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## SPIRITUAL WELL-BEING, SLEEP DISTURBANCE, AND MENTAL AND PHYSICAL HEALTH STATUS IN HIV-INFECTED INDIVIDUALS

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A growing body of evidence demonstrates a significant relationship between spirituality and health. HIV-infected individuals often find new meaning and purpose for their lives while establishing new connections and strengthening old ones. This descriptive, correlational study examined the relationships among spiritual well-being, sleep quality, and health status in 107 HIV-infected men and women. Spiritual well-being was found to be a significant factor related to both sleep quality and mental and physical health status. Every study participant reported sleep disturbance. The findings suggest that spiritual well-being and sleep quality need to be assessed so appropriate interventions can be implemented to improve health outcomes in this population.

New cases of HIV infection are appearing at increasing rates in the United States, reversing an earlier trend that showed a temporary reduction in the incidence of diagnosed HIV infection (Centers for Disease

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Control; CDC, 2003). Although the rate of new AIDS cases is declining due to the life-prolonging benefits of highly active antiretroviral therapy (HAART), HIV infections continue to progress to AIDS, although at a slower rate (CDC, 2003). As HIV infection progresses, the immune system becomes increasingly compromised leading to a variety of HIV-related symptoms and a decreased quality of life. HAART, which combines protease inhibitors with reverse transcriptase inhibitors, has dramatically slowed viral replication and disease progression leading to longer, healthier, more productive lives, thus a better health-related quality of life (Nieuwkerk et al., 2001). In this era of immune system reconstitution, improving quality of life has become a top priority for health care practitioners.

HIV disease challenges every aspect of an HIV-infected individual's life, often contributing to spiritual distress. The existing literature indicates that, over time, persons who are HIV-infected often find new meaning and purpose for their lives and establish new connections and strengthen old connections with their family, friends, acquaintances, the world around them, and their spiritual belief systems (McCormick, Holder, Wetsel, & Cawthon, 2001). Spirituality has been found to be significantly associated with beneficial outcomes in HIV-infected individuals (Woods, Antoni, Ironson, & Kling, 1999).

Sleep disturbance is a frequent and troublesome complication of HIV infection with prevalence rates reaching over 70% (Darko, Mitler, & Miller, 1998; Gardner, Petrin, Collier, & Paauw, 1997; Mock, Phillips, & Sowell, 2002; Nokes & Kendrew, 2001). Often, sleep disturbance appears before the diagnosis of HIV infection and becomes more severe over the course of the illness (Darko et al., 1998; Mock et al., 2002; Nokes & Kendrew, 2001). Poor sleep quality has been associated with increased morbidity in HIV-infected individuals (Darko, McCutchan, Kripke, Gillin, & Golshan, 1992; Darko et al., 1998).

The term "quality of life" is a general term used to describe all aspects of an individual's well-being. Health status is a more specific term that applies to the current level of functioning and overall satisfaction with life compared to some self-actualized ideal. In HIV-infected people, this value is often used as an indicator of the patient's physical and mental health status. Health status is influenced by many aspects of HIV disease and decreases as the disease progresses (Bing et al., 2000). Lower health status scores are associated with higher levels of disability and morbidity among both asymptomatic and symptomatic HIV-infected individuals (Lubeck & Fries, 1997).

Spiritual distress has the potential to decrease both sleep quality and quality of life of HIV-infected individuals, thus spiritual interventions

might increase quality of life. Therefore, the primary purpose of this research was to determine the relationship between spiritual distress and health status and between spiritual distress and sleep quality in HIV-infected individuals.

#### BACKGROUND

## **Spiritual Well-Being**

A growing body of evidence suggests that spiritual well-being, or spirituality, enhances health and contributes to quality of life for HIV-infected individuals (Chibnall, Videen, Duckro, & Miller, 2002; Coleman & Holzemer, 1999; Gray & Cason, 2002; Ironson et al., 2002). Paloutzian and Ellison (1982) viewed spiritual well-being as having two components: religious well-being and existential well-being. Religious well-being is defined as a person's relationship with a higher being (Paloutzian & Ellison, 1982). Existential well-being is concerned with a person's ethical and moral intentions and behaviors that affect the physical world and human interactions (Paloutzian & Ellison, 1982).

Spiritual well-being has been associated with health and resilience in HIV-infected individuals. In a study of 52 men living with HIV, a positive relationship was found among overall quality of life, social support, effective coping strategies, and existential well-being (Tuck, McCain, & Elswick, 2001). Tuck and colleagues (2001) also found a negative relationship between existential well-being and not only perceived stress, but also uncertainty, psychological distress, and emotional-focused coping. Flannelly and Inouye (2001) found that resilience was significantly related to religious affiliation, religious faith, number of symptoms, level of physical functioning, and socioeconomic status. In a study of 96 HIVinfected individuals, resilience was found to be significantly related to spirituality, and spirituality and social support combined explained the variance in resilience (Poblete, 2000). In a study of 80 HIV-infected females, Gray and Cason (2002) found that spiritual perspective, defined as "one's frame of reference consisting of beliefs and attitudes of connectedness with something or someone greater than self" (p. 45), was positively correlated with mastery over stress, which is defined as successfully coping with stress and experiencing change, growth, acceptance, and enhanced life meaning. Spiritual well-being also is associated with reduced feelings of death distress in patients with life-threatening illness (Chibnall et al., 2002). Although association does not show causality, these results suggest that health, resilience, and spiritual well-being are closely related.

#### **Sleep Disturbance**

Sleep disturbance is a frequent symptom of HIV infection because of many factors. The symptoms of opportunistic infections and malignancies that accompany HIV disease are factors that often contribute to sleep disturbance (Phillips, 1999). Additionally, psychological factors, such as perceived stress, anxiety, and depression, have been implicated in sleep disturbance in HIV-infected individuals (Cohen, Ferrans, Vizgirda, Kunkle, & Cloninger, 1996; Darko et al., 1992; Mock et al., 2002). Even medical interventions can cause sleep disruption. The side effects of many antiretroviral therapies and drugs used to treat the opportunistic infections and malignancies that result from HIV disease also may result in sleep disturbance (Phillips, 1999).

Sleep disturbance is common in HIV-infected individuals. Rubinstein and Selwyn (1998) surveyed a systematic sample of 115 patients in an urban HIV/AIDS clinic and reported that 73% of the HIV-infected persons were classified as having a significant sleep disturbance using the Pittsburgh Sleep Quality Index (PSQI). Hand, Phillips, Sowell, Rojas, and Becker (2003) surveyed 73 patients in a primary care medical practice and found that all the participants in that study were classified as having a significant sleep disturbance using the PSQI. However, documentation of sleep disturbance is rarely found in the medical records of HIV-infected individuals (Rubinstein & Selwyn, 1998), indicating that health care professionals are failing to assess this very prevalent symptom associated with HIV-infection.

#### **Health Status**

Health status is a multi-factorial construct consisting of physical and psychological components. Increasingly, health status is important in HIV-infected individuals due to the chronic nature of the disease, and it is a critical factor to consider in the introduction and implementation of interventions (Bing et al., 2000). In HIV patients, the presence of even one disease symptom, whether caused by medical intervention or the disease process itself, can adversely affect the health of the afflicted (Bing et al., 2000). Flannelly and Inouye (2001) found that both religious faith and religious affiliation contributed to improved health in HIV-infected individuals. Existential well-being also may contribute to health status by providing meaning and purpose in life (Nilsson, 2002). In a sample of HIV-infected women, Gielen, McDonnell, Wu, O'Campo, and Faden (2001) reported that quality of life was associated with education level, social support, and health-promoting behaviors (getting enough sleep

and exercise, eating a healthy diet, and stress management). Although HIV infection does adversely affect the health of those afflicted, 49% of 51 patients surveyed by Tsevat and colleagues (1999) reported that their lives are better since being diagnosed.

#### **METHODS**

## Design

A descriptive, correlational design was used to test the relationships among spiritual well-being, sleep quality, and health status in a sample of HIV-infected adult men and women. Subsequently, the relationships among religious well-being and existential well-being and health status were tested.

## Sample and Setting

These analyses are from a study of psychoneuroimmunological correlates of sleep in HIV disease. The participants were 107 HIV-infected men and women between 18 to 50 years of age. All participants were recruited from AIDS service organizations in South Carolina.

#### **Instruments**

## Sleep Quality

The PSQI is a self-report instrument that measures sleep quality and sleep disturbances (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989). The PSQI contains seven components: subjective sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbances, use of sleep medications, and daytime dysfunction (Buysse et al., 1989). This instrument contains 19 self-report items and 5 items that are rated by a roommate or bed partner. Only the 19 self-report items were administered in this study. The 19 self-reported items generate a global PSQI score. Homogeneity has been demonstrated by a Cronbach's alpha of .83. A test-retest reliability of r = .85-.87 has demonstrated stability over time (Backhaus, Junghanns, Broocks, Riemann, & Hohagen, 2002; Buysse et al., 1989). Validity has been supported by significant correlations with sleep log data and polysomnography (Backhaus et al., 2002). The PSQI has demonstrated a sensitivity of 98.7 and a specificity of 84.4 as a marker for sleep disturbances in primary insomnia (Backhaus et al., 2002). Completion of this instrument requires fiveten minutes. Possible total scores for the PSQI range from 0-21. A

higher score on the PSQI indicates poorer sleep quality and a score greater than five indicates severe difficulties with sleep (Buysse et al., 1989).

## Spiritual Well-Being

The Spiritual Well-being Scale (SWBS) was used to measure spiritual well-being (Ellison, 1983; Paloutzian & Ellison, 1982). The SWBS is a 20-item self-report instrument with two subscales, the Religious Wellbeing Scale (RWBS) and the Existential Well-being Scale (EBWS). The RWBS contains ten items that assess an individual's relationship with God, and there are ten items that assess a person's relationship with the physical world and other individuals (EWBS). Each item is rated on a six-point scale that ranges from (1) strongly disagree to (6) strongly agree. The reliability of the SWBS has been well-supported in the existing literature. Alpha coefficients greater than .82 for the total instrument support the reliability of this instrument (Kirschling & Pittman, 1989; Paloutzian & Ellison, 1982). The alpha coefficients for the RWBS range from 82-.99 and from .73-.98 for the EWBS (Brinkman, 1989; Brinkman & Bufford, 1990). Test-retest reliability coefficients for 100 student volunteers at the University of Idaho were .93 for the SWBS, .96 for the RWBS, and .86 for the EWBS (Paloutzian & Ellison, 1982). The item content of this instrument supports its face validity, and construct validity has been supported by factor analysis (Ellison, 1983; Ledbetter, Smith, Fischer, Vosler-Hunter, & Chew, 1991; Ledbetter, Smith, Vosler-Hunter, & Fischer, 1991). The SWBS correlates positively with self-concept, greater meaning and purpose in life, higher assertiveness, lower aggressiveness, and physical health (Brinkman, 1989; Brinkman & Bufford, 1990). Negative associations are found with ill health, emotional maladjustment, and dissatisfaction with life (Brinkman, 1989; Brinkman & Bufford, 1990). Possible scores for the total instrument range from 20-120 and from 10-60 for both the RWBS and the EWBS. A higher score indicates greater spiritual well-being.

#### Health Status

Health status was measured using the SF-12, (Short From-12) which was developed from the Medical Outcomes Study (Ware, Kosinski, & Keller, 1998; Ware & Sherbourne, 1993). The SF-12 assesses eight components of health status including: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, and mental health. Scores also can be calculated for the physical

and mental dimensions of health status, using a standard algorithm. Scores range from 0–100 with a higher score indicating a greater degree of health in that domain or dimension (Ware et al., 1998; Ware & Sherbourne, 1993).

#### **Procedure**

Subject interviews took place in the Clinical Research Laboratory of the Department of Exercise Science in the School of Public Health at the University of South Carolina. The participants were fully informed of the nature and duration of the study. They were informed of what would be required of them if they chose to participate. The participants were informed of the voluntary nature of the study and that they would suffer no loss of benefits if they chose not to participate. Confidentiality was assured. After the informed consent was read to the participants, they were asked to sign the informed consent statement. An investigator or a trained interviewer conducted the interviews and recorded the participants' answers verbatim.

#### **Data Analysis**

Frequencies and percentages were calculated for each of the categorical variables; Means and standard deviations were calculated for each of the continuous variables. The three research questions were tested using Pearson's coefficient of correlation (Pearson's r). All questions were answered on a voluntary basis. Some participants refused to answer certain questions, leading to discrepancies in the number of responses reported for each measure. An alpha level of .05 was established as the level of statistical significance. Data were analyzed using SAS 8.2e.

#### **RESULTS**

# **Description of the Sample**

Seventy (66.7%) HIV-infected men and 35 (33.3%) HIV-infected women participated in this study. Two participants did not report their gender. The participants ranged between 20 to 50 years of age (mean =  $40.0 \pm 7.3$ ). Of those subjects responding to the question, 71 classified themselves as African American (82.6%), 13 as Caucasian (15.1%), and 2 as Hispanic (2.3%); the remaining 22 participants did not respond to the question. On the question of sexual identity, 64 subjects

(64.6%) identified themselves as heterosexual, 23 (23.2%) as homosexual, and 12 (12.1%) as bisexual. Nine subjects did not respond to the question about sexual identity. Of the 67 subjects self-reporting T helper cell count, 18 reported a cell count below 200 mg/dL, 31 reported T helper cell counts between 200 and 500 mg/dL, and 18 reported T helper cell counts over 500 mg/dL (range 0–1400). Viral load scores ranged from 0 to 750,000 (mean = 38,521,  $SD = 112,046 \, n = 55$ ). Years of education ranged from 6 to 22 years (12.4  $\pm$  2.5). There was a wide variation in the number of hours worked per week, with 50 subjects (54.3%) reporting that they worked 0 hours per week, 19 subjects (20.7%) reporting between 0 and 40 hours per week, and 23 (25.0%) reporting 40 hours per week or more of work (16 did not answer). See Table 1.

## **Description of Sleep**

The mean value of the PSQI was  $12.3 \pm 3.8$  (range = 5 to 20), indicating that all (100%) of the subjects had considerable sleep disturbance. Subjects reported spending an average of  $8.2 \pm 2.3$  hours (range 1–17) in bed each day, but only getting  $6.2 \pm 2.0$  hours (range 2–12) of actual sleep. The PSQI calculates total time in bed by asking subjects what time they go to bed and what time they get out of bed. This structure does not allow participants to count separate daytime sleeping in their total time in bed score, so participants may indicate that they sleep more hours than they spend in bed. The high PSQI scores were supported with subjects self-rating their overall sleep quality as fairly bad on a scale from 0–3, with a 3 indicating very bad sleep quality (mean  $2.3 \pm 0.9$ ). Relationships of sleep quality to other variables are shown in Table 2.

## **Description of Spiritual Well-Being**

The mean value reported for total spiritual well-being was  $95.3 \pm 17.4$  (range 57-120). The mean score reported for religious well-being was  $49.9 \pm 9.1$  (range 27-60), while the mean score for existential well-being was  $45.4 \pm 9.9$  (range 17-60). Both existential well-being (r=0.92, p<0.0001) and religious well-being (r=0.90, p<0.0001) were highly correlated with total spiritual well-being. Religious well-being and existential well-being also were significantly correlated with each other (r=0.67, p<0.0001). Sleep quality was significantly related to existential well-being (r=-0.29, p<0.0031) and to total spiritual well-being (r=-0.22, p=0.0293), but not to religious well-being (p=.3378, r=-0.10). (See Table 2)

**TABLE 1.** Demographic Characteristics of the Sample (n = 105)

Demographic characteristic	n	%
Gender		
Male	70	66.7
Female	35	33.3
Missing data	2	
Ethnicity		
African American	71	82.6
Caucasian	13	15.0
Hispanic	1	1.2
Other	1	1.2
Missing data	21	
Sexual identity		
Heterosexual	64	63.4
Homosexual	23	22.8
Bisexual	12	11.9
Other	2	1.9
Missing data	10	
Relationship status		
Single	56	53.3
Married	13	12.4
Separated	9	8.6
Divorced	2	1.9
Steady relationship	19	18.1
Other	6	5.7
Missing data	2	
Route of infection		
Sexual intercourse	84	80.0
Intravenous drug use	12	11.4
Blood/blood by-products	3	2.9
Accidental exposure	1	0.9
Other	6	4.8
Missing data	1	
Education		
Less than 9 years	4	3.8
9–12 years	65	61.9
13–16 years	30	28.6
More than 16 years	6	5.7
Missing data	2	

# **Description of Health Status**

Health status was measured using the SF-12. The mean score for the physical health status was  $43.2\pm10.4$ . The mean score for mental health status was  $43.3\pm12.1$ . Both of these scores place the subjects

Variable	1	2	3	4	5
1. Spiritual well-being					
2. Religious well-being	0.90****				
3. Existential well-being	0.92****	0.67****			
4. Sleep quality	$-0.22^{*}$	-0.10	-0.29**		
5. Physical health status	0.41****	0.29**	0.45****	-0.37***	
6. Mental health status	0.27**	0.18	0.31**	-0.22*	0.08

**TABLE 2.** Associations among Spiritual Well-Being, Sleep Quality, and Health Status

in the lowest quartile of physical and mental health status compared to the general U.S. population (Ware et al., 1998). Physical health status was significantly related to total spiritual well-being (r=0.41, p=0.0001), religious well-being (r=.29, p<.01), and existential well-being (r=0.45, p<.0001). Mental health status significantly correlated with total spiritual well-being and (r=0.27, p=0.0082) and existential well-being (r=0.31, p=0.0027). (See Table 2.)

#### **DISCUSSION**

South Carolina ranked seventh in the nation for rates of new HIV/AIDS cases in 2003 (South Carolina Department of Health and Environmental Control; SCDHEC, 2003), and Columbia, SC ranks 14th among major U.S. metropolitan statistical areas (SCDHEC, 2003). We recruited subjects from different clinics in an attempt to gain a representative sample of HIV-infected individuals in South Carolina and we feel we were largely successful. The majority of HIV-infected individuals (78%) in South Carolina are African American (SCDHEC, 2003). In our sample 83% of the subjects were African American, which is close to the demographic makeup of HIV infections in South Carolina. Among HIV-infected African Americans, 89% were between 20 and 50 years of age (SCDHEC, 2003).

The Spiritual Well-Being Scale has been used previously in HIV-infected individuals, and it has been found that HIV/AIDS patients show lower levels of spiritual well-being than cancer patients (Pace & Stables, 1997). The difference in spiritual well-being between that sample of HIV-infected individuals and our own sample may be due to racial differences in spiritual perspective. The sample in the Pace and Stables study was composed mainly of Caucasians, while our sample was mainly African American. The higher spiritual well-being values for

<sup>\*\*\*\*</sup> p < .0001; \*\*\* p < .001; \*\* p < .01; \* p < .05.

this population may be due to the higher level of spirituality in general among African Americans (Coleman & Holzemer, 1999).

The PSQI has been used to examine sleep quality in HIV-infected individuals. A score of five or greater on the PSQI indicates severe sleep disturbance. The range of PSQI scores for this sample was 5–20, indicating that every subject in this study (100%) experienced significant sleep disturbance. Rubinstein and Selwyn (1998) reported sleep disturbance in 73% of HIV-infected subjects. The majority of their subjects were Caucasian (56%) and the sample was taken in the Northeastern United States compared to our predominantly African American sample in the Southeastern United States. The subjects in this study had low health scores according to the SF-12. These results are similar to those found in two studies by Delate and Coons (2000, 2001) using both the MOS-HIV (Medical Outcomes Study-HIV) and the SF-12 to assess health status in HIV-infected individuals. Our results support their findings that HIV-infected individuals have lower health related quality of life scores than the general US population.

Sleep quality was significantly related to total spiritual well-being and existential well-being, but not to religious well-being. Total spiritual well-being was significantly correlated with physical and mental health status as measured by the SF-12. A significant correlation was found between physical health status and religious well-being, but this was not the case for mental health status. Mansfield, Mitchell, and King (2002) reported that African Americans in the Southeastern United States had stronger religious feelings than Caucasians in the same area. These results may represent a ceiling effect where the higher baseline religiousness in our mostly African American population may have resulted in an inflated spiritual well-being score. The mean for religious well-being in this sample was very high, less than one standard deviation below the highest possible score, indicating a considerable amount of religiosity. In samples of highly religious individuals, high religious well-being scores artificially limit the range of possible scores. This artificial limit of the religious well-being scores does not allow certain samples to score as high as they could if the scale measured the full range of spiritual wellbeing. Since this sample was possibly limited in how high it could score, variability in the sample also is restricted.

#### **CLINICAL IMPLICATIONS**

Due to the physically damaging nature of HIV disease, many facets of an individual's health that are not customarily assessed during patient care visits are assessed, including stress levels, coping, concerns about the meaning and purpose of life, energy levels, and role fulfillment. Additional assessments and interventions are important in holistically treating the HIV patient.

As with all patients afflicted with chronic and potentially fatal diseases, nurses need to actively promote improved health status through a variety of interventions. Although the hope for a cure or the halting of progression of the disease is often foremost in the patient's mind, nurses must consider all factors that can affect the individual's daily life and prognosis. Spirituality has long been recognized as a resource that can improve physiologic and psychological factors for patients with chronic illness.

Clinicians often are uncomfortable discussing spirituality with their patients, yet the assessment may begin by simply asking the patient if they attend religious services. Patients may need to be reminded to resume their traditional religious activities or to seek out new connections with established spiritual resources. Religious services can be a resource for individuals in many ways by providing social support, structure and stability, meaning and purpose in life, and an outlet for spiritual expression.

Individuals also may need to be supported in their existential awareness and concerns in order to maximize their health. This may simply mean encouraging patients to start or continue volunteer work that they have done in the past. Participating in research studies, helping out at a service organization, or contributing to a food drive are all activities that support having a purpose in life and self-transcendence, and could improve existential spiritual well-being. Creative activities can improve an individual's existential well-being: The nurse might suggest keeping a journal, writing a poem, drawing, or gardening, as ways of tapping into creative energies. Creative activities such as these may even help a person find purpose and meaning in life and help with an individual's need to create a legacy. In conclusion, a wide range of physical, mental, and psychosocial factors influence quality of life in HIV-infected individuals. Additional studies are needed to elucidate the relationship between spirituality and health in this and other clinical populations.

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