


# Improving Caregiver Burden by a Peer-Led Mentoring Program for Caregivers of Patients With Chronic Kidney Disease: Randomized Controlled Trial

Journal of Patient Experience  
Volume 9: 1-8  
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DOI: 10.1177/23743735221076314  
journals.sagepub.com/home/jpx  


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## Abstract

Chronic kidney disease (CKD) is associated with substantial morbidity, mortality, cost, and increased caregiver burden. Peer mentoring (PM) improves multiple outcomes in various chronic diseases. The effect of PM on caregiver burden among caregivers of patients with CKD has not been studied. We conducted a randomized clinical trial to test the effectiveness of a structured PM program on burden of care among caregivers of patients with CKD. We randomized 86 caregivers to receive 6 months of intervention in 1 of 3 groups: (1) face-to-face PM ( $n = 29$ ); (2) online PM ( $n = 29$ ); and (3) usual care: textbook-only ( $n = 28$ ). Peer mentors were caregivers of patients with CKD, who received 16 h of instruction. All participants received a copy of a textbook, which contains detailed information about kidney disease. Participants in the PM groups received FTF or online PM for 6 months. The outcome was time-related change in the Zarit Burden Interview (ZBI) score. There was a statistically significant decrease in the ZBI score (SE:  $-3.44$ ; CI:  $-6.31, -0.57$  [ $p = 0.002$ ]) compared with baseline, among the online PM group. Online PM led to decreased caregiver burden among caregivers of patients with CKD. The study was limited to English-speaking subjects with computer literacy.

## Keywords

chronic kidney disease, caregiver burden, peer mentoring, Zarit Burden Interview

## Introduction

Chronic kidney disease (CKD) and end stage renal disease (ESRD) are associated with considerable patient morbidity and mortality, as well as caregiver burden (1,2). CKD and its treatment influence a patient's role and function within the family and affects the entire household (3,4). Family members of patients with CKD are engaged in both the practical aspects of being caregivers (eg, transportation) as well as providing psychological and cognitive support during the decision-making process, particularly about the choice of renal replacement therapy (5,6). As a result of their role as caregivers, family members often experience stress, depression, negative changes in the relationship quality, marital dissatisfaction, and poor quality of life (QOL) (2,7). Yet, their needs are often neglected and under-prioritized, despite the obvious impact they may have on patient-centered care.

Knowledge about goals of care can help prepare family members for the practical aspects of the burden related to treatment options, engaging them in the patient's care. Educational interventions addressing factors that CKD patients and their

families consider important are likely to facilitate choice of treatment that is congruent with the patients' and their families' wishes and values (5). Such interventions will improve the family members' understanding of the risks and benefits of various treatments, facilitating discussions about expectations and goals of care. Patients have expressed concern about the often devastating impact of CKD on caregivers and have suggested assessment of caregiver burden and improvement of support for caregivers among research priorities (8).

Despite the increasing awareness of the burden and adverse effects of CKD on caregivers, high-quality evidence is lacking about the effect of information or support interventions on the psychosocial well-being of caregivers (9). Peer

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mentoring (PM) for caregivers of patients with chronic diseases has been shown to be perceived as positive, resulting in feeling of being understood and empowered, reducing anxiety and reducing sense of isolation. Much of the published work has focused on PM for parents of children with cancer, diabetes, inflammatory bowel diseases, and brain tumor (10–14). In a randomized clinical trial, we studied the effectiveness of structured mentoring by trained peers on burden of care as measured by Zarit Burden Interview (ZBI) (15), among caregivers of patients with CKD.

## Materials and Methods

### Study Overview

The protocol is fully described in the research report submitted to the Patient-Centered Outcomes Research Institute (PCORI) (16). We randomized caregivers of patients with CKD into 3 groups: (1) face-to-face (FTF) PM, (2) online PM, and (3) only usual care: review of a textbook about CKD. Participants in all 3 groups received a copy of a textbook, which contains detailed information about kidney disease. The research was conducted according to principles having their origin in the Declaration of Helsinki. All participants provided written informed consent. The protocol was reviewed and approved by the Pennsylvania State University College of Medicine Institutional Review Board. The clinical trial was registered with [Clinicaltrials.gov](http://Clinicaltrials.gov) (NCT02429115).

**Mentor Training (the Patient and Family Partner Program [PFPP]).** Details of the mentor training program which have been previously reported (17) are briefly outlined. Since 2004, the Kidney Foundation of Central Pennsylvania (KFCP) has operated a comprehensive patient engagement and empowerment program (PFPP). The program trained CKD patients and their caregivers to serve as volunteer mentors to other CKD patients and their caregivers (17,18). In this trial, mentors were adult caregivers of patients with CKD, who received 16 h of formal training to become peer mentors (Supplemental Appendix A).

**Participants:** We recruited participants from caregivers of patients with CKD. Inclusion criteria were (1) caregiver to a CKD patient, (2) at least 18 years of age, (3) able to read and write in English at the 8<sup>th</sup> grade level, (4) access to a computer with internet and email capability, and (5) willingness to participate. Exclusion criteria were (1) participation in previous PM as CKD caregiver, (2) inability to provide consent, (3) current incarceration, and (4) physical condition precluding participation in mentoring program. We sent flyers about the study to dialysis units and nephrologist practices to be delivered to patients with CKD and their caregivers. The flyers encouraged caregivers interested in exploring being matched with a mentor to contact the unit social worker, the PFPP coordinator or the research coordinator. Following informed consent, candidates were randomly assigned to one of the 3 groups: “FTF PM,” “online PM,” and “textbook-only.” The investigators did not have access

to the identity of the participant assignment until they confirmed participant eligibility. Recruitment occurred continuously until we achieved the target sample sizes. To improve retention, each participant was provided with \$50 stipend for the baseline assessment and for each of the follow-up assessments for a total of \$150 per participant. Participation in the study was totally voluntary and participants were clearly informed of their right to withdraw from the study at any point without requirement for explanation.

### Interventions and Comparators (17)

**FTF PM Group:** During the first meeting, the mentor presented an overview of the mentoring program, and along with the mentee, reviewed their common goals and expectations. The mentors introduced the textbook and empowered the mentees to ask questions or voice any concerns during weekly phone calls or at monthly FTF meetings. The mentor was required to contact the mentee at least weekly by telephone, and monthly in a FTF visit. If needed, the mentee could initiate more frequent contact. The mentor maintained a log of the meetings to present to the program coordinator at the end of each month.

**Online PM Group:** Mentor-mentees exclusively communicated through a secure, password-protected, interactive online platform consisting of a web-based bulletin-board designed specifically for this study. During the initial session, the mentors presented an overview of the mentoring program, and along with the mentees, reviewed their common goals and expectations. The mentors introduced the textbook and empowered the mentees to post any questions. The mentors were also encouraged to post any questions and to update their status using written statements or mood and symptom icons. The mentors responded to questions or posted queries probing the mentees’ status update. Mentees received at least weekly reminder emails from mentors to review the posted educational material and to post a weekly action plan. They were encouraged to discuss any questions with their individual mentors. The program coordinator regularly communicated, via email or phone call, with the mentors and mentees and closely monitored the frequency and content of the exchanges between mentors and mentees. The mentors and mentees had the option of meeting with the program coordinator, in-person, as they felt needed, particularly to discuss concerns or to clarify specific issues relating to the program.

**Textbook-only Group:** This group independently reviewed a textbook which includes general information about the kidneys, causes of kidney failure, diet in patients with kidney disease, and treatment options for CKD. Adherence to review of the book relied on self-report.

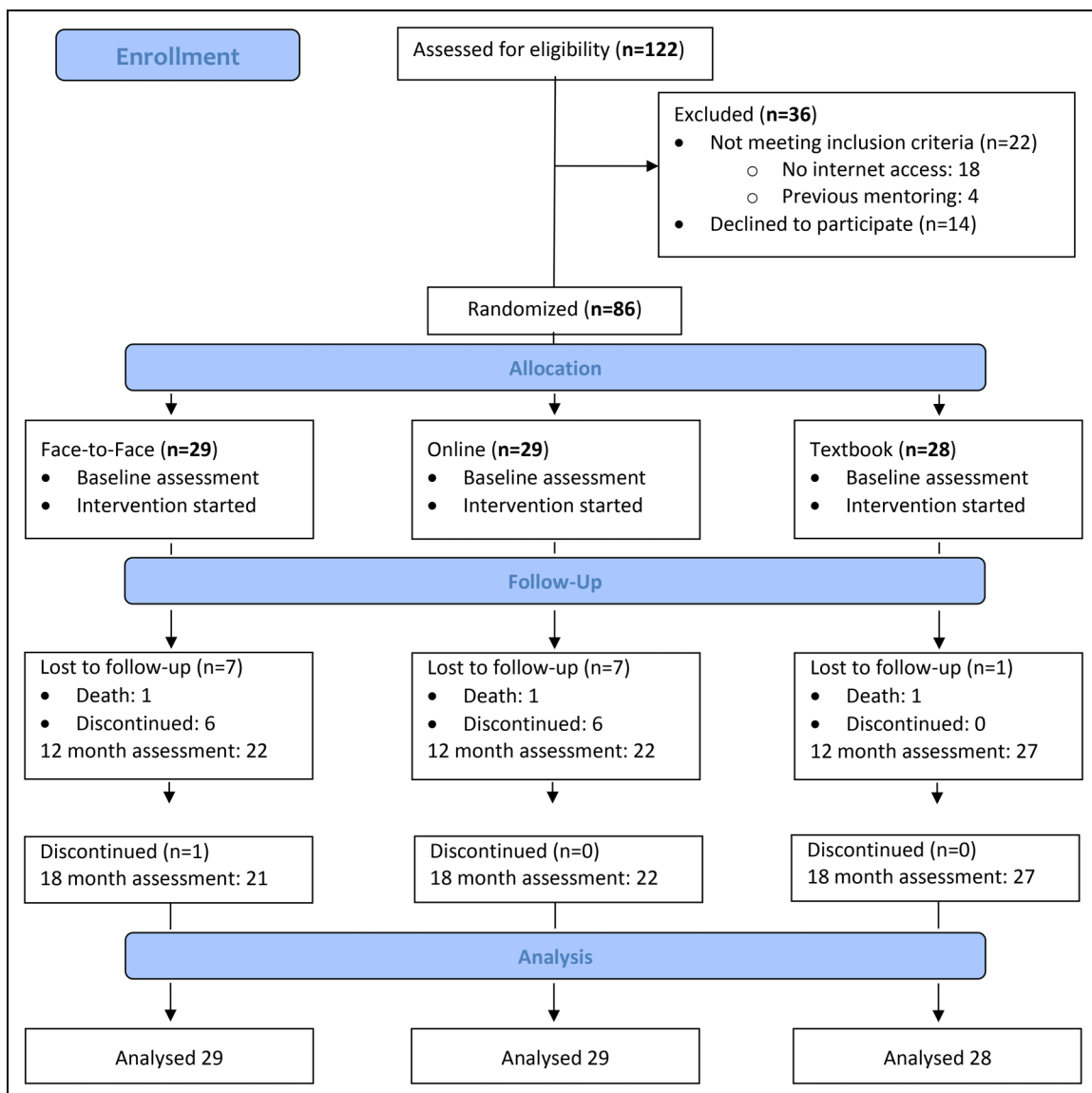
**Outcome:** The outcome was caregiver burden as measured by the ZBI. The caregivers completed the ZBI at baseline, 12 months, and 18 months. The ZBI is a self-administered questionnaire of 22 items that measures the impact of caregiving in psychological, physical, and social domains. The items are rated on a five-point Likert scale (15). The total score is calculated from 0 to 88; the higher the score, the

heavier the burden (19) ZBI has been used to measure caregiver burden among caregivers of dialysis patients (20) and numerous other chronic disease states (21–27). Higher ZBI scores are associated with depression and anxiety (28).

**Sample size calculations and power.** Change in ZBI was the primary outcome. We computed the number of subjects needed using data from a study assessing burden among caregivers of peritoneal dialysis (PD) patients, in which the mean combined caregiver burden score ( $\pm$  standard deviation) was  $12.5 \pm 8.7$  (20). For our study, we selected one standard deviation as the MCID. Assuming an effect size of 1 SD, an alpha of 0.05, and a comparison of three means, we expected that a sample size of 23 would yield a statistical power of 0.8. Our target total sample size was 84 caregivers (28 for each of the 3 study groups) to adjust for a dropout rate of 15%.

**Time Frame for the Trial.** According to published studies, the effective duration of PM for chronic diseases varies between 6 weeks and 2 years (29–33). Hence, we selected 6 months as the length of intervention, and 12 months post-enrollment (6 months after completion of intervention) for quantitative follow-up assessments. To evaluate sustained intervention effect, we repeated assessments at 18 months.

**Data Collection and Sources.** Quantitative data included responses to self-administered survey instruments. We transferred electronically coded data into a secure password protected database with no linkage to any personal identifiers. We used statistical alterations to prevent identification of individuals. The program coordinator regularly encouraged the participants to complete the surveys by sending email reminders and by telephone calls.



**Figure 1.** CONSORT diagram for flow of caregivers through the trial.

**Table 1.** Baseline Characteristics of Caregivers According to Intervention Group.

Demographic variables	FTF PM	Online PM	Textbook-only	Total	P
N	29	29	28	86	–
Male, n (%)	11 (38)	9 (31)	11 (39)	31 (36)	.78
White, n (%)	13 (45)	13 (45)	14 (50)	40 (47)	.90
Hispanic, n (%)	2 (7)	4 (14)	2 (7)	8 (9)	.59
Age (years)					.78
Age ≤ 47	7 (24)	11 (38)	8 (29)	26 (30)	.51
47 < age ≤ 54	7 (24)	5 (17)	6 (21)	18 (21)	.81
54 < age ≤ 62	9 (31)	6 (21)	5 (18)	20 (23)	.46
62 < age	6 (21)	7 (24)	9 (32)	22 (26)	.60
Married, n (%)	20 (69)	20 (69)	18 (64)	58 (67)	.91
Attended or completed college, n (%)	11 (38)	12 (41)	9 (32)	32 (37)	.77
Employed, n (%) <sup>a</sup>	11 (38)	13 (45)	12 (43)	36 (42)	.86
Rural, n (%)	6 (21)	11 (38)	8 (29)	25 (29)	.35

Abbreviations: FTF, face-to-face; PM, peer mentoring.

<sup>a</sup>Employed: employed, student, and homemaker.

**Analytical and Statistical Approaches** (17). The independent variable was allocation to the FTF PM, online PM, or textbook-only groups. The outcome variable was the score on ZBI, which was continuous and measured at baseline, 12 months, and 18 months. Covariates were age, sex, race and ethnicity, marital status, attended or completed college, employment status, and rural versus urban location. We used repeated measures analysis of variance (ANOVA) in a linear mixed-effects model to estimate time-related changes in scores. The data source for covariates other than rural/urban location was predominantly by participant self-report. The data source for rural versus urban location was based on the address and Rural-Urban Commuting Area (RUCA) code (34). We used type 3 fixed effects to test the statistical significance of each of the demographic variables. None of the variables had >10% missing data. Analyses were by intention to treat. The statistical analyses based on restricted maximum likelihood estimation for the linear mixed-effects model allowed for valid and unbiased conclusions in the presence of data that are missing at random. We used SAS, version 9.4 (SAS Institute Inc., Cary, NC) for data analysis.

## Results

**Study Population and Demographics.** Figure 1 is the CONSORT diagram which describes the flow of participants through the study interventions. We evaluated 122 caregivers to CKD patients for eligibility. We excluded 36 caregivers; 22 did not meet inclusion criteria (no internet access: 18; previous mentoring experience: 4); 14 eligible caregivers declined to participate after receiving more information about the study due to the perceived burden of the study. Using permuted block randomization with 1:1:1 allocation, we randomized 86 caregivers to the 3 groups. All caregivers completed the baseline assessment and started participation in the interventions. Of these, 70 caregivers completed the interventions, the 12-month, and the 18-month assessments. Among the FTF PM group, 22 participants completed the

**Table 2.** Mean Unadjusted Zarit Burden Interview Scores Through the Study Period Among the Intervention Groups (Intention to Treat Analysis).

Assessment points	FTF PM Mean ± SD	Online PM Mean ± SD	Textbook-only Mean ± SD
Baseline	21.1 ± 9.4	23.6 ± 12.1	22.1 ± 9.3
12 months	16.0 ± 7.6	16.5 ± 9.1	18.6 ± 9.7
18 months	14.0 ± 7.8	15.2 ± 9.9	22.0 ± 9.9

Abbreviations: FTF, face-to-face; PM, peer mentoring.

allocated intervention and the 12-month assessment and 21 participants completed the 18-month assessment. Among the online PM group, 22 participants completed the allocated intervention, the 12-month and the 18-month assessments. Among the textbook-only group, 27 participants completed the allocated intervention, the 12-month and the 18-month assessments. Fifteen participants were lost to follow-up prior to the 12-month assessment and one participant withdrew from the trial after completing the 12-month assessment. We included 86 participants in the final analysis. Assessments consisted of completion of the ZBI. Table 1 presents the primary baseline characteristics of the caregivers. Baseline demographic characteristics did not differ statistically significantly across the 3 groups. Supplemental Appendix B presents details of caregiver demographics.

## Caregiver Burden Scores

In Table 2, we document the mean unadjusted ZBI scores in the 3 groups at baseline, 12 months, and 18 months. The mean unadjusted baseline scores did not statistically differ among the 3 groups.

Table 3 shows the changes in mean unadjusted ZBI scores over the study period. FTF PM was associated with a statistically significant decrease (improvement) in the mean ZBI score at 12 months (change in mean [ $\Delta$ ]:  $-5.1$ ; 95% confidence interval [CI]:  $-10.0$ ,  $-0.2$  [ $P = .04$ ]). FTF PM was

**Table 3.** Changes in Mean Unadjusted Zarit Burden Interview (ZBI) Scores Through the Study Period by Intervention Group (Intention to Treat Analysis).

Assessment points	FTF PM group Change in mean score $\pm$ SE; 95% CI; P	Online PM group Change in mean score $\pm$ SE; 95% CI; P	Textbook-only group Change in mean score $\pm$ SE; 95% CI; P
12 months compared with baseline	$-5.1 \pm 2.5$ ; $-10.0$ , $-0.2$ ; .04	$-7.1 \pm 3.1$ ; $-13.3$ , $-0.9$ ; .03	$-3.5 \pm 2.6$ ; $-8.6$ , $1.6$ ; .18
18 months compared with 12 months	$-2.0 \pm 2.4$ ; $-6.7$ , $2.7$ ; .40	$-1.3 \pm 2.9$ ; $-7.2$ , $4.6$ ; .66	$3.4 \pm 2.7$ ; $-1.95$ , $8.75$ ; .21
18 months compared with baseline	$-7.1 \pm 2.5$ ; $-12.2$ , $-2.1$ ; .007	$-8.4 \pm 3.2$ ; $-14.9$ , $-1.9$ ; .01	$-0.1 \pm 32.6$ ; $-5.3$ , $5.1$ ; .97

Abbreviations: FTF, face-to-face; PM, peer mentoring; SE, standard error; CI, confidence interval.

**Table 4.** Changes in Mean Adjusted Zarit Burden Interview Score Through the Study Period Among the Groups<sup>a</sup> (Intention to Treat Analysis).

Interventions and comparisons	ZBI slope estimate <sup>b</sup> ( $\pm$ standard error)	95% confidence interval	P value
FTF PM slope	$-2.49 \pm 1.64$	$-5.85$ , $0.87$	.14
Online PM slope	$-3.44 \pm 1.40$	$-6.31$ , $-0.57$	.02
Textbook-only slope	$-1.26 \pm 1.37$	$-4.06$ , $1.54$	.36
FTF PM slope vs online PM slope	$0.95 \pm 2.16$	$-3.47$ , $5.38$	.66
FTF PM slope vs textbook-only slope	$-1.23 \pm 2.12$	$-5.58$ , $3.11$	.57
Online PM slope vs textbook-only slope	$-2.18 \pm 1.96$	$-6.19$ , $1.82$	.27

Abbreviations: FTF, face-to-face; PM, peer mentoring.

<sup>a</sup>Adjusted for race, ethnicity, sex, age quartile, marital status, education, employment status, rural/urban location.

<sup>b</sup>The slope estimates represent change in scores in standard points over 18 months.

also associated with a statistically significant improvement in the ZBI score at 18 months ( $\Delta$ :  $-7.1$ ; CI:  $-12.2$ ,  $-2.1$  [ $P = .007$ ]). Online PM was associated with a statistically significant improvement in the mean ZBI score at 12 months ( $\Delta$ :  $-7.1$ ; 95% CI:  $-13.3$ ,  $-0.9$  [ $P = .03$ ]). Online PM was also associated with a statistically significant improvement in the ZBI score at 18 months ( $\Delta$ :  $-8.4$ ; CI:  $-14.9$ ,  $-1.9$  [ $P = .01$ ]).

Table 4 shows the changes in mean ZBI scores over the study period, adjusted for demographic variables (race, ethnicity, sex, age quartile, marital status, education, employment status, rural/urban location). ZBI scores decreased significantly in the study period in the online PM group (SE:  $-3.44$ ; CI:  $-6.31$ ,  $-0.57$  [ $P = .02$ ]). No demographic variables had a significant independent effect on the change in ZBI scores among the groups.

## Discussion/Conclusion

The results from this study support the hypothesis that, among caregivers of patients with CKD, PM, particularly

online PM, improves caregiver burden. We expected FTF PM to lead to at least similar results as online PM. We were surprised to find that online PM was associated with a better outcome. This is consistent with our previous finding of superiority of online PM compared with FTF PM in regards to improvement in QOL among CKD patients (17). We believe the accessibility and flexibility of online communication are the main contributors to the improved outcomes associated with online PM. This was noted by several mentors in their reports to the program coordinator.

In general, conclusions from previous studies about the impact of PM have been limited due to variations in PM programs, loose definitions of PM and lack of clear outcomes. Our clinical trial addressed those limitations by studying a structured PM program, in which mentors received formal training, the delivery of the PM program was relatively consistent and continuously monitored. The outcome was distinct and measured over a period of 18 months. Other strengths of our study include the engagement of patients, caregivers, and stakeholders during study design, recruitment, and delivery of the intervention, as well as close collaboration with a patient advocacy organization. A vast majority of the information about the role of PM among caregivers relates to parents of children with chronic conditions (10–14). Evidence regarding the role of PM among caregivers of adult patients is limited (35,36). This study is unique in reporting quantitative results of the effect of PM on caregiver burden.

This study has three main limitations. The first limitation is that participants were limited to English-speaking subjects with computer literacy and those with internet access. The second limitation is reliance on self-report as the source of information for adherence to the review of textbook and to the PFPP protocol. The third limitation is that insufficient number of rural and ethnically diverse participants resulted in limitations regarding geographic and ethnic generalizability. Future larger studies with participants from diverse backgrounds, including non-English speaking participants from rural and urban settings will allow for appropriate subgroup analyses. Development of a Spanish version of the PM program would facilitate inclusion of a more diverse group of participants. Furthermore, given the relative accessibility of smart phones compared with online platforms that

require computer access, future studies of PM might allow for improved participation by employing a phone-based PM application.

Although certain aspects of the study are unique to caregivers of patients with CKD, and although the study benefited considerably from the already existing infrastructure of the Kidney Foundation of Central Pennsylvania (KFCP) and the Patient and Family Partner Program (PFPP), the protocol and results may be generalizable to caregivers in other chronic disease settings. Future areas of potential research include assessment of the impact of PM among caregivers of children and adolescents with CKD and among caregivers of patients with other chronic medical conditions.

The specific aim of this study was to evaluate the effect of a PM program on caregiver burden among caregivers of patients with CKD. Online PM was associated with decreased burden of care among caregivers of patients with CKD. We conclude that online PM is an effective strategy that leads to improved caregiver burden in CKD with potential for use in other chronic disease states. The COVID-19 pandemic has underscored the need for online alternatives to in-person mentoring. Online programs also allow access to mentoring by populations with limited ability to travel and for regions with limited resources. The study was limited to English-speaking caregivers with computer literacy. Future, larger studies with participants from diverse ethnic and geographic backgrounds will permit subgroup analyses, allowing for conclusions about generalizability.

## Data Sharing Statement

De-identified participant data will be made available to qualified external researchers, for a specific purpose in accordance with the PCORI Policy for Data Management and Data Sharing Plan: <https://www.pcori.org/about-us/governance/policy-data-management-and-data-sharing>.

## Acknowledgments

The investigators wish to acknowledge the following for their assistance in various stages of the study:

- All patients and caregivers who participated in the study as peer mentors, as members of the advisory groups, or as study subjects; without their active and enthusiastic participation, this study would not have been possible.
- The Kidney Foundation of Central Pennsylvania (KFCP) and members of its Board of Directors who served as members of the Community Advisory Board.
- Parts of this study were presented in abstract form at the Annual Meeting of the American Society of Nephrology November 7–10, 2019 in Washington, D.C.

## Author Contributions

Research idea and study design: NG, VC, JK, EL, CS; data acquisition: NG; data analysis/interpretation: NG, VC, JK, EL, CS; statistical analysis: VC. Each author contributed important intellectual content during manuscript drafting or revision, accepts personal

accountability for the author's own contributions, and agrees to ensure that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

## Ethical Approval

The research was conducted according to principles having their origin in the Declaration of Helsinki. Written informed consent was obtained from all participants. The protocol was reviewed and approved by the Pennsylvania State University College of Medicine Institutional Review Board (Approval #STUDY00001339). The clinical trial was registered with Clinicaltrials.gov (NCT02429115).

## Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the Pennsylvania State University College of Medicine Institutional Review Board (Approval #STUDY00001339) approved protocols.

## Informed Consent

Written informed consent was obtained from the caregiver participants for their anonymized information to be published in this article.

## Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Research reported in this article was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award CDR-1310-07055 (to Nasrollah Ghahramani). The statements in this article are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI), its Board of Governors or Methodology Committee. VC, JK, EL, and CS were co-investigators on the study. The funding agency (Patient Centered Outcomes Research Institute), and the employer (Penn State College of Medicine/Penn State Health) did not have a role in the study design; collection, analysis, and interpretation of data; writing the report; and the decision to submit the report for publication.

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## Trial Registration

Clinicaltrials.gov identifier: NCT02429115.

## Supplemental Material

Supplemental material for this article is available online.

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