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Health Literacy Mediates Racial Disparities in Cardiopulmonary Resuscitation Knowledge among Chronic Kidney Disease Patients

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Abstract

Black patients with chronic kidney disease (CKD) receive more cardiopulmonary resuscitation (CPR) than other racial groups, and knowledge of CPR influences preferences for care. As limited health literacy disproportionately affects Blacks and contributes to disparities in end-of-life (EOL) care, we investigated whether health literacy mediates racial disparities in CPR knowledge. Black and White adult patients with advanced CKD completed CPR knowledge surveys. Health literacy was assessed using the Rapid Estimate of Adult Literacy in Medicine. Among 149 patients, Black patients were more likely to have limited health literacy and lower mean CPR knowledge scores than White patients. In adjusted analyses, health literacy mediated racial differences in CPR knowledge. Knowledge of CPR is lower among Black compared with White CKD patients and health literacy is a mediator of this difference. Future CPR educational interventions should target health literacy barriers to improve informed decision-making and decrease racial disparities at the end-of-life.

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Keywords

Racial disparities; end of life; chronic kidney disease; CPR knowledge; advance directives; advance care planning

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Patients with chronic kidney disease (CKD) are at high risk of developing arrhythmias that lead to sudden cardiac arrest; however, patients with CKD have a much lower rate of survival after cardiopulmonary resuscitation (CPR) compared with other patient populations.[1–5] Furthermore, studies of patients with CKD who progress to end-stage renal disease and receive dialysis show that Black patients are more likely to receive CPR compared with White patients—these disparate trends have persisted over time.[4, 6, 7] Patients' decisions about whether they should undergo CPR are a key part of informed decision-making, goals of care discussions, and completion of advance directives. Therefore, understanding racial differences in patient knowledge of CPR may provide insight into differences in patterns of end-of-life (EOL) care between racial groups in this patient population.[6, 8]

Racial disparities in EOL treatment preferences among patients with CKD have been attributed to differences in communication and knowledge of EOL treatments (e.g., hospice) among Black and White patients.[9] However, given the higher incidence of limited health literacy among Black patients, there is evidence that health literacy is a mediator of racial disparities across several parts of care.[10–13] Limited health literacy impedes an individual's capacity to understand basic information to make informed medical decisions and approximately 28–32% of patients with CKD are afflicted.[14–16] Patients' understanding of the risks and benefits of CPR has been shown to be associated with subsequent treatment preferences and more recent studies of general medicine patients have focused on the effect of health literacy on racial disparities in preferences for EOL care and advance care planning.[11, 17–21] Still, the role of race and health literacy in EOL treatment knowledge in the CKD population has not been fully explored. We therefore sought to investigate whether health literacy would mediate racial disparities in understanding of CPR among Black and White patients with advanced CKD.

Methods

Setting and study participants.

We performed a cross-sectional study of patients with Stage 4 or 5 CKD (as defined by the Modification of Diet in Renal Diseases estimation of glomerular filtration rate 16 to 29 ml/min/1.73m^2 and <15 ml/min/1.73m^2 respectively)[22] between August 2013 and February 2015. We recruited patients from outpatient nephrology clinics affiliated with two academic centers in Boston, Massachusetts. Patients were included if they were 45 years and older, English-speaking, Black or White race, and were referred by their primary nephrologist. We excluded patients if they were on the waiting list for a kidney transplantation. Patients with a documented history of dementia in the medical record or who could not independently give consent to participate in this study were also excluded. All enrolled patients were also screened with the Short Portable Mental Status Questionnaire[23] and excluded if they were found to have severe cognitive deficits (as determined by eight or more errors). This study was approved by the Institutional Review Boards at Partner's Health Care and Boson Medical Center.

Data collection.

All study personnel underwent training in performing study procedures using interviewer-assisted study questionnaires. All interviews were performed in a quiet and private room in the outpatient clinic during a scheduled routine visit. Study personnel ready survey questionnaires out loud to all patients. Patient demographic information including age, ethnicity, income, and education were self-reported. Health literacy was assessed using the Rapid Estimate of Adult Literacy in Medicine (REALM) survey which has been used in previous studies of patients with advanced and end-stage kidney disease.[24–26] Limited health literacy was defined as a total score of ≤ 60. Electronic medical records were reviewed for co-morbidities and this information was used to calculate the Charlson Comorbidity Index for each patient.[27] Advance care planning, which was defined as having EOL discussions with their health care providers within the last year as well as completion of advance directives, was assessed for all patients. Patients were asked if they had: 1) any EOL discussion with any health care provider (yes/no), 2) any EOL discussion with their nephrologist (yes/no), 3) a health care proxy form (yes/no), or 4) a Do-Not-Resuscitate form/living will (yes/no). We reviewed electronic medical records to validate each patient's report of advance directives. If there was no evidence of any advance directives or discordance in documentation, the patient's spoken response was used in analyses.

Outcomes.

The primary outcome was CPR knowledge. The knowledge questionnaire was developed based on a literature review including previously published CPR knowledge surveys and information found on the American Heart Association website.[28–31] We aimed to assess the domains of CPR purpose, risk/benefits, and outcomes data. The survey consisted of eight multiple-choice questions that included knowledge about cardiac arrest, cardiopulmonary resuscitation, respiratory failure/intubation and survival post-CPR for hospitalized patients with advanced CKD (see Supplement). Authors (NDE, AEV, and MKP) developed and reviewed the survey items using guidelines for readability and clarity as per recommendations from the Institute of Medicine.[16] These questions were piloted among CKD patients using standard cognitive interview techniques and modified to produce the final version.

Statistical analysis.

Patient characteristics were evaluated as proportions for categorical variables or means with standard deviations for continuous variables. We calculated the proportion of patients who had any EOL discussions with their providers as well as possession of health care proxy forms and Do-Not-Resuscitate forms/living wills. We also tabulated the proportion of correct responses for each CPR knowledge question as well as mean summary scores. Chi-square and independent sample *t*-testing were used to determine differences in demographic, health literacy, advance care planning, and CPR knowledge among Black and White patients.

We used multivariate linear regression to determine unadjusted and adjusted associations of CPR knowledge with race. Statistical significance from univariate analysis determined which demographic variables would be included in multivariable regression models. Three different linear models were estimated: 1) race alone; 2) age, education, and income; and 3) age, education, income, and health literacy. In addition, to assess the impact of advance directives on racial differences in CPR knowledge, we added 1) possession of a Do-Not-Resuscitate form/living will; and, 2) possession of a health care proxy form to the fully adjusted model. We used the R^2 statistic to summarize model fit and plots of residuals, residuals versus fitted values, and residual versus quantiles as regression diagnostics to determine the appropriateness of the model. A variance inflation factor of less than 10 was used to indicate the absence of multicollinearity. We used the Baron and Kenny approach to determine whether health literacy mediated the relationship between CPR knowledge and race.[32] This approach considered the following questions: 1) Does race significantly predict CPR knowledge? 2) Does race significantly predict health literacy? 3) Does health literacy significantly predict CPR knowledge when controlling for race? All analyses were performed using SAS version 9.4 (SAS Institute, Inc. Cary, NC, USA). Statistical significance was determined by p values < 0.05.

Results

Two hundred and sixty-eight patients were approached to participate in the study. Sixty-one patients declined participation, 54 were ineligible, and one patient stopped the study early. Among the 152 patients who provided informed consent and enrolled in the study, 149 were included in the analysis, as three patients did not complete all variables needed for analyses. The mean age of the entire cohort was 68 (± 11) years; 77% of White patients were aged 65 years or greater compared with 55% of Black patients (p < .01, Table 1). Sixty-one percent of patients were male and 98% had health insurance. Most patients had completed high school; however, 32% of Black patients had not attained a high school diploma compared with 5% of White patients (p < .01). Additionally, more Black patients reported an annual income of less than $30,000 compared with White patients (69% vs. 27%, p < .01). Although the proportion of patients with limited health literacy was 34% among all patients, 63% of Black patients had limited health literacy compared with 14% of White patients (p < .01). There was no racial difference in comorbidity burden.

Twenty-three percent of patients had not had any EOL discussion with any health care provider and only 8% reported having this discussion with their nephrologist (Table 1). There were no differences between Black and White patients in terms of EOL discussions, however racial differences were observed in self reports of advance care planning. Thirty-two percent of patients had a Do-Not-Resuscitate form/living will with Black patients reporting that they completed these forms less often than White patients (23% vs. 39%, p < .01). Black patients also less commonly possessed health care proxy forms compared with White patients (48% vs. 70%, p = .01).

The proportion of correct responses to CPR knowledge items are displayed in Table 2. Overall, less than half of all patients knew: 1) the correct definition of cardiac arrest (46%), 2) the possibility of traumatic sequelae after receiving CPR (43%), 3) the possibility of respiratory failure after successful CPR (48%), 4) about the inability to speak after initial intubation (44%), and, 5) the chance of post-CPR survival for hospitalized patients with advanced chronic kidney disease (6%). Overall, patients had a mean summary knowledge score of 51 ±20, with Black patients scoring significantly lower than White patients (45 ±19 vs. 56 ±20, $p = .01$).

In the unadjusted model predicting the relationship between race and CPR knowledge (Model 1; Table 3) as well as in a multivariate model adjusted for race, age, education and income (Model 2; Table 3), we demonstrated a significant racial difference in CPR knowledge. Patients with limited health literacy also had significantly lower CPR knowledge scores compared with those with adequate health literacy (−8.28 (−16.00, −0.56)). In addition, all three criteria for the Baron Kenny approach to mediation were fulfilled (Figure 1). Specifically, race significantly predicted CPR knowledge (Step 1, $p < .01$) and health literacy (Step 2, $p < .01$). Finally, health literacy significantly predicted CPR knowledge while controlling for race (Step 3, $p < .01$). After the addition of health literacy to Model 2 (Model 3; Table 3), the point estimate for race reduced by 38% (from −8.14 to −5.05) and was no longer significant.

After the addition of Do-Not-Resuscitate form/living wills (Model 4, Table 4) and after the addition of health care proxy forms (Model 5, Table 4) to the fully adjusted model (Model 3, Table 3), patients with limited health literacy continued to have significantly lower CPR knowledge than those with adequate health literacy.

Discussion

In this study of Black and White patients with advanced CKD, we found a higher proportion of Black patients had limited health literacy, less advance directives and lower knowledge of CPR compared with White patients. However, health literacy significantly mediated racial differences in CPR knowledge. Additionally, after accounting for possession of advance directives, health literacy continued to remain a significant predictor of CPR knowledge.

Discussing the risks and benefits of life-sustaining treatments such as CPR, mechanical ventilation, and feeding tubes is fundamental to promoting effective informed decision-making in the event of critical illnesses. Advance care planning, which encompasses communication and documentation of goals of care at the end of life between health care providers, patients, and their families, occurs infrequently among patients with CKD and ESRD.[33, 34] Importantly, studies have shown that knowledge of what CPR entails and perceptions of one's survival affects preferences and subsequent decision-making about this treatment.[20, 21, 30, 31] One study of older inpatients with end-stage cancer showed that only 11% of patients could describe more than two components of CPR and that less than 3% correctly knew that the success rate of CPR was less than 10%.[31] We found similar results and although patients knew the overall purposes of CPR and mechanical ventilation, most were not aware of the bodily trauma, inability to speak initially after intubation or chances of survival after receiving CPR. Additionally, patients who have limited health literacy may have poor insight into these aspects of care and our findings showed health literacy remained a significant predictor of CPR knowledge after controlling for several demographic variables. These findings remained consistent even after controlling for possession of advance directives. This is consistent with previous work that show the completion of EOL documentation is not always associated with improved knowledge of life-sustaining therapies.[30] Patients with CKD have high rates of limited health literacy and experience frequent complications and poor survival during hospitalizations when they receive CPR.[2, 35] Therefore, it is imperative that providers delineate the risks of this therapy and confirm understanding with patients and their loved ones during advance care planning discussions. To our knowledge, there have not been any studies that have investigated the impact of health literacy-sensitive interventions to improve EOL treatment knowledge within nephrology. However, advance directives and video decision-aids that have been developed to address the needs of patients with limited health literacy have been particularly useful in improving advance care planning and EOL decision-making outcomes in other medical disciplines.[36–39]

Although we demonstrated differences in CPR knowledge and possession of advance directives between Black and White patients, we did not find racial differences with regard to frequency of EOL discussions with health care providers and this was consistent with other studies.[9, 33] Patients may feel more inclined to have discussions with their providers whom they feel comfortable with however, relationships with health care providers may have less of an impact on subsequent treatment decision-making among minority racial patients. For instance, Smith et al. showed that although the quality of the physician-patient relationship (e.g., perceived respect, listening, help in navigating the medical system) was lower among Black patients compared with White patients, this did not influence advance care planning or preferences for life-sustaining treatments.[40] Factors such as relationships with families and communities, negative beliefs regarding advance care planning, and limited health literacy have been proven to impact EOL care preferences especially among Black patients.[41] Health care teams should therefore tailor advance care planning conversations to account for these cultural, educational and social support differences to effectively engage minority populations in the advance care planning process.[42] For example, Song et al. randomized an advance care planning intervention among Black and White hemodialysis patients and their surrogates.[43] Specifically, the intervention aimed to discern the emotional and spiritual beliefs that patients and family members had in relation to the illness. This intervention led to significantly improved congruence on goals of care (between patients and surrogates) as well as surrogate decision-making confidence for Black patients compared with White patients who also received the intervention. Furthermore, surrogates of Black patients had less bereavement depressive symptoms compared with surrogates of White patients. Similarly, Perry et al. used a peer-mentoring program to improve end-of-life planning among hemodialysis patients.[44] The peer mentors were specifically trained in addressing facts, myths, and barriers to completing advance directives. Among Black patients, the program had a larger impact on completion and comfort with discussion of advance directives compared with White patients. Although racial differences in health literacy were not accounted for in the aforementioned studies, interventional approaches that specifically focus on understanding of health statuses and EOL care options appear to be effective in decreasing racial disparities in advance care planning. These results, along with the findings of the current study, indicate that addressing health literacy barriers (e.g., expectations, understanding) as well as belief systems during advanced care planning is a promising approach to decreasing racial disparities in care received at the end of life.

Our study has a few limitations. The limited racial diversity and language capability among the study cohort may limit generalizability to other study populations. We did not specifically explore reasons for lower health literacy in Black versus White patients living in the Boston area and acknowledge these findings may differ among patients from the same racial groups who live in other US regions. Additionally, we aimed to confirm advance directives with chart review, however only 37% (n=55) had documentation of a health care proxy form and 9% (n=13) had documentation of a Do-Not-Resuscitate form/living will. However, of these, 87% (n = 48) and 92% (n = 12) were respectively concordant with what patients reported to us regarding health care proxy forms and Do-Not-Resuscitate form/living wills in their surveys. We also did not include patient EOL preferences in this study, which prevents us from assessing the impact of CPR knowledge on preferences. Although patients were provided the option of stopping the study early or skipping any questions if they felt discomfort or anxiety, we did not specifically screen patients for anxiety related to decision-making which could have affected survey responses. Additionally, although survey items to assess possession of DNR/living will and health care proxies had readability that was appropriate for patients with limited health literacy, we did not specifically assess patient understanding of these legal terms. Lastly, we recognize that although CPR knowledge questions were derived from similar surveys and publicly available information regarding CPR facts and outcomes in the CKD population, the questionnaire had not been validated and newer data regarding survival post-CPR for CKD patients has since been published.[2] Despite these limitations, we believe our data reliably demonstrate key differences in understanding of CPR between Black and White CKD patients and the mediating effect of health literacy in this relationship.

In conclusion, our study is the first to identify the association of health literacy with CPR knowledge and its mediatory effect on racial differences in knowledge among Black and White patients with advanced CKD. These findings indicate that health literacy is one of the factors that should be considered when engaging patients in advance care planning to optimize informed-decision making and decrease racial disparities in EOL care among patients with CKD. Future studies may be helpful in defining the relationships between health literacy, belief systems, and decision-making among diverse patient populations to improve patient centered-care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.

Racial Differences in CPR Knowledge Mediated by Helth Literacy[1,2]

[1]CPR=Cardiopulmonary resuscitation; [2]White patients serve as the reference group for this analysis; β_{Total} = Point estimate for race in Step 1; β_{Indirect} = Point estimate for race in Step 3

Table 1.

Patient Characteristics

	Total (N=149)	Black (N=62)	White (N=87)	P-Value
Age, years[1]	68 (11)	66 (11)	70 (10)	0.01
Age ≥ 65 years (%)	68	55	77	<0.01
Hispanic ethnicity (%)	2	3	1	0.16
Male (%)	61	52	66	0.08
Less than high school education (%)	24	32	5	< 0.01
Income less than $30,000 (%)	44	69	27	< 0.01
Health insured (%)	98	97	99	0.36
Limited health literacy[2]	34	63	14	< 0.01
Charlson comorbidity index score[1,*]	7 (2)	7 (2)	7 (2)	0.96
Charlson comorbidity index score ≥ 3 (%)	97	95	98	0.40
Advance care planning				
Have had any EOL[3] discussion with provider	23	24	23	0.86
Have had any EOL discussion with nephrologist	8	13	5	0.06
Possession of DNR[4] form or living will	32	23	39	0.03
Possession of HCP[5] form	61	48	70	0.01

[1] Presented as mean (± SD);

[2] Limited health literacy =REALM score ≤ 60,

[3] EOL =End-of-Life,

[4] DNR=Do-Not-Resuscitate,

[5] HCP=Healthcare proxy form,

[*] Charlson comorbidity index score is derived from age and comorbidities including myocardial infarction, congestive heart failure, peripheral vascular disease, cerebrovascular disease, dementia, chronic pulmonary disease, connective tissue disease, ulcer disease, mild liver disease, diabetes, hemiplegia, moderate or severe renal disease, solid tumor (non-metastatic), leukemia, lymphoma/multiple myeloma, moderate or severe liver disease, metastatic solid tumor, and AIDS.

Table 2.

Percentage of Correct CPR[*] Knowledge Items

	Total (N=149)	Black (N=62)	White (N=87)	P-Value
CPR Knowledge Items (%)				
Knowledge of meaning of “cardiac arrest”	46	39	52	0.12
Knowledge of CPR purpose	84	77	89	0.07
Knowledge of CPR causing physical trauma	43	34	49	0.06
Knowledge of respiratory failure occurring after successful CPR	48	31	60	< 0.01
Knowledge of ventilator purpose	81	77	83	0.42
Knowledge of ability to speak after initial intubation	44	31	54	< 0.01
Knowledge of post-CPR survival in CKD patients	6	8	5	0.38
Knowledge of change in ability to perform daily activities post-CPR survival	60	60	60	0.99
Mean summary score (±SD)	51 (±20)	45 (±19)	56 (±20)	0.01

[*] CPR=Cardiopulmonary resuscitation

Table 3.

Unadjusted and Adjusted Analyses for Mean CPR[*] Knowledge Score by Race

	MODEL 1: Unadjusted	**MODEL 2: Multivariable, no health literacy**	**MODEL 3: Multivariable + health literacy**
	B (95% CI)	B (95% CI)	B (95% CI)
Intercept	56.32 (52.17, 60.47)	57.02 (52.29, 61.75)	57.86 (53.12, 62.60)
Race: Black vs. White	−11.77 (−18.20, −5.33)	−8.14 (−15.44, −0.83)	−5.05 (−12.82, 2.72)
Age, years: < 65 vs. ≥ 65		−7.34 (0.57, 14.13)	7.51 (0.81, 14.20)
Education < HS[**] vs. ≥ HS		−9.77 (−18.82, −0.73)	−7.00 (−16.31, 2.31)
Income: < 30K vs. ≥ 30K		−6.47 (−13.15, 0.20)	−6.02 (−12.63, 0.58)
Health literacy: Limited vs. Adequate			−8.28 (−16.00, −0.56)
Model R^2	0.08	0.16	0.19

[*] CPR=Cardiopulmonary resuscitation;

[**] HS = High school

Table 4.

Adjusted Analyses Including Advance Directives for Mean CPR[1] Knowledge Score by Race

	MODEL 4: Multivariable + DNR form/ living will	**MODEL 5: Multivariable + HCP form**
	B (95% CI)	B (95% CI)
Intercept	61.46 (55.54, 67.37)	58.93 (54.08, 63.78)
Race: Black vs. White	−4.56 (−12.28, 3.15)	−4.69 (−12.42, 3.03)
Age, years: < 65 vs. ≥ 65	9.55 (2.61, 16.49)	8.94 (2.11, 15.77)
Education < HS vs. > HS	−6.65 (−15.88, 2.56)	−7.23 (−16.47, 2.01)
Income: < 30K vs. ≥ 30K	−5.90 (−12.45, 0.64)	−4.93 (−11.60, 1.74)
Possession of DNR[2] form or living will: No vs. Yes	−6.78 (−13.57, 0.02)	–
Possession of HCP[3] form: No vs. Yes	–	−5.98 (−12.59, 0.63)
Health literacy: Limited vs. Adequate	−8.21 (−15.85, −0.56)	−7.76 (−15.44, −0.07)
Model R^2	0.21	0.21

[1] CPR=Cardiopulmonary resuscitation,

[2] DNR=Do-Not-Resuscitate,

[3] HCP=Healthcare proxy form