HHS Public Access

Author manuscript

Am J Kidney Dis. Author manuscript; available in PMC 2019 August 01.

Published in final edited form as:

Am J Kidney Dis. 2018 August ; 72(2): 198–204. doi:10.1053/j.ajkd.2017.11.016.

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

Mi-Kyung Song, PhD, RN[1], **Sudeshna Paul, PhD**[1], **Sandra E. Ward, PhD, RN**[2], **Constance A. Gilet, MSN, RN**[3], and **Gerald A. Hladik, MD**[3]

[1]Emory University, Center for Nursing Excellence in Palliative Care, Nell Hodgson Woodruff School of Nursing

[2]University of Wisconsin-Madison, School of Nursing

[3]University of North Carolina at Chapel Hill, UNC Kidney Center

Abstract

Background—This study evaluated one-year linear trajectories of patient-reported dimensions of quality of life among patients on 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, 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. The linear trajectories of the five dimensions were jointly modeled as a multivariate outcome over time.

Corresponding author: Mi-Kyung Song, Professor & Director, Center for Nursing Excellence in Palliative Care, Nell Hodgson Woodruff School of Nursing, Emory University, 1520 Clifton Rd NE, Atlanta, GA 30322-4027, mi-kyung.song@emory.edu, 404-727-3134.

Financial Disclosure: The authors declare that they have no other relevant financial interests.

Authors' Contributions: Study concept and design: M-KS, SEW, CAG, GAH; acquisition of data: M-KS; data analysis/ interpretation: M-KS, SP, SEW, CAG, GAH; statistical analysis: SP; Funding obtainment: M-KS; administrative, technical, or material support: M-KS; study supervision: M-KS. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

Results—Although the dimension scores fluctuated greatly from month to month, overall symptoms, cognitive functioning, emotional well-being, and spiritual well-being improved over time. Older compared to younger participants reported higher scores across all dimensions (all *P value*s <0.05). Higher comorbidity scores were associated with worse scores in most dimensions (all *P value*s <0.01). Non-white participants reported better spiritual well-being compared to their white counter parts (*P*<0.01). Clustering analysis of the dimension scores revealed two 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.

Keywords

quality of life (QoL); patient-reported outcome measures (PROMs); symptom burden; Physical Functioning; Cognitive Functioning; Emotional Well-being; Spiritual Well-being; Dialysis; end-stage renal disease (ESRD); trajectory; comorbid conditions; illness burden; questionnaire

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 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 in order to sustain life. Yet the burden of ESRD is under-recognized by both patients (or families) and their healthcare 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 of these dimensions longitudinally. Mapping these trajectories is a way to assess how healthcare needs of patients change over time.[9,10] Therefore, the purposes of this longitudinal observational study were to 1) identify one-year trajectories of five 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 one month, and were able to speak English fluently. Patients were excluded if they had uncompensated hearing impairment, were kidney transplant candidates, were too ill to participate in an hour-long data collection session, had more than three 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 four-hundred and fifty-two 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 non-dialysis 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 three, the participant was contacted in the next 2–3 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 (e.g., pain, nausea) was rated on a scale ranging from 0 (no) to 10 (severe). Cronbach's 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 four 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's 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 less than once a week) to 3 (frequently or 5–7 days a week). A summated score of 10 or higher is considered as abnormal.[26,27] The Cronbach's 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's alpha = 0.75 in the study). The PANAS-PA was used to measure positive affect. It contains 10 adjective items (e.g., interested, 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's 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 SF-36.[28] Cronbach's 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 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. The mixed models were adjusted for baseline variables such as age, race (white vs non-white), Charlson Comorbidity Index (CCI) score, and dialysis vintage as potential covariates (all βs reported are adjusted estimates). The Akaike Information Criterion and the Bayesian Information Criterion were used to select the most parsimonious model. Each measure's internal consistency reliability in this study was reported using Cronbach's alpha (≥ 0.7, "acceptable"[29]).

To explore the relationships between the five dimensions, Pearson (or Spearman rank) correlation coefficients were computed as appropriate. Also, the five-dimension trajectories were jointly modeled as a multivariate outcome over time. A multivariate generalized linear mixed effects model with a mixture of normally distributed random effects was used to model the individual symptom trajectories (from baseline to 1 year) and eventually classify them in clusters.[30] A Bayesian inferential approach based on the Markov chain Monte Carlo was used to fit the model parameters. The optimal number of clusters was chosen by penalized expected deviance and posterior distribution of deviances. Chi-square and T-tests were used to examine associations between demographic and clinical characteristics and cluster membership. For statistical testing a significance level of 0.05 was used. Data

management and statistical analyses were performed in SPSS version 23, SAS 9.3 and R version 3.4 (R Foundation for Statistical Computing).

Results

Participants

At baseline, the 227 participants' mean age was 58.7 ± 12.6 (standard deviation) (range, 19–90) years, 52% were men, and 74% were African American (Table 1). These three demographic characteristics of patients who declined to participate (n=77) did not differ from those who joined. Monthly completion rates ranged from 80% (month 12) to 95% (month 1). Participants completed a median of 13 (interquartile range [IQR], 11–13) data collection sessions contributing to 2,571 monthly assessments in total. Eighteen participants (8%) died during the study, and 23 (10%) dropped out over 12 months. Those who dropped out or died during the study did not differ from their counterparts in baseline characteristics, including age, race, CCI scores, and dialysis vintage, and the numbers of ED visits and hospitalizations.

ED Visits and Hospitalizations

Participants had a total of 141 (median, 0; IQR, 0–1) ED visits; 138 (62%) had no ED visit during the study period. There were a total of 303 hospitalizations. The median number of hospitalization was 1 (IQR, 0–2); 145 (66%) had one or no hospitalization.

Trajectories of Multidimensional QoL

Pain and Other Symptoms—Individual participants' ESAS total scores varied widely from month to month. Nonetheless, for every 1-standard deviation (SD) increase in time, the cohort's ESAS total scores showed a gradual improvement of 1 unit ($\beta = -0.06$; 95% CI, −0.1 to −0.03). (Table 2). Age was inversely associated with the ESAS total scores ($\beta = -0.01$; 95% CI, −0.02 to −0.002), while CCI scores were positively associated with ESAS total scores ($\beta = 0.01$; 95% CI, 0.004–0.02). At baseline, 121 participants (53.3%) reported moderate to severe pain (rating ≥4; total sample mean, 3.9 ± 3.1), and the trajectory of pain ratings did not change over time.

Physical Functioning—Most participants experienced no impairment in daily activities at baseline; 179 (80%) scored 0 (no impairment) on ADLs and 145 (64%) scored 0 on IADLs. Although both ADLs and IADLs fluctuated monthly, the probability of an IADLs score ≥ 1 slightly decreased (by 5% per month) over time (odds ratio [OR] per 1-month increment, 0.95; 95% CI, 0.90–0.99) whereas ADLs scores were stable. Each 1-SD increase in CCI score was positively associated with greater odds of ADLs score ≥ 1 (OR, 1.47; 95% CI, 1.21–1.78) and IADLs score ≥ 1 (OR, 1.31; 95% CI, 1.06–1.61).

Cognitive Functioning—In general, participants reported low levels of difficulties in cognitive functioning. For 1-SD increase in time, the total PAOFI scores improved by 1.67 ($\beta = -0.09$; 95% CI, −0.1 to −0.06). On average, white participants reported a higher score, of 6.58 (95% CI, 1.0–12.1), indicating more difficulties in cognitive functioning than non-white participants. Age and CCI score were not associated with the PAOFI scores.

Emotional Well-being—Though individual participants' scores fluctuated monthly, the trajectory of anxiety scores showed an improvement of 1 unit over 1-SD increase in time (β = −0.1; 95% CI, −0.2 to −0.08) whereas the depression score trajectory was stable. Age was inversely associated with both anxiety (β = −0.01; 95% CI, −0.02 to −0.002) and depression (β = −0.02; 95% CI, −0.02 to −0.01) scores, and CCI scores were positively associated with anxiety (β = 0.01; 95% CI, 0–0.02) and depression (β = 0.01; 95% CI, 0.003–0.02) scores. Positive affect scores improved by 1.4 unit for 1-SD increase in time (β = 0.1; 95% CI, 0.1–0.2); no other factors were associated with the positive affect scores.

Spiritual Well-being—For every 1-SD increase in time, spiritual well-being scores improved by 1.4 (β=0.2; 95% CI, 0.1–0.2). Age (β=0.01; 95% CI, 0.002–0.02) and non-white race (β=3.1; 95% CI, 0.9–5.4) were positively associated with spiritual well-being scores.

Relationships Between the Dimension Scores

At baseline, ESAS total scores were associated with all other dimension scores. Correlations among the dimension scores are presented in Table 3. The directions and strengths of these relationships among the dimension scores were stable over 12 months.

Multivariate Longitudinal Clusters—Model based clustering of the five representative dimension scores (ESAS, ADL, PAOFI, CES-D, and FACIT-sp) over time indicated two trajectory clusters (Table 4). Cluster 1 was characterized by lower (better) ESAS (symptoms), PAOFI (cognitive functioning) and CES-D (depression), and higher (better) FACIT-sp (spiritual well-being) scores at baseline compared to cluster 2 and gradually improved over time. In contrast, cluster 2 was characterized by higher (worse) ESAS, PAOFI, CES-D and lower (worse) FACIT-SP scores at baseline and remained unchanged over time, except that FACIT-sp slightly improved over time. The ADL scores were nearly equal between the two clusters. No sociodemographic and clinical variables were associated with cluster membership; the cluster membership was determined solely by the dimension score profiles.

Discussion

This study provides a snapshot (one-year view) of QoL among adults receiving maintenance dialysis. We observed that most dimension scores were highly variable from month to month, but overall symptoms, cognitive functioning, emotional well-being (SAI and PANAS-PA), and spiritual well-being improved over time. Older compared to younger participants reported better dimension scores, and higher comorbidity scores were associated with worse scores in most dimensions. Non-white compared to white participants were more likely to report better spiritual well-being. Exploratory analysis of the five representative dimension scores revealed two distinctive clusters. Cluster 1 was characterized by better scores than those of cluster 2 in all dimensions except ADLs at baseline and gradual improvement over time. No sociodemographic or clinical factors were associated with cluster membership.

To our knowledge, a study by Weisbord *et al*.[5,7,8] and our present study are the only two longitudinal studies involving frequent (i.e., monthly) assessments to detect the course of patient reports on QoL. As in the Weisbord study, in which depressive symptom scores varied monthly, our study demonstrated strong monthly fluctuation in symptoms, physical and cognitive functioning, and emotional and spiritual well-being. It is important to note that in addition to using well-validated measures, our study used a rigorous data collection protocol to minimize measurement errors; each data collection session started with cognitive screening, and for hemodialysis patients, data collection sessions were conducted on a non-dialysis day. Because so many factors—life circumstances, family issues, and other events that occurred for the month in addition to clinical factors—may be playing a role, it is difficult to attribute monthly variations in scores to any one particular factor.[5] However, this finding should not be interpreted as meaning that patient self-reports are invalid. Rather, it suggests that patients' illness experiences are complex phenomena that are not predicted reliably by a set of clinical factors but that nonetheless cause considerable suffering and require clinicians' attention.

Our analysis revealed that roughly half of the sample (cluster 2, n=110) had higher (worse) symptom and other dimension scores at baseline compared to cluster 1, and their trajectories remained unchanged over time. This finding raises concern as to how well symptoms were being monitored and treated in these relatively high-functioning dialysis patients. Attention to symptoms should not be withheld until patients are in late stages of illness; rather, symptom palliation should be part of care at every stage of illness since, as demonstrated in our study, symptom scores were associated with every other dimension of QoL. Finding no predictors of those who fell into cluster 2 raises another issue: all patients need to be assessed for symptom burden on a regular basis to determine who needs attention. Clinicians cannot rely on predictors (e.g., over a certain age or albumin over a certain level) to trigger attention to symptom management. Instead, dialysis care should incorporate routine systematic assessment of all patients. In fact, the Centers for Medicare & Medicaid Services requirements for dialysis centers include annual measurement of health-related QoL (HRQoL) using the Kidney Disease Quality of Life 36-item survey (KDQOL-36) and reporting of the number of patients who completed a KDQOL-36,[31] which measures burden of kidney disease, symptoms and problems, and effects of kidney disease on daily life. However, requiring *annual* attention to these matters is clearly inadequate. Furthermore, whether and how QoL information obtained from the measure influences clinical management is largely unknown.

Given that dialysis therapy is not curative, there is particular reason to focus on helping patients on dialysis to "feel better".[32] Although interest in the potential of patient-reported outcomes to improve clinical care has sharply increased over the past decade, systematic reviews of the impact of patient-reported outcomes have consistently shown that these reports do not have a positive impact on clinical management, patients differ in terms of their desire to discuss HRQoL, and patient desires and the clinicians' willingness to talk about specific HRQoL domains frequently are at odds.[32–36] Clinicians report considering HRQoL a high priority in their clinical decision making, but in actuality HRQoL issues are often overruled by biomedical factors.[33] When clinicians discuss HRQoL issues in their practice, they rely on their own clinical judgement rather than using standardized HRQoL

measures.[32–36] Furthermore, although a User's Guide for Implementing Patient-Reported Outcomes Assessment in Clinical Practice (http://www.isoqol.org/UserFiles/file/UsersGuide.pdf) is available, there has been little guidance on how to use the guide or how to fit the approach into daily dialysis care.

Our study has several limitations that may reduce generalizability. It was conducted in a single region and included a cohort of highly functional patients, most of whom had a very low number of ED visits and hospitalizations. The data collection frequency and duration required for study participation might have contributed to selection bias. The follow-up period was limited to one year, which might have been too short to identify sociodemographic and clinical factors that influence the trajectories of QoL. On the other hand, the strengths of our study include data completeness, with a low dropout rate and a small amount of missing data, and robust data collection procedures to minimize recall bias and measurement errors, including computer-assisted interviews.[37]

In conclusion, our findings suggest that, to improve illness experiences and QoL among dialysis patients, care of patients on dialysis should go beyond managing the primary condition (ESRD) and dialysis therapy. Future research should be directed toward identifying the best approaches to meaningfully incorporate patient-reported outcome measures into dialysis care, including research to determine an optimal frequency of routine symptom assessment and management pathways that may fit within the clinical workflow, and research to evaluate the value of using patient-reported outcomes in dialysis care.

Acknowledgments

Support: This study was funded by a National Institutes of Health, National Institute of Nursing, grant (R01 NR013359 to Dr. Song). The funding source had no role in the design and conduct of the study; the collection, management, analysis, and interpretation of the data; the preparation, review, or approval of the manuscript; or the decision to submit the manuscript for publication.

The authors thank Jessica Bridgman, Erin Lutz, Teresa Reed, and Linda Shaw for their tireless efforts on participant recruitment and retention and data collection.

References

1. Berger JR, Hedayati SS. Renal replacement therapy in the elderly population. Clin J Am Soc Nephrol. 2012; 7(6):1039–46. [PubMed: 22516288]
2. Bowling CB, O'Hare AM. Managing older adults with CKD: individualized versus disease-based approaches. Am J Kidney Dis. 2012; 59(2):293–302. [PubMed: 22189037]
3. Braun L, Sood V, Hogue S, Lieberman B, Copley-Merriman C. High burden and unmet patient needs in chronic kidney disease. Int J Nephrol Renovasc Dis. 2012; 5:151–63. DOI: 10.2147/IJNRD.S37766 [PubMed: 23293534]
4. Almutary H, Bonner A, Douglas C. Symptom burden in chronic kidney disease: a review of recent literature. J Ren Care. 2013; 39(3):140–50. [PubMed: 23826803]
5. Belayev LY, Mor MK, Sevick MA, Shields AM, Rollman BL, Palevsky PM, Arnold RM, Fine MJ, Weisbord SD. Longitudinal associations of depressive symptoms and pain with quality of life in patients receiving chronic hemodialysis. Hemodial Int. 2015; 19(2):216–24. [PubMed: 25403142]
6. von der Lippe N, Waldum B, Brekke FB, Amro AA, Reisaeter AV, Os I. From dialysis to transplantation: a 5-year longitudinal study on self-reported quality of life. BMC Nephrol. 2014; 15:191. [PubMed: 25465066]

7. Weisbord SD, Mor MK, Green JA, Sevick MA, Shields AM, Zhao X, Rollman BL, Palevsky PM, Arnold RM, Fine MJ. Comparison of symptom management strategies for pain, erectile dysfunction, and depression in patients receiving chronic hemodialysis: a cluster randomized effectiveness trial. Clin J Am Soc Nephrol. 2013; 8(1):90–9. [PubMed: 23024159]
8. Weisbord SD, Mor MK, Sevick MA, Shields AM, Rollman BL, Palevsky PM, Arnold RM, Green JA, Fine MJ. Associations of depressive symptoms and pain with dialysis adherence, health resource utilization, and mortality in patients receiving chronic hemodialysis. Clin J Am Soc Nephrol. 2014; 9(9):1594–602. [PubMed: 25081360]
9. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005; 330(7498):1007–11. [PubMed: 15860828]
10. Murtagh FE, Preston M, Higginson I. Patterns of dying: palliative care for nonmalignant disease. Clin Med. 2004; 4(1):39–44.
11. Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. J Am Geriatr Soc. 1975; 23(10):433–41. [PubMed: 1159263]
12. Song MK, Gilet CA, Lin FC, Machardy N, Devitodabbs AJ, Fine JP, Stalberg KD, Fuller E 3rd. Characterizing daily life experience of patients on maintenance dialysis. Nephrol, Dialysis, Transplant. 2011; 26(11):3671–7.
13. Davison SN, Jhangri GS, Johnson JA. Longitudinal validation of a modified Edmonton symptom assessment system (ESAS) in haemodialysis patients. Nephrol, Dialysis, Transplant. 2006; 21(11): 3189–95.
14. Davison SN, Jhangri GS, Johnson JA. Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis patients: a simple assessment of symptom burden. Kidney Int. 2006; 69(9):1621–5. [PubMed: 16672923]
15. Katz S, Downs TD, Cash HR, Grotz RC. Progress in development of the index of ADL. Gerontologist. 1970; 10(1):20–30. [PubMed: 5420677]
16. Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. Gerontologist. 1969; 9(3):179–86. [PubMed: 5349366]
17. Kuo HK, Al Snih S, Kuo YF, Raji MA. The Cross-Sectional Associations of Albuminuria and C-Reactive Protein With Functional Disability in Older Adults With Diabetes. Diabetes Care. 2011; 34(3):710–7. [PubMed: 21300788]
18. Suchy Y, Kraybill ML, Franchow E. Instrumental activities of daily living among community-dwelling older adults: discrepancies between self-report and performance are mediated by cognitive reserve. J Clin Exp Neuropsychol. 2011; 33(1):92–100. [PubMed: 20623400]
19. Plantinga LC, Johansen K, Crews DC, Shahinian VB, Robinson BM, Saran R, Burrows NR, Williams DE, Powe NR. Association of CKD With Disability in the United States. Am J Kidney Dis. 2011; 57(2):212–27. [PubMed: 21036441]
20. CheluneCJ, , HeatonRK, , LehmanRAW. Neuropsychological and personality correlates of patients' complaints of disability. In: GoldsteinG, , TarterRE, editorsAdvances in clinical neuropsychologyNew York, NY: Plenum Press; 198695126
21. Richardson-Vejlgaard R, Dawes S, Heaton RK, Bell MD. Validity of cognitive complaints in substance-abusing patients and non-clinical controls: the Patient's Assessment of Own Functioning Inventory (PAOFI). Psychiatry Res. 2009; 169(1):70–4. [PubMed: 19619901]
22. Hutchinson AD, Hosking JR, Kichenadasse G, Mattiske JK, Wilson C. Objective and subjective cognitive impairment following chemotherapy for cancer: a systematic review. Cancer Treat Rev. 2012; 38(7):926–34. [PubMed: 22658913]
23. Andresen EM, Malmgren JA, Carter WB, Patrick DL. Screening for depression in well older adults: evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). Am J Prev Med. 1994; 10(2):77–84. [PubMed: 8037935]
24. SpielbergerCD. State-Trait Anxiety Inventory for adults Form Y review set: Manual, Test, Scoring KeyCA: Mind Garden, Inc; 2000
25. Watson D, Clark LA, Tellegen A. Development and validation of brief measures of positive and negative affect: the PANAS scales. J Pers Soc Psychol. 1988; 54(6):1063–70. [PubMed: 3397865]

26. Bosworth HB, Bastian LA, Kuchibhatla MN, Steffens DC, McBride CM, Skinner CS, Rimer BK, Siegler IC. Depressive symptoms, menopausal status, and climacteric symptoms in women at midlife. Psychosom Med. 2001; 63(4):603–8. [PubMed: 11485114]
27. Brown WJ, Ford JH, Burton NW, Marshall AL, Dobson AJ. Prospective study of physical activity and depressive symptoms in middle-aged women. Am J Prev Med. 2005; 29(4):265–72. [PubMed: 16242588]
28. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy--Spiritual Well-being Scale (FACIT-Sp). Ann Behav Med. 2002; 24(1):49–58. [PubMed: 12008794]
29. NunnallyJC, , BernsteinIH. Psychometric theoryNew York, NY: McGraw-Hill; 1994
30. Komárek A. A New R package for Bayesian Estimation of Multivariate Normal Mixtures Allowing for Selection of Number of Components and Interval-Censored Data. Comput Stat Data Anal. 2009; 53(12):3932–3947.
31. Centers for Medicare and Medicaid Services. Clinical Performance Measures (CPM) Project2013[cited 2017 June 10]. Available from: https://www.cms.gov/Medicare/End-Stage-Renal-Disease/CPMProject/index.html?redirect=/cpmproject
32. Snyder CF, Aaronson NK, Choucair AK, Elliott TE, Greenhalgh J, Halyard MY, Hess R, Miller DM, Reeve BB, Santana M. Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. Qual Life Res. 2012; 21(8):1305–14. [PubMed: 22048932]
33. Greenhalgh J, Long AF, Flynn R. The use of patient reported outcome measures in routine clinical practice: lack of impact or lack of theory? Soc Sci Med. 2005; 60(4):833–43. [PubMed: 15571900]
34. Valderas JM, Kotzeva A, Espallargues M, Guyatt G, Ferrans CE, Halyard MY, Revicki DA, Symonds T, Parada A, Alonso J. The impact of measuring patient-reported outcomes in clinical practice: a systematic review of the literature. Qual Life Res. 2008; 17(2):179–93. [PubMed: 18175207]
35. Marshall S, Haywood K, Fitzpatrick R. Impact of patient-reported outcome measures on routine practice: a structured review. J Eval Clin Pract. 2006; 12(5):559–68. [PubMed: 16987118]
36. Greenhalgh J. The applications of PROs in clinical practice: what are they, do they work, and why? Qual Life Res. 2009; 18(1):115–23. [PubMed: 19105048]
37. Unruh M, Yan G, Radeva M, Hays RD, Benz R, Athienites NV, Kusek J, Levey AS, Meyer KB, Group HS. Bias in assessment of health-related quality of life in a hemodialysis population: a comparison of self-administered and interviewer-administered surveys in the HEMO study. J Am Soc Nephrol. 2003; 14(8):2132–41. [PubMed: 12874468]

Table 1

Participant characteristics at baseline

Characteristic	Value
Age, y	58.7 ±12.6
Age < 65 years	154 (67.8)
Female sex	109 (48.0)
Race	
African American	168 (74.0)
White	52 (22.9)
Other	7 (3.1)
Education	
< High school	46 (20.3)
High school	113 (49.8)
> High school	68 (30.0)
Marital status, married or living with significant other	98 (43.2)
Employment status, currently employed	18 (7.9)
Annual household income	
<$20,000	119 (52.4)
$20,000 – $49,999	73 (32.2)
≥$50,000	26 (11.5)
Refused to answer	9 (4.0)
Dialysis modality	
Traditional center hemodialysis	216 (95.2)
CCPD	6 (2.6)
CAPD	5 (2.2)
Dialysis vintage, mo	
Mean±SD	4.3 ±5.3
Median [IQR]	3 [0.8–5.4]
Comorbidity	
CCI score	7.3 ± 2.1 (2–15)
Diabetes	168 (74.0)
Congestive heart failure	106 (46.7)
Peripheral vascular disease	73 (32.2)
Depression	34 (15.0)
Laboratory values	
Kt/V	1.7 (0.4)
Hemoglobin (g/dl)	11.0 (1.9)
Albumin (g/dl)	4.4 (8.6)
Calcium (mg/dl)	9.0 (0.8)
Phosphorous (mg/dl)	5.3 (1.5)

Note: N = 227. Values for categorical variables are given as number (percentage); for continuous variables, as mean ± standard deviation or mean ± standard deviation (range).

CCI, Charlson Comorbidity Index; CCPD, continuous cycling peritoneal dialysis; CAPD, continuous ambulatory peritoneal dialysis.

Table 2

Five dimension scores at baseline and 3, 6, 9, and 12 months[a]

Dimension	Measure (possible range)	BL	3 mo	6 mo	9 mo	12 mo	P-value[b]
Overall symptoms	ESAS (0–100)	24.2 (13.5)	23.4 (13.1)	22.6 (13.0)	21.8 (13.2)	21.0 (13.6)	< 0.01
Physical functioning	ADL scale (0–21)[c]	0.2 (0.38)	0.2 (0.36)	0.2 (0.36)	0.2 (0.36)	0.2 (0.36)	0.6
	IADL scale (0–7)[c]	0.3 (0.47)	0.3 (0.45)	0.3 (0.45)	0.2 (0.43)	0.2 (0.43)	0.02
Cognitive functioning	PAOFI (0–165)	27.0 (16.3)	25.7 (16.1)	24.3 (16.3)	22.9 (16.7)	21.6 (17.4)	< 0.001
Emotional well-being	CESD-SF (0–30)	6.3 (3.4)	6.2 (3.4)	6.0 (3.5)	5.9 (3.7)	5.8 (3.9)	0.07
	SAI (20–80)	30.0 (8.1)	29.1 (7.8)	28.3 (7.7)	27.5 (7.7)	26.6 (7.7)	< 0.001
	PANAS-PA (10–50)	35.5 (5.9)	36.6 (6.1)	37.7 (6.5)	38.9 (6.9)	40.0 (7.3)	< 0.001
Spiritual well-being	FACIT-sp (0–48)	38.2 (6.4)	39.3 (6.5)	40.4 (6.6)	41.6 (6.8)	42.7 (6.9)	< 0.001

Note: Values are given as mean ± standard deviation. Higher scores indicate greater burden, distress, or difficulty in functioning, except for PANAS-PA and FACIT-sp.

BL, baseline; ADL, Activities of Daily Living; CESD-SF, Center for Epidemiologic Studies Depression Scale–Short Form; ESAS, modified Edmonton Symptom Assessment System; FACIT-sp, Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale; IADL, Instrumental Activities of Daily Living; PANAS-PA, Positive and Negative Affect Schedule–Positive Affect; PAOFI, Patient's Assessment of Own Functioning Inventory; SAI, State Anxiety Inventory

[a] Adjusted for age, race, months on dialysis, and comorbidity score based on the mixed effects models. Marginal means calculated at the mean value of the continuous covariates (age, moths on dialysis and comorbidity scores) and at the race of the reference group (whites).

[b] Fixed linear time effect in the mixed effects model

[c] Estimated proportion of participants with a score ≥ 1(at least one impairment)

Table 3

Bivariate correlations (*Pearson or Spearman Rank correlation coefficient*) among the five dimension scores at baseline

Dimension	Measure	ESAS	ADL scale	IADL scale	PAOFI	CESD-SF	SAI	PANAS-PA	FACIT-sp
Overall symptoms ESAS									
Physical functioning	ADL scale	0.2*							
	IADL scale	0.3*	0.5*						
Cognitive functioning	PAOFI	0.4*	0.2*	0.4*					
Emotional well-being	CESD-SF	0.5*	0.06	0.2*	0.5*				
	SAI	0.6*	0.09	0.2*	0.4*	0.6*			
	PANAS-PA	−0.2*	0.07	−0.1	−0.2*	−0.3*	−0.4*		
Spiritual well-being	FACIT-sp	−0.4*	−0.03	−0.08	−0.2*	−0.5*	−0.5*	0.5*	

ESAS, modified Edmonton Symptom Assessment System; ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; PAOFI, Patient's Assessment of Own Functioning Inventory; CESD-SF, Center for Epidemiologic Studies Depression Scale–Short Form; SAI, State Anxiety Inventory; PANAS-PA, Positive and Negative Affect Schedule–Positive Affect; FACIT-sp, Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale.

Note: Except for PANAS-PA and FACIT-sp, higher scores indicate greater burden, distress, or difficulty.

*$P < 0.01$.

Table 4

Estimated mean scores from multivariate mixed effects model of overall symptoms, cognitive functioning, emotional well-being, spiritual well-being, and physical functioning at baseline and 3, 6, 9, and 12 months

	Cluster 1 (n = 121)					Cluster 2 (n = 106)				
	BL	**3 mo.**	**6 mo.**	**9 mo.**	**12 mo.**	**BL**	**3 mo.**	**6 mo.**	**9 mo.**	**12 mo.**
Overall symptoms (ESAS)	21.2(15.2)	16.9(13.5)	14.1(11.5)	14.3(11.5)	12.9(11.5)	32.0 (16.9)	28.0(15.2)	28.8(16.0)	28.7(15.7)	30.5(16.4)
Cognitive functioning (PAOFI)	22.0(14.8)	22.0(12.0)	17.7(13.2)	16.5(13.1)	15.6(12.5)	35.1(23.8)	28.4(17.5)	27.7(21.7)	28.4(21.9)	29.6(22.5)
Depression (CESD-SF)	4.9(3.6)	4.1(3.4)	3.6(3.4)	3.5(3.0)	3.4(3.0)	9.4(5.0)	8.0(4.7)	8.5(4.9)	8.2(5.1)	8.5(5.3)
Spiritual well-being (FACIT-sp)	36.9(4.5)	45.2(3.9)	45.9(3.1)	46.0(3.3)	45.7(4.2)	30.0(7.6)	35.9(9.4)	37.0(8.8)	37.0(8.6)	37.1(8.6)
Physical functioning (ADL scale)	0.2(0.4)	0.2(0.4)	0.2(0.4)	0.2(0.4)	0.2(0.4)	0.2(0.4)	0.2(0.4)	0.1(0.3)	0.1(0.3)	0.2(0.4)

BL, baseline; ESAS, modified Edmonton Symptom Assessment System; ADL, Activities of Daily Living; PAOFI, Patient's Assessment of Own Functioning Inventory; CESD-SF, Center for Epidemiologic Studies Depression Scale–Short Form; FACIT-sp, Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale.

Note: Values are given as mean ± standard deviation. Except for FACIT-sp, higher scores indicate greater burden, distress, or difficulty.