
Assessing the Effect of a Technology-Based Peer-Mentoring Intervention on Renal Teams' Perceived Knowledge and Comfort Level Working With Young Adults on Dialysis

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*The study presented in this article was part of a larger project to develop and evaluate a technology-based peer-mentoring program for empowering young adults (YAs) on dialysis and their renal teams. In this article, we focus on how the program has influenced the renal team members' perceived knowledge of, and comfort levels with, working with YAs, and their perceptions of YA behavior. We conducted surveys with 110 renal team staff members (not including the renal social workers who served as study coordinators) from 16 dialysis units in a midwestern state. The overall intervention included: (1) staff viewing a DVD of other staff discussing how to work with YAs; (2) YAs viewing a DVD of peer mentors discussing life with CKD; and (3) an opportunity for YAs to virtually "meet" with peers via a website we developed called **ktalk.org**. We found that the staff intervention led to improved staff perceptions of knowledge, YAs' behavioral adherence and comfort talking with the team. However, our results also revealed that staff experienced decreased comfort levels working with the young patients on dialysis.*

INTRODUCTION

Young adults (YAs) between ages 20 and 30 account for only 2.7% of patients on all forms of dialysis in the United States, as the average age of dialysis onset is 65 (U.S. Renal Data System, 2009). While small in number, provision of care to YAs on dialysis presents significant challenges to renal teams.

How is the experience of chronic kidney disease (CKD) different for a 20 year old, as opposed to that of a 65-year-old retiree? As compared with older adults, YAs with CKD experience unique psychosocial hardships because their life course is less defined, and their adult identities have not yet emerged. The demands of kidney disease and its treatment not only pull young adults away from their usual social lives, but they also derail them from their developmental trajectories of individuation, maturation and independence (Ferris, Gipson, Kimmel, & Eggers, 2006). With an undermined self-concept and self-image, YAs with CKD often develop psychological defenses that may manifest as anger, depression and withdrawal, as well as uncommunicative and unapproachable interactions with their renal teams (Bell, 2007). Furthermore, their perceptions of the disease and the consequences of treatment non-adherence are not based on potential health risks; rather, they relate to the ways in which treatment interferes with school, recreation and daily routines, and the ways in which their peers react to their illness (Harwood & Johnson, 1999). As a result, YAs with CKD are less likely to adhere to treatment, thus increasing their morbidity and mortality risks (Saran et al., 2003;

Smith & Shuchman, 2005). The long-term kidney transplant outcomes of YAs, for example, are considerably poorer than those in older age groups (Rianthavorn & Ettenger, 2005). A recent report issued to Congress describes that while young adults with CKD have the most successful 1-year kidney transplant survival rates, they also have the worst 5-year graft survival rates largely due to non-adherence to kidney transplant medications. This report also describes the significant financial impact on society and advocates for innovative interventions (U.S. Government Accountability Office, 2007). Unfortunately, there is a paucity of nephrology research regarding potential intervention strategies to help patients in this age group (Jennette & Ferris, 2006). In a few studies focused on pediatric and adolescent patients, researchers have shown that psychosocial services, as compared to traditional psychotherapy, could achieve better results (Dittman, Hesse, & Wallis, 1984; Jarzembowski et al., 2004); for example, increasing staff support time for pediatric patients after kidney transplantation leads to improved preventive care outcomes (Jarzembowski et al., 2004). Additionally, during YAs' transition from pediatric to adult programs, it is recommended that they receive open communication and be given choices by their peers, families and trusted renal team staff (Watson & Shooter, 1996). This transition clearly triggers a cultural shift from a child-centered milieu—where parents have had major input—to an adult unit where the late adolescent and YA needs to increasingly engage in autonomous decision making (Watson & Shooter, 1996).

Peer mentoring—training selected patients to listen to, empathize with, role model for and empower other patients—has been demonstrated to be an effective approach to enhancing communication and providing patients with opportunities for informed choice (Kapron, Perry, Bowman, & Swartz, 1997; Heisler & Piette, 2005). The National Kidney Foundation of Michigan (NKFM) has experienced significant success with an adult-focused peer mentoring program; indeed, it has been shown to alleviate patients' fears about the disease and to help patients cope with dialysis and life after a kidney transplant (Wright, 2000). Additionally, in a randomized trial, this program was shown to increase CKD patients' rates of advance directive completion and to increase their comfort in discussing their wishes with their renal team (Perry et al., 2005). However, there are important challenges in extending the benefits of peer mentoring to YAs on dialysis. Because YAs constitute such a small portion of the patient population with kidney failure, many dialysis units lack access to appropriate peer mentors to advise patients in this age group.

In this research, we developed and tested a technology-enabled peer-mentoring program to support YAs on dialysis and their renal teams. This article, as part of a larger project evaluating the program's effectiveness, presents our findings on how it affected renal teams' perceived knowledge regarding the disease's impact on YAs; perceptions of YA adherence and comfort talking with the team; and staff comfort levels in working with YA patients. We were interested in studying renal team staff because, first, we suspected that much of renal teams' frustration in working with YAs on dialysis is due to the fact that they have not focused on YAs' unique challenges and care needs because they are such a small portion of their patient population. Second, we believed that if renal team members could better serve YAs, this would in turn result in improved psychosocial and health outcomes for YAs. Therefore, we created two DVDs of interviews: one with YA peer mentors and one with renal staff who have abundant experience working with dialysis patients in this age group. The YA DVD included young men and women, both African American and Caucasian, discussing how CKD and renal failure affected their lives in terms of relationships, insurance, body image, sexuality, education and careers. It also discussed their experiences in communicating with renal staff. The renal team DVD included an experienced team of nephrologists, nurses, social workers, dietitians and a physician assistant discussing the uniqueness of YAs on dialysis and effective approaches to working with them. Finally, based on extensive consultation with NKFM staff and peer mentors, we developed an online patient community website, **ktalk.org**. This website allows YAs on dialysis to anonymously interact with the YAs featured in the DVD, who acted as peer mentors on the website, as well as other YA patients who joined the community.

METHODS

Study Participants

With the assistance of the Council of Nephrology Social Workers, we first reached a sample of 46 YAs on dialysis between the ages of 18 and 32 in 18 dialysis clinics across a midwestern state. Three health care professionals (referred to as "renal team members" in this article), including nurses, dietitians, dialysis technicians and clinical coordinators, were also recruited in the study to work closely with each of the YAs. We did not include renal social workers in this study group because we relied on renal social workers in these units to serve as our study coordinators. The initial staff sample contained a total of 138 renal team members.

Study Design

We conducted a prospective, pre-post trial to assess the impact of the technology-based peer-mentoring program on renal team members' perceived knowledge and comfort levels in working with YAs. Prior to introducing the intervention, we collected baseline data from the renal staff using mailed surveys. Then, the renal social workers in the study dialysis units, as part of the intervention research team, distributed the YA and renal team DVDs in all study dialysis units in March 2009. They also helped ensure that the DVDs were viewed by the intended audience within a week of receipt. Next, a registration code for **ktalk.org** was provided to all YA participants, who were told that they could talk to the YAs featured in the DVD, and others, at this website. Following this initial intervention, we allowed 2 months for YAs to register and use **ktalk.org** to interact with peers. In July 2009, we collected post-intervention data from the renal team members assessing their perceived knowledge of developmental differences between young adults and the older dialysis population, comfort working with the YAs and their perceptions of their YA patients' behavioral adherence and comfort in interacting with the renal team.

To evaluate the program's impact on renal team members' comfort in dealing with YAs on dialysis and their perceived knowledge of YA-specific treatment issues, we developed a simple renal team self-evaluation (RTSE) questionnaire. The questionnaire consisted of four items: "The patient is comfortable talking about his or her problems with me," "The patient really tries to follow the treatment plan," "Compared to other renal patients, to what degree do you feel that young adults with kidney failure are at risk for increased mobility and mortality?" and "How would you assess the renal team's level of comfort in dealing with young adults?" The first two items were assessed on a 5-point Likert scale (from 1 to 5: "strongly disagree," "mildly disagree," "neutral," "mildly agree" and "strongly agree," respectively); the third question was assessed using a 4-point Likert scale (from 1 to 4: "a great deal," "somewhat," "very few differences" and "no differences"); and the fourth question was assessed

using a 5-point Likert scale (from 1 to 5: “very uncomfortable,” “uncomfortable,” “neither comfortable nor uncomfortable,” “comfortable” and “very comfortable”).

The RTSE questionnaire was administered once at the baseline (T_0) and once at the end of the intervention period (T_1). The Institutional Review Board of the Michigan Department of Community Health reviewed and approved the research protocol.

Data Analysis

Descriptive statistics were computed for demographic characteristics as well as key study measures obtained through the RTSE questionnaire. We examined whether the renal team members’ responses to the RTSE changed before and after the intervention. Accordingly, we performed paired t-tests to compare the value of these measures at T_0 and T_1 , respectively.

RESULTS

Twenty-eight renal staff left the study prior to completion for various reasons. Several were excluded from the data analysis because they changed jobs or the YAs to which they provided care left the dialysis clinic during the study period. Further, 2 social work study coordinators withdrew from the study due to lack of time, resulting in a loss of 7 YAs and 21 renal team members associated with them. The final renal team study sample therefore included a total of 110 renal team members from 16 dialysis units. The breakdown of the staff sample based on their clinical roles is depicted in Figure 1. The majority of the staff participants were patient care technicians (35%), registered nurses (34%) and dietitians (25%). On average, the renal staff participants had approximately 10 years of experience working with dialysis patients (median = 7 years).

Table 1. Statistical Analysis Results

Variable	Pre	Post	<i>p</i> -value
1. Perceived young adult adherence (“The patient really tries to follow the treatment plan.”)	3.16 ± 1.08	3.35 ± 1.00	0.09
2. Perceived young adult comfort (“The patient is comfortable talking about his or her problems with me.”)	3.71 ± 0.87	3.94 ± 0.79	0.05
3. Perceived staff knowledge (“Compared to other renal patients, to what degree do you feel that young adults with kidney failure are at risk for increased mobility and mortality?”)	3.38 ± 0.45	3.57 ± 0.35	0.01
4. Perceived staff comfort (“How would you assess the renal team’s level of comfort in dealing with young adults?”)	4.26 ± 0.40	3.67 ± 0.89	<0.01

Items 1, 2 and 4 were assessed on a 5-point Likert scale; item 3 was assessed on a 4-point Likert scale. Higher scores indicate higher levels of agreement or self-assessments.

Figure 1. Demographics of Staff Participants ($N = 110$)

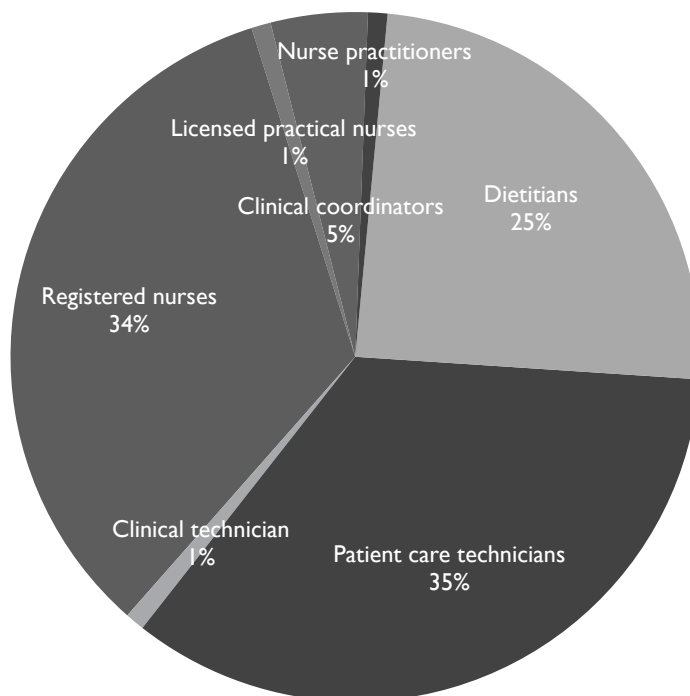


Table 1 reports the survey results obtained using the RTSE questionnaire. Before the intervention, the score for renal team assessment of YA adherence was 3.16, indicating

a value between “neutral” and “mildly agree” that “The patient really tries to follow the treatment plan.” At the post-intervention follow-up (T_1), this score was slightly higher, indicating movement in the direction of greater, though still mild, agreement. The results were marginally significant ($p = 0.09$).

Similarly, before the intervention, the score for the renal team's assessment of YAs' comfort talking with the staff was 3.71, again representing a value between "neutral" and "mildly agree." At the follow-up, this score was improved and the change was statistically significant ($p = 0.05$).

Further, in the RTSE questionnaire, the renal team was asked: "Compared to other renal patients, to what degree do you feel that YAs on dialysis are at risk for increased morbidity and mortality?" The mean response at T0 was 3.38, indicating an average perception between "somewhat" and "a great deal." At the post-test, this score had increased to 3.57, indicating that renal team perception of risk to YAs had increased. This change was statistically significant ($p = 0.01$). Finally, the renal team was asked about their comfort level working with YAs on dialysis. The mean score before the intervention was 4.26, indicating a response between "very comfortable" and "comfortable." At the end of the intervention period, this level of comfort had fallen to 3.67, indicating a response between "neither comfortable nor uncomfortable" and "comfortable." This change was statistically significant ($p < 0.01$).

DISCUSSION

This pilot study points to the need for further investigation regarding appropriate supportive interventions for young dialysis patients, a small but highly vulnerable population. Because of poor dialysis outcomes and the high kidney transplant rejection rates linked to YAs' treatment non-adherence, it behooves renal care providers to provide support programs specifically designed for YAs on dialysis. Indeed, such programs may help YAs on dialysis develop better self-management behaviors while on dialysis and help assure kidney transplantation success. Clearly, traditional psychosocial services and intervention strategies designed for older adults may not be as effective when applied to the YA population, because of the many unique challenges that young patients confront. Moreover, health care providers who are unfamiliar with YAs' unique needs may be stymied in their efforts to provide appropriate support.

The results of this pilot study demonstrate the potential use of media and communication technologies to help renal team members better support YA patients with renal failure. The intervention led to improvements in several measures, including the staff's perceived knowledge about YAs' experience and the staff's perception of YA behavioral adherence and comfort level talking with the team.

The intervention may have helped improve the YAs' behavioral adherence as perceived by the renal team members. However, this change might not signify actual YA adherence improvement but a change in how staff work with YAs on dialysis based on their increased perceived knowledge of working with YAs. We suspect that as renal team members become more attuned to the unique needs of YAs on dialysis, their expectations with respect to YA behavioral adherence might readjust. In addition, there may be an interaction

between YAs' motivation to adhere to treatment, alterations in staff members' approaches to care with YAs and a deepening of rapport between YAs and renal team staff.

The finding that staff members' comfort in working with YAs on dialysis decreased after the intervention was unexpected. It may suggest that, as renal team members learned more about the particular struggles of these YAs, they realized that they couldn't treat YAs exactly like other patients. This, in turn, could take them out of their "comfort zone" by upsetting previous assumptions. The decrease in staff comfort, therefore, may not necessarily represent a negative, adverse consequence of the program itself.

There are many limitations in this pilot study. First, constrained by the small sample size, we were not able to utilize the traditional randomized control trial methodology, nor could we control for variables such as staff members' years of experience or patient characteristics. The latter issue may be relevant because YAs who began dialysis as young children—who experienced the failure of several kidney transplants and never grew beyond 5 feet tall or finished high school—may face different issues than those who developed CKD and renal failure in relatively late adolescence and adulthood. Second, the program's impact was evaluated only through the staff's subjective assessments, some of which may deviate from outcomes that could be objectively measured (e.g., measures of YAs' behavioral adherence). Nonetheless, we deem staff's self-reported perception to be a critical measure of the program's success, as the quality of the relationship and communication between YAs on dialysis and their renal teams is likely driven by such self-perceived knowledge and comfort. Third, our study findings may not apply to other CKD patient populations that should receive equal attention, such as pediatric patients.

Another inherent study weakness is the notion that great change could occur for YAs within a short period of time. Clearly, providing DVDs and the opportunity for YAs to meet with peers online are not all that it takes to create a "new normal" peer group with whom to identify and develop future dreams. The authors were encouraged, however, that at the time this article was written (4 months after the trial), the YA participants were still communicating on **ktalk.org**.

CONCLUSION

In this article, we report a study assessing the effect of a technology-based peer-mentoring program on renal team members' perceptions of knowledge and comfort working with young patients on dialysis between ages 18 and 30, as well as their perceptions of YA patient adherence and comfort interacting with the team. Despite its pilot nature, the findings reveal that this intervention shows great promise for improving these elements of renal team–YA patient relationships. We will continue to offer the website, **ktalk.org**, to the YAs participants of the study as well as other YAs with CKD, as a platform for them to connect with peers to

share information and exchange emotional and social support. We will also study the YAs' activities on the **ktalk.org** website to shed light on the experiences of this group so that renal teams can proactively address their unique needs, rather than simply react to the challenges brought forward by these young patients.

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