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Patient Care, Practice Management & Professional Development Information for HIV Care Providers

HIV Specialist

Spirituality, Religion and HIV

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COVER:STOCK

Spirituality, Religion and HIV

BY MAGDALENA SZAFLARSKI, PH.D.

Why We Care, What We Know, and How We Are Addressing It

SPIRITUALITY AND RELIGION are important to many people living with HIV (PLWH). Health professionals across the different fields—medicine, nursing, social work, and public health—have already identified the need for, but often struggled with finding, appropriate spiritual and faith-based HIV interventions.

The nature of interventions remains unclear, partly because they are not universally accepted or supported, and partly because the relationship between spirituality/religion and HIV-related outcomes is not well understood. This article defines the concepts of religion and spirituality; describes the scientific evidence regarding the role of spirituality and religion in HIV; and, discusses HIV prevention and care approaches that incorporate spirituality and religion, as a way to curb infections and improve outcomes in PLWH.

Definitions

Religion and spirituality are distinct but overlapping concepts[1,2]. *Religion* is often defined as a belief in the Sacred, the Divine, God, or Higher Power, as well as practices and institutional arrangements (organized religion, religious institutions) that are involved in the expression of that belief.

Beliefs and trust in a higher power are also referred to as *faith*. Religion is typically grounded in a set of scriptures or teachings that provide the meaning to the world and a moral code that guides followers' behaviors. To be religious means to have faith, engage in religious practices (e.g., church attendance, prayer/meditation), and rely on religion in one's life.

While religion is the formal, institutional, and outward expression of belief in a higher power, *spirituality* denotes the internal, personal, and emotional side of the sacred. Spirituality was traditionally understood as a religious form (going back to early or "elementary" religions[3]). However, contemporary definitions of spirituality extend beyond and often have little to do with religion[1].

Spirituality has been defined as meaning and purpose in life, inner peace and comfort, connection with others, social support (received or given), feelings of love or happiness, and so on. This definition of spirituality works well in clinical settings because some patients are spiritual but non-religious, and sometimes they do not distinguish between "religious" and "spiritual."

Evidence

There is a growing body of scientific research examining spirituality/religion in relation to HIV[4]. Several distinct themes are noted in this literature: (1) meaning and impact of spirituality/religion in PLWH; (2) associations between spirituality/religion and HIV-related outcomes; (3) assessment of spirituality/religion in PLWH; and, (4) design and efficacy of spiritual and faith-based interventions to improve HIV prevention, care, and health outcomes.

For example, some studies based on qualitative interview or narrative data have explored the meaning and impact of spirituality/religion in PLWH and at-risk populations, in particular men who have sex with men (MSM), racial/ethnic minorities, women, youth, and people living in the areas of expanding HIV epidemics (e.g., the South/Southeast).

In one study[5], young black MSM living in the deep South implicated religious doctrine, churches, and faith leaders as significant sources of homophobia and discrimination toward gays. This view was expressed despite their high religiosity and religious involvement. Some of these men accepted the doctrinal rejection of homosexuality and internally struggled to explain their lifestyles within a religious framework. Religious or spiritual struggles are often noted among PLWH who are trying to understand their HIV status in the context of their religious faith.

In another study[6], HIV-positive African American women discussed the importance of faith and religious affiliation in their lives. The women described their spirituality as a journey or connection to God, spiritual expression of their faith (e.g., church attendance), and spiritual benefits, such as healing and support.

Notably, the women reported that HIV brought them closer to God, a finding corroborated in other studies[7-9]. In general, qualitative research has shown that spirituality/religion is a significant source of support as well as stress among PLWH[10,11], and it is a barrier to or facilitator of HIV prevention, diagnosis, and treatment[12,13]. PLWH also rely on their faith as a way to cope[12,14] and find meaning and peace toward end of life[15].

In addition to qualitative reports, quantitative studies have examined the importance of spirituality/religion to PLWH and mechanisms linking spirituality/religion and HIV patient outcomes. These studies have used standardized assessments (e.g., scales) of spirituality/religion and other psychosocial correlates of HIV outcomes, such as coping or stigma. In quantitative research, strong associations have been found between spirituality/religion and will to live among PLWH[16] and feeling that "life is better" post- compared with pre-HIV diagnosis[2].

Further research has clarified that spirituality shapes the view of HIV as a positive or negative turning point in one's life[17]. The results of this research show that PLWH who experienced increased spirituality after HIV diagnosis perceived their infection as the most positive turning point in life, while those who experienced declines in spirituality saw HIV as the most negative turning point in their lives. A subsequent study demonstrated that a positive view of God predicted slower, while a negative view of God predicted faster, HIV disease progression.

Other quantitative research considered spiritual peace as a coping resource that might buffer the negative effects of stress and HIV-related stigma on mental well-being[18]. The results showed that spiritual peace and pro-active coping predicted lower, while HIV stigma predicted greater, likelihood of severe depressive symptoms. In addition, at high levels of stigma, persons reporting high spiritual peace were less likely than those reporting low peace to have severe depressive symptoms. These findings suggest that spiritual peace-based interventions might benefit PLWH.

Some research also has considered the role of spirituality/religion in successful aging[19,20]. Although levels of spirituality/religiosity did not vary significantly by age and HIV status, spirituality/religion in the HIV-positive group was associated with larger social networks, better mood, higher self-reported health, and fewer medical problems. Additional research showed that spirituality and positive reframing predicted better psychological

adaptation than reliance on social support among HIV-positive women[21].

Spirituality/religion has also been studied in the context of HIV treatment. While higher spirituality has been found to be associated with returning to HIV care in US settings[22], in some non-Western regions, spirituality has shown associations with concurrent use of alternative therapies and less adherence to antiretroviral treatments[23].

Measurement of spirituality/religion has been challenging. Spirituality/religion is a multidimensional concept, which is not easy to assess. Global and disease- and population-specific measures have been advocated. There are several studies and review articles that help to validate and/or clarify the existing spirituality/religion measures for use in HIV populations[2,24,25]. The dimensions of spirituality/religion that have been shown salient in PLWH include: meaning and peace, tangible connection to the Divine, positive religious coping, love and appreciation, negative religious coping, positive congregational support, negative congregational support, and cultural practices.

Interventions

Considering the important role of spirituality/religion among PLWH and its strong links to HIV outcomes, two types of interventions have emerged to enhance HIV prevention, care, and outcomes. First, there have been calls for incorporating spirituality/religion into the management of HIV disease as a way of coping to improve physical and mental outcomes of PLWH. Another body of work has focused on engaging faith communities in HIV prevention and care to improve both individual and population-level outcomes.

The literature describing spiritual interventions among PLWH is limited. One reason for this has been mixed support for conducting spiritual assessments and providing spiritual care in healthcare settings. The existing studies tend to be small, targeted clinical trials.

For example, in one study, patients shared personal and communal views of spirituality as a way to connect with the self, nature, and God[26]. However, the study found only limited support for the cause-effect relationship of spiritual intervention to participants' well-being. Another,

Medical centers and public health agencies have begun partnering with black churches to reduce HIV stigma, offer HIV education and testing, and encourage counseling and support[28-30].

mantram-based program was shown to help participants to increase calm and peace, adjust behaviors, manage symptoms, and enhance social relationships[27]. However, there were no differences between the intervention and control groups in decreases in anxiety and perceived stress in this program. Despite limited evidence, spiritual interventions are believed to be beneficial in certain populations and settings, especially in children receiving palliative care. Further work is under way to develop and test such interventions.

The second type of interventions are partnerships that engage faith communities in HIV prevention and care. Survey research indicates that over 10,000 US congregations have PLWH, and congregations located in high HIV-risk areas are more likely to have PLWH[28]. Religious and faith-based organizations, in particular black churches, are uniquely suited to address HIV-related needs of their communities.

PLWH often rely on congregations for spiritual and social support, but congregations have not always responded to or welcomed PLWH. On the one hand, religious organizations were the first ones to care for people dying of AIDS. On the other hand, stigma of HIV is pervasive in faith communities, especially in conservative black churches, and it hampers HIV prevention and care.

Black churches have played a central role in the social life of African American communities and in advancing social justice goals. With the HIV epidemic concentrated in African American communities, strong efforts are needed to engage relevant community stakeholders. Medical centers and public health agencies have begun partnering with black churches to reduce HIV stigma, offer HIV education and testing, and encourage counseling and support[28-30].

Even though black Protestant congregations are more likely than other types of congregations to offer HIV programming, the majority of them, have no HIV programs[31]. Furthermore, research indicates diverse views on HIV and PLWH across U.S. congregations.

Studies have found HIV-related attitudes in congregations ranging from highly judgmental and exclusionary to accepting[32], again indicating faith communities' mixed responses to HIV. Stigma has been closely linked with the level of congregational engagement in HIV work, with low-activity congregations being more likely to view homosexuality as a sin and promoting sexual abstinence before marriage, medium-activity congregations shifting to understanding and acceptance, and high-activity congregations more fully engaging in advocacy and stigma reduction on behalf of PLWH. However, stigma has also been reported in high-activity congregations[32].

One approach to reduce stigma in faith communities is to educate faith leaders and engage them in the development of community interventions. Researchers in Philadelphia worked with faith leaders to discuss HIV stigma and design a strategy to address HIV prevention and care using a faith-based approach[33].

The proposed plan of action included the following recommendations from faith leaders: enhancing leadership and advocacy efforts; normalizing HIV testing and sexuality-related discussions in congregations to reduce stigma;

tailoring programs to individual congregations/denominations; and encouraging, interfaith collaborations. Similar collaborative frameworks have been proposed based on pilot programs in different parts of the country[24,29,30,33]. However, systematic evidence about the effectiveness of faith-community engaged interventions remains limited.

Future Directions

Research clearly shows that spirituality and religion play a multi-faceted role in HIV, and that spiritual and faith-based interventions can be beneficial at the individual and population level. However, there are still gaps in the literature and frameworks for interventions.

First, the knowledge is spread across disciplines, and its tightening is recommended through state-of-the-art evidence reviews.

Second, certain populations (e.g., bisexual men and transgenders) have been largely absent in the current research. Further systematic assessment of these populations' issues related to spirituality/religion is recommended.

Third, use of advanced methods, such as randomized controlled trials (RCTs) in intervention studies, and longitudinal and multilevel studies, would strengthen the knowledge of the social and individual-level impacts of spirituality/religion on PLWH.

Fourth, any studies and interventions should be developed by engaging various community stakeholders.

Finally, clinical and policy implications of spirituality/religion-based approaches in different settings deserve further attention (how to afford and finance such interventions; what works/what doesn't; compare programs and outcomes across settings and populations; etc.). **HIV**

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