Recommended Practices for Religious Communities to Address HIV-Related Stigma

A Review of Training Materials for Religious Leaders

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Summary

Religious leaders and communities can play a significant role in reducing HIV-related stigma. In order to strengthen that role, training materials and toolkits for religious leaders have been developed and used in a variety of contexts and religious traditions. Different materials focus on different aspects of stigma and the HIV epidemic and in some cases emphasize different approaches. Nonetheless, there are many similarities and broad areas of agreement, and thirteen specific recommended practices have been identified that reflect the accumulated experience embodied in the materials.
Recommended Practices (1-7)

1. Talk openly about HIV and AIDS, consistently and repeatedly giving messages of compassion and hope, rather than judgment and rejection
2. Motivate the HIV response by explicitly referring to sacred values and sacred texts
3. Provide accurate information about HIV and AIDS and correct myths and rumors
4. Always speak about HIV infection as a medical condition, not a punishment for immoral behavior
5. Be careful to use non-judgmental language
6. Encourage all members to know their HIV status and, if HIV-positive, to adhere to medical treatment protocols
7. Develop a support program for members living with HIV

Detailed descriptions of all recommended practices are on slides 9-34

Recommended Practices for Religious Communities to Address HIV-Related Stigma

Recommended Practices (8-13)

8. Provide information and guidance about methods for preventing HIV transmission
9. Educate and empower young people to deal with life challenges
10. Openly discuss HIV stigma and the ways that religion can both help and hurt
11. Acknowledge and openly discuss topics related to HIV that may be challenging or controversial
12. Encourage interaction and discussion with people living with HIV and with marginalized populations
13. Work closely with other community organizations to advocate for universal access to HIV prevention, testing, and treatment services for all who need them

Detailed descriptions of all recommended practices are on slides 9-34

Recommended Practices for Religious Communities to Address HIV-Related Stigma
Source Materials


Note: The recommended practices are the result of analysis by the author. Reference to a source document does not imply official endorsement of the recommended practice by the organization that produced the source document.

Recommended Practices for Religious Communities to Address HIV-Related Stigma

Observations

• There is widespread agreement about practices for faith communities to address HIV-related stigma
  • Most of the source materials include most of the recommended practices, either explicitly or implicitly
  • All the source materials agree on the importance of speaking openly and providing accurate up-to-date information and guidance
  • All the source materials emphasize the importance of care and support for members living with HIV

• There are a few areas with notable differences of emphasis
  • Different source materials describe different methods of preventing HIV transmission, with some sources being significantly more comprehensive than others.
  • All the source materials emphasize the importance of reaching out to people living with HIV. Some materials also explicitly recommend reaching out to marginalized and vulnerable populations at increased risk of HIV infection.
Research Questions

• How widespread are the recommended practices?
  • In areas of high HIV burden, how many religious communities implement the recommended practices?
  • In areas of high HIV burden, how many people participate in religious communities that implement the recommended practices?

• How effective are the recommended practices?
  • Within a religious community, is there a correlation between implementation of the recommended practices and reduction of stigmatizing attitudes toward members living with HIV or toward marginalized and vulnerable populations at increased risk of HIV?
  • In areas of high HIV burden, is there a correlation between widespread implementation of the recommended practices and reduction of societal stigma related to HIV?

Recommended Practices for Religious Communities to Address HIV-Related Stigma

Resources

African Christian Health Associations Platform
ACHAP has coordinated and supported faith-based action against HIV and AIDS in Africa for more than a decade, www.africachap.org

Christian AIDS Bureau for Southern Africa
CABSA developed the original Channels of Hope program for training religious leaders, www.cabsa.org.za

Framework for Dialogue Between Religious Leaders and Networks of People Living with HIV
A tool for encouraging interaction, especially at the national level, www.frameworkfordialogue.net

Gilead COMPASS Faith Coordinating Center
Gilead and Wake Forest University recently announced an initiative to mobilize faith leaders to fight HIV and AIDS in the southern United States, www.divinity.wfu.edu/compass-initiative-faith-coordinating-center

Faith and Community Initiative – Communication Prototypes
A broad set of training and communication materials for religious leaders produced by the PEPFAR/UNAIDS Faith Community Initiative, www.faithandcommunityinitiative.org

International Network of Religious Leaders Living with or Personally Affected by HIV and AIDS
INERELA+ provides training and resources for the SAVE framework to reduce SSDDIM (stigma, shame, denial, discrimination, inaction and misaction), www.inerela.org

Stigma-Free Faith Communities
Resources for faith communities, including a guidebook for faith leaders and a white paper that proposes stigma-reduction targets and a framework for measuring progress, www.empactstigmafree.org
1. Talk openly about HIV and AIDS, consistently and repeatedly giving messages of compassion and hope, rather than judgment and rejection

“Break the Silence” has been a rallying cry for AIDS activists for decades. Open discussion about HIV and AIDS, when done in a non-judgmental and respectful manner, is often the first step toward changing negative attitudes and helping people living with HIV to feel welcome in the religious community. Open discussion can take many forms, including messages at weekly worship gatherings, small group meetings, wall posters, and performance of songs or skits.

References for Practice 1

This practice is so fundamental that it is not always stated explicitly. Rather, the practice is implicit in all the training materials for religious leaders.

Representative references include:

“Our responsibility: To break the silence by speaking the truth in love” [1, Slide 8]
“We will preach and pray about HIV/AIDS at church, in schools and in concerts” [8, Page 15]
Section about Messages of Hope [7, Slides 50-57]
“Let them know that they deserve to be treated with respect and sensitivity at all times.” [5, Page 45]
“All people are equal before God, he cares for us equally regardless of status.” [6, Page 30]
“A Stigma-Free Faith Community consistently and repeatedly gives messages of compassion, not judgment, toward people living with HIV.” [4, Page 5]
Section about SSDDIM: Stigma, Shame, Denial, Discrimination, Inaction, Misaction [3, Pages 34-98]
2. Motivate the HIV response by explicitly referring to sacred values and sacred texts

The actions of religious leaders and communities are often motivated by the divine guidance that is central to their religious tradition. Such guidance may be expressed either by referencing sacred values, many of which are common among different traditions, or by explicitly referring to their own tradition’s sacred texts. Common themes that help reduce stigma include the obligation to treat all people with dignity and respect and a commitment to protecting the vulnerable and reaching out to the marginalized.

References for Practice 2

Most of the HIV training materials include specific references to such guidance. In some cases, specific texts are cited in the context of different elements of the HIV response.

Representative references include:

“The involvement of religious leaders in HIV counseling should be grounded in scriptural teachings.” [5, Page 20]

“The Bible serves as the foundation for Channels of Hope. ... The following core beliefs and calls provide a framework for what we believe and how that drives us to action.” [2, Chapter 6.1, Page 369]

“These principles form a fundamental basis and affirm our Islamic-ethical response to issues surrounding HIV and AIDS.” [2, Chapter 7.1, Pages 483-484]

“Relevant and Responsible Use of the Bible” [1, Slides 17-20]

Document includes specific lists of sacred texts for use by Christian, Muslim, Hindu, and B’hai leaders [6]

Resource section includes prayers, litanies, and specific Quranic and Biblical verses [8, Pages 20-22]
3. **Provide accurate information about HIV and AIDS and correct myths and rumors**

Fear of the unknown is one of the drivers of stigma. Religious leaders and communities can remove the unknown by providing accurate information about HIV and AIDS, including the distinction between HIV and AIDS, modes of transmission through the exchange of certain bodily fluids, disease progression when not treated, and medical treatments that are available to manage HIV effectively. Religious communities must also correct misinformation, clarifying ways in which HIV is not spread, such as casual human contact, and refuting false claims about prevention methods and cures. Religious communities can provide this information through a variety of communication channels, including messages from religious leaders and brochures.

**References for Practice 3**

All the HIV training materials are clear and consistent about the importance of providing accurate information.

Representative references include:

- "The role of religious leaders in education around HIV and AIDS is frequently underestimated." [3, Page 6]
- "Correct HIV information reduces stigma." [6, Page 36]
- "Stigma and discrimination are rooted in ignorance." [5, Page 45]
- "How HIV is not transmitted" [1, Slide 60]
- "A conscious effort to recognise the fears, and through good information, reduce fear; thereby reducing the drivers of SSDDIM." [3, Page 38]
- "A Stigma-Free Faith Community provides basic facts about HIV and AIDS, including methods of transmission, treatment, and prevention." [4, Page 7]
- "Correct information becomes the most powerful tool in breaking myths and stigma around HIV and AIDS." [3, Page 11]
4. Always speak about HIV infection as a medical condition, not a punishment for immoral behavior

Infection with HIV is a medical condition, similar to other medical conditions that are caused by viruses. However, since HIV is often transmitted in the context of behavior that many people consider immoral, there is a tendency to view HIV infection as divine punishment for that behavior. This tendency can be countered by consistently referring to HIV transmission in medical terms, and by clarifying the distinction between the “safe” dimension of human behavior, as determined by science and medicine, and the “moral” dimension, based on divine guidance as understood within the community’s religious tradition.

References for Practice 4

All the HIV training materials consistently refer to HIV infection in medical terms. Some include specific exercises intended to clarify the distinction between the “safe” and “moral” dimensions of human behavior.

Representative references include:

"A Stigma-Free Faith Community describes HIV and AIDS as medical conditions, not punishment for immoral behavior" [4, Page 3]

"Integrate HIV with other health care services" [7, Slide 14]

Exercise about the distinction between behavior that is “safe” and behavior that is “moral” [1, Slides 75-79]

Section about Safer Practices [3, Pages 172-272]
5. Be careful to use non-judgmental language

Many words and phrases, in addition to factual content, include an emotional or judgmental element, reflecting stigma on the part of the speaker and causing self-stigma on the part of the listener. Sometimes the emotional or judgmental element is obvious and intentional, but often it is subtle and unintended. So it is important for religious leaders and communities to be careful about the language they use, especially when referring to people living with HIV and to marginalized populations.

References for Practice 5

Most of the training materials emphasize the importance of non-judgmental language. Some include specific lists of judgmental words and phrases, along with suggested alternatives.

Representative references include:

"Refrain from using wrong or stigmatising language" [2, Chapter 4.3, Page 9]

"Certain words can foster positive attitudes about people living with HIV while other words and phrases we choose can fuel stereotypes, stigma and discrimination." [8, Pages 6-9, including list of words and phrases]

"As Christians and members of the church, think about what we say, what we hear other Christians saying, that stigmatizes HIV and AIDS and stigmatizes people living with HIV/AIDS." [1, Slide 124]

"Do not judge the client." [5, Page 8]
6. Encourage all members to know their HIV status and, if HIV-positive, to adhere to medical treatment protocols

Knowing one’s HIV status is vital to leading a healthy life. However, despite the importance, fear and stigma often keep people who are at risk from getting tested. Religious communities can counter that fear and stigma by spreading messages of compassion and hope. With recent advances in medical treatment, HIV is no longer the death sentence that it once was. By following medical treatment protocols, it is possible to lead a normal productive life and not transmit the disease to someone else.

Religious communities can encourage testing in a variety of ways, including frequent messaging, public testing of religious leaders, and test facilities at religious gatherings. Recently, other approaches have been taken, including self-test kits and indexed testing to reach people potentially exposed to HIV. When encouraging members to know their HIV status, religious communities should also stress the importance of starting anti-retroviral therapy immediately and of adhering to therapy protocols. This is especially important in contexts where some religious leaders advocate exclusive reliance on faith healing.

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References for Practice 6

All the training materials stress the importance of knowing one’s HIV status, but they emphasize different approaches. Early materials focus on encouraging all members to get tested. More recent materials reflect the use of self-testing and indexed testing to reach those with greatest risk. All the training materials also emphasized the importance of adherence. Some specifically mentioned messaging to counter the promotion of faith healing.

Representative references include:

“Encourage people to get tested; Encourage people living with HIV to take their medication.” [7, Slide 45]

“Everybody should know their status...” [1, Slide 66]

“HIV self-testing is safe, accurate, and easy to use!” [7, Slide 22]

“Index testing is an important way to help identify those who were exposed to HIV and link them to care quickly if they test positive.” [7, Slide 25]

“Encourage congregants to adhere to treatment.” [6, Page 25]

“The benefits of adherence are profound in the lives of people living with HIV.” [5, Page 15]

“Stay on treatment and you won’t spread HIV to people you care about” [7, Slides 35-41]

“While prayer is important, it must be accompanied by taking medication, and living healthy. This is the only way to keep the viral load low and avoid opportunistic diseases. Be sure to warn the client against people who advise against medication to prove one’s faith or spiritual healing.” [5, Page 40]
7. Develop a support program for members living with HIV

A strong support program within a religious community can significantly reduce stigma toward people living with HIV. It demonstrates that members living with HIV have value and it breaks down the separation of “us” and “them.” A faith-based support program is also an opportunity to go beyond physical well-being to provide holistic support for emotional, psychological, and spiritual well-being. Support programs can take many forms, including dedicated teams, mutual support groups, and logistical help with medical protocols. It is important to include people living with HIV in the development and implementation of the program and to recognize that different people may require different kinds of support. Whatever the form, the goal of a support program is to ensure that all members living with HIV receive treatment, adhere to medical protocols, and achieve viral suppression.

References for Practice 7

All the training materials emphasize the importance of support programs for members living with HIV.

Representative references include:

"Demonstrate that we care! Be involved in care initiatives such as home-visiting, home-based care, support groups, etc." [2, Chapter 4.3, Page 9]

"PLHIV should be supported in maintaining adherence. This support may include discussing reasons for non-adherence and exploring solutions, referring for adherence counseling and support when necessary, engaging treatment supporters/buddies such as family members or peers, and using adherence aids where available, such as reminders and pill boxes." [5, Page 16]

"Acceptance and support reduce societal stigma." [6, Page 36]

"We pledge to draw people living with HIV/AIDS close and to encourage them to live positively." [8, Page 14]

"Call on communities and families to support people living with HIV” [7, Slide 45]

"There is the need to realise that the body, mind and soul together make up the "holistic" self and working on all these areas leads to a healthy state." [1, Slide 104, Quotation from Dr. Ashraf Grimwood]

"Encourage people living with HIV and who have been open about their HIV status, to share their experiences and be involved in congregational HIV-related planning and activities." [2, Chapter 4.3, Page 9]
8. Provide information and guidance about methods for preventing HIV transmission

Prevention of HIV is obviously an important topic, but it can be especially challenging for religious communities. Many prevention methods relate to personal behavior that is considered safe from a medical perspective. However, among religious communities there is often an associated fear that providing information about behavior that is safe may encourage behavior that they consider immoral. In addition, a discussion of prevention necessarily implies a personal responsibility to avoid HIV transmission. Therefore, a person who becomes infected is often assumed to have failed to exercise that responsibility, which can lead to significant self-stigma on the part of the newly infected person. This effect is common, even if the transmission occurred in a context where the person did not have free choice, such as a woman who is raped and cannot force her attacker to use a condom.

The latest list of prevention methods is long, including abstinence, delay of sexual debut, reduction in sexual partners, condoms, medical male circumcision, pre- and post-exposure prophylaxis (PrEP and PEP), sterilized needles, treatment as prevention, and anti-retroviral therapy for pregnant women. Information and guidance about these methods should always be discussed in medical terms and can be provided in a variety of forms, including messages from leaders, discussion groups, counseling sessions, and brochures.

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References for Practice 8

The training materials provide a wide range of recommendations about HIV prevention. All agree that the topic should be addressed openly by providing information and guidance, but they differ significantly in the prevention methods they describe or emphasize, and in some cases, there is not a clear separation of guidance about “safe” behavior from guidance about “moral” behavior.

Representative references include:

“Understanding how HIV is passed from one person to another provides us with the knowledge needed to help educate our communities and loved ones about HIV prevention” [7, Slides 6-7]

“A Stigma-Free Faith Community affirms the responsibility of all members to know their HIV status and to refrain from behavior that risks transmission of HIV.” [4, Page 12]

“Prevention of sexual transmission: abstinence, delay of first sexual intercourse, mutual faithfulness, reduce sexual partners, medical male circumcision, reduce sexual transmitted infections, condoms” [1, Slide 74]

“SAFER Practices: Responsible Sexual Health, Delaying Sexual Debut, Abstinence, Masturbation, Mutual Fidelity, Condoms, Male Circumcision, Female Genital Mutilation (FGM), Safe Surgical Practices” [3, Pages 173-272]

“There are various ways to reduce the risk of acquiring or transmitting HIV.” [5, Page 16]

“To empower people, especially women, with knowledge and skills to protect themselves against HIV infection” [1, Slide 70]

“Messages of personal responsibility must be delivered carefully, to avoid driving away people who may feel they are being judged.” [4, Page 14]

In recent discussions with authors of several of the materials, all agreed that discussions about prevention should be as comprehensive as possible, but recognized that such discussions may present theological or cultural challenges for members of religious communities.
9. **Educate and empower young people to deal with life challenges**

A major risk in the next decade is that there will be a significant increase of HIV in a growing youth population. Religious communities can significantly reduce this risk by educating and empowering young people, but this can also be very challenging. It involves the same challenges as talking about prevention – in fact, some prevention methods are specifically for young people, such as “delay of sexual debut” – but these discussions are even more difficult in the context of young people who are going through a very challenging period of their lives. One valuable technique for educating and empowering young people involves the establishment of safe spaces for peer-led discussions.

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**References for Practice 9**

All the training material recognize the importance of helping young people and many specifically recommend providing safe spaces for discussion. There is some disagreement about the best venue for such safe spaces, either within the physical structures of the worship center or at a location that is distinct, thereby avoiding religious overtones.

Representative references include:

- “Create safe spaces for adolescents and young people within places of worship.” [6, Page 62]
- “Is there a safe space for young people, where they can talk to someone about issues, sex and prevention in a non-disclosure, private environment?” [3, Page 203]
- “Young people are also more comfortable talking or asking questions to a peer than to an adult” [7, Slide 42]
- “If children and teens know their status and are given good information, we reduce HIV transmission and empower young people to take control of their bodies and to live positively.” [3, Page 167]
10. Openly discuss HIV stigma and the ways that religion can both help and hurt

One of the strengths of religious communities is that they provide divine guidance about human behavior based on their religious tradition. An unfortunate side-effect of such guidance is a tendency to judge and stigmatize people whose behavior does not align with the guidance, a tendency that has had a very harmful effect on the HIV epidemic. It is important for religious communities to acknowledge this effect and to understand the way that stigma affects individuals. Based on this understanding, the religious community can determine ways to counter stigma, for example, by referring to divine guidance about treating human beings with respect and dignity and by reaching out to the marginalized. In order to make a significant difference, it is important for such discussions to be open and to include all members of the religious community.

References for Practice 10

All the training materials strongly emphasize the need to explicitly address stigma. Some include specific exercises for religious leaders to develop a deeper, personal understanding of stigma.

Representative references include:

"The word 'stigma' is often associated with discrimination, negative feelings and attitudes." [2, Chapter 4.3, Page 1]

"In HIV/AIDS, it is not the condition that hurts most (because many other diseases and conditions lead to serious suffering and death), but (what hurts most is) the stigma and the possibility of rejection and discrimination, misunderstanding and loss of trust that HIV-positive people have to deal with." [1, Slide 125, Quotation from Canon Gideon Byamugisha]

"We resolve to discuss the issue in community gatherings." [8, Page 14]

"Preach and teach about overcoming the stigma of HIV and AIDS." [4, Page 14]

Exercise about what it feels like to stigmatize or to be stigmatized [1, Slides 122-123]
11. Acknowledge and openly discuss topics related to HIV that may be challenging or controversial

Depending on the cultural and religious context, it may be important for religious communities not only to discuss stigma generally but to discuss other specific topics that members may find challenging or controversial. A partial list of topics includes pre- and extra-marital sex, human sexuality and gender identify, gender-based violence, sex work, drug use, and female genital mutilation. Discussions about such topics must be conducted in a way that is safe for all participants. The discussions may not necessarily lead to firm conclusions. Simply acknowledging that the topic is challenging and open for discussion is a major step.

References for Practice 11

Most of the training materials reference difficult topics. Many include specific exercises to help leaders and members address and discuss these topics.

Representative references include:

"People of faith often struggle with moral, ethical and theological questions that keep us from effective and comprehensive implementation of strategies to address various issues that affect the lives of people, especially those relating to HIV and AIDS." [2, Chapter 7.2, Page 506]

"Support candid institutional and community dialogue about sexual and reproductive health." [8, Page 14]

"Lack of discussion about sex, sexuality and gender is a huge driver of SSDDIM." [3, Introduction, Page 13]

"A Stigma-Free Faith Community talks openly about HIV and AIDS, as well as related topics such as sexual behavior and gender identity" [4, Page 4]

"Do not impose a specific view on the group. Take an inclusive, comprehensive, respectful approach and guide the discussion to clarify misunderstandings and to consider different views. ... There are no clear-cut answers. Share your opinions freely. You are encouraged to disagree with other people and facilitators." [2, Chapter 6.2, Pages 395, 398]

"Religious leaders should be actively involved in sensitizing their members on Sexual and Gender-Based Violence" [6, Page 50]
12. Encourage interaction and discussion with people living with HIV and with marginalized populations

Personal interactions are a remarkably powerful way to reduce stigma. The more people get to know each other, the harder it is to stigmatize. Religious communities, following the common sacred value of reaching out to the marginalized, can encourage interaction and discussion not only with people living with HIV, but also with members of key populations at increased risk of HIV infection, including men who have sex with men, sex workers, people who inject drugs, and transgender people. Depending on the religious tradition and the community context, different approaches may be appropriate for different populations, ranging from personal testimonies, to discussion groups, to community activities.

References for Practice 12

All the training materials recommend such interactions, but they emphasize different populations. Some materials focus solely on interactions with people living with HIV. Others also explicitly recommend reaching out to marginalized populations.

Representative references include:

- “Faith communities reach those beyond the reach of formal health systems, including the most marginalized and stigmatized and least served populations” [1, Slide 138]
- “You may consider inviting a person living with HIV to share their testimony before calling others to action for National Faith HIV/AIDS Awareness Day.” [8, Page 14]
- “Present personal testimonies by people who are HIV-positive or personally affected by HIV.” [4, Page 14]
- “This toolkit ... also emphasises including people, whether people of faith, key groups, or PLHIV” [3, Page 10]

In recent discussions with authors of several of the materials, there was a strong consensus that it is important to reach out broadly, including marginalized populations as well as people living with HIV, but there was also recognition that such outreach might be very difficult for some members of some religious communities.
13. Work closely with other community organizations to advocate for universal access to HIV prevention, testing, and treatment services for all who need them

Religious leaders and communities often have significant influence in the wider community beyond their membership, especially with respect to stigma reduction. This influence will occur naturally as a side-effect of contacts between members and non-members. In addition, the religious community can take direct action by working together with other community organizations, including other religious communities as well as secular organizations. The specifics obviously depend on the community context, but one clear goal should be that HIV services are available to all who need them without stigma or discrimination.

References for Practice 13

Most of the training materials recommend interaction with the wider community, often in the context of advocacy for universal access to HIV services.

Representative references include:

“Faith communities influence people, have moral authority and enjoy the trust of communities” [1, Slide 138]
“A Stigma-Free Faith Community works proactively with other organizations to address HIV and AIDS in the wider community.” [4, Page 13]
“HIV education workshops for faith community and larger community” [8, Page 14]
Section about Advocacy and Human Rights [3, Pages 416-443]
“Advocate for care and prevention for those living with HIV” [7, Slide 45]
“Work with other faith leaders on HIV/AIDS campaigns.” [8, Page 14]