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Psychological symptoms and end-of-life decision making confidence in surrogate decision-makers of dialysis patients

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Abstract

This cross-sectional descriptive study explored surrogate decision-makers' psychological symptoms and their own assessment of decision-making abilities before actual involvement in end-of-life decision-making for their loved ones. One hundred-twenty dialysis patients' surrogates (79 African Americans and 41 Caucasians) completed scales measuring decision-making confidence, anxiety and depression, Post-Traumatic Symptoms (PTSS), and a sociodemographic questionnaire. Forty-two (35%) and 14 (11.7%) surrogates showed abnormal scores on anxiety and depression, respectively. Seven (5.8%) surrogates showed abnormal scores on PTSS. While surrogates decision making confidence was high ($M=17.70$, $SD=2.88$), there was no association between decision-making confidence and the three psychological variables. Surrogates' confidence was associated only with the quality of relationship with patient ($r=0.33$, $p=0.001$).

Surrogate decision-makers, individuals who have been designated as a health care agent for another, are expected to make medical decisions on behalf of another person who is not capable of decision-making. Typically these decisions are complex and can cause emotional distress for the surrogate decision-makers, particularly when end-of-life treatment decisions are involved (Wendler & Rid, 2011). For example, symptoms of anxiety, depression, and post-traumatic stress are common in surrogates who have experienced difficult decision-making for their loved ones, such as decisions to limit life-sustaining treatment (Abbott, Sago, Breen, Abernethy, & Tulskey, 2001; Braun, Beyth, Ford, & McCullough, 2008; Hebert, Schulz, Copeland, & Arnold, 2009; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008; Tilden, Tolle, Nelson, & Fields, 2001). Even at 6 – 12 months after the

patient's death, family members and other surrogates experience intrusive thoughts of regret or search for evidence that they made the right decision (Braun, et al., 2008; Hansen, Archbold, & Stewart, 2004; Shiozaki et al., 2008; Tilden, et al., 2001; Wright et al., 2008).

Much of the current literature calls for interventions to support surrogates prior to and/or during the decision-making process so that negative psychological effects may be reduced (Hebert, et al., 2009; Wendler & Rid, 2011). If surrogates of patients with serious chronic illness are already experiencing psychological symptoms (e.g., anxiety and depression symptoms), this may predispose them to substantial psychological distress after end-of-life decision-making experiences (Siegel, et al., 2008). Yet surrogates' psychological status and their own assessment of their decision-making abilities before they are involved in end-of-life decision-making have received little attention.

The purpose of this study was to explore the relationships among surrogates' psychological variables, sociodemographic characteristics, and end-of-life decision-making confidence using a sample of surrogates of dialysis patients who had not yet engaged in end of life decision-making for those dialysis patients. Specifically we addressed the following aims: To 1) describe the psychological symptoms and end-of-life decision-making confidence of surrogates who are likely to make treatment decisions on behalf of dialysis patients; 2) examine the association between surrogates' psychological symptoms and decision-making confidence; and 3) explore surrogates' sociodemographic characteristics, including race/ethnicity (non- Hispanic African American or non-Hispanic Caucasian) that are associated with their psychological symptoms and decision-making confidence.

METHODS

Design and Sample

We used baseline data from 120 dialysis patients' surrogates who participated in an on-going randomized controlled trial to test the effect of an end-of-life communication intervention on patient and surrogate decision-making outcomes over 12 months post-randomization. Patients were eligible for the parent study if they met the following criteria: self-identified African American or Caucasian, receiving dialysis for at least six months prior to enrollment, Charlson Comorbidity Index (CCI; Fried, Bernardini, & Piraino, 2001) score ≥ 6 or CCI score = 5 and having been hospitalized in the last six months (criteria associated with an estimated 30% one-patient year mortality; Charlson, Szatrowski, Peterson, & Gold, 1994; Fried, et al., 2001; Fried, Bernardini, & Piraino, 2003). The CCI includes 19 comorbid conditions, including myocardial infarction, congestive heart failure, AIDS, cerebrovascular disease, and liver disease. A higher score indicates a greater risk of mortality (Charlson, et al., 1994; Fried, et al., 2001, 2003). In addition, patients had to have an English-speaking surrogate over age 18 who could participate in the study with the patient.

Patients were recruited from 15 outpatient dialysis centers in 9 counties in North Carolina. Social workers at the dialysis centers approached potential patient participants to assess their interest in the study after confirming that they met the criteria of race, age, and months on dialysis. The research staff reviewed medical records of 610 potential patient participants to further assess their eligibility and approached the patients for informed consent and a

cognitive screening test, the 10-item Short Portable Mental Status Questionnaire (SPMSQ; Pfeiffer, 1975). Patients with >2 errors on the SPMSQ (i.e., abnormal cognitive functioning) were deemed ineligible.

Of the 249 eligible patients, 159 (63.9%) consented to join the study. After patient consent was obtained, the research staff contacted their surrogates and invited them to join the study if they were over 18 years old, able to speak English, and willing to participate in the intervention with the patients. Of the 159 surrogates invited, 120 (75.5%) provided written consent to participate in the study.

Measures and Data Collection

The study procedures were approved by the Institutional Review Board of the University of North Carolina at Chapel Hill and the Office of Clinical Trials of the participating dialysis organizations. Baseline data were collected over the telephone by the research staff, a process that took approximately 30 minutes. The measures and questionnaires relevant to our research questions are described below.

Decision-Making Confidence Scale (Song et al., 2010; Song et al., 2009)—This scale measured surrogate's confidence in end-of-life decision-making for their loved ones. It consists of five items that have response options from 0 (Not Confident At All) to 4 (Very Confident), reflecting an individual's level of comfort in the role of surrogate (Cronbach's $\alpha = 0.85$ with the study sample). For example, one item was "I feel confident that I understand what my loved one's preferences are." A sum of the 5 items was used for analysis; thus scores range from 0 to 20.

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)—This scale measured surrogate anxiety and depression (7 items for each subscale). The scale is not designed to make a diagnosis of a psychiatric disorder but rather to identify individuals who have symptoms that may require further psychiatric evaluation and assistance. Response options for each item are on a 4-point Likert type self-report rating scale (0 – 3). Both subscale scores range from 0 – 21 with the following categories: 0 – 7 = normal; 8 – 10 = borderline abnormal (mild); and 11 – 21 = abnormal (11 – 14 = moderate, 15 – 21 = severe). Reported internal consistencies and test-retest reliabilities are .88 – .90 and .84 – .94, respectively, for each subscale (Lowe et al., 2004; Whelan-Goodinson, Ponsford, & Schonberger, 2009). The scale has been widely used to assess symptoms of anxiety and depression in patients and in family members of patients (Herrmann, 1997; Pochard et al., 2001). For the 120 surrogates in this study, internal consistency (Cronbach's α) was 0.81 and 0.73 for anxiety and depression, respectively.

The Post-Traumatic Symptoms Scale-10 (PTSS-10; Eid, Thayer, & Johnsen, 1999)—This self-report scale measured the presence and intensity of ten post-traumatic distress symptoms during the preceding seven days (e.g., sleep problems, nightmares, tension in the body, irritation, startle, and so on) each rated on a seven-point Likert scale from 1 (Never/Rare) to 7 (Very Often/Always). A total score (range 10 – 70) of > 35 is associated with a high probability that the person meets the diagnostic criteria for post-

traumatic stress disorder (Weisaeth, 1993). The PTSS-10 has been shown to have high sensitivity and specificity (Eid, et al., 1999; Johansen, Wahl, Eilertsen, & Weisaeth, 2007; Schelling et al., 1998). Cronbach's α for this sample was 0.83.

Other descriptive data included sociodemographic information, such as age, gender, race/ethnicity, years of formal education completed, marital status, annual household income, whether the patient and surrogate reside in the same household, surrogate relationship to the patient, the importance of religious or spirituality in life on a 4-point scale from 1 (Not At All Important) to 4 (Extremely Important), and surrogates' perceived relationship quality with the patient using an overall rating in response to "How would you rate the quality of relationship with your ...?" from 1 (Poor) to 5 (Excellent).

Data analysis

Descriptive statistics (mean, SD, frequency, percent) were used to summarize sample characteristics, anxiety, depression, and PTSS symptom scores, and decision making confidence. To examine the bivariate relationships between psychological variables (anxiety, depression, and PTSS scores) and surrogate decision-making confidence, Pearson correlation coefficients were used. To test the significance of the difference between correlation coefficients of African American and Caucasian groups, a z score was calculated using the Fisher r-to-z transformation with a one-tailed test. The relationships between sociodemographic characteristics and psychological variables as well as decision-making confidence were determined using Pearson correlation coefficients, t-tests, and ANOVA as appropriate.

RESULTS

Characteristics of Study Participants

Table 1 presents surrogates' sociodemographic characteristics. Of the 120 surrogates, 79 (65.8%) were African Americans. The majority of surrogates were female (69.2%), spouses or partners of the patients (44.2%), married (61.7%), and currently living with the patients (62.5%). Fifty-seven surrogates (47.5%) reported a total annual household income of less than \$30,000. On average, surrogates' rating of quality of relationship with the patient was 4.39 (SD=0.75), between 'Good' and 'Excellent'. A majority of the surrogates (94.2%) said that they had lost a close family member or a friend, though only 29.2% were involved in difficult medical decision-making for that family member or friend.

Patients had a mean (SD) age of 62.9 (10.9) years. Seventy patients (58.1%) were 61 years or older, 61.9% were female, and 92.3% were receiving in-center hemodialysis. Patients' median months on dialysis was 32 (range, 6–296). The mean CCI score was 7.40 (SD=1.7).

Surrogates' Psychological Status and End-of-Life Decision-Making Confidence

Table 2 displays mean symptom scores of anxiety, depression, and PTSS. For all three variables, mean scores were within normal ranges. However, 35% (n=42) and 11.7% (n=14) of surrogates showed a score of 8 or higher on the anxiety and depression scales, respectively. Seven (5.8%) surrogates' PTSS scores were higher than 35.

Surrogates' end-of-life decision making confidence was high with a scale mean (SD) of 17.7(2.9). For each of the five items within the scale, mean scores were all greater than 3.0, suggesting that surrogates felt quite confident about end-of-life decision-making for their loved ones (Table 3).

In the total sample, there was no association between surrogates' end-of-life decision-making confidence and any of the three psychological variables. Alternatively, within the African American surrogate group, depression symptom scores were inversely correlated with decision-making confidence ($r=-0.24$, $p=0.049$), but that association was not significantly different from the correlation seen in the Caucasian group ($z=-1.43$, $p_{1-tailed}=0.07$), which was close to zero ($r=-0.04$).

Associations between Sociodemographic Characteristics, Psychological Symptoms, and Decision-Making Confidence

Of the sociodemographic characteristics of the surrogates, gender, years of formal education, total annual income, and overall rating of relationship quality were significantly associated with anxiety, depression, and PTSS symptom scores and decision-making confidence scores (Table 4). Specifically, although the magnitude of the associations was small, years of formal education, total income, and relationship quality were inversely correlated with anxiety and depression symptom scores. Female sex, total income and relationship quality were also inversely associated with PTSS scores. On the other hand, surrogates' decision-making confidence was positively associated only with the quality of relationship with patient ($r=0.33$, $p=0.001$). Patients' sociodemographic and clinical variables were not associated with surrogates' psychological symptoms or decision-making confidence.

DISCUSSION

We examined relationships between psychological status and end-of-life decision-making confidence among surrogates of dialysis patients. One important finding is that many surrogates in this sample were experiencing meaningful levels of anxiety ($n = 42$) and depression symptoms ($n = 14$) and a few ($n = 7$) reported PTSS symptoms. Despite these rates of psychological symptoms, we found no association between these psychological variables and end-of-life decision-making confidence.

The lack of association between depressive symptoms and decision-making confidence is noteworthy in light of literature on “depressive realism” (Alloy & Abramson, 1988; Dobson & Franche, 1989). This literature suggests a somewhat counterintuitive relationship between psychological status and decision-making confidence. Specifically, persons with more depressive symptoms may be more realistic/accurate about their decision-making abilities, and thus less confident, compared to their less depressed counterparts. Alternatively, it has been shown that depressive symptomatology is associated with difficulty in making decisions; that is to say, an inability to decide one way versus another (Clark, vonAmmon Cavanaugh, & Gibbons, 1983; Koo, et al., 2005). The current body of evidence, including our study findings, does not suggest a consistent relationship between psychological symptoms and one's own confidence in acting as a surrogate decision-maker.

Similar to findings in studies by Nolan et al (2009) and Song et al (in press), surrogates in this study were highly optimistic about their ability to make end-of-life decisions for their loved ones. We found that this confidence was significantly related to their perceived quality of relationship with their loved ones. In the study by Song et al (in press), surrogates' confidence was not based on the actual understanding of their loved one's end-of-life care preferences and surrogate decision-maker roles they would need to play during end-of-life decision-making. In other words, surrogates who perceive a good relationship with their loved ones may be overly confident about end-of-life decision making. Further studies are needed to examine the role of decision-making confidence in actual end-of-life decision making and the psychological outcomes afterward.

We did not find an association between surrogates' psychological symptoms and whether or not they had been previously involved in end-of-life decision-making for their loved ones. However, we recognize that the way we had operationalized “previous end-of-life decision making experiences” was likely insufficient to identify its relationship with surrogates' current psychological symptoms as we did not include questions to assess their experiences comprehensively. In addition to the limited operationalization of previous end-of-life decision making experiences, another study limitation is that decision-making confidence was skewed toward the positive, high, end of the scale and had limited variability. These features of the variable's distribution may have limited its association with other study variables. Most critically, this was a descriptive correlational study that sets the stage for but does not accomplish the need to examine linkages between surrogates' psychological variables before and after experiencing the challenge of engaging in end of life decision making for a loved one. In summary, we did not find the associations between surrogates' psychological symptoms and end-of-life decision making confidence. Surrogates' decision-making confidence was high in general and significantly associated with their perceived quality of relationship with their loved ones (dialysis patients). There were no racial/ethnic differences found in these relationships. Because of our study limitations described above, the lack of relationships between psychological symptoms and end-of-life decision-making confidence warrants further research. Nonetheless, our finding of surrogates' overconfidence in end-of-life decision making that may be based on their perceived relationship quality suggests that significant efforts are needed to help surrogate decision-makers realize that they might not be fully aware of their loved ones' wishes or how they would handle such a stressful situation. The clinical implication of this finding is to consider re-directing the current emphasis on clarifying and documenting patients' wishes in advance care planning to inclusion of better preparing the surrogates.

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Table 1

Sample Characteristics

Variable	African American (<i>n</i> = 79)	Caucasian (<i>n</i> = 41)	Total sample (<i>n</i> = 120)
<i>Surrogate</i>			
Age, <i>M</i> ± <i>SD</i>	51.96 ± 13.72	56.95 ± 14.47	53.67 ± 14.12
Female, <i>n</i> (%)	51 (64.6)	32 (78.0)	83 (69.2)
Relationship to patient			
Spouse or partner	31 (39.2)	22 (53.7)	53 (44.2)
Parent	3 (3.8)	3 (7.3)	6 (5.0)
Sibling	12 (15.2)	1 (2.4)	13 (10.8)
Child	26 (32.9)	12 (29.3)	38 (31.7)
Friend	3 (3.8)	3 (7.3)	6 (5.0)
Other relative	4 (5.1)	0	4 (3.3)
Years of formal education	13.41 ± 2.27	13.73 ± 2.42	13.52 ± 2.32
Married	45 (57.0)	30 (73.2)	74 (61.7)
Currently employed full time	36 (45.6)	13 (31.7)	49 (40.8)
Total annual household income			
< \$13,000	15 (19.0)	7 (17.1)	22 (18.3)
\$13,000 – \$29,999	25 (31.6)	10 (24.4)	35 (29.2)
\$30,000 – \$49,000	16 (20.3)	11 (26.8)	27 (22.5)
> \$49,000	19 (24.1)	11 (26.8)	30 (25.0)
Refused to answer	4 (5.0)	2 (4.9)	6 (5.0)
Currently live with patient, <i>n</i> (%)	47 (59.5)	28 (68.3)	75 (62.5)
Religion, Protestant	69 (87.3)	33 (80.5)	102 (85.0)
Importance of spirituality or religious belief in life			
Very important – extremely important	75 (94.9)*	28 (68.3)	103 (85.8)
Have lost a close family or friend	76 (96.2)	37 (90.2)	113 (94.2)
Involved in tough medical decisions for the family or friend	26 (32.9)	9 (22.0)	35 (29.2)
Quality of relationship with patient (1–5), <i>M</i> ± <i>SD</i>	4.41 ± 0.78	4.38 ± 0.71	4.39 ± 0.75

**p* < 0.001.

Table 2

Mean Scores of Symptoms of Anxiety, Depression, and PTSS

	African American (<i>n</i> = 79)	Caucasian (<i>n</i> = 41)	Total sample (<i>n</i> = 120)
Anxiety, <i>M</i> ± <i>SD</i>	5.84 ± 3.81	6.41 ± 3.45	6.03 ± 3.69
8, <i>n</i> (%)	30 (31.7%)	12 (29.2%)	42 (35.0%)
Depression	3.53 ± 2.79	4.44 ± 2.93	3.84 ± 2.86
8	7 (17.1%)	7 (8.9%)	14 (11.67%)
PTSS	18.81 ± 10.14	20.24 ± 8.56	19.30 ± 9.61
>35	3 (3.8%)	4 (9.8%)	7 (5.8%)

Table 3

Mean Scores of Surrogate Decision Making Confidence by Item and Overall

Item	African American (n = 79)	Caucasian (n = 41)	Total sample (n = 120)
<i>I feel confident that ...</i>			
1. I understand what my loved one's preferences are	3.40 ± 0.88	3.58 ± 0.72	3.46 ± 0.83
2. I can make a decision for my loved ones as to what treatment he/she should have, even in a highly stressful situation	3.40 ± 0.90	3.34 ± 0.71	3.38 ± 0.83
3. I can ask questions to get the facts about the benefits or risks of each medical choice without feeling discouraged	3.74 ± 0.59	3.79 ± 0.41	3.75 ± 0.53
4. I can handle unwanted pressure from others, such as other family members or health care providers, in making decisions for my loved one	3.35 ± 1.03	3.37 ± 0.71	3.36 ± 0.93
5. I can communicate with doctors and nurses about my loved ones wishes	3.78 ± 0.62	3.66 ± 0.75	3.74 ± 0.67
Total score	17.66 ± 3.15	17.76 ± 2.38	17.70 ± 2.88

Table 4

Associations between Sociodemographic Variables and Psychological and Decision-Making Confidence Scores in Total Sample

	Anxiety	Depression	PTSS	Decision-making confidence
Sex	$t=1.74$	$t=1.83$	$t=2.93^*$	$t=0.19$
Years of formal education	$r=-0.24^*$	$r=-0.22^*$	$r=-0.07$	$r=0.11$
Total annual household income	$r=-0.34^*$	$r=-0.32^*$	$r=-0.29^*$	$r=0.10$
Quality of relationship with patient	$r=-0.21$	$r=-0.35^*$	$r=-0.20^*$	$r=0.33^\dagger$

* $p < 0.016$ (Bonferroni correction for 3 tests, anxiety, depression, PTSS that are highly correlated).

$^\dagger p=0.001$.