One-Year Linear Trajectories of Symptoms, Physical Functioning, Cognitive Functioning, Emotional Well-being, and Spiritual Well-being Among Patients Receiving Dialysis

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Background: This study evaluated 1-year linear trajectories of patient-reported dimensions of quality of life among patients receiving dialysis.

Study Design: Longitudinal observational study.

Setting & Participants: 227 patients recruited from 12 dialysis centers.

Factors: Sociodemographic and clinical characteristics.

Measurements/Outcomes: Participants completed an hour-long interview monthly for 12 months. Each interview included patient-reported outcome measures of overall symptoms (Edmonton Symptom Assessment System), physical functioning (Activities of Daily Living/Instrumental Activities of Daily Living), cognitive functioning (Patient's Assessment of Own Functioning Inventory), emotional well-being (Center for Epidemiologic Studies Depression Scale, State Anxiety Inventory, and Positive and Negative Affect Schedule), and spiritual well-being (Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale). For each dimension, linear and generalized linear mixed-effects models were used. Linear trajectories of the 5 dimensions were jointly modeled as a multivariate outcome over time.

Results: Although dimension scores fluctuated greatly from month to month, overall symptoms, cognitive functioning, emotional well-being, and spiritual well-being improved over time. Older compared with younger participants reported higher scores across all dimensions (all $P < 0.05$). Higher comorbidity scores were associated with worse scores in most dimensions (all $P < 0.01$). Nonwhite participants reported better spiritual well-being compared with their white counterparts ($P < 0.01$). Clustering analysis of dimension scores revealed 2 distinctive clusters. Cluster 1 was characterized by better scores than those of cluster 2 in nearly all dimensions at baseline and by gradual improvement over time.

Limitations: Study was conducted in a single region of the United States and included mostly patients with high levels of function across the dimensions of quality of life studied.

Conclusions: Multidimensional patient-reported quality of life varies widely from month to month regardless of whether overall trajectories improve or worsen over time. Additional research is needed to identify the best approaches to incorporate patient-reported outcome measures into dialysis care.

Complete author and article information provided before references.

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End-stage renal disease (ESRD) is rarely a single disease, but rather comprises a family of chronic and acute illnesses. Persons with ESRD must manage not only the demands of dialysis therapy, but also challenges posed by comorbid conditions and symptoms.[1,2] No other patient population receives an invasive therapy every day or every other day to sustain life. However, the burden of ESRD is under-recognized by both patients (or families) and their health care providers.[3,4]

Illness burden and quality of life (QoL) are subjective and can only be known through patient self-report. The number of studies that characterize longitudinal patterns of symptoms and other dimensions of QoL among dialysis patients has been limited,[5-8] and we have little information about the trajectories of multidimensional QoL, including symptoms, physical and cognitive functioning, and emotional and spiritual well-being. No studies have examined all these dimensions longitudinally. Mapping these trajectories is a way to assess how health care needs of patients change over time.[9,10] Therefore, the purposes of this longitudinal observational study were to: (1) identify 1-year trajectories of 5 patient-reported dimensions of QoL in patients receiving maintenance dialysis, including symptoms, physical functioning, cognitive functioning, and emotional and spiritual well-being; and (2) explore the relationships among those dimensions over time.

Methods

Study Design

This was an exploratory study using a longitudinal cohort design with monthly telephone-based data collection for 12 months.

Setting and Participants

From April 2012 through January 2015, participants were recruited from 12 freestanding outpatient dialysis centers in North Carolina. Approximately 1,030 adult patients were receiving dialysis care at these centers during the

study period. Patients were eligible for the study if they were 18 years or older, had been receiving maintenance dialysis for at least 1 month, and were able to speak English fluently. Patients were excluded if they had uncompensated hearing impairment, were kidney transplantation candidates, were too ill to participate in an hour-long data collection session, had more than 3 errors on a gross cognitive screening test (the 10-item Short Portable Mental Status Questionnaire [SPMSQ][11]), or had documented advanced dementia. A total of 452 potentially eligible patients were referred to the research team by care providers. Of those, 301 were deemed eligible and 227 (75%) provided written consent. The University of North Carolina Institutional Review Board approved the study protocol.

Data Sources and Measurement

Participants completed an hour-long data collection session over the telephone that included a battery of questionnaires (described in the following paragraphs) at baseline and then monthly for 12 months, for a total of 13 sessions. Participants were compensated for their time and effort to complete questionnaires: $20 at the completion of each session and additional compensation of $20, $30, $40, and $50 at 3-, 6-, 9-, and 12-month follow-up, respectively. We used computer-assisted interviews. For hemodialysis patients, all data collection sessions were conducted on a nondialysis day to minimize measurement errors, such as the influence of dialysis on their perspectives on QoL.[12] At baseline, we collected the participant's sociodemographic information and clinical characteristics. Each follow-up session began with cognitive function screening using the SPMSQ. If the number of errors was more than 3, the participant was contacted in the next 2 to 3 days to rescreen for cognitive functioning before being deemed unable to complete the data collection session. Hospital admissions and emergency department (ED) visits were abstracted from the patient's medical record monthly.

Overall symptoms were measured using the modified Edmonton Symptom Assessment System (ESAS; range 0-100).[13,14] The severity of each of 10 symptoms (eg, pain and nausea) was rated on a scale ranging from 0 (no) to 10 (severe). Cronbach alpha with the study sample was 0.82. Physical functioning was measured using the Activities of Daily Living (ADLs)[15] and Instrumental Activities of Daily Living (IADLs) Scales.[16-19] Cognitive functioning was measured using the 33-item Patient's Assessment of Own Functioning Inventory (PAOFI). This measure asks participants to rate how often they experience difficulty in 4 areas: memory, language/communication, sensory-motor ability, and executive function, with response options from 0 (almost never) to 5 (almost always).[20] The PAOFI is a widely used questionnaire to assess perceived multidimensional cognitive functioning in various populations.[21,22] Construct validity has been demonstrated by comparing neuropsychiatric patients with healthy controls.[20] Cronbach alpha with the study sample was 0.89.

Emotional well-being was measured using the Center for Epidemiologic Studies Depression Scale–Short Form (CESD-SF),[23] the State Anxiety Inventory (SAI),[24] and the Positive and Negative Affect Schedule—Positive Affect (PANAS-PA).[25] The CESD-SF includes 10 items that tap psychological depressive symptoms, each with response options of 0 (rarely or <1 time a week) to 3 (frequently or 5-7 days a week). A summated score ≥ 10 is considered abnormal.[26,27] Cronbach alpha in the study was 0.71. The SAI includes 20 items that measure how respondents feel at the moment on a scale of 1 (not at all) to 4 (very much so). A summated score was used in analyses (Cronbach alpha = 0.75 in the study). The PANAS-PA was used to measure positive affect. It contains 10 adjective items (eg, interested and attentive), and respondents rate the extent to which they have experienced each mood during the past week on a 5-point scale ranging from 1 (very slightly or not at all) to 5 (extremely). The items are summed to yield a positive affect score (Cronbach alpha = 0.87 in the study).

Spiritual well-being was measured using the 12-item Functional Assessment of Chronic Illness Therapy—Spiritual Well-being (FACIT-Sp) scale.[28] The FACIT-Sp measures the extent to which individuals have experienced aspects of spiritual well-being in the past week on a 5-point scale from 0 (not at all) to 4 (very much). Higher scores (range, 0-48) indicate greater spiritual well-being. Criterion validity has been demonstrated by comparison with the 36-Item Short Form Health Survey (SF-36).[28] Cronbach alpha in the study was 0.88.

Statistical Analysis

For the primary analysis, linear mixed-effects models were used to identify patterns of change over time in the dimensions, except for ADLs/IADLs, for which a generalized mixed-effects model was used to model the probability of ADLs (or IADLs) ≥ 1 versus 0 (no impairment) due to the skewed distributions. A fixed and continuous linear time effect was included to assess trends (at baseline and over time) after accounting for participant specific random intercepts. A random coefficient for time was also included to model participant specific slopes over time. Mixed models were adjusted for baseline variables such as age, race (white vs nonwhite), Charlson Comorbidity Index (CCI) score, and dialysis vintage as potential covariates (all βs reported are adjusted estimates). The Akaike information criterion and Bayesian information criterion were used to select the most parsimonious model. Each measure's internal consistency reliability in this study was reported using Cronbach alpha (≥0.7, "acceptable"[29]).

To explore relationships among the 5 dimensions, Pearson (or Spearman rank) correlation coefficients were