Religion and HIV: A Review of the Literature and Clinical Implications

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Despite substantive research documenting the connection between various religious dimensions and physical and mental health, surprisingly little attention has been given to the study of religion among individuals with the human immunodeficiency virus (HIV). Although initially considered to be a white, "gay man's" disease, today women and ethnic minorities are subgroups that are the most severely affected by the HIV pandemic. Importantly, these disenfranchised subgroups report greater use of religion in their everyday lives. A small but growing number of studies conducted mostly within the past few years have recognized the importance of religion in the lives of individuals with HIV.

In particular, research has noted the frequent use of religious coping by men and women with HIV to deal with the loss of their loved ones to AIDS, to overcome their sense of guilt and shame in engaging in risky behaviors, and to find a renewed sense of purpose in life. However, clinical interventions with persons with HIV have largely neglected religiousness and spirituality as resources for treatment and, to date, few spirituality-based interventions exist that can be empirically evaluated. In this paper, we review the literature on religious coping among individuals with HIV and outline a clinical intervention that incorporates religious issues relevant to this population. We first provide an overview of religious coping.

Framework of Religious Coping

Pargament has developed a transactional model of religious coping wherein religion is viewed as contributing to the coping process by shaping the character of life events, coping activities, and the outcomes of events. Religion can also be a product of coping such that people can increase their religious faith as a result of life events. As part of an individual's general orienting system, religion influences how individuals appraise situations, participate in activities, and develop goals for themselves. In particular, when faced with difficult situations, individuals have reported using a wide variety of religious coping methods, such as benevolent religious appraisals, seeking spiritual support, discontent with congregation and God, negative religious reframing, and expressing interpersonal religious discontent. One parsimonious way of clustering or distinguishing these various coping methods is to define "positive religious coping" strategies (eg, seeking God's love and care, asking for forgiveness) and "negative religious coping" strategies (eg, expressing anger at God, feeling punished by God). Positive religious coping methods rest on a secure relationship with God, a belief in a larger, benevolent purpose to life, and a sense of connectedness with a religious community. Negative religious coping methods reflect a religious struggle that grows out of a more tenuous relationship with God, a more ominous view of life, and a sense of disconnectedness with a religious community. In some sense, negative religious coping occurs when major life stressors pose a threat or challenge not only to physical and psychological health and well-being but also to the individual's religious and spiritual world view.

Key Points
- Empirical studies suggest that religion and spirituality can be both resources for people with HIV and sources of pain and struggle.
- Practitioners have begun to develop spiritually integrated interventions for this population.
- "Lighting the Way: A Spiritual Journey to Wholeness" is an 8-session, nondenominational, group program that was designed to help women draw on their spiritual resources and address their spiritual struggles in coping with HIV.
In cross-sectional and longitudinal studies, the use of religious coping has been associated with a variety of indicators of mental health (ie, depression, positive affect, life satisfaction), after controlling for the effects of sociodemographic variables, global religious measures (eg, frequency of prayer and church attendance, and self-rated importance of religion), and nonreligious coping measures. Importantly, the relation between religious coping and mental health is shaped by the kinds of religious coping methods used by individuals. For example, more use of positive religious coping strategies, such as spiritual support and benedict religious appraisals of negative situations, has been associated with greater well-being, such as improved mental health status, reduced rates of mortality, stress-related growth, and spiritual growth. Conversely, greater use of negative religious coping strategies (alternatively called religious struggles), such as attributions of situations to a punishing God and dissatisfaction with clergy, is tied to indicators of more psychological distress, such as greater depression and anxiety and poorer resolution of the negative life event.

Religious coping methods have also been associated with physical health. For example, a longitudinal study by Fitchett et al indicated a positive association between anger at God and poor recovery in activities of daily living (ADL). In a recent 2-year longitudinal study conducted by Pargament et al, greater religious struggle (eg, demonic reappraisal, spiritual discontent) among elderly ill men and women was associated with increased risk of mortality. Krause found strong improvements in the self-rated health of elderly residents in deteriorating neighborhoods who reported more positive religious coping. Overall, these studies underscore the multidimensional nature of religious coping as well as the importance of studying the role both positive and negative religious coping strategies play in the coping process.

Examples of religious and spiritual coping methods identified among individuals with HIV:

- Spiritual transformation
- Belief in a higher power
- Prayer
- Belief in miracles
- Collaboration between themselves and God/higher power

Religion and Religious Coping Among Individuals With HIV

Surprisingly, fewer studies (mostly qualitative) have attended to the role of religion/spirituality among individuals with HIV. Importantly, many studies have observed that much of the religiosity among HIV-negative persons is expressed in terms of a God or a higher power rather than belonging to a religious denomination or attendance of religious services. This is not surprising, given the stigma many religious institutions attach to the HIV disease and related modes of transmission. However, it is important to note that many individuals with HIV still retain their spiritual beliefs and might choose to attend religious services at their church/temple (perhaps disclosing their HIV status to a few members).

Virtually every study on religion and spirituality conducted among men and women with HIV attests to the significance of this construct for these individuals. For example, working with a sample of hospitalized patients with HIV, Kaldjian et al reported that "religious belief was the rule," with 98% indicating belief in a divine being called God, 84% expressing a personal relationship with God, and 81% believing in God's forgiveness. In a study of 125 caregivers of individuals with HIV, Richards and Folkman reported that at the time of bereavement, 56% of the caregivers (some of whom were HIV-positive) made spontaneous, explicit references to spiritual phenomena (eg, beliefs in experiences of a higher order). Some studies have shown that those with HIV report greater use of religion and spirituality when compared with similar HIV-negative individuals, with racial/ethnic minority groups and women reporting the most use of religion and spirituality.

Several religious and spiritual coping methods have been identified among individuals with HIV. Research with gay men suggests that spiritual transformation and belief in a higher power are strategies that reportedly help them deal with the challenges caused by their illness as well as their status as a sexual minority. Among inner city, HIV-positive drug users, prayer, and belief in a higher power are common religious and spiritual coping methods. In studies on women (mostly black) with HIV, collaboration between themselves and God/higher power, belief in miracles, and prayer are coping methods that have been reported. A few studies that have included both men and women with HIV have also noted the use of many of the religious and spiritual coping methods listed above.

Global measures of spirituality have also been significantly associated with positive psychological outcomes. Specifically, among women with HIV, greater engagement in spiritual activities is tied to decreased emotional distress, lower depression, greater optimism, and overall better psychological adaptation. Ironson et al found that among men and women with HIV, specific dimensions of spirituality (eg, sense of peace, faith in God) were associated with better immune status (ie, lower cortisol) and mental health (ie, lower anxiety, perceived stress). In a 14-month prospective study of HIV-negative relatives and friends of persons who had died as a result of AIDS, those who professed stronger spiritual
beliefs seemed to resolve their grief faster than those with no spiritual beliefs. In sum, research among both men and women with HIV suggests that spirituality occupies a significant role, often providing them with a context in which they can find meaning in their lives, and stimulating psychological and spiritual growth.

As with research on religion and health within other samples, the mechanisms through which religious and spiritual coping exercises its influence on the mental and physical health of individuals with HIV are not well understood. However, a few studies have attempted to elucidate these connections. In their study with Puerto Rican women with HIV, Simoni and Ortiz reported that the relation between their measure of spirituality and depression was mediated by self-esteem and mastery. In examining the relation between spirituality and physical health, Ironson et al found that the “sense of peace” aspect of their spirituality measure was tied to lower cortisol levels, highlighting the importance of subjective aspects of religious/spiritual practices. The sense of purpose from spirituality may play another important explanatory role. In their 2-year follow-up of bereaved caregivers of HIV-positive individuals, Richards and Folkman found that spirituality increased in 77% of the entire cohort, such that individuals discovered a sense of value and direction. As told by one participant in the study of drug users with HIV, “He brought me back for a reason. And then I’m living with HIV. There’s got to be something out there He wants me to do.”

Interview studies suggest a few other potential mechanisms through which religious and spiritual coping methods might be exerting their influence on mental and physical health, such as offering a sense of control, relieving fear and uncertainty associated with death, and facilitating forgiveness of self and others. Finally, it is also important to note that religiousness and spirituality may have direct effects on health; that is, these phenomena may make distinctive, even unique, contributions to health and well-being.

In sum, empirical studies suggest that religious and spiritual resources hold particular value for people with HIV. It is also important to note that religion and spirituality may represent a source of pain and struggle for at least some people with HIV. As yet, researchers have not generally focused on the role of negative religious coping methods among people with HIV. In one exception, Jenkins found that men with HIV who reported more spiritual struggles (e.g., anger or alienation from God) experienced more depressive symptoms and loneliness. Given the links between religious struggles and poorer health documented in other groups, the religious stigma attached to HIV, and its potential to challenge the individual’s most deep-seated assumptions about the world, people with HIV may be particularly likely to experience spiritual struggles and their potential ill-effects.

As one woman with HIV put it: “Before I found out I was HIV positive, I believed in God, I believed in saints, and when I found out I was HIV positive, I lost hope, I lost faith, and I lost my spirit. I was a bad person. A gray person. I thought I was never going to get out of that stage.” Be it a resource or a burden, the spiritual dimension of HIV may carry significant implications for treatment.

### From Research to Practice

With the notable exceptions of hospital chaplaincy and pastoral care, spiritual issues have been largely disconnected from health care. In recent years, however, this picture has begun to change. Several books have addressed the integration of spirituality into treatment. A few investigators have begun to evaluate the efficacy of spiritually integrated forms of treatment, with some promising results. These treatments draw on a variety of spiritual coping resources: meditation, prayer and ritual, reading of scriptures, spiritual imagery, forgiveness, and spiritual schemas. Unfortunately, spiritually integrated programs for treating HIV have not as yet been developed and evaluated. This oversight is particularly striking, given the salience of spirituality as a resource for people with HIV as well as a source of struggle.

#### A Case Example: Lighting the Way

Over the past year, we have developed and begun to test an 8-session group intervention for women who have been diagnosed with HIV. The program entitled “Lighting the Way: A Spiritual Journey to Wholeness” grew out of interviews with poor, urban black women with HIV about the impact of the disease on their spirituality as well as a review of the literature on spirituality, HIV, and spiritually based interventions. There are several distinguishing features of this intervention. First, it is tailored to the critical existential issues commonly faced by women dealing with HIV: healing; body and spirit; control and surrender; letting go of anger; shame and guilt; intimacy and isolation; and hopes and dreams. Certainly these issues could be addressed in secular interventions. What form might a spiritually integrated intervention take for those facing HIV?

Seven issues common to women dealing with HIV/AIDS, and addressed in “Lighting the Way”:
- Healing
- Body and spirit
- Control and surrender
- Letting go of anger
- Shame and guilt
- Intimacy and isolation
- Hopes and dreams

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Introduction and healing

Because HIV affects people spiritually as well as psychologically, socially, and physically, the biopsychosocial model of disease and treatment is inadequate to the task of assisting people with HIV. Rather, we adopted a biopsychosocial model that is more inclusive of the needs of this population.

In the first session, participants are introduced to an intervention that addresses the many dimensions of their lives, including the spiritual. This session focuses on the meaning of healing and employs activities that draw upon the metaphor of a journey toward wholeness and healing. Healing is described as a process, one that involves struggles and barriers along the way. Participants identify the specific barriers (ie, roadblocks) that have interfered with their own personal healing journey, and then identify resources (ie, rest stops) that can help them overcome these barriers. Particular attention is paid to the key role spiritual resources may play in this journey to healing, including spiritual supplies (eg, prayer, religious support, finding hope, gratitude) as well as other emotional, social, and physical supplies. Participants are also introduced to the critical existential and spiritual challenges (eg, healing, control and surrender, letting go of anger, shame and guilt, intimacy and isolation, hopes and dreams) that must be faced and addressed if the participants are to succeed in their journey. These existential and spiritual themes are the organizing foci for subsequent group sessions. Finally, the participants take part in an opening prayer/candle ritual that will lend continuity to each session.

Body and spirit

Individuals diagnosed with HIV often report feeling physically violated; every part of their lives seems to be affected by the disease. One interviewee put it this way, “I truly thought I had HIV tacked on my forehead. I thought someone could just look at me and see it.” The primary goal of this session is to help women identify places within themselves that have not been damaged and aspects of life that remain eternal despite the ravages of the disease. Toward this end, participants begin by drawing pictures of their bodies as they see themselves now with the disease, followed by pictures of their souls. They are then asked to discuss the differences in their pictures and consider whether their spirits and souls transcend disease, pain, and suffering. Participants read from spiritual poetry that reminds them they contain a spark of God and that spark cannot be contaminated by anything earthly.

Another goal of the session is to help participants find effective ways to "feed their spirit." Participants are encouraged to identify unhealthy forms of coping (ie, “spiritual junk food”) that may make them feel good initially but ultimately leave them feeling empty. Spiritual forms of “junk food” include alcohol/drugs, abusive relationships, unhealthy eating, and denial of their disease. Participants are then invited to identify and build a “healthy spiritual food pyramid,” with activities such as laughter, prayer and meditation, self-care, and nourishing relationships, including their relationship with a higher power. One woman illustrated this process: “I felt like something was missing in my life. All my life I was looking for something to fill that space. And I never found it. Friends, good friends, didn’t fill that space. Drugs didn’t fill it. And finally, I met God, and I feel like my whole chest is full of flowers.” The session concludes with a ritual in which participants use the Biblical imagery of living water to help them replenish their spirits, followed by a group prayer that summarizes the session.

Control and surrender

Links between a sense of control and psychological health and well-being among individuals with a chronic illness have been consistently reported in the literature. In coping with a disease such as HIV, it may be especially important for people to distinguish between those aspects of life that are controllable and those that lie outside the individual’s control. In this vein, Thompson et al worked with a sample of HIV-positive men and found that believing in their ability to manage the daily consequences of a specific stressor (consequence-related control) had a greater impact on psychological well-being than believing that they could control the stressor itself (central control).

Based on this literature, this session helps participants
identify and distinguish between those aspects of life that are under their control (eg, diet, exercise, taking medication, participation in hobbies) from those aspects of life that are beyond their control (eg, final outcome of treatment, how family copes with illness/death). Group members are encouraged to focus on those things over which they have control and actively surrender those things that they cannot control. One interviewee illustrated this process: “Some things you can deal with, but if you know you can’t change something, that’s like it’s daylight outside. I cannot go and turn daylight into night. So why stress myself out?” Active surrender is not to be confused with passivity, hopelessness, or resignation. Rather, participants can let go or surrender the uncontrollable aspects of their lives to a benevolent external force, such as a higher power or God. After identifying potential barriers to the process of surrender (eg, fear of loss of control, sadness, anger), the group members participate in a guided imagery relaxation exercise in which they are encouraged to surrender those things beyond their control to God. Exercises similar to this one have proven helpful in other programs.67,65

**Letting go of anger**

Anger is an emotion that often accompanies the diagnosis of HIV; anger has also been associated with faster progression to AIDS.68 Anger at God and distress associated with that anger may be particularly relevant to people who are seropositive. One interviewee described her anger and confusion toward God: “I asked God, why me? I wasn’t using drugs, I wasn’t drinking, I wasn’t in the streets, I was in my house with my kids. Why did you give me this disease? I want to die now, and what about my kids, what’s going to happen to them?” Although no studies have specifically examined anger at God among people with HIV, a few studies have demonstrated that anger at God is not uncommon in response to major life crises.27,69 And, as noted earlier, anger at God and other signs of spiritual struggle, have been associated with declines in physical health and mental health.

The main objective of this session is to validate the participants’ experiences of anger, while encouraging them to let go and move beyond it. This goal is approached through a variety of cognitive and experiential activities. First, because anger repression has been associated with poorer health among HIV patients,70 participants engage in a discussion about adaptive and maladaptive ways to express their anger. Second, participants identify the targets of their anger and are asked to consider whether these targets are appropriate or inappropriate. Third, participants engage in a discussion about anger at God. In this discussion, anger toward God is normalized and validated; participants are reminded that “God is big enough to handle their feelings.” Finally, group members participate in an experiential activity in which they draw on their relationship with God to let go of any self-destructive anger they may be harboring.

**Shame and guilt**

Individuals living with HIV often experience shame and guilt.71,72 These feelings are all the more prominent among women who anticipate leaving their children behind when the illness claims them.73 Shame and guilt have been associated directly and indirectly with higher levels of depression, avoidance coping, hopelessness, alienation, and loneliness among people with HIV.74,75 One interviewee described the despair she felt after her diagnosis: “I felt like I wanted to die. I wanted it to happen now. I wanted to throw myself under a car. I wanted to take all the pills and kill myself.” Conversely, the disclosure of shameful and guilty feelings may help to alleviate the burden of these emotions.72,76

The purpose of this session is to normalize feelings of shame and guilt, explore their impact on healing, and encourage emotional disclosure, self-acceptance, and forgiveness. The first half of the session focuses on identifying potential messages of shame (eg, “You are a bad person”) and guilt (“I am forgivable”), including spiritual messages of shame and guilt (eg, “I have let God down”).77 The second half of the session attempts to help the women move toward spiritual and emotional healing. First, to counter the negative internalized messages of shame and guilt, affirming spiritual responses (eg, “I love you, I accept you as you are, I will not leave you, I forgive you, I want you to be whole, I am always with you, I know you and I think you are beautiful”) and potential barriers to these affirming messages are presented and discussed. The women engage in a two-way journaling exercise in which they write a letter to God about their true feelings and listen for God’s response. If they receive a response they are asked to write about that as well. Then, in an exercise intended to encourage disclosure, the women are guided through a visualization in which they imagine shedding the weights of shame and guilt by immersing themselves in a healing lake.75 Participants are encouraged to disclose their feelings of shame and guilt to God, to safe figures in their lives, to themselves, and to seek forgiveness.

**Social intimacy and support is promoted by:**

- Normalizing the experiences of isolation
- Identifying the risks and benefits of intimacy
- Exploring the disconnection from God that can result from living with HIV
- Beginning to move toward greater closeness with others

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*Featured CME Topic: Spirituality*
Isolation and intimacy

Empiric studies suggest that the stigma associated with HIV can lead to punitive and prejudicial thoughts and actions by others. Women, particularly black women with AIDS, are even less likely to be supported by families, partners, and friends. One of our interviewees spoke powerfully of this stigma: “In people’s book you’re dirty. Yeah, that’s what you’re living with. It makes you feel dirty. People don’t know how you received HIV. They speculate, just assume. They treat you like nothing.” According to another interviewee: “A lot of people with HIV deeply in their hearts want to talk about it. Their experiences, their traumas, their glories, and they don’t have a chance. They die and they don’t have a chance for anyone to listen to them. I wish everybody has that chance.” Stigma and the lack of social support can lead to declines in preventative behaviors (eg, condom use), higher rates of depression, and even suicidality.

This session is designed to promote social intimacy and support by normalizing the experiences of isolation, identifying the risks and benefits of intimacy, exploring the disconnection from God that can result from living with HIV, and beginning to move toward greater closeness with others. Group members begin by discussing their own feelings of isolation, including feelings of abandonment from God. Nevertheless, the need for intimacy remains. Participants are encouraged to talk about their fears that accompany reaching out to others for greater intimacy. For people with HIV, interpersonal closeness comes with the risk of stigma and rejection. Thus, it takes a “leap of faith” to connect with other people in the hope that they can be there for them. Group members read stories of people who have been successful in garnering social intimacy. They also generate a list of potential sources of spiritual as well as interpersonal support. One woman described the support she found from talking with God: “When I am in the street, I am always whispering to myself. But when I’m whispering to myself, I’m really talking with the Lord, asking Him to stay with me. Wherever I’m going, I’m asking Him to guide me back safe.” Through a group activity in which participants pass a ball of yarn to each other, they are reminded of how they have become interconnected with each other. The session concludes with a prayer to thank God and ask for His presence in the participants’ journeys to healing and connectedness.

Hopes and dreams

Research on the impact of HIV has neglected the importance of hope in the face of this pervasive life-altering event. However, it is important for people to sustain a sense of meaning and hope during this traumatic time. One woman we interviewed illustrated how spiritual resources can play an important role in the movement toward hope. She stated: “I know He’s looking at me, and He’s going to make a better day each day. He’s going to make it better and better. Because He’s alive and He’s right here, everywhere. We do everything through him.”

The challenge for people grappling with HIV is to acknowledge their limitations while simultaneously realizing that hope and meaning remain a part of their lives. In this session, participants acknowledge and discuss the dreams that have been lost as a result of their infection, including dreams that they held sacred (eg, watching their children grow up; being part of a community of faith). They are then encouraged to identify dreams that are still possible despite their illness. Participants are asked to distinguish possible dreams from false dreams (ie, those that cannot be achieved or those that can lead them in destructive directions). To illustrate the experience of dangerous dreams and hopes, they watch a clip from a movie that describes a depressed and lonely woman who becomes involved in an abusive relationship. Finally, the women identify new dreams that are sacred in character; that is, dreams that allow them to see God’s purpose and meaning in their lives. They read and discuss the true story of a young woman who became a quadriplegic after an accident and was able to find a new spiritual purpose for herself over time. The women are then asked to consider how God might help them change and pursue their own dreams.

A review of the journey

The final session reviews the journey to healing. Participants are given symbols to remind them of the barriers they have addressed and the resources they have been able to access. They are also given “travel kits” so they can be reminded of their resources by referring to their symbols when they face difficult times in the future. The symbols are: a compass to remind them of the need to find a true direction along the path toward wholeness and healing; a cup to help them recall that they can replenish themselves with living water when their spirits become dry; a card containing the serenity prayer to recall the importance of distinguishing the controllable from the uncontrollable; a rock to remind them how anger may seem strong and powerful at first but becomes a burden over time that can be released; an umbrella to help participants remember the sheltering function of God’s love in the face of feelings of shame and guilt; a piece of yarn to remind them of their connectedness to God and each other;
and a dream catcher to remind participants that despite their illness they still have sacred dreams that can provide them with meaning and purpose in their lives. The program ends with a prayerful poem entitled, “Somewhere Within,” that illustrates an individual’s growth through the various seasons of life.\(^2\)

Conclusion

A small but growing body of empirical evidence indicates that religiousness and spirituality play an important role in the health and well-being of people living with HIV. Further studies are needed that examine the longer-term impact of religiousness and spirituality, the specific coping resources and burdens that contribute to the positive or negative effects of these phenomena, and the mechanisms through which religiousness and spirituality affect health status. Nevertheless, the data are sufficiently compelling to suggest that we can begin to move (albeit cautiously) from research to practice. Researchers and practitioners have begun to design, implement, and evaluate spiritually integrated forms of intervention for people dealing with a variety of physical and emotional problems.

It is time to extend this work to people facing HIV. “Lighting the Way: A Spiritual Journey to Wholeness” is not the only spiritually sensitive program that could be designed for people with HIV. It does, however, illustrate how spiritual coping resources and spiritual struggles can be addressed within the context of the major existential issues so commonly raised by the encounter with this disease. We believe the program could be helpful to people from a variety of religious traditions and also those with spiritual interests and concerns who are not affiliated with any particular religion. However, the program would be contraindicated for those who have no interest in talking about spiritual matters, those who would prefer a program linked exclusively to one religious tradition, and those with serious physical or psychological problems that would preclude their ability to attend or participate meaningfully in a group (e.g., alcohol/drug abuse, dementia, active psychosis). Clearly, the next step in this evolving area of research and practice involves empirical evaluations of the efficacy of spiritually integrated treatments, such as “Lighting the Way.” Are spiritually integrated interventions for people with HIV helpful? Do they add a valuable component to existing models of treatment? Are they particularly helpful to specific groups? These are some of the exciting questions that grow out of the attempt to integrate the religious and spiritual dimension more fully into our efforts to understand and treat people confronting HIV.

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It is better to have a permanent income than to be fascinating.

—Oscar Wilde