Original Clinical Research Quantitative

Ethnic Differences in Health Literacy, Self-Efficacy, and Self-Management in Patients Treated With Maintenance Hemodialysis

Uchenna Ibelo[1] (iD), Theresa Green[2,3], Bejoy Thomas[4],
Sandra Reilly[3], and Kathryn King-Shier[3]

Abstract

Background: There is a gap in research investigating the potential impact of ethnicity on health literacy, self-efficacy, and self-management in patients treated with maintenance hemodialysis (MHD).

Objective: To explore (1) the associations between health literacy, self-efficacy, and self-management among outpatients with kidney failure receiving treatment with MHD, and (2) the differences in health literacy and self-efficacy based on characteristics of ethnicity (ie, physical resemblance and proficiency in the language of the host population), known to be associated with health care access and health outcomes.

Design: Cross-sectional

Setting: Outpatients receiving MHD at 7 adult hemodialysis centers in Calgary, Alberta from September 2014 to December 2014.

Patients: Participants were grouped into 2 groups based on a proposed 4-quadrant framework of a multicultural society. Quadrant 1 comprised outpatients with physical resemblance and first language of the host population (ie, white and English as a first language), whereas quadrant 4 participants comprised outpatients with physical resemblance and first language not of the host population (ie, non-white and first language other than English). A total of 78 patients ($n_{Q1} = 44$, $n_{Q4} = 34$) were included.

Measurements: Heath literacy, self-efficacy, and self-management were measured using the Health Literacy Questionnaire (HLQ), Strategies Used by People to Promote Health (SUPPH), and Patient Activation Measure-13 (PAM-13), respectively.

Methods: Convenience sampling was used to recruit participants at each of the 7 adult hemodialysis centers. All participants completed a study package, which included a demographic questionnaire, HLQ, SUPPH, and PAM-13. Spearman rho was calculated to identify correlations between patient activation level and HLQ and SUPPH scores. Independent *t* tests were performed to identify differences in HLQ and SUPPH scores between Q1 and Q4 participants. Stepwise regression was performed in other analyses to identify predictor variables of patient activation level.

Results: Statistically significant correlations were identified between patient activation level and the health literacy domains of "ability to actively engage with health care providers" ($r_{HLQ6} = .535$, $P < .001$), "ability to find good health information" ($r_{HLQ8} = .611$, $P < .001$), and "understanding health information well enough to know what to do" ($r_{HLQ9} = .712$, $P < .001$). There was a statistically significant difference between Q1 and Q4 participants in the health literacy domain of "ability to find good health information" ($P = .048$). "Understanding health information well enough to know what to do" and "actively managing health" were included in the final stepwise regression model, $F(2, 72) = 32.232$, $P < .001$.

Limitations: The cross-sectional design limits the generalizability of the results. The small sample size limits the power to identify significant associations and differences. Although English was not the first language of Q4 participants, all were proficient in English, meaning potential differences of a key subgroup of Q4 (ie, those who did not speak any English) were not captured.

Conclusion: The HLQ allowed for the creation of a health literacy profile of patients with end-stage kidney disease receiving treatment with MHD. The findings suggest possible associations between specific domains of health literacy and patient activation. Outpatients' representative of Q4 receiving treatment with MHD appear to struggle more with finding good health information, which may leave them at a disadvantage in the early phases of their self-management efforts. The findings highlight potential opportunities to better tailor patient care to support patients in their self-management, particularly for patients from ethnic minority backgrounds.

Abstract

Abrégé Contexte: Il existe des lacunes dans la recherche sur la possible incidence de l'origine ethnique des patients traités par hémodialyse d'entretien (HDE) sur les connaissances en matière de santé, ainsi que sur le sentiment d'efficacité et l'autogestion liés à la santé.

Objectifs: L'étude explore deux aspects : 1) les associations entre les connaissances, le sentiment d'efficacité et l'autogestion en matière de santé chez les patients atteints d'insuffisance rénale recevant des traitements d'HDE en mode ambulatoire; et 2) les différences dans les niveaux de connaissances et le sentiment d'efficacité selon les caractéristiques de l'origine ethnique (c.-à-d. la ressemblance physique et la compétence dans la langue officielle de la population hôte), lesquelles sont connues pour être associées à l'accès aux soins et aux résultats en matière de santé.

Conception: Étude transversale

Cadre: Des patients ayant reçu des traitements d'HDE en ambulatoire dans sept centres d'hémodialyse pour adultes de Calgary (Alberta) entre septembre 2014 et décembre 2014.

Sujets: Les sujets ont été séparés en deux groupes selon un cadre proposé de quatre quadrants représentant une société multiculturelle. Le quadrant 1 regroupait des patients ambulatoires ressemblant physiquement à la population hôte et ayant comme langue maternelle celle de la population hôte (c.-à-d. Caucasiens avec l'anglais comme langue maternelle). À l'opposé, le quadrant 4 regroupait des patients ambulatoires sans ressemblance physique (non caucasiens) avec la population hôte et dont la langue maternelle n'était pas l'anglais. Un total de 78 patients (n_{Q1}=44, n_{Q4}=34) a été inclus.

Mesure: Les connaissances, le sentiment d'efficacité et l'autogestion liés à la santé ont été respectivement mesurés à l'aide du questionnaire HLQ (Health Literacy Questionnaire), de l'outil SUPPH (Strategies Used by People to Promote Health) et de la Mesure d'activation du patients-13 (PAM-13).

Méthodologie: Les participants ont été recrutés par échantillonnage de commodité dans chacun des sept centres d'hémodialyse pour adultes. Tous ont complété la trousse d'étude constituée d'un questionnaire sur les données démographiques, du HLQ, du SUPPH et du PAM-13. Les valeurs rho de Spearman ont été calculées pour établir les corrélations entre le niveau d'activation du patient et les scores HLQ et SUPPH. Des tests t indépendants ont été effectués pour établir les différences dans les scores HLQ et SUPPH entre les participants du Q1 et du Q4. Une régression par étapes a été réalisée dans d'autres analyses afin de déterminer les variables prédictives du niveau d'activation du patient.

Résultats: Des corrélations statistiquement significatives ont été observées entre le niveau d'activation du patient et des domaines de connaissances en matière de santé, à savoir : « la capacité de communiquer activement avec les fournisseurs de soins de santé » (r_{HLQ6}= 0,535; $p<0,001$); « la capacité de trouver de bonnes informations sur la santé (r_{HLQ8} = 0,611; $p<0,001$); et « comprendre suffisamment les informations de santé pour savoir quoi faire » (r_{HLQ9} = 0,712; $p<0,001$). Une différence statistiquement significative a été observée entre les participants du Q1 et du Q4 dans les connaissances en santé en ce qui concerne « la capacité de trouver de bonnes informations sur la santé » (p = 0,048). Le modèle final de régression par étapes ($F[2,72]$ = 32,232; $p<0,001$) incluait « comprendre suffisamment les informations de santé pour savoir quoi faire » et « la gestion active de la santé ».

Limites: La conception transversale de l'étude limite la généralisabilité des résultats. La faible taille de l'échantillon limite la possibilité d'identifier des associations et des différences significatives. Même si l'anglais n'était pas leur langue maternelle, tous les participants du Q4 le parlaient couramment, ce qui signifie que les possibles différences d'un sous-groupe clé du Q4 (ceux qui ne parlent pas l'anglais) n'ont pas été saisies.

Conclusion: Le questionnaire HLQ a permis de créer un profil des connaissances en santé chez des patients atteints d'insuffisance rénale terminale traités par HDE. Les résultats suggèrent de possibles associations entre des domaines précis des connaissances en santé et l'activation des patients. Le représentant du Q4 des patients externes traités par HDE semble avoir plus de difficultés à trouver de bonnes informations de santé, ce qui pourrait désavantager ces patients dans les premières phases de leurs efforts d'autogestion. Ces résultats soulignent les possibilités de mieux adapter les soins des patients, particulièrement des patients issus des minorités ethniques, afin de les aider dans leur autogestion de la maladie.

[1]Alberta Health Services, Calgary, Canada
[2]School of Nursing Midwifery and Social Work, The University of Queensland, Brisbane Saint Lucia, Australia
[3]Faculty of Nursing, University of Calgary, AB, Canada
[4]Cumming School of Medicine, University of Calgary, AB, Canada

Corresponding Author:
Uchenna Ibelo, Alberta Health Services, 1403 29 St NW, Calgary, AB T2N 2T9, Canada.
Email: Uchenna.Ibelo@ahs.ca

Introduction

Background

At least 4 million people in Canada live with chronic kidney disease (CKD). More than 40 000 have progressed to end-stage kidney disease (ESKD) representing a 33% increase in ESKD since 2010.[1] Notably, there is a greater risk of CKD progression among non-whites compared with whites.[2,3] The CKD progressed to ESKD requires kidney replacement therapy, often in the form of maintenance hemodialysis (MHD). Active patient participation in self-management activities plays an important role in achieving optimal health for those receiving MHD. Those activities include managing complex medication regimens; attendance at dialysis which typically entails 4-hour sessions 3 to 4 days per week; making significant diet modifications to adhere to low sodium, potassium, protein, and phosphorous restrictions; significantly restricting daily fluid intake; and managing other comorbidities (eg, diabetes) associated with ESKD. Managing these activities in addition to activities of daily living can be overwhelming.

Health literacy comprises the "cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health."[4] Self-efficacy is the belief an individual has about his or her ability to execute actions to achieve a desired outcome. Higher health literacy and self-efficacy have been shown to positively influence self-management behaviors in chronic disease populations[5,6] and specifically related to kidney disease.[7,8] However, limited health literacy is common among those with kidney disease.[9] Furthermore, there is a paucity of research examining how health literacy[10] and self-efficacy may be impacted by ethnicity in patients with ESKD receiving treatment with MHD.

As the burden of kidney disease and its progression continues to grow in Canada,[1] the need to identify best practices to support patients with their self-management has become more urgent. Understanding how ethnicity can influence self-management behavior is especially important in a multicultural society such as Canada. A better understanding can guide health services and providers to provide patient-centered care that is equity-oriented.

Objectives

The objectives of this study were to analyze (1) the potential relationships between health literacy, self-efficacy, and self-management among patients with kidney failure receiving treatment with MHD; and (2) differences in health literacy and self-efficacy based on characteristics of ethnicity (ie, physical resemblance and proficiency in the language of the host population), known to be associated with health care access[11] and health outcomes.[12]

Methods

Study Design

This work was part of a master's thesis which used a cross-sectional design to explore associations between health literacy, self-efficacy, and clinical markers of self-management in patients receiving kidney replacement therapy by MHD between September 2014 and December 2014 in Calgary, AB.[13] This study was reviewed and approved by the Conjoint Health Research Ethics Board (CHREB) at the University of Calgary.

Setting

There are 7 adult hemodialysis sites in Calgary, AB. Participants were recruited, at morning, afternoon, and evening HD sessions at each site. Recruitment and data collection occurred between September 2014 and December 2014 and lasted 1 to 2 weeks at each center. The number of beds ranged from 9 to 30, with a median of 15. Patients typically receive MHD 3 to 4 days per week with morning, afternoon, and evening sessions usually lasting 3 to 4 hours. Nocturnal sessions were offered at one site; however, recruitment did not occur at this session.

Participants

Participants were included if they were at least 18 years of age and had received regular MHD for a minimum of 3 consecutive months at the time of recruitment. Figure 1 represents a proposed framework of a multicultural society[14] highlighting 2 key characteristics that have been shown to impact health care outcomes[12] and patient decision-making.[15] Participants were eligible if they were characteristic of quadrant 1 (Q1) or quadrant 4 (Q4). Participants were limited to Q1 and Q4 as these 2 quadrants exhibit the greatest difference in the framework and would presumably highlight the greatest contrast between the variables of interest.

Participants were excluded from the study if they had one or more hospital admissions or received peritoneal dialysis or nocturnal hemodialysis within 3 months prior to the date of recruitment. Participants were also excluded if they received MHD for less than 3 months from the date of recruitment.

Convenience sampling was used to recruit participants receiving MHD treatment. The HD staff nurses assisted with recruitment. Nurses approached potential candidates first, at the start of their dialysis session, and asked if they would like to receive information about the study. If the potential participant agreed, they received further information from the researcher and, if still interested, completed the screening questionnaire (Supplement 1). If the potential participant met the screening criteria and still agreed to participate, informed consent was obtained, and participants were given the study

	Visible Majority of host population (P+)	Visible Minority in the host population (P-)
First language or only language of the host population (L+)	(P+) (L+) Quadrant 1	(P-) (L+) Quadrant 2
First language not of the host population (L-) (may be proficient or limited proficient in language of host population)	(P+) (L-) Quadrant 3	(P-) (L-) Quadrant 4

Figure 1. Framework of a multicultural society.[14]

package to complete. Participants had the option to complete the package during their HD session or to take the package home to complete and return it to the researcher at their next dialysis session. Assistance, from the researcher, to complete the study package during the HD session was available upon request.

Variables

Health literacy and self-efficacy were included in the analysis as the independent variables, whereas self-management was considered the dependent variable of interest. Ethnicity was defined in terms of the 2 key characteristics identified in the above framework (Figure 1). In the context of Alberta, Canada as the host population, visible majority and language of the host population is represented as white and first language of English (Q1); visible minority and first language not of the host population is represented as non-white and a first language other than English (Q4).

Data Measurement

The study package included an investigator-designed demographic questionnaire (Supplement 2), the Health Literacy Questionnaire[16] (HLQ), Strategies Used by People to Promote Health[17] (SUPPH), and Patient Activation Measure-13[18] (PAM-13). The HD nursing staff had identified Mandarin and Vietnamese as languages commonly spoken among the patients receiving MHD and the HLQ and PAM-13 were already available in simplified Chinese and Vietnamese. Therefore, the remaining documents were translated to simplified Chinese and Vietnamese using a professional translation service then back translated by 2 lay people and 2 translation professionals. Any discrepancies noted

were sent back to the professional translation service for correction. Translations to other languages were not possible, due to time constraints.

Demographic questionnaire. Data collected from the demographic questionnaire included ethnic background, primary language spoken at home, age, gender, marital status, education, employment status, CKD etiology, other chronic health conditions, years on hemodialysis, and the number HD sessions attended per week.

Health literacy. The HLQ,[16] a 44-item instrument, measures 9 domains of health literacy: (1) feeling understood and supported by health care providers, (2) having sufficient information to manage my health, (3) actively managing my health, (4) social support for health, (5) appraisal of health information, (6) ability to actively engage with health care providers, (7) navigating the health care system, (8) ability to find good health information, and (9) understanding health information well enough to know what to do. Questions were asked on a 4-point Likert-type scale for domains 1 to 4 and scores ranged from 1 to 4. Questions were on a 5-point Likert-type scale for domains 6 to 9 and scores ranged from 1 to 5. The domain scores are not summed together. Instead, each scale forms a stand-alone score and together the scales generate a health literacy profile of individuals, groups, and populations.[19] Higher scores indicate greater health literacy for the given domain.

Self-efficacy. The SUPPH[17] is a 29-item self-report scale, based on self-efficacy theory, that measures self-care self-efficacy in hemodialysis patients. The SUPPH is scored for 3 dimensions: (1) positive attitude, (2) stress reduction, and (3) making decisions. Questions were asked on a 1 to 5

Likert-type scale and scores are generated by the summation of all items across the dimension. The overall score is the sum of the dimension scores with a higher score indicating greater self-care self-efficacy.

Self-management. The PAM-13[18] was used to measure self-management. The PAM-13 provides a score from 0 to 100 that corresponds to 1 of 4 levels of patient activation: (1) believes active role important, (2) confidence and knowledge to act, (3) taking action to maintain or improve one's health, and (4) staying the course under stress. A higher activation level indicates a greater capacity to participate and persist in managing one's own health and health care.

Bias

Given time constraints and potential recruitment rate, convenience sampling was felt to be the most feasible approach for participant selection. In an effort to reduce selection bias, participants were recruited from all 7 adult HD sites in Calgary, at all morning, afternoon, and evening HD sessions.

Study Size

The a priori sample size was calculated of 50 participants per group based on the recruitment goal of 20 cases per independent variable (HL and SE) for regression analysis in the larger study[13] and a potential attrition rate of 20%.

Statistical Methods

All statistical analyses were completed in SPSS v. 22.

Descriptive statistics were used to report demographic characteristics, HLQ, SUPPH, and PAM-13 scores for both groups. Spearman rho was calculated to identify weak ($r = .10-.29$), moderate ($r = .30-.39$), or strong ($r = .50-1.0$) associations between HLQ and PAM-13 scores as well as SUPPH and PAM-13 scores. Pairwise exclusion was used to manage missing data in the correlation analyses. Independent *t* tests were used to identify differences in health literacy and self-efficacy scores between Q1 and Q4 participants. Missing data points were pro-rated for the SUPPH leading to one case missing the subscale scores for "decision-making" and "stress reduction" and an additional case missing the subscale score for "stress reduction." Stepwise regression was performed to explore which health literacy variables accounted for the most variance in patient activation level. The SUPPH scores were not included to prevent singularity in the regression analysis. At each step, $p = .05$ was set as entry criteria and $p = .1$ was used to set a limit on the total number of variables included in the final model. Listwise exclusion of cases was used to handle missing data.

Results

Participants

Of the 139 individuals initially approached, 39 declined to participate, 18 were excluded because they did not meet the inclusion criteria, and 4 returned incomplete study packages. A total of 78 participants were included in the study ($n_{Q1} = 44$; $n_{Q4} = 34$). Figure 2 outlines the recruitment in a flow diagram.

Descriptive Data

Demographic characteristics. Q1 participants identified as Canadian, American, European, or "other" backgrounds. Twenty-eight of the participants grouped in Q4 (82.4%) self-identified their ethnicity as Asian, South Asian, or Pacific Islander. The remaining Q4 participants (17.6%) indicated their ethnicity as being from other backgrounds; grouping was not specified further to maintain participant anonymity. All Q4 participants indicated English was not their first language. However, all were proficient in English and opted to complete the study package in English including those who were initially offered study packages in simplified Chinese or Vietnamese. Two participants from Q4 received assistance from the family members, whereas 18 participants from Q1 received assistance from the investigator.

Table 1 presents the demographic profile of study participants. The average age among Q1 participants was 63.5 (SD = 13.9) and the average age among Q4 participants was 59.4 (SD = 12.4). Twenty-three (52.3%) participants from Q1 and 25 participants (73.5%) from Q4 were male. Fifteen (34.1%) participants from Q1 and 18 (52.9%) from Q4 indicated completing postsecondary education. Twenty-four participants from Q1 (54.5%) and 14 (41.2%) from Q4 were retired. Diabetes ($n_{Q1} = 17$; $n_{Q4} = 11$) and/or high blood pressure ($n_{Q1} = 12$; $n_{Q4} = 12$) were common causes of kidney disease in both groups. The average number of years on hemodialysis was 4.4 years for Q1 participants and 3.5 years for Q4 participants. Dialysis attendance was an average 3 days per week for both groups. Among Q1 participants, 12 (27.3%) indicated having depression or anxiety compared with 5 (14.7%) Q4 participants.

Main Results

Self-management. Q1 and Q4 participants both had a median patient activation level 3 (interquartile range: 2-3) corresponding to "taking action to maintain or improve one's health."

Health literacy and self-efficacy correlations with self-management. Spearman rho correlation revealed a positive moderate association between patient activation level and the "ability to actively engage with health care providers" (HLQ
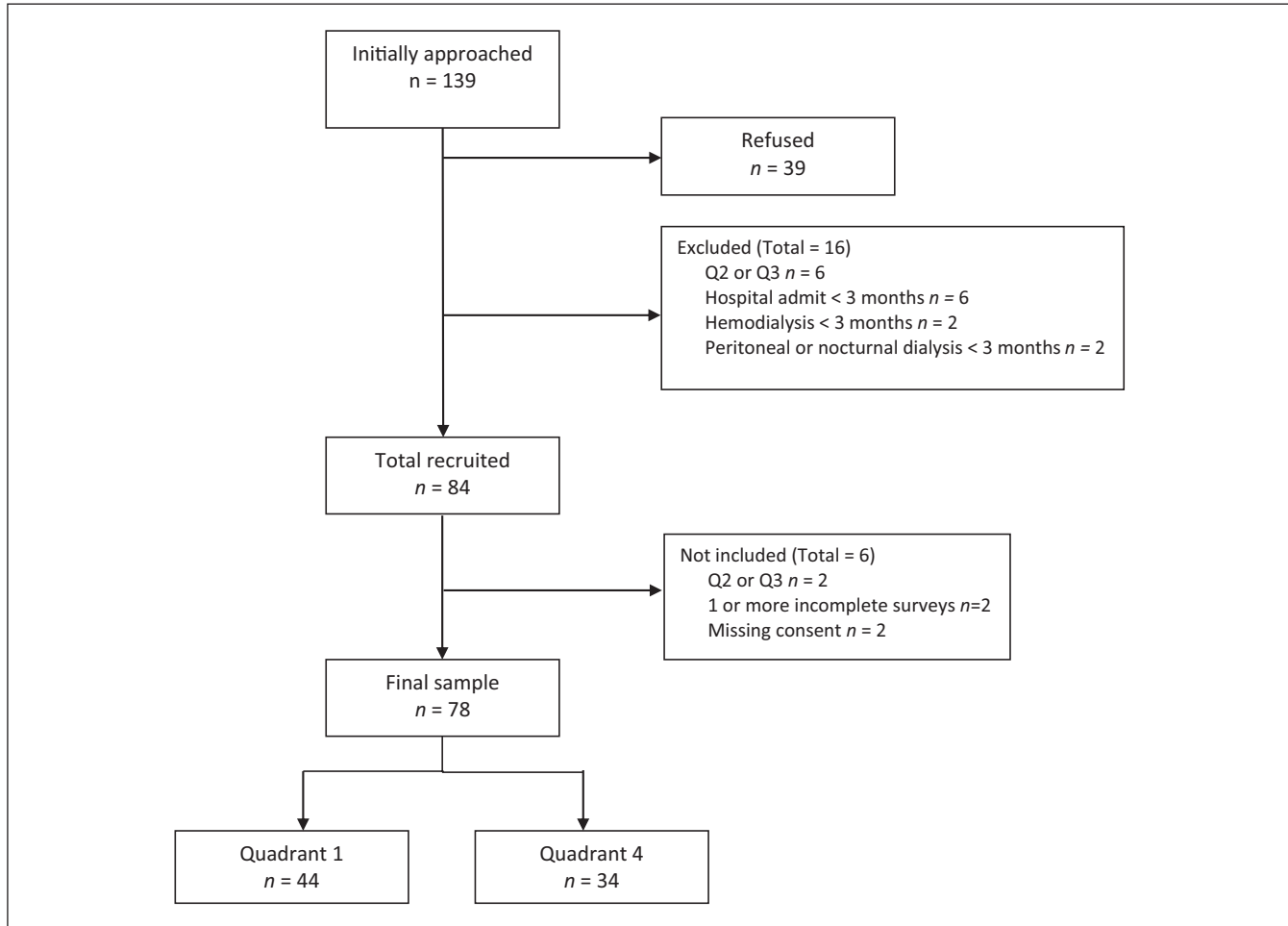
Figure 2. Recruitment flow diagram.

scale 6; $r_{HLQ6} = .535$, $P < .001$). There was also a positive moderate association between patient activation level and the "ability to find good health information" (HLQ scale 8; $r_{HLQ8} = .611$, $P < .001$). There was a strong positive correlation between "understanding health information well enough to know what to do" (HLQ scale 9) and patient activation level ($r_{HLQ9} = .712$, $P < .001$). The associations between self-efficacy and patient activation were significant but weak (Table 2).

Health literacy and self-efficacy differences. Table 3 displays the differences in health literacy and self-efficacy scores by quadrant. There was a statistically significant difference between Q1 and Q4 participants for HLQ domain 8 "ability to find good health information" ($M_{Q1} = 4.07$, SD = .53; $M_{Q4} = 3.81$, SD = .57; $P = .048$) suggesting finding up-to-date health information from a variety of sources was a greater struggle for quadrant 4 participants than for quadrant 1 participants. However, the magnitude of the difference between the 2 groups was small (mean difference = .25, 95% confidence interval: .00028 to .50; Cohen's $d = 0.472$).

Q1 participants scored higher than Q4 participants in all HLQ domains, except domain 5, "appraisal of health information" ($M_{Q1} = 2.89$, SD = .419; $M_{Q4} = 2.91$ SD = .493). However, these differences were not significant.

Both groups had moderate overall SUPPH scores ($M_{Q1} = 102.1$, SD = 27.6; $M_{Q4} = 98.0$ SD = 25.6) indicating moderate perceived self-confidence in maintaining a positive attitude, stress reduction, and decision-making related to alternative treatments. Like the HLQ domains, Q1 participants scored higher than Q4 participants for all SUPPH scores. There was weak evidence to suggest a statistically significant difference in "making decisions" between quadrant 1 and quadrant 4 participants ($M_{Q1} = 11.4$, SD = 3.4; $M_{Q4} = 9.6$ SD = 3.2 $P = .05$).

Other analyses. The stepwise regression equation was reached in 2 steps. The final model identified "understanding health information well enough to know what to do" (HLQ scale 9) and "actively managing health" (HLQ scale 3) as predictors of patient activation level, $F(2, 72) = 32.232$, $P < .001$. The raw regression coefficient (B), the standard error

Table 1. Q1 and Q4 Participant Characteristics.

	Q1 (n = 44)	Q4 (n = 34)
Age[a], mean (SD)	63.5(13.9)	59.4(12.4)
Gender		
Male	23 (52.3%)	25 (73.5%)
Female	21 (47.7%)	9 (26.5%)
Marital status		
Partnered	21 (47.7%)	28 (82.4%)
Unpartnered	21 (47.7%)	5 (14.7%)
No response	2 (4.5%)	1 (2.9%)
Living status		
Live alone	6 (13.6%)	5 (14.7%)
Live with others	29 (65.9%)	21 (61.6%)
No response	9 (20.5%)	8 (23.5%)
Highest level of education		
High school	17 (38.6%)	15 (44.1%)
Some postsecondary	10 (22.7%)	0 (0.0)
Postsecondary	15 (34.1%)	18 (52.9%)
No response	2 (4.5%)	1 (2.9%)
Employment status		
Employed	4 (9.1%)	8 (23.5%)
Unemployed	13 (29.5%)	11 (32.4%)
Retired	24 (54.5%)	14 (41.2%)
No response	3 (6.8%)	1 (2.9%)
Cause of kidney disease[a]		
Diabetes	17 (40.5%)	11 (32.4%)
Hypertension	12 (28.6%)	12 (35.3%)
Autoimmune disease	7 (16.7%)	4 (11.8%)
Other	10 (23.8%)	6 (17.6%)
Unknown	5 (11.9%)	8 (23.5%)
Chronic health conditions		
Arthritis or chronic pain	26 (59.1%)	14 (41.2%)
Cardiovascular	22 (50.0%)	10 (29.4%)
Depression or anxiety	12 (27.3%)	5 (14.7%)
Other	17 (38.6%)	9 (26.5%)
Average number of years on HD[b], mean (SD)	4.4 (6.3)	3.5 (2.9)
Average number of HD sessions per week[c], mean (SD)	3 (0.6)	3 (0.3)

[a]$n_{Q1} = 42$.
[b]n = 74.
[c]n = 77.

(SE), the standardized regression coefficient (β), the correlation coefficient (*R*), and the squared semipartial correlation coefficients (*sr²*) are outlined in Table 4 for the predictor variables. The coefficient of determination (adjusted R^2) of the final model is also included. "Understanding health information well enough to know what to do" (HLQ scale 9) accounted for 25% of the variance of patient activation level ($sr^2 = .256$) and "actively managing health" (HLQ scale 3) accounted for 4% of the variance ($sr^2 = .038$).

Discussion

Associations between health literacy, self-efficacy, and self-management were examined among patients with ESKD receiving treatment with MHD. Differences in health literacy and self-efficacy by key characteristics of ethnicity known to impact health and health care were also examined. Nearly a quarter of all participants indicated having depression or anxiety; however, this was represented by a higher proportion of participants in the Q1 group compared with Q4 group. Patient activation level of both Q1 and Q4 participants corresponded to an ability to take action to maintain or improve health. The median patient activation levels did not correspond to an "ability to stay the course during times of stress." By using the HLQ, a health literacy profile among patients with ESKD receiving MHD was generated and multiple dimensions of health literacy could be measured. There were moderate associations between patient activation level and

Table 2. Health Literacy and Self-Efficacy Correlations With Patient Activation Level.

	Spearman rho	P value
Health Literacy Scores		
Domain 1. Feeling understood and supported by health care providers	.333	.003*
Domain 2. Having sufficient information to manage my health	.400	<.001*
Domain 3. Actively managing my health	.471	<.001*
Domain 4. Social support for health	.308	.007*
Domain 5. Appraisal of health information	.472	<.001*
Domain 6. Ability to actively engage with health care providers	.535	<.001*
Domain 7. Navigating the healthcare system	.487	<.001*
Domain 8. Ability to find good health information[a]	.611	<.001*
Domain 9. Understanding health information well enough to know what to do	.712	<.001*
Self-Efficacy Scores		
Total SUPPH	.352	.002*
SUPPH Scale 1 Positive Attitude	.353	.002*
SUPPH Scale 2 Stress Reduction	.315	.006*
SUPPH Scale 3 Making Decisions	.391	<.001*

Note. SUPPH = Strategies Used by People to Promote Health.
[a]n_{Q1} = 43; n_{Q2} = 34.
*$P \leq$ .05.

Table 3. Health Literacy and Self-Efficacy Differences by Quadrant.

	Q1 (n = 44)	Q4 (n = 34)	P value
	Health Literacy Scores	Mean (SD)	Mean (SD)
Domain 1. Feeling understood and supported by health care providers	3.11 (0.535)	3.10 (0.320)	.899
Domain 2. Having sufficient information to manage my health	3.05 (0.329)	3.03 (0.421)	.851
Domain 3. Actively managing my health	3.08 (0.374)	3.06 (0.416)	.838
Domain 4. Social support for health	3.03 (0.503)	3.01 (0.476)	.818
Domain 5. Appraisal of health information	2.89 (0.419)	2.91 (0.493)	.841
Domain 6. Ability to actively engage with health care providers	4.19 (0.571)	4.05 (0.438)	.247
Domain 7. Navigating the healthcare system	4.01 (0.584)	3.91 (0.523)	.437
Domain 8. Ability to find good health information	4.07 (0.532)[a]	3.81 (0.568)	.048*
Domain 9. Understanding health information well enough to know what to do	4.15 (0.636)	3.92 (0.591)	.105
Self-Efficacy Scores			
Total SUPPH (/145)	102.1 (27.6)[a]	98.0 (25.6)[b]	.51
SUPPH Scale 1 Positive Attitude (/80)	58.1 (16.6)	54.5 (15.9)	.34
SUPPH Scale 2 Stress Reduction (/50)	33.5 (10.2)[a]	32.8 (9.9)[b]	.76
SUPPH Scale 3 Making Decisions (/15)	11.1 (3.4)[a]	9.6 (3.2)[b]	.05

Note. SUPPH = Strategies Used by People to Promote Health.
[a]n = 43.
[b]n = 33.
*$P \leq$ .05.

the health literacy domains of "ability to actively engage with health care providers" and "ability to find good health information," and a strong association with "understanding health information well enough to know what to do." On the contrary, the associations between patient activation level and self-efficacy were weak. There was a statistically significant difference between Q1 and Q4 participants in the health literacy domain of "ability to find good health information." In additional analyses, "understanding health information well enough to know what to do" and "ability to find good health information" contributed to the variance of patient activation level.

Table 4. Stepwise Regression Predicting Patient Activation Level.

Model 2	B	SE	β	R	sr^2	Adjusted R^2
Constant	−2.691	.719				
Understanding health information	.878	.148	.564	.659	.256	
Actively managing health	.541	.238	.217	.465	.038	.458

Many of the respondents who indicated having depression or anxiety belonged to Q1. However, specific signs and symptoms of depression or anxiety (eg, irritability, fatigue, restlessness) were not included on the questionnaire, which could have impacted some participant responses if they were not aware of what the signs and symptoms of depression or anxiety entail. The difference between Q1 and Q4 might also be attributed to differences in how mental health is perceived. Previous reports have pointed to stigma toward mental health problems as a common phenomenon among ethnocultural and racialized populations.[20] Previous research has also identified that ethnic minorities are also less likely to use mental health services compared with whites.[21] While reporting of mental health problems and use of mental health services occur less often in ethnic minority groups, there is evidence to suggest that when mental health is assessed in minority groups, there can be higher degree of severity of mental illness experienced in general[22] and specifically in the ESKD population.[23] Damery et al[23] note that not all patients with ESKD who experience emotional distress want support and not all patients with ESKD who want support want it from their kidney health care providers. Nonetheless, providers should pay close attention to screening for depression and anxiety, particularly among ethnic minority patients, as they may be less likely to voice their concerns.

Previous research has demonstrated that interventions aimed at developing coping skills in patients with kidney disease can decrease depression and anxiety and these effects can persist over time.[24,25] However, current self-management resources for these patients have been found to be lacking in the provision of emotional management resources.[26] Moreover, there appears to be a gap in investigating if the impact of such interventions translates to persistent positive self-management behaviors even during times of distress. Identifying best practices to help patients receiving MHD develop coping skills is worth investigating further, given the indication by both groups of an ability to take action with their self-management (patient activation level of 3), but not necessarily an ability to stay the course with their self-management under stress (patient activation level of 4).

The overall moderate association between "ability to engage with health providers" and patient activation highlights the importance of the patient-provider encounter. The difference between Q1 and Q4 participant scores for this health literacy domain was not statistically significant in the current study. However, this may be attributed to Q4 participants being English proficient, demonstrated by the fact that all opted to complete the surveys in English. Limited English-proficient and non-English HD patients were not captured in this study sample meaning the experience of a key Q4 subgroup was not included. Previous research has demonstrated language barriers do impact patient-provider encounters by altering patient perceptions about their health. A study by Gany et al[27] found that among immigrant and migrant cancer patients, those whose language of preference was not English were more than twice as likely to have incorrect knowledge of their cancer diagnosis compared with their English-speaking counterparts. Language barriers can also impact provider perceptions regarding patient encounters. For example, Sandal et al[28] conducted a qualitative study examining health professional perceptions of barriers to discussing living kidney donation with patients with CKD. Patient-level barriers noted by health providers included cultural background and language barriers as factors that made discussing living kidney donation difficult for health providers. Face-to-face interactions have been identified as the second most common method of delivering self-management information to patients with CKD, in Canada.[26] If language barriers create difficulties for providers, the quality of the patient-provider encounter can be significantly diminished.

Professional translation services[29] and newer technologies, such as virtual remote interpretation services,[30] offer potential solutions to addressing this barrier. Nonetheless, providers should be aware of their own communication style to ensure their verbal communication with patients is at an appropriate level.[29] Effective strategies to verify patient understanding include using "teach-back method" and "chunking." In the case of the latter, information is broken down into smaller "chunks" and reviewed over multiple sessions.[29] This is supported by a qualitative study, by Ferreira da Silva et al,[31] which analyzed interview data of patients from 5 Canadian hemodialysis centers receiving in-center hemodialysis, their caregivers, and health providers. The researchers explored the barriers and solutions to delivery of information related to hemodialysis and identified patients felt overwhelmed with the amount of information they received when first initiating hemodialysis which made it difficult to retain. Patients suggested delivering the information gradually rather than all at once. Providers also expressed concern about the amount information given to patients initiating dialysis and did make attempts to try to break the information down. Provider perceptions about their communication with HD patients compared with patient perceptions about communication with their

providers is an area that could be further explored. This may reveal valuable information about gaps in provider communication that impact patient experiences and the patient-provider relationship.

The associations between patient activation with "ability to find good health information" and "understanding health information well enough to know what to do" are not surprising. Accessing the right information and having the ability to synthesize that information to make informed choices contributes to greater empowerment and better patient decision-making. A qualitative study by Donald et al[32] interviewed CKD patients stages 1 to 5 (though not receiving kidney replacement therapy) and their caregivers across Canada to identify their self-management needs. Among the themes identified, participants indicated that knowledge leading to awareness and understanding of subjects including kidney disease, diet, and physical and mental health consequences of the kidney disease contributed to empowerment. In the current study, there was no appreciable difference between Q1 and Q4 participants' ability to "understand health information well enough to know what to do." However, the statistically significant difference between Q1 and Q4 participants' "ability to find good health information" does suggest Q4 patients may be at a disadvantage at the very first step of their self-management efforts. In the same study by Donald et al,[32] participants indicated that while access to information contributed to activation, this information needed to be timely, meaningful, the right amount, and relevant to their needs. Participants in that study were predominantly white and English-speaking, thereby limiting the generalizability of their results. However, given the difference identified between Q1 and Q4 participants' "ability to find good health information" in the present study, it should be considered that not only is access to information important, but patients with kidney disease who are representative of Q4 could potentially be at a greater disadvantage in finding meaningful and culturally relevant information to meet their needs. Many clinics across Canada offer CKD self-management resources that have been developed or modified to meet local, individual, and ethnocultural needs, but a gap still exists in content (eg, emotional management, general CKD knowledge, symptom management) and most resources are only offered in English.[26] Furthermore, Ferreira da Silva et al[31] also identified the importance of ensuring education materials meet the needs of a culturally diverse dialysis population. As the amount of available information has drastically increased and intensified over time, navigating misinformation and disinformation to access usable content has become more important. Resources and interventions should be contextually tailored and culturally relevant to facilitate equitable access to self-management supports for ethnic minority patients and families.[33]

Limitations

First, the cross-sectional design and use of convenience sampling limits the generalizability of the results. Second, the final sample size for each group was smaller than the a priori sample size calculation, limiting the power to identify significant associations between variables or group differences. Third, while English was not the first language of Q4 participants, these participants were still proficient in English. The perspectives of completely non-English participants were not captured again limiting the generalizability of the results. Fourth, while moderate to strong associations were identified between some domains of health literacy and patient activation level, correlation does not equal causation. Furthermore, correlations in unadjusted analyses should be interpreted cautiously due to the risk of confounding by other variables including education level and socioeconomic status, both of which are associated with limited health literacy in CKD.[9] Finally, in stepwise regression, the variables are ordered and entered by statistical software meaning it is not guaranteed the best predictors have been selected or that unimportant predictors have been excluded.

Conclusions

Limited health literacy represents considerable concern in the kidney disease population.[9,34] By using the HLQ, a health literacy profile of patients with ESKD receiving MHD can be created to examine relationships between specific health literacy domains with patient self-management behaviors. It also offers an opportunity to examine possible differences by selected markers of ethnicity. The relationships identified in the current study may add further support to the body research that has identified links between health literacy and self-management among patients with kidney disease. However, study replication involving more dialysis centers to increase the sample size and to capture Q4 participants who do not speak any English would be needed to confirm the results of the current study.

The HLQ is a useful instrument in that can be used to help facilitate the planning and provision of equity-oriented health services. In that regard, considerations should be made for how to incorporate the cultural and linguistic needs of this diverse patient population to avoid a pattern of exclusion that may lead to inequitable health and health care.

Availability of Data and Materials

Data generated and analyzed during this study are included in this published article [and it's supplementary information files].

Declaration of Conflicting Interests

Funding

Ethics Approval and Consent to Participate

This study was approved by the Conjoint Health Research Ethics Board (Study ID: REB14-0773). Informed consent was obtained from all research participants.

Consent for Publication

All authors provided consent for publication.

ORCID iD

Uchenna Ibelo https://orcid.org/0000-0002-7339-291X

Supplemental Material

Supplemental material for this article is available online.

References

1. Canadian Institute for Health Information. Annual Statistics on Organ Replacement in Canada: Dialysis, Transplantation and Donation, 2010 to 2019. Ottawa, ON: CIHI; 2020. https://www.cihi.ca/sites/default/files/document/corr-dialysis-transplantation-donation-2010-2019-snapshot-en.pdf.

2. Hounkpatin HO, Fraser SDS, Honney R, et al. Ethnic minority disparities in progression and mortality of pre-dialysis chronic kidney disease: a systematic scoping review. *BMC Nephrology*. 2020;21:217. doi:10.1186/s12882-020-01852-3.

3. Perl J, McArthur E, Tan VS, et al. ESRD among immigrants to Ontario, Canada: a population-based study. *J Am Soc Nephrol*. 2018;29:1948-1959. doi:10.1681/asn.2017101055.

4. Nutbeam D. Health promotion glossary. *Health Promot Int*. 1998;13:349-364.

5. Aaby A, Friis K, Christensen B, et al. Health literacy is associated with health behaviour and self-reported health: a large population-based study in individuals with cardiovascular disease. *Eur J Prev Cardiol*. 2020;24:1880-1888. doi:10.1177/2047487317729538.

6. Olesen KF, Reynheim AL, Joensen L, et al. Higher health literacy is associated with better glycemic control in adults with type 1 diabetes: a cohort study among 1399 Danes. *BMJ Open Diabetes Res Care*. 2017;5(1):e000437. doi:10.1136/bmjdrc-2017-000437.

7. Curtin RB, Walters BA, Schatell D, Pennell P, Wise M, Klicko K. Self-efficacy and self-management behaviors in patients with chronic kidney disease. *Adv Chronic Kidney Dis*. 2008;15(2):191-205. doi:10.1053/j.ackd.2008.01.006.

8. Green JA, Mor MK, Shields AM, et al. Associations of health literacy with dialysis adherence and health resource utilization in patients receiving maintenance hemodialysis. *Am J Kidney Dis*. 2013;62(1):73-80. doi:10.1053/j.ajkd.2012.12.014.

9. Taylor DM, Fraser SDS, Bradley JA, et al. A systematic review of the prevalence and associations of limited health literacy in CKD. *Clin J Am Soc Nephrol*. 2017;12:1070-1084. doi:10.2215/cjn.12921216.

10. Mantwill S, Monestel-Umaña S, Schulz PJ. The relationship between health literacy and health disparities: a systematic review. *PLoS One*. 2015;10(12):e0145455. doi:10.1371/journal.pone.0145455.

11. Mucsi I, Bansal A, Famure O, et al. Ethnic Background is a potential barrier to living donor kidney transplantation in Canada: a single-center retrospective cohort study. *Transplantation*. 2017;101(4):e142-e151. doi:10.1097/TP.0000000000001658.

12. Crews DC, Liu Y, Boulware LE. Disparities in the burden, outcomes, and care of chronic kidney disease. *Curr Opin Nephrol Hypertens*. 2014;23(3):298-305. doi:10.1097/01.mnh.0000444822.25991.f6.

13. Ibelo U. *Exploring the Relationships Between Ethnicity, Health Literacy, Self-efficacy, and Self-management in Patients Receiving Maintenance Hemodialysis* [Unpublished master's thesis]. University of Calgary, AB; 2016.

14. Thomas BC, Carlson LE, Bultz BD. Cancer patient ethnicity and associations with emotional distress—the 6th vital sign: a new look at defining patient ethnicity in a multicultural context. *J Immigr Minor Health*. 2008;11:237. doi:10.1007/s10903-008-9180-0.

15. Hawley ST, Morris AM. Cultural challenges to engaging patients in shared decision making. *Patient Educ Couns*. 2017;100(1):18-24. doi:10.1016/j.pec.2016.07.008.

16. Osborne RH, Batterham RW, Elsworth GR, et al. The grounded psychometric development and initial validation of the Health Literacy Questionnaire (HLQ). *BMC Public Health*. 2013;13:658. doi:10.1186/1471-2458-13-658.

17. Lev E, Owen S. A measure of self-care self-efficacy. *Res Nurs Health*. 1996;19:421-429. doi:10.1002/(SICI)1098-240X(199610)19:5<421::AID-NUR6>3.0.CO;2-S

18. Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res*. 2005;40(6 pt 1):1918-1930. doi:10.1111/j.1475-6773.2005.00438.x.

19. Dodson SGS, Osborne RH. Health literacy toolkit for low and middle-income countries: a series of information sheets to empower communities and strengthen health systems. New Delhi, India: World Health Organization, Regional Office for South-East; 2015.

20. Mental Health Commission of Canada. The Case for Diversity: Building the Case to Improve Mental Health Services for Immigrant, Refugee, Ethno-cultural and Racialized Populations. 2016. Ottawa: ON: Mental Health Commission of Canada.

21. Chiu M, Amartey A, Wang X, Kurdyak P. Ethnic Differences in mental health status and service utilization: a population-based study in Ontario, Canada. *Can J Psychiatry*. 2018;63(7):481-491. doi:10.1177/0706743717741061.

22. Chiu M. Ethnic differences in mental health and race-based data collection. *Healthc Q*. 2017;20:6-9. doi:10.12927/hcq.2017.25296

23. Damery S, Sein K, Nicholas J, et al. The challenge of managing mild to moderate distress in patients with end stage renal disease: results from a multi-centre, mixed methods research study and the implications for renal service organisation. *BMC Health Serv Res*. 2019;19:989. doi:10.1186/s12913-019-4808-4

24. Craig JA, Miner D, Remtulla T, et al. Piloting a coping skills group intervention to reduce depression and anxiety symptoms in patients awaiting kidney or liver transplant. *Health Soc Work*. 2017;42:e44-e52. doi:10.1093/hsw/hlw064.

25. Tsay SL, Lee YC, Lee YC. Effects of an adaptation programme for patients with end-stage renal disease. *J Adv Nurs*. 2005;50(1):39-46. doi:10.1111/j.1365-2648.2004.03347.x.

26. Donald M, Gil S, Kahlon B, et al. Overview of self-management resources used by Canadian chronic kidney disease clinics: a national survey. *Can J Kidney Health Dis*. 2018;5:2054358118775098. doi:10.1177/2054358118775098.

27. Gany F, Yogendran L, Massie D, et al. "Doctor, what do I have?" Knowledge of cancer diagnosis among immigrant/migrant minorities. *J Cancer Educ*. 2013;28(1):165-170. doi:10.1007/s13187-012-0429-x.

28. Sandal S, Charlebois K, Fiore JF Jr, et al. Health professional–identified barriers to living donor kidney transplantation: a qualitative study. *Can J Kidney Health Dis*. 2019;6:2054358119828389. doi:10.1177/2054358119828389.

29. Collister D, Russell R, Verdon J, et al. Perspectives on optimizing care of patients in multidisciplinary chronic kidney disease clinics. *Can J Kidney Health Dis*. 2016;3:122. doi:10.1186/s40697-016-0122-9.

30. Provincial Health Services Authority, Office of Virtual Health. New virtual interpreting service gives patients with limited English proficiency better access to care. *BC*; 2020. http://www.phsa.ca/about/news-stories/stories/new-virtual-interpreting-service-gives-patients-with-limited-english-proficiency-better-access-to-care.

31. Ferreira da Silva P, Talson MD, Finlay J, et al. Patient, caregiver, and provider perspectives on improving information delivery in hemodialysis: a qualitative study. *Can J Kidney Health Dis*. 2021;8:20543581211046078. doi:10.1177/20543581211046078.

32. Donald M, Beanlands H, Straus S, et al. Identifying needs for self-management interventions for adults with CKD and their caregivers: a qualitative study. *Am J Kidney Dis*. 2019;74: 474-482. doi:10.1053/j.ajkd.2019.02.006.

33. Browne AJ, Varcoe CM, Wong ST, et al. Closing the health equity gap: evidence-based strategies for primary health care organizations. *Int J Equity Health*. 2012;11:59. doi:10.1186/1475-9276-11-59.

34. Dageforde LA, Cavanaugh KL. Health literacy: emerging evidence and applications in kidney disease care. *Adv Chronic Kidney Dis*. 2013;20:311-319. doi:10.1053/j.ackd.2013.04.005