Received: 15 September 2021 | Revised: 6 March 2022 | Accepted: 24 March 2022

DOI: 10.1111/hdi.13013

ORIGINAL ARTICLE

Quality of Life, Outcomes

Changes in patient activation in people starting dialysis: A prospective longitudinal, observational study

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Abstract

Introduction: Increased patient activation is associated with improved health outcomes; however, little is known about patient activation in people with end-stage kidney disease at the start of their dialysis journey. This study aimed to measure activation status changes over the first 4 months of dialysis.

Methods: Prospective, longitudinal, and observational study. Incident patients initiating dialysis at 25 in-center hemodialysis and 17 home dialysis programs across three US states managed by the same dialysis provider completed the 13-item Patient Activation Measure (PAM-13) survey at baseline (month 1 after commencement of dialysis) and follow-up (month 4). The survey yields a score (0–100) that corresponds to four levels (1–4), with higher scores or levels indicating higher activation.

Findings: One hundred eighty-two participants (139 center, 43 home) completed both baseline and follow-up surveys. Mean age was 60 ± 15 years, 40% female. Mean PAM-13 scores were 65.1 ± 16.8 and 64.8 ± 17.8 at baseline and follow-up, respectively; mean intraindividual change: −0.3 ± 17.3. The proportions of patients at levels 1–4 at baseline were 11%, 23%, 35%, and 31% respectively. At follow-up, 50%, 64%, 52%, and 37% of participants at levels 1–4, respectively, changed to a different PAM level (Spearman correlation = 0.47; $p < 0.001$). Home dialysis was associated with higher PAM scores when compared to in-center hemodialysis in multivariable analyses, adjusted for sociodemographic variables, comorbidities, and predialysis nephrology care ($\beta = 5.74$, 95% confidence intervals [CI]: 0.11–11.37 and 9.02, 95% CI: 3.03–15.02, at baseline and follow–up, respectively).

Discussion: Although aggregated group scores and levels remained stable, intra-individual patient activation changed significantly during the first 4 months of dialysis. This novel finding is foundational to future projects aiming to design interventions to improve patient activation.

KEYWORDS
dialysis-dependent kidney disease, end-stage kidney disease, hemodialysis, incident dialysis patients, PAM, patient activation, peritoneal dialysis, self-management

INTRODUCTION

People commencing dialysis pass through a major transition in their lives, which includes changes to their diet and fluid intake, medications, scheduling activities around dialysis, and interacting with a new health care team.[1] Navigating this new life, incident dialysis patients need to integrate information provided by the health care team and make decisions that align with their personal values and preferences.[2] This transitional period requires a patient and family to be responsive and active to undertake necessary changes.

Patient activation is a concept that describes the patient's readiness, willingness, and ability to manage their own health and care, and incorporates three domains: knowledge, skills, and confidence.[3] Activation is positively associated with healthy behaviors such as exercise and diet. Activated people are more likely to follow-up with their doctor visits and to adhere to their medications.[4] They are more likely to have a healthier body mass index, HbA1c, and blood pressure.[5] There are fewer emergency room visits and unplanned hospitalizations among activated people, and they have a lower cost of care.[6,7] Reported satisfaction with care, even from the same provider, is higher among people with high activation than with less activation.[8]

Patient activation has been studied in multiple chronic diseases such as diabetes, heart failure, and cancer.[9,10] Yet, research is limited in the kidney disease field, and more so in patients on dialysis.[11] In a British study of specifically predialysis patients, 59% were found to score low in activation (levels 1 and 2).[12] Center hemodialysis (HD) patients reported lower activation (53% with levels 1 and 2) than peritoneal dialysis patients (32%), chronic kidney disease patients (40%), and those with kidney transplant (25%).[13] A recent US study reported that 37% of prevalent HD patients had low activation (levels 1 and 2).[14] Notwithstanding this marked differences in reported Patient Activation Measure (PAM) scores between predialysis and dialysis cohorts, few studies have reported longitudinal changes in this population and no studies have measured activation at the start of a person's dialysis journey.

The US Center for Medicare and Medicaid Services (CMS) has selected an increase in PAM score as a quality metric in the Advancing American Kidney Health (AAKH) initiative.[15] Contained in this proposition is the repeat examination of people with PAM levels of 1–3 (lower PAM levels) while not re-examining level 4. The decision not to include measuring level 4 in follow-up surveys may have implications for people if they decrease their activation and self-management capacity. Thus, the examination of whether people change activation score over time requires attention.

The commencement of dialysis is a critical time in a person's health journey. People starting center dialysis may assimilate into an inactive recipient of care, rather than an activated self-manager who is ready, willing, and able to manage their own health and care. In contrast, others commencing dialysis may learn the knowledge and develop the skills to confidently manage their own health care and be highly activated. We sought to explore the activation status of incident dialysis patients at start of dialysis and at month 4, with the hypothesis that patient activation may change in the first 4 months of dialysis with current standard of care. Understanding these changes will help tailor individualized care in the early stages of dialysis in our quest to support dialysis patient self-management.

MATERIALS AND METHODS

Study design and participants

In this longitudinal, observational study, patient activation was measured in all incident dialysis patients initiating dialysis care at 25 center HD and 17 home dialysis facility programs under the management of one nonprofit dialysis organization in the United States; 35 centers in total: 18 centers provided center HD only, 10 home only, and 7 provided both modalities. These centers were in California (27 centers), Texas (5 centers), and Tennessee (3 centers). Activation was measured using the PAM 13-item survey (PAM-13), which is further described below. Surveys were completed at baseline two time points: first month of dialysis (baseline survey), and during the fourth month of dialysis (follow-up survey).

Individuals admitted to facilities participating in the study during the recruitment period, who were identified as end-stage kidney disease on the End Stage Renal Disease Medical Evidence Report (form 2728), and who started dialysis no more than 3 weeks prior to identification were included in the study. Individuals younger than 18 years, those transitioning to dialysis after kidney transplant failure, and those unable to participate because of

cognitive impairment or an active psychological condition as determined by the social worker were excluded.

Recruitment started on June 19, 2019 and completed when a target recruitment goal was reached on December 11, 2019 (sample size details below). The study was completed with submission of the last follow-up survey on April 3, 2020, see Figure 1.

Outcome measures

Study outcomes were (1) patient activation scores at month 1 of dialysis initiation (baseline) and at month 4 (follow-up), (2) the within-patient change in activation scores among incident dialysis patients over time from baseline to follow-up with current standard of care, (3) factors associated with activation scores, and (4) factors associated with change in activation scores over time. We also reported on activation levels at baseline and follow-up, and changes in activation levels over time.

DATA SOURCES AND DEFINITIONS

Patient activation data

PAM-13 is a 13-item instrument that measures knowledge, skills, and confidence for self-management among patients who have a chronic illness. Components of the survey assess the belief that an active role is important, level of confidence and knowledge to take action, ability to take action, and ability to stay the course under stress are important in self-management.[16] The survey yields a score between 0 and 100, with higher scores denoting higher activation. Scores correspond to four activation levels: level 1 (score $\leq$ 47.0) indicates participant not believing activation is important, level 2 (47.1–55.1) indicates lack of confidence and knowledge to take action, level 3 (55.2–72.4) beginning to take action, and level 4 ($\geq$72.5) taking action or staying the course.[6] Studies also dichotomized activation levels to low and high (low = level 1 and 2, high = level 3 and 4).[17]

We collected the PAM-13 surveys at two time points. Baseline survey was collected during month 1, specifically between day 8 and day 21 of commencing dialysis. Follow-up surveys were administered during the fourth month of dialysis, specifically between 90 and 120 days following commencement of dialysis, see Figure 1b. We avoided collection of data in the first week after dialysis initiation because of the stress related to the dialysis initiation[18,19] and because of recommendation to PAM-13 surveys following a new diagnosis.[20]

Social workers at participating centers invited patients to the study and introduced the survey with the use of a standard patient information script. When a patient's language was not English, a staff member who

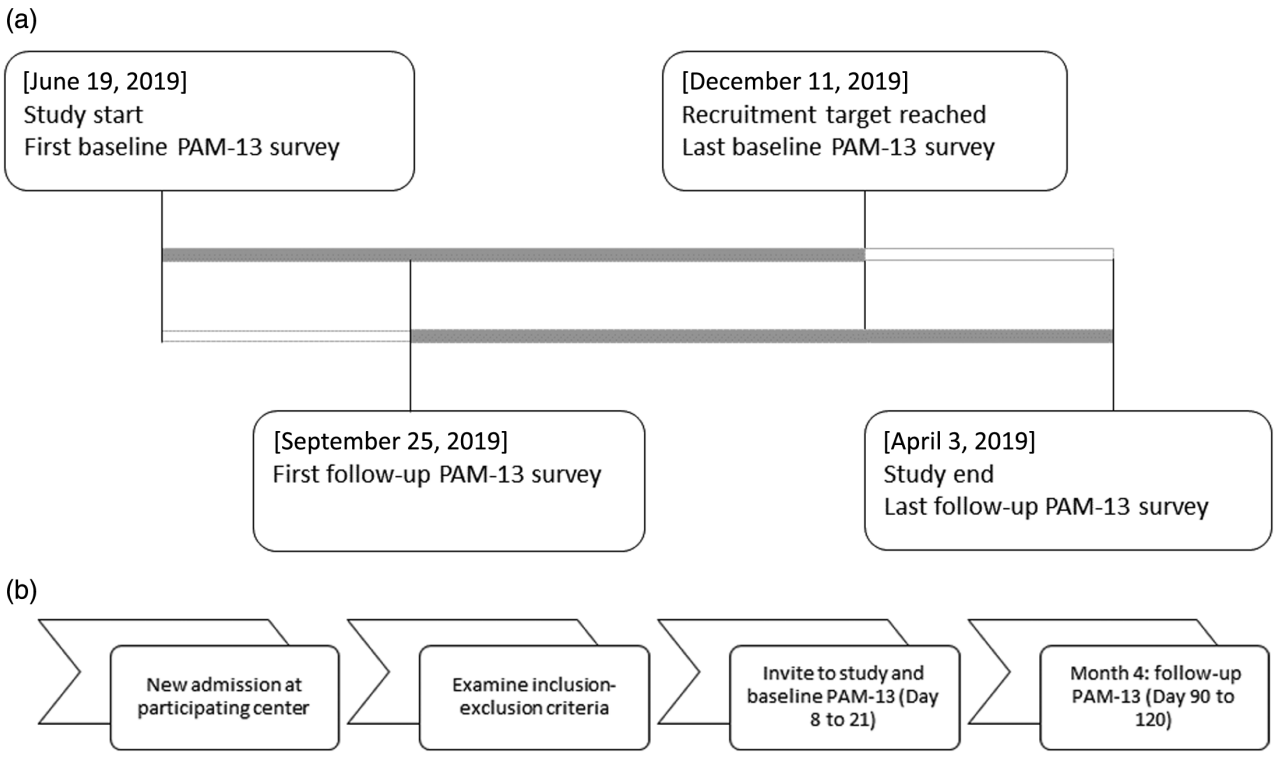

FIGURE 1 Study timelines. (a) Timelines of the baseline and follow-up surveys. (b) Participant's timeline

spoke the language was asked to read the patient information script provided in that language. Patients either completed the survey independently or with the assistance of the clinician in line with PAM-13 survey guidelines. Patients who did not complete the baseline survey were withdrawn from the study. We recorded reasons for not completing the survey at either time point.

Exposures

Sociodemographic and clinical variables were collected from the provider's electronic health record system. Based on the review of the literature and expert opinion, subgroups were defined a priori for dialysis modality (home, in-center; reference [ref]: in-center), age group (<50, 50 to <70, 70+; ref: 70+), race (Black race vs. not; ref: not), ethnicity (Hispanic or Latinx vs. not Hispanic or Latinx, ref: not), medical coverage at start of dialysis (Medicare, Medicaid or no insurance, Commercial or other; ref: Medicare), employment status (employed or student vs. not; ref: not), educational level (less than high school diploma, high school diploma, some college or trade school or above; ref: less than high school diploma), and pre-dialysis nephrologist care (none or unknown, less than 6 months, 6 months or more; ref: none). We tested the association of PAM scores with comorbid conditions as presence versus absence of individual comorbid condition (hypertension, diabetes mellitus, atherosclerotic heart disease, other cardiac disease, cerebrovascular disease, peripheral vascular disease, and alcohol or substance abuse) and number of comorbid conditions as continuous variable and as groups (one or less, two, three, and four or more).

Ethical approval was granted by an external institutional review board (Aspire IRB), with waiver of consent. Waiver of consent was granted on the bases of the low risk of participation, and because consenting may bias participation by particularly deterring those with low activation. The study was registered at ClinicalTrials.gov (Identifier: NCT04066140).

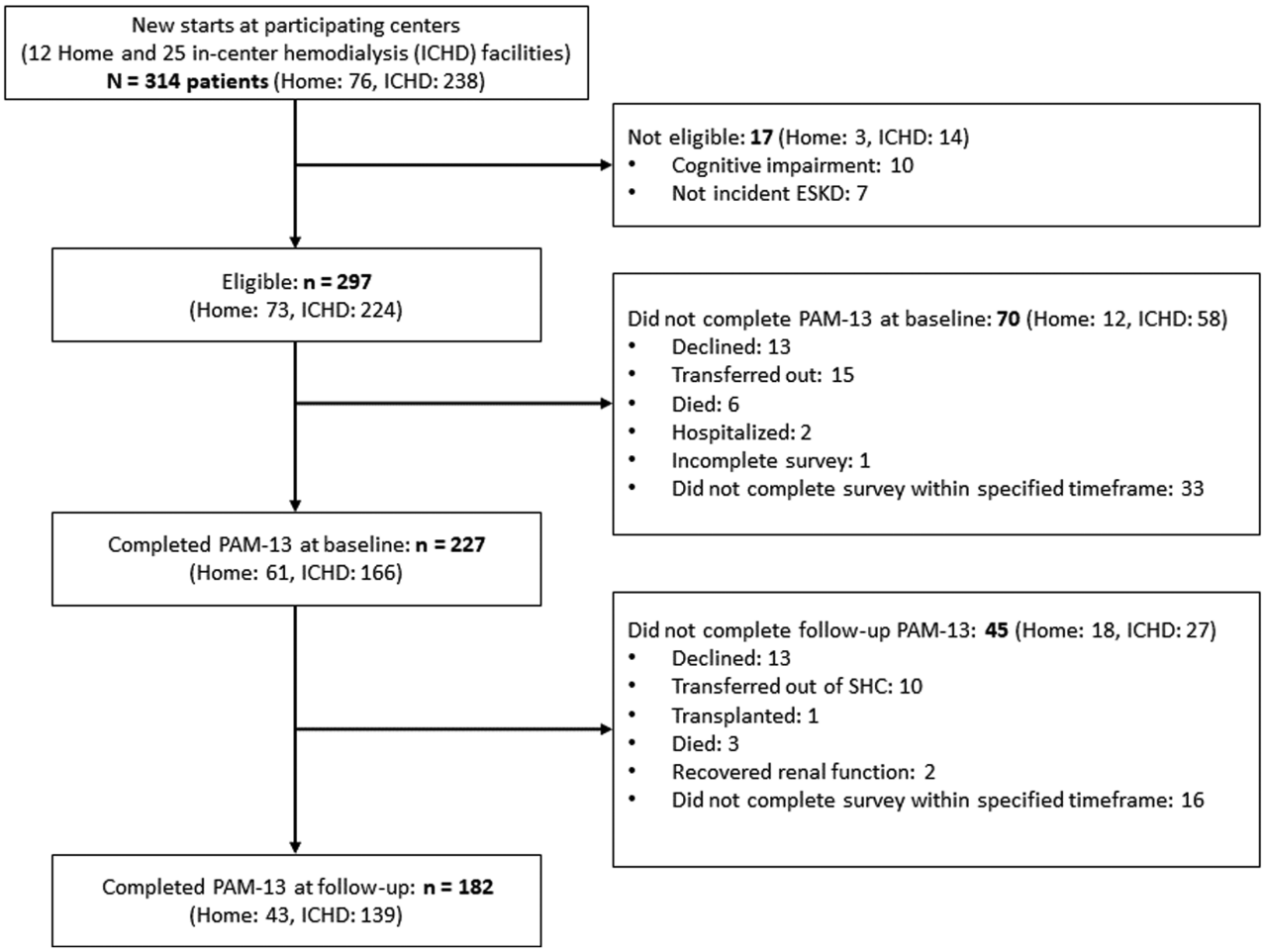

FIGURE 2 Study flow diagram. Baseline and follow-up surveys completed during the first and fourth month of dialysis, respectively. PAM-13, Patient Activation Measure 13-item survey

TABLE 1 Baseline characteristics of study participants

Characteristic	Group	Enrolled total: 227	Completed total: 182
Age (mean [SD]), years	-	60 [16]	60 [15]
Age group (years)			
	Less than 50	62 (27)	51 (28)
	50 to <70	91 (40)	71 (39)
	More than 70	74 (33)	60 (33)
Gender			
	Female	92 (41)	73 (40)
	Male	135 (60)	109 (60)
Race			
	White	160 (71)	126 (69)
	Asian	29 (13)	23 (13)
	Black/African American	28 (12)	25 (14)
	Native Hawaiian or Other Pacific Islander	6 (3)	5 (3)
	American Indian/Alaskan native	2 (1)	1 (1)
	Missing	2 (1)	2 (1)
Ethnicity			
	Hispanic or Latino	83 (37)	71 (39)
	Not Hispanic or Latino	144 (63)	111 (61)
Primary cause of kidney disease			
	DM	127 (56)	107 (59)
	Hypertension	40 (18)	32 (18)
	Glomerular disease	28 (12)	18 (10)
	Other	23 (10)	19 (10)
	Unknown	9 (4)	6 (3)
Comorbidities			
	Hypertension	191 (84)	157 (86)
	Diabetes mellitus	148 (65)	124 (68)
	Atherosclerotic heart disease	21 (9)	17 (9)
	Other cardiac	55 (24)	41 (23)
	Cerebrovascular disease	14 (6)	13 (7)
	Peripheral vascular disease	13 (6)	11 (6)
	Alcohol/substance abuse	5 (2)	3 (2)
Medical coverage			
	Medicaid/none	55 (24)	43 (24)
	Medicare	81 (36)	66 (37)
	Commercial/other	91 (40)	73 (40)
Employment status			
	Employed or student	41 (18)	33 (18)
	Unemployed	184 (81)	149 (82)
	Missing	2 (1)	0

(Continues)

TABLE 1 (Continued)

Characteristic	Group	Enrolled total: 227	Completed total: 182
Education level			
	Less than high school diploma	65 (29)	55 (30)
	High school	84 (37)	67 (37)
	College or trade school	77 (34)	60 (33)
	Missing	1 (0)	0
Predialysis nephrologist care			
	None or unknown	53 (23)	41 (23)
	Less than 6 months	43 (19)	37 (20)
	Six months or above	131 (58)	104 (57)

Note: Numbers are n (percent) except for the age variable (mean [standard deviation]).

Statistical methods

Baseline characteristics are presented as means and standard deviations (±SD), and as numbers and percentages for continuous and categorical data, respectively. Activation status results are presented for participants who completed both the baseline and follow-up surveys (per protocol analysis). We reported the mean ± SD of scores at baseline and follow-up and change in activation score (follow-up score minus baseline score), and 95% confidence interval (CI) of change in score.

Univariate and multivariable analysis of variance (ANOVA) was employed to evaluate the variation in scores for subgroups at the baseline and follow-up time points. We forced the modality and age group variables into the multivariable models and added variables that had a p value of ≤0.15 in univariate analyses. Variables were allowed to remain in the model if they had a p value of ≤0.05. We reported the coefficients and 95% CIs for identified factors. A paired t-test was used to evaluate the difference between baseline and follow-up scores for the whole group. Pearson and Spearman correlation coefficients were used to evaluate the associations between baseline and follow-up scores and with baseline and follow-up levels, respectively.

Repeated measures analysis was employed to identify factors associated with the changes in scores from the baseline to the follow-up time point. In the multivariable repeated measures analysis, we forced the dialysis modality and age group variables into the model, and added between subjects variables that had a p value of ≤0.15 in univariate analyses. Between subjects variables were allowed to remain in the model if they had a p value of ≤0.05.

Sample size calculations were performed as follows. We estimated that 60 participants completing the study were needed to detect a clinically meaningful difference in PAM scores of six points, assuming a standard deviation of 14, 0.90 power, and 0.05 alpha.[21–23] It was further determined that a sample size of 122 subjects was required for a multivariable analysis of 11 independent variables, assuming an effect size of 0.15, power = 0.8 and alpha = 0.05. Allowing an attrition rate of about 40% (recovery, transfer out of participating centers, transplant, death, decline to complete follow-up survey), the target recruitment was 200 patients to achieve at least 122 subjects completing the surveys at both time points.

There were no missing data in the sample of participants who completed both surveys. All statistical analyses were performed using SAS 9.4 (SAS Institute).

RESULTS

Study flow

During the study period, a total of 314 patients started dialysis at participating centers, 307 were incident dialysis patients. Ten patients were excluded because of cognitive impairment. Of the eligible 297 patients, 69 patients did not complete the baseline survey: 13 declined, 15 transferred out to another center, 6 died, 2 hospitalized, and 33 missed the completion window. One patient provided an incomplete survey. Of 227 patients who completed the baseline survey, 45 did not complete the follow-up survey (13 declined, 16 not available because of recovery of renal function [2], transplanted [1], or transferred out to another center [10]) and 16 did not complete the survey within the designated time window. A total of 182 participants completed the follow-up survey at month 4. The study flow with reasons for ineligibility, nonparticipation, and noncompletion is shown in Figure 2.

Baseline characteristics

The mean age was 60 ± 15 years, and 40% were female. The predominant primary cause of kidney disease was

TABLE 2 Baseline and follow-up activation scores

Variable	Baseline (month 1) Mean ± SD	Baseline (month 1) Pr > F for subgroup variable[a]	Follow-up (month 4) Mean ± SD	Follow-up (month 4) Pr > F for subgroup variable[a]
Whole group	65.1 ± 16.8		64.8 ± 17.8	
Dialysis modality		0.05***		0.003***
Home dialysis	69.4 ± 14.5		71.1 ± 15.9	
In-center dialysis	63.7 ± 17.3		62.7 ± 18.0	
Age group		0.37		0.10*
<50	67.1 ± 14.6		68.4 ± 18.3	
50 to <70	65.7 ± 17.3		65.3 ± 17.1	
70+	62.7 ± 17.9		61.2 ± 18.0	
Sex		0.47		0.95
Female	66.2 ± 16.4		64.7 ± 18.3	
Male	64.4 ± 17.1		64.9 ± 17.6	
Race		0.99		0.99
Black/African American	65.1 ± 15.7		64.8 ± 15.4	
Not Black/African American	65.1 ± 17.0		64.8 ± 18.2	
Ethnicity		0.47		0.59
Hispanic or Latinx	64.0 ± 16.7		65.7 ± 19.4	
Not Hispanic or Latinx	65.9 ± 16.9		64.2 ± 16.9	
Medical coverage		0.23		0.003***
Medicaid/none	64.7 ± 17.0		66.3 ± 21.7	
Medicare	62.7 ± 16.6		59.1 ± 14.0	
Commercial/other	67.6 ± 16.8		69.1 ± 17.3	
Employment status		0.06**		0.05***
Employed/student	70.2 ± 15.1		70.4 ± 15.8	
Not employed/student	64.0 ± 17.0		63.6 ± 18.1	
Educational level		0.17		0.01***
Less than high school diploma	62.4 ± 18.4		61.4 ± 20.6	
High school	64.6 ± 16.3		62.7 ± 15.4	
College or trade school	68.2 ± 15.6		70.2 ± 16.7	
Predialysis nephrologist care		0.01***		0.13
None or unknown	59.1 ± 15.2		61.4 ± 20.0	
Less than 6 months	63.6 ± 18.8		62.2 ± 18.2	
Six months or above	68.1 ± 16.1		67.1 ± 16.6	
Comorbid conditions				
Hypertension		0.04***		0.32
Yes	66.2 ± 17.3		65.3 ± 18.0	
No	58.6 ± 11.6		61.5 ± 16.6	
Diabetes mellitus		0.94		0.92
Yes	65.1 ± 17.5		64.7 ± 18.9	
No	65.3 ± 15.3		65.0 ± 15.6	

(Continues)

TABLE 2 (Continued)

Variable	Baseline (month 1) Mean ± SD	Baseline (month 1) Pr > F for subgroup variable[a]	Follow-up (month 4) Mean ± SD	Follow-up (month 4) Pr > F for subgroup variable[a]
Atherosclerotic heart disease		0.62		0.88
Yes	67.0 ± 19.2		65.4 ± 18.2	
No	64.9 ± 16.7		64.7 ± 17.9	
Other cardiac disease		0.93		0.20
Yes	65.3 ± 18.8		61.6 ± 19.9	
No	65.1 ± 16.3		65.7 ± 17.2	
Cerebrovascular disease		0.86		0.62
Yes	65.9 ± 16.4		62.5 ± 15.3	
No	65.1 ± 16.9		65.0 ± 18.1	
Peripheral vascular disease		0.81		0.98
Yes	66.3 ± 20.7		64.7 ± 15.0	
No	65.0 ± 16.6		64.8 ± 18.1	
Alcohol or substance abuse		0.19		0.67
Yes	52.7 ± 3.4		69.2 ± 27.0	
No	65.3 ± 16.9		64.7 ± 17.8	
Number of comorbid conditions		0.79		0.93
≤1	65.3 ± 14.7		64.2 ± 15.5	
2	64.6 ± 17.1		65.6 ± 17.8	
3	64.6 ± 18.7		64.0 ± 22.6	
4 or more	70.0 ± 19.7		62.8 ± 14.9	

Notes: N = 182. *, **, ***: statistically significant at 0.15, 0.10, and 0.05 levels, respectively.
[a]Univariate ANOVA of PAM scores.

diabetes (59%), followed by hypertension (18%). The majority were not employed (82%). Educational level was less than high school, high school, and college in 30%, 37%, and 33%, respectively. Seventy-seven percent of the participants had some predialysis nephrologist care. Eligible patients who were not included (n = 70; 12 on home dialysis, and 58 on center HD), were older (mean age 68 ± 14), and predominantly male (n = 50 [71%]). The distribution of baseline characteristics among participants enrolled in the study (completed at least the baseline survey) and those who completed the study (baseline and follow-up surveys) is shown in Table 1.

Activation status at months 1 and 4

The mean PAM scores were 65.1 ± 16.8 and 64.8 ± 17.8 at baseline and follow-up, respectively. The mean scores for home dialysis and in-center dialysis were 69.4 ± 14.5 and 63.7 ± 17.3 respectively at baseline, and 71.1 ± 15.9 and 62.7 ± 18.0 at follow-up. Distribution of scores across other subgroups at baseline and follow-up is shown in Table 2. The mean score at baseline for all 227 participants who completed at least the baseline PAM-13 survey was 64.5 ± 16.1. Correspondingly, 11%, 23%, 35%, and 31% participants were at levels 1–4 respectively at baseline. The corresponding percentages at follow-up were 11%, 24%, 32%, and 34%.

Change in patient activation from months 1 to 4

The mean change in PAM score from baseline to follow-up was −0.3 ± 17.3, 95% CI: −2.9 to 2.2, $p = 0.80$. There was only a moderate correlation between baseline and follow-up PAM scores; Pearson correlation coefficient: 0.5, $p < 0.0001$. Figure 3 shows the relationship between baseline and follow-up PAM scores. Changes in activation score for patients at levels 1–4 were 5.1 ± 15.9,

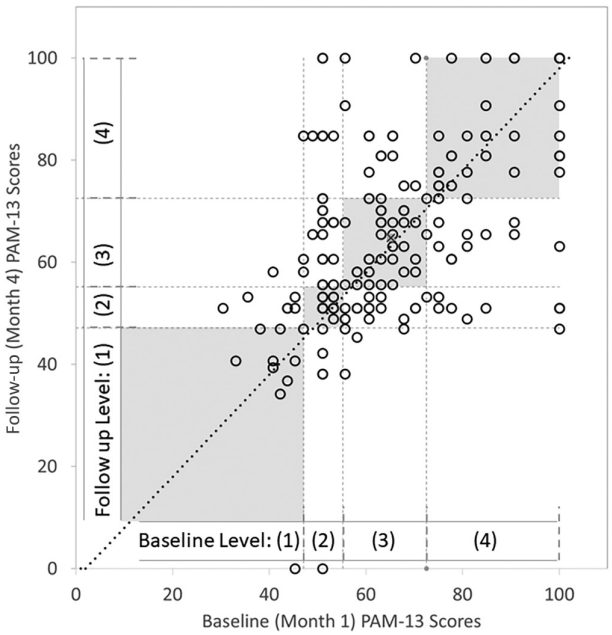

FIGURE 3 Relationship between baseline and follow-up patient activation scores. Correlation coefficient (R) = 0.5, $p < 0.0001$. Diagonal dotted line indicates where points would land on the graph if there was no change from baseline to follow-up scores. Points above this line indicate improvement and points below the line indicate deterioration in follow-up scores. Shaded areas indicate the same level for baseline and follow up scores. Dashed gray lines indicate the boundaries between the four PAM levels. × mark indicates mean score

8.5 ± 17.8, 1.2 ± 13.4, and − 10.6 ± 16.7, respectively. Table 3A shows mean activation scores at each time point and change from baseline to follow-up by baseline activation level. Table 3B shows follow-up activation levels for participants at each baseline activation level. There was a weak correlation between baseline and follow-up activation levels; Spearman correlation = 0.47; $p < 0.001$. Of participants at levels 1–4 at baseline, only 50%, 36%, 48%, and 63% remained at their respective levels at follow-up. Change from baseline to a *higher* level of activation at follow-up was noted in 50%, 52%, and 25% in participants at levels 1–3 at baseline, respectively. Change from baseline to a *lower* level of activation was noted in 12%, 26%, and 38% in participants at levels 2–4, respectively. In all, 50% of people reported changed activation status from months 1 to 4.

Factors associated with baseline PAM scores

In univariate analysis, dialysis modality ($p = 0.05$) and predialysis nephrologist care ($p = 0.01$) were significantly associated with baseline PAM scores. At follow-up, modality ($p = 0.003$), medical coverage ($p = 0.003$), employment status ($p = 0.05$), and educational level ($p = 0.01$) were associated with PAM scores. Linear regression coefficients and 95% CIs of these associations

TABLE 3 Activation status and change over time by baseline activation level

(A) Changes in activation scores

Baseline activation level	n	Baseline score[a]	Follow-up score[a]	Change in score[a]
1	20	42.2 ± 4.8	47.3 ± 15.6	5.1 ± 15.9
2	42	51.5 ± 1.2	60 ± 17.6	8.5 ± 17.8
3	64	62.8 ± 4.5	64 ± 13.4	1.2 ± 13.4
4	56	86.2 ± 10.4	75.6 ± 16.6	−10.6 ± 16.7

(B) Changes in activation levels

Baseline activation levels		Follow-up activation levels, N (Col %)			
	N (Col %)	Level 1	Level 2	Level 3	Level 4
Level 1	20 (11)	10 (50)	6 (30)	3 (15)	1 (5)
Level 2	42 (23)	5 (12)	15 (36)	13 (31)	9 (21)
Level 3	64 (35)	4 (6)	13 (20)	31 (48)	16 (25)
Level 4	56 (31)	1 (2)	9 (16)	11 (20)	35 (63)
Total N (Row %)	182	20 (11)	43 (24)	58 (32)	61 (34)

Notes: (A) Activation scores changes by different magnitudes in patients at different baseline levels. (B) Significant changes from baseline to follow-up activation levels were observed. Shaded cells indicate that follow-up activation level remained similar to baseline activation level. Spearman correlation: 0.47, $p < 0.0001$.

Abbreviations: Col %, column percent.

[a]Mean ± standard deviation.

TABLE 4 Factors associated with patient activation scores

	Association with baseline scores				Association with follow-up scores			
	Univariate analysis		Multivariable analysis		Univariate analysis		Multivariable analysis	
Variable	***β* (95% CI)**	***p***	***β* (95% CI)**	***p***	***β* (95% CI)**	***p***	***β* (95% CI)**	***p***
Home dialysis (Ref: in-center hemodialysis)	5.71 (0.14 to 11.28)	0.05	5.74 (0.11 to 11.37)	0.05	9.11 (3.14 to 15.09)	0.003	9.02 (3.03 to 15.02)	0.004
Age group								
<50	4.34 (−1.93 to 10.62)	0.18	3.96 (−2.27 to 10.19)	0.21	7.19 (0.58 to 13.81)	0.03	6.62 (0.13 to 13.10)	0.05
50 to <70	3.00 (−2.78 to 8.78)	0.31	3.48 (−2.27 to 9.23)	0.24	4.13 (−1.96 to 10.22)	0.19	4.86 (−1.12 to 10.84)	0.11
70+ (Ref)	Ref	-	Ref	-	Ref	-	Ref	-
Female (Ref: male)	1.84 (−3.15 to 6.83)	0.47	-	-	−0.16 (−5.46 to 5.15)	0.95	-	-
Race: Black (Ref: not)	−0.05 (−7.17 to 7.06)	0.99	-	-	0.05 (−7.50 to 7.61)	0.99	-	-
Ethnicity: Hispanic or Latinx (Ref: not)	−1.86 (−6.88 to 3.15)	0.47	-	-	1.45 (−3.88 to 6.77)	0.59	-	-
Medical coverage			-	-			-	-
Medicaid/none	2.00 (−4.44 to 8.44)	0.54	-	-	7.19 (0.51 to 13.86)	0.04	-	-
Medicare (Ref)	Ref	-	-	-	Ref	-	-	-
Commercial/other	4.89 (−0.69 to 10.47)	0.09	-	-	10.00 (4.22 to 15.79)	< 0.001	-	-
Employed or student (Ref: not)	6.16 (−0.13 to 12.45)	0.06	-	-	6.86 (0.19 to 13.53)	0.05	-	-
Educational level			-	-			-	-
Less than high school diploma (Ref)	Ref	-	-	-	Ref	-	-	-
High school	2.27 (−3.69 to 8.24)	0.46	-	-	1.24 (−5.01 to 7.48)	0.70	-	-
College or trade school	5.85 (−0.27 to 11.97)	0.06	-	-	8.79 (2.38 to 15.20)	0.01	-	-
Predialysis nephrologist care			-	-			-	-
None or unknown (Ref)	Ref		-	-	Ref	-	-	-
Less than 6 months	4.54 (−2.78 to 11.87)	0.23	-	-	0.84 (−7.05 to 8.72)	0.84	-	-
Six months or more	8.99 (3.03 to 14.95)	0.004	-	-	5.72 (−0.69 to 12.13)	0.08	-	-

Notes: N = 182. Variables tested as candidates for the multivariable model: forced, dialysis modality, age groups; other variables included in the multivariable model for baseline associations (backward elimination): employment, and predialysis nephrologist care, hypertension. Other variables included in the multivariable model for follow-up scores: education, medical cover, employment, and predialysis nephrologist care. Multivariable model for baseline scores *R*-squared: 0.03, adjusted *R*-squared: 0.02. Multivariable model for follow-up scores *R*-squared: 0.07, adjusted *R*-squared: 0.06.
Abbreviations: *β*, regression coefficient; CI, confidence interval.

TABLE 5 Factors associated with change in PAM score over time (repeated measures ANOVA)

	Univariate analysis					Multivariable analysis (interaction with time variable)		
Effect	df	F value	Pr > F for between subjects variable	Pr > F time variable	Pr > F interaction of time with between subjects variable	df	F value	Pr > F
Baseline modality	1	7.92	0.005***	0.81	0.36	1	0.75	0.39
Age group	2	2.14	0.12*	0.85	0.69	2	0.33	0.72
Gender	1	0.14	0.71	0.69	0.45	-	-	-
Black	1	0.00	1.00	0.88	0.98	-	-	-
Hispanic	1	0.01	0.93	0.98	0.21	-	-	-
Educational level	2	3.94	0.02***	0.83	0.42	-	-	-
Medical cover	2	4.46	0.01***	0.90	0.16	-	-	-
Predialysis nephrologist care	2	4.10	0.02***	0.98	0.54	-	-	-
Employment	1	5.20	0.02***	0.95	0.83	-	-	-

Notes: N = 182. *, **, ***: statistically significant at 0.15, 0.10, and 0.05 levels, respectively. Variables forced in the multivariable analysis: Baseline modality and age group. Other candidate variables were those significant at the 0.15 level in univariate analysis: education, medical cover, predialysis nephrology care, and employment.

are shown in Table 4 for baseline and follow-up scores, respectively. The adjusted R-squared results for these models were low, indicating that these variables explain very little of the variability of PAM scores.

Factors associated with a change in patient activation score over time

Using repeated measures analysis, none of the tested variables had a significant association with change in scores over time (interaction of time with between subjects variable) in univariate or multivariable analyses, see Table 5.

DISCUSSION

This is the first study to report the changes in individual activation status among incident dialysis patients during the first 4 months of dialysis. Half of all dialysis patients reported an increased or decreased activation status over this early period after dialysis initiation. This change in activation status has significance in relation to the proposal by CMS AAKH initiative to exclude patients with level 4 at baseline from follow-up surveys.[15] Firstly, approximately one-third of those at level 4 at baseline reported a reduced lower activation level at follow-up, with 18% at levels 1 and 2. This means ignoring these level 4 participants from follow-up surveys, as proposed by CMS, may miss an opportunity to identify patients who need attention. Secondly, given what appears to be a regression to the mean phenomena, with CMS methodology, improvement will be demonstrated because of removal of those at level 4 at baseline from the evaluation. Therefore, this will give a false impression of improving activation when this may not be the case. In our cohort, we observed less than 1 point average change in PAM score, but if we exclude baseline level 4 patients, the average score change is 4.2 (SD 15.6).

An important recent contribution to understanding activation reported the proportions of "prevalent" activation levels were very similar to our findings with 9%, 27%, 31%, and 32% in levels 1–4, respectively.[14] These comparable results may support the validity of this instrument across different dialysis populations. In saying that, a prevalent cross-sectional scan is limited in understanding the factors that influence activation changes in each individual person. The only other US study included only 19 participants on HD from a broader CKD sample and found patients with more advanced kidney disease had lower activation.[24] Further long-term studies may inform to what extent activation changes through a person's predialysis and dialysis journey.

As expected, activation scores were higher in people starting home dialysis and those who had predialysis nephrology care. In saying that, people with higher education attainment and those who are employed are likely to have predialysis nephrology care. Importantly, predialysis nephrologist care would in-turn increase knowledge and

self-management skills,[25] which is associated with increasing home dialysis likelihood.[26] At follow-up, predialysis nephrology care lost that association, and factors that were associated with activation were home modality, employment status, educational level, and medical coverage. At both time points, the only factor with significant association with activation was dialysis modality. The explained variance of the models was very low, indicating that these characteristics poorly explain the activation. Nevertheless, the finding of higher activation among home dialysis patients supports the face validity of the PAM-13 instrument in the dialysis population.

Activation can address the learned helplessness phenomenon that occurs when people commence center HD.[27] Early recognition of learned helplessness through low activation offers several opportunities to improve care delivery. Firstly, given that patients with low activation are less likely to engage with the health care system in response to signals of impending events, this group may benefit from more intensified surveillance and related interventions.[27] Secondly, our approach to education is best tailored to the patient's level of activation; for example, those with low activation can become overwhelmed with information, and need to be approached with small pieces of information repeatedly, focusing on small goals.[3] Those with high activation may only need pointing to the source of information and only when needed.[10] Thirdly, we need to develop programs to increase activation, such as motivational interviewing,[28] chronic disease self-management programs,[29,30] and involving the patient in their dialysis treatment.[31] These approaches can be enhanced by leveraging technology (telehealth), increasing patient's access to their own health records and measures such as patient reported outcomes.[27] These interventions have resulted in increased engagement[32] and confidence, reduced anxiety,[31] improved clinical outcomes,[30,33] improved patient-reported quality of life,[34] satisfaction with care,[35] increased satisfaction with modality decision making,[36] and potentially increased number of patients moving to home dialysis.[31]

The ultimate goal of our early dialysis care would be to increase a person's activation by increasing their knowledge, skills, and confidence so that they are able to manage their own health and health care. The expected improvements in healthy behaviors and ownership of one's health care is the essence of person-centered care, and will support the transition to value-based care and the achievement of the quadruple aim: better patient outcomes; improved clinical experience; improved patient experience; and lower costs.[27]

This study has several limitations and strengths. Data were obtained from 35 centers from three different states to improve generalizability. However, this is limited by the fact that all centers are under the management of the same dialysis provider, with the same dialysis induction processes, such as clinical pathways and patient education. In addition, baseline characteristics such as age, sex, employment status, and length of predialysis nephrologist care were similar to those of incident dialysis patients in the United States.[37] We did not aim to investigate the association with health care behaviors such as adherence to dialysis, or to health outcomes such as hospitalization. Identified associations do not indicate causation. We did not collect income, poverty, or zip code data, which may have limited our analysis. Nevertheless, this is the first to measure patient activation in incident dialysis patients, and the largest study on activation of dialysis patients in the United States to date. It is also the first study to report on changes over time associated with current standard of care with limited attrition. This study provides foundational information necessary for design of future projects, including exploratory and interventional studies in this field.

CONCLUSION

In this cohort of people starting dialysis, despite minimal aggregated group changes, we observed significant intra-individual changes in activation and self-management status over the first 4 months of dialysis. Further examination of these phenomena may assist in improving the self-management of people receiving dialysis. This information is the foundation of future projects aiming to design interventions to improve or maintain patient activation.

ACKNOWLEDGMENTS

We acknowledge patients who participated in this study and social workers at participating centers for their help in completing the surveys. We thank Jugjeet Atwal and Veronica Legg for their contribution to the administration of the study.

CONFLICT OF INTEREST

P Bennett: Consultant to Satellite Healthcare, Vifor Advisory Board, Amgen paid speaker. B Schiller: Employee of Satellite Healthcare, Advisory Board Quanta Medical and Rockwell, BOD Unicycive. A Carrasco: Past employee at Satellite Healthcare. All other coauthors are current employees of Satellite Healthcare and have no other disclosures.

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How to cite this article: Hussein WF, Bennett PN, Carrasco A, Sun S, Reiterman M, Watson E, et al. Changes in patient activation in people starting dialysis: A prospective longitudinal, observational study. Hemodialysis International. 2022;26(3):435–48. https://doi.org/10.1111/hdi.13013