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The Journal of Nephrology

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Nephrology Social Work

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

The Council of Nephrology Social Workers of the National Kidney Foundation

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The Journal of Nephrology Social Work is always interested in attracting talented CNSW members to serve as Editorial Board members to help with the planning, solicitation, and review of manuscripts for publication.

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The Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The *JNSW* contains articles addressing contemporary issues/topics relevant to nephrology social work. Authors may wish to address any of the following topics, which are listed as guidelines:

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The Journal of Nephrology Social Work (*JNSW*) is the official publication of the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Its purpose is to stimulate research and interest in psychosocial issues pertaining to kidney and urologic diseases, hypertension, and transplantation, as well as to publish information concerning renal social work practices and policies. The goal of *JNSW* is to publish original quantitative and qualitative research and communications that maintain high standards for the profession and that contribute significantly to the overall advancement of the field. *JNSW* is a valuable resource for practicing social work clinicians in the field, researchers, allied health professionals on interdisciplinary teams, policy makers, educators, and students.

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Conflict of Interest. The *JNSW* fully abides by the National Association of Social Workers' (NASW) Code of Ethics [**http://www.socialworkers.org/pubs/code/code.asp**]; see clause 5.02 (a)-(p) focused on research. This portion of the code pertains to conflicts of interest, research with human participants, and informed consent. Per the code, "Social workers engaged in evaluation or research should be alert to and avoid conflicts of interest and dual relationships with participants, should inform participants when a real or potential conflict of interest arises, and should take steps to resolve the issue in a manner that makes participants' interests primary." Authors who submit manuscripts to *JNSW* must disclose potential conflicts of interest, which may include, but are not limited to, grants, remuneration in payment or in kind, and relationships with employers or outside vendors. When in doubt, authors are expected to err on the side of full disclosure. Additional information about conflicts of interest may be obtained via the International Committee of Medical Journal Editors' Uniform Requirement for Manuscripts Submitted to Biomedical Journals (URMSBJ): Ethical Considerations in the Conduct and Reporting of Research [**http://www.icmje.org/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html].**

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A submitted manuscript should be accompanied by a letter that contains the following language and is signed by each author: "**In compliance with the Copyright Revision Act of 1976, effective January 1, 1978, the undersigned author(s) transfers all copyright ownership of the manuscript entitled ___________ to *The Journal of Nephrology Social Work* in the event this material is published.**"

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TYPES OF MANUSCRIPTS BEING SOUGHT

Research and Review. The *JNSW* welcomes reports of original research on any topic related to renal social work. The editors will also consider manuscripts that document the development of new concepts or that review and update topics in the social sciences that are relevant to professionals working in the field of renal social work.

Reports and Commentary. The *JNSW* welcomes manuscripts that describe innovative and evaluated renal social work education programs, that report on viewpoints pertaining to current issues and controversies in the field or that provide historical perspectives on renal social work. Commentaries are published with the following disclaimer: "The statements, comments, or opinions expressed in this article are those of the author, who is solely responsible for them, and do not necessarily represent the views of the Council of Nephrology Social Workers or the National Kidney Foundation."

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Practical Aspects Section. Contributions to this section are detailed protocols, forms, or other such materials that are successfully utilized for delivery of outcomes-based clinical social work services.

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Order of the Manuscript Sections

1) Title page
2) Abstract
3) Text
4) References
5) Appendices (optional)
6) Author note
7) Tables
8) Figures with captions

Title Page. The manuscript's title page should contain the title of the manuscript and the name, degree, and current affiliation of each author. Authors are generally listed in order of their contribution to the manuscript (consult the APA style guide for exceptions). The title page should also contain the complete address of the institution at which the work was conducted and the contact information for the primary author. A running head (a shortened version of the manuscript's title) should be set in the upper left-hand corner of the page, in all uppercase letters. Page numbering should begin in the upper right-hand corner of this page. With the exception of the page numbers and running heads, all text on the title page should be centered.

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The Importance of Reporting Negative Findings:

Results from a Pilot Study on the Role of Social Support in Transplant Adherence

Janice Firn, PhD, MSW, Carly Fritsch, MSW, Rebecca Congdon, MSW, University of Michigan Health System; Emma Rathe, MSW, The University of Iowa Hospitals and Clinics; and Claire Kalpakjian, PhD, MS, University of Michigan Health System

Social support is associated with adherence to medical treatments (Chisholm-Burns, Spivey, & Wilks, 2010). This is the first study to explore social support and adherence 6 weeks post-kidney transplant. Fifty-eight adult deceased-donor kidney transplant recipients participated in the study. Social support was assessed using the Modified Social Support Survey; adherence was defined as the proportion of appointments kept, immunosuppressant blood values, and the Immunotherapy Barrier Scale. Measures were completed at transplant, and at 2, 4, and 6 weeks post-transplant. Data were analyzed using linear mixed models with random effects for person. Variance in participants' adherence was hypothesized. However, all participants were adherent; no statistically significant relationship between adherence and social support was identified. Immediately following transplant, qualitative or mixed-method approaches may give better insight into facilitators of adherence.

INTRODUCTION

Prevention of graft loss in kidney transplant patients is the primary goal of the transplant team. Extant literature supports the association of social support and adherence to medical treatments across populations and diagnoses, including organ transplant (Chisholm-Burns, Spivey, & Wilks, 2010). Thus, an important aspect of psychosocial candidacy for transplant is a robust and reliable social support plan (Coffman, 2010; DiMatteo, 2004). The level and quality of transplant candidates' social support is weighed carefully by the transplant team, and social workers in particular, before approving a patient for transplant. In kidney transplantation, social support post-transplant has been shown to have an impact on adherence, which is directly related to return to dialysis, re-transplantation, and morbidity and mortality of transplant recipients (Chisholm-Burns et al., 2010; Coffman, 2010; Denhaerynck et al., 2005; Stilley et al., 2010). Conversely, inadequate social support post-transplant impacts adherence, health-related quality of life, and can lead to graft loss, and even death (Muehrer & Becker, 2005).

Previous studies have examined social support during the post-transplant period typically beginning at around 3 or more months post-transplant (Hilbrands, Hoitsma, & Koene, 1995; Nevins, Krause, Skeans, & Thomas, 2001; Vlaminck et al., 2004). However, the 6 weeks immediately following transplant surgery require a high level of consistent, practical, and emotional social support. Because these first few weeks are medically critical and psychosocially demanding, understanding social support during this time period may be crucial to post-transplant success. Yet, little is known about the role of social support in adherence within the first 6 weeks following transplant, because extant literature does not explore this time period.

Given the gap in knowledge and the importance of this time period, research is needed to explore how social support, comprised of both practical and emotional support, impacts adherence in the first 6 weeks following transplant. Greater information about the role of social support in adherence during this early post-transplant time period may provide further insights into how best to prevent graft loss. Therefore, the overall goal of this study was to examine the role of social support in the initial 6-week period following kidney transplantation, and whether it was associated with greater adherence to the post-transplant regimen. How predictors of social support, such as gender and caregiver relationship, and whether geographical distance from the transplant center, and ability to financially meet daily needs affected adherence were also explored (Sholz et al., 2012).

METHODS

In this study, we used a longitudinal cohort design. There are no agreed-upon gold-standard questionnaires for measuring patient adherence, and there are a number of validated questionnaires available to choose from (Fairman & Motheral, 2000). The use of self-report measures to identify non-adherence are advantageous for obtaining information from the patient's perspective. In adherence research, the patient's viewpoint is recognized as an important component of information for understanding perceived barriers, attitudes, and behaviors associated with adherence (Fairman et al., 2000).

Corresponding author: Janice Firn; jfirn@med.umich.edu; 734.936.4637.

Sample

Adults aged 18 and older, with the ability to speak and read English, who successfully (i.e., the graft is functioning during the transplant admission) received a deceased donor kidney transplant at the academic hospital transplant center were eligible to participate in this study. Exclusion criteria included individuals who had previously undergone transplant, because they had prior experience with the post-transplant regimen, or were multiple-organ transplant recipients (e.g., combined kidney/pancreas transplant recipients), and those who experienced kidney graft loss during the transplant admission and required immediate return to dialysis. Individuals who were not able to provide informed consent due to mental status changes were also excluded.

Severity of disease was not controlled for in the design of the study because people actively listed for transplant were required to meet specific medical and functional status criteria, such as end-stage renal disease diagnosis with a glomerular filtration rate (GFR) of ≤ 20 and the ability to complete activities of daily living. Given that the transplant listing process eliminates people who are either too well or too ill for transplant, participants had a relatively similar severity of disease. The researchers were also part of the participants' care teams. To minimize potential conflict and risk of coercion, researchers ensured that potential participants were aware they did not have to join in the study and that their decision to participate or not would not impact the services or the care they received from the social work staff, and that their survey responses would not be shared with the treatment team or entered into the medical record.

Recruitment

First-time adult recipients of deceased donor kidney transplants were recruited to participate in this prospective, longitudinal cohort study from February 8, 2013 through January 15, 2015. One hundred forty-three people met eligibility criteria. Eighty-eight were approached; 28 declined to participate. Reasons for declining included not feeling well enough, or being too overwhelmed with post-transplant healthcare needs to participate. A total of 60 participants were recruited and consented during the post-transplant hospital admission. Upon further review, 2 participants did not meet inclusion criteria, resulting in a total of 58 participants. Basic demographics, including age, gender, nationality, living arrangement, marital status, employment status, level of education, adequacy of income to meet basic needs, and travel time from home to the transplant center were collected at the time of consent.

Ethics Approval

Ethics approval was given by the University of Michigan Institutional Review Board (approval number HUM00059851). Participation was voluntary. All participants signed a written informed consent form.

Study Outcomes and Measures

The primary outcome measurement of this study was adherence to post-transplant medication regimen. Adherence was assessed by the proportion of post-transplant appointments kept, and whether immunosuppression medication blood levels were within targeted ranges. Patients were typically required to have frequent follow-up appointments with the transplant team, weekly for the first month, and bi-weekly for second and third months. However, the exact number of appointments varied from person to person, based on the person's health status, and distance from the hospital. Thus, it was decided that in this study that the proportion of appointments kept, rather than the frequency of appointments, would be the best indicator of adherence.

Per renal transplant protocol at our academic medical center, lab values for tacrolimus and cyclosporine were taken twice a week for the first 90 days post-transplant, and were recorded in the medical record. Tacrolimus levels should have been between 8 and 12 ng/mL. For desensitized patients tacrolimus levels should have been between 10 and 12 ng/mL. Cyclosporine levels should have been between 250 and 300 ng/mL for the first 30 days and between 200 and 250 ng/mL for days 31–60. Any deviations from target tacrolimus or cyclosporine levels were noted in the electronic medical record. Typically, during this time period, ongoing adjustments to drug dosages at the direction of the medical team were needed while patients were reaching a therapeutic level. These adjustments were not unexpected and may have been unrelated to adherence. Variations in blood values of this type were not viewed as non-adherent. It was expected that deviations not explained by these anticipated adjustments would indicate that medication was not taken regularly or as prescribed, and therefore would be a clinical indicator of non-adherence.

Self-reporting of adherence was measured by the Immunotherapy Barrier Scale (ITBS) (Chisholm, Lance, Williamson, & Mulloy, 2004). The ITBS is a 13-item Likert scale used to assess the self-reported perceptions of participants' adherence to post-transplant medications. It has been validated in the post-kidney transplant population (Chisholm et al., 2004; Constantiner & Cukor, 2011). Responses were scored from 1, "strongly disagree" to 5, "strongly agree." The total score was comprised of two subscores measuring uncontrollable factors (i.e., not intentional or a result of the respondent's own doing), and controllable factors (i.e., the respondent's intentional deviation from regimen). A higher score indicates poorer adherence.

The primary predictor of interest in this study was social support. We used the Modified Social Support Survey (MSSS) which is an 18-item Likert scale measure of functional social support (Sherbourne & Stewart, 1991). It represents four dimensions of support: emotional/informational, affectionate, positive social interaction, and tangible, which yield four subscale scores that are combined for the total score. Responses are scored from 1, "strongly disagree" to 5, "strongly agree." Each of these scores range from 0 to 100, with higher scores indicating greater perceived support. The MSSS survey has been shown to be valid and reliable in populations of chronically ill people (Sherbourne et al., 1991).

Basic demographic information was collected, including age, gender of participant and caregiver, relationship of the primary caregiver to participant (i.e., spouse, family member, non-family member), distance from participants' home to the transplant center, and financial status (assessed using the question: "Do you have enough money to meet your daily needs?") (World Health Organization, 2004).

Data Collection Procedures

Self-report measures were administered to participants during the initial transplant admission (MSSS only), and at 2, 4, and 6 weeks post-transplant (MSSS and ITBS). These assessment points are important, as kidney transplant recipients are expected to have 24-hour caregiver support for the 2 weeks following surgery, and transplant recipients are generally on driving restriction until 4 weeks post-transplant, and are expected to have transportation from an identified support person. The entire time period (0–6 weeks post-transplant) is important, as transplant recipients are typically expected to have the most intense and frequent follow-up. Participants were contacted within a 1- to 3-day window, around the 2, 4, and 6 week follow-up assessments. Throughout the study, social work services were provided at standard levels of care, with no change in the frequency of social work contacts or the number or intensity of services provided. Post-transplant appointments were obtained from the medical record, as were the immunosuppression medication blood level values.

Statistical Analysis

Descriptive analyses were used to describe demographic characteristics and study outcomes. Linear mixed modeling (LMM), with random effects per person and repeated effects for time (data collection period), was used to test the relationship of social support and adherence, accounting for the effects of time, gender, gender of caregiver, and relationship to caregiver (family or spouse vs. non-family). To determine optimal covariance structures for each analysis, the Swartz's Bayesian Criteria was used to the best model fit; these are reported in Table 2 and 3 footnotes (Raftery, 1995). IBM SPSS version 22.0 (IBM Corp., 2013) was utilized for statistical analysis.

RESULTS

Participant Characteristics

Fifty-eight deceased donor kidney transplant recipients participated in the study. The attrition rate was 24.1% over the study. They were evenly distributed by gender. Participants reported 2 to 50 people in their social circle, with a mean of 8 people. Most, 86.2% participants, reported they had enough money to meet their daily needs.

Table 1. Participant demographics ***(N=58)***

Sex	31 (53.4%) male 27 (46.6%) female
Age	Ranged between 29 – 73 years old Mean age of 57 years
Distance from medical center	50% ≤ 100 miles
Caregivers	30 cared for by spouse/ significant other 24 cared for by other family members 4 cared for by non-family members

Medication and Appointment Adherence

All participants were adherent, in terms of medication and appointments kept, without variation in adherence levels, during the time period studied. The total number of clinic appointments, with the transplant surgeon or transplant team across all participants was 495 within the 6-week time period, with a total of 493 (99%) appointments kept. Appointments ranged from 3 to 5 per participant, with a mean of 4 appointments per person in 6 weeks. Across all participants, the total number of immunosuppressant blood level values recorded was 641; with 2–3 blood values recorded each week per participant within the 6-week time period. Participants were within the immunosuppression target range 60% of the time. Participants had contact with transplant nurses on average every other day during the 6-week time period of the study to discuss their blood levels and make medication adjustments. Each contact was documented in the medical record. Review of medical record documentation revealed that although immunosuppressant blood levels were not within range 40% of the time, participants seemed to be taking their medications as prescribed. As these conversations were self-reported, there was no way to determine whether being out of the target range was really the result of anticipated dosage adjustments or if nonadherence was actually the cause. Because no variance in adherence to medications and appointments was identified, we did not test the relationship of these factors with social support. The lack of variance made assessing the original hypothesis impossible.

Self-reporting of Adherence

In terms of self-reported adherence, perceived social support had an impact on participants' perceptions of adherence to post-transplant medications. Participants who perceived social support to be high (high MSSS total scores) also reported higher perceptions of adherence to post-transplant medications (low ITBS total scores; see **Table 2**).

Table 2. Perception of adherence (ITBS total score) and perceived social support (MSSS total score)

Parameter	Estimate	Std. Error	df	t	Sig.	95% Confidence Interval	
						LB	UB
Intercept	23.31	5.33	67.15	4.37	0.00	12.66	33.96
Week 2 (vs. week 6)	1.00	1.06	56.03	0.95	0.35	-1.11	3.12
Week 4 (vs. week 6)	0.31	0.96	74.63	0.33	0.75	-1.60	2.23
Female vs. Male	0.56	1.47	45.64	0.38	0.70	-2.39	3.52
Spouse vs. non-family caregiver	6.27	3.87	48.47	1.62	0.11	-1.50	14.04
Family caregiver vs. non-family caregiver	5.13	3.84	47.25	1.33	0.19	-2.60	12.86
Total social support (MSSS total)	**-0.11**	**0.05**	**96.92**	**-2.21**	**0.03**	**-0.22**	**-0.01**

Covariance structure: First order autoregressive ITBS = Immunotherapy Barrier Scale, MSSS = Modified Social Support Survey

We explored the relationship between perceptions of adherence (ITBS total score) and two sub-scores from the MSSS, tangible and emotional/informational. These two sub-scores were chosen above and beyond the other sub-scores, as it was thought that, alongside emotional/information support, tangible support may have the most impact on adherence during this time period. In particular, tangible support was chosen because during the first 6 weeks post-transplant, there are a greater number of tangible needs requiring a high level of commitment from caregivers. Due to the greater number of tangible needs during this time period, we expected perceived tangible support to have a greater impact on perceptions of adherence. However, statistical analysis revealed that higher perceived emotional/information support is significantly related to higher perceptions of adherence to post-transplant medications, rather than tangible support (see **Table 3**).

Table 3. Perception of adherence (ITBS score) and perceived emotional and tangible support (MSSS sub-scale score)

Parameter	Estimate	Std. Error	df	t	Sig.	95% Confidence Interval	
						LB	UB
Intercept	23.22	5.87	75.07	3.96	0.00	11.53	34.90
Week 2 (vs. week 6)	0.86	1.06	54.95	0.81	0.42	-1.26	2.98
Week 4 (vs. week 6)	0.41	0.98	73.52	0.42	0.68	-1.54	2.37
Female vs. Male	0.43	1.44	43.61	0.30	0.77	-2.47	3.33
Spouse vs. Non-family caregiver	4.82	3.77	45.36	1.28	0.21	-2.77	12.42
Family caregiver vs. Non-family caregiver	3.86	3.78	44.96	1.02	0.31	-3.76	11.48
Total social support (MSSS total)	-0.11	0.05	96.92	-2.21	0.03	-0.22	-0.01
Tangible support (MSSS subscale)	0.01	0.05	122.44	0.25	0.80	-0.09	0.12
Emotional support (MSSS subscale)	**-0.11**	**0.05**	**125.30**	**-2.22**	**0.03**	**-0.21**	**-0.01**

Covariance structure: First order autoregressive ITBS = Immunotherapy Barrier Scale, MSSS = Modified Social Support Survey

DISCUSSION

We expected that a greater perceived social support would be positively and significantly associated with participants' ability to keep post-transplant appointments and take their medications. However, we found a lack of variability in adherence, with all participants 100% compliant. Although the association between perceived emotional support and self-reported adherence from the ITBS scale mirror results from previous studies, showing that perceptions of adherence are high for transplant recipients who perceive social support to be high (Chisholm-Burns et al., 2010), no statistically significant relationship was found between social support, and medication and appointment adherence as we defined it in this study.

A lack of significant findings is often viewed as disappointing by researchers, and as undesirable by journal editors, as the preference and publication bias for positive results is well-known throughout the history of science (Matosin, Frank, Engel, Lum, & Newell, 2014). However, scientific thinking and future studies may be improved through the inclusion and reporting of non-significant and/or negative findings (Matosin et al., 2014). Reporting these types of findings is a valuable part of analyzing and validating current thinking, and necessary for a more complete scientific understanding (Matosin et al.). With this aim in mind, the non-significant findings from our pilot study are reported here.

The general lack of support for the relationship between social support and adherence in the acute post-transplant period in this study suggests that other factors likely play an important role in adherence during the 6-week period immediately following kidney transplantation. One such factor may be that in large, highly structured transplant programs the process for screening patients and assessing whether they have the appropriate level of caregiving is well established, leading to a pool of participants who are highly adherent, at least initially. Immunosuppressant medications may not have been an informative indicator of adherence because they required many adjustments to be made by participants at the direction of their physician or nurse, often multiple times per week. These adjustments in the initial post-transplant period may be due to individual variation in absorption and metabolism of the medication. Minor adjustments to find the right dose to produce the desired blood level in a particular individual are not necessarily indicative of a lack of adherence, but rather an expected adjustment process. Given the variability in blood level values during this time period, participants' ability to communicate effectively with their providers regarding these changes, and their ability to follow directions regarding medication management, may be better indications of their capacity to adhere, than the blood level value itself. Future studies of adherence in the 6 weeks post-transplant may need to account for medication adjustments to more accurately account for what is actually occurring in regards to variations in immunosuppressant blood values.

Existing evidence shows that education, and reinforcement of the medication regimen by social work and other clinic staff is important, especially when patients are unsure about their medication regimen, which can lead to non-adherence (Srinivas & Shoskes, 2010). Anecdotal comments from this study are consistent with previous findings, and also suggest that education is important. Standardized measures showed that participants had no concerns about taking immunosuppressant medications. Despite these scores, anecdotal comments from participants to researchers and other staff suggested that a portion of them did not understand when to take their medications and could not tell if the medications were helping. Participants' anecdotal comments, and the observations of the researchers may have implications for all members of the transplant team when working with recipients in the 6 weeks following transplant. For example, telephone contacts between nursing staff and patients are frequent during this time period. This appears to be an opportunity to reinforce medication and post-transplant education and the importance of adherence. This may be an opportunity for transplant centers to have a more formal approach to conversational content in these already occurring interactions. A more formalized approach may have implications for staffing, hiring, and training.

There continues to be a great need for psychosocial research studying patients' attitudes and perceptions regarding their perceptions of managing everyday life and the role of social support (Vermeire, Hearnshaw, Van Royen, & Denekens, 2001). Patients' own beliefs and lived experiences are important for determining adherence (Vermeire et al., 2001). Anecdotally, while most participants in the study reported perceptions of high emotional support on the MSSS, they sometimes reported differently in conversations with transplant clinic nurses and social workers as recorded in the medical record. These comments, often informal, suggest that support provided by the transplant team may have contributed to participant's overall perceptions of social support (Denhaerynch et al., 2005). While social support has long been known to improve adherence, the quality, duration and frequency of interactions between the patient and doctor also appear to be related to adherence (Vermeire et al., 2001). In this study, adherence could have been impacted by the patients' relationships with the transplant team, particularly the clinic nurse, given the frequency of interaction between them. Future studies should account methodologically for these different sources of support and explore how they each contribute to adherence.

STRENGTHS AND LIMITATIONS

Targeting an early period post-transplant addresses an important gap in the literature. Also, collecting data via mobile phone may have increased the likelihood of participants responding, as it allowed for rapport building between the interviewer and participant, and did not rely on participants remaining at the same address during the study (Freedman, Thornton, & Camburn, 1980; Johnson et al., 2015). The literature suggests that recall for time spans greater than 3 months is difficult for respondents, and is therefore not recommended. Asking patients to think back over the most recent two weeks likely helped to improve recall (Chisholm et al., 2004).

In addition to the lack of variance in adherence outcomes, there are several limitations to this pilot study. The sample is small and from a single institution. Recruitment was also a challenge, as some potential participants could not be approached due to the timing of the transplant (e.g., weekends), and availability of the researchers (e.g., work schedules, time off). It is possible that, with a larger sample or multiple study sites, there could be greater variability in adherence. The researchers were also members of the healthcare team, which could have influenced participants to underreport nonadherence. Engagement by participants during this time period may be high given the recentness of the transplant, and frequent contact with transplant team; non-adherence to medications and appointments may be more clearly discernible further out from transplant. Some unknown or unaccounted factors could also have influenced the outcome. One such unanticipated factor that was not controlled in this study was the transition to a new electronic medical record, which occurred part way through the study. This change may have impacted the ability to track missed appointments if the cancelled or missed appointment data did not transfer accurately from one system to the next.

FUTURE DIRECTIONS

There were several lessons from this study that will help to inform and shape future research in the area of social support and adherence in the immediate post-kidney transplant period. Anecdotal comments provided by participants and caregivers during our study indicated that patients' lived experiences of adhering to medications and appointments in the first 6 weeks post-transplant may be different from what they reported on the MSSS and ITBS measures. Using standardized measurement tools may not fully capture all that is occurring during this important time period. Given the lack of statistically significant results, but important anecdotal information, the next step in our research will be to use a qualitative approach to more fully understand the lived experience of adherence, and the role of social support in the post-operative period. This will help to inform the design of future quantitative studies. In addition, we will continue to examine the impact of social support on adherence and outcomes at 3 months, 6 months, and 1 year post-transplant to assess whether the trajectory demonstrated in the initial post-transplant phase will remain the same or change over time, and at what point in time that change takes place. It is possible that even those lacking adequate social support may have been able to manage well for 6 weeks due to the limited time span and the overall trajectory may change with time.

This study utilized a combination of self-reporting tools and non-self-reporting measures. In the literature, self-report measures and diaries of medication adherence are usually concordant with non-self-report measures, such as blood or metabolic testing (Garber, Nau, Erickson, Aikens, & Lawrence, 2004). Given the lack of variance in adherence found here, different outcomes or approaches to data collection may be indicated, such as a more formal examination of phone calls or interview-based measures. In the adherence literature, interview-based measures do not perform as well as standardized measures, and are less likely than self-report measures or diaries to result in information about adherence (Garber et al., 2004). However, future studies exploring the role of social support in adherence during the first 6 weeks post-transplant may want to use a combination of interviews and non-self-report measures. While interviews may not give particularly useful information about adherence, they may be able to give meaningful insights into patients' lived experiences of the post-transplant period and their understanding of the medical regimen. This combination of assessment tools in future studies may allow for greater discovery and more fully reveal outcomes related to the phenomena being studied.

Lastly, future studies should carefully consider how to interpret immunosuppressive medication levels during this time period, as they run the risk of false negative results. Additionally, future studies may want to account for home care nursing visits, emergency room visits, and hospital readmissions, as these may also reveal information about adherence during this time period. Further research is also needed regarding the impact of frequent interactions by professional providers to ascertain how professional support is incorporated into participants' perceptions of overall social support, as well as its effect on adherence.

CONCLUSION

Reporting non-statistically significant findings with reflections on the ways in which research methodology could be improved is a key aspect of improving and guiding future research. In transplant, early identification of nonadherence may help prevent future graft loss. For well-established transplant programs, it is not surprising that adherence is high in the first 6 weeks post-transplant. Standardized self-reporting scales may be limited in fully capturing patients' experiences of social support and medication adherence immediately after transplant. Utilizing immunosuppressant blood level values and appointment attendance rates may also fail to reveal which patients could be at risk for non-adherence during this time period. Self-reported measures, while informative about the ways in which perceived social support may impact perceptions of adherence, may not always provide enough information about the behaviors or attitudes which may be indicative of future non-adherence. Qualitative or mixed-method approaches in the 6 weeks post-transplant may be more useful in this inquiry and better capture the nuances and depth of patients' experiences immediately following transplant. Gathering in-depth data in this manner may help identify which factors contribute to or are indicative of non-adherence later in the post-transplant period. Early identification of these factors could give providers guidance regarding prevention and early intervention for barriers to adherence.

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“Talking Control” as a Method to Improve Patient Satisfaction with Staff Communication in the Dialysis Setting

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Heartland Kidney Network developed the Take 5 to Tune In project utilizing the technique of “talking control” to improve communication between staff and patients in the dialysis facility. Face-to-face talking control encounters with a five-minute minimum were conducted with patients from June 1, 2014, through September 30, 2014. Five questions from the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) experience of care survey were used to evaluate the success of the project. Overall, there was an increase of 5 percentage points in the combined rate of positive responses to the five ICH CAHPS questions. Talking control is an effective and simple means to improve dialysis provider communication and patients’ satisfaction with their care.

INTRODUCTION

Heartland Kidney Network promotes high quality care for dialysis and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska. To ensure that quality standards are met, Heartland Kidney Network leads and coordinates quality improvement activities (QIAs) throughout the four-state area. Patients’ perceptions of the quality of healthcare they receive are highly dependent on the quality of their interactions with their healthcare clinicians and team (Institute for Healthcare Communication, 2011). As described in the Institute of Medicine’s report Crossing the Quality Chasm (2001), patient-centered care is defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.” Effective communication is a cornerstone of high-quality patient-centered care (Guastello & Hale, 2014). In order to respond to the unique needs, values, and preferences of individual patients, healthcare professionals should incorporate communication skills, such as open-ended inquiry, reflective listening, and empathy in their interactions with patients.

Positive communication techniques work in partnership with other key elements to have an impact on patient satisfaction. In a review of medical literature, Carolyn Thiedke, MD, examined the patient-related factors, physician-related factors, and system-related factors impacting patient satisfaction with family physicians (2007). The physician-related factors contributing to patient satisfaction include:

- **Communication:** Healthcare providers take a problem seriously, explain information clearly, and try to understand the patient’s experience.
- **Expectations:** The patient has the opportunity to tell his or her story.
- **Control:** The patient is encouraged to express their ideas, concerns, and expectations.
- **Decision-making:** The patient’s social and mental functioning is acknowledged as much as physical functioning.
- **Time spent:** Patient satisfaction rates improve with length of time spent.
- **Technical skills:** Physicians’ technical skills impact on patient satisfaction varied in the studies reviewed.
- **Appearance:** Patients appear to respond to a physician’s appearance, preferring semi-formal attire and a smile.

The study suggests that treating patients with dignity and inviting them to partner in healthcare decisions can improve patient satisfaction. The dialysis setting differs in that although the physician is required to visit monthly, they are not “primary” care providers. Patient satisfaction for dialysis patients also includes the staff (nurses, dialysis technicians, social workers, and dietitians) who provide care on a daily basis. Patients are more likely to be satisfied with their care when they feel that providers listen carefully, spend time with them, show respect, and demonstrate concern about them as a person.

BACKGROUND

Heartland Kidney Network has found that there are many factors that contribute to patients filing a grievance regarding staff communication. Patients’ experience of care and perception of staff interactions are impacted by the people providing care, the dialysis setting itself, and the culture of the dialysis facility. Per the CMS contract requirements, Heartland Kidney Network conducted a focused audit of grievances reported to the Network from July 1, 2013, through March 31, 2014. Review of 30 grievances identified a common area of concern related to poor staff communication. Of the 30 grievances, 11 grievants (37%) reported communication as a concern. Of those 11, 8 (72%) stated staff did not provide explanations for treatment or actions taken, four (36%) reported staff did not listen to them, and two (18%) reported that staff were slow to respond. Through root cause analysis, the Network identified additional factors contributing to poor staff-patient communication which included:

- Facility staff members do not take enough time to listen to patients.
- Facility staff members do not follow up with patients after a concern is addressed to assess patient satisfaction.
- Facility staff members assume that the patient understands without confirming comprehension.
- Facility staff members feel rushed.
- Staffing ratios have changed; there are fewer facility staff members to care for more patients.
- Educational opportunities for facility staff members are limited due to availability and affordability. Many organizations no longer provide paid time off to attend conferences.

Based on the results of the focused audit, Heartland Kidney Network developed an innovative quality improvement activity (QIA) to improve staff and patient communication in the dialysis setting. The Network conducted the Take 5 to Tune In project from May 2014 to September 2014.

The Take 5 to Tune In QIA utilized the technique of "talking control" to improve patient and staff communication. Talking control has been utilized successfully in healthcare settings, including primary care and mental health, as a comparator in the evaluation of cognitive-behavior therapy. In a study of depressed older people in primary care, therapists were asked to show interest and warmth while encouraging participants to discuss neutral topics such as hobbies, sports, and current affairs. Therapists did not challenge dysfunctional beliefs, give advice, engage in problem solving, or suggest behavioral tasks (Serfaty, Haworth, Blanchard, Buszewicz, Murad, & King, 2009).

The only study to use talking control in the dialysis setting was in 2012 (Beto, Schury, Nicholas, Moravcik, Baldovino, & Bansal, 2012) at a single independent non-for-profit dialysis center, using the method developed by Serfaty (Serfaty, Csipke, Haworth, Murad, & King, 2011). Talking control consisted of general conversations about lifestyle without the specific intent of educational change. Beto describes talking control as a cognitive behavioral technique used to drive information sharing. It is similar to "befriending," in that it allows staff to develop rapport with patients by engaging them in patient-led "free-floating" conversations. The "talk" is controlled by focusing on factual information while providing warmth and interest, but not focusing on underlying beliefs or emotional problems. In Beto's study, patients were randomly approached to participate until 50 patients were recruited. Two waves of talking control were completed during dialysis treatment for a 10–12-week period. Sessions of either 5–10 minutes or 20–30 minutes per week were held over 12 months by a group of 26 interdisciplinary health professionals, including 18 students. A cart with rotating items (pens, notebooks, pill boxes, visual aids, games, brochures, and single serve food items) was used to initiate conversations about potential general lifestyle topics. The results included a 12% increase in the dialysis facility patient satisfaction score from the prior annual patient satisfaction survey, including a higher score on staff involvement in their care compared to pre-talking control. Beto proposed that talking control may be an effective, low-cost patient support technique that can involve all members of the interdisciplinary team.

PROJECT DESIGN

The Network's Take 5 to Tune In QIA was modeled after Dr. Beto's study (Beto, 2014) because it had been successful in including all staff and its ease of use. Several adaptations were made to address CMS timelines, Network limitations, and possible barriers to facility engagement. These included the length of time for the sessions (facility staff often report they do not have enough time). There was no use of a "getting better" cart to minimize the work required by facility staff. The Network's resources were limited and the project only lasted for 4 months.

Following patient selection, facility staff and patients volunteered to participate in the project for 4 months. Staff was asked to complete a five-minute talking control session with each patient who volunteered monthly during their dialysis treatment.

The purpose of the sessions was not to determine an action or intervention but to provide an opportunity for patients to feel that staff was interested in them as individuals. The goal was for the patient to have a positive experience, and was not focused on the content of the discussion. For instance, if the patient shared having gone to a wedding, the staff would not ask if they had gone over their fluid goal, but instead ask about the couple or where the wedding was held.

FACILITY SELECTION

Heartland Kidney Network is the End-Stage Renal Disease (ESRD) Network for the states of Iowa, Kansas, Missouri, and Nebraska. The dialysis patient population in January 2014 was 15,017. The QIA's goal was to include 10% of patients in the Network's four-state service area. The criteria for participation included facilities from the four states that had one or more grievances in the identified topic area of "communication" from July 1, 2013, through March 31, 2014, and facilities with more than 75 patients that had any grievance in 2013. Transplant centers were excluded, as well as facilities with a history of multiple grievances due to a documented mental health diagnosis affecting a patient's perception. Through this process, 17 facilities serving 1,517 patients were selected for participation. Participants included both facilities belonging to large dialysis organizations (LDOs) and independent providers. Facilities 1 and 15 were the two independently owned providers, while the others were owned by one of two LDOs serving the region. Three facilities operate in rural communities (facilities 1, 10, and 17) and the remainder in urban areas.

METHODS

On May 12, 2014, a project kick-off webinar was conducted by Dr. Beto and Network staff with facility administrators and social workers identified as project leads. The project leads were trained on the talking control method and project requirements were reviewed. Each facility received an implementation packet with a project overview, staff in-service guide entitled *Take 5 To Tune In* (2014), session tracking form, patient invitation, pre- and post-questionnaires, note cards, and two five-minute sand timers. The Network provided simplified conditions, guidelines, and expectations of the project as shown in **Table 1**.

In May 2014, project leads conducted an in-service for facility staff. All staff was encouraged to participate, including nephrologists, direct care staff, and support staff. Patients were invited to participate in the project as a way to get to know staff better. Staff randomly selected each patient to speak with by drawing a name blindly from a group of patient names. The timing for each patient's monthly Take 5 to Tune In talking control session was unplanned to allow for flexibility. Sessions were held from June 1, 2014, through September 30, 2014.

Sessions were a minimum five-minute face-to-face conversation between a staff member and a patient during dialysis treatment. To provide ongoing support for the project, dialysis staff members were encouraged to attend monthly check-in meetings with Heartland Kidney Network staff and other project participants. These check-in meetings served as a place for facilities to share best practices, and learn from the successes of other participating facilities. This was also an opportunity for the Network to identify any barriers facilities were experiencing, and to assist with strategies for improvement. The feedback collected during these calls was documented in meeting minutes. Facilities were required to track and submit the number of sessions held, as well as patient and staff comments, monthly to the Network through an online survey tool.

Table 1. Conditions, Guidelines and Expectations for Talking Control Sessions

Conditions	• Encounters will be random, staff randomly selecting the patient and time • Staff members are seated at eye level at the chairside during a dialysis treatment • A time limit is set at the onset (five minute minimum) • Fellow staff members will provide coverage to allow staff to be fully engaged and free from distraction while participating in a session
Guidelines and Expectations of Staff	• Sessions are patient-led • Staff shows enthusiasm and interest towards the patient • Staff "lends a sympathetic ear" towards the patient allowing him/her to share their feelings but then steers the conversation away from more emotional topics • Staff is non-judgmental • Staff focuses on neutral topics such as hobbies, news, or holidays • Staff uses a neutral tone, words, and body language • Staff encourages the patient to talk about their family and friends • Staff uses self-disclosure in moderation
Staff Should Avoid	• Setting an agenda for the session • Focusing on a key problem area or treatment-related concern • Trying to collaborate with patients to solve problems • Providing handouts or written materials • Giving specific advice • Providing a plan of action

This project was approved as a Quality Improvement Activity by the Network's Centers for Medicare & Medicaid Services Contract Officer Representative.

MEASURE

The Take 5 to Tune In project utilized the number of grievances related to communication, and the results of five questions from the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems (ICH CAHPS) (CMMS & AHRQ, 2005) survey to measure the impact of the project. Grievance data from the patient contact utility (PCU), the CMS-designated case review system for ESRD Networks, was collected monthly from May through September 2014.

The ICH CAHPS survey is a standardized questionnaire produced by the Agency for Healthcare Research and Quality (AHRQ). This survey is designed to measure the experiences of people receiving in-center hemodialysis care from Medicare-certified dialysis facilities. The survey asks questions about dialysis facility staff regarding communication, professionalism, competence, and caring. Patient responses to the questions could be "always," "usually," "sometimes," "never," "yes," or "no." Facilities were provided with the option of either distributing a pre-questionnaire to collect patient responses or sharing their results from the 2013 ICH CAHPS survey. Five questions related to staff interactions were utilized to establish the baseline measure for this QIA. After the project was completed, facilities conducted a post-survey with all facility patients using the same five ICH CAHPS questions. The five questions selected to measure the effectiveness of the Take 5 to Tune In project are shown in **Table 2**.

Table 2. ICH CAHPS Questions Pertaining to Patient Satisfaction with Staff Interactions

Question Number	ICH CAHPS Question
1	In the last 3 months, how often did dialysis center staff listen carefully to you?
2	In the last 3 months, how often did the dialysis center staff show respect for what you had to say?
3	In the last 3 months, how often did the dialysis center staff spend enough time with you?
4	In the last 3 months, how often did you feel the dialysis center staff really care about you as a person?
5	In the last 3 months, how often did you feel comfortable asking the dialysis center staff everything you wanted about dialysis care?

RESULTS

From June 1, 2014, through September 30, 2014, 1,278 Take 5 to Tune In sessions were conducted. This is equivalent to at least 6,390 minutes or 106 hours of one-to-one patient and staff interactions. The monthly average percentage of patient participation was 24% per facility.

PCU data were reviewed monthly, and analyzed to determine the number of grievances related to communication. During the project, there were no grievances reported to the Network regarding communication for the 17 facilities. Data from the five ICH CAHPS questions were collected and analyzed for the 14 facilities that completed the project. Two facilities (Facilities 15 and 16, serving 87 patients), out of the original 17, did not submit post-assessment data, and one facility (Facility 17, serving 22 patients) closed. Data analysis included the percentage of positive responses ("Always," "Usually" or "Yes") to each of the five ICH CAHPS questions per facility pre- and post-intervention. The average percent positive response rate of the five questions was then calculated per facility for pre- and post-data. This data allowed the Network to determine the aggregate improvement of the 14 facilities for the five ICH CAHPS questions. The goal for improvement was to increase the rate of positive responses to the questions by five percentage points.

Facilities had an average of 83% positive responses on all five questions prior to the intervention. Following the intervention, the group's average rate of positive responses increased to 88% (**Figure 1**). The Network's goal was met. Post-intervention data also revealed an overall improvement for seven facilities (Facilities 3, 4, 5, 7, 9, 11, and 14), an overall decrease for six facilities (Facilities 1, 2, 6, 8, 12, and 13), and one facility with no change (Facility 10). Of the facilities that showed an improvement, there was an average of a 14% increase, while the facilities that showed a decline averaged a 6% decrease in positive responses (**Figure 2**). Facilities 4, 5, and 9 presented the greatest opportunities for improvement in satisfaction, and each did. As shown in **Figure 2**, Facility seven had an 11 percentage point increase in the percentage of positive responses. Facility 14 had a seven percentage point increase of positive responses and reported that over 75% of its patients participated in the project. Facility 14 planned to continue conducting Take 5 to Tune In sessions with patients after the conclusion of the project as standard practice, and presented its success to its dialysis company's regional directors for sharing with other dialysis facilities.

Overall, the positive response rate, aggregated across all facilities, improved for each question as shown in **Figure 3**. Question 3 demonstrated a 6% improvement, while questions 4 and 5 both demonstrated 5% improvements.

Individual results were reviewed for each facility. Eight facilities demonstrated improvement in three or more questions. Although six facilities experienced a decline in the aggregate percent of positive responses, every facility but one improved or maintained its score for at least one question. 11 facilities showed improvement in the percentage of positive responses to question 5. Question 5 is, “In the last three months, how often did you feel comfortable asking dialysis center staff everything you wanted about dialysis care?” One facility maintained 100% positive responses to question 5 and only two facilities showed a decrease.

When the response rate was reviewed, two facilities with a decrease in positive responses (Facilities 8 and 12) had more respondents post-intervention, although when all those with a decrease were reviewed as a group the average difference was -1.33. The aggregate data for Facility 6 changed by -6 in responses; however, when individual questions were reviewed, the facility average percent positive responses improved by 3% from the pre-intervention data.

The location of the facilities did not appear to have an impact the results. Of the three rural clinics, one closed, one showed a decline, and the other showed no improvement or decline. The two facilities that did not complete the project were in urban areas. The results were equally split with seven facilities showing an improvement, and seven a decrease in positive responses.

The facilities with patient participation greater than 60% showed a greater improvement than those with smaller numbers of participants. All facilities (Facilities 7, 9, 14) that reported an average of 60% or more of patient participation showed an average of 10% improvement. While facilities (Facilities 2, 3, 4, 5, 11, 13) reporting less than 24% had an average of 7% improvement.

Both patient and staff feedback indicated that the project provided positive communication opportunities for all involved. Facility staff shared that although they talk with their patients during each treatment, the sessions provided a unique opportunity because they were able to completely focus on the patient. Participating patients were asked what they liked best about the project.

The responses included such statements as:

- “The staff showed concern about what I had to say.”
- “I enjoyed being able to talk about things that interested me and my family.”
- “Staff was more than willing to listen to things that were interesting to me.”
- “They all seem like family and seem to care about my life away from the dialysis center.”
- “It is good that someone comes and sits with you and is willing to listen to your comments.”
- “Getting to know people and being like family.”

Figure 1. Percentage of Positive Responses for 5 ICH CAHPS Questions Pre- and Post-Intervention

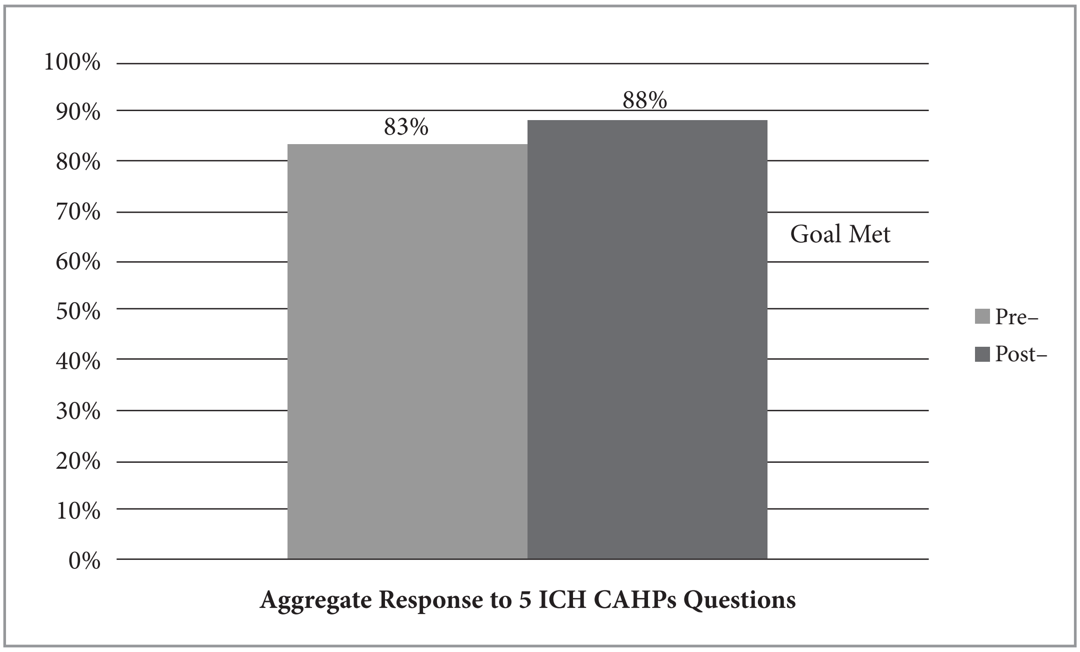
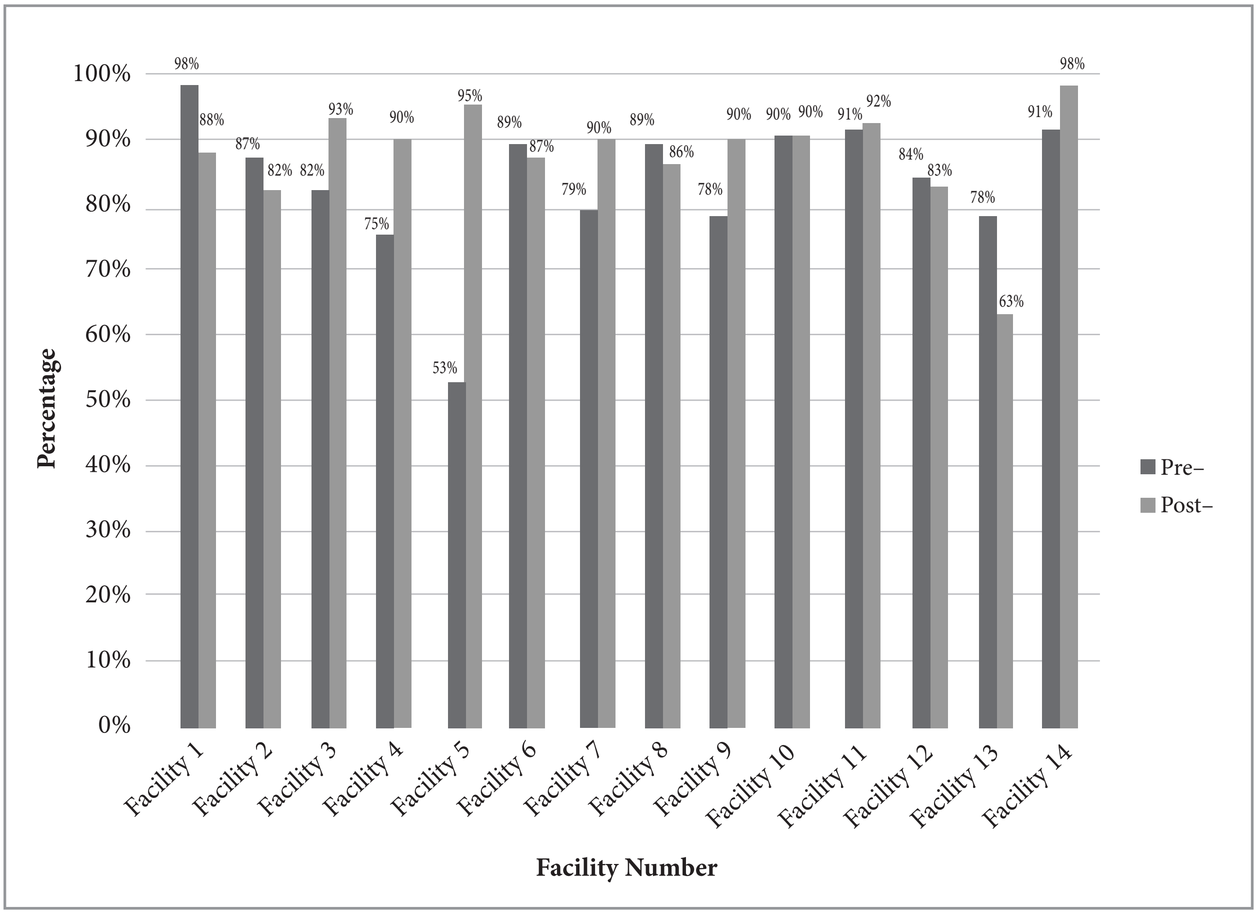


Figure 2. Percentage of Positive Responses for 5 ICH CAHPS Questions for Participating Facilities Pre- and Post-Intervention



When facility staff members were asked what they liked about the project, responses included:

- "It was fun and did not take long."
- "It was relatively easy to find time to sit and talk with patients."
- "It is fun to talk about other things and get to know patients better."
- "Patients remember and look forward to it month to month."
- "The patients seemed to enjoy some one-on-one time and talked about a lot of things."
- "The 'difficult' patients are even enjoying it."

Staff shared several concerns and barriers to the project including:

- "Staff turnover has been a challenge."
- "Staff and patient vacations and hospitalizations were a challenge."
- "We already do this [talk to our patients]."
- "Community issues impacting the mood in the facility."
- "There have been a lot of initiatives with the organization and, with new staff training, time has been the barrier."
- "Project lead is responsible for multiple units and time constraints have been the biggest barrier."
- "Patients not wanting to do paperwork."
- "Patients reluctant to share about themselves."
- "Patients want to sleep through treatment."
- "Sometimes it's hard to get away."

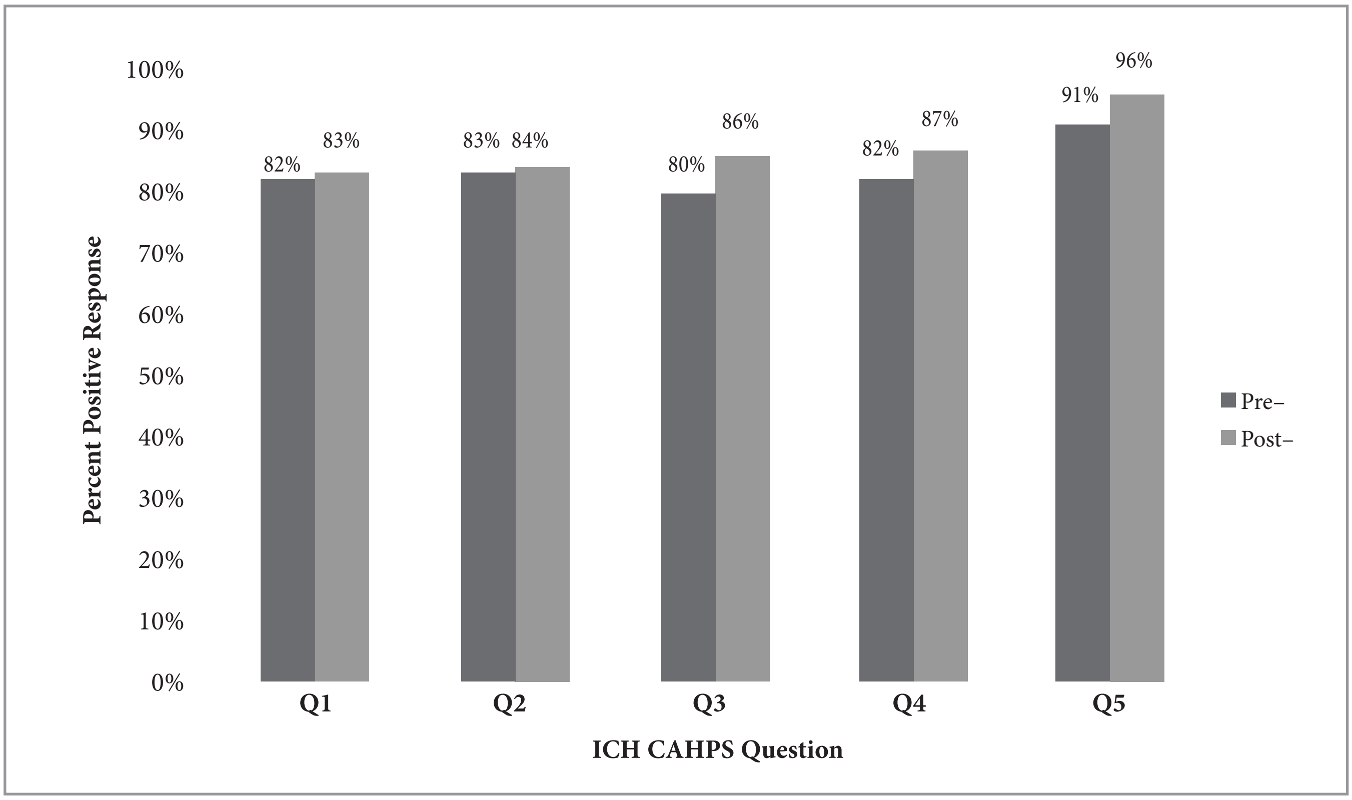


Figure 3. **Aggregate Improvement for Each of 5 ICH CAHPS Questions Pre- and Post-Intervention**

LIMITATIONS

This project had several limitations that should be considered when planning future implementation. First, the data reviewed represented a small sample size of 30 grievances. This was due to the pre-set parameters by the CMS contract for an audit time period of 15 months. Review of multiple years of data may have provided additional information on the types of grievances received and specific issues presented. Facilities were selected from the small sample size of those that had grievances reported. Secondly, some of the facilities were resistant because leadership did not feel patient grievances were valid. This included the two facilities that did not complete the project by failing to submit the post-assessment results to the Network. These facilities were required to continue the project and follow it within their Quality Assurance and Performance Improvement (QAPI) activities for the remainder of 2014.

Additionally, limited resources, Network staff time constraints, and distance to facilities, were limitations. Although Network staff provided webinar training for project leads, on-site training for each of the facilities was not completed. This limited the ability of the Network to ensure that facility staff were trained effectively, felt confident using talking control, and that the project was implemented as directed. Reliance on anecdotal reporting was a significant limitation.

DISCUSSION

The Take 5 to Tune In project has been recognized as a promising practice due to the innovative approach used. The most common recommendation by the Network to dialysis facilities to improve communication is to provide staff with in-services on professionalism, boundaries, and active listening. Although training is a part of the project, it builds in simple, yet multiple opportunities for patient-staff interactions. This helps the staff build a positive relationship with patients and engenders trust. Although talking control has been utilized successfully in other settings (e.g., primary care and mental health), Dr. Beto's study was the only resource found related to its use in dialysis facilities.

According to the Institute for Healthcare Communication, "The connection that a patient feels with his or her clinician can ultimately improve their health mediated through participation in their care, adherence to treatment, and patient self-management" (Institute for Healthcare Communication, 2011). The improvements made in question 5 demonstrate that participating patients felt more comfortable connecting with their dialysis facility staff and with asking questions about their care after the project.

The Take 5 to Tune In project encouraged patients to express their ideas while providing a safe environment for sharing, thus improving patient satisfaction with staff interactions. The approach is unique in that, typically, staff-patient interactions in the dialysis facility are initiated by staff who come with an agenda. In contrast, Take 5 to Tune In provides patients with a voluntary, time-limited opportunity for staff's undivided attention, focused on a topic of their choosing. As care providers, staff members have the tendency to use information sharing as "teachable moments"; the talking control sessions required staff to be engaged in what the patient wanted to talk about at the moment. Staff found this to be both difficult and refreshing. Staff from one participating facility indicated that "it was hard to not give advice, but it was fun to just be able to listen." They noted that participating patients enjoyed the time and looked forward to the next session, and many who initially chose not to participate joined later because they "wanted their special time, too."

Ongoing project monitoring through monthly calls allowed the Network to facilitate rapid cycle improvement and the sharing of best practices. Project leads shared strategies they had developed to address common concerns. For example, although all of the facilities received 5-minute timers, some preferred other methods of monitoring time: a clock, cell phone timer, or the dialysis machine timer. Participants encouraged each other by sharing the positive responses they were receiving from patients and staff. Additionally, participating facilities reported that the project encouraged teamwork because of the need to provide coverage for individual staff members to complete Take 5 to Tune In sessions without distraction.

The Network identified some challenges during the project implementation, including facility staff buy-in and project timelines. Lack of time was a barrier for facilities with changing or stretched leadership, but others stated that once training was completed, it was easy to find the time. Staff buy-in was the most significant challenge. Both of the facilities that did not complete the project had project leads who expressed indifference to the project, because they did not feel the grievances were valid. However, the Network found that once a project lead embraced the project and trained staff on how the Take 5 to Tune In sessions were different from their typical interactions, there was an improvement in staff engagement. The need to achieve buy-in caused a delay in some facilities becoming fully engaged. Staff buy-in also may have impacted patient recruitment, because the project may not have been presented in a way that encouraged participation. One facility shared that their patients were more agreeable to participating if it was not presented as a "project" that was being tracked, but that staff was taking extra time to talk with them. Additionally, the limited control the Network had on facility implementation and staff training may be improved by providing opportunities for individual facility staff in-services, and requiring project leaders to verify staff confidence with use of talking control.

CONCLUSION

The Take 5 to Tune In QIA demonstrated that talking control may be a successful strategy to improve communication between dialysis facility staff and patients, as well as improve patients' satisfaction with staff. The use of talking control provided opportunities for patients to have positive interactions in which they felt staff listened carefully, showed respect, and cared about them. Participating facilities learned an innovative method of using ICH CAHPS results to determine potential opportunities for quality improvement. Facilities were encouraged to continue the project as part of their Quality Assurance and Performance Improvement (QAPI) plans. Several dialysis facilities incorporated the talking control sessions into their standard practice, based on the impact of the project. One facility administrator's comment summarizes the impact of the Take 5 to Tune In project:

> Being in the project has allowed the facility and staff to move out of their comfort zone to do something different than they have in the past. The project opened the eyes of team-mates; many thought they knew the patients as they talk with them daily, but have found a difference in the conversations. We found that our patients opened up more and shared more information than [we] knew before. Patients really have enjoyed it and want to get more. We are planning to continue to do the project in the facility.

ACKNOWLEDGEMENT

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NKF Peers Mentoring Program:

An Overview and Lessons Learned

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The article provides an overview of the National Kidney Foundation's Peers mentoring program. Following a brief discussion of the evidence behind peer support across disease states, the article reviews data collected since the program's official launch in September 2011 through December 31, 2015. Potential challenges and lessons learned from the program to date are highlighted and discussed.

INTRODUCTION

Chronic kidney disease (CKD) is a growing public health concern, although much of the general public remain unaware of CKD and its risk factors. 1 in 3 American adults is currently at risk for developing kidney disease (Nwankwo, Yoon, Burt, & Gu, 2013). Additionally, more than 661,000 Americans have kidney failure. Of these, 468,000 individuals are on dialysis, and approximately 193,000 live with a functioning kidney transplant (USRDS, 2015). Eighty-nine percent of ESRD patients reported that the disease caused many changes in their lifestyles (Kaitelidou, Maniadakis, Liaropouls, Ziroyanis, Theodorou, & Siskou, 2005).

Peer support is reported to be effective in helping kidney patients adjust to kidney disease, long-term dialysis therapy (Hughes, Wood, Smith, 2009; Perry, Swartz, Brown, Smith, Kelly, & Swartz, 2005), and kidney transplantation (Faulk, 1999; Leshowitz, 1995). It also improves depression (Travis et al., 2010), social isolation, self-esteem, and self-management (Feroze, Martin, Reina-Patton, Kalantar-Zadeh, & Kopple, 2010; Symister & Friend, 2003). This, in turn, leads to better health outcomes and survival (Thong, Kaptein, Krediet, Boeschoten, & Dekker, 2007).

Peer support programs utilize someone who is living with the same disease to assist patients in managing their own health. This can be particularly effective when the patient is newly diagnosed or is having trouble coming to terms with the disease (Taylor, Gutteridge, Willis, & Carol, 2016).

In addition, peer support has become strongly linked with attempts to increase patients' ability to self-manage their condition, and the drive to improve healthcare outcomes (Heisler, 2006).

Peer support works because patients are able to give each other something the clinician does not have—shared life experience. It is valuable to be able to talk to someone who can listen and empathize to help gain confidence and a greater sense of control, and to have access to practical information based on the lived experience of treatment from the perspective of someone who has "been there" (Taylor et al., 2016).

People diagnosed with a new medical condition have the added pressure of feeling isolated, often not knowing anyone else in their social circle who has experience with the condition (House, 2001). Patients often seek knowledge, strength, and hope when the path ahead seems uncertain or scary. Research shows that people often cope better when they interact with peers with whom they identify and share common experiences. In this way, feelings are validated, social isolation and stigma are reduced, hope for the future and optimism grows, and experiences are normalized (Dunn, Steginga, Rosoman, & Millichap, 2003).

Additionally, quality time with healthcare professionals seems to be increasingly limited. Past surveys of dialysis facilities found that 15%–36% of patients on hemodialysis were seen by a physician or advanced practitioner at least one time per week, whereas 21% of patients were seen monthly or less (Erickson, Tan, Winkelmayer, Chertow, & Bhattacharya, 2013; McClellan, Soucie, & Flanders, 1998; Plantinga et al., 2004). Between 2007 and 2010, outpatient dialysis social workers experienced an average increase of 7.6% in mean caseload size (Merighi, Browne, & Bruder, 2010).

NKF PEERS PROGRAM

The National Kidney Foundation's Peers program was developed in 2011 to provide support to stage 4 kidney patients, dialysis patients, and transplant recipients.

The first group of mentors was trained in August 2011, and the program was launched in September 2011.

Program Development

NKF Peers was created after conducting a needs assessment and thorough review of the literature and known peer mentoring programs, particularly in nephrology. There were no national peer support programs in nephrology to draw from, but there were a variety of local programs. The NKF of Michigan has been running a successful peer-support program since 1994, and was particularly instrumental in the development of the national NKF Peers program. However, the Michigan program provides support in person, and at the national level this was not a possibility. The mentor training manual was adapted from the manual developed by the NKF of Michigan.

Some of the anticipated barriers to the long-term success and sustainability of peer programs for kidney patients were issues securing physical space, transportation, difficulty scheduling around dialysis treatments, and high staff turnover in dialysis units.

To help overcome some of these barriers, and to provide a program that would be accessible nationally, NKF decided to create a telephone-based peer mentoring program for kidney patients. Telephone-based support has been shown to be effective and beneficial in numerous patient populations, such as cancer (Colon, 1996; Mathews, Backer, Hann, Denniston, & Smith, 2002; Rudy, Rosenfeld, Galassi, Parker, & Schanberg, 2001), diabetes (Heisler, 2010; Heisler & Piette, 2005; Heisler, Vijan, Makki, & Piette, 2010), heart disease (Heisler, et al., 2007; Parry et al., 2009), depression (Travis et al., 2010), HIV/AIDS (Stewart et al., 2001), pain management (Arnstein, Vidal, Wells-Federman, Morgan, & Caudill, 2002), and other conditions.

CKD stage 4 patients, dialysis patients, and transplant patients were the initial target audience of the NKF Peers program. While all kidney patients would likely benefit from peer support, the unique challenges and particular emotional strain for those facing kidney failure and coping with life on dialysis or with a transplant were important factors in these groups.

Telephone-based peer support allows mentors and mentees to connect regardless of their location. It also allows pairs to be better matched, based on their needs, experiences, or demographic factors, such as age.

Program Overview

The NKF Peers program matches mentors and mentees one-to-one through a toll-free phone system. Interested mentees are matched with a trained mentor who has experienced a similar situation with kidney disease. Interactions vary in length per call and duration over time. NKF matches and tracks pairs via Inquisit Health's 1-to-1 Mentoring Platform (www.inquisithealth.com). This platform automatically provides toll-free phone numbers to mentors once they have accepted a new mentee match. The platform then tracks frequency and length of calls between pairs and automatically sends emails to seek feedback on the call from mentors and mentees once a call is completed.

NKF Staff

Since the program's inception, one full-time MSW has overseen and managed the program. About 40% of the staff member's time is allocated for management of the NKF Peers program. Additionally, two first-year MSW student interns assisted with the program.

MSW Role

The necessity of having an MSW clinician overseeing the NKF Peers program cannot be understated. A social worker's unique ability to assess a mentee's needs, history, and current situation (i.e., medical, support system, etc.) is an important part of successfully matching pairs. Additionally, an MSW's skills are imperative in providing training to mentors and support to mentors and mentees when difficult situations arise.

The National Association of Social Workers Standards of Classification considers the Master's in Social Work degree a specialized level of professional practice that requires a demonstration of skill or competency in performance (Anderson, 1986). This additional training in the biopsychosocial model of understanding human behavior enables the master's-prepared social worker to provide cost-effective interventions, such as assessment, education, and therapy, and to independently monitor the outcomes of these interventions to ensure their effectiveness (Browne, 2006).

All interested participants are interviewed, assessed, matched, and supported throughout their involvement in the program by a masters-level social worker (MSW). Mentees are supported by initial assessment of needs and frequent follow-up contact to ensure that matches are appropriate and meeting their needs. Additionally, the MSW provides psycho-educational information and appropriate resources to supplement the peer mentoring as needed. For mentors, MSW support includes regular communication about how matches with mentees are progressing, addressing any concerns regarding interactions with their mentees, and providing guidance on how to approach difficult situations. The MSW also provides ongoing emotional support for mentors who may be faced with their own emotional reactions brought up by mentoring relationships.

Recruitment of Peer Participants

Patients learn about the program through NKF's marketing efforts, which include flyers mailed to dialysis units, nephrology clinics, and transplant centers throughout the United States. Additionally, NKF mobilizes its professional members to share information about the program with their patients. Program information is also shared in NKF's various printed and online newsletters, blogs, and social media outlets.

Peer Mentor Selection and Training

Peer mentors are volunteers who express interest in being a mentor by reaching out to the NKF or applying online. Mentors undergo a telephone assessment by a masters-level social worker before taking part in an extensive telephone-based training program developed and provided by NKF.

The mentor training is based largely on the training program developed by the NKF of Michigan. This comprehensive mentor training program includes topics such as: confidentiality/HIPAA; values and beliefs; empathy; problem-solving; initiating, maintaining, and ending relationships; loss and grief;

cultural sensitivity; and more. There is a strong focus on role playing and group interaction throughout the training.

Initially the NKF Peers training was designed as 6 1-hour sessions with multiple attendees on conference call. However, after a few trainings it became evident that coordinating schedules for a group of mentors across the country presented a challenge. The training continues to cover the same material but is now 3 1.5 hour long sessions by conference call. This has improved attendance and has made scheduling easier.

Typically, a peer mentor training group will consist of 10–15 people. However, the largest group was 22 people, which proved to be too large to effectively accommodate by conference call. This was largely due to the fact that the training relies heavily on participation, interaction and role play, and, with 22 people, there was not enough time for each potential mentor to participate.

NKF hosts two trainings each year, which has adequately met the needs of the program as it has grown over time. Eighty of the 102 mentors trained completed all the requirements of training and became active mentors.

Mentors must have web access and an email address in order to access the online platform and to accept and track their matches.

Matching

NKF does not accept referrals from professionals to the NKF Peers program. Interested mentees and mentors must call or email NKF on their own accord.

After completing the mentee's assessment, the oversight clinician choses an appropriate mentor based on the mentee's stated preferences. These preferences always include modality type (either current or what they are interested in), age, and gender. Additionally, some patients feel strongly about talking with someone who has the same cause of kidney disease. This tends to be important to those whose primary or cause of kidney disease has profound symptoms, affects their pre-ESRD health management, or who have had transplant -related concerns. Common causes of kidney disease that people specifically request talking about are: polycystic kidney disease, lupus, and diabetes, particularly for those with a kidney/pancreas transplant.

Every effort is made to find a mentor who best meets the mentees' needs. At times this requires having the mentee speak with more than one mentor.

How the System Works

To connect to each other, mentors are given a toll-free telephone number generated by the 1-to-1 Mentoring Platform (www.inquisithealth.com) to connect to their mentees. Neither party discloses their personal phone number or incurs long-distance charges. The telephone system allows participants to talk directly with each other, leave voicemail messages, block calls at certain hours, and initiate reminder calls, if needed. Telephone services are provided free-of-charge by NKF.

During the interview and assessment of interested mentees, the oversight clinician documents their preferred availability. The oversight clinician chooses an appropriate mentor in Inquisit Health's 1-to-1 Mentoring Platform and an automatic email will go to the chosen mentor to ask if they are interested and available at the given times to talk with the new mentee. Once a mentor accepts the match, they are given a unique toll-free number and are able to call the mentee at any of the available times. Mentors always initiate contact with mentees. Times zones are always taken into account.

Mentors also have access to a "dashboard" with basic information on their mentees, as well as the toll-free number and available times. While mentees can call the toll-free number back if they miss a call, they will not be able to connect directly with their mentors, as it will not ring the mentor's phone. However, the mentors will be alerted that mentees tried to call them, and mentees are able to leave messages for their mentors.

DATA

Since its inception, the NKF Peers program has trained 102 peer mentors. 80 out of 102 mentors completed all the requirements of training and became active mentors. The program has connected over 423 people seeking support with peer mentors from September 2011 through December 31, 2015.

Demographic

Stage of Kidney Disease

Of NKF's mentees in the time period cited, 9% were CKD Stage 3, 38.5% were CKD Stage 4/5 not on dialysis, 35% were on hemodialysis, 11% were on peritoneal dialysis, and 5% had a transplant when they initially engaged with the program.

All mentors are either already on dialysis or have a kidney transplant. Mentors with experience in home hemodialysis, nocturnal HHD, peritoneal dialysis, in-center hemodialysis, as well as transplants from living and deceased donors are available. The program also includes mentors who have participated in paired exchange programs, or were listed for a transplant in multiple regions.

Age

Mentors and mentees range in age from 15 – 89 years old (See **Table 1**).

Gender

As of December 31, 2015, NKF Peers has 298 female and 124 male mentees, and 56 female and 48 male mentors.

Call Details

Since inception, NKF Peers mentor/mentee pairs have completed 2,111 calls. The average duration of calls is 26 minutes, with a range of 1 – 241 minutes. Excluding completed calls under 5 minutes, data shows an average call duration of 33 minutes (see **Table 2**). The average number of calls per matched mentor/mentee pair is 6.

Table 1. **Age of Mentees**

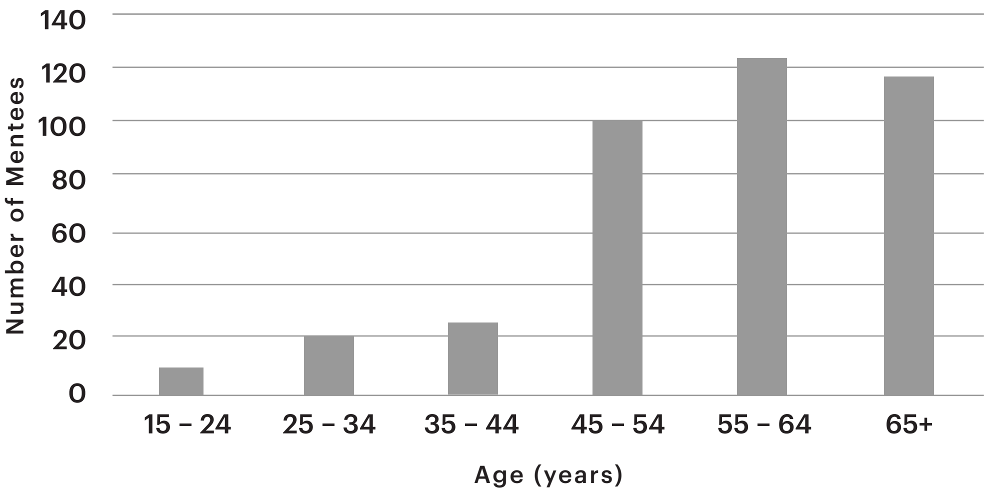
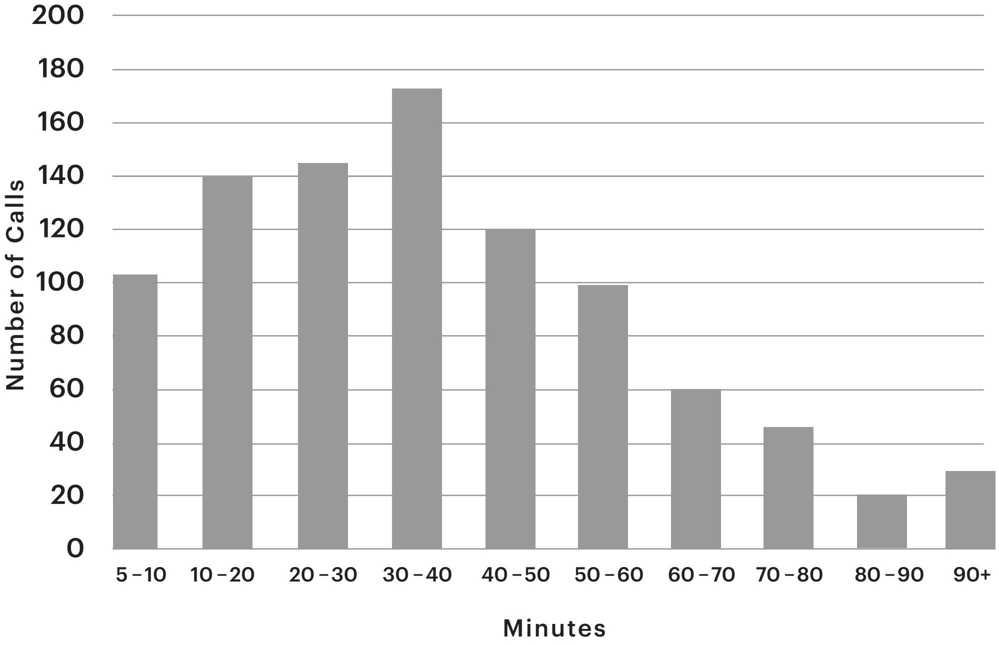


Table 2. **Length of Calls (in minutes)**



Mentor Training

The oversight clinician has facilitated 7 training sessions for new mentors since August 2011. The overall mentor evaluation for the training sessions showed that 100% of the trainees rated the training as "excellent" or "good."

When asked to match their perception to the statement, "I feel well-prepared to be a peer mentor," following training, 60% of the trainees designated "strongly agree," and 40% designated "agree." Evaluation data also shows that the telephone-based training format is effective and convenient, and that the information shared in the training sessions and training manual is "easy to understand," "important," and "valuable" to success as a mentor. In addition, the telephone format is successful in that there is significant interaction between trainees and NKF facilitators. Mentor trainees were fully engaged and participatory in the learning activities, discussions, and role playing exercises.

Mentors said they "feel proud" to be providing support to their peers, and "confident" in their skills as mentors after the training. They also expressed much enthusiasm for their new role.

Patient Activation Measure (PAM)

To measure knowledge, skills, and confidence for self-management, NKF utilized the Patient Activation Measure (PAM), developed by Insignia Health. The PAM is a valid, highly reliable, unidimensional, probabilistic Guttman-like scale that reflects a developmental model of activation. Activation appears to involve four stages: 1) believing the patient role is important; 2) having the confidence and knowledge necessary to take action; 3) actually taking action to maintain and improve one's health; and 4) staying the course even under stress. The measure has good psychometric properties, indicating that it can be used at the individual patient level to tailor intervention and assess changes (Hibbard, Stockard, Mahoney, & Tusler, 2004).

Participants' responses to the PAM translate into a numerical score, ranging from 0 to 100, which assesses a participant's knowledge, skills, and confidence for self-management. The mean pre-participation mentor PAM score was 82.2, which demonstrated they have "made most of the necessary behavior changes."

For our baseline measurements, mentees were asked to complete the PAM prior to being matched with a peer mentor. 405 mentees out of 423 interviewed (95.7%) for the program completed the pre-participation PAM. The mean mentee PAM score before being matched was 53.4, which indicated that they had "begun to take actions." In the initial interview, mentees often expressed concerns about isolation and were looking for validation that their feelings were not necessarily unique. They also often expressed being "hopeful that things can get better."

Both mentor and mentee pre-participation mean scores were consistent with NKF's expectations and, especially for mentees, indicate room for growth and improvement in their knowledge, skills, and confidence in their ability to self-manage their healthcare.

NKF continues to collect post-participation PAM scores for mentees. Of the 405 who completed the pre-PAM, excluding the 57 patients still active in the program, NKF has received 146 completed post-participation PAMs (42%) to date. Those completed reflect an improvement compared with pre-PAM scores, with a mean of 65.96 demonstrating a significant improvement from average pre-scores (53.4), and indicating they have "made most of the necessary behavior changes."

Mentee Satisfaction

After being matched with a mentor and completing the peer program, a survey is given to all mentees to assess their satisfaction with the program. The survey includes Likert scale(s) and open-ended questions. Mentees participating in the NKF Peers program were highly satisfied in their experience:

- 88% of mentees rate their overall experience with NKF Peers as positive (11% fair, 1% poor).
- 97% found their mentor to be helpful.
- 96% found their mentor to be supportive.
- 98% found their mentor to be knowledgeable.
- 97% would recommend NKF Peers to someone in a similar situation.

For those who were not satisfied with the program, issues identified were: problems with the phone system, particularly wishing they were able to initiate calls as mentees, preferring in-person mentoring, or not being matched with someone from their area.

Mentees express immense gratitude for the support they are receiving. Below are some examples of feedback:

- *My peer answered questions I thought were stupid, but I wanted an answer and she told me no question was stupid and gave me an answer.*
- *My mentor was extremely helpful with letting me know how she has moved through the process of diagnosis to PD to transplant. I hope I will be as successful as she has been with the process! Thanks so much to the NKF for helping me to understand some of the challenges that will face me down the road. It was extremely helpful to me and my family.*
- *Speaking with my mentor on a regular basis has been extremely helpful. She is very bright, helpful, and knowledgeable and speaks from experience. Since speaking with my*

mentor on a regular basis I have adopted a more positive attitude about being one of the millions of people living with CKD. I don't feel as negative and grim as I once did. I still struggle with my many dietary challenges; however, I have been utilizing many helpful resources, including NKF. Having a positive role model has made incorporating the renal-diabetic dietary guidelines much easier. I don't feel as alone coping with kidney disease as I once did. Overall, I feel that having an NKF peer has been an extremely rewarding and positive experience in my life as a kidney patient. Thank you so much.

- *It was easy to use and the people involved seem to be knowledgeable about the health concerns. The program was also free to the person who needed support and NKF was readily available and positive to my feelings and concerns.*
- *I could let my hair down with my mentor. I could talk to a real person who had gone through the things I am facing — dialysis and transplant. There is nothing better than receiving support from a person who has (or is having) similar experiences to your own.*
- *The best part of the NKF Peers program was the opportunity to talk to someone my age and in similar circumstances, and also already on dialysis…gave me an idea of what I could expect for myself in the near future.*

POTENTIAL CHALLENGES

Telephone-based Peer Mentoring

Both mentoring and training by phone pose unique challenges. While some people value the anonymity of phone-based peer mentoring, others prefer face-to-face connections. Some even go a step further and feel strongly about talking with someone from their local area, state, or region of the country. There are others who are specifically seeking a group setting so that their families can join, or because they feel more comfortable in a group where they can potentially be a listener, versus a more vocal participant.

Calls between mentors and mentees are not monitored or recorded. Where a support group may be facilitated by a licensed clinician, one-on-one peer mentoring, particularly by phone, precludes the level of oversight some practitioners believe to be optimal. However, the numerous successful uses of telephone-based peer programs reviewed in the introduction, as well as the NKF Peers program itself, demonstrate the relevance of such programs and the capability of patients as peer mentors. Additionally, when taking into consideration the benefit of accessibility that a telephonic program offers to patients, regardless of their location, the value is further illuminated. Furthermore, NKF's robust, comprehensive mentor training, MSW oversight, and ongoing quality assessment are important factors in the ongoing success of the program.

Technology

Initially, NKF Peers utilized a toll-free phone provider that allowed NKF to buy as many toll-free numbers as needed and manually route calls according to matches. While this system initially met the needs of the program, as the program grew it became increasingly time consuming to manually set up call routing and track matches.

In April 2015, NKF moved to a new online peer management platform through InquisitHealth. This platform allows the oversight clinician to match and track pairs throughout their participation in the program. The system also automatically provides a toll-free number for each mentor/mentee pairing.

Enhanced technology has greatly improved the ability of the NKF oversight clinician to manage large numbers of pairs in varying stages of the mentoring process. As any successful program grows, technology will be important to support growth. InquisitHealth continues to be an ideal partner in being open to tailoring the platform, based on the program's evolving needs over time.

However, despite the benefits and necessity of technology, participants also highly value the direct person-to-person contact by phone. This is true both of the mentor/mentee relationship, as well as the oversight clinician/mentor and mentee relationships.

Anticipating Growth – Staffing

While one NKF staff member has managed the program to date (comprising about 40% of their time), the future success of the program is dependent on growth. This growth will necessitate additional staff time and/or additional staff.

Even with improved technology in place, the level of follow-up and tracking required is immense. Following pairs throughout the different stages of their interactions requires regular communication with both mentor and mentee, and comprehensive documentation. Administrative support staff could assist with follow-up calls, emails, mailings and surveys. This may improve completion rates of post-follow up surveys and PAM questionnaires.

Anticipating Growth – Mentors

Initially, NKF was cautious about promoting NKF Peers too widely before enough mentors were trained. Maintaining the right amount of mentors to accommodate the influx of mentees is a constant balancing act.

Additionally, making sure to have enough of the "right type" of mentors is important, and can change over time. This means anticipating why people will call looking for support. For example, as demonstrated in the age range for mentees, a large proportion of those seeking support are aged 45–64. Although NKF may receive interest from many mentors who are under 45, it would not be prudent to train too many young mentors unless the participation of mentees in that age group increases. We aim to provide a core group of mentors with experience in different modalities across age ranges.

Also, training too many mentors can also be problematic. Mentors who are trained and then not utilized results in once enthusiastic, valuable volunteers feeling deflated and let down. This has been especially notable in a large portion of interested volunteers having preemptive transplants. While their experience is valuable, the majority of mentees reaching out to the program are looking to speak with someone who has also had dialysis experience. Training too many mentors with preemptive transplants does not benefit the program, and often these mentors feel neglected and under-utilized.

Attrition

There is a natural attrition of mentors due to changes in their personal health, family life, or careers. There are also very well-intentioned peer mentors who underestimate the amount of free time they have to offer and end up being unable to participate in a meaningful way, despite completing the training. For these reasons, it can be difficult to gauge how many successfully trained mentors will be ongoing peer mentors. Providing bi-annual trainings for new mentors has maintained a core group of active mentors throughout the year to adequately accommodate the current volume and needs of mentees contacting NKF Peers for support.

THE FUTURE OF NKF PEERS

As NKF Peers continues to grow, NKF will continue to train new mentors and match them with appropriate mentees. NKF hopes to eventually expand the program to provide support to other groups, such as early-stage CKD patients, care partners, families, parents, and others.

Recent Expansion for Living Donation

As of October 2015, the NKF Peers program began matching living kidney donors and prospective living donors with trained peer mentors who have already gone through the kidney donation process, providing a place for altruistic individuals to discuss concerns and address questions.

NKF worked with their Living Donor Council Executive Committee, along with additional living donors and Living Donor Advocates, to create and develop this program. Training materials, as well as mentor and mentee assessments and tools, were based on the NKF Peers program, but were tailored to meet the specific needs of this population.

Ongoing Support for Mentors

While NKF's oversight clinician provides support individually to peer mentors, NKF does not currently have a standard process for providing ongoing support to the mentors as a group. In the future, NKF is looking to formalize ongoing training and support for mentors. This would allow mentors to connect with each other for support, to share their experiences as mentors and discuss common challenges/issues that arise, either via conference call or an online platform.

Ongoing Support for Mentees

Once mentees complete the NKF Peers program, many would like to find a way to keep in touch, or to be able to connect to others in a semi-structured way. Many mentees note that they would like the opportunity to continue to keep in touch with their mentors by email after it is determined that they no longer need regular calls.

NKF will continue to look for opportunities to connect people in different ways. However, NKF is committed to telephone-based peer support being a central feature of the NKF Peers program.

CONCLUSION

NKF Peers has demonstrated success during its initial four years, with a notable change in pre- versus post-PAM scores, as well as highly positive participant feedback. NKF looks forward to both continuing and growing this successful program, and continuing to provide support to those affected by kidney disease.

Social support for people living with kidney disease and kidney failure is imperative. Peer support for those with chronic illnesses has been shown to improve depression, social isolation, self-esteem, and self-management, which in turn increases involvement in care and overall health and wellbeing. Despite well-established and growing evidence of the efficacy of peer support, the availability of such programs is lacking in the kidney community.

We encourage nephrology professionals to share information about NKF Peers (1.855.653.7337; **nkfpeers@kidney.org**) with their patients and to reach out to this writer with any questions about the program. NKF offers free marketing materials to share with patients, which can be sent to clinicians free of charge upon request at **www.surveymonkey.com/r/freenkf**.

In addition, we hope our successes and challenges are helpful to others developing or running peer support programs for patients with chronic disease.

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Depression Among Dialysis Patients

Attending a Tertiary Care Hospital in Kerala, Southern India

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Identification and treatment of depression in chronic kidney disease (CKD) is important, since it can impair recovery, treatment, self-management, and quality of life. One hundred and twenty-one people undergoing hemodialysis in a tertiary care center in southern India were included in this study to assess depression in this population. Depression was evaluated using the Beck Depression Inventory (BDI). Among the patients, 33 (27.3%) were suffering from mild depression, 49 (40.5%) were suffering from moderate depression, and 19 (15.7%) had severe depression. Lower educational status [OR 3.77 (95% CI 1.34-10.63)], longer duration of dialysis [OR 5.75 (95% CI 1.79-18.44)], and hospitalization for indications other than dialysis in the last year [OR 3.88 (95% CI 1.34-11.27)] were associated with higher depression scores. It is important that all patients on routine hemodialysis be screened for signs and symptoms of depression, and this study contributes an international perspective to this important psychosocial determinant of patient outcomes.

INTRODUCTION

Around the world, diseases of the kidney and urinary tract are responsible for approximately 0.7 million deaths every year (World Health Organization (WHO), 2008). It has been estimated that the prevalence of end-stage renal disease (ESRD) will rise over the coming decades, driven by aging population, and increasing prevalence of diabetes mellitus and hypertension (Reikes, 2000). The exact number of ESRD patients needing dialysis or renal transplantation in India is not known. However, the prevalence of chronic kidney disease (CKD) in this country ranges from 0.7% to 1.4%, and the incidence of ESRD is estimated to be 180 to 200 per million population (Rajapurkar & Dabhi, 2010).

Depression has been identified as the primary mental health problem among dialysis patients, with a 2 – 10 times higher prevalence, compared to the general population (Watnick, Kirvin, & Mahnensmith, 2003). Identification and treatment of depression during the early stages of CKD is important, since depression can impair recovery, result in poor treatment adherence, and worsen patient quality of life and mental health status (Saravanan, 2009). Studies have investigated the relationship between depressive symptoms in ESRD patients and demographic and socioeconomic variables, however there is a lack of such studies about patient depression in India.

In India, hemodialysis is the predominant ESRD treatment regime, and is provided in private hospitals. Patients are responsible for the dialysis cost (in India, 60% of total healthcare expenditures are paid out of pocket). The average hemodialysis cost in India ranges between 1200 and 2000 rupees per treatment (about 17 to 29 U.S. dollars). Dialysis is usually offered three times a week. However, if patients cannot afford this frequency, they may receive 2 longer hemodialysis treatments weekly.

60% of total health expenditure in India was paid by patients from their own pockets. This study was conducted to estimate the prevalence of depressive symptoms among hemodialysis patients, and its relationship with clinical, demographic, and socioeconomic characteristics in a tertiary care center in Kerala, southern India.

MATERIALS AND METHODS

This was a cross-sectional study conducted in a tertiary care private hospital in Kollam district, Kerala. The hospital has 850 beds, with all specialties and super-specialty departments, and has an average outpatient attendance of 1300 patients per day. The dialysis unit in this hospital opened in 2009 with 15 beds.

The current study was conducted among the patients attending the hospital for dialysis for more than 3 months consecutively (*N* = 121). Seven patients were not included due to reasons like hearing loss (2) and serious illness (5). Data was collected using a structured and pilot-tested questionnaire created by the study team, and by verbal interviews with patients. Interviews were conducted by the investigators, and each interview lasted for about 20 minutes. Informed consent for this study was obtained from the participants prior to the surveys. Human subject approval for the study was obtained from the Institutional Review Board of Travancore Medical College, Kollam.

Depression was evaluated using the Beck Depression Inventory (BDI). It is a validated screening tool to detect

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depression with sensitivity and specificity rates of more than 90% (Sharp & Lipsky, 2002). The instrument has been used for the assessment of depression in patients with CKD (Andrade & Sesso, 2012). Grading of depression was based on the score levels: mild depression (14 – 19), moderate depression (20 – 28), and severe depression (29 – 63).

Socioeconomic status was evaluated using revised Kuppuswamy's Socioeconomic Status Scale, which takes into consideration education, occupation, and monthly income (Oberoi, 2015). Grading of socioeconomic status was based on score levels: upper class (≥ 26), middle class (11 – 25), and lower class (≤ 10). We also measured patients' family status. "Joint family" is defined as a type of extended family comprised of parents, their children, children's spouses, and offspring in one household, while "nuclear family" is defined as a social unit comprised of two parents and their children.

Data was entered into a Microsoft Excel sheet and analyzed using SPSS Version 20. Depression was dichotomized with "none" and "mild" as one group, and "moderate" and "severe" as the depressed group. Chi-square and odds ratios were used to determine factors associated with depression in this population. *P* value less than 0.05 was considered statistically significant. The characteristics were entered into a logistic regression model, and adjusted odds ratios were calculated.

RESULTS

One hundred and twenty-one patients were included in the study. Of the study subjects, 78 (64.5%) were male. The mean age of the dialysis patients was 52.89 ±11.02 years. Of the study subjects, 67 (55.4 %) were 36 – 55 years old. Among patients, 57 (47.1%) were unskilled workers. Eighty-eight (72.7%) of the respondents were living in nuclear families. The majority (77.7%) of the study population belonged to middle socioeconomic status class. Sociodemographic characteristics of the study subjects can be found in **Table 1**.

Among the study subjects, 77 (63.6%) patients received dialysis twice weekly. More than a third of the sample (40.4%) had diabetes mellitus. Additional comorbidities were anemia (*n* = 52, 42.9%), peripheral neuropathy (*n* = 13, 10.8%), and diabetic retinopathy (*n* = 11, 9.1%). The majority of respondents (*n* = 95, 78.5%) were on dialysis less than 5 years. Only 3 patients were on anti-depressants. A majority of the sample (*n* = 96, 79.3%) had some kind of insurance coverage that covered their dialysis costs, and the rest were personally paying for their treatments.

Out of the 121 dialysis patients, a majority of them (*n* = 101, 83.5%) were depressed according to the BDI scale. Among these patients, 34 (28.1%) had mild depression, 48 (39.7%) had moderate depression, and 19 (15.7%) had severe depression. Among those who had not completed high school education, 56 (63.6%) had significantly higher scores on the depression scale (*p* = 0.003). Among those who have been on dialysis more than five years or more, 73.1% were depressed, compared to the 50.5% of patients who have been on dialysis less than 5 years and experiencing depression (*p* = 0.032). In the multivariate analysis of the study findings, lower educational status [OR 3.77(95% CI 1.34-10.63)], longer duration of dialysis [OR 5.75 (95% CI 1.79-18.44)], and hospitalization for reasons other than dialysis in last year [OR 3.88 (95% CI 1.34-11.27)] were associated with higher depression scores. The results of univariate and multivariate analysis are outlined in **Table 2**.

Table 1. Sociodemographic Characteristics of Study Population

Characteristic	*Frequency*	*Percentage*
Age group		
15 – 35	6	5.0
36 – 55	67	55.4
56 – 75	45	37.2
>75	3	2.4
Gender		
Male	78	64.5
Female	43	35.5
Type of Family		
Joint	33	27.3
Nuclear	88	72.7
Education		
Primary	33	27.3
High school	55	45.5
Higher secondary	14	11.6
Graduate	12	9.9
Professional	7	5.7
Economic Status		
Lower	8	6.6
Middle	94	77.7
Upper	19	15.7
Occupation		
Skilled	36	29.7
Unskilled	57	47.1
Clerical	3	2.5
Unemployed	25	20.7

Table 2. Analysis of Factors Associated with Depression Among Study Subjects *N* **= 121**

Characteristics	*BDI Score*		*Chi Square p Value*	*Odds Ratio (95% CI)*	*Adjusted OR (95% CI)*
	Depression ≥ 20	*No Depression*			
Age					
> 50 years	46 (59.7%)	31 (40.3%)	0.255	1.62	1.59
< 50 years	21 (47.7%)	23 (52.3%)		(0.77-3.42)	(0.76-3.32)
Gender					
Male	42 (53.8%)	36 (46.2%)	0.482	1.31	1.24
Female	26 (60.4%)	17 (39.6%)		(0.61-2.79)	(0.54-2.68)
SES					
Lower SES	60 (58.8%)	42 (41.2%)	0.085	2.44	1.56
Higher SES	7 (36.8%)	12 (63.2%)		(0.89-6.73)	(0.43-5.64)
Education					
High school	56 (63.6%)	32 (36.4%)	0.003	3.50	3.77*
> High school	11 (33.3%)	22 (66.7%)		(1.50-8.14)	(1.34-10.63)
Type of family					
Nuclear	43 (48.9%)	45 (51.1%)	0.015	0.35	0.28*
Joint	24 (72.7%)	9 (27.3%)		(0.15-0.85)	(0.09-0.81)
Time on dialysis					
≥ 5 Years	19 (73.1%)	7 (26.9%)	0.032	2.65	5.75*
< 5 Years	48 (50.5%)	47 (49.5%)		(1.02-6.90)	(1.79-18.44)
Insurance status					
Insurance	56 (58.3%)	40 (41.7%)	0.145	1.78	2.01
No insurance	11 (44.0%)	14 (56.0%)		(0.73-4.33)	(0.70-5.76)
Hospitalization other than dialysis					
Yes	25 (73.5%)	9 (26.5%)	0.10	2.97	3.88*
No	42 (48.3%)	45 (51.7%)		(1.24-7.10)	(1.34-11.27)

*significant < .05

DISCUSSION

In this study we found a very high percentage (83.5%) of depression among the patients, with 15.7% of study subjects having severe depression. In the multivariate analyses, lower educational status, more years on dialysis, and hospitalization for reasons other than dialysis in the last year were associated with higher depression scores.

The prevalence of depressive symptoms among dialysis patients in the current study was higher than previously reported in other states in India. In the The Dialysis Outcomes and Practice Patterns Study (DOPPS) done among 9382 patients randomly selected from dialysis centers in 12 countries outside India, 43% of the patients were depressed (Lopes, Albert, Young, Satayathum, Pisoni, & Andreucci, 2004). In a study done in Mysore, a city in southern India, 65% of ESRD patients were depressed (Sanathan, Menon, Alla, Madhuri, Shetty, & Ram, 2014). Cohen and colleagues reported prevalence of depression among dialysis patients in the United States as 45% (Cohen, Norris, Acquaviva, Peterson, & Kimmel, 2007). These differences might be due to the variations in the assessment of depression, as well as the location of the patients. All these studies highlight that depressive symptoms need to be studied and incorporated into assessment and treatment of ESRD patients. Accordingly in the United States, this is now mandated for all dialysis units.

In our study, a significant association was observed between depression and lower educational status. A similar finding was observed in another study done by Sanathan and colleagues (Sanathan, Menon, Alla, Madhuri, Shetty, & Ram, 2014). Many studies have reported that the period after initial diagnosis of ESRD, and the first year after initiation of HD, is associated with a greater risk of developing depression (Chen, Tsai, Hsu, Wu, Sun, & Chou, 2015; Sanathan, Menon, Alla, Madhuri, Shetty, & Ram, 2014). This is in contrast to what we observed, with greater depression in patients who were on dialysis longer. More research is needed to identify the risk factors for depression in dialysis patients in India. Dialysis social workers in India can help patients with their depression and work with dialysis teams to help improve patient outcomes regarding depression and its effects.

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Strengthening Chronic Kidney Disease Knowledge

Among Students Attending a Historically Black University

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Chronic kidney disease (CKD) affects African Americans in a disproportionately high manner and progresses more rapidly than in other races. Lack of knowledge of CKD risk factors and progression may contribute to this disparity. The purpose of this non-random cross-sectional study was to determine the level of CKD knowledge among students attending a historically black college and university (HBCU). Men and women enrolled in healthcare administration, health education, social work, and public health courses were asked to participate in the study. The Chronic Kidney Disease Knowledge in College Students Questionnaire was utilized. A total of 270 participants from a single HBCU were included. The results demonstrate that CKD knowledge was low in this population, particularly among the younger college students. This study provides a foundation for CKD community education, and will be helpful to nephrology social workers in CKD settings and kidney organizations for specifically targeting and educating at-risk individuals.

INTRODUCTION

Chronic kidney disease (CKD) affects more than 26 million people in the United States at varying levels of severity, with most being undiagnosed (Centers for Disease Control and Prevention (CDC), 2015). According to the CDC, CKD is the ninth leading cause of death in the U.S. (CDC, 2015). There has been a drastic increase in the number of CKD patients who eventually develop end-stage renal disease (ESRD). ESRD is projected to increase in prevalence by 50% over the next decade (Collins, Gilbertson, Snyder, Chen, & Foley, 2010). Hence, CKD is a major public health problem with widespread socio-economic impact. Among the general Medicare population, the cost to treat CKD represents 20.1% of Medicare spending at $50.4 billion. Additionally, the ESRD population adds 7% to (Medicare spending United States Renal Data System (USRDS, 2015).

A key issue with this disease is that it disproportionately affects racial and ethnic minorities (Muntner, et al., 2012). The ESRD incidence rate is three times higher in African Americans, compared to Caucasians (USRDS, 2015). Indeed, although African Americans make up only 13% of the U.S. population (U.S. Census Bureau, 2015), 35% of ESRD patients on dialysis are from this community (USRDS, 2015). Moreover, dialysis patients have higher mortality rates compared to the general population. However, African American and Caucasian dialysis patients younger than 45 years-old have similar mortality rates (USRDS, 2015).

Diabetes and hypertension are among the main risk factors contributing towards development of CKD and progression to ESRD. Approximately 11% of all African Americans age 20 or older have diabetes, with one-third of the cases being undiagnosed (National Medical Association (NMA), n.d.). In 2013, Mississippi had the third highest prevalence of diabetes in the United States, affecting approximately 12.9% of the adult population (Mississippi State Department of Health (MSDH), 2015a).

Similarly, hypertension is more common in African Americans. This population is more likely to develop hypertension at an earlier age, and it is more likely to be severe and inadequately controlled (MSDH, 2015b; Moulton, 2009). Mississippi has the second highest prevalence of hypertension in the nation, affecting more than 700,000 adults (MSDH, 2015b; Trust for America's Health & Robert Wood Johnson Foundation, 2015).

While the rates of ESRD due to hypertension have decreased for Caucasians younger than 40, it has actually increased among African Americans (NMA, n.d.). However, despite this rather alarming trend, this community lacks basic understanding of CKD and the risk factors contributing to the disease process (Plantinga, Tuot, & Powe, 2010). Interestingly, while many individuals are aware of diabetes and hypertension as health problems, they fail to correlate diabetes and hypertension to CKD, or view CKD as a health problem (Chow, et al., 2012; Plantinga, Tuot, & Powe, 2010). This suggests that there are substantial shortcomings in CKD knowledge in the African American community. Thus, the primary aim of this study was to perform a pilot in which we assessed CKD knowledge of college students enrolled in health courses at a historically black college and university (HBCU).

Healthcare professionals have an important role in promoting CKD awareness. Many of the study participants had the potential to perform leadership roles within CKD facilities as social workers and administrators. With proper knowledge, they could play an important role in the health education of individuals and groups to eliminate the CKD health

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disparity. The goal of this study was to help discover the population who would most likely benefit from CKD education, and have a positive impact in health awareness within the African American community. Its intended audience is nephrology social workers who work in CKD settings. Social workers are key in educating and promoting awareness for individuals and communities at risk for CKD. They are integral in advocating for and educating vulnerable populations, and have the potential to significantly expand CKD knowledge in the African American community through culturally competent practices.

METHODS

Study Design

The study followed a descriptive cross-sectional design with a quantitative approach to assess CKD knowledge of students at a HBCU. Descriptive research was the most direct option for assessing the knowledge of students to further assist with the development of interventions for the target population.

Study Participants and Data Collection

The surveys were administered at a HBCU located in Mississippi, after obtaining permission from the university's Institutional Review Board (IRB). A non-random convenience sample of undergraduate and graduate students pursuing bachelors, masters, and doctoral degrees, and enrolled in healthcare administration, health education, social work, and public health courses were recruited to participate. Study participants who agreed to complete the survey included both males and females, 18 years or older. We chose this particular population because the courses they were studying focused on preventive health, and prepared students to address the health challenges of individuals, groups, and communities. Various professors for the identified courses at the university were contacted for permission to enter their class for approximately 15–20 minutes to administer the survey. Prior to administering the survey, a script was read that explained the intent of the research. Informed consent was obtained before the survey was administered. The surveys and copies of the informed consent forms, which included the purpose of the study, were provided to the participants. The sample size was 270 students. Participants completed the survey during class, and returned them immediately after completion. Non-participants were asked to remain quiet during the survey administration. Study participation was voluntary, and participants were informed that they could withdraw at any stage while completing the survey. All surveys were anonymous and the data kept confidential.

Study Questionnaire

The survey included 7 questions designed to assess CKD knowledge. Five of the 7 questions were obtained, with permission, from a Singapore CKD knowledge survey designed by Wai Leng Chow et al. (2012). Their study assessed CKD knowledge in 1520 patients from 3 Singaporean primary care centers (Chow et al., 2012). The CKD knowledge questions adapted from the survey were tested for face validity and content saturation. Survey questions were based on the physiology, etiology, presentation, progression, complication, identification, and anatomy of CKD. Responses to the questions were scored 0–7, depending on the number of correct answers. All questions were weighed equally (0 points if not correct; 1 point if correct).

Statistical Analysis

Participants were divided by the following characteristics for purposes of analysis: gender, race (African American vs. Non-African American), age, and academic classification. Descriptive statistics were used to analyze each item of the survey to include demographic information. Pearson's chi-square ($\chi 2$) analysis was used to measure the difference in the dispersion of the data. An alpha level of .05 was established for determining significance.

RESULTS

Sample Characteristics

The demographic characteristics of the participants are presented in **Table 1.** This study included a total of 270 men and women enrolled in a health-related course during the 2014 summer and fall semesters. The study sample was comprised of more female (82.6%) than male students, and more African American (89.3%) than any other race. The average age of the participants was 26.52 (SD = 8.121), median age was 24, and range was 18–56. The age categories for the study were defined according to the National Center of Education Statistics (NCES, 2014). Of the participants' age, a majority were 20-21 (22.2%), with the following age groups in descending order: 22-24 (20%), 25-29 (18.1%), 35 and older (14.8%), 18-19 (11.4%), and 30-34 (10.8%). The majority of the participants were classified as juniors (31.5%), followed by graduate students (28.9%), and seniors (21.1%), while freshmen and sophomores each represented the lowest participation at 8.9% each.

Table 1. Demographic Characteristics

Variable		*N = 270*
Gender *n* **(%)**		
	Male	46 (17.0%)
	Female	223 (82.6%)
Race *n* **(%)**		
	African American	241 (89.3%)
	Non-African American	25 (9.4%)
Age *n* **(%)**		
	18–19	30 (11.4%)
	20–21	60 (22.2%)
	22–24	54 (20.0%)
	25–29	49 (18.1%)
	30–34	29 (10.8%)
	35 and older	40 (14.8%)
Classification *n* **(%)**		
	Freshman	24 (8.9%)
	Sophomore	24 (8.9%)
	Junior	85 (31.5%)
	Senior	57 (21.1%)
	Graduate	78 (28.9%)

Note: Due to missing data, counts do not total 270.

In **Table 2**, the survey question addressing knowledge about what can cause kidney disease (Question 2), and what type of test should be performed to detect kidney disease (Question 6), showed higher correct responses at 85.5% and 84.4%, respectively. Approximately, 83.3% correctly responded to the question identifying the function of a kidney in a human body (Question 1). A majority of the participants (67.4%) correctly answered how many healthy kidney(s) a person needs to lead a normal life (Question 7). The question regarding the complications of kidney disease (Question 5) was correctly answered by 41.5% of the participants. Among all questions, those identifying the statement that was incorrect about kidney disease (Question 4), and the symptoms of early kidney disease that might progress to kidney failure (Question 3) were found to be low among the participants at 35.2% and 4.1%, respectively. As for overall knowledge, 67% of the participants answered 4 or more knowledge questions correctly.

CKD Knowledge Questions

Table 3 shows the association between CKD knowledge and age. There was a statistically significant relationship between the participants who knew the function of a kidney in a human body (physiology) and age (p = .032). The age group of the participants with the highest correct responses for physiology were 25–29 (91.8%), and 35 and older (90.0%). The age group with the least number of correct responses was 18–19 (70%). Ninety-five percent (95.0%) of participants 35 and older responded correctly to what can cause kidney disease (etiology), but there was no significant relationship (p = .648). The least correct etiology responses were in the 18–19 and 20–21-year age ranges (80%). Also of note in **Table 3** is the fact that most participants had no knowledge of the symptoms of early kidney disease that might progress to kidney failure (presentation). The highest percentage of participants who responded correctly were in the 25–29-year age range, however those results did not reach statistical significance (p = .122). Results indicated the most significant relationship when examining the progression of kidney disease (p = <.001). The lowest correct responses for identifying the statement that was incorrect about kidney disease (progression) were demonstrated in the 18–19 age range (6.1%). Participants 30–34 had the highest correct response (65.5%). Overall, the lowest knowledge of identifying the complications of kidney disease (complication) was demonstrated in younger participants aged 18–19 (33.3%), 20–21 (36.7%), and 25–29 (36.7%). Participants in 22–24-year age range had the highest correct responses (53.7%), however there was no significant relationship (p = .076) **(Table 3)**.

A significant relationship was seen in the identification of kidney disease (p = .044). Approximately 97.5% of participants in the age category of 35 years and older correctly responded to the type of test that should be performed to detect kidney disease (identification), the lowest percentage of correct responses were in the age category of 18–19 (76.7%). The highest percentage of correct responses identifying the number of healthy kidney(s) a person needs to lead a normal life (anatomy) was seen in participants in the 35 years and older age range (80%), and in the age category of 25–29 years (73.5%). Participants in the age category of 22–24 and 20–21 had the lowest percentage of correct responses at 61.1% and 63.3%, respectively, but did not reach significance (p = .691) **(Table 3)**.

Table 2. Participants' Response to Chronic Kidney Disease Knowledge Questions

		Correct (%)	*Incorrect (%)*	*Don't Know (%)*
1.	What is the function of a kidney in a human body? (Physiology)	225 (83.3)	32 (12.3)	11 (4.1)
2.	What can cause kidney disease (Etiology)	230 (85.5)	22 (8.1)	16 (5.9)
3.	What are the symptoms of early kidney disease that might progress to kidney failure (Presentation)	11 (4.1)	228 (84.5)	29 (10.7)
4.	Which of the following statements about kidney disease is INCORRECT (Progression)	95 (35.2)	106 (39.3)	69 (25.6)
5.	What are the complications of kidney disease? (Complication)	112 (41.5)	107 (39.7)	51 (18.9)
6.	What type of test should be performed to detect kidney disease? (Identification)	228 (84.4)	30 (11.1)	11 (4.1)
7.	How many healthy kidney(s) does a person need to lead a normal life (Anatomy)	182 (67.4)	82 (30.4)	5 (1.9)

Note: Due to missing data, counts do not total 270.

Table 3. Participants Response to Knowledge Question by Age Category

CORRECT RESPONSE BY AGE

Question Type	18-19 *n* (%)	20-21 *n* (%)	22-24 *n* (%)	25-29 *n* (%)	30-34 *n* (%)	35 and older *n* (%)	*P*
Physiology	21 (70.0)	47 (79.7)	45 (83.3)	45 (91.8)	24 (82.8)	36 (90.0)	.032
Etiology	24 (80.0)	48 (80.0)	45 (84.9)	42 (85.7)	24 (85.7)	38 (95.0)	.648
Presentation	1 (3.3)	1 (1.7)	3 (5.6)	3 (6.1)	1 (3.6)	2 (5.1)	.122
Progression	2 (6.1)	17 (28.3)	16 (29.6)	21 (42.9)	19 (65.5)	18 (45.0)	<.001
Complication	10 (33.3)	22 (36.7)	29 (53.7)	18 (36.7)	14 (48.3)	16 (40.0)	.076
Identification	23 (76.7)	48 (80.0)	43 (81.1)	45 (91.8)	23 (79.3)	39 (97.5)	.044
Anatomy	20 (66.7)	38 (63.3)	33 (61.1)	36 (73.5)	19 (65.5)	32 (80.0)	.691

Note: Full questions are displayed in Table 2. Values and frequency (percent) for categorical variables; Chi-Square tests for variables to obtain p-value.

STUDY STRENGTHS

To the best of our knowledge this is the first study to specifically address the extent of CKD knowledge in African American college students. It assists in identifying the knowledge gap in a population that is disproportionately affected by CKD, based on race, geographic location, and risk factors such as diabetes and hypertension. It aims to provide a foundation for future research studies specifically targeting at-risk populations. It also provides information regarding areas of low knowledge in the target population and will be beneficial when designing and implementing future educational interventions and social work practice.

STUDY LIMITATIONS

This study had several limitations. First, all variables were self-reported and may have resulted in some participants providing the answer they thought the researcher wanted, thus not being reliable. Second is the use of a cross-sectional design. The information was gathered from the participants at a single point in time. Third, the sample population was from one HBCU, and the findings cannot be generalized to other HBCUs. Fourth, study participants were enrolled in health-related courses and may have had more knowledge regarding CKD. Fifth, the study used a convenience sample and the findings cannot be generalized. Lastly, this was a pilot study and therefore the sample size may be underpowered to draw firm conclusions.

DISCUSSION

Findings of this study demonstrate the relative lack of awareness regarding CKD in the study population. Although the survey was conducted among college students who were studying preventive health-related subjects and may have more knowledge than the general population, there was an overall lack of knowledge in CKD presentation, progression, and complications. An age difference in CKD knowledge was seen in participants identifying the cause of kidney disease and the type of test that should be performed to detect kidney disease; specifically, we found that younger, undergraduate students (18–21-year-olds) had the lowest knowledge compared to the older participants (35 and older). This signifies a discrepancy in educating young adults about the risks associated with kidney disease.

Each year millions of people are diagnosed with a chronic disease, and unfortunately millions more die from the illness (World Health Organization (WHO), 2014). The first step in increasing awareness about CKD is through education. In order to understand the impact of CKD and take preventive measures, there must be knowledge of the disease. Family members of CKD patients have a high prevalence of CKD and its risk factors, therefore, it is recommended to screen the family members of CKD patients in an effort to prevent kidney disease (Kazancioglue, 2013). The results of this study can assist clinic-based nephrology social workers with providing patient education about the increased risk of CKD to pass on to their family members, with a focus on younger adults, and begin conversations about early screenings and detection.

Community-based social work interventions with this population should focus on educating young adults about their increased risk of CKD, based on having diabetes, hypertension, and a family member with the illness. Educational initiatives should explore the possibility of risk factor screening for young adults in order to learn their glucose and blood pressure levels so early measures can be taken to prevent these risk factors. Social workers must promote organizations such as the National Kidney Foundation and other organizations that offer free community kidney health screenings and educational materials to increase awareness of CKD. The National Kidney Disease Educational Program (NKDEP) (2016) offers health guides and educational toolkits that promote family and community CKD conversations and screenings. Nephrology social workers are advocates and can educate patients to become "kidney champions" and utilize these free resources to engage family members. We must actively empower patients and the communities to participate in local screenings to become aware of their risk for CKD. Nephrology social workers in CKD settings, as well as macro-level workplaces, such as kidney organizations and ESRD Networks can reference this study to target interventions for individuals at greatest risk for ESRD.

AUTHOR NOTE

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