Aspects of Spirituality in Persons Living With HIV/AIDS

by

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To the faculty of Washington State University:

The members of the committee appointed to examine the ICN research requirements and manuscript of Leanne M. Zilar find it satisfactory and recommend that it be accepted.

Chair

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DEDICATION

This manuscript is dedicated to my father, Lee E. Smith, January 5, 1916 to November 6, 2000 and my mother, W. Jean Smith, February 20, 1925 to October 20, 2000. You were right, I can have it ALL!

To all my clients and friends with HIV/AIDS, without you, none of this would have come into being.
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ABSTRACT

Holistic care addresses the physical, emotional, psychological and spiritual dimensions of the client. Frequently, the spiritual dimension is over looked by healthcare providers. This article presents a comprehensive overview of current research regarding spirituality and HIV/AIDS.

Fourteen qualitative articles were reviewed. Four core concepts emerged a) finding meaning and purpose in life b) hope c) spirituality or relationship with a higher power and d) positive thinking and caring for one’s self. Five quantitative studies were reviewed. The major theme that emerged was spiritual and existential well being as a positive relationship to physical, psychological, and emotional well being.

A deeper understanding of spirituality enhances the potential for healthcare providers to identify spiritual needs and incorporate spiritual caring into practice. Assessment and interventions for spiritual exploration are suggested for healthcare professionals, emphasizing the spiritual needs of people with HIV/AIDS.
Introduction

The human immunodeficiency virus (HIV) is a ribonucleic acid (RNA) retrovirus which infects the lymphocyte helper-T cell (CD4+) of the host’s immune system.

Eventually, the proliferation of the virus undermines the host’s immune system which becomes compromised enough that opportunistic infections begin to take a toll on the body, leading to multi-system organ failure and death. Acquired immunodeficiency syndrome (AIDS) is a syndrome, not a disease, which means that the virus can express itself in many ways. No one symptom typifies either HIV infection or AIDS (Copstead & Banasik, 2000). The Centers for Disease Control and Prevention (CDC) has been reporting AIDS since 1981. The definition of AIDS has changed several times, but the devastating effects are the same.

As of December 2000, 774,467 Americans have been reported with AIDS. (Centers for Disease Control and Prevention [CDC], 2001). New treatments have slowed the progression from HIV to AIDS to death for people infected with HIV. In 1996, estimated AIDS incidence dropped for the first time, declining 6%. Deaths among people with AIDS also declined for the first time in 1996, dropping 25% (CDC, 2001). However, these statistics can be misleading, since many states are not currently reporting HIV positive status. Estimates suggest that 800,000 to 900,000 Americans are now living with HIV, and at least 40,000 new infections occur each year. (CDC, 2001). These statistics suggest that HIV infected people may be living longer lives, and HIV may be moving from the terminal illness status to chronic illness. However, the healthcare professionals who are providing care for these individuals cannot ignore the devastating effects on the human spirit.
The purpose of this article is to present an overview of current research on aspects of spirituality in people living with HIV/AIDS.

Theoretical Framework: Spirituality Defined

One of the problems hindering healthcare personnel to assess and intervene in the spiritual dimension of the client is a lack of a concise definition of what spirituality encompasses. In contrast to religion, spirituality is not concerned with a specific system of belief. Spirituality, rather, is concerned with finding meaning in this life, with finding a sense of connectedness to others and to the rest of the universe and a belief in a higher power. Wilt and Smucker (2001) state, “Spirituality is the recognition or experience of a dimension of life that is invisible, and both within us yet beyond our material world, providing a sense of connectedness and interrelatedness with the universe” (p. 4). Several theorists in the field of psychology and nursing have pioneered the idea that spirituality is an essential part of overall wellness and have introduced spirituality into a holistic paradigm of nursing.

Frankl (1962) spent many years in the concentration camps of Germany during World War II. His entire family, except for a sister, died in these camps and all of his possessions were taken from him. Out of these experiences, he developed his essential definition of spirituality:

To live is to suffer, to survive is to find meaning in the suffering. If there is a purpose in life at all, there must be a purpose in suffering and in dying. But no man can tell another what this purpose is. Each must find out for himself, and must accept the responsibility that his answer prescribes. If he succeeds he will continue to grow in spite of all indignities (Frankl, 1962, p. xi).
Therefore, each person must find his or her own meaning in life, what makes his or her life worth living, no matter what the obstacles. Even though people must discover these truths for themselves, clients in a healthcare setting may want and need help exploring their spirituality and how it affects their health status and quality of life.

Parse, a nurse theorist, has developed the “Human Becoming Theory” (Parse, 1987) in which spirituality is an integral part of health with three basic dimensions:

1. “Illuminating meaning involves shedding light through the uncovering of what was, and will be, as it is appearing now.” (p. 168)

2. “Synchronizing rhythms happens in dwelling with the pitch, yaw, and roll of interhuman cadence- the turning, spinning, and thrusting of human relationships. Pitch, yaw, and roll represent the ups and downs, the struggles, the moments of joy, the unevenness of day-to-day living.” (p. 168)

3. “Mobilizing transcendence happens through moving beyond the meaning moment to what is not yet. It focuses on dreaming of the possibles and planning to reach for the dreams.” (p. 169)

During physical health challenges, clients may be uncovering the changes in their health through grieving, loss, joy, or newfound meaning in their life. Overcoming the present moment of disability or pain may bring new dimensions of strength in spirit, which the client never knew existed. This discovering of spirit may be assessed and integrated into the holistic picture of client health.

Spirituality encompasses hope; faith; self-transcendence; a will or desire to live; the identification of meaning, purpose, and fulfillment in life; the recognition of mortality; a relationship with a ‘higher power,’ ‘higher being,’ or ‘ultimate’; and
the maintenance of interpersonal and intrapersonal relationships. (Relf, 1997, p. 2).

In each of these contexts, the person must find their own meaning in life, the definition of spirituality that he or she finds meaningful. Healthcare personnel are in a unique position to facilitate this personal process of defining spirituality and assessing the need for spiritual guidance or interaction. Recommendations for appropriate individual interventions can then be made through the wellness-illness continuum.

Review of Literature: Spirituality and HIV

Quantitative Studies

"Those who know how close the connection is between the state of mind of a man—his courage and hope, or lack of them—and the state of immunity of his body will understand that the sudden loss of hope and courage can have a deadly effect" (Frankl, 1962, p. 75). This becomes especially important with clients living with HIV/AIDS, as we are just beginning to document the quantitative results, on the effects of spirituality and the immune system.

In a study of one hundred HIV+ clients, done by Carson and Green (1992) spiritual well being (SWB) and hardiness in HIV positive patients was assessed. This study was specifically based on Viktor Frankl’s theories. The spiritual well being scale used in this study measures both the existential and the religious aspects of meaning. The scale defines SWB as the affirmation of life in a relationship with God, self, community and environment that nurtures and celebrates wholeness. Hardiness was defined as follows:

Hardiness is a personality characteristic touted by Kobasa (1979) as a resource in resisting the negative effects of stress, thus decreasing the incidence and severity
of stress related illnesses. Hardiness is a composite measure composed of the	hree subdimensions of commitment, challenge and control. (p. 211)
The two hypotheses were: (a) persons who are either HIV positive or who have
diagnoses of ARC (AIDS related complex, which is no longer used) or AIDS have a
positive relationship between SWB and hardiness, and (b) persons who are either HIV
positive or who have a diagnosis of ARC or AIDS have a positive relationship between
existential well being (EWB) and hardiness. EWB was part of the SWB scale and was
never defined. This was a quantitative, correlational study in which each participant
completed the Spiritual Well Being Scale, the Personal Views Survey, and the
Demographic Data Survey. The study determined the extent to which variation in SWB
and selected demographic variables are associated with variation in the construct of
hardiness. Both hypotheses were upheld in this study, and were significant at the .001
level. A limitation of this study was inclusion of primarily gay men in the Baltimore, MD
area, with no other populations being represented.
Somlai et al., (1996) conducted a correlational study with 65 HIV positive
participants and a comparison group of 27 participants who were demographically
similar, but were HIV negative. The purpose of this study was to evaluate levels of
psychological distress, coping mechanisms, and the relationship with religious or spiritual
practices and persons living with HIV/AIDS. Five spiritual dimensions (formal religion,
spiritual beliefs, punishment, alternative practices, and prayer practices) were compared
to the participants’ HIV diagnoses. Three specific questions were addressed: (a) Can the
religious and spiritual needs of people living with HIV/AIDS be operationalized and
measured, (b) what is the relationship between religious and spiritual practices and more
traditional indices of emotional distress and coping, and (c) are there differences in the spirituality dimensions between HIV positive individuals and HIV negative individuals?

Each participant was administered a 21-item spirituality and religion survey. They were also administered the Beck Depression Inventory, the University of California Los Angeles Loneliness Scale, the State-Trait Anxiety Scale, and the Suicide Scale. “Our results indicate a strong relationship between spiritual dimensions and indices of mental health, psychological adjustments, and coping among persons with HIV infection and AIDS” (Somlai et al., 1996, p. 189). The most significant results were that HIV positive Christians (n=25) were more likely than HIV positive non-Christians (n=30) to believe that AIDS was some form of “divine retribution” (p. 187) (Christian > 0.6 correlation to punishment and non-Christian < -0.4 correlation to punishment). Further, HIV positive Christians had significant, positive correlation to all five areas measured (prayer practices p<.01, alternative practices p<.05, formal religions p<.01, spiritual beliefs p<.01, and punishment p<.01). Limitations of the study include the following: 87% of the participants in the study were gay men and an unreported number of the HIV positive participants were asymptomatic (different spiritual needs and issues may be faced at different points in the HIV illness spectrum).

In a related quantitative study, Riley, et al., (1998) looked at spirituality and persons with chronic illness. A convenience sample of 216 inpatients, from a midwestern medical center, were described by disease, demographic characteristics, and employment status.

The purpose of this study was to identify various types of spiritual well being among persons with physical limitations, and chronic illness, and to determine the
relationship between spiritual well being, physical health, and quality of life. Using the Functional Assessment of Cancer Therapies – Spiritual Well Being (FACT-SP) and the Spiritual Well Being Scale (SWBS), cluster analyses were performed. Cluster analyses were used to develop a spiritual well being classification. Three cluster groups emerged and were then labeled: religious (n = 146) defined as “a direct, personal relationship with god” (p. 260), existential (n = 30) defined as “the perception that life has a purpose apart from any specifically religious reference” (p. 260), and nonspiritual (n = 37). “Items that addressed perceived strength and well being derived from one’s own spiritual faith and items pertaining to the existence of a close, personal relationship with God were most predictive of cluster membership” (p. 261). Analysis of variance was used to compare cluster groups on various dimensions of quality of life. The researchers found that:

Compared with the religious and existential groups, the nonspiritual group reported significantly [p<.03 to p<.001] lower levels of quality of life domains and life satisfaction and the highest proportion of health status change with respect to both improvement and decline in health.” Further, “the existential cluster had the highest levels of vitality and physical, social, emotional, and mental health functioning. In addition, persons in the existential cluster were found to have the lowest incidence of change in health status. (p. 258)

The study was limited by the fact that six different surveys were conducted and most were self-administered. The indication is that the protocol for administration was not standardized. Riley et al. are not clear whether any of the relations were causal or correlational. Further, the researchers do not define spirituality for the purpose of the
research, nor do they attempt to synthesize others’ definitions of spirituality. They simply note four different definitions of spirituality and spiritual well being as proposed by other authors.

Sowell et al., (2000) studied spiritual activities as a resistance resource for 184 HIV positive women. In their quantitative research, spiritual practices were defined as “practices by which an individual operationalizes or expresses his or her spiritual beliefs or connectedness to a Higher Power” (p. 74).

"Using the data collected from the focus groups and open-ended interview questions, the content of the measures were further developed or revised to ensure that they were both culturally and contextually relevant to women with HIV disease” (p. 75).

Demographical information was recorded. Statistical measures of causal variables were designed, resulting in measures for a) spiritual activities, b) functional impairment, c) work impairment, d) HIV symptoms, e) emotional distress, and f) quality of life. Of the 184 women who completed all five interview phases, 176 women completed the study questionnaire.

The finding suggests that spiritual activities acted to protect against emotional distress even in the presence of disease-related stressors [i.e. HIV symptoms, work impairment, and impaired function], providing support for the theorized role of spirituality as a resistance resource in the stress and coping process. (p. 79)

Quality of life was inversely proportional to emotional distress (p ≤ 0.01), as were spiritual activities (p ≤ 0.01). However, the relationship between quality of life and emotional distress had a greater magnitude (-0.508) than the relationship between spiritual activities and emotional distress (-0.212).
The study cannot be generalized to all populations (75% were single, 84% were African American, 69% were residing in urban areas, and 74% had an annual household income of less than $10,000). The researchers' assertion that the test-retest reliability of the study was high ($r=0.67$) is debatable. The researchers suggest this study be seen as a causal study when because no control group was used and no independent variables were manipulated. Lastly, there was no correlation between spiritual activities and impaired function (-0.018), work impairment (0.068) and HIV symptoms (0.055).

In a correlational study of 117 African-American men and women, Coleman and Holzemer (1999) explored the relationships between HIV disease, spiritual well being, and psychological well being by correlating data from six instruments. The six instruments included a sociodemographic questionnaire, the Spiritual Well Being Scale (which breaks down spiritual well being into two components: existential well being and religious well being), the HIV Signs and Symptoms Checklist for Persons with HIV Disease, the Beck Depression Inventory, the Spielberger State-Trait Anxiety Inventory, and the Nowotny Hope Scale. The researchers contended that African-Americans rely on churches as spiritual resources, and therefore they would benefit from increased psychological well being. However, only 45% of the participants attended church on a regular basis. Further, the researchers chose psychological well being as the independent variable (as opposed to symptomatic HIV infection or spiritual well being). Variables were reduced to composite scores by using Statistical Package for the Social Sciences (SPSS) factor analysis.

Results indicated that there were no significant differences between those who were diagnosed with AIDS and those who were not. Existential well being and HIV
symptoms were significantly related to all four components of psychological well being (depression, state anxiety, trait anxiety, and hope). In general, the data suggests an inversely proportional relationship exists between psychological well being and existential well being with symptomatic HIV. The findings were significant at the \( p<.05 \) level. Though the researchers chose psychological well being as the independent variable, it is unclear how the three variables correlate. Is health a predictor of spiritual and/or psychological well being or is psychological well being a predictor of health? The researchers remind the readers that the instruments’ normative sampling data did not include cultural variations. Therefore, generalization to the African-American HIV positive population, would be questionable at best.

Though these five studies do not define spirituality or spiritual well being in the same way, all indicate that not only is spirituality a part of health, but that spiritual well being actually improves quality of life for clients.

**Qualitative Studies**

Thomas and Retsas (1999) examined the spiritual meanings people with terminal cancer give to their everyday lives. The sample included 12 females and 7 males between the ages of 30 and 90. This qualitative, descriptive study consisted of successive iterations of sampling, interviewing, inductive analysis of the data using constant comparative method, and development of grounded theory. After the initial interviews, additional questions were developed to help define the conceptual categories more densely.

"The study was based on an assumption that spiritual matters become more significant and the degree to which people focus on other matters in their life become less
important when they are aware of their approaching death from cancer” (Thomas & Retsas, 1999, p.192). The purpose of the study was to explain how spirituality of people diagnosed with cancer develops as they make sense of their diagnosis. The results indicated that people with terminal cancer develop a spirituality which strengthens them. The authors termed this development of spirituality:

Transacting self-preservation, a process that reflects people’s ways of finding spiritual meaning in their experiences of terminal cancer and show they achieve deeper levels of spirituality during the three phases of this process. These phases incorporate “taking it all in,” “getting on with things” and “putting it all together,” that describe coping strategies people with terminal cancer use to overcome the barriers that hinder the discovery of a meaningful existence when facing death. (p. 192)

The authors indicate the study showed that the search for meaning arises from a person’s need for self-preservation. Further, participants’ spiritual perspectives were deepened, regardless of their beliefs.

The authors’ assumptions were based on their personal and professional experiences. Thus, it is possible that they read into participants’ answers, looking for clues that the participants were, in fact, developing a sense of spirituality. It was not so difficult to do so when the authors’ broad definition of spirituality was based on Thomas’ unpublished master’s thesis (as cited in Thomas & Retsas, 1999):

For the purposes of this paper, spirituality is viewed as an inherent aspect of the individual self incorporating a source of strength developed through a person’s faith in self, others, God and/or another Higher Being. Spirituality reflects an
expanded consciousness beyond a biopsychosocial awareness and gives meaning and purpose to a person's life as they transcend their everyday experiences. (p. 191)

Hermann (2001), in a descriptive study of 19 (10 female and 9 male) hospice patients, found that “participants perceived spirituality as a broad concept that may or may not involve religion” (p. 67). The participants were all from a large outpatient hospice in southeastern United States. Their mean age was 72 and all were terminally ill. Approximately 75% were Caucasian and most were Protestants.

The purpose of this study was to find out dying patients’ definitions of spirituality and their spiritual needs. The interviews were semistructured. Recruitment of participants ended when it became clear that the themes had reached saturation. The two primary questions asked were 1) “What does the word spiritual mean to you personally” and 2) “What needs can you identify related to your spirituality as you described it.”

Hermann found that participants initially related the word spiritual to God or religion, but as each of their interviews progressed, began defining spirituality as a part of their total existence. “Although most people initially equated spirituality with religiosity, the broadness of spirituality became apparent” (p. 71).

The participants yielded 29 unique spiritual needs, which were then grouped into 6 themes: 1) Need for religion (such as praying, going to church, reading the Bible), 2) Need for companionship (such as being with family and friends or talking with others), 3) Need for involvement and control (such as staying as independent as possible, having input into one's own life, and having things in life stay the same), 4) Need to finish business (such as resolving bitter feelings, finishing life tasks, and doing a life review), 5)
Need to experience nature (such as being outside or having flowers in the room), and 6) Need for a positive outlook (such as seeing others smile, laughing, and thinking happy thoughts).

A qualitative, phenomenological, study done by Hall (1998), used an interpretive interactionistic format to describe the structures of spirituality people have when in advanced stages of AIDS. A total of 5 men and 5 women, all of whom had advanced stage AIDS, participated in the study. All 10 were interviewed with questions such as “What is going on in your life right now, as you deal with HIV,” and “describe in detail any spiritual experiences and beliefs that have helped you deal with HIV.” The responses were then bracketed and contextualized using a hermeneutic format. Three major themes were found: (a) purpose in life emerges from stigmatization, (b) opportunities for meaning arise from a disease without a cure, and (c) after suffering, spirituality frames the life. Hall (1998) states:

These data suggest that the spirit can frame the interpretation of the state of the body and mind. Pain or fear can create a signal from the organism of both heightened and diminished spiritual awareness, and can act as an impetus for spiritual meanings to emerge that will explain the suffering. (p. 152)

Researcher bias may have been present; Hall was a cancer survivor and states, “Often what rang true for the participants rang true for me. I had to be careful not to harden the themes before I examined whose life they were describing: mine, the participants’ or both” (p. 147). Hall’s study is an example of how physical health may affect spirituality, showing that the two dimensions go hand in hand and are not mutually exclusive.
In a qualitative, descriptive study, Guillory, Sowell, Moneyham, and Seals (1997) explored the meaning and use of spirituality in women infected with HIV. Forty-five women (12 white women and 33 black women) were part of a focus group study which served as formative research concerning the impact of HIV on individual and family functioning. Participants were recruited from 5 urban and 3 rural service organizations. The geographic locations were not reported.

The following questions were addressed: (a) What does the term “spirituality” mean to you, (b) do you believe in a supreme being, and (c) how important is spirituality in your life? Content analysis was used and data was categorized and coded. Revisions were made until 100% agreement among the researchers was achieved. A total of six themes were revealed in the analysis: (a) relationship with a supreme being, (b) prayer and meditation, (c) peace, (d) love, (e) healing, and (f) religiosity. In this study, all but 3 of the participants identified themselves as Christian. Because of the relatively small sampling, the use of a focus group format, the qualitative nature of the study, and the fact that nearly all the participants were Christian women, this study is not generalizable.

Somlai, Heckman, Hackl, Morgan, and Welsh (1998) investigated religious and spiritual factors and coping strategies employed by ten women living with HIV disease. Intensive semi-structured interviews were conducted with a series of open-ended probe questions, in an ethnographic approach. This was designed to elicit a narrative to explore the developmental life histories of HIV positive women and how spiritual practices and religion were used as elements of the coping process. The findings showed that “The development of a personal spirituality based on intercessory prayer is an important coping
strategy to overcome the stressors of isolation, a potentially shortened life, and inability to provide life-long child caretaking” (p. 239).

In three case illustrations from a naturalistic study of 13 participants, Kendall et al., (1989) found that each participant “Sought understanding of what having AIDS meant to them, which led to a reconnection to themselves and to a new perspective on the meaning of their lives” (p. 163). A 2-year qualitative investigation generated an understanding of doing well with AIDS. The specific research question addressed was, “what are the subjective experiences of people with AIDS who view themselves as doing well?” The design consisted of three elements: purposive sampling, intensive interviewing, and inductive analysis of interview data. Five themes emerged which included (a) autonomy, (b) spiritual/ existential beliefs, (c) self acceptance, (d) stay active and involved, and (e) positive thinking. Limitations include only describing three case illustrations. More research is needed to generate mid-range theories concerning wellness and AIDS.

Coward (1994) in an exploratory study used a phenomenological research approach to investigate the structure of self-transcendence in 10 men and 10 women with AIDS. “Self-transcendence was defined for the participants as an experience during which one reached outward beyond personal concern or inward toward increased understanding, the outcome of which was feelings of increased connectedness with others, increased self-esteem and well being, and increased purpose and meaning in life” (p. 332). Participants were then asked to describe transcendent situations. Eight themes were developed for the women (experiencing fear and aloneness, experiencing uncertainty, using others as role models, finding inner strength, reaching out, having
purpose/making a difference, viewing AIDS as an opportunity, and having hope), and
nine themes for the men (experiencing fear, taking care of themselves, seeking out
challenge, creating a legacy, accepting that which cannot be changed, connecting with
others, letting go, accepting help, and having hope).

All of the participants, although they expressed feelings of fear and sadness
associated with having AIDS, described experiences of increased self
understanding and increased connectedness to others that helped them find
meaning and a sense of mental well being within the context of their illness (p.
335).

Further research is needed to describe positive psychosocial experiences earlier in
the HIV disease trajectory which might uncover ways in which self-transcendence views
and behaviors may be fostered in earlier stages of disease.

In a study of long-term progressors, Barroso (1999) found that spirituality was one
of the five recurring themes. This was an ethnographic study using a naturalistic field
design. Ethnographic interviewing techniques were employed. All twenty-five
participants were required to be over 18 years old, English-speaking, diagnosed with HIV
for at least 7 years, have a CD4 count of at least 500, and be free from opportunistic
diseases and/or AIDS-defining illnesses. The interviews began with the question, “what
have you done to become a long-term nonprogressor with HIV disease?” The themes
found by Barroso were (in order of descending frequency) taking care of my physical
health, viewing HIV as a manageable illness, human connectedness, taking care of my
emotional/mental health, and spirituality. Spirituality was manifested in two ways: A
belief in a protective higher power and a surrender to a higher power. A limitation of the
study is that Barroso used self-reported CD4+ counts, which participants may have erroneously reported.

Kendall (1994) examined wellness in a grounded theory study on the role of human relationships of 29 gay men with HIV infection. Demographics indicated that the sampling was primarily well-educated white males. This qualitative, descriptive study consisted of successive iterations of sampling, interviewing, inductive analysis of the data using constant comparative method, and development of grounded theory. The research focused on two main questions: (a) What are the factors involved in the process of doing well with HIV infection and (b) how does human relationship influence well being? After the initial interviews, additional questions were developed to help define the conceptual categories more densely. The follow-up interviews were conducted with 15 of the original participants. Demographics of these 15 participants were not given. Data analysis was iterative at the time of data collection. Through a process of constant analysis of the data, codes and categories were progressively refined until conceptual saturation had been reached. The results indicated that spirituality played an important role in the well being of the participants. Quotes from the participants gave further evidence that they were highly educated. It may be that the participants’ level of education was an important factor in their spiritual well being.

Though Kendall attempted to reduce researcher bias, her admission that “the majority of the data analysis was by the primary investigator” (p. 30) shows that the study may have bias limitations. Interestingly, Kendall suggests that this study confirms other findings. As it turns out, some of the “other findings” include three of her own earlier studies.
Barroso (1997a) used ethnographic interviewing techniques in a naturalistic study to report the ways of becoming a long-term survivor of AIDS as perceived by the participants. There were 6 women and 14 men in the study. Content analysis and the techniques of constant comparison were used to analyze the transcripts. The results were then grouped in clusters. The clusters were then formed into categories, or dimensions: 1) Normalizing, 2) Focusing on living, 3) Taking care of oneself, 4) Being in relation to others, and 5) Triumphing. The conclusion was that participants first saw AIDS as a threat, then as a challenge. This enabled participants to reframe their experience into something they could live with instead of dying.

Conclusions further state that in normalizing illness, participants were able to deal positively with AIDS. The dimension of taking care of oneself served to give them a sense of control within the context of uncertainty of the disease. In regards to the dimension of being in relation to others, this study had a broad perspective of the concept, expanding it to include the participant’s relationship with a higher power. The higher power, as perceived by the participants, was a nurturing entity which contributed to positive outcomes in experiencing their illness. According to Barroso, the cognitive reframing (i.e., of first seeing AIDS as a threat and then as a challenge) enabled participants to take a negative situation and change their meaning into a positive one.

Barroso says that redundancy began occurring “after about 12 participants” (p. 60). Although a variety of individuals were used in this study, a wider group of ethnic backgrounds and socioeconomic groups should be replicated. In addition, continued study on long-term survivors of other terminal illnesses should be conducted to see if they have similar experiences and outcomes.
Several comments made by Barroso appear unfounded. Two of the twenty participants were African-American. She states, “this is probably a fairly accurate representation of their proportions among long-term survivors of AIDS.” (p. 60) She later discusses transferability. Instead of addressing it in the traditional research model (i.e. this research is not generalizable due to the small number of participants, etc.), she implies that the research is generalizable because she has given several presentations about this research and has been told by several audience members that they agree with her findings.

Lakomy (1994) did a phenomenological study including 10 men; 4 clients were diagnosed as HIV positive, and 6 clients were diagnosed with AIDS. The research question for this study was: What are the healing rituals experienced by persons living with HIV-related infections? Phenomenological analysis was used, as well as Ethnograph software program to assist with data manipulation tasks. The six formulated experiences of healing rituals in persons with HIV included:

a) Positive philosophical outlook on life,

b) Involvement with caring, spiritual environments and places,

c) Experience of the caring process,

d) Activation of the self healer within the person,

e) Engagement in a variety of healing therapies, and

f) Reliving the memories of the dying process from persons who had lived with AIDS. (p. 246)

The study was limited to 10 English speaking men between the ages of 28 and 55, in one community based center, with no further description offered.
Hudson and Morris (1994) ethnographically studied the perceptions of support systems of 5 people diagnosed with AIDS. All 5 were African-American; 1 female and 4 males. Three subjects had completed high school, 2 had 2-years of college. All of the participants made less than $20,000 per year. Participants were interviewed and the data was analyzed using constant comparative analysis. Seven themes emerged: independence and control over one’s environment, support from significant others, keeping a positive attitude, spirituality, lack of family support, appreciation of case management, and avoidance of support groups. The researchers found that the strongest support relationships were with friends, significant others, and nursing care managers. Family relationships were tenuous and relationships with church were stressful. Though all participants shunned regular church attendance, they still sought spirituality outside traditional paths. The researchers were surprised to find participants avoiding church: “It was not consistent with published reports that religion is the sustaining force within the lives of many African-Americans” (Hudson & Morris, 1994. p. 45). This study was limited to just 5 African-Americans, thus, generalization to other populations cannot be done. Also, the researchers seem to have associated religion or formal church attendance with spirituality. The underlying question, the researchers focused on was, “Since spirituality was a strong part of the participants’ lives, why were they avoiding church?” As stated earlier in this paper, in contrast to religion, spirituality is not concerned with a specific system of belief. In fact, spirituality does not necessarily build around God or the belief that there is a god. Rather, spirituality is concerned with finding meaning in this life, with finding a sense of connectedness to others and to the rest of the universe. It appears that the participants in this study do not equate religion and spirituality.
Dunbar, Mueller, Medina, and Wolf (1998) did a qualitative, ethnographic, study with 34 women, living with various stages of HIV. The women ranged in age from 26 to 53. Twenty-five of the women were mothers, and one-third had known their HIV status for more than 5 years. The ethnic composition of the participants was diverse. Interviews were semi-structured, consisting of open-ended questions followed by prompts to elicit further information or clarifications. The verbatim responses were recorded and organized into a text management program (AskSam for Windows, 1994). Five themes emerged: (a) reckoning with death, (b) life affirmations, (c) creation of meaning, “To live fully in recognition of death, some women spoke of finding new meaning in life” (p. 148), (d) self-affirmation, and (e) redefining relationships. “Our findings suggest that many and probably most women living with HIV can describe positive psychological and spiritual growth, consistent with the five themes described in this article” (p. 151). This is a snapshot of the lives of 34 women living in various stages of HIV disease. A longitudinal study designed to detect important social, psychological, and spiritual changes would be a valuable addition to this work.

In a qualitative, ethnographic study, Fryback and Reinert (1999) interviewed a convenience sample of 10 women with cancer and 5 men with HIV/AIDS. Content analysis was done throughout data collection and interview questions were refined. The three emerging categories were: belief in a higher power, recognition of mortality, and self-actualization. The researchers contend that all three are evidence of spiritual health. With regard to belief in a higher power, three sub-categories emerged: church attendance/religion, spiritual beliefs, and transcendence. One participant expressed anger at God. Three participants expressed distrust of organized religion. Ten mentioned
church attendance or the desire to attend church. Two stated they did not attend church. Church attendance, however, was not necessarily the participants’ definition of spirituality:

- Despite their negative experiences with the people in organized religions, the study subjects did not abandon their search for a spiritual connection. They discovered spirituality was not dependent on a particular religion or church.
- They found strength in their spirituality that they felt made them healthier. (p. 16)

Evidence existed of a better quality of life after diagnosis, rather than before diagnosis. Participants found meaning and purpose in their diagnosis. They improved themselves, became closer to a higher power, helped others with the same disease, formed closer relationships, and changed their life goals. Two participants said that without the disease, it would have taken them until they were in their 70’s to gain the same amount of self knowledge, that they gained because of the disease. Participants expressed issues related to beliefs, a high power, religion, and spirituality. Examples of this include self-love, living in the moment, appreciation of nature, and appreciation of life. Though there were many similarities between participants, one limitation which seemed to stand out was the apparent differences between males and females. The researchers never addressed this issue, possibly because there were so few participants or because it simply was not the question they were answering. It is unclear whether the differences in participants’ comments were sexual orientation related, gender related, or disease related.
Literature Critique

In general, the review of literature shows that the phenomenon of interest was clearly stated, in terms of development of what spirituality means to persons living with HIV/AIDS (Coleman & Holzemer, 1999; Dunbar et al., 1998; Guillory et al., 1998; Hall, 1998; Kendall et al., 1989; O'Neill & Kenney, 1998; Riley et al., 1998; Somlai et al., 1996, 1998). This type of research demands a qualitative approach, because little is known about spirituality and HIV. In many of the research articles, the philosophical underpinnings or theoretical framework is related to Viktor Frankl's (1962) work of finding meaning in life from suffering.

The purpose of these qualitative research articles was to find out more about people's experience of spirituality, phenomenologically (Coward, 1994; Hall, 1998; Kendall et al., 1989; Lakomy, 1994), ethnographically (Barroso, 1997a, 1997b, 1999; Dunbar et al., 1998; Fryback & Reinert, 1999; Hudson & Morris, 1994; Somlai et al., 1998), and the process the participants go through in the grounded theory studies (Kendall, 1994). There are many references in these research articles to the significance of research regarding spirituality to nursing (Barroso, 1997a, 1997b, 1999; Carson & Green, 1992; Clark & Heidenreich, 1995; Coleman & Holzemer, 1999; Coward, 1994; Dunbar et al., 1998; Fryback & Reinert, 1999; Guillory et al., 1997; Harrison, 1997; Hudson & Morris, 1994; Kendall, 1996; Kendall et al., 1989; Lakomy, 1994; O'Neill & Kenny, 1998; Peri, 1995; Relf, 1997; Riley et al., 1998; Somlai et al., 1996, 1997). This includes the recommendation that providers should have a better understanding of what the client is going through in their disease process with regards to spirituality. "Nurses need to engage people with HIV disease, either individually or in groups, in ways that
foster human connection." (Kendall, 1996, p. 202) Spiritual assessments of clients (Coleman & Holzemer, 1999; Harrison, 1997; Kendall, 1994; Kendall et al., 1989; Riley et al., 1998) and interventions are referenced in many of the articles (Barroso, 1997a, 1997b; Carson & Green, 1992; Clark & Heidenrich, 1995; Coleman & Holzemer, 1999; Fryback & Reinert, 1999; Lakomy, 1994; O’Neill & Kenny, 1998; Peri, 1995) as significant recommendations for nurses and practitioners.

Many of the qualitative articles reviewed are descriptive in nature only, sometimes because much is yet unknown about the phenomenon of spirituality and HIV. Of the articles reviewed, there are fewer ethnographic and phenomenological studies, and even fewer grounded theory methodology studies. Lastly, there were only a handful of quantitative studies (Carson & Green, 1992; Coleman & Holzemer, 1999; Riley et al., 1998; Somlai et al., 1996; Sowell et al., 2000) to measure aspects of spirituality.

As more is known and theory is built, this author believes there will be more qualitative work done. At this point in time, descriptive research regarding spirituality and its connection to well being in persons with HIV/AIDS is building a base to go forward.

As is typical of qualitative research, most sample sizes were small and purposive (Barroso, 1999; Fryback & Reinert, 1999; Hall, 1998; Hudson & Morris, 1994; Kendall et al., 1989; Lakomy, 1994; Somlai et al., 1998). More research needs to be done, with more diverse populations, in different settings, with different cultures and with larger sample sizes. This would give a richer description of the aspects of spirituality in people living with HIV/AIDS.
Every article described data collection strategies. Protection of human participants is addressed (Barroso, 1999; Carson & Green, 1992; Dunbar et al., 1998; Guillory et al., 1997; Riley et al., 1998; Somlai et al., 1998). Only one study discussed data saturation: “Once no new categories were generated from the open codes and the remaining gaps in the emerging theory were filled, conceptual saturation had been reached” (Kendall, 1994, p.29). Open-ended and/or semi-structured interviews were commonly used (Barroso, 1999; Dunbar et al., 1998; Guillory et al., 1997; Kendall, 1996) as evidenced by “What does the term spirituality mean to you?” (Guillory et al., 1997, p.57), “What has been your experience of doing well with AIDS?” (Kendall et al., 1989, p.160), “What have you done to become a long-term nonprogressor with HIV disease?” (Barroso, 1999, p.244), “Was there any event during your hospitalization that contributed to your sense of well being or provided hope? (Clark & Heidenreich, 1995, p.79).

Data analysis was discussed and demonstrated in the literature review section of this paper. In many of the studies, participants were asked to review the data for accuracy to increase the credibility of the study (Barroso, 1999; Dunbar et al., 1998; Fryback & Reinert, 1999; Guillory et al., 1997; Hall, 1998; Kendall, 1994; Lakomy, 1994). The use of themes and core concepts helped the reader follow the researchers’ thinking.

Correlations and Differences

In the quantitative studies (Carson & Green, 1992; Coleman & Holzemer, 1999; Riley et al., 1998; Somlai et al., 1996; Sowell et al., 2000) the major theme that emerged was spiritual and existential well being, as a positive relationship to physical, psychological, and emotional well being. Thus, a patient’s strong spirituality correlates positively to his or her perception of his or her disease, i.e., spiritual people feel better.
In the review of qualitative studies, four core concepts emerged: a) finding meaning and purpose in life (Barroso, 1997a and b; Coward, 1994; Dunbar et al., 1998; Fryback & Reinert, 1999; Hall, 1998), b) hope (Coward, 1994; Dunbar et al., 1998 Lakomy, 1994), c) spirituality or relationship with a higher power (Barroso, 1999; Dunbar et al., 1998; Guillory et al., 1997; Hall, 1998; Hudson & Morris, 1994; Kendall et al., 1989; Lakomy, 1994; Somlai et al., 1998), and d) positive thinking and caring for one's self (Barroso, 1997a 1997 b, 1999; Coward, 1994; Hudson & Morris, 1994; Kendall et al., 1989; Lakomy, 1994). These four core concepts were well described in the clients' own words, over and over again, in the in-depth, open-ended interviews and correlated well with Relf's (1997) definition of spirituality.

Spirituality includes finding meaning in this life and in feeling a sense of connectedness to others and to the universe, and the belief in a higher power. It becomes visible that the qualitative studies are comparable to this author's description of spirituality, as well as, Frankl's "finding meaning,"; Parse' "illuminating meaning,"; Relf's "identification of meaning and relationship with a higher power."; and Wilt and Smucker's "connectedness and interconnectedness with the universe."

In the quantitative studies, it appeared as if spirituality positively affected clients' health, slowing the progression and or severity of HIV disease as perceived by the clients. (Carson & Green, 1992; Coleman & Holzemer, 1999; Riley et al., 1998; Somlai et al., 1996; Sowell et al., 2000). Though the quantitative studies did not go so far as to say there was a causal relationship between spirituality and HIV/AIDS progression, the implications were clearly present:
The finding that Spiritual Well Being and, specifically, Existential Well Being are predictive of hardiness is also consistent with the writings of Bernard Gavzer (1988) and the experiences of William Calderon (Bolen, 1985). Gavzer interviewed long-term survivors of AIDS and discovered that these individuals attributed their hardiness to spiritual renewal. William Calderon experienced a similar renewal with a subsequent reversal of the Kaposi’s sarcoma lesions that covered his body. (Carson & Green, 1992, p. 217)

However, in many of the qualitative studies, the converse seemed to be described, that HIV/AIDS had given clients a new, more powerful spirituality. “Spiritually, they now believed that God permitted their infection for a reason. For these women, HIV infection was very beneficial in assisting spiritual issues to surface” (Somlai et al., 1998, p.237). Many clients described their disease as a blessing. “For many, their lives before they contracted HIV were shallow and lacked meaning, and having AIDS changed that.” (Barroso, 1997a, p.68) “When asked whether they had discovered any unexpected positive outcomes in the face of this very serious illness, 28 of the 34 women (82%) answered in the affirmative. (Dunbar et al., 1998, p.147).

Participants lived out their spirituality in sundry ways. There were a few conflicting results regarding involvement in an organized religion. “Some participants reported using the church as a bridge to spirituality, whereas others felt that the church had failed them.” (Guillory et al., 1997, p. 59). Support group involvement was another area of diversity. “Some of the participants got a great deal of assistance from support groups” (Barroso, 1997b, p.561). “Subjects in this study did not use support groups” (Hudson & Morris, 1994, p. 43).
Recommendations for Practice

Spiritual Assessment

How then do we as healthcare personnel begin to accurately assess the client’s spirituality? For many providers this may seem out of context to practice, an area better suited to the clergy or client’s personal life outside of the healthcare setting. However, a more holistic approach would include a spiritual assessment as part of the standard, just as psychosocial assessments are included with physical assessments.

Spirituality is a mechanism for finding meaning, meaning in life and meaning in death. The patient may be struggling with finding meaning in a diagnosis such as HIV or AIDS. Spirituality is a mechanism for feeling connected. The patient newly diagnosed with HIV or AIDS may feel isolated, alone or lonely. He or she may have a sense of shame and might become reclusive. Somlai et al., (1998) found that the women in their study often used poor coping strategies such as isolation and withdrawal. It becomes the practitioner’s responsibility to assess the patient’s spirituality, in order to help the patient find meaning and feel connected.

According to Parse (1995) “the nurse bears witness, in true presence, to the lived experience of the person—the coherent whole of the person’s life experience as it is appearing and evolving in the moment” (p. 120). In contrast to traditional practice, Parse advocates the client becomes the expert on their condition, instead of the provider. The provider is there to facilitate the unfolding of the client’s meaning of life, as they see it. Therefore the assessment is done informally, without a questionnaire or protocol. By being present and really listening to the client, we can reflect on their spirituality, as they define it.
Riley et al., (1998, p. 263) states “professionals may serve an important role in improving the quality of life of patients by helping them identify ways their lives can be meaningful and purposeful.” This approach may be initiated by asking the client to tell their story, describe what is meaningful and important in their life. The provider might ask what goals or dreams the client has in life.

A more directed approach might be to ask the client, “is religion or spirituality important to you?” or “would you like me to address your religious or spiritual beliefs with you?” Asking the client, if prayer is a part of their spirituality may be indicated, or asking the family, if prayer is important to the client’s sense of well being might be appropriate. Referring to their research participants, Somlai et al., (1998, p. 239) state:

The development of a personal spirituality based on intercessory prayer is an important coping strategy to overcome the stressors of isolation, a potentially shortened life, and inability to provide life-long child caretaking.

In accordance with Frankl’s definition of spirituality (1962, p. xi), Coleman and Holzemer (1999, p. 47) give several suggestions for assessment of spirit by “exploring activities that give persons with HIV/AIDS a sense of meaning and purpose in life. First, having an awareness of verbal and nonverbal cues pertaining to spiritual matters is necessary. In addition, the author states that spiritual assessment tools are available that could be used to conduct a spiritual assessment.”

Kendall et al. (1989, p.164) state that the provider should:

Be aligned and sensitive to the patients’ spiritual and existential needs. Be empathetic, listen to what is said, be there. Let the patients know that you are
respectful of their process, and although it is done primarily alone, they do not have to be lonely.

Again, sometimes just being present and listening will let the client build a trusting relationship where they will find comfort in sharing their spiritual journey.

Participants began speaking about wellness and well being almost exclusively in spiritual terms, stating that their ability to experience wellness was primarily a spiritual process—a process of emanating from deep within the self, ‘the soul’.

(Kendall, 1994, pp. 30-31)

Wellness is not always defined in physical terms, especially by those experiencing life-threatening illness. Health care providers need to expand their own wellness definition to meet the holistic needs of the clients. Guillory et al. (1997) stated:

Many of those who eschewed medical treatment had previously submitted to medical care and stopped for various reasons, but were now attempting spiritual healing. For some, the decision to stop conventional medical treatment was based on the belief that the treatment was unnecessary or inconsistent with their beliefs.

(p. 59)

Is this decision to stop medical treatment due to inconsistency with their beliefs or the fact that medical personnel did not recognize or support their beliefs in a holistic approach to their illness? Again, this becomes an important dimension when assessing patients in a holistic approach.

**Spiritual Intervention**

“When the impossibility of replacing a person is realized, it allows the responsibility which a man has for his existence and its continuance to appear in all its
magnitude” (Frankl, 1962, p. 80). Providers are in a position to build a trusting, intimate relationship with clients living with HIV. This realization that each individual is ultimately unique and has a valuable purpose to his or her life may be the most caring aspect we can provide.

In true presence with the person/family, the nurse invites the person/family to share their health experiences. In the telling of the story, feelings and thoughts are shared which ‘shed light’ on the meaning of the experience. As the person, family, and nurse listen to the story together and dwell with the rhythms of the moment in true presence, new awareness can emerge, and all participants move on. (Parse, 1995, p.88)

As providers, we are able to assist the client to move through their experience and find what is important to them, as well as develop our own more effective therapeutic relationships.

The role of the practitioner should be one of a trusted listener. It is important that the practitioner understands that proselytizing is not an acceptable part of spiritual intervention. “The establishment of trust in the nurse-patient relationship provides the essential foundation for inspiring hopefulness and the provision of spiritual care” (Clark & Heidenreich, 1995, p. 80). “Key nursing interventions derived from this study included listening to patients’ concerns and participating as a facilitator among family and clergy” (Clark & Heidenrich, 1995, p. 81).

Listening for references made by clients about church attendance, God, and reading the Bible, as well as for request for priests or ministers or expressions of how activities such as meditation, music, and imagery help could be used as
opportunities to open a discussion about spiritual beliefs and issues. (Coleman & Holzemer, 1999, p.47)

Often, the sensitivity of the individual nurse who allows himself or herself to be vulnerable and open to the struggle that the client is undergoing will provide direction for the appropriate client intervention. If the nurse is comfortable with it, praying with the client or reading a favorite scriptural passage may be suggested (Harrison, 1997, p. 14).

“If the patient desires, the nurse can facilitate a meeting with clergy or other religious counselors to help the person with AIDS become connected with his or her faith and to provide spiritual guidance” (Peri, 1995, p.73). Using a team approach to client care is an excellent way to facilitate the spiritual interventions needed, that the provider may not have time to deal with. By considering clergy as part of the healthcare team, we are able to expand the holistic approach to client health.

Becoming aware of complimentary therapies, developing skills in imagery or visualization and having resource lists for activities in the community is another way in which the provider is able to more effectively provide holistic care to the client.

Perhaps, if patients were told how important activities such as prayer, meditation, use of imagery or visualization, exercise, use of vitamins, and participation in AIDS-related activities are they would be more likely to engage in these behaviors (Carson & Green, 1992, p. 217).

Another clinical role includes informing patients and families about the importance of finding meaning in illness and not assuming the victim role. O’Neill and Kenny (1998) state:
Nurses can support those who are suffering by assisting them to marshal their strength and actualize their potential for self growth. The nurse’s role in helping the dying AIDS patient face the fear of death and dying is to gently guide the patient to search for meaning in life (p.278).

Lakomy (1994, p. 246) found six formulated Experiences of Healing Rituals in persons with HIV. These included a) positive philosophical outlook on life, b) involvement with caring, spiritual environments and places, c) experience of the caring process, d) activation of the self healer within the person, e) engagement in a variety of healing therapies, and f) reliving the memories of the dying process from persons who had lived with AIDS. Knowing that these types of rituals may be important to the client with HIV/AIDS, providers can facilitate the honoring of a spiritual environment, coordinate healing therapies to be delivered to the client, express a caring attitude, and share in the telling of the client’s stories.

Barroso (1997b, p. 571) states:

Interventions need to be individualized, culturally sensitive, and should use as a starting point wherever the person is in the spectrum of the illness and in their current use of social support. Creativity is the keyword in developing interventions and must extend beyond traditional notions of social support. Individualized care has certainly been the hallmark of nursing for a long time, one in which providers incorporate all aspects of the client and what is important to them in defining their health. Fryback and Reinert (1999, p. 21) state:

When spirituality is viewed as including the concepts of accepting mortality and self-actualization as well as belief in a higher power, many avenues for discussion
and intervention appear. Nurses can talk with patients and families about living each day as it comes, since none of us know when death will come.

Simply listening and accepting what clients have to say is often enough. Dealing with spiritual health requires that providers have caring or person-centered skills.

Gaps In Knowledge

Much of the research identifies how life-threatening illness affects a person’s spirituality, their definition of what is important in life, and their connection with a higher power or purpose. Yet the quantitative research focused on how spirituality affected the patients’ physical health. Which is it? Does spirituality affect people’s health or does their health affect their spirituality? More quantitative research needs to be done to determine the answer to both of these questions.

“If spirituality is discussed at all, it is usually in the context of a holistic notion of the human person and from the perspective of Christian theological tradition.” (Narayanasamy, 1999 p 124). Spirituality was almost exclusively defined or discussed in terms of Judao-Christian tradition in most of the research articles reviewed. A broader definition of spirituality including biological roots may be helpful.

Two studies were done on long-term nonprogressors of HIV, there were no longitudinal studies designed to detect important social, psychological, and spiritual changes over time, which may affect the course of clients HIV disease. More longitudinal research needs to be done to determine the effects of HIV infection on the HIV positive person’s spirituality, as well as the effects of the HIV positive person’s spirituality on the progression of their disease.
More in-depth research is needed to explore the way spirituality is used as a resource for coping with HIV/AIDS in different ethnic groups. There were only a few studies specifically involving African-American populations, and not many studies with Hispanics, Native Americans, or other cultures. What important spiritual practices are being used in different cultures to assist the HIV client? What are the cultural differences in perception of what it means to live with HIV? In addition, to more diverse ethnic groups, what about different religious affiliations? Are there differences in spirituality among members of various religious groups and how they relate this to their HIV disease?

Summary

This paper has explored the frequently overlooked dimension of spirituality in healthcare, specifically in persons with HIV/AIDS. A theoretical framework for spirituality has been defined. Nineteen articles were reviewed. Four core concepts emerged from the qualitative studies: a) finding meaning and purpose in life, b) hope, c) spirituality or relationship with a higher power, and d) positive thinking and caring for one’s self. The major theme that emerged from the quantitative studies was spiritual and existential well being as a positive relationship to physical, psychological, and emotional well being.

A deeper understanding of spirituality enhances the potential for healthcare providers to identify spiritual needs and incorporate spiritual caring into practice. Assessment and interventions for spiritual exploration are suggested for healthcare professionals.
Very little theory has been generated clarifying the role of spirituality in the well-being of the individual with HIV, therefore as providers of health care, rather than illness care, we need to explore this role further. In addition, relationships between concepts of wellness and human connections to holism and quality of life need further exploration.
References


