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ORIGINAL ARTICLE

Home run—results of a chronic kidney disease Telemedicine Patient Education Study

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ABSTRACT

Background. Chronic kidney disease (CKD) incidence is increasing and associated mortality and morbidity are high. Educating patients is effective in delaying progression and establishing optimal renal replacement therapy (RRT). Tele-education/telemedicine (TM) can be an effective tool to provide such education, but there are no available data quantifying its effectiveness. We attempted to establish such evidence correlating the effect of education in patient choices and with the start of actual RRT. We present results from a 3-year pilot study evaluating the effectiveness of comprehensive predialysis education (CPE) through TM for CKD patients compared with a standard care group [face to face (FTF)]. The patient's ability to choose RRT was the primary endpoint.

Methods. This was a randomized controlled study providing CPE over three classes at nine sites (one FTF and eight TM). Three assessment tools were utilized to compare groups: CKD knowledge, literacy and quality of life.

Results. A total of 47.1% of FTF and 52.2% of TM patients reported not having enough information to choose a modality. This decreased by the third visit (FTF 7.4%, TM 13.2%). Home modality choices more than doubled in both groups (FTF 25.8–67.7%, TM 22.2–50.1%). In patients that completed one visit and needed to start RRT, 47% started on a home modality or received a pre-emptive transplant (home hemodialysis 6%, peritoneal dialysis 38%, transplant 3%).

Conclusions. Results show almost 90% (TM 87%, FTF 95%) of the attendees could choose a modality after education. Home modality choices doubled. Patients were able to make an informed choice regardless of the modality of education.

Keywords: awareness, CKD, home dialysis, patient education, tele-education

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INTRODUCTION

Chronic kidney disease (CKD) is one of the fastest growing chronic diseases and is the ninth leading cause of death in the USA [1]. Awareness of the disease is poor despite its financial and societal impact. Countrywide efforts to increase awareness regarding this disease are in progress on multiple fronts. Leading nephrology groups like the American Society of Nephrology and the National Kidney Foundation are attempting to address this with many new ideas encouraging innovations.

One area of need is educating CKD patients so that they have a better understanding of their disease, increase efforts to slow down progression and become active partners in their health care team [2]. When there is a decline in kidney function, patients should be in a position to choose the optimal modality individualized to their lifestyle. Currently in-center hemodialysis (ICHD) forms the mainstay of renal replacement therapy (RRT) for most patients with end-stage renal disease (ESRD).

Home modalities offer significant advantages in multiple clinical parameters important to the management of patients with ESRD and are also more cost effective for the health care system, with ~US$20 000 per patient per year savings in Medicare expenditures [3]. It is now well established that a comprehensive predialysis education (CPE) leads to greater choice of home modalities among the incident ESRD patients, with nearly 30–50% of patients opting for a home modality. Most programs do not follow-up with patients to see what modality they start when RRT is actually needed. Home modalities are underutilized in the management of ESRD, but there is agreement among nephrologists and professional societies that this rate needs to be increased.

Despite these factors, the rates of use of home modalities remain low. It is likely that the lack of provider and patient awareness and education play a critical role in the low incident home modality rates [4–6]. The factors that contribute to this lack of patient awareness and education include the fact that CPE is a time- and resource-consuming process, needs multidisciplinary expertise and is only partially compensated by the current reimbursement standards [7, 10]. Hence only limited medical universities and a few nephrology practices provide these programs. Tele-education/telemedicine (TM) has the potential to address some of these issues by enabling a team of multidisciplinary professionals to deliver patient education to more patients over a wider geographical area in a cost-effective manner through real-time interactive video technologies.

TM provides the virtual bridge needed to connect patients in need of education to specialists not otherwise available in their community or region. Tele-based CPE simplifies resource allocation and patient access to CPE. A centralized site with necessary expertise can provide CPE to multiple patient locations irrespective of their distance from the facility where the educational program is offered [8]. Educated patients mostly favor home modalities, and even a modest increase in the rate of home modalities would be significant for the health care system since cost savings are large. Multiple efforts are ongoing to increase awareness of the need to promote home modalities [9]. Though these ideas are well established, data quantifying the effectiveness of education are needed. Comparing tele-platforms with standard of care [face to face (FTF)] modalities is also required to assess whether the platform providing the education would make a difference to the choices patients make. In addition, the question of whether making a choice would translate into an eventual start of the RRT of choice is not supported by previous studies. Our study is innovative because it addresses these concerns.

Table 1. CKD demographic summary

Variable	Overall	FTF	TM	P-value
Female,[a] *n* (%)	94 (56)	42 (51.2)	52 (60.5)	0.228
Caucasian,[a] *n* (%)	68 (40)	34 (41.0)	34 (39.5)	0.850
Age (years), mean ± SD	58.4 ± 15.0	57.7 ± 15.4	58.3 ± 14.3	0.792
Smoker,[a] *n* (%)	84 (51)	44 (53.7)	40 (48.2)	0.483
Started therapy,[a] *n* (%)	62 (39)	34 (45.3)	28 (32.9)	0.108
CKD stage,[a] *n* (%)				0.923
3	28 (17)	13 (16.1)	15 (17.9)	
4	65 (39)	33 (40.7)	32 (38.1)	
5	72 (44)	35 (43.2)	37 (44.0)	

[a]Variable contained missing observations. Some sections of all the forms were left incomplete by the participants.

Our hypothesis is that a well-designed predialysis education program will result in patients eventually starting with a treatment modality of their choice and that home dialysis will be chosen preferentially. The platform of education, TM or FTF, would be comparable as long as the education format (content and method of teaching) remains the same.

MATERIALS AND METHODS

The initial study design was a randomized controlled study to evaluate the effectiveness of CPE provided through TM compared with a standard care group (FTF). A permuted block randomization process was used. Participants being educated at the TM sites were randomized into either an education or control arm. However, due to poor referrals to TM sites, the control arm was subsequently stopped. Comparisons were made between education groups ($n = 182$), control groups ($n = 13$), initial dropouts (enrolled but never attended a class, $n = 45$) and Arkansas and US incident ESRD rates.

Inclusion criteria

We included all adults with an established diagnosis of Stage 4 and 5 CKD as defined by an estimated glomerular filtration rate (eGFR) $\leq$30 mL/min/1.73 m^2 within 3 months of enrollment and not on dialysis.

Exclusion criteria

Patients who were unable to read or speak English, had a history of significant cognitive dysfunction, were not personally independent or were without any social support were excluded. The study included adult, English-speaking subjects referred to University of Arkansas for Medical Sciences nephrology clinics or to local Arkansas Department of Health clinics by their providers. We sent out letters to providers across the state regarding this program. Recruitment was by direct referral from a provider (Table 1).

Class structure

Both the FTF and TM groups attended classes at the same time, but at different venues; TM groups were connected through a Cisco platform (Cisco, San Jose, CA, USA). The live classroom format allowed for real-time interaction between the FTF as well as the TM groups. The classes were held separate from clinics in designated classrooms. Patients were encouraged to bring their care partners to the classes. Three interactive, live

Table 2. Class structure

Class FTF/TM	Presenter	Time (h)	Chapters
1	APN-CNN-NP	3	Understanding CKD, slowing progression, renal replacement options and labs
2	APN-CNN-NP + renal dietician	2.5	Diet and medications
3	APN-CNN-NP + renal social worker	2.5	Coping with CKD finances
Control visit			Handouts given
1			Introduction letter, a list of local nephrologists and a smoking cessation pamphlet
2			A list of web-based CKD resources
3			Workbook

APN: advanced practice nurse; CNN: certified nephrology nurse; NP: nurse practitioner.

Table 3. Descriptive statistics of questions about kidney transplant, dialysis start and making a decision by assessment period

Group	Measure	Pre, *n* (%)	Post, *n* (%)	Visit 2, *n* (%)	Visit 3, *n* (%)
	Interested in kidney transplant?				
FTF	Yes	78 (91.8)	73 (90.1)	62 (84.9)	60 (88.2)
	No	7 (8.2)	8 (9.9)	11 (15.1)	8 (11.8)
TM	Yes	83 (92.2)	76 (91.6)	71 (91.0)	61 (88.4)
	No	7 (7.8)	7 (8.4)	7 (9.0)	8 (11.6)
	If you had to start dialysis today, which of the following would you choose?				
FTF	HHD	11 (12.9)	17 (20.7)	20 (27.0)	17 (25)
	ICHD	18 (21.2)	19 (23.2)	13 (17.6)	15 (22.1)
	PD (CAPD/APD)	11 (12.9)	27 (32.9)	26 (35.1)	29 (42.7)
	Not enough information	40 (47.1)	17 (20.7)	12 (16.2)	5 (7.4)
	No dialysis	5 (5.9)	2 (2.4)	3 (4.1)	2 (2.9)
TM	HHD	12 (13.3)	23 (27.7)	13 (16.9)	15 (22.1)
	ICHD	20 (22.2)	22 (26.5)	23 (29.9)	21 (30.1)
	PD (CAPD/APD)	8 (8.9)	16 (19.3)	20 (26.0)	19 (27.9)
	Not enough information	47(52.2)	18 (21.7)	13 (16.9)	9 (13.2)
	No dialysis	3 (3.3)	4 (4.8)	8 (10.4)	4 (5.9)
	Enough information to make decision?				
FTF	Yes	45 (52.9)	65 (79.3)	62 (83.8)	63 (92.7)
TM	Yes	43 (47.8)	65 (78.3)	64 (83.1)	59 (85.8)

APD: ambulatory PD; CAPD: continuous ambulatory PD.

classes were held in groups containing usually four to six attendees for FTF and at the same time at TM sites. The curriculum covered was from the CKD education workbook. The workbook underwent literacy testing and was assessed to be at Grades 5–7 literacy level, corresponding to the literacy of the majority of our patient population (Table 2).

A CKD patient advocate attended most classes in both sessions, FTF and TM. All groups had quarterly phone follow-ups after their third visit. Participants were encouraged to attend monthly classes unless their eGFRs were <20 mL/min/1.73 m^2, and then weekly classes were recommended. The control group was also planned for three visits, but as stated earlier, we had to stop this arm.

Statistical analysis

Initially, descriptive statistics were used to describe the patient population. We reported frequencies and percentages for categorical measures and means and standard deviations for continuous variables. To ensure balance in patient characteristics across the two groups (FTF versus TM), chi-square or Fisher's exact test, as appropriate, was used to evaluate categorical measures, whereas two-sample *t*-test or Wilcoxon rank test, as appropriate, was used for continuous measures.

The primary study aim was the ability of the participants to choose a dialysis modality by the end of their third education class. We provide descriptive statistics to examine the trend in the patients' ability to choose a dialysis modality, level of interest in kidney transplant and having enough information to decide across the four assessment periods. Additionally, a generalized estimating equation (GEE) model was used to evaluate these trends between the two intervention groups while accounting for key demographic characteristics along with CKD stage. We reported both the adjusted odds ratio (OR) and respective 95% confidence intervals (CIs). All statistical analyses were performed using SAS 9.4 (SAS Institute, Cary, NC, USA) based on two-sided tests with a significance level of 0.05.

RESULTS

Table 1 describes our patient population stratified by the intervention groups. A total of 240 patients were enrolled. Of these, 195 attended one class, of which 175 prequestionnaires were answered (TM 90, FTF 85). After class 1, 165 questionnaires were answered. At class 2, 151 postclass questionnaires were answered and at class 3 there were 136. More than half of our patients were female and the average age of the population was ~58 years. The majority of the patients were non-Caucasian and

approximately half of the patients were smokers. Less than half (44%) of the study participants were CKD Stage 5. Overall, there were no statistical differences among any of the patient characteristics across the two intervention groups. The major aim was for participants to be able to choose a dialysis modality by the end of their third education class. Of those attending at least one class, 85% attended all three classes (C1 $n = 195$, C2 $n = 178$, C3 $n = 166$). Pretests showed that 47.1% of the FTF group and 52.2% of the TM group did not have enough information to decide. By the end of the third visit, only 7.4% of the FTF and 13.2% of the TM groups were still unable to decide on a dialysis modality. Not all questions were answered by every participant (see Table 3).

Table 4 provides the results of the GEE analysis to examine the ability to make a dialysis modality decision. There were no differences between the two intervention groups or any of the key demographic characteristics, including stages of CKD. Not surprisingly, the odds of deciding increased significantly with each subsequent assessment period. More specifically, the OR of a patient's ability to make a dialysis modality decision at class 2 was 5.91 times (95% CI 3.51–9.56) the odds at the pretest, holding all other covariates constant. During class 3, the OR was 9.27 (95% CI 4.87–17.73).

Table 3 also provides descriptive statistics for the questions addressing interest in kidney transplant and choice of dialysis.

Table 4. GEE results modeling the level of interest in kidney transplant and ability to make a decision

Measures	Kidney transplant, OR (95% CI)	Make decision, OR (95% CI)
FTF	Ref.	Ref.
TM	1.64 (0.72–3.76)	0.82 (0.49–1.35)
Visit	Ref.	Ref.
Pre		
Post	0.83 (0.42–1.62)	3.74 (2.36–5.93)[a]
Class 2	0.58 (0.25–1.38)	5.91 (3.51–9.56)[a]
Class 3	0.62 (0.26–1.50)	9.27 (4.87–17.63)[a]
Female	Ref.	Ref.
Male	0.84 (0.40–1.75)	0.98 (0.59–1.62)
Age (5 U)	0.56 (0.45–0.69)[a]	0.92 (0.83–1.01)
Caucasian	Ref.	Ref.
Non-Caucasian	1.37 (0.61–3.11)	1.29 (0.78–2.15)
Smoking	Ref.	Ref.
Non-smoking	1.51 (0.77–2.96)	1.24 (0.75–2.06)
CKD Stage 3	Ref.	Ref.
CKD Stage 4	1.13 (0.47–2.71)	1.12 (0.57–2.22)
CKD Stage 5	2.22 (0.93–5.31)	1.75 (0.84–3.62)

[a]Wald test $P < 0.001$.

On pretesting, both groups reported high rates of interest in transplantation (91.8% FTF, 92.2% TM) and by the end of the third class, those percentages decreased to 88.2% FTF and 88.4% TM. The results of the GEE model for interest in transplantation can be found in Table 4. There was no difference in the proportion of participants stating that they were interested in kidney transplant among any of the measures except for age. More specifically, every 5-unit increase in age was associated with a 44% decrease in the odds of being interested in kidney transplant [OR 0.56 (95% CI 0.45–0.69)]. Participants choosing home therapies were high in both groups, with the FTF group choosing home dialysis at a rate of 25.8% on the pretest [12.9% for both home hemodialysis (HHD) and peritoneal dialysis (PD)] and increasing to 67.7% by the end of the third class (25% HHD, 42.7% PD). The TM pretest rate was 22.2% (13.3% HHD, 8.9% PD) and increased to 50% at the end of the third class (22.1% HHD, 27.9% PD).

Few participants chose no dialysis. Interestingly, the FTF group's 'no dialysis' rate decreased from 5.9% on the pretest to 2.9% on the third posttest, while the TM group rate increased from 3.3% on the pretest to 5.9% on the third posttest.

Of the 240 patients enrolled, 45 (19%) were initial dropouts (never attended a class), and of the 13 dropouts that needed to start RRT, only 1 (8%) started on a home modality, the rest started ICHD (92%) (Table 5). This is similar to the small control group that had no home modality of the three that reached ESRD. The 2015 Arkansas home modality incidence rate was 10.6% and the 2015 US Renal Data System (USRDS) rate was 9.6%, which are both considerably less than 43% for the educated participants starting home modalities in this study. Of the 68 participants (FTF, TM and controls) that needed to start RRT by the end of the study, 43% started on home dialysis (30.9% FTF, 13.2%TM), 38% started PD (25% FTF, 13% TM), 4% started HHD (all FTF) and 3% were able to get preemptive transplants (all FTF). Of the 13 controls, none started on home dialysis and 3 started on ICHD.

DISCUSSION

The incidence of CKD is increasing exponentially and the associated mortality and morbidity are significant. However, there are major deficiencies in awareness of its impact. There is literature that has assessed awareness in CKD patients themselves, as well as awareness in the general public, populations at risk and health care providers, with alarming results.

In the National Health and Nutrition Examination Survey (2001–12), <50% of the participants with CKD were aware they had kidney disease. In 2017, <48% of Stage 4 CKD patients were

Table 5. Participant status at the end of the study: among the 68 participants who attended at least one class and started RRT, 44% (HHD 6%, PD 38%) started on a home modality and 3% received preemptive transplants

Group ($N = 240$)	HHD, *n* (%)	PD, *n* (%)	TXPT, *n* (%)	ICHD, *n* (%)	Remain CKD, *n* (%)	Died, *n* (%)
Telemedicine ($n = 93$)	0 (0)	9 (13.2)	0 (0)	19 (27.9)	64	1
FTF ($n = 89$)	4 (5.9)	17 (25)	2 (2.9)	14 (20.5)	44	8
Control ($n = 13$)	0 (0)	0 (0)	0 (0)	3 (4.4)	9	1
Total by modality start (n=68)	4 (5.9)	26 (38.2)	2 (2.9)	36 (52.8)		
Enrolled but never attended (n=45)	0	1	0	12	28	4
Study totals, *n*	4	27	2		145	14
AR incident ESRD rate 2016 ($n = 1212$)		10.6	0.6	88.8		
USRDS incident ESRD rate 2015 (n=107 198)	3.5	9.6	2.4	84.3		

The majority of the FTF participants were enrolled in the first 2 years and the majority of the TM participants in the last 2 years (2014–17).
TXPT: Pre-emptive transplant.

aware they had kidney disease (USRDS data). In a survey of urban African American adults, <3% named kidney disease as an important health problem compared with 61% and 55% naming hypertension and diabetes, respectively [5]. Physician documentation of CKD with International Classification of Diseases, Ninth Revision codes in a large managed care cohort with >10 000 individuals with CKD Stages 3–5 was only 14.4% [6]. These data show that there is a general lack of awareness regarding CKD. Considering the expense and impact of the disease, there are many attempts being made to address this situation at the national level, with many leading societies targeting innovations and addressing these issues. Our study was one such intervention hoping to address early CKD education [11, 12].

We attempted to reach adult patients in CKD Stages 3–5 and teach in a manner everyone could understand (literacy level Grades 5–7), with validated, standardized and reproducible teaching tools [13]. Non-English-speaking patients were excluded (Supplementary Data).

Barriers to establishing and conducting this educational program were identified at multiple levels and addressed over the years with protocol revisions, additional efforts and team reorganizations.

The revised protocol began a collaboration with the Arkansas Department of Health and University of Arkansas for Medical Sciences, utilizing the infrastructure and TM capabilities of both. The control arm was stopped due to low referrals and high control dropout rates (24%) at TM sites. However, we included them along with the dropout rates in our results, as it is notable that the control outcomes and the dropout noneducated patient outcomes are the same as the national rates (majority in-center dialysis 92%).

The structure of the study was simplified to two groups: FTF education and TM. We provided >5 h of comprehensive, multidisciplinary patient education over three visits. The CKD questionnaire was administered before and after the first visit and then after the second and third visits. The 29th and 30th questions on the questionnaire dealt with modality choice, which was the basis of the primary outcome (i.e. the patient being able to choose an appropriate dialysis modality by the end of the CPE; Table 3). The secondary outcome was the number of patients choosing a home modality. These results show that when educated and given a choice, >50% of patients with CKD will choose a home modality (67.7% FTF, 50% TM), which was more than double the percentage in pretesting. Other secondary aims, including CKD knowledge, literacy, quality of life and quality of care (anemia, secondary hyperparathyroidism and CKD progression), were also collected and will be reported later. Most were able to choose a modality after one educational session; however, three sessions appear to be optimal. Almost all participants were interested in kidney transplant in pretesting (91.8% FTF, 92.2% TM). The rates of both groups declined to 88% by the end of their third visit. Our patients wished they had been educated earlier in their disease state and expressed feelings of renewed hope and empowerment. The role of shared decision making has been studied and recommended [14]. The importance of improved hope and a feeling of empowerment is difficult to address in measurable scales, although it is critical to a person's quality of life and should be a target for directed health care efforts. Becoming active members of their own health care team enabled 47% of those requiring RRT to actually start on a home modality (PD or HHD) or get a preemptive transplant [15]. Although not reported here, we anticipate that the education resulted in better hospitalizations and economic outcomes as well [16].

Limitations of the study include very low numbers in the control group and a high dropout rate. The project itself had to undergo major revisions from what the initial investigators envisioned, due to a lack of/changes in internal infrastructure, materials and workforce availablity. Distal site buy-in was negligible. Reaching underserved areas, where the majority of patients resided, was difficult even after provider education. The project was almost lost for a year, was extensively revised and was eventually revived to a successful outcome. This information underscores the fact that we now have a structure for a program that works and is likely to be applicable in any location. Establishing a program like this needs effective collaboration and repeated attempts at reevaluating progress. The most important factor for a successful education program is the core team's dedication to follow through in the face of challenges.

Low referral rates to even the distal TM sites highlighted the need for provider education and improved system and infrastructure intelligence. We identified the need for community engagement to evaluate current systems of care. These areas require more focused future research, policy changes and resource allocations. The collaborative effort from this study has led to initiatives to take a statewide approach to evaluate CKD awareness and care.

SUPPLEMENTARY DATA

Supplementary data are available at ckj online.

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CONFLICT OF INTEREST STATEMENT

None declared.

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