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Relationships between Psychosocial-Spiritual Well-Being and End-of-Life Preferences and Values in African-American Dialysis Patients

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Abstract

The purpose of the study was to examine whether psychosocial and spiritual well-being is associated with African-American dialysis patients' end-of-life treatment preferences and acceptance of potential outcomes of life sustaining treatment. Fifty-one African Americans with end stage renal disease (ESRD) completed a socio-demographic questionnaire and interview with measures of symptom distress, health-related quality of life, psychosocial and spiritual well-being, and preferences and values related to life sustaining treatment choices. The subjects were stratified by end-of-life treatment preferences and by acceptance of life sustaining treatment outcomes and compared for psychosocial and spiritual well-being as well as socio-demographic and clinical characteristics. Individuals who desired continued use of life sustaining treatment in terminal illness or advanced dementia had significantly lower spiritual well-being ($p = .012$). Individuals who valued four potential outcomes of life sustaining treatment as unacceptable showed a more positive, adaptive well-being score in the spiritual dimension compared to the group who valued at least one outcome as acceptable ($p = .028$). Religious involvement and importance of spirituality were not associated with end-of-life treatment preferences and acceptance of treatment outcomes. African Americans with ESRD expressed varied levels of psychosocial and spiritual well-being, and this characteristic was associated with life sustaining treatment preferences. In future research, the assessment of spirituality should not be limited to its intensity or degree but extended to other dimensions.

Keywords

Spirituality; end-of-life preferences

Although studies have indicated that African Americans generally prefer more aggressive treatment at the end of life than Caucasians [1-4], the characteristics of those who desire to delay death with life sustaining measures have not been well described. Some experts hypothesize that one of the reasons African Americans prefer life sustaining treatment more than do Caucasian counterparts may be their strong religiosity or spirituality [5-11]. However, surprisingly little empirical evidence supports the theory that African-Americans' spirituality influences their end-of-life preferences. Furthermore, in empirical studies, religiosity or

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spirituality typically has been assessed in a restrictive and simplified manner by asking individuals' religious affiliation, degree of religiosity or spirituality, and the frequency of religious involvement. These methodological approaches assume that religion or spirituality vary only in intensity and do not have more complex effects or manifestations.

A recent study [11] examined the role of ethnicity and spiritual coping in cancer patients' end-of-life treatment preferences and reported that African Americans were more likely to desire life sustaining measures than were Caucasians. Among all study participants, belief in divine intervention, turning to higher power for strength, support and guidance, and using spirituality to cope with cancer were significantly associated with preference for CPR and life-sustaining measures, but only at a modest level ($r < .40$). Spirituality in this study was assessed with dimensions beyond what has been typically asked in other studies, and the study findings reflect an association between individuals' spiritual coping style and their preferences for life sustaining treatment.

This research raises further questions about how spiritual well-being within illness experience is associated with African-Americans' views on life sustaining treatment. We explored this question using the baseline interview data collected from African Americans with end-stage renal disease (ESRD). The purposes of the study were 1) to examine differences in socio-demographic and clinical characteristics and psychosocial-spiritual well-being between African-American dialysis patients who would and who would not prefer comfort care only at the end of life and 2) to determine whether psychosocial-spiritual well-being is associated with their acceptance of potential outcomes of life sustaining treatment.

Methods

Sample and Setting

This study used the baseline interview data from 51 individuals who participated in a randomized clinical trial of an end-of-life communication intervention, who met the following inclusion criteria: 1) self-identified African American, 2) ≥ 18 years of age, and 3) receiving dialysis for at least 3 months prior to the study enrollment. Subjects were recruited from five dialysis clinics in western Pennsylvania. They were first approached by a social worker at the dialysis clinic between January 2007 and January 2008. Those who indicated an interest in the study were subsequently approached by the research staff for informed consent and a cognitive function test, the 10-item Short Portable Mental Status Questionnaire (SPMSQ) [12]. Patients with ≤ 2 errors on the SPMSQ, indicating normal cognitive functioning, were eligible and enrolled in the study after giving informed consent. Of 101 patients who deemed eligible and initially approached, 1 failed SPMSQ and 49 refused to participate in the study. The study procedures were approved by the University of Pittsburgh Institutional Review Board.

Instruments

Data were collected using a brief written questionnaire, a structured chart review and in-person interview. The written socio-demographic questionnaire included data on age, gender, education, marital status, employment status, annual household income, health insurance, religious preference and involvement, and a single item asking the individual to rate the importance of spirituality in life on a 4-point scale (from ‘not at all important’ to ‘extremely important’). Clinical data collected by chart review included duration of dialysis and co-morbidities using the modified Charlson Comorbidity Index (CCI). The CCI incorporates the underlying illness condition for dialysis and other known predictors of complications, such as age, albumin level, diabetes, and cardiovascular disease and has shown its usefulness as a predictor of mortality in dialysis patients [13]. Scores range from 2 to 14 with a higher score

indicating a greater risk of mortality. Good inter-rater reliability for the index has been reported (kappa = 0.93) in dialysis patients [14].

The in-person interviews included measures of symptom distress, health-related quality of life, psychosocial-spiritual well-being, and preferences and values related to life sustaining treatment choices. Symptom distress was assessed using the Dialysis Symptom Index (DSI), which is comprised of 30 items that measure the presence (yes/no) of specific physical or emotional symptoms experienced during the previous 7 days [15, 16]. Each item is attached with a 5-point Likert scale (1 = “not at all bothersome” to 5 = “bothered very much”) to assess the distress of each symptom. The overall symptom burden score is computed by summing the number of symptoms present (range 0 – 30). A total symptom distress score is calculated by summing distress scores for individual symptoms (range 0 – 150). The scale's content validity and test-retest reliability have been reported with African-American and Caucasian dialysis patients (percent total agreement = 0.80, kappa = 0.48 – 0.90) [15]. The SF12v2® Health Survey was used to measure health-related quality of life based on 8 dimensions: physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. Each dimension is scored using a norm-based method to have a mean of 50 and a SD of 10 in the general U.S. population. These 8 scores are aggregated to compute two standardized summary scores, Physical Component Summary (PCS) and Mental Component Summary (MCS)[17].

Psychosocial-spiritual well-being was measured using the 28-item Self-Perception and Relationship Tool (S-PRT) [18]. This instrument measures perceptions of the impact of illness experience on physical and mental-emotional, social and spiritual dimensions. Each item is scored with a 7-point semantic rating scale (+3 to -3) between word pairs. A mean score between +1 and +2 indicates adaptive well-being with the current illness. The tool has consistently shown good internal consistency ($\alpha \geq 0.94$), convergent and criterion-related validities (0.49 - 0.67) in renal and cancer patients [18].

Specific items in the interview were used to clarify the patient's threshold for unacceptable conditions/outcomes of life sustaining treatment. In our pilot study [19], four outcomes of life sustaining treatment were chosen based on a comprehensive literature review and in-depth interviews with 10 African Americans with ESRD who identified conditions that would be unacceptable and considered worse than death. These items ask patients to imagine that they develop cancer that has spread or has a severe stroke or heart attack and become seriously ill at the hospital. Patients then were asked to think about conditions that for them would be worse than death and they would want their family member to make a decision to stop life sustaining treatment, including dialysis, and focus on treatment to make them as comfortable as possible. Patients were presented with four outcomes and asked whether the outcome would be “Acceptable”, “Not acceptable”, or “Unsure.” The outcomes of life sustaining treatment include: *cannot recognize my family or friends*, *only responding to pain and yet in untreatable pain most of the time*, *can no longer control my bowels*, and *have to live in a nursing home until death*. Patients were encouraged to add any other conditions that were not addressed in the four outcomes.

End of life treatment preferences were assessed using the Goals of Care document that presents two scenarios describing medical conditions that commonly occur in patients with ESRD. The first scenario describes a condition where the patient develops cancer that spreads or severe complications and cannot speak for him/herself. The medical team believes that he/she is unlikely to recover and that continuing life sustaining treatment, including dialysis, is no longer beneficial to him/her. The second scenario describes a condition where the patient develops advanced dementia and he/she can no longer be him/herself. His/her dementia is no longer responding to treatment. For each scenario, patients choose one of three options, “the goals of

care should be focused on delaying my death, and thus I want to continue life sustaining treatment", "the goals of care should be focused on my comfort and peace, and thus I do not want life sustaining treatment, including dialysis", and "I am not sure".

Data Analysis

Descriptive statistics were used to summarize the sample characteristics. The subjects' responses were stratified by end of life treatment preferences (comfort care only in both scenarios, continue use of dialysis in both scenarios, or mixed preferences). Responses were also stratified by how they valued four potential life sustaining treatment outcomes (unacceptable for all four outcomes vs. acceptable for at least one outcome). Non-parametric tests (χ^2-test Fisher's exact test, or Mann Whitney U test as appropriate) were used to examine group differences in socio-demographic and clinical characteristics. To test the hypotheses, whether psychosocial and spiritual well-being differs by end-of-life preferences and by values of life sustaining treatment outcomes, permutation tests were used with Monte Carlo estimation procedures [20-23]. Permutation tests are a resampling approach and are particularly useful for statistics based on small samples where asymptotics do not work properly [20]. The procedures began with computing a test statistic (either t or F as appropriate) for the data. Second, the data were permuted (rearranged) repeatedly. The number of repetitions was 10,000 based on Lunneborg's formula [24]. Third, the test statistic was computed for each of the resulting data permutations. Those data permutations, including the one representing the obtained results, comprise the reference set for determining significance. Fourth, the significance or probability value was computed. The proportion of data permutations in the reference set that have test statistic values greater than or equal to (or less than or equal to) the value for the observed results was the *p*-value.

Results

Sample Characteristics

Table 1 presents the characteristics of the overall sample and the three groups stratified by their end-of-life treatment preferences in two clinical scenarios. The mean age of the overall sample was 58 and roughly half of subjects were male. Seven patients completed less than high school education. Over 90% (n = 47) of the sample were retired or disabled. Seventeen (33.3%) were currently married or living with a significant other and 12 (23.5%) were never married. The patients were undergoing dialysis treatment for nearly 4 years on average. The mean of CCI was 6.18, a high score suggesting a 27% of one year mortality rate [25]. The patients were experiencing a total of 13 symptoms currently. The mean PCS of SF12 (SD) was 34.13 (9.95), which is somewhat worse physical health related quality of life than 50th percentile for the US kidney disease population [17]. However, the mean MCS (SD) was 49.03 (12.72), which is somewhat higher mental health related quality of life than 50th percentile for the U.S. kidney disease population of a similar age (= 44.82). Of the 51 subjects, two patients were listed on the kidney transplant candidate list at the time of study participation. All subjects had a durable power of attorney for health care document in their medical charts. However, it was unknown whether they had a living will because having an advance directive was not an inclusion criterion.

Religiosity and Spirituality Variables and Psychosocial-Spiritual Well-Being

Sixty-five percent of the total sample responded that they followed religious customs and practices frequently or always and 61% reported spirituality is extremely important in their lives. The social and spiritual well-being scores (≥ 1.0) in the total sample indicated a positive, adaptive well-being in those dimensions. The mental-emotional well-being scores (M = .88) reflect the subjects' less than optimal emotional well-being.

End-of-Life Treatment Preferences and Values of the Life Sustaining Treatment Outcomes

Of the 51 participants, 27 selected comfort care for both scenarios of terminal illness and advanced dementia, 11 selected continued use of dialysis and other forms of life sustaining treatment in both scenarios, and 13 had mixed preferences. Seventeen (33.3%) responded all four outcomes of life-sustaining treatment presented were unacceptable. The outcome endorsed as unacceptable most often was *If I can no longer control my bowels* (n = 41, 80.4%) followed by *If I am only responding to pain and yet in untreatable pain most of the time* (n = 38, 74.5%) and *If I cannot recognize my family or friends* (n = 34, 66.7%). A half of the sample (n = 25) found the outcome, *If I have to live in a nursing home until death after surviving hospitalization*, to be unacceptable.

Associations of the Socio-demographic and Clinical Characteristics with End-of-Life Treatment Preferences and Values of the Life Sustaining Treatment Outcomes

There were no significant differences among the three groups stratified by the end-of-life treatment preferences in socio-demographic and clinical characteristics. Religious involvement and importance of spirituality were not associated with those treatment preferences. Similarly, socio-demographic and clinical characteristics as well as religious involvement and importance of spirituality did not significantly differ between the two groups stratified by the values of the life sustaining treatment outcomes.

End-of-life Treatment Preferences, Values of the Life-Sustaining Treatment Outcomes and Psychosocial-Spiritual Well-Being

Spiritual well-being was associated with participants' choices in goals of care in end-of-life scenarios. Likewise, spiritual well-being was associated with their willingness to accept potential poor health outcomes from life-sustaining treatments. Individuals who desired continued use of life-sustaining treatment in both scenarios of terminal illness and advanced dementia had significantly lower spiritual well-being compared to those favoring comfort care in one or both scenarios (obtained $F = 4.83$, $p = 0.012$) (Table 1). Similarly, the group endorsing all four poor health outcomes as *unacceptable* showed a more positive, adaptive well-being score in the spiritual dimension (obtained $t = 2.17$, $p = .028$) compared to the group endorsing at least one outcome *acceptable*. (Table 2)

Discussion

This study is the first to examine spiritual well-being as a dimension of religious and spiritual influences on clinical treatment choices. In a group of African Americans with ESRD on dialysis, we found that greater spiritual well-being characterized those individuals who would choose comfort care only if faced with terminal cancer or advanced dementia. Individuals with higher spiritual well-being also expressed a greater tendency to stop life sustaining treatments if faced with 4 adverse health outcomes. Notably, common assessments of religious practices and importance of spirituality were not associated with these preferences or values. These findings indicate that the intensity of religious or spiritual expression may not explain African-Americans' preference for more use of life sustaining treatment. Rather, those with better spiritual well-being may be more willing to forgo life sustaining treatment, while those who do not derive a sense of well-being from spiritual sources of support may be less willing to do so. This result may appear counter-intuitive or contradictory to the current literature. However, it is important to note the conceptual distinction among religiosity, spirituality, and spiritual well-being. Religiosity or religiousness often refers to the various organized, individual, and attitudinal manifestations of different faith tradition [26]. Spirituality refers to the individual's personal experience, commonly seen as connected to some formal religion but increasingly viewed as independent of any organized religion [27, 28]. Spiritual well-being is defined as a sense of harmonious interconnectedness between self and others or a transcendent being and

achieved through an integrative growth process that leads to a realization of the ultimate purpose and meaning of life [29]. These three constructs are related but distinctive, and it is possible that people with strong religiosity or spirituality may not necessarily be in high spiritual well-being, particularly in a time of illness or suffering. In this study, the majority of the sample endorsed a high degree of religious involvement and the importance of spirituality in life, yet the level of spiritual well-being varied. Furthermore, the correlations of religious involvement and the importance of spirituality in life with spiritual well-being were modest ($r < .45$).

The findings that spiritual well-being, not the degree of religiousness or spirituality, are correlated with African-Americans' preferences and values underscore the importance of exploring end-of-life preferences and values in the context of individuals' illness experiences. Previous studies indicated that patients with ESRD experience severe burden of illness and existential suffering (e.g., questioning life on life support) during the course of illness [30, 31]. Therefore, other dimensions of spirituality should be assessed in order to better understand what mediates the relationship between spirituality and end-of-life treatment preferences. Our findings also suggest that African American dialysis patients who report strong religiosity and spirituality may have varying level of spiritual well-being and may express differing end-of-life treatment preferences and values than the existing, common belief that they would prefer aggressive treatment at end of life. This is important knowledge for health care providers as they are facing increasing responsibility for spiritual care for those with serious illness [32-36, 37].

The four outcomes of life sustaining measures used in this study were selected based on interviews with a group of African Americans dialysis patients who had similar characteristics of the study sample. Although others also used scenarios reflecting values of treatment outcomes to understand treatment preferences of serious ill patients [38-40], our approach to assessing African American dialysis patients' acceptance of potential outcomes of life sustaining measures differs in that the four treatment outcomes were drawn from the members of the study patient population and individual responses to the outcomes reveal their unique values as shown in the results. Again, that these values were significantly associated with spiritual well-being enhances our understanding of factors influencing end-of-life treatment preferences and values.

Conclusions drawn from our findings are preliminary, given study limitations. First, our sample size is small although it was determined based on a number of subjects required for the original clinical trial of an end-of-life communication intervention. Although the sample appeared to be similar to African Americans in the national dialysis population [41], our sample was somewhat younger and consisted of patients who met our specific inclusion criteria. Therefore, our study findings may not be generalizable to a lager patient group. Secondly, the study included solely dialysis patients without comparison groups of African Americans with other serious illness and thus caution is needed for interpreting the results.

Although religiosity or religion may provide intellectual, behavioral and social form to spiritual expression [42, 43], the common assessment of spirituality has been limited to degree/intensity of spirituality or the frequency of religious involvement. However, several studies revealed that spirituality provides African Americans with guidance and hope and is a major resource for adjustment to and coping with serious illness [44-46]. Religion and spirituality are complex and heterogeneous aspects of the human experience. Variation in intensity of belief alone is unlikely to represent individual differences in interpretation of health and healing in relationship with spiritual belief. Future research should include the assessment of other dimensions of spirituality rather than a simplified measure of intensity in order to explore how spirituality manifests and contributes to African-Americans' treatment preferences and values.

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Table 1

End-of-Life Treatment Preferences by Sample Characteristics

Characteristic	Total Sample (n = 51)	End-of-Life Treatment Preferences in Two Scenarios		
		Both Continue Dialysis (n = 11)	Mixed (n = 13)	Both Comfort Care Only (n = 27)
Sociodemgraphic				
Age	57.78 ± 13.18	52.91 ± 14/66	62.15 ± 13.50	57.67 ± 12.14
Male	29 (56.90)	7 (63.64)	8 (61.54)	14 (51.85)
Female	22 (43.10)	4 (36.36)	5 (38.46)	13 (48.15)
Currently married	15 (29.40)	3 (27.30)	2 (15.40)	10 (37.00)
Disabled/unable to work	30 (58.80)	11 (100.0)	8 (61.5)	11 (40.70)
Education in year	13.63 ± 2.68	13.82 ± 2.93	12.85 ± 1.77	13.93 ± 2.95
Annual household income				
< $13,000	23 (45.10)	7 (63.64)	6 (46.15)	10 (37.04)
≥ $13,000	28 (54.90)	4 (36.36)	7 (53.85)	17 (62.96)
Clinical				
Duration of dialysis in month	47.77 ± 49.22	45.68 ± 51.69	53.35 ± 55.31	45.94 ± 46.89
CCI	6.18 ± 2.49	4.91 ± 1.97	7.00 ± 2.83	6.30 ± 2.38
Dialysis Symptom Distress	40.96 ± 24.68	39.09 ± 30.43	41.92 ± 24.38	41.26 ± 23.21
SF12v2, PCS	34.14 ± 9.95	35.84 ± 9.52	28.98 ± 7.85	35.92 ± 10.45
MCS	49.03 ± 12.72	45.88 ± 11.62	51.01 ± 11.78	49.36 ± 13.75
Religious custom and Psychosocial-spiritual				
Extent of following religious customs and practices				
Never or sometimes	18 (35.29)	5 (45.45)	3 (23.08)	10 (37.04)
Frequently or always	33 (64.71)	6 (54.55)	10 (76.92)	17 (62.96)
Importance of spirituality in life				
< Extremely	20 (39.22)	5 (45.45)	5 (38.46)	10 (37.04)
Extremely	31 (60.78)	6 (54.55)	8 (61.54)	17 (62.96)
Psychosocial-Spiritual Well-Being				
Mental-Emotional[a]	.88 ± 1.12	.95 ± 1.26	1.20 ± 1.26	.69 ± .99
Social[b]	1.91 ± 1.11	1.51 ± 1.49	2.04 ± .97	2.01 ± 1.0
Spiritual[*]	1.53 ± 1.32	.51 ± 1.76	1.88 ± 1.16	1.77 ± .98

[a] F = .926, p = .40; p values are based on permutation tests.

[b] F = .929, p = .41; p values are based on permutation tests.

[*] F = 4.830, p = .012; p values are based on permutation tests.

CCI: Charlson Comorbidity Index, PCS: Physical Component Summary, MCS: Mental Component Summary.

Table 2

Acceptance of Outcomes of Life-Sustaining Treatment by Religious Involvement, Important of Spirituality and Psychosocial-Spiritual Well-Being

Dimension	"Unacceptable" for All 4 Outcomes (n = 17)	"Acceptable" for At Least One Outcome (n = 34)
Extent of following religious customs and practices, n (%)		
Never or sometimes (n = 18)	7 (41.18)	11 (32.35)
Frequently or always (n = 33)	10 (58.82)	23 (67.66)
Importance of spirituality in life		
< Extremely (n = 20)	7 (41.18)	13 (38.24)
Extremely (n = 31)	10 (58.82)	21 (61.76)
Psychosocial-Spiritual Well-Being Dimensions, M ± SD		
Mental-Emotional[a]	.66 ± 1.00	.99 ± 1.18
Social[b]	2.29 ± .82	1.72 ± 1.20
Spiritual[*]	2.03 ± 1.02	1.28 ± 1.39

[a] t = .98, p = .41; p values are based on permutation tests.

[b] t = 1.78, p = .08; p values are based on permutation tests.

[*] t = 2.17, p = .043; p values are based on permutation tests.