adherence.^{2,3,5,6}

Notably, there was a discrepancy in the answers between HIV-positive and HIV-negative individuals regarding community acceptance and perception of stigma regarding taking HIV medications. This is especially important considering that some of our HIV-negative participants had higher training about HIV because of their role in the health system, and thus may not fully represent communities where HIV-positive participants normally reside and face stigma.²⁰ This likely suggests that stigma has more profound reasons and causes that may not be completely overcome by more formal education, or simply increasing exposure to HIV-positive communities or their plight. This might also suggest a need to incorporate more targeted training regarding stigma itself, and ways to address it for both the community and for health workers.

As in other studies, physical isolation and rejection from family and community are the dominant forms of discrimination against infected persons. In our study, women were believed to be more vulnerable to acquire HIV and less empowered to prevent infection. Because they suffer from more gossip, they likely experience more community rejection as a result of infection.²⁻⁵ Commonly, exposure to information about both treatment and prevention does not occur in a comprehensive way prior to positive diagnosis. As some of our HIV-positive participants explained, they did not learn about accurate modes of transmission before being diagnosed. Thus, their previous discriminations against infected people were efforts to prevent infection, borne out of fear and lack of knowledge. An important player in these experiences is health education.^{20,22} As awareness in the community and education about the disease increases, persons could have a better understanding of the mechanisms of transmission and be less afraid of casual physical contact with HIV-positive persons.¹⁵

Sources of information and health education were varied among our participants, including health centers, kebele, church, hearsay, and mass media. Spiritual leaders and the church have immense influence over information dissemination. Healthcare providers and targeted health education are not always the dominant channels of information about HIV. Community misconceptions about treatment may also be caused by the community’s limited exposure to the health system that specifically treats HIV.²⁰ HIV-negative community members may also lack exposure to examples of HIV treatment success because infected persons often hide their status and treatment because of stigma.⁶ In addition, word of mouth, magazines, and radio programs create a perception of evidence that persons have been cured by holy water.³ The high belief in the efficacy of ARV among health facility

and school staff, who work with HIV-positive patients and children, suggests that with increased interaction with an HIV-positive population, misconceptions about prevention and treatment (although not necessarily stigmatizing behaviors) could be reduced.

Consistent with our data, the impact of mass media coverage in the perceptions of HIV has been demonstrated in other studies.^{2,15,22} Previous mass media coverage was mostly targeted towards fear of HIV. Participants remember images shown in the past of people dying of HIV. Those targeted media campaigns and images are not easy to reverse, and may hold a lasting influence on the community's negative perceptions of infected patients and currently available treatments.³ New educational programs through mass media venues, tailored towards success stories and the effectiveness of current treatment modules, could be a feasible and successful strategy to address some of these issues.^{2,15} As our participants elaborated, increasing community understanding about transmission and prevention, along with addressing stigma directly, might to some extent help improve stigma and discrimination.^{2-4,15}

Any approach taken by mass media needs to stay relevant to Ethiopian society, and to use the systems and structures already in place, such as Kebele and other community forums. There is a need for participatory community-based approaches that empower the HIV-positive community to openly discuss their experiences and help the community to address their concern more effectively.^{2,5}

There is a recurrent theme of discord between traditional religious healing and modern medicine. Spiritual leaders have a unique position to impact the community by spreading information and forming community perception about holy water and HIV treatment. Our participants told us that the community trusts, at time without question, spiritual leaders' guidance on health matters. It is then imperative to collaborate with the religious community as a powerful and untapped resource for community outreach and health education. In fact, the priests who have begun to encourage treatment alongside holy water seem to have been influential on both patients and the general community. This positive attitude shift by itself might be caused by exposure to the health system and positive reinforcement by health professionals, as well as improved mass media education about existing effective treatment and better responses to therapies.^{2,12,22} However, this trend needs further exploration. Such weighty influence could well provide a gateway to potentially encourage greater acceptance among the community and help with adherence, and to possibly ally with health systems to share information about preventative behavior and treatment.

Our study is not without limitations. It was conducted in Addis Ababa, and thus reflects an urban population in Ethiopia. Exposure to health education and interaction with HIV-positive persons is likely higher among our participants than in rural areas. Further research exploring rural populations may well show lower health awareness, higher level or different forms of misconception about treatment options and their efficacy, and more discriminatory attitudes. Confidence in changing community perception and improved acceptance may have been slightly exaggerated, possibly because of the influence of the location itself, WWO, a supportive environment for HIV-positive persons. It is also possible that participants gave more willingly answers that they perceived as socially acceptable. To reduce the effects of peer pressure and create an open environ-

ment, we chose to use smaller focus groups with different groups of participants, as was suggested by community leaders. Further research on community perceptions in rural Ethiopia and among broader populations is warranted, and would provide insight into approaches that would be appropriate outside of urban centers.

Men were underrepresented in our study because of factors discussed in the Methods section. Our study more strongly reflects women's views. The limited size and breadth of our sample may not fully represent the population at large; further studies are needed to explore this important issue.

It is important to explore how the lack of knowledge, misconceptions, and stigma about prevention and treatment of HIV that exist in Addis Ababa serve as significant barriers in the proper management of HIV. Stigma and discrimination against PLWHA is worsened by incomplete or inaccurate knowledge, creating serious hardships for those living with the disease.

Strategies to raise awareness and to educate community members, in collaboration with local cultural and religious institutions, are crucial. Use of updated mass media campaigns, such as radio programs, newspapers, and TV news, could potentially reach a major part of the community that has little exposure to health staff or facilities. Targeted direct training/education during community gatherings in kebele and churches could be a culturally appropriate and effective venue for general community members. Educational programs for HIV-negative community members should focus on increasing awareness about the efficacy of HIV medications, to address misconceptions about the compatibility of HIV treatment and holy water, along with clarifying modes of transmission and safe interaction. Programs for HIV-positive persons should encourage them that medical treatment does not equate with renouncement of faith. Existing locally adapted support groups should address and discuss the issue of non-adherence and pressures felt by patients in a potentially unsupportive community environment. The most effective approach in improving acceptance and attitudes about HIV prevention and treatment would need to be a multifaceted approach, with cooperation and collaboration among local initiatives, government agencies, local practitioners, religious and spiritual leaders, staff of non-governmental organizations, and local health bureaus. Structural, environmental, developmental, and community-wide barriers ought to be addressed, through vertical and horizontal approaches that take into account Ethiopian society, the individual challenges faced by PLWHA, and other fundamental obstacles such as general formal education and access to healthcare.

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Authors' addresses: Ramin Asgary, Department of Medicine, New York University School of Medicine, New York, NY, E-mail: ramin.asgary@caa.columbia.edu. Sheila Antony, Department of Medicine, Yale New Haven Hospital, New Haven, CT, E-mail: sheila.antony@yale.edu. Zoya Grigoryan, Hunter College, City University of New York, New York, NY, E-mail: zoya.gr@gmail.com. Jane Aronson, Worldwide Orphan Foundation, Maplewood, NJ, E-mail: orphandoctor@gmail.com.

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