

RESEARCH LETTER

An Interactive Education Program for Advanced CKD: The ABCs of Kidney Disease Program

To the Editor:

An estimated 23% of patients with chronic kidney disease (CKD) have limited health literacy,¹ defined as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”² Limited health literacy in patients with CKD is associated with cardiovascular disease, fewer transplant referrals, and increased mortality.^{1,3-5} CKD-specific patient knowledge is an important patient-centered outcome measure.⁶ Previous trials have demonstrated that improved patient knowledge is associated with positive clinical outcomes such as increased time to initiation of kidney replacement therapies.⁷ Educational interventions may improve patient knowledge; however, there is sparse guidance for the optimal delivery and format of patient education programs. The Johns Hopkins Nephrology Patient Education Program, “The ABCs of Kidney Disease,” was designed with the aim of educating patients, families, and caregivers interested in CKD care in the Baltimore–Washington area. We hypothesized that participants would improve CKD-specific knowledge. The Johns Hopkins Medicine Institutional Review Board granted this project the exemption status and deemed it a quality improvement activity on February 27, 2017.

“The ABCs of Kidney Disease” began in October 2015 as a monthly educational program to serve the patients of the Johns Hopkins Nephrology Clinic and surrounding communities. The topics covered in each session included normal kidney function, diagnosis of kidney disease, causes of CKD, complications of CKD management, and treatment of kidney failure, including conservative care, in-center and home dialysis modalities, and transplantation. Each session included a 1.5-hour lecture, followed by a question-and-answer period led by 2 attending nephrologists. The lectures were interactive and employed educational models and dialysis equipment. More details of the program’s content are presented in [Items S1](#) and [S2](#). Attendance was limited to 20 participants per session.

Preceding each session, the participants filled out voluntary registration forms to obtain self-reported participant demographics and a pretest 28-question standardized kidney disease knowledge survey developed by Wright et al⁶ ([Item S3](#)). Following each session, the participants were asked to complete the kidney disease knowledge survey. Before 2019, the registration forms did not include information on sex, race or ethnicity, and education level; consequently, we collected this information via a chart review of the participants’ demographics and social history sections using electronic medical records. Demographics and patient scores were

collected between October 2015 and February 2020 ([Items S4](#) and [S5](#)).

The primary outcome was a change in kidney disease knowledge. Kidney disease knowledge scores from the pre- and posttest surveys were compared using paired t tests. The secondary outcomes included assessment of the educational session using various Likert scales (from 1 to 5) ([Item S6](#)). The scores for Likert questions were averaged.

From October 2015 to February 2020, 307 participants completed the registration forms ([Table 1](#)). The mean age of the participants was 63 years, 56% were women, 47% were African American, and 43% were White. Among the registered participants, 223 (73%) completed the pretest kidney disease knowledge survey and 165 (54%) completed the posttest kidney disease knowledge survey, with 144 completing both the pre- and posttest kidney disease knowledge surveys (47%). The average posttest score (76%) was significantly higher than the pretest score (62%) ($P < 0.001$) ([Item S7](#)). The classes were well rated ([Table 2](#)); the averaged scores ranged from 4.6 to 4.9 out of a possible maximum of 5.

In this educational intervention aimed at informing individuals with kidney disease and caregivers of key aspects pertaining to CKD management and kidney replacement therapies, we found that the kidney disease knowledge scores improved among the participants. Improving CKD knowledge and awareness has become a prominent issue, especially because previous research has suggested that lack of disease-specific knowledge among patients with CKD is not a reflection solely of late referral but of the delivery of nephrology care.⁸ Deficiencies in pre-end-stage kidney disease education, for example, are associated with underutilization of home dialysis modalities and likely contribute to delays in transplantation.⁹

Our intervention has several strengths, including its comprehensive approach to teaching CKD care, small class sizes to facilitate interactive participation, and the use of a standard instrument to evaluate kidney disease knowledge. The limitations include missing demographic variables for several participants; however, based on available data, knowledge scores appeared to increase similarly across the subgroups ([Item S7](#)). Apart from education level, participant socioeconomic variables were not evaluated. The original kidney disease knowledge survey did not list home dialysis or conservative care as treatment options for end-stage kidney disease. We can modify future knowledge surveys, as others have done,¹⁰ to include these additional treatment options. For several questions, the participants had a 50% chance of guessing the correct answer. Improvements in immediate CKD knowledge scores may have been affected by patient selection bias. Lastly, we did not address the psychosocial effect of our educational program.

In general, our educational intervention was associated with improvements in immediate CKD-specific knowledge and was well received by the participants. Future studies

Table 1. Participant Characteristics

Participants in The ABCs of Kidney Disease ^a N = 307	
	Mean (standard deviation)
Age (n = 291)	63 (15.3) y Missing from total N: 16 (5.2%)
Sex (n = 266)	n (%) Female: 149 (56) Male: 117 (44) Missing from total N: 41 (13.4%)
Race/ethnicity (n = 260)	African American: 123 (47) American Indian or Alaskan Native: 3 (1) Asian or Pacific Islander: 13 (5) White: 112 (43) Hispanic: 4 (2) Other: 5 (2) Missing from total N: 47 (15.3%)
Education (n = 91)	Less than high school: 3 (3) High school: 19 (21) Some college: 21 (23) College: 27 (30) More than college: 21 (23) Missing from total N: 216 (70.4%)

^aParticipants between December 2015 to December 2018 who completed registration forms.

should focus on evaluating long-term CKD knowledge and psychosocial elements, such as hope, inclusion of additional demographic variables, and tracking of long-term outcomes such as rates of dialysis started with a catheter, home dialysis initiation, and preemptive and living donor transplantation.

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SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

Item S1: Introduction Sheet for “The ABCs of Kidney Disease” Program

Item S2: Slides for “The ABCs of Kidney Disease”

Item S3: Kidney Knowledge Survey (KiKS)

Item S4: Educational Session Registration Form

Item S5: Educational Session Registration Form, Updated 2019

Item S6: Evaluation of “The ABCs of Kidney Disease”

Item S7: Paired t Test Comparing Pretest and Posttest Scores, For All Participants and by Subgroup

ARTICLE INFORMATION

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Table 2. Averaged Ratings from Participant Evaluations

Questions	Rating
On a scale of 1 (not well at all) to 5 (extremely well), how well was each topic explained?	
Normal kidney function (n = 254)	4.8
The causes and stages of chronic kidney disease (n = 257)	4.8
The effects of kidney disease on the body (n = 256)	4.8
Treatment options for kidney disease and failure (n = 255)	4.8
On a scale of 1 (strongly disagree) to 5 (strongly agree), evaluate the faculty and sessions.	
The session information will help me manage my kidney disease (n = 242)	4.6
The session met or exceeded my expectation (n = 253)	4.7
I can use the information I learned right away (n = 255)	4.6
Overall, the speakers for the session were knowledgeable (n = 257)	4.9
Overall, the speakers for the session were engaging (n = 257)	4.9
The handouts and materials were useful (n = 254)	4.8

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