

Quality of Life among Patients with End-Stage Renal Disease on Hemodialysis in a Patient-Centered Medical Home Intervention [Version 1, Approved]

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Original Submission

Received: May 26, 2017

Accepted: June 10, 2017

Published: June 16, 2017

Last Updated: October 16, 2017

Open Peer Review Status: Approved

How to cite this article: Anna C Porter, Marian L Fitzgibbon, Michael J Fischer, Ifeanyi Beverly Chukwudozie, Michael L Berbaum, Linda Schiffer, Denise M Hynes. Quality of Life among Patients with End-stage Renal Disease on Hemodialysis in a Patient-Centered Medical Home Intervention [Version 1, Approved]. *Insights Intern Med.* (2017) 1: 3.1

Ethical approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. The study was approved by the University of Illinois at Chicago Institutional Review Board.

Informed consent: Informed consent was obtained from all individual participants included in the study.

Funding: This study was funded by the Patient-Centered Outcomes Research Institute (PCORI), contract #IH-12-11-5420

Conflict of interest/competing interests: Authors declare there is no conflict of interest

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Acknowledgments and Financial Disclosure: This work is supported by funding from the Patient-Centered Outcomes Research Institute (PCORI), contract #IH-12-11-5420. Additional support for this project was provided by the Office of the Vice President for Health Affairs at the University of Illinois at Chicago. Dr. Hynes is supported on a US Department of Veterans Affairs Research Career Scientist Award. The content is solely the responsibility of the authors and does not necessarily reflect the views of PCORI or the US Department of Veterans Affairs.

Abstract

Purpose

To describe baseline quality of life (QOL) among a racially and ethnically diverse cohort in a study of the implementation of a Patient-Centered Medical Home for Kidney Disease for patients with end-stage renal disease (ESRD) on hemodialysis, and to evaluate the associations of QOL and patient-reported outcomes and sociodemographic and clinical characteristics.

Methods

QOL was measured using the Kidney Disease Quality of Life-36 (KDQOL-36) at baseline, and sociodemographic and clinical data were collected, along with multiple patient-reported outcome measures: care coordination, health literacy, self-efficacy, hemodialysis knowledge, depression, medication compliance, patient satisfaction, and compliance with and attitudes toward dietary restrictions.

Results

Data were available for 171 participants. The majority were African-American (49%) or Hispanic (47%), and had household income below \$20,000/year (68%). Older participants reported lower physical QOL than younger participants, and Hispanics reported lower burden scores compared to African-Americans. Participants with lower health literacy, lower self-efficacy scores, or depressive symptoms reported lower QOL scores.

Conclusions

Although QOL is known to be low in ESRD participants, this study identifies additional subgroups at risk for low QOL. Hispanic patients, those with low health literacy, low self-efficacy, and depression are at particular risk. Further study is needed to determine how to improve QOL in this population.

Keywords

Patient-Centered Outcomes; Quality Of Life; End-Stage Renal Disease; Patient-Centered Medical Home

Introduction

Over 400,000 people in the U.S. receive chronic hemodialysis for end-stage renal disease (ESRD) and the prevalence of ESRD is greater for minorities than non-Hispanic whites.[1,2]. Despite the relatively low prevalence of ESRD, government healthcare expenses for these patients are disproportionately high [1,3] and people with ESRD have significantly higher morbidity, mortality, and poorer quality of life (QOL) compared to those in the general population [1,4-7]. While some of the excess morbidity, mortality, and poor QOL associated with ESRD are due to the disease state itself as well as to comorbid illness from which many ESRD patients suffer,[4] the fragmentation in the current delivery of healthcare in the U.S. for ESRD patients may exacerbate these issues. Patients with ESRD who undergo in-center maintenance hemodialysis do so for 3-5 hours three times per week according to a fixed schedule determined by dialysis units. Adherence to this schedule for treatment of only one of potentially multiple medical problems for a given ESRD patient can create challenges for managing other illnesses, could further erode quality of life, and could lead to increased risk of medical complications from this fragmented care.

In contrast to the “disease-centered” model of care currently in use for dialysis delivery to ESRD patients, a more patient-centered model could potentially streamline, unify, and improve care. One such model is the Patient-Centered Medical Home (PCMH), which uses a comprehensive team approach to care for patients with complex chronic illnesses. Its implementation has been found in some populations to reduce hospitalization risk and healthcare costs [8,9] yet it has not been previously studied in the ESRD population in the U.S.[10].

We undertook the implementation of a Patient-Centered Medical Home for Kidney Disease (PCMH-KD) in a cohort of predominantly lower-income African-American and Hispanic ESRD patients on maintenance dialysis in an urban setting in the U.S.[11]. The goal of the study was to evaluate the effectiveness of this care model, compared to usual care, in improving patient-reported outcomes, clinical outcomes, and utilization of emergency health care. In this report, we describe the baseline quality of life characteristics of this population, and the associations of quality of life and other patient-reported measures evaluated at baseline.

Methods

Study Design

The full study design of the PCMH-KD has been reported in detail previously[11]. Briefly, this study was a non-randomized quasi-experimental intervention trial of implementation of a PCMH-KD over 18 months at two dialysis units in Chicago, an academic medical-center affiliated unit, and a private, for-profit unit. Participants were English- and Spanish-speaking adults aged 18 and over with end-stage renal disease on maintenance hemodialysis. The PCMH-KD intervention expanded the exist-

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ing care team of the dialysis unit (comprised of a nephrologist, dialysis nurse/nurse manager, dialysis technician, social worker, and dietitian) to include a nurse coordinator, general internist, pharmacist, and community health workers, all of whom saw the patient during dialysis treatments and separately as needed (Figure 1).

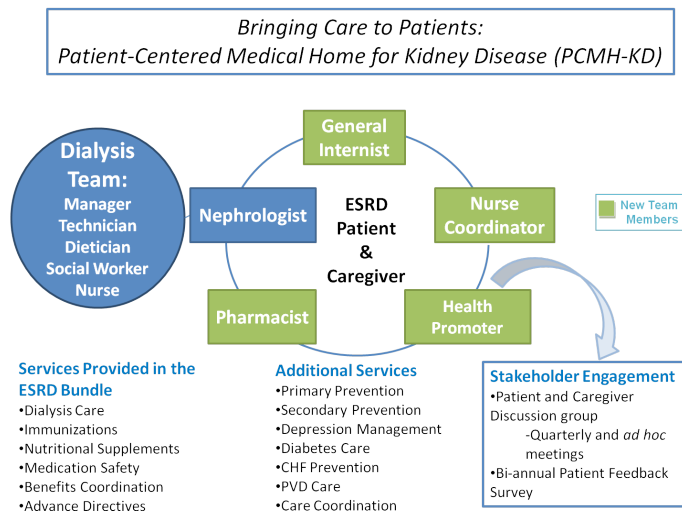


Figure 1: Patient-Centered Medical Home for Kidney Disease (PCMH-KD) model of care.

Overall, 175 participants were recruited and enrolled in the study from the two dialysis units. Baseline quality of life data and other patient-reported measures were available for 171 of these participants, which forms the cohort for these analyses. The study procedures were approved by the University of Illinois at Chicago Institutional Review Board, are in accordance with the Declaration of Helsinki, and written informed consent was obtained for all participants.

Variables and Data Sources

Sociodemographic data such as age, sex, race or ethnicity, educational level, marital status, and annual household income, were reported by participants at baseline, along with comorbid medical conditions and dialysis history. Patient-reported outcomes were obtained using structured interviews of each participant by a member of the research team. Both English and Spanish versions of each instrument were available, and participants chose their preferred language for the interview. Primary care coordination was assessed using a modified version of the Primary Care Assessment Survey [12]. This version includes a screening question (if there is a doctor who the patient considers to be his or her primary physician) and questions for the following 5 scales: Longitudinal Continuity, Knowledge of Patient, Integration, Communication, and Interpersonal Treatment. Quality of life (QOL) was measured using the Kidney Disease Quality of Life-36 (KDQOL-36) survey, a kidney-disease-specific quality of life instrument that assesses both general mental and physical health QOL domains as well as kidney-disease and

dialysis-related domains of QOL [13]. The five subscales of KDQOL-36 include: mental component summary (MCS), physical component summary (PCS), burden of kidney disease (burden), effects of kidney disease (effects), and symptoms and problems of kidney disease (symptoms). The MCS and PCS were derived from the Medical Outcomes Study Short Form 12 (MOS-SF-12) a generic HRQOL survey instrument that can be used in healthy individuals and across all disease states [14]. Health literacy was assessed using a 3-question screening instrument developed by Chew et al [15,16]. Patient confidence in self-management of chronic disease was assessed using the Self-Efficacy for Managing Chronic Disease instrument, a 6-item survey [17]. The Chronic Hemodialysis Knowledge Survey, a 23-item questionnaire regarding aspects of dialysis care, was used to assess patient knowledge of hemodialysis [18]. For depression screening, the Patient Health Questionnaire-9 was used; it has been validated as a screening tool for depression in the ESRD population [19]. Medication compliance was evaluated with the Morisky Medication Adherence instrument, an 8-item survey which has been shown to be reliably associated with blood pressure control[20]. Patient satisfaction with dialysis was determined using the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems Survey (ICH CAHPS) [21]. Compliance with the dietary and fluid restrictions necessary for ESRD patients was assessed with the Renal Adherence Attitudes Questionnaire (RAAQ) and the Renal Adherence Behavior Questionnaire (RABQ) which characterizes attitudes toward adherence to dietary restrictions as well as self-reported adherence behaviors[22].

Statistical Methods

One aim of this study was to investigate potential associations between quality of life at baseline and demographic and clinical characteristics: age, sex, race/ethnicity, primary language, dialysis vintage, self-reported comorbidities, dialysis center, dialysis access, and having a PCP at baseline. Differences in mean KDQOL scale scores across categories of these variables were tested for significance using t-tests and analysis of variance. Sample size calculations were based on the KDQOL scores, and as described previously, account for a minimum sample size of 77 subjects¹¹. The second aim was to examine potential associations between quality of life and patient-reported measures: hemodialysis knowledge, health literacy, medication adherence, self-efficacy, depression, satisfaction with dialysis, and attitudes toward and compliance with dietary and fluid restrictions. Scores from each patient-reported measure were divided into clinically relevant categories if possible; if not, they were divided at the sample median. Differences in mean KDQOL scale scores across categories were tested for significance using t-tests and analysis of variance. The statistical analyses were performed with SAS version 9.4 (Cary, NC).

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Results

Participants and Characteristics

Three of the total 175 enrolled participants were excluded from these analyses due to incomplete or missing KDQOL-36 data; one participant was excluded because most of the other patient-reported measures were missing, giving a total of 171 participants. The majority (63%) of participants were dialyzed at the academic medical center, and 37% received their treatment at the private, for-profit dialysis center. The sociodemographic characteristics of the participants can be found in Table 1. The mean age was 54.2 years, and 56% were men. The racial/ethnic breakdown of the cohort was as follows: 49% African-American, 47% Hispanic, 2% non-Hispanic white, 1% Asian-American. The majority (61%) of participants reported English as their primary language, while 30% were primarily Spanish-speaking. Fifty-eight percent of participants were high school graduates, 35% reported a level of educational attainment below a high school diploma, and 8% had a college degree. The annual household income was below \$20,000 per year for 68% of participants, 19% reported an annual household income between \$20,000 and \$40,000 per year, and 13% had an income above \$40,000 per year. Participants had been on dialysis for a median of 36 months at the baseline study visit. A majority (53%) of participants reported having a diagnosis of diabetes, 83% reported having hypertension, 10% had a diagnosis of cardiovascular disease, 22% reported a diagnosis of congestive heart failure, and 6% had non-skin cancer. The most prevalent dialysis access type for participants was arteriovenous fistula (52%), followed by catheter (33%), and arteriovenous graft (16%). At study entry, 60% of participants reported having a primary care doctor.

Table 1: Baseline Sociodemographic Characteristics and KDQOL Sub-scale Scores.

Age (years), mean (SD)	54.2 (15.1)
Male, % (N)	56% (95)
Race/ethnicity, % (N)	
African American	49% (84)
Hispanic	47% (81)
Primary language, % (N)	
English	61% (105)
Spanish	30% (52)
Both equally	8% (13)
Education, % (N)	
Not high school graduate	35% (59)
High school graduate	58% (99)
College graduate	8% (13)
Married or living with partner, % (N)	36% (61)
Annual household income, \$, % (N)	
<\$20,000	68% (106)
\$20,000-<\$40,000	19% (30)
≥ \$40,000	13% (21)
Dialysis vintage (months), median (IQR)	36.0 (60.0)
Comorbidities, self-reported, % (N)	
Diabetes	53% (90)
Hypertension	83% (142)
Congestive heart failure	22% (37)
Cardiovascular disease ^a	10% (17)
Cancer, except skin	6% (11)
Center, % (N)	
Academic	63% (107)
Private, for-profit	37% (64)
Dialysis access, % (N)	
Graft	16% (26)
Fistula	52% (84)
Catheter	33% (53)
Has primary care MD	
Yes	60% (103)
No	40% (68)

N=171 of 175 enrolled participants: 3 participants with incomplete KDQOL data and 1 participant with KDQOL data only were excluded. N=157 for income, N=163 for self-reported dialysis access.

^aHeart attack in last year or angina.

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Table 2: Association between mean KDQOL subscale score and sociodemographic and clinical factors.

	N	PCS	MCS	Burden	Symptoms	Effects
All participants	171	35.6 (10.2)	49.2 (10.7)	46.4 (27.2)	76.6 (15.8)	71.9 (20.5)
Age, years						
≥ 60	66	33.3 (10.1)	48.9 (11.6)	43.7 (28.4)	75.0 (15.5)	74.9 (18.0)
< 60	105	37.0 (10.0)	49.3 (10.1)	48.1 (26.4)	77.5 (15.9)	69.9 (21.8)
p ^a		.02	.82	.30	.31	.12
Sex						
Male	95	36.6 (10.5)	49.7 (10.7)	46.7 (27.8)	78.1 (17.2)	71.6 (22.8)
Female	76	34.3 (9.7)	48.4 (10.6)	46.0 (26.7)	74.6 (13.6)	72.2 (17.3)
p ^a		.14	.43	.86	.15	.83
Race/ethnicity						
African American	84	36.9 (10.3)	51.0 (10.1)	54.9 (28.1)	77.0 (16.7)	75.1 (19.5)
Hispanic	81	34.4 (10.1)	47.4 (10.6)	37.3 (23.3)	76.5 (14.8)	69.4 (21.6)
Other (Caucasian, Asian)	6	32.9 (8.0)	47.2 (15.2)	49.0 (29.2)	71.5 (16.1)	59.4 (7.1)
p ^b		.22	.08	<.001	.72	.06
Primary language						
English	105	36.8 (10.1)	50.5 (10.5)	52.8 (27.7)	77.1 (16.0)	73.6 (19.9)
Spanish	52	32.4 (10.1)	47.1 (9.9)	33.7 (23.4)	74.4 (15.2)	67.7 (21.9)
Both equally	13	39.1 (8.9)	47.2 (13.8)	43.3 (19.8)	80.8 (17.1)	75.5 (19.0)
p ^b		.02	.14	<.001	.38	.19
Dialysis vintage						
≥ 1 year	130	35.7 (10.6)	49.1 (10.5)	47.5 (28.2)	76.1 (16.1)	73.1 (19.9)
< 1 year	41	35.3 (8.9)	49.2 (11.2)	43.0 (23.8)	78.0 (14.6)	67.9 (22.1)
p ^a		.82	.96	.36	.49	.16
Diabetes						
Yes	90	33.6 (9.6)	48.2 (11.1)	44.2 (27.0)	75.5 (16.5)	72.0 (19.9)
No	81	37.8 (10.4)	50.3 (10.1)	48.8 (27.4)	77.8 (14.9)	71.7 (21.3)
p ^a		.006	.19	.28	.35	.92
Hypertension						
Yes	142	35.2 (10.0)	49.4 (10.9)	46.1 (26.8)	76.0 (16.0)	71.2 (20.5)
No	29	37.6 (10.8)	48.0 (9.2)	47.6 (29.8)	79.1 (14.5)	75.1 (20.9)
p ^a		.24	.52	.79	.34	.35
Congestive heart failure						
Yes	37	31.3 (8.9)	48.3 (11.3)	43.1 (29.9)	70.9 (17.9)	67.8 (26.6)
No	134	36.8 (10.2)	49.4 (10.5)	47.3 (26.5)	78.1 (14.8)	73.0 (18.4)
p ^a		.003	.60	.41	.01	.18
Cardiovascular disease						
Yes	17	30.6 (9.5)	46.8 (10.7)	40.1 (29.1)	65.1 (21.6)	63.1 (24.2)
No	154	36.1 (10.1)	49.4 (10.7)	47.1 (27.0)	77.8 (14.5)	72.8 (19.9)
p ^a		.03	.33	.32	.001	.06
Cancer, except skin						
Yes	11	32.6 (10.6)	47.0 (13.0)	27.8 (19.8)	65.9 (23.5)	63.4 (26.1)
No	160	35.8 (10.1)	49.3 (10.5)	47.7 (27.2)	77.3 (14.9)	72.4 (20.0)
p ^a		.31	.49	.02	.02	.16
Dialysis center						
Academic	107	35.6 (10.0)	50.2 (10.1)	47.2 (29.2)	76.7 (16.8)	71.2 (21.1)
Private, for-profit	64	35.5 (10.5)	47.5 (11.5)	45.0 (23.8)	76.4 (14.0)	72.9 (19.6)
p ^a		.94	.11	.61	.92	.62
Dialysis access						
Graft	26	36.5 (11.3)	49.4 (11.9)	51.7 (28.4)	80.2 (14.0)	76.9 (21.0)
Fistula	84	36.3 (9.9)	49.8 (10.3)	48.0 (27.8)	78.1 (14.3)	72.8 (19.0)
Catheter	53	34.4 (10.5)	49.0 (10.6)	42.9 (26.3)	74.8 (16.1)	70.0 (21.5)
p ^a		.55	.91	.36	.26	.35
Has primary care MD						
Yes	103	35.3 (10.3)	49.2 (10.7)	48.5 (28.0)	75.4 (16.3)	72.4 (21.0)
No	68	36.0 (10.1)	49.1 (10.7)	43.2 (25.9)	78.3 (14.9)	71.1 (19.9)
p ^a		.70	.95	.22	.24	.68

Mean (SD). N=171 of 175 enrolled participants: 3 participants with incomplete KDQOL data and 1 participant with only KDQOL data were excluded from all analyses. N=170 for primary language and 159 for dialysis access. For all KDQOL subscales, a higher score indicates higher quality of life.

^a From t-tests with pooled variance. ^b From ANOVA.

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Table 3: Association between mean KDQOL subscale score and patient-reported outcomes.

	N	PCS	MCS	Burden	Symptoms	Effects
Chronic Hemodialysis Knowledge Survey (CHKS, 0-100)						
≥ 65% correct	46	36.4 (9.9)	49.4 (10.4)	46.6 (24.3)	76.1 (15.9)	72.2 (18.3)
< 65% correct	125	35.3 (10.3)	49.1 (10.8)	46.3 (28.3)	76.7 (15.8)	71.7 (21.3)
p ^a		.52	.86	.95	.83	.91
Health literacy (3-15)						
Adequate (3-8)	103	36.8 (9.8)	50.6 (10.2)	53.3 (27.4)	78.6 (14.8)	74.6 (18.3)
Inadequate/marginal (9-15)	68	33.8 (10.5)	46.9 (11.0)	35.8 (23.4)	73.5 (16.7)	67.8 (23.0)
p ^a		.06	.02	<.001	.04	.03
Medication adherence (0-8)						
Low (0-5)	71	35.2 (9.3)	46.9 (10.8)	43.4 (28.1)	72.9 (15.8)	68.3 (21.3)
Medium (6-7)	54	35.1 (9.7)	49.6 (9.6)	48.5 (26.0)	77.9 (16.1)	74.3 (19.7)
High (8)	46	36.9 (12.0)	52.1 (11.2)	48.5 (27.5)	80.6 (14.3)	74.5 (19.8)
p ^b		.61	.03	.49	.03	.16
Self-efficacy (SEMCD, 1-10)						
≥ 7.5 (at median or above)	89	38.1 (11.0)	52.6 (8.9)	55.5 (27.5)	80.7 (13.3)	78.1 (18.9)
< 7.5 (below median)	82	32.8 (8.5)	45.4 (11.2)	36.4 (23.3)	72.1 (17.1)	65.1 (20.1)
p ^a		<.001	<.001	<.001	<.001	<.001
Depression (PHQ-9, 0-27)						
None or mild (0-9)	141	36.4 (10.6)	51.3 (9.7)	51.5 (25.8)	78.8 (15.1)	77.2 (16.6)
Moderate to severe (10-27)	30	31.9 (7.0)	38.9 (8.9)	22.3 (20.0)	66.0 (14.8)	46.8 (18.6)
p ^a		.03	<.001	<.001	<.001	<.001
CAHPS Global rating of kidney doctors (1-3)						
1 (0-6, lowest rating)	38	34.6 (9.1)	48.8 (11.0)	41.3 (24.7)	75.2 (14.1)	70.6 (19.5)
2 (7-8)	40	37.8 (10.0)	48.0 (9.3)	46.6 (28.5)	77.3 (17.4)	70.2 (22.3)
3 (9-10, highest rating)	90	35.5 (10.5)	49.6 (11.1)	49.0 (27.4)	77.1 (15.8)	73.3 (20.3)
p ^b		.34	.75	.35	.79	.66
CAHPS Global rating of dialysis staff (1-3)						
1 (0-6, lowest rating)	20	34.4 (11.0)	46.2 (12.3)	38.1 (33.8)	74.6 (16.9)	66.3 (16.3)
2 (7-8)	55	35.1 (9.1)	47.9 (9.3)	47.2 (28.9)	75.0 (13.8)	72.5 (23.7)
3 (9-10, highest rating)	96	36.1 (10.6)	50.5 (10.9)	47.7 (24.6)	77.9 (16.6)	72.7 (19.3)
p ^b		.72	.14	.35	.47	.43
CAHPS Global rating of dialysis center (1-3)						
1 (0-6, lowest rating)	10	32.3 (5.5)	49.4 (13.2)	33.1 (19.8)	68.5 (16.7)	72.8 (16.9)
2 (7-8)	54	35.6 (9.8)	46.7 (10.9)	41.9 (28.5)	75.5 (14.7)	71.7 (20.9)
3 (9-10, highest rating)	107	35.9 (10.7)	50.4 (10.2)	49.9 (26.6)	77.9 (16.1)	71.8 (20.8)
p ^b		.58	.13	.06	.17	.99
CAHPS Nephrologists' communication and caring (1-4)						
≥ 3.50 (at median or above)	96	36.6 (10.4)	51.0 (10.8)	53.3 (28.3)	78.2 (16.7)	74.7 (20.7)
< 3.50 (below median)	73	34.5 (9.8)	46.6 (10.1)	37.7 (22.7)	74.3 (14.6)	68.1 (19.8)
p ^a		.19	.009	<.001	.11	.04
CAHPS Quality of center care and operations (1-4)						
≥ 3.64 (at median or above)	86	36.4 (10.6)	50.9 (10.6)	51.7 (27.5)	77.6 (17.5)	73.6 (20.8)
< 3.64 (below median)	85	34.8 (9.7)	47.4 (10.5)	41.0 (26.0)	75.5 (13.9)	70.1 (20.2)
p ^a		.31	.03	.009	.37	.28
CAHPS Providing information to patients (0-1)						
≥ 0.75 (at median or above)	93	37.2 (10.1)	50.7 (10.6)	51.5 (27.9)	77.6 (16.7)	74.5 (19.2)
< 0.75 (below median)	78	33.7 (10.0)	47.3 (10.5)	40.3 (25.3)	75.3 (14.6)	68.7 (21.7)
p ^a		.02	.04	.007	.36	.07
RAAQ Attitudes towards social restrictions (8-40)						
≥ 28 (at median or above)	97	36.6 (10.4)	50.8 (10.5)	55.5 (26.0)	79.2 (14.2)	77.4 (17.5)
< 28 (below median)	74	34.3 (9.8)	47.0 (10.6)	34.5 (24.1)	73.1 (17.1)	64.5 (21.9)
p ^a		.15	.02	<.001	.01	<.001
RAAQ Attitudes towards well-being (11-55)						
≥ 40 (at median or above)	106	36.3 (9.9)	50.6 (10.7)	50.6 (27.9)	76.9 (15.7)	72.6 (20.7)
< 40 (below median)	65	34.4 (10.5)	46.9 (10.3)	39.4 (24.8)	76.0 (15.9)	70.7 (20.4)
p ^a		.24	.03	.009	.71	.57
RAAQ Acceptance (11-55)						
≥ 38 (at median or above)	90	37.2 (10.8)	50.8 (10.6)	54.7 (27.4)	78.2 (15.9)	76.6 (18.3)
< 38 (below median)	81	33.8 (9.2)	47.3 (10.5)	37.2 (24.0)	74.7 (15.5)	66.6 (21.6)
p ^a		.03	.03	<.001	.15	.001
RABQ Adherence to fluid restrictions (11-55)						
≥ 39 (at median or above)	95	36.2 (10.5)	49.5 (11.2)	48.2 (26.4)	76.5 (16.8)	73.3 (21.1)
< 39 (below median)	76	34.8 (9.8)	48.7 (9.9)	44.2 (28.3)	76.6 (14.5)	70.0 (19.7)
p ^a		.35	.62	.34	.98	.30
RABQ Adherence to K/P (5-25)						
≥ 20 (at median or above)	107	36.0 (10.3)	48.8 (11.2)	44.1 (28.3)	77.6 (14.6)	70.4 (21.8)
< 20 (below median)	64	34.8 (10.0)	49.7 (9.8)	50.2 (25.1)	74.8 (17.6)	74.3 (18.0)
p ^a		.46	.59	.16	.27	.23
RABQ Adherence to Na (2-10)						
≥ 9 (at median or above)	94	34.2 (10.7)	50.1 (10.9)	47.5 (27.9)	75.2 (17.3)	70.1 (23.0)
< 9 (below median)	77	37.3 (9.3)	48.1 (10.3)	45.0 (26.4)	78.2 (13.6)	74.0 (17.0)
p ^a		.047	.22	.54	.22	.21

Mean (SD). N=171 of 175 enrolled participants: 3 participants with incomplete KDQOL data and 1 participant with only KDQOL data were excluded from all analyses. N is slightly lower for some variables due to missing data. For all KDQOL subscales, a higher score indicates higher quality of life.

^aFrom t-tests. ^bFrom ANOVA.

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Differences in KDQOL scores by sociodemographic and clinical factors are reported in Table 2. The mean baseline (SD) KDQOL subscale scores were as follows for the cohort: Physical Composite Scale (PCS) was 35.6 (± 10.2), Mental Composite Scale (MCS) was 49.2 (± 10.7), Burden was 46.4 (± 27.2), Symptoms was 76.6 (± 15.8), and Effects was 71.9 (± 20.5). Participants age 60 and older had a significantly lower PCS score (33.3 ± 10.1) compared to those under 60 years of age (37.0 ± 10.0 , $p=0.02$), though none of the other subscale scores were significantly different between age groups. Male and female participants had similar baseline KDQOL subscale scores. Hispanic participants had significantly lower burden subscale scores (37.3 ± 23.3) compared to African-American and Caucasian/Asian participants (54.9 ± 28.1 and 49.0 ± 29.2 , respectively, $p<0.001$), though all other subscale scores were similar between racial/ethnic groups. Participants who reported that their primary language was Spanish had significantly lower PCS scores (32.4 ± 10.1) compared to those whose primary language was English or those who used both Spanish and English equally (36.8 ± 10.1 and 39.1 ± 8.9 , respectively, $p=0.02$), and they also had lower burden scores (33.7 ± 23.4 vs. 52.8 ± 27.7 and 43.3 ± 19.8 , $p<0.001$). The remaining subscale scores were not significantly different based on reported primary language. In terms of comorbid medical conditions, baseline PCS scores were significantly lower for diabetic participants compared to nondiabetics (33.6 ± 9.6 vs. 37.8 ± 10.4 , $p=0.006$), as well as for those with congestive heart failure (31.3 ± 8.9 vs. 36.8 ± 10.2 , $p=0.003$), and cardiovascular disease (30.6 ± 9.5 vs. 36.1 ± 10.1 , $p=0.03$). Lower symptom subscale scores were reported by those with congestive heart failure (70.9 ± 17.9 vs. 78.1 ± 14.8 , $p=0.01$), participants with cardiovascular disease (65.1 ± 21.6 vs. 77.8 ± 14.5 , $p=0.001$) and participants with non-skin cancer (65.9 ± 23.5 vs. 77.3 ± 14.9 , $p=0.02$) compared to those without these conditions. Burden subscale scores were lower only for participants with comorbid cancer compared to those without it (27.8 ± 19.8 vs. 47.7 ± 27.2 , $p=0.02$). There were no significant differences in baseline subscale scores based on dialysis vintage, presence of hypertension, dialysis setting (academic vs. private, for-profit), dialysis access type, or having a primary care physician at study entry.

The association between mean KDQOL subscale score and participant responses to patient-reported outcome instruments is found in Table 3. Participants with higher self-efficacy scores (defined as at or above the median) at baseline had significantly higher KDQOL-36 subscale scores compared to those who scored below the median of self-efficacy at baseline ($p<0.001$, see Table 3). Participants who reported moderate to severe depressive symptoms on the PHQ-9 had significantly lower KDQOL subscale scores at baseline compared to those who reported no or mild depressive symptoms on the PHQ-9 ($p<0.05$, see Table 3). Participants with adequate health literacy reported higher QOL than those with inadequate or marginal health literacy for all subscales except for PCS ($p<0.05$ except for PCS, Table 3). The relationship between baseline medica-

tion adherence scores and KDQOL-36 was less consistent, with participants with low medication adherence scores reporting lower baseline KDQOL scores on the MCS and symptoms subscales but none of the others, compared to those with medium or high medication adherence scores ($p<0.05$). On the CAHPS, nephrologists' communication and caring appeared to be most strongly associated with baseline KDQOL-36 scores, with those responding at or above the median on this measure also reporting significantly higher subscale scores of MCS, burden, and effects, compared to those whose response was below the median ($p<0.05$, Table 3). Participant responses to the RAAQ acceptance measure appeared to be consistently associated with baseline KDQOL subscale scores, with those responding at or above the median on this measure reporting higher subscale scores in PCS, MCS, burden, and effects, compared to those responding below the median ($p<0.05$, Table 3). RAAQ attitudes towards social restrictions were also associated with 4 of the 5 KDQOL subscales. Those responding at or above the median on this measure had significantly higher KDQOL subscale scores for MCS, burden, symptoms, and effects, compared to those with responses below the median ($p<0.05$, Table 3). Regarding the RAAQ attitudes towards well-being measure, participants with scores at or above the median reported better KDQOL-36 scores on the MCS and burden subscales, but none of the others, compared to those with responses below the mean ($p<0.05$, Table 3). Adherence to sodium restrictions was associated with PCS ($p<0.05$) but not with any of the other subscales. There were no differences in KDQOL subscale score based on hemodialysis knowledge as assessed by the Chronic Hemodialysis Survey (CHeKS), global rating of kidney doctors as assessed by CAHPS, global rating of dialysis staff as assessed by CAHPS, global rating of dialysis center as assessed by CAHPS, or adherence to fluid restriction or potassium or phosphorus restriction as assessed by the RABQ.

Discussion

While QOL has been described previously within the ESRD population and is lower than that of the general population, [5-7] little is known about racial/ethnic differences in QOL among ESRD patients and the association with other patient-reported outcomes. In general, individuals from racial/ethnic minority groups report more difficulty with care coordination than non-Hispanic whites, which potentially contribute to the risk of hospital readmissions and negative health outcomes[23]. In our sample of a predominantly minority and lower income cohort of hemodialysis patients, we found significant disparities in QOL based on ethnicity and preferred primary language other than English. Additionally, we found associations between low QOL and low health literacy, low self-efficacy, depressive symptoms, some measures of low patient satisfaction with care, and lack of adherence to dietary restrictions associated with ESRD.

Previous studies of racial/ethnic differences in QOL in ESRD patients have shown that African-Americans report better

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QOL than non-African-Americans [24-26]. We are unaware of studies that have specifically examined differences in QOL between African-American and Hispanic ESRD patients, or according to language preference. In our study, Hispanic participants and those who reported primary Spanish language preference had significantly lower burden QOL scores compared with African-American participants. We do not know to what extent the cultural and linguistic barriers between providers and patients may contribute to this difference and whether the implementation of a PCMH-KD can be leveraged to improve this patient-reported outcome among Spanish-speaking Hispanic ESRD patients [27].

Our study demonstrated that participants with low health literacy and depressive symptoms reported worse QOL at baseline among almost all subscales of KDQOL-36. Both are prevalent among the U.S. ESRD population, and low health literacy and moderate-to-severe depression are known to be associated with increased mortality in ESRD patients [28,29]. Unfortunately, neither health literacy nor depression are readily addressed using the current ESRD care model, and thus both represent an opportunity for improved care using a PCMH-KD care model.

In summary, the ESRD population in the U.S. represents a patient population with a high burden of comorbid illness, a current care framework that is in itself burdensome, and a high prevalence of poor patient-reported outcomes such as quality of life, depression, and acceptance of the current care model. In this study focusing on a sample of predominantly minority patients, we have identified a subgroup of ESRD patients who are at further risk for poor outcomes including Hispanic patients, Spanish-speaking patients, and those with poor health literacy and depression. Despite high Medicare expenditures on the ESRD population, morbidity, mortality, and overall care burden remains high in ESRD patients. The need for enhanced care coordination among Medicare patients is evident by a decision by the Centers for Medicare and Medicaid Services (CMS) to compensate primary care providers for additional visits for those patients with two or more co-morbid conditions[30]. Further research on improved care models, particularly, PCMH-KD, are needed to address poor outcomes and improve patient quality of life.

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