

EDITORIAL

The Importance of Spirituality/Religion and Health-Related Quality of Life Among Individuals with HIV/AIDS

Recent advances in treatment modalities for HIV/AIDS have led from considering this disease as a death sentence to a life-long chronic disease. As a result of this transition, investigators have turned their attention from assessing outcomes such as mortality and morbidity to quality of life (QOL) and factors that mediate/moderate the relationship between HIV/AIDS and these outcomes. The current supplement makes an important contribution to this reconceptualization of HIV/AIDS, specifically our understanding of how QOL and psychosocial factors, particularly spirituality/religion, are associated with this disease.

HIV/AIDS is accompanied by multiple stressors, which include the management of treatment regimens that are complex. In addition, the long-term benefit of pharmacotherapies remains a source of uncertainty. Disease management often requires significant lifestyle modifications and adaptation of daily activities to the demands of prescribed treatment regimens. Adherence to HIV/AIDS treatment is required to be among the most rigid of any disease given the potential for compromising the future effectiveness of these treatments and the development of resistance to the prescribed medication(s).

In addition to stressful disease-management and treatment adherence issues, persons living with HIV/AIDS experience ongoing psychosocial stressors, both interpersonal and intrapersonal, associated with diagnosis of a life-threatening chronic illness. These multiple, severe, and unrelenting stressors may profoundly affect the individual's QOL and tax existing coping resources.^{1,2} Thus, given the potential impact of HIV/AIDS, understanding the interaction and relationships among biological, psychological, social, and spiritual dimensions is imperative. Models such as those proposed by Szaflarski et al.³ help us conceptualize the impact of HIV/AIDS and can guide interventions to improve outcomes and decrease health risks and costs.

An important message of this supplement is that traditionally, the success of medical therapies have been evaluated with objective physiological data only (e.g., survival time). However, such measurements do not account for the many important clinical and human subjective reactions.⁴ In addition, there are minimal direct relationships between biological indices such as viral load and CD4 counts as observed in Mrus et al.'s study.² Thus, understanding patients' perceptions of their disease and QOL have implications for outcomes⁵ and treatment strategies.

Quality of life offers a comprehensive patient-defined outcome and has proven useful to characterize health disparities, track population trends, and monitor progress in achieving na-

tional objectives.^{6,7} Disease-specific QOL measures often are structured as deficiency checklists and therefore do not account for the personal growth and normalization that may occur while living with a chronic disease. In these disease-specific QOL measures, patients are asked to assess how much a particular symptom or concern has prevented them from living the way they may have wanted. However, investigators have found strong support for adaptation to this progressive illness in which people are able to maintain equilibrium or even thrive^{8,9} in the face of increasing health threats.^{10,11} Thus, a measure that captures what QOL means for patients should consider adaptation and coping and not merely focus on limitations.

Normalization of coping with a chronic disorder is an important defense strategy for patients¹²; therefore, effective treatment strategies are likely to be those that support psychosocial adjustment to illness.¹³ A better understanding of coping with HIV/AIDS may also help identify patients with lesser support and who are, subsequently, at greatest risk for future problems. Identifying both deficiencies and strengths of patients presents an opportunity for the clinician to build upon individual resources in an attempt to intervene if necessary where heightened need in particular domains exists.

Spirituality/religion is a way to cope and re-frame one's life and bring a sense of meaning and purpose to one's life in the face of a disease such as HIV/AIDS. The central role of spirituality in chronic illnesses has been examined in several studies and many of the current studies encompassed in this supplement do as well. Investigators examining cultural differences and the contributing etiological factors for HIV/AIDS and other chronic diseases have reported that individuals often attribute their illness to spiritual distress and beliefs.¹⁴ While results indicate the importance of spirituality/religion, prior research examining spirituality and religion among individuals with HIV/AIDS has been limited by small samples, lack of coherent measures of spirituality, cross-section designs, and single site studies. Studies in the current supplement examine the role spirituality/religion in 2 large, longitudinal studies. Some of the more interesting findings include spirituality/religion is relatively constant over short periods of time and the multidimensional aspects of this concept. A useful technique that can be used to examine the multidimensional aspects of the construct spirituality/religion is latent profile analysis (see Kudel et al.¹⁵ for more details).

Physicians may question the appropriateness and their role in probing patients' spiritual distress and the practicality of addressing such issues in the time-limited, clinical encounter. Yet, patients' spirituality often influences treatment choices and endows personal resources during serious illness. A practical, evidence-based approach to discussing spiritual concerns in a scope suitable to a physician-patient relationship may improve quality of the clinical encounter.

Based upon our prior work with individuals at the end of life, we asked individuals a single question—"are you at

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peace?"¹⁶ The purpose of this item is not to reduce spiritual, religious, or emotional concerns to a construct of peace, nor does use of the item constitute a full spiritual history. Rather, we liken its use to the single question, "Are you depressed?" which works well as a screening tool indicating need for a fuller psychological assessment.¹⁷ These data indicate use of the concept of peacefulness as a gateway to larger discussions, framed according to patients' values, preferences, and life experiences.

In conclusion, advances in pharmacotherapy notwithstanding, HIV/AIDS continues to be among the most devastating of illnesses, having multiple and profound effects upon all aspects of the biopsychosocial and spiritual being. The current supplement provides further information regarding both the roles of QOL and psychosocial factors from 2 large longitudinal studies of patients with HIV/AIDS. Further consideration of incorporating spirituality/religion for certain individuals as a pathway to improve QOL may be beneficial. Understanding QOL issues remain paramount, particularly identifying factors and interventions that may improve the QOL.—**Hayden B. Bosworth, PhD,^{1,2,3,4}** ¹*Center for Health Services Research in Primary Care, Durham VAMC, Durham, NC, USA;* ²*Division of General Internal Medicine, Department of Medicine, Duke University, Durham, NC, USA;* ³*Department of Psychiatry and Behavioral Sciences, Duke University, Durham, NC, USA.* ⁴*Center for Aging and Human Development, Duke University, Durham, NC, USA.*

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