

Spirituality in HIV+ Patient Care

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Melia¹ was a 39 year old, mother of 2 young children. She was actively involved in her church and had strong Christian beliefs. Melia was married to her husband for 15 years when her husband left her for another woman, and Melia discovered that her husband had given her HIV as a result of his affairs. When she disclosed her HIV status, she was shunned by many of her friends and family members. She was devastated and isolated. In therapy, she and her psychologist explored the topics of healing versus curing, holiness of the body, and using her spiritual resources as a source of strength and a means to begin rebuilding her life. These themes were woven into treatment alongside traditional cognitive-behavioral therapy practices to reduce depression and social isolation. By the end of therapy, Melia was no longer depressed and isolated. She was able to view HIV as part of her, but not the only thing that defines who she is as a person. She was able to recognize her other strengths and use those strengths to deal with the daily challenges of being a single mother with HIV.

Life expectancy after HIV infection has increased significantly due to highly active antiretroviral therapy, and changing care for HIV/AIDS patients from treatment of a terminal illness to ongoing management and monitoring of a chronic medical condition (Litwinczuk & Groh, 2007). Despite aggressive medical therapy, functioning continues to be dramatically compromised by HIV and can result in reduced quality of life, increased dependency on others,

¹Name has been changed to protect this individual's privacy



negative mental health outcomes such as depression, anxiety, hopelessness, and fear, as well as negative social outcomes including isolation and stigmatization (Corless, 2002). In addition, there are important spiritual impacts a diagnosis of HIV can confer, including dramatically shaping patients' belief in self competence, their ability to cope with the disease, and even the physiological course of the disease. For individuals living with chronic illnesses such as HIV, spirituality and religion are often centrally important as patients face a unique array of existential challenges as a result of the diagnosis and management of the disease. Thus, it is critical for healthcare providers to be cognizant of the spiritual component of HIV/AIDS and to be knowledgeable regarding what the current literature base suggests in terms of addressing spirituality with patients.

Research has frequently examined the roles of patients' religious coping styles and patients' spirituality on health trajectories. Religion and spirituality are two separate but related constructs that both involve methods of meaning-making and purpose-finding, which are particularly relevant for the chronically

ill, especially during the initial adjustment period to a diagnosis (Kremer, Ironson, & Kaplan, 2009).

It is important to differentiate religion from spirituality, particularly with respect to the HIV/AIDS population who has often faced stigmatization by institutionalized religion. Definitions of each have evolved in the research literature, but religious activity is often identified as a behavioral reflection of internal spiritual beliefs (Pargament, Ano, & Wachholtz, 2005). Spirituality may refer to subjective transcendent experiences which give everyday life a sense of deeper meaning (Emmons, 1999). By understanding this distinction, healthcare providers can use clinically appropriate methods to assess a patient's existential concerns.

Research indicates that people reflect on their spirituality after being diagnosed with HIV/AIDS by incorporating their understanding of God and previous religious/spiritual experiences as part of their coping repertoire (Jacobson, Luckhaupt, Delaney, & Tsevat, 2006; Tarakeshwar, 2006). Spirituality uniquely predicts health and well-being outcomes in those with HIV/AIDS such as improvements in life satisfaction, functional health status, and health-related quality of life after controlling for factors such as age and HIV symptoms (Pargament et al., 2004). Higher levels of spirituality have been associated with less pain and increased energy (Ramer, Johnson, Chan, & Barrett, 2006), less psychological distress (Simoni, Martone, & Kerwin, 2002), less depression (Coleman, 2004; Simoni & Ortiz, 2003), better mental well-being (Braxton, Lang, Sales, Wingood, & DiClemente, 2007; Coleman, 2004), better cognitive and social functioning, and fewer HIV symptoms (Coleman, 2004).

However, the kind of spirituality (i.e., positive or negative) adopted by the patient may have a critical impact on the course of the disease. Ironson, Stuetzle, & Fletcher, (2006) conducted a study in which 45% of participants reported an increase in positive spirituality following an HIV diagnosis. Heightened positive spirituality after an HIV diagnosis was a protective factor for physiological disease progression in HIV patients, compared to patients whose spirituality decreased following HIV diagnosis (Trevino et al., 2010). On the other hand, negative aspects of spirituality

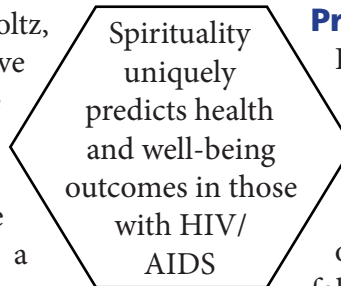
such as spiritual struggle, anger at God, or viewing HIV as a sin are associated with poor medical compliance (Parsons, Cruise, Davenport, & Jones, 2006), and faster disease progression (Ironson, Stuetzle, & Fletcher, 2006; Trevino et al., 2010). Therefore the type of spiritual beliefs and practices will help determine if spirituality will be a protective or risk factor to the progression of HIV.

Recommendations for Service Providers

Healthcare providers can improve their practice approaches with HIV patients by considering ways to assess and identify how spirituality serves as a basis for giving meaning to the patient's experience of HIV. Trevino et al. (2010) offer the following suggestions for providers with HIV/AIDS patients:

- Assess positive religious coping and spiritual struggle early in treatment; assessing early is especially important to mitigate the effects of patients experiencing spiritual struggle;
- Support and encourage patients utilizing religious resources to cope;
- Be open to incorporating religious coping techniques into treatment plans. Appropriate interventions include discussing religious/spiritual beliefs, referral to pastoral counselor or religious clergy, referral for psychotherapy to address spirituality; and
- Consider manualized psychological/spiritual interventions for patients with HIV such as "Lighting the Way: A Spiritual Journey to Wholeness" (Pargament et al., 2004), a spiritual coping intervention for adults living with HIV/AIDS (Tarakeshwar, Pearce, & Sikkema, 2005), or a Spiritual Self-Schema therapy for treatment of addiction and HIV (Avants et al., 2005).

In summary, it is important for health care providers to understand that spirituality plays a critical role in the prognosis of HIV in many patients. The type of spiritual beliefs and practices determines whether spirituality is a protective or risk factor to the progression of HIV. Providers should strive to assess spirituality in HIV patients and make referrals for empirically supported treatments and/or pastoral/clinical counseling to address spirituality as indicated.



References

- Avants, S.K., Beitel, M., & Margolin, A. (2005). Making the shift from 'addict self' to 'spiritual self': Results from a stage I study of Spiritual Self-Schema (3-S) therapy for the treatment of addiction and HIV risk behavior. *Mental Health, Religion and Culture*, 8, 167-177. doi: 10.1002/jclp.20407
- Braxton, N.D., Lang, D.L., Sales, J.M., Wingood, G.M., & DiClemente, R.J. (2007). The role of spirituality in sustaining the psychological well-being of HIV-positive black women. *Women and Health*, 46, 113-129. doi: 10.1300/J013v46n02_08
- Corless, I.B. (2002). The HIV-AIDS patient: Holier than thou. In R. B. Gilbert (Ed.), *Health care and spirituality: Listening, assessing, caring* (pp. 189-200). Amityville: Baywood Publishing Company, Inc.
- Coleman, C.L. (2004). The contribution of religious and existential well-being to depression among African American heterosexuals with HIV infection. *Issues in Mental Health Nursing*, 25, 103-110. doi: 10.1080/01612840490249028-26
- Emmons, R.A. (1999). *The psychology of ultimate concerns: Motivation and spirituality in personality* (pp. 89). New York: Guilford.
- Ironson, G., Stuetzle, R., & Fletcher, M.A. (2006). An increase in religiousness/spirituality occurs after HIV diagnosis and predicts a slower disease progression over 4 years in people with HIV. *Journal of Internal Medicine*, 21, 62-68. doi: 10.1111/j.1525-1497.2006.00648.x
- Jacobson, C.J. Jr., Luckhaupt, S.E., Delaney, S., & Tsevat, J. (2006). Religio-biography, coping, and meaning-making among persons with HIV/AIDS. *Journal for the Scientific Study of Religion*, 45, 39-56. doi: 10.1111/j.1468-5906.2006.00004.x
- Kremer, H., Ironson, G., & Kaplan, L. (2009). The fork in the road: HIV as a potential positive turning point and the role of spirituality. *AIDS Care*, 21, 368-377. doi: 10.1080/09540120802183479
- Litwinczuk, K.M. & Groh, C.J. (2007). The relationship between spirituality, purpose in life, and well-being in HIV-positive persons. *Journal of the Association of Nurses in AIDS Care*, 18, 13-22. doi: 10.1016/j.jana.2007.03.004
- Pargament, K. I., Ano, G. G., & Wachholtz, A. B. (2005). The religious dimension of coping: Advances in theory, research, and practice. In R.F. Paloutzian & C.L. Park (Eds.), *The handbook of the psychology of religion and spirituality* (pp. 479-495). New York: Guilford.
- Pargament, K.I., McCarthy, S., Shah, P., Ano, G., Tarakeshwar, N., Wachholtz, A., et al. (2004). Religion and HIV: A review of the literature and clinical implications. *Southern Medical Journal*, 97, 1201-1209. doi: 0038-4348/04/9712-1201
- Parsons, S.K., Cruise, P.L., Davenport, W.M., & Jones, V. (2006). Religious beliefs, practices, and treatment adherence among individuals with HIV in the southern United States. *AIDS Patient Care and STDs*, 20, 97-111. doi: 10.1089/apc.2006.20.97
- Ramer, L., Johnson, D., Chan, L., & Barrett, M.T. (2006). The effect of HIV/AIDS disease progression on spirituality and self transcendence in a multicultural population. *Journal of Transcultural Nursing*, 17, 280-289. doi: 10.1177/1043659606288373
- Simoni, J.M. & Ortiz, M.Z. (2003). Mediational models of spirituality and depressive symptomatology among HIV-positive Puerto Rican women. *Cultural Diversity and Ethnic Minority Psychology*, 9, 3-15. doi: 10.1037/1099-9809.9.1.3
- Simoni, J.M., Martone, M.G., & Kerwin, J.F. (2002). Spirituality and psychological adaptation among women with HIV/AIDS: Implications for counseling. *Journal of Counseling Psychology*, 49, 139-147. doi: 10.1037/0022-0167.49.2.139
- Tarakeshwar, N., Khan, N., & Sikkema, K.J. (2006). A relationship-based framework of spirituality for individuals with HIV. *AIDS and Behavior*, 10, 59-70. doi: 10.1007/s10461-005-9052-8
- Tarakeshwar, N., Pearce, M.J., & Sikkema, K.J. (2005). Development and implementation of a spiritual coping group intervention for adults living with HIV/AIDS: A pilot study. *Mental Health, Religion, and Culture*, 8, 179-190. doi: 10.1080/13694670500138908
- Trevino, K.M., Pargament, K.I., Cotton, S., Leonard, A.C., Hahn, J., Caprini-Faigin, C.A., & Tsevat, J. (2010). Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: Cross-sectional and longitudinal findings. *AIDS Behavior*, 14, 379-389. doi: 10.1007/s10461-007-9332-6