Kidney Medicine

CKD Knowledge and CKD Report Card Use During a Nephrology Encounter: A Randomized Trial

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Rationale & Objective: Higher chronic kidney disease (CKD) knowledge and health literacy (HL) are associated with improved CKD outcomes. We sought to determine if the CKD Report Card intervention increased CKD knowledge in patients regardless of HL level.

Study Design: A block-randomized trial by clinic session.

Setting & Participants: Patients with CKD 3 or above in an urban academic nephrology clinic.

Intervention: The intervention group received the CKD Report Card, a 2-sided information sheet, before the clinic visit.

Outcomes: Kidney Knowledge Survey pre–post-visit score change.

Results: Of 91 participants, the average age was 66.2 years, 64.8% identified as African American, 41.8% were male, and 11.0% had inadequate HL. The control group's (n = 53) mean pre-visit knowledge score was 55.8% with a post–pre-score change of 0.9 (95% confidence intervals [CI], −1.3 to 3.2). The intervention group's (n = 38) mean pre-visit score was 60.2% with a score change of 19.2 (95% CI, 15.2-23.3). The difference in score change between the control group and intervention group was −18.4 (95% CI, −22.6 to −14.1). In addition, there was no significant difference in knowledge gained by adequate and inadequate HL for the control group ($P = 0.6$) or the intervention group ($P = 0.6$). In the fully adjusted multivariable model, the HL × group interaction term was not significant (β = −6.1; $P = 0.4$). Pre-visit score (β = −0.2; $P < 0.01$) and intervention group (β = 19.0; $P < 0.001$) were significant.

Limitations: Limited generalizability because the study took place at 1 academic medical center and there were only a small proportion of patients with inadequate HL.

Conclusions: The CKD Report Card is a low-touch, low-cost intervention that improved CKD knowledge for all patients in our urban nephrology clinic regardless of HL level.

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Chronic kidney disease (CKD) affects 15% of US adults and is associated with increased morbidity and mortality.[1] While CKD is common, some groups are disproportionately impacted. CKD prevalence is higher among individuals with low income and low educational attainment.[1] Rates of advanced CKD are higher in racial and ethnic minoritized populations in the United States.[1] African American and Hispanic individuals often have a faster rate of CKD progression and are more likely to progress to end-stage kidney disease than those in other racial-ethnic groups.[1-3] Reducing these disparities will likely require long-term, large-scale changes to increase access to high-quality health care and to address the social drivers of health.[4,5] However, improving CKD awareness and knowledge for patients is an actionable step to improve CKD outcomes.

CKD-specific knowledge is associated with better CKD self-management and slower kidney function decline.[6] Unfortunately, many people with CKD, including those receiving nephrology care, lack basic CKD knowledge.[7,8] Our prior work with hospitalized and nephrology clinic patients at an urban academic medical center with a high proportion of low-income and minoritized patients demonstrated that many patients with CKD lacked awareness of their CKD, understanding of their CKD stage, information about specific laboratory tests related to their kidney health, and knowledge about CKD self-care.[9-12] Patients reported that they found it challenging to make the necessary lifestyle changes that were recommended to help slow their disease progression.[13] Other studies investigating nephrology clinic patients have had similar findings.[14-17]

Health literacy, the ability to access, understand, and use health-related information, is associated with many CKD-related outcomes. Health literacy is associated with having greater kidney disease knowledge, better self-management, and more active engagement with health care providers.[6] Health literacy is increasingly important as CKD progresses because kidney failure requires more patient engagement and understanding to adhere to dietary restrictions, attend dialysis appointments, and access kidney transplantation.[18] Low health literacy is common among individuals with CKD, with estimates ranging from 17%-33%.[19-21] In a systematic review, low health literacy was associated with increased hospitalizations, emergency department use, missed dialysis appointments, and other outcomes associated with CKD-related morbidity and mortality.[22] To date, many CKD educational interventions require high staff effort and are not focused on low-literacy populations.[22] Low-touch interventions are needed to increase patients' CKD knowledge, particularly for those with low health literacy.

The CKD Report Card, a 1-page patient education resource, was developed to improve CKD knowledge in

nephrology patients. Our previous pilot study using the CKD Report Card demonstrated that patients who received this 1-page resource before their nephrology visit had greater post-visit CKD knowledge.[12] We sought to test the CKD Report Card through a randomized trial to determine if the CKD Report Card effectively increases CKD knowledge in patients regardless of health literacy.

METHODS

This was a block-randomized trial of a patient education tool, the CKD Report Card, in patients seen at an adult nephrology clinic at an urban academic medical center. Nephrologists assented to have their patients approached for the study. Patients in the nephrology clinic were block randomized by half-day clinic session either to receive the CKD Report Card before their nephrology visit or to usual care. Allocation was determined using a random number generator at the beginning of each clinic day. Nephrologists were blinded to allocation, although they could see the CKD Report Card if a patient elected to show them. The participants and research assistant were aware of the group allocation. Inclusion criteria were patients in the nephrology clinic who were English-speaking adults with CKD stage 3 or above. Exclusion criteria were patients who were non-English speaking or patients with CKD stage 1 or 2, or a diagnosis of end-stage kidney disease on dialysis or post-transplant. Data were collected from June-July 2019. Study approval for this research was obtained by The University of Chicago Institutional Review Board (IRB19-0958-AM001), and the study was registered with ClinicalTrials.gov (Trial Registration Number NCT04119570).

Intervention

The CKD Report Card is a 1-page, double-sided document modified from the National Kidney Disease Education Program.[23] On one side, there is general information about the functions of kidneys and CKD risk factors. This side includes an illustration of the kidneys in the body, as well as descriptions of several important kidney functions written in plain language, such as "keep your body's chemicals in balance" and "help to control blood pressure." It describes how kidney disease is diagnosed with blood and urine tests and provides basic dietary and exercise recommendations for preventing CKD progression. The other side contains patient-specific information. This side includes spaces for patients to fill in their creatinine and estimated glomerular filtration rate and to use a graphic to match those values to their CKD stage. Additionally, there is space to mark whether their blood pressure and other CKD-related laboratory tests are "at goal" or "not at goal" and to write notes about how to reach those goals (Item S1).

Participants in both conditions completed a demographic information form and a pre- and post-visit survey. The pre-survey assessed health literacy and CKD knowledge. After completing the survey, patients attended the appointments with their nephrologist. Those who were in the intervention group were given the CKD Report Card to use however they liked during the clinic visit. After the clinic visit, all patients were asked to complete the post-visit CKD knowledge assessment. Neither the intervention nor control group could use the CKD Report Card during either pre-visit or post-visit survey completion.

Measures

Our primary outcome was CKD knowledge, as measured by pre- and post-visit scores on the CKD Knowledge Questionnaire, modified from the Kidney Disease Knowledge Survey.[24] Participants received 1 point for each correct answer out of 12 questions, for a total of 29 points, as some questions had multiple correct answers. Our predictor, health literacy, was measured using the Brief Health Literacy Screen, a 3 question validated tool to assess health literacy.[25] Each question of the Brief Health Literacy Screen is scored on a 5-point response scale and is summed to produce a total score ranging from 3 to 15, with higher scores corresponding to higher health literacy. Patients who scored ≤9 were considered to have inadequate health literacy, and those who scored >9 were considered to have adequate health literacy. Other covariates were participant self-report of their age, race/ethnicity, sex, and education level. CKD stage was abstracted from the electronic medical record.

All statistical analyses were performed using Stata SE-17.0 (StataCorp LLC) and R studio (R version 4.2.0). We summarized all quantitative outcomes with basic descriptive statistics. Wilcoxon signed rank test was used to compare the kidney disease knowledge score before and after intervention within each group. Wilcoxon rank sum test was used to compare the knowledge gained between control versus intervention group, then to compare participants by health literacy group within experimental condition to each other. Additionally, a multivariable regression was performed to determine which covariates were significant predictors for the change in scores. We used post-estimation marginal effects to estimate between-group effects and within-group effects by health literacy status. To assess the difference in difference among subgroups, we used the "contrast" function of package "emmeans" in R, which calculates the difference of the score change between subgroups with 95% confidence intervals (CIs) computed using the t-distribution due to the small sample size.[26,27] Tukey's method was also applied to adjust for multiple comparisons.[28]

RESULTS

We approached 107 patients over 6 weeks and recruited 96. Five patients were excluded from the analysis due to CKD stage outside of the inclusion criteria (CKD stage 1 or 2). Of the 91 participants (Table 1), the mean age was 66.2 years

Table 1. Participant Characteristics—Overall and By Group

	Overall	Control	With Report Card	*P*
n	91	53	38	
Age, mean (SD)	66.2 (11.6)	66.99 (10.6)	65.1 (13.0)	0.3
Male, n (%)	38 (41.7%)	23 (43.4%)	15 (39.5%)	0.7
Race, n (%)				0.2
African American	59 (64.8%)	38 (71.6%)	21 (55.3%)	
White	26 (28.6%)	13 (24.5%)	13 (34.2%)	
Other	6 (6.6%)	2 (3.8%)	4 (10.5%)	
Education level, n (%)				0.8
12th grade or less	26 (28.5%)	15 (28.3%)	11 (28.9%)	
Some college	33 (36.3%)	18 (3.0%)	15 (39.5%)	
College graduate or more	32 (35.2%)	20 (37.7%)	12 (31.5%)	
First nephrology visit	17 (18.7%)	11 (20.8%)	6 (15.8%)	0.5
CKD stage (%)				0.4
3	60 (66.7%)	33 (63.5%)	27 (71.1%)	
4	23 (25.6%)	16 (30.8%)	7 (18.4%)	
5	7 (7.8%)	3 (5.8%)	4 (10.5%)	
Pre-visit score, mean (SD)	57.6 (19.0)	55.8 (18.7)	60.2 (19.5)	0.2
Inadequate health literacy, n (%)	10 (11.0%)	4 (7.5%)	6 (15.8%)	0.3
Health literacy score, mean (SD)	12.1 (2.8)	12.1 (2.6)	12.0 (3.0)	0.9

Abbreviations: CKD, chronic kidney disease; SD, standard deviation.

(standard deviation [SD], 11.6), 59 (64.8%) identified as African American, and 38 (41.8%) were male. The average pre-visit knowledge score was 57.6% overall, 55.8% for control and 60.2% for the intervention ($P = 0.3$). Our study sample was not significantly different with regard to age, race, or sex from the nephrology clinic patients with CKD stage 3 or above who were seen during that time period (Table S1).

Report Card Intervention

The mean pre-clinic visit score for the control group ($n = 53$) was 55.8% (SD, 18.7%), and the mean post-visit score for this group was 56.7% (SD, 17.7%). Control group participants had a post–pre-score difference of 0.9 (SD 8.1, 95% CI, −1.3 to 3.2; $P = 0.9$) (Figure 1). The mean pre-visit score for the CKD Report Card group ($n = 38$) was 60.2% (SD, 19.5%), and the mean post-visit score for this group was 79.4% (SD, 17.6%). Intervention group participants had an average post–pre-score difference of 19.2 (SD, 12.2; 95% CI, 15.2-23.3; $P < 0.001$) (Figure 1). t tests demonstrated that the difference in the change in scores between the control group and the CKD Report Card group was also significant (−18.3; 95% CI, −22.6 to −14.1; $P < 0.001$). In a multivariable model controlling for race, educational attainment, CKD stage, pre-visit score, health literacy score, age, and first nephrology visit, only pre-visit score ($\beta = -0.19$; $P = 0.01$) and intervention group ($\beta = 18.84$; $P = 0.001$) were significantly associated with the change in knowledge score (Table S2).

By Health Literacy Status

We also examined the effect of the intervention by health literacy status. There were 10 (11.0%) patients in the inadequate health literacy group, and 81 (89.0%) in the adequate health literacy group. Within the control group, 7.5% of participants had inadequate health literacy compared with 15.8% in the intervention group ($P = 0.3$). The mean health literacy score was 12.1 (SD, 2.6), and 12.0 (SD, 3.0) for the control and intervention groups, respectively (Table 1).

Overall participants pre-visit score was 59.7% (SD, 21.3%) for those with inadequate health literacy and

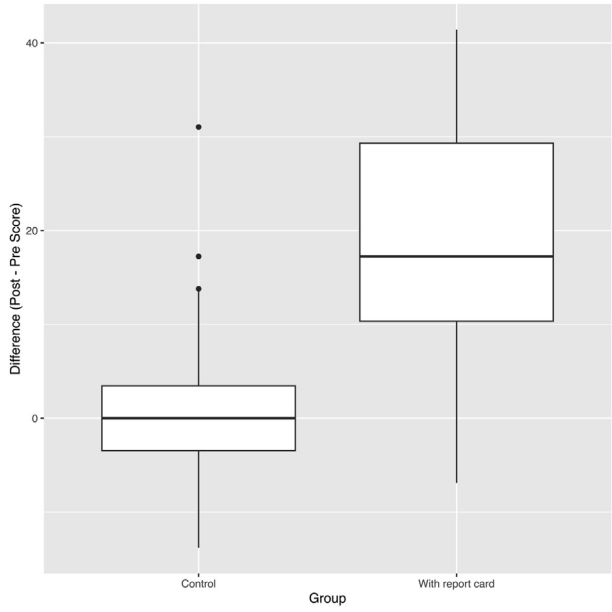

Figure 1. Differences in Chronic Kidney Disease Knowledge Questionnaire score (Post–Pre) by intervention group. There was a significant difference in the change in score between the control group and the report card group.

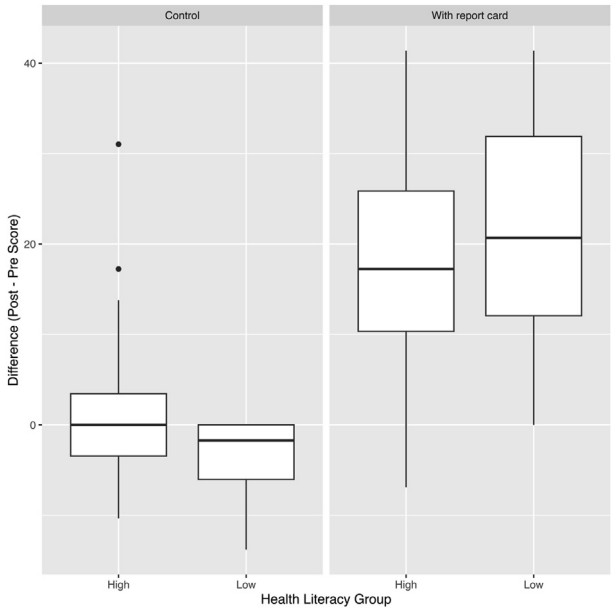

Figure 2. Differences in Chronic Kidney Disease Knowledge Questionnaire score (Post–Pre) by intervention group and health literacy status. There was a significant difference in the change in score between the control group and the report card group, but the knowledge gain in the low health literacy report card users was not significantly different from the knowledge gain in the high health literacy report card users.

57.3% (SD, 18.9%) for those with adequate health literacy ($P = 0.7$). There was no significant difference in knowledge gained by adequate and inadequate health literacy for control group ($P = 0.6$) or the intervention group ($P = 0.6$). The average post-visit–pre-visit score difference for control group participants with inadequate health literacy ($n = 4$) was −4.3 (SD, 6.5), indicating that on average their scores were lower after their nephrology visit, versus 1.3 (SD, 8.2) for those with adequate health literacy ($n = 49$). Intervention group participants with inadequate health literacy ($n = 6$) had an average post–pre-score difference of 21.3 (SD, 15.3) compared with 18.9 (SD, 11.82) for those with high health literacy ($n = 32$) (Figure 2).

Finally, in a multivariable model to test the interaction of the intervention with health literacy level, we found that the health literacy × group interaction term was not significant (β, −6.1; 95% CI, −7.4 to 19.5; $P = 0.4$). In this model, only the pre-visit score (β,−0.2; 95% CI, −0.30 to −0.06; $P < 0.01$) and intervention group (β, 19.0; 95% CI, 14.5-23.5; $P < 0.001$) were significantly associated with change in score. In the fully adjusted model in the control group, there was no significant difference in pre-post-visit score change in the adequate health literacy group compared with the inadequate health literacy group (4.7; 95% CI, −9.0 to 18.4; $P = 0.80$) (Table 2). Similarly, in the intervention group, the adequate health literacy group score change was not significantly different than that of the inadequate health literacy group (−1.3; 95% CI, −14.2 to 11.6; $P = 0.99$). Additionally, there was a significantly greater pre-post score change in the intervention group than in the control group for participants with both low health literacy (19.0; 95% CI, 13.1-24.8; $P < 0.001$) and the high health literacy groups (25.0; 95% CI, 8.2-41.8; $P < 0.05$).

DISCUSSION

In our single-clinic randomized trial, patients who used the CKD Report Card during their nephrology appointment had a greater CKD knowledge gain than patients who did not use this resource. No other factors, including education, CKD stage, or health literacy, were significantly associated with knowledge gain. Patients were able to use this tool in any way they chose and may have experienced benefits for different reasons. Having the CKD Report Card may have activated some patients to ask questions about their CKD. It may also have helped patients better understand or recall the information they received. The intervention also could have improved the quality of physicians' communication with the patient. To our knowledge, no prior work has assessed the content and effectiveness of nephrologist–patient communication. However, in a study of primary care providers, clinicians' communication with patients with CKD or at risk for CKD was often not patient-centered, used jargon and technical language without explanation, and included little patient participation.[29] The CKD Report Card might have prompted clinicians to provide more information to patients. Alternatively, clinicians may have been able to communicate more effectively because the sheet provides visual cues and uses plain language. Thus, while the patient education tool did improve patient–physician communication, we do not yet know how. No matter how it was used, there was a clear benefit to patients using the CKD Report Card, a low-cost, low-touch intervention.

Table 2. Post-Visit Score Change by Intervention and Health Literacy Status

Group Comparison	Point Estimate	95% CI	SE	*P*
Intervention vs control (overall)	19.6	15.4, 23.8	2.1	<0.001
High HL intervention vs high HL intervention control (between-group)	19.0	13.1, 24.8	2.2	<0.001
Low HL intervention vs low HL control (between-group)	25.0	8.2, 41.8	6.4	0.001
High HL intervention vs low HL intervention (within-group)	−1.3	−14.2, 11.6	4.9	0.99
High HL control vs low HL control (within-group)	4.7	−9.0, 18.4	5.2	0.8

Abbreviations: CI, confidence interval; HL, health literacy; SE, standard error.

The CKD Report Card was effective in improving CKD knowledge from pre-nephrology clinic visit to post-visit, and its effectiveness did not vary based on patients' health literacy scores. Both health literacy groups showed significant improvement in their CKD knowledge using the report card. In contrast, neither health literacy group in the control group had a significant pre-post-visit change in CKD knowledge. In fact, control group participants with inadequate health literacy performed *worse* on the CKD Knowledge Questionnaire after their visit. It was also surprising that low health literacy was not associated with kidney disease knowledge. We found that individuals with both high and low health literacy had low baseline CKD knowledge and showed improvement using the report card. CKD knowledge has been correlated with health literacy in other studies.[6,20] Those with higher health literacy had a better understanding of their chronic illness, and they were better able to communicate with providers and use the information shared for self-management.[3] Our findings are consistent with work by Devraj et al,[30] who found that CKD awareness was not significantly associated with health literacy. Surprisingly, other patient characteristics such as education level and current CKD stage were not associated with knowledge gain after the nephrology visit. Thus, it is important to implement "universal precautions" to consistently use methods shown to be helpful for low-literacy populations to improve health understanding and outcomes for all patients.[31] Many of these strategies—encouraging questions, using plain language, avoiding medical jargon, and checking for understanding through teach-back and show-me—should be embedded in most physician–patient communication.

Our work had important limitations that will inform future research. Only a small proportion of participants in our study had low health literacy. Prior work in other CKD populations found a higher prevalence of low health literacy, 25% on average.[19] Because health literacy was assessed only in study participants, we were not able to determine if the health literacy of the study participants was representative of the overall clinic population. Additionally, it was not possible to stratify by health literacy in advance because health literacy was assessed after enrollment and assignment to either the control or intervention group. The CKD Report Card was associated with knowledge gain during the clinic visit, but we still do not know how the change occurred. Our future qualitative work will examine how patients and providers communicated during these appointments and will determine if there was a difference in communication between patients who had the report card and those who did not. Finally, we were not able to determine whether the CKD knowledge gain persisted or changed patient behavior. While the results after one nephrology appointment are promising, it will be important to determine whether the knowledge gained from the report card leads to long-term increases in CKD knowledge and to meaningful changes in self-care behavior. Future work should include a larger population with low health literacy, across multiple centers, and with longer follow-up.

In conclusion, patients with CKD often have a poor understanding of kidney disease. To reduce CKD progression and morbidity, it is important that patients understand their CKD and how to prevent and manage CKD-related conditions and complications. The CKD Report Card and similar patient education tools can be an effective way to improve patients' understanding of their own illness. In our urban nephrology clinic, all patients—both those with high and low health literacy—had low baseline CKD knowledge and showed improvement using the CKD Report Card.

SUPPLEMENTARY MATERIALS

Supplementary File (PDF)

Item S1: The CKD Report Card.

Table S1: Comparison of Study Population with Clinic Population.

Table S2: Factors Associated With Post-Visit Score Change.

ARTICLE INFORMATION

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