


The ABCs of Kidney Disease: Knowledge Retention and Healthcare Involvement

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Abstract

Low health literacy in the chronic kidney disease population results in lower rates of pre-dialysis preparation and understanding of management to slow progression. The ABCs of Kidney Disease education class provided education in a more consistent manner outside of routine office visits. We aimed to study whether a structured education program would increase kidney disease-specific knowledge and healthcare involvement. Knowledge retention at least 6 months after the class assessed by the Kidney Disease Knowledge Surveys (KIKS) and healthcare involvement based on surveys sent to referring providers were found to have increased. Incorporation of a structured education program would be important for providers to improve long-term knowledge and lead to greater healthcare involvement. Providing an education class outside of the routine office visits will provide a greater impact on health literacy.

Keywords

patient education, patient engagement, patient feedback, clinician–patient relationship

Introduction

About 37 million people in the United States have chronic kidney disease (CKD) (1). Twenty-three percent of individuals with CKD have limited health literacy, which is associated with missed dialysis sessions, increased emergency department visits, higher morbidity/mortality, and fewer referrals for transplantation (2–4). The Institute of Medicine defines health literacy 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” (5). CKD is highly prevalent among groups with low health literacy, such as in certain racial/ethnic minorities, immigrants, non-native English speakers, and patients with low socioeconomic status or advanced age (4,6).

Although health literacy can be improved through educational interventions, the lack of consistency in the delivery, duration, and intensity has made this process challenging and difficult to assess. In studies of education program effectiveness, the largest effects observed were in the gain of CKD-specific knowledge, and some positive impact on health-related outcomes (7,8). In prior CKD education studies, improving CKD knowledge has been linked to higher rates of pre-dialysis preparation, preservation of

kidney function, higher rates of peritoneal dialysis (PD), and higher rates of transplant evaluations prior to dialysis (2). These improvements are linked to better patient outcomes and quality of life. The purpose of this pilot study was to assess change in kidney disease-specific knowledge and the level of healthcare involvement after attending a structured CKD education session.

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Methods

In 2015, in an effort to improve and standardize our patient education, a monthly free, in-person 90-min education class called the ABCs of Kidney Disease was started. The class addresses normal kidney function, and CKD causes, stages, complications/management, as well as treatments for kidney failure. Classes were limited to 20 participants to facilitate discussion. Participants are allowed to attend multiple classes, if desired. Participants were given a registration form and a pre-class Kidney Disease Knowledge Survey (pre-class KiKS), immediate post-class KiKS and a class evaluation form (9). The classes were conducted by the same 2 nephrology faculty members for the period studied. Information was delivered via a lecture format with PowerPoint presentation, open discussion, and hands-on models. Participants are given printed copies of the PowerPoint presentation.

This pilot study recruited from 228 attendees from the Johns Hopkins nephrology clinic who voluntarily attended the education classes from October 2015 to December 2018 (see Appendix for flow diagram). The objective was to assess retention of knowledge at least 6 months after completing the class and level of involvement in healthcare as assessed by the participant and their nephrologist. A retrospective chart review was completed of those participants that agreed to the follow-up in 2019 (27 of the 228 original attendees). In addition, these participants received a follow-up study participant questionnaire and their respective nephrologist were sent questionnaires as well. These study participants provided verbal consent for a chart review and participation in the questionnaires. The study was approved

by the Johns Hopkins Medicine Internal Review Board on August 1, 2019.

The retrospective chart review was conducted in 2019 to confirm self-reported information on the registration forms for the class regarding their CKD stage, proteinuria, hematuria, family history of CKD, history of hypertension, diabetes, or cardiovascular disease, and prior dialysis needs. Next, clinical outcome changes such as dialysis preference/initiation were recorded from follow-up visit notes with their nephrologist before and after attending the class.

Study participants received a follow-up questionnaire, assessing retention of knowledge (long-term post-class KiKS (9)) and involvement in healthcare. Nephrologists received a questionnaire assessing their perception of the patients' involvement in their care. The KiKS includes 28 questions related to kidney disease topics, with a total score of 28 points. It has been tested for reliability and validity. The Kuder-Richardson-20 reliability coefficient was 0.72. Participants completed tests on paper, which were hand-graded (9). The participant and nephrologist questionnaires were designed specifically for this pilot study with input from nephrology faculty and survey design experts. These questionnaires were a combination of free text and multiple-choice answers. They were completed and tallied through an online survey tool. These were one-time questionnaires.

Results

Of the 228 patients, 27 agreed to participate (100 refused, 101 were unreachable). Multiple attempts were made to reach the 101 that were unreachable. This was the first time attendees had been contacted for follow-up since the education classes were started 4 years prior. With the greater time between the class attendance, there was some drop-off due to death, change of address/contact numbers, and transition to dialysis or transplantation. No specific reason for refusal was given by the 100 participants. Ten of the 27 participants completed all 3 KiKS. Table 1 illustrates the baseline characteristics collected. Information was gained from the registration and verified with the electronic medical record. The average age was 61 years. Most participants were female (56%) and Caucasian (41%). Also, most patients had stage 5 CKD (33%) and proteinuria (70%). Frequent comorbidities included hypertension (85%), coronary artery disease (15%), and diabetes mellitus (22%). There was no prior dialysis history. The average time from attendance of the ABCs of Kidney Disease educational class to receipt of the questionnaire and participation in this study was 1055 days (or 2.9 years).

The preferred or current dialysis modality at the time of long-term questionnaire was recorded. Eighteen of the 27 had dialysis plans after the educational session; with one-third having plans for a home dialysis modality (3 for home hemodialysis [HHD], 4 for PD). Eight of the 27 started dialysis at the time of follow-up with 3 starting on a home dialysis modality (1 on HHD and 2 on PD).

Table 1. Participant Baseline Characteristics.

Characteristics of ABCs of Kidney Disease Follow-up Participants	Frequency (n = 27)		Percent (%)
Mean age (years)	61 (22–83)		
Sex			
Male	12		44%
Female	15		56%
Race			
Caucasian	11		41%
African American	10		37%
Asian	2		7%
Chronic kidney disease (CKD) Stage			
Stage G3a	3		11%
Stage G3b	5		19%
Stage G4	7		26%
Stage G5	9		33%
Proteinuria	19		70%
Hematuria	9		33%
Family History of CKD	2		7%
Hypertension	23		85%
Diabetes Mellitus	6		22%
Coronary artery disease	4		15%

Abbreviation: CKD, chronic kidney disease.

Determination of significance was limited due to the sample size.

One of the primary outcomes was to assess the change in kidney disease knowledge by attending the class. Of the 27 who agreed to participate, there was a 12% increase in knowledge in the immediate post-class KiKS, and a 3% increase in the long-term post-class KiKS, compared to the pre-class findings. Despite the 8% drop-off in knowledge with time, the preservation of a 3% increase almost 3 years later suggests the impact of even a single session. Figure 1 shows graphically the change in pre-class, immediate post-class, and long-term post-class for the 10 participants that had all 3 completed.

Participants found the topics “Dialysis options,” “Chronic kidney disease complications,” and “Chronic kidney disease management” the most useful. Participants reported incorporating the behaviors of “Track your labs” and “Monitor your blood pressure, weight, etc. at home.”

Nephrologists referred patients to the educational sessions for dialysis planning (94%) and cited this as the most observed benefit (71%). Attendees were more apt to discuss dialysis modalities, access, and transplantation following the session. Expressing interest in a specific modality was the most reported level of involvement in their healthcare by nephrologists. Anxiety surrounding kidney disease (82%) was noted by nephrologists to be a barrier to the involvement in healthcare.

Discussion

The main purpose of this pilot study was to gauge kidney disease knowledge retention for a period >6 months

(labeled as “long-term”) and involvement in healthcare by the participants. The study demonstrates an increase in kidney disease knowledge from the pre-class to immediately post-class KiKS and is consistent with prior studies (10,11). This immediate increase in kidney disease knowledge has implications as to the impact of single class improving knowledge in the short term and the impact of having a dedicated time for education versus presenting the material during a routine office visit or via printed material. Individuals attended this class on a voluntary basis suggesting a degree of motivation in learning more about their health condition and it can be reasonably inferred sought out other educational options such as online resources and printed materials. This group demonstrated further improvement in their knowledge through attendance of an in-person class suggesting the importance of utilizing multiple strategies for education for maximal impact. Although the immediate compared to the long-term post-class KiKS showed a mean decrease over time, there was retention and an overall increase in knowledge compared to pre-class KiKS. It suggests the value of a single session for long-term impact. Few historical studies address long-term CKD knowledge retention (7,11). Devin et al. (12) evaluated kidney disease knowledge at baseline, 18, 30, 42, and 54 months in 47 patients and showed that a single-session pre-dialysis psychoeducational intervention produced substantial knowledge gains that were retained for at least 54 months. Other studies have demonstrated increased time to dialysis and survival (8,13).

Most nephrologists noted the primary benefit from the ABCs of Kidney Disease was dialysis planning. Attendees discussed dialysis modalities, access, transplantation,

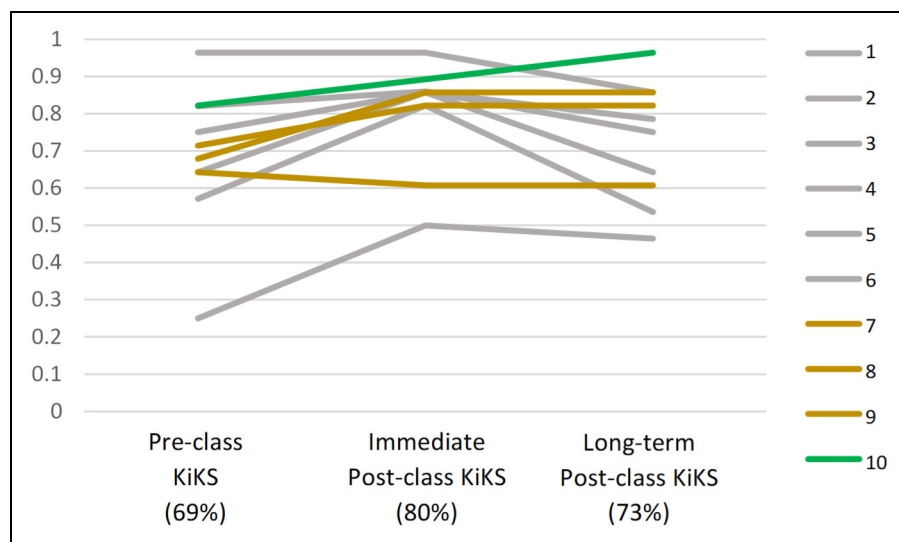


Figure 1. Data for each individual participant (1 thru 10) kiKS changes are shown. Average scores for pre-class, immediate post-class, and long-term post-class KiKS are listed in “(.)” Gray means the long-term post-class KiKS was lower than immediate post-class KiKS, Yellow means the long-term post-class KiKS was the same as the immediate post-class KiKS. Green had better score at long-term post-class KiKS than immediate post-class KiKS.

nutrition, and blood pressure more after the educational sessions. Surveys of the nephrologists are a strength of the study providing an account of attendees' use of the information from the class. This educational intervention was provided by nephrologists, which is not a common approach among educational programs for kidney disease (7).

A promising and important finding is that participants had dialysis plans that involved self-management (ie, 7 of 18 preferred home modalities). Nationally, HHD accounts for 2% of dialysis patients, and PD accounts for about 10% (14).

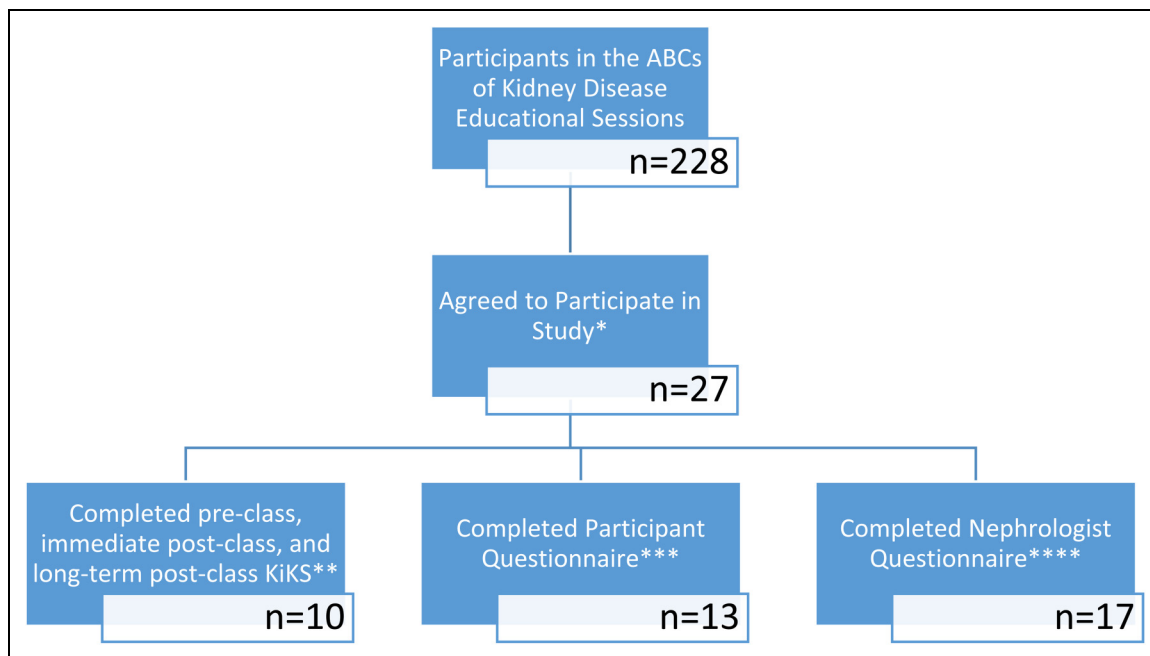
In summary, this pilot study showed an overall gain of knowledge when comparing the pre-class to the long-term post-class KiKS, as well as an increased involvement in healthcare decisions, confirmed by a higher preference of home dialysis modalities, which coincides with prior studies in the literature. The decline in knowledge from the immediate and long-term post-class KiKS indicates a potential need for a refresher class to maintain the initial gains in knowledge. The impact of a single class is significant and suggests that providers should be incorporating this education strategy in concert with other modalities to improve the health literacy. The Advancing American Kidney Health Initiative set forth a goal of 80% of patients with ESKD to be treated with either home dialysis or kidney transplantation by 2025 (15). Incorporation of a structured education program would be important for pro-

viders to improve long-term knowledge and lead to greater healthcare involvement. Providing an education class outside of the routine office visits will provide a greater impact on health literacy.

Limitations

Limitations include the small sample size, lack of a control group, potential recall bias as both providers and participants report from memory on a questionnaire, and long duration of time between testing for some of the participants. The average duration between finishing the education session and the long-term post-class KiKS was 2.9 years. Participants could have received other CKD education during this time frame that might have influenced their knowledge regarding CKD. Also, our study participants agreed to take part in the study, thereby constituting a selection bias since it does not represent a random sample of our CKD population. Those who participated may be more proactive and be more likely to use the information gained from the class. Future large, randomized controlled trials could address this limitation. There was a drop-off in KiKS returned to the investigators with each testing period (pre-class, immediate post-class, and long-term post-class KiKS), decreasing the sample size, and limiting interpretation of these results.

Appendix



Flow diagram of participants through study. * 100 declined participation (no reason given) and 101 were unable to be reached. ** 2 participants had no KiKS, 4 participants had a pre-class KiKS only, 7 participants had a pre-class KiKS and immediate post-class KiKS, 1 participant had an immediate post-class KiKS and long-term post-class KiKS, 1 participant had a long-term post-class KiKS only, and 2 participants had a pre-class KiKS and long-term post-class KiKS (n = 17). *** 14 participants did not return the questionnaire. **** 10 nephrologists did not return the questionnaire.

Authors' Note

Ethical approval to report this study was obtained from the Johns Hopkins Medicine Institutional Review Board Office of Human Subjects Research on August 1, 2019 (IRB00200528). The study was approved by the Johns Hopkins Medicine Internal Review Board on August 1, 2019. All procedures in this study were conducted in accordance with the Johns Hopkins Medicine Institutional Review Board Office of Human Subjects Research (IRB00200528) approved protocols. Verbal informed consent was obtained from the patients for their anonymized information to be published in this article.

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Declaration of Conflicting Interests

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