Center for Nursing Excellence in Palliative Care

Trajectories of Multidimensional Quality of Life among Patients Receiving Chronic Dialysis

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Aim Statement

To examine one year trajectories of pain and symptoms, physical functioning, cognitive functioning, emotional well-being, and spiritual well-being among patients on chronic dialysis

Background

Individuals with ESRD, no other population, must receive an invasive therapy every day or every other day to sustain life.

Attention to patient-reported multidimensional quality of life over time has been inadequate.

Design and Sample

- **Study Design**

Prospective, longitudinal observation study with monthly repeated assessment over 12 months, or until death, after baseline (T1-T13)

- **Sample**

A cohort of 227 patients on chronic dialysis recruited from 12 free-standing dialysis centers in North Carolina, U.S.

Inclusion Criteria

- 18 years of age or older
- On maintenance dialysis (either HD of PD) at least for a month
- < 3 errors on the Short Portable Mental Status Questionnaire (SPMSQ)
- Able to understand and speak English

Exclusion Criteria

- Kidney transplant candidate
- Uncorrectable hearing impairment

Measures and Data Collection Procedures

Pain and other symptoms	• Modified Edmonton Symptom Assessment System (ESAS)
Physical functioning	• Activities of Daily Living (ADL) • Instrumental Activities of Daily Living (IADL)
Emotional wellbeing	• State anxiety (STAI) • Depressive symptoms (CESD-10)
Cognitive functioning	• Patient Assessment of Own Functioning Inventory (PAOFI)
Spiritual wellbeing	• Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp)

- All data collection was telephone-based and conducted on a non-dialysis day for HD patients.
- Each session began with cognitive function screening; sessions continued only when < 3 errors on SPMSQ.
- Duration: 45-60 minutes
- Monthly medical record reviews to keep track of ED visits and hospitalizations.

- **Retention strategies**
  - Two backup contacts at enrollment
  - Post-card reminders 1 week prior to each session
  - Confirmation phone call 2 days prior to each session
  - Special occasion cards (e.g., birthday, holiday)
  - The same data collector whenever possible
  - A cell phone matched with the patient's service provider whenever possible
  - $20 at each completion and an additional incremental incentive at 3, 6, 9, and 12 months

Analysis

A linear mixed effects model was used to identify patterns of change over time in the five dimensions. A fixed and continuous time effect was used 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.

Adjusted analyses include baseline variable such as age, race (white vs non-white), Charlson Comorbidity Index (CCI) score, and months on dialysis as potential covariates.

For any statistical testing, a significance level of 0.05 was used.

Data management and statistical analyses were performed in SPSS version 23 and SAS 9.3.

Results

- **Completion rate**
  - Monthly completion rates ranged from 80% (Month 12) to 95% (Month 1) after baseline.
  - Participants completed a median of 11 data collection session contributing to 2,517 monthly assessments in total.
  - 18 (8%) died during the study.
  - 23 (10%) dropped out over 12 months.

Sample characteristics at baseline (N = 227)

Characteristic	n (%)
Age (yr), M (SD)	58.7 (12.6)
Women	109 (48.0)
Race	
African American	168 (74.0)
White	52 (22.9)
Other	7 (3.1)
≥ high school	181 (79.8)
Married/living with significant other	98 (43.2)
Income, < $20,000 annual	119 (52.4)
Traditional center HD	216 (95.2)
Years on dialysis, median (IQR)	3 (0.8, 5.4)
CCI score, M (SD)	7.3 (2.1)

Results (cont'd)

Laboratory values at baseline

Lab values	M (SD)
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)
Phosphorus (mg/dl)	5.3 (1.5)

Adjusted dimension scores from the mixed effects models[a]

Dimension	Measure (Range)	Baseline M (SD)	3 months	6 months	9 months	12 months	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 (0-21)**	**0.6 (1.7)**	**0.7 (1.7)**	**0.8 (1.8)**	**0.8 (1.9)**	**0.9 (2.1)**	**0.04**
	IADL (0-7)	0.9 (1.4)	0.9 (1.4)	0.9 (1.4)	0.9 (1.4)	0.9 (1.5)	0.89
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-10 (0-30)	6.3 (3.4)	6.2 (3.4)	6.0 (3.5)	5.9 (3.7)	5.8 (3.9)	0.07
	STAI (20-80)	**30.0 (8.1)**	**29.1 (7.8)**	**28.3 (7.7)**	**27.5 (7.7)**	**26.6 (7.7)**	**< 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**

[a] Adjusted for age, rage, months on dialysis, and CCI score.
[b] Fixed time effect.

- **Pain and other symptoms**

The cohort's trajectory of ESAS total scores showed a gradual improvement over time (adjusted β = -0.27). Age was inversely associated with the ESAS total scores (adjusted β = -0.20, p = 0.02).

- **Physical functioning**

ADL scores slightly worsened over time (adjusted β = 0.02) whereas the trajectory of IADL scores was stable. CCI scores were positively associated with both ADL (adjusted β = 0.25, p < 0.001) and IADL (adjusted β = 0.14, p < 0.01).

- **Cognitive functioning**

The trajectory of total PAOFI scores showed an improvement over time (adjusted β = -0.46). White participants reported a higher level of difficulties in cognitive functioning (adjusted β = 6.58, p = 0.02) than non-white participants. Age and CCI were not associated with the PAOFI scores.

- **Emotional well-being**

The trajectory of anxiety scores (STAI) showed an improvement over time (adjusted β = -0.28) whereas the depression score (CESD-10) trajectory was stable. Age was inversely associated with both STAI and CESD-10 scores, and CCI scores were positively associated with STAI (adjusted β = 0.6, p = 0.04) and CESD-10 (adjusted β = 0.37, p < 0.01).

- **Spiritual well-being**

FACIT-sp scores gradually improved over time (adjusted β = 0.37). Age (adjusted β = 0.1, p = 0.02) and non-white rate (adjusted β = 3.12, p < 0.01) were positively associated with FACIT-sp scores.

Conclusions

- First study to describe how multi-dimensions of quality of life change over time in chronic dialysis patients, offering a snap shot of quality of life trajectories.
  - All dimension scores severely fluctuated monthly.
  - Overall symptom scores improved over time.
  - Physical functioning (ADL) worsened over time.
  - Anxiety, cognitive functioning, and spiritual well-being improved over time.
  - Overall, older and none-white participants reported better quality of life and comorbidity undermined quality of life.

- **Limitations**
  - A short follow-up period (12 months)
  - Telephone-based data collection
  - Small sample size
  - A sample from a single region of the U.S.

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