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Patient-to-patient peer mentor support in dialysis: Improving the patient experience

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Abstract

Greater focus on patient-reported outcome measures for dialysis patients and an increased patient engagement focus has highlighted a lack of formal patient-generated strategies. Patient-to-patient peer mentoring is one approach that may improve the outcomes for people receiving dialysis. This review aims to synthesize quantitative and qualitative studies investigating dialysis-associated patient-to-patient peer mentor support among adults with chronic kidney disease and end stage kidney disease. Research studies describe the benefits of peer mentor programs in dialysis to include: improved goal setting, decision-making and increased self-management. While a variety of program formats exist, a combination of face-to-face and telephone peer support models are recommended and formal training of mentors is required. In addition, the formal support of dialysis clinicians, nephrologists and administrators is vital for the success of a dialysis patient-to-patient peer mentor program.

1 | INTRODUCTION

The anxiety and stress of coping with a diagnosis of advanced kidney disease, commencing dialysis, or preparing for a life-changing kidney transplantation can be overwhelming. Patients are required to process complex information about new treatments and future treatment options in the adjustment to these new and different stages of their lives. Throughout this journey, patients are frequently provided advice, education, and information from healthcare professionals who have not experienced kidney failure themselves, and thus, may not fully comprehend the challenges that each individual patient faces.[1] In contrast, their fellow end-stage kidney disease (ESKD) patient peers, better relate and understand these challenges because they have lived through them and therefore are more "expert" through their patient experience.

The patient-to-patient peer relationship is one that is nonhierarchical and reciprocal with peers sharing similar experiences and knowledge with others who have undergone similar challenges.[2] Thus, the strategy of peer mentor programs is based on this premise that people who have gone through these experiences are best placed to assist others.[3] Peers can develop relationships and provide additional emotional support and informational assistance to address common health-related issues.[4,5] These relationships have been found to influence decisions regarding kidney treatment therapy choices and major life decisions, such as moving into assisted living.[6] In some cases, peers can have greater influence on a decision than the patients' physician.[7] Therefore, a strategy by healthcare professionals to bring together peers, mentors, and mentees, in formal patient-to-patient peer support programs may encourage improved decision-making, increased self-management, and improved health outcomes.

The aim of this paper is to review patient-to-patient peer mentoring studies relevant to those with ESKD, receiving dialysis, and describe how mentoring may be positively implemented. The conceptual framework guiding this review is based on Bandura's theory of self-efficacy and behavior change.[8] Bandura has proposed that, the more personal the education and information is, the more likely it is that people will make major changes in their lives and initiate (or improve) positive self-management in chronic disease. The notion of peers providing information and support to other peers may result in higher self-efficacy, given the source of the information: the peer "patient expert."

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2 | RESEARCH METHODS

A striking feature of this review was the paucity of peer-reviewed research studies reporting patient peer support programs in the CKD and ESKD populations. Of the 6 studies meeting our search criteria, 2 followed randomized control methods with the other 4 using exploratory descriptive methods. Given the challenges of designing rigorous trials to determine the effectiveness of peer mentoring, the overused claim that more research is required in this area is highly applicable in the pursuit of improved support for people with ESKD on dialysis.

3 | THE DIALYSIS CENTER CULTURE

Following the entry into a dialysis program, patients receive education about kidney disease and treatment options from health professionals located in the hemodialysis centers. The culture and education practices in each hemodialysis center can affect the quality, type, and amount of health-related information patients with ESKD receive. This education is delivered when the clinician has time, rather than when the patient is ready to synthesize new information.

Patients receiving hemodialysis in these centers spend large amounts of time with other patients during transportation to and from the centers, in waiting rooms, and during the extended treatment times of 3-5 hours. While this can be a somewhat social occasion with many socially appropriate conversations,[9] many patients feel isolated from others and are reluctant to share their concerns or healthcare challenges with other peer patients.[10] When healthcare issues are shared and patients are providing advice to other patients, concerns have been raised that inappropriate information may be informally shared.[11] Thus, for dialysis patients to receive appropriate, constructive peer support, centers are required to engage in, or to develop, peer support programs to "allow" and encourage patients to provide peer support to each other.

This review of the literature focused on studies that had implications for peer mentoring in adult dialysis centers. Databases searched were Medline, CINAHL, Embase, Proquest Central, Cochrane, Science Direct and Web of Science. Specific search terms were used as follows: ("peer"/exp OR peer) AND ("mentor"/exp OR mentor OR "mentoring"/exp OR mentoring) AND (((end AND stage AND ("kidney"/exp OR kidney) AND ("disease"/exp OR disease) OR end) AND stage AND renal AND ("disease"/exp OR disease) OR chronic) AND ("kidney"/exp OR kidney) AND ("disease"/exp OR disease) OR "dialysis"/exp OR dialysis OR "kidney"/exp OR kidney) AND ("transplant"/exp OR transplant). Studies addressing CKD only were excluded; however, studies that had implications for dialysis were included. Studies containing quantitative and qualitative methods, or a combination of both, were included. Non-English studies and studies published before the year 2000 were excluded. Studies focusing on children and/or adolescents, including those focusing on kidney camps as an intervention, were excluded. Reference lists of included articles were searched for further titles. One author (PNB), read and screened the titles and abstracts of each identified study and excluded duplicates (Figure 1). A second author (JSR) reviewed the accepted titles and abstract to confirm review eligibility. To limit the potential for overlooking recent insights, methodological flaws were not stringently applied as part of this review process. Our search strategy resulted in 6 studies reporting primary research, focused on patient-to-patient peer mentoring that were relevant to dialysis context (Table 1). Study results were synthesized to provide information regarding mentor program models, mentor training, mentor/mentee interactions, and the role of dialysis personnel, including the nephrologists role, in peer mentor programs.

4 | MENTOR PROGRAM MODELS

Patient-to-patient peer mentor program models are generally dependent on the aim of the program, ranging from professionally led group visits and peer coaches through telephone and web-based programs.[2] In the peer-reviewed literature, combined face-to-face and telephone supported, group-based, and web-based models have been reported and summarized in Table 2.

The most prevalent programs reported have been face-to-face and telephone combined, over an extended period, where strong personal relationships can develop.[2,12] This may be effective when a mentor who has been on dialysis in a center can help orientate a mentee new to treatment or new to the center. The systematic use of patient peers in formal introduction into the dialysis unit orientation program can provide the mentee with a patient expert who can relate to the anxiety and fears of the new dialysis patient.[6]

Programs utilizing shorter conversations by peers that do not aim to develop long-term relationships have been successfully implemented. Such conversations do not facilitate the long-term befriending aspect of peer mentoring, but nevertheless have been associated with improved decision-making, decreasing the feelings of loneliness, increased hope, and increased empowerment in patients with kidney disease.[5] These shorter, more targeted interactions can be in person or via telephone, or a combination of both. The timing of these conversations can be when a person is first diagnosed with ESKD, when dialysis is imminent, or when the discussion of transplant is considered. These shorter conversations have shown benefit in the ESKD population, particularly when experiences are shared with both mentor and mentee providing support for each other.[3]

In addition to one-on-one patient peer support, support groups have been used with success. Organizing groups of people together, rather than just 2, can be logistically difficult, so increasingly these are run via online support groups in the form of chat forums, shared blogs, or social media pages. Patient peer support groups, as part of a suite of self-management interventions, have been associated with decreased progression from CKD to ESKD when used with a range of self-management strategies.[13]

Mentor programs can be coordinated by a local dialysis or outpatient center or can be run from a renal network or region.[3,14] The

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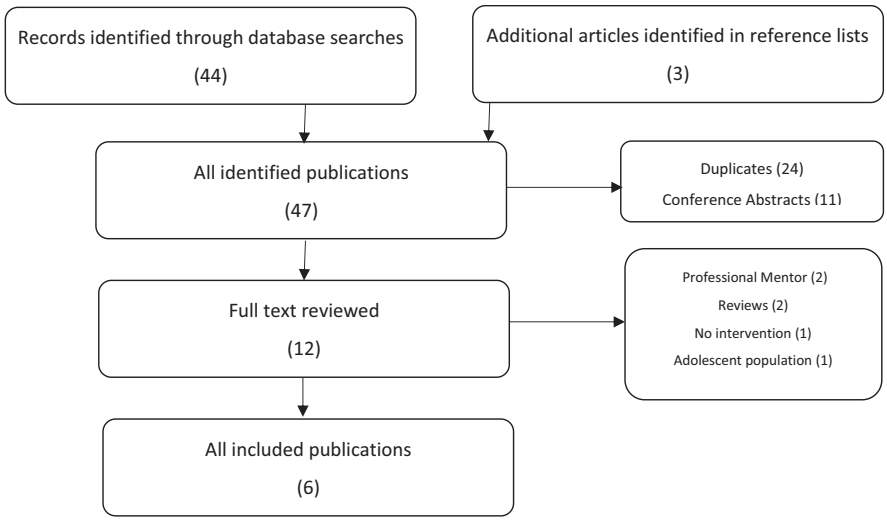


FIGURE 1 Literature review flow chart

National Kidney Foundation (NKF) has developed this to a national basis through their NKF Peers program.[15] Over the first 4 years, the peer support program has shown evidence of a beneficial impact on healthy behaviors. Network groups can use online forums with varying success, particularly in younger adults who prefer to use more popular social media platforms.[10] Although various patient-to-patient peer mentor models have been reported, the importance of mentor training is at the forefront of successful programs, whatever the model.

5 | MENTOR TRAINING

Mentor training is most frequently performed through 1-2 days of face-to-face training. The training consists of knowledge sharing, communication skills training, role-playing, experiential responses, and nonjudgmental training.[5] Knowledge relating to confidentiality, sharing experiences without sharing medical information, when to refer to health professionals and self-management is commonly presented.[15] Other processes that are undertaken may be confidentiality agreements and background checks.[3] The ultimate aim of the training is to ensure the mentor is well prepared to facilitate an optimal mentor/mentee experience.

In our experience, in 1 US dialysis center, we had no difficulty in recruiting 8 mentors who were keen to acquire mentoring skills through a 2-day training workshop based on the *Peer Up!* program.[11] *Peer Up!* is a comprehensive patient-to-patient peer mentor program developed by the Mid Atlantic Renal Network and available at https://www.esrdnet5.org/Special-Initiatives/Peer-Up!-Program.aspx. Detailed recruitment and training resources including mentor training and assessment and evaluation resources can be freely downloaded from this site.

While mentor training is vital, encouraging and recruiting mentees to the program is equally as important. Some dialysis patients are stoic, putting on a brave face where acknowledging anxiety and stress can be uncomfortable. Helping mentees understand that their mentors can offer truer, experiential knowledge that cannot be provided by clinicians can mitigate apprehension to participate in a peer support program. Further, encouraging mentees to discuss their anxiety about dialysis, vascular access surgery, and lifestyle questions can play an important role in positive mentor/mentee outcomes.[5]

6 | MENTOR-MENTEE INTERACTIONS

Prior to the mentor/mentee interactions, there is the requirement to match patients who will better understand the challenges that each go through. Examples of this can be type of treatment (hemodialysis, peritoneal dialysis), gender, age group, ethnicity, family circumstances, and job status.[5] However, the logistics of matching patients may not be straightforward, given that volunteer mentors are more likely to be female, white, educated and from a higher socio-economic background.[16] Individual attributes such as how mentors present themselves and communication styles are more important than demographic characteristics.[3]

Interactions can be effective on a one-off basis or over a long period of time, depending on the aim of the patient peer program. An example of an effective single use mentor comes from kidney disease prevention, dialysis and transplant expos where patients can provide a patient perspective on their journey through kidney disease and the important elements of a kidney transplant.[17] These expos consist of booths in shopping malls or health centers where kidney health education and information is provided. More commonly, patient peer mentors can be used over a longer period, for example 2-4 months when a person is just commencing dialysis. These can be either telephone or face-to-face interactions,[12] with the importance of at least one face-to-face reported as being essential.

The details of what mentees and mentors discuss can be varied and will depend on the needs and skills of each. During the mentors'

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TABLE 1 Peer mentoring in chronic kidney disease and end-stage kidney disease studies

Author, (year), country	Conceptual framework	Sample	Intervention	Design	Variables measurement	Data analysis methods	Attrition/Results	Significance of findings	Limitations
Perry et al (2005), US	Not stated	203 HD	Patients mentor V printed materials V control	RCT	Depression, anxiety, suicidal ideation, subjective wellbeing, completion of ADs	Intraclass correlation, LR, Student *t* test, ANOVA, MANOVA	11 lost to follow up ↑subjective wellbeing ↓anxiety ↑AD completion for peer intervention group	Assisted AD progression. More successful in African American participants	Biases in the study design related to contact time between peer mentors and patients
Hughes et al (2009), UK	Not stated	18 CKD & RRT imminent; 1 wife; 1 daughter	Peer mentoring	Qualitative; purposive sampling; face-to-face and telephone interviews	N/A	Framework method	Lived experience information; improved decision-making; not alone in suffering; hope: normalized adherence regimen; increased empowerment	Positive experience of peer mentoring from the mentees' perspective	Retrospective, respondents "opted-in," interview about peer support may have increased the significance of support that was accorded.
Perry et al (2011), US	Not stated	7 pre ESKD, 10 Tx; 18-32 y/o; 13m, 4f	Website containing videos, message board, blogs, profile, and resources	Qualitative descriptive. Semi-structured Interviews	N/A	Thematic Analysis	Concern in transition to adult clinic; isolated from CKD peers; online community interest; divergent opinions on public to blog/chat	Online web-based tools can be useful for adolescents with CKD and kidney transplants	Small sample size from a single center
Chen et al (2011), Taiwan	Self-management theory	54, CKD, 30m, 24f	Peer support is an element of a self-management program	RCT	Absolute eGFR, number of hospitalizations, eGFR decrease, ESKD requiring RRT, mortality	Kaplan-Meier, Cox proportional hazards model,	Suite of self- management interventions decreased CKD progression and decreased hospitalizations	As part of a suite of tools peer support can decrease kidney disease progression and hospitalization	Peer support may not have been the effect variable. 1 year follow-up, possible control group information contamination,
Swartz et al (2011), US	Not stated	497 Screened by 78 CKD/HD peers	Peer mentors in CKD screening	Descriptive Cross-sectional	Proteinuria, glycosuria or microhematuria, BP, weight and BMI, ADA diabetes self-test, Healthy Behavior Checklist	Standard chi-squared	Promoting trust and credibility, especially among various ethnic populations like African Americans.	Peer mentors can contribute to CKD screening	The impact of the peer mentors was not quantifiably measured
Taylor et al (2015), UK	Dennis' model of peer support	15, HHD, CKD, HD, PD 11 care partners 10m, 15f	N/A	Qualitative Grounded Theory; Semi-structured Interviews	N/A	Constant comparison	Peer support beneficial; the peer support occasion; permission to engage; an attractive peer relationship.	Clinician promotion of peer support is required	Predominantly white, female sample.

AD, advance directive; ADA, American Diabetes Association; ANOVA, analysis of variance; BMI, body mass index; BP, blood pressure; CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; ESKD, end-stage kidney disease; f, female; HD, hemodialysis; HHD, home hemodialysis; LR, logistic regression; m, male; MANOVA, multiple analysis of variance; N/A, not applicable; PD, peritoneal dialysis; RCT, randomized control trial; RRT, renal replacement therapy; Tx, transplant; UK, United Kingdom; US, United States; V, versus.

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TABLE 2 Models of patient-to-patient peer support

Model	Features	Benefits	Negative aspects
Support Group[13]	Group of like patients in similar health contexts	• Increased diversity of information from multiple perspectives • Can increase knowledge and compliance	Discomfort for some in-group settings
Individual, Long-Term (Greater than 2 meetings), Face-to-Face, Telephone Combined[12]	Facilitates diverse methods of contact over a long time period	• Can increase self-management (eg, advance directive completion) • Greater comfort level when dis cussing sensitive health aspects	Require monitoring to ensure long-term relationship is not negative
Individual, Short-Term (1 to 2 meetings), Face-to-Face, Telephone Combined[3,5,15]	Facilitates diverse methods of contact over a short time period	• Practical aspects of transitioning to dialysis, access information, catheter information • Immediate reassurance • More benefits if similar features of mentor and mentee • Can enhance preventative aspects of further disease progression	Short negative experiences cannot be easily reflected on
Web-based[10]	Web-based form, monitored or unmonitored	• Access to more than 1 mentor/mentee • No need for physical space to meet	More likely to use traditional online communication methods and social network platforms

training sessions, issues such as regimen adherence, confidentiality, advance directives, effects of chronic illness, strengths, fears, and goals can be discussed. These can be prescribed as structured meetings or left unstructured.[12] Transplant discussion can be encouraged focusing on the realities of the transplant experience.[18,19] For the longer model of peer support, each mentor/mentee dyad will develop their own methods of communication. There is no one method; however, our experience has found that encouraging and developing a structured "conversation theme" for each mentor/mentee meeting can assist these conversations.[20]

7 | ADVANTAGES OF PEER MENTORING

The greatest advantage of patient-to-patient peer mentoring is that the experiences of both mentor and mentee are real and authentic, leading to benefits for both. Both individuals can share common feelings because of the knowledge that both are likely to have gone through similar experiences.[21] Both can assist each other in feelings of normality, that they are not the only ones going through this.[5] The support is less clinical, and less hierarchical than interactions with the clinician-led education program.[3] This has been shown to provide a greater hope for future life goals to be achieved.[5]

The few studies focused on patient peer support in the ESKD population have shown a particular advantage for certain ethnic groups who have strong oral traditions. Patient peer support promoted greater credibility and trust in these groups, particularly if face-to-face meetings were included.[15] The person-to-person approach of a peer can make sensitive subjects, such as quality of life and advance directives more acceptable to discuss, rather than written or didactic instructions.[12]

The mentor relationship can enhance decision-making for both mentee and mentor through a more sensitive understanding of the kidney disease journey.[22] Decisions related to treatment options, home dialysis, advance directives and encouraging family kidney disease screening have all been enhanced by patient peer support.[5,15,23] Specific practical skills have been transferred, such as self-cannulation skills.[3] Although these can be clinical skills or knowledge that clinicians can also address, the information is far more authentic coming from a peer patient.

8 | PEER MENTOR NEGATIVES

Research studies on peer mentoring in dialysis are limited; however, most research describes the advantages of patient peer mentoring suggesting a researcher positive bias. In saying this, in 1 study exploring renal patients' experience with mentoring, some mentees described episodes where their anxiety was heightened.[5] This was a result of the mentee's view of the mentor's apparent poor communication skills. Given the possibility that sensitive information is discussed, high level communication skills are required from the mentor supporting the need for comprehensive mentor training.

9 | NEPHROLOGIST AND DIALYSIS STAFF ROLE

Although there are a variety of reported patient peer support models, the involvement of health professionals to coordinate a formal approved structure is mandatory. Furthermore, health professionals can exert considerable positive or negative influence over the success of the program.[5] A program team is required to identify mentors and mentees, match peers, provide appropriate locations, and assist with logistical aspects, such as transport and dialysis shifts. Support from the nephrologist, medical director, social worker and

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dialysis center senior staff, including patient care technicians, is vital for logistic and referral purposes. In particular, the nephrologist will be able to refer newer patients into the peer support program or recognize individuals who could contribute as patient mentors.

To best sustain patient peer mentor programs mentoring, a culture where staff promote peer support as an intervention suitable for everyone is required, not just those who are perceived as needy.[3] This includes reflection and monitoring of the regular mentor/mentee meetings to ensure that the meetings are achieving the goals of the patient peer support program. This may also include care partners whose lives are affected by their partner's disease and also need peer support.[3]

10 | STARTING A PATIENT-TO-PATIENT PEER MENTOR PROGRAM IN A DIALYSIS CENTER

Aspects of planning, starting and sustaining a patient-to-patient peer mentor program in a dialysis center are summarized in Figure 2. In the peer review literature and in our recent experience, the most important ingredient is to involve patients in the beginning and develop the program "with" them rather than "for" them.[11] Starting with a small number of patients as mentors (5-10) and formally training these mentors is necessary. This involves clearly communicating the expectations, roles, and responsibilities to mentors and mentees. This training ideally requires hands-on practice and role-playing by the mentors rather than simply didactic lectures.

Dialysis center staff and management need to be fully educated regarding the aims and progression of the program to ensure their support. Thus, in-service education prior and updates during the program are essential. Furthermore, sustaining management support for the program will require meaningful outcome metrics that may include hospitalization, treatment adherence, medication adherence, and access to transplant list.

11 | CONCLUSION

Published studies provide a taste of the potential for patients to support other patients in formal patient-to-patient peer mentor programs. Researchers demonstrate that support is particularly valued when delivered by peers who can genuinely empathize with each other. Where possible, face-to-face or telephone-based programs are recommended, with the length of each mentor/mentee contact dependent on the aims of the mentoring program and mentees' needs. However, these programs are unlikely to be sustained without the formal support of dialysis professionals to organize logistical aspects of the peer support programs. Providing time investments into a formal program may result in time savings in other areas of care, such as patient counseling and education.

Ultimately, the benefits of peer mentor programs in dialysis include improved goal setting, improved decision-making, and self-management. Given the anxiety and stress involved in living with ESKD and receiving dialysis therapy, formal peer mentor programs can provide positive support for this vulnerable group. As busy healthcare professionals, we may underestimate the untapped resource of patient experts. We should not be blinded to this potential resource; we often view our patients as needing support, but must remember that these patients may often have useful skills that adapt well to mentoring others.

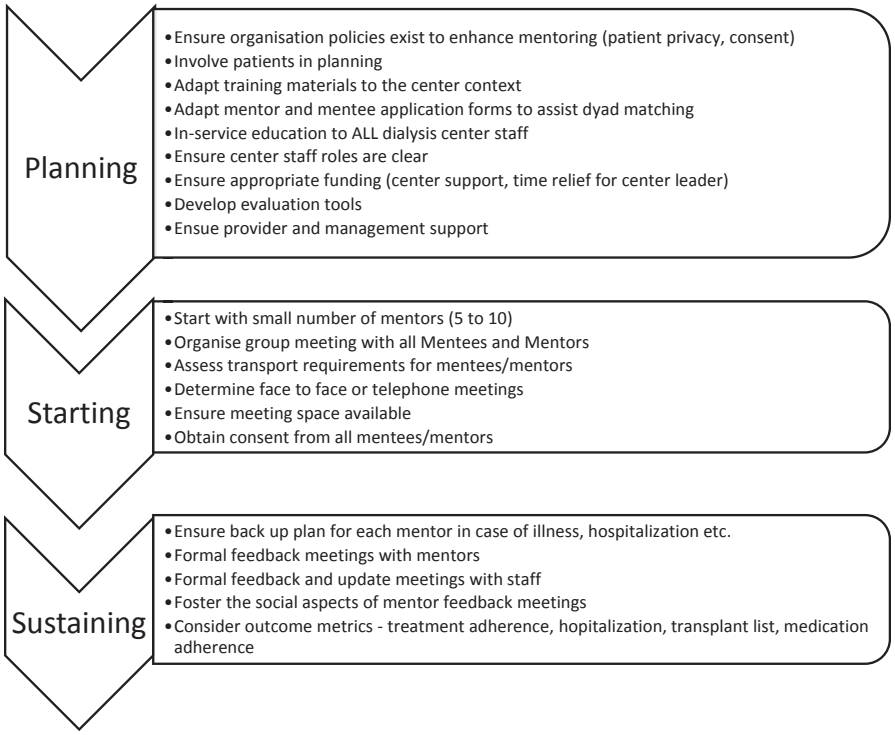


FIGURE 2 Planning, starting, and sustaining a dialysis center-based patient-to-patient peer mentor program [Color figure can be viewed at wileyonlinelibrary.com]

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