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The Journal of Nephrology Social Work

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- The Most Important Thing We Can Do Is Listen: Making Peer Mentoring Available for All
- How Organ Transplant Recipients Cope with the Deaths of Their Donors
- Application of the Family Resilience Framework to Dyadic Shared Decision-Making in Dialysis: An Interpretive Phenomenological Inquiry

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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.

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THE JOURNAL OF
NEPHROLOGY SOCIAL WORK

VOLUME 45
ISSUE 2

TABLE OF CONTENTS

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TYPES OF MANUSCRIPTS BEING SOUGHT

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

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The Most Important Thing We Can Do Is Listen: Making Peer Mentoring Available for All

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The purpose of this research was to increase the availability of mentor training materials for people with kidney disease, learning disabilities, and vision difficulties through the creation of an audiobook and a large font textbook to improve their participation in the training process. A qualitative approach was utilized to evaluate the participants' training experience. A secondary goal of this project was to assess the mentee's quality of life (QOL) prior to being matched with a mentor and then 3–6 months after the match. During our yearlong study, 11 participants completed the peer mentor training classes and 5 mentees were matched with the mentors. Mentee QOL was measured by the CDC's Healthy Days Measure before participating in the peer mentoring program and reflected variable QOL for mentee participants. Findings indicate that participants utilized the audiobook and felt it aided their training experience.

INTRODUCTION

The Kidney Foundation of Central Pennsylvania (KFCP), in Harrisburg, PA, has a peer mentoring program, The Patient and Family Partner Program (PFPP). Since its inception in 2004, the PFPP has given people affected by kidney disease opportunities to mentor others going through similar experiences. The pioneer behind the PFPP, Peggy Jayne Pierce, identified the need to connect with someone who "has been there." Peggy was a registered nurse and a patient with chronic kidney disease (CKD). She wanted to move beyond statistics and textbooks, and towards lessening anxieties and increasing knowledge about kidney disease. Peggy recognized this alternate way of coping and, with the help of various renal professionals, developed the PFPP curriculum, now known as the *Certified-Partner Candidate Handbook*.

Nationally, peer mentoring programs continue to grow to support people affected by kidney disease and are effective in improving quality of life (QOL) and reducing caregiver burden (Ghahramani, 2019). Peer mentoring is known to enhance the health and well-being of individuals and families affected by kidney disease. Peer-led mentoring is an effective strategy in patient education for those considering various treatment methods (Ghahramani, 2015). Peer mentors may also encourage patient engagement.

Current research suggests that patients with chronic illnesses, such as kidney disease, can also have depressive symptoms, significantly higher than the general population (Nelson et al., 2003). Depressive symptoms can also lead to worsened quality of life, impair recovery, result in poor treatment adherence, and worsen mental health status (Saravanan, 2009). Living with a chronic illness can be isolating. The effectiveness of peer mentoring may be attributed to the notion of relating and shared experiences.

The purpose of the PFPP is to provide a valuable resource to those affected by kidney disease and begins with the training of mentors. The mentors are people with kidney disease or family members of people with kidney disease who have learned to live well with their disease and want to help others. The participants attend weekly two-hour classes for six weeks. Traditionally, these classes are led by the PFPP coordinator and are face-to-face using the *Certified-Partner Candidate Handbook*. Participants have required readings and homework each week. During the classes, a PFPP trainer reviews the chapter materials with attendees via a PowerPoint presentation. These trainers are volunteers from the community with kidney disease experience.

It is imperative that the PFPP be available to all and our goal in this project was to increase the availability of the training classes through the creation of an audiobook and a large font textbook to be used by peer mentors with reading or vision issues. Like many states, Pennsylvania has a growing number of patients with a CKD diagnosis. The most common cause of kidney failure is diabetes. A common complication of diabetes is diabetic retinopathy, a condition that affects eyesight and may lead to difficulties with vision. According to the Centers for Disease Control and Prevention (CDC, 2019), approximately 3% of Pennsylvania and almost 5% of the United States populations have received a diagnosis

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of blindness or have serious difficulty seeing. In addition, 4.6 million Americans report having a learning disability (Cortiella & Horowitz, 2014). The secondary aim of this study was to assess mentee's quality of life (QOL) prior to participating in the peer mentor program to describe baseline mentees' QOL, measure change, and inform other peer mentor programs.

This work was inspired by R.R., a patient with kidney failure receiving in-center hemodialysis. She struggled with our training materials and was frustrated with the learning process. On multiple occasions, she even considered not completing the training. She was unsure if she should share her diagnosis of dyslexia with the PFPP coordinator and volunteer trainers. R.R. shared that when she was growing up, many did not have knowledge about learning disabilities. She struggled with learning and did not complete high school. Life experience had taught her to be an advocate for herself.

R.R. took a risk and shared her frustrations and her diagnosis of dyslexia with her dialysis social worker. She was encouraged when her social worker assisted her with the reading materials and the homework for the PFPP. Due to this positive experience, she was willing to share her story with others in the mentor training class. This encouraged others to express barriers in completing the coursework, such as blindness and sight issues. R.R. felt that her anger and frustration with dyslexia were relieved by sharing her story. R.R. completed the mentor training class and felt that being a mentor was like being in a "mini-support group" for persons with kidney disease. R.R. and others inspired a reevaluation of our training materials.

METHOD

Following modifications to the overall administration of the program due to the COVID-19 pandemic, two mentor training classes were held virtually in 2020, using the new training materials. Eligibility criteria for this study were peer mentor trainees who were: 1) patients or caregivers living with kidney disease, preferably stages 4–5 CKD; 2) adults over age 18; and 3) residents of Central Pennsylvania (the coverage area for the KFCP).

After the conversion of the *Certified-Partner Candidate Handbook* to an audiobook, an evaluation was conducted. The goals were to: a) assess if the audiobook increased the number of peer mentor trainees who have visual or learning disabilities and improved their participation in the training process; and b) assess QOL of mentees. QOL was measured by the Healthy Days Measure which is used by the CDC (2018). The study was approved by the Kidney Foundation of Central PA Board. Written consent was obtained by each participant.

As stated, due to COVID-19, the mentor training classes were held virtually. The classes were facilitated by the PFPP coordinator and were held one evening per week over six weeks. Volunteer trainers remained and provided the weekly presentations and goals of the program, despite the transition from face-to-face classes to virtual classes. Upon completion of the class, participants completed a questionnaire to collect their thoughts and opinions regarding the updated training materials and the impact on their learning. Upon successful completion, each mentor was attempted to be matched with a mentee. For those who were able to be matched, the mentees were provided with the Healthy Days Measure for baseline QOL prior to matching and 3–6 months later.

RESULTS

From January 1 to December 31, 2020, 11 participants received the mentor training, consisting of two mentor training classes, held virtually. The audiobook was given to each participant in addition to the printed mentor training manual and other class materials. The response rate for the post-assessment questionnaire was 100%. Two participants did not complete all the coursework for training. One declined to do the homework assignments and one was unable to attend all the classes due to health issues and hospitalizations during the training period. Both were offered opportunities to complete the coursework.

Demographic characteristics of the trainees are highlighted in **Table 1**. Participants included seven men and four women ranging in age from 30 to 74 years. Six participants were receiving in-center hemodialysis, two participants were receiving peritoneal dialysis, one participant was on home hemodialysis, one participant was a kidney transplant donor and one was a caregiver. Two of the participants had a history of receiving a kidney transplant.

Of the participants, five self-reported visual difficulties, including diabetic retinopathy, cataracts, partial and complete blindness, glaucoma, and nearsightedness. Three participants also reported they wore eyeglasses and one trainee used reading glasses to read small print. Two participants self-reported attention deficit hyperactivity disorder (ADHD) as a learning disability, while one participant reported visual perceptual and visual motor deficits. Educational levels were also reported: three had graduated high school or obtained a general educational development (GED), two reported "some college," four had college degrees and one had a graduate degree.

The self-reported use of the audiobook is highlighted in **Figure 1**. Of the participants, five used the audiobook during the mentor training. Three participants listened 1–2 times per week, while two participants listened to the materials

3–5 times per week. All participants felt the audiobook improved their training experience and one of these participants reported the audiobook was "well done." Five of the participants who didn't use the audiobook reported that they preferred reading the printed mentor training manual. One participant didn't use the audiobook due to "forgetting about it," and suggested that the program coordinator remind participants of the materials during the training period.

Five mentees were matched with the participants who completed the mentor training classes during our research period. Demographic characteristics of the mentees are highlighted in **Table 2**. Each of the mentees was asked to complete the Healthy Days Measure (see **Figure 2** for questionnaire) with the PFPP program coordinator prior to being matched with their mentor. For *question 1*, no mentees reported excellent, very good or good health. For those who completed the measure, one reported fair health, one reported poor health, and two reported fair/poor health. For *question 2*, one reported 2 days in a 30-day period that physical health was not good, one reported 5 days, one reported 20 days, and two reported 30 days. For *question 3,* one reported 0 days in a 30-day period that mental health was not good, one reported 1 day, one reported 28 days, and two reported 30 days. For *question 4*, one reported 0 days in a 30-day period where their physical or mental health kept them from doing their usual activities, two reported 20 days, one reported 25 days, and one reported 28 days. Additional data points about mentee quality of life will be assessed in the future to compare these findings before and after participating in the peer mentor program.

DISCUSSION

People who experience a chronic disease, like chronic kidney disease, have many stressors. A peer mentoring program is a valuable tool for people who are doing well with their disease to help others who may be struggling. Mentors who have participated in this program in the past have shared how helpful the education from the mentor classes has been with managing their own disease and lives. There have been people who have requested to participate in the classes, but did not enroll due to sight issues or learning disabilities. Providing an adequate learning environment for those with learning disabilities or visual difficulties is integral to the program's success. This research study was motivated by a participant who shared her struggles with dyslexia and her concern that she could not complete the homework without assistance. Further exploration into other vulnerable populations' possible participation in this program may result in increased healthcare engagement, as well as autonomy in healthcare decisions.

One limitation of this study was the small sample size, due to the restructuring of the mentor training classes due to COVID-19. Because of COVID-19, an online platform was created and there were delays with starting the first training class. Another limitation was that participants needed access to the internet and needed to be familiar with Zoom or willing to download and learn this software platform. Kidney disease care providers who made referrals to the program also had to be educated about the new processes and requirements. Prior to COVID-19, mentors would typically meet face-to-face with their mentees. During the research period, the mentors were encouraged to use phone calls, texts, or emails for their meetings with mentees. This may have also limited participants' interest in the mentor training classes. During the first class, 5 participants did not use the audiobook and one participant during the first class suggested the PFPP program coordinator provide reminders to use the audiobook during the training period and this was implemented during the second training period. The lack of reminders could have contributed to lessened use of the audiobook during the first training class.

The large font textbook was not used during mentor training classes due to delays in the editing process. Because of this, the research team was unable to assess participants' thoughts or opinions on it. The reformatted textbook has since been completed and will be offered to all participants with sight issues in upcoming mentor training classes.

Despite these limitations, we are encouraged by the results and promise of this study. As an innovative approach to aiding those who live with CKD, peer mentoring may increase both caregiver and patient quality of life. Offering these services to those who have vision or learning difficulties broadens the potential audience. Peer mentoring could be translated for other chronic health conditions and lessen patient anxiety. Mentors encourage and empower those in similar situations through the strength of shared experiences.

Author Note*: This study was funded in part by a 2020 National Kidney Foundation Council of Nephrology Social Workers (NKF-CNSW) Research Grant.*

Table 1. **Characteristics of the peer mentor trainees**

	Number of participants (*n* = 11)
Gender	
Male	7
Female	4
Age	
30–40	3
40–50	2
50–60	2
60–70	3
70–80	1
Visual Difficulties	
Cataracts	4
Diabetic retinopathy	3
Glaucoma	1
Partial or complete blindness	1
No vision difficulties	2
Learning Disabilities	
ADHD	2
Visual perceptual and visual motor deficit	1
No learning disabilities	8

Table 2. **Characteristics of the peer mentor mentees**

	Number of mentees (*n* = 5)
Gender	
Male	4
Female	1
Age	
30–40	0
40–50	1
50–60	1
60–70	2
70–80	1
Ethnicity	
White, non-Hispanic	4
African American	1
Educational Level	
High school	4
Bachelor degree	1
Master's degree	0

Figure 1. **Peer mentor trainee self-reported use of the training audiobook (*n* = 11)**

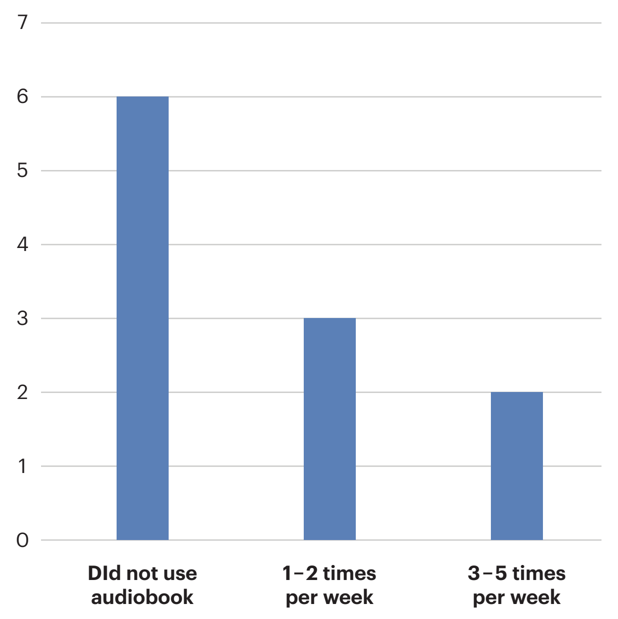

Figure 2. **Healthy Days Measure Questions (Centers for Disease Control and Prevention (CDC), 2018).**

1. Would you say that in general your health is excellent, very good, good, fair, or poor?
2. Now thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?
3. Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?
4. During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?

Source: Centers for Disease Control and Prevention (CDC). (2018 October 31). Health-Related Quality of Life (HRQOL); Methods and measures. CDC website. Available at: https://www.cdc.gov/hrqol/methods.htm

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How Organ Transplant Recipients Cope with the Deaths of Their Donors

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There has been limited research about how people who have received organ transplants from deceased donors cope with their donors' deaths. A study was conducted with 77 anonymous recipients to determine how their coping methods may differ qualitatively or quantitatively. Results indicate that females and males use a variety of methods, with several differences noted in their levels of importance, frequency of use, and impact. Some differences, based on age, were also noted. Four overarching themes were identified in the coping process, including: resolving whether the donor "died for" the individual, the random-chance nature of receiving an organ acting as an emotional defense, thanks/faith in God being beneficial, and gratitude toward the donor and their family.

INTRODUCTION

There is a substantial body of literature regarding the mental health concerns and functioning of people during the pre- and post-organ transplantation process. The literature has focused on topics such as quality of life (QOL) (Pinson et al., 2000), depression (Dew et al., 2001), and employment (De Baere et al., 2010). Transplantation is like no other medical procedure, in that, in most cases, for someone to live someone else has to die. This has the potential for major psycho-emotional impacts in recipients. Yet, we know little about how those who have received a deceased donor organ cope with their donors' deaths. One might expect that survivor guilt is a critical developmental hurdle for recipients; however, anecdotal evidence points more toward a desire to find meaning in the donor's death. This study was completed to investigate several core questions, including: how do people cope with their donors' deaths? Do these methods vary, based on gender? Do people discuss this topic with their transplant professionals?

METHOD

A research proposal was submitted and approved by a university independent review board (IRB) prior to initiating the study. A secure, anonymous online questionnaire was created, using both numerical rating scales, as well as open-text qualitative comment boxes. A mailing list was generated of all organ transplant support groups in the United States noted on the United Network for Organ Sharing (UNOS) internet site. An email message was sent to the specified contact person for each of these groups. The message asked them to distribute the online address link for the questionnaire to their constituents. It was noted that it was only for people in the United States who were over the age of 18 who had received a solid organ transplant from a deceased donor. Instructions, along with a statement regarding the voluntary and anonymous nature of the questionnaire, were incorporated as part of the informed consent. No individually identifiable information was collected. Participants were informed that the content of the questions (i.e., death) could potentially cause emotional upset; it was recommended that they not participate if they felt this would cause them any anguish.

RESULTS

A total of 77 respondents completed the questionnaire; 50.6% (39) identified as female and 49.4% (38) as male. Respondents were 87% (67) White, 11.6% (9) Black/African American, and 1.4% (1) Asian-American. Liver transplant recipients comprised the largest group at 28.5% (22), followed by kidney (24.6% (19)), lung (22% (17)), heart (12.9% (10)), multi-organ transplants (9% (7)), and other (3% (2)). The mean current age was 60.4 (*SD* 11) and mean age at time of transplantation was 51.7 (*SD* 12).

The first group of research questions dealt with the ways that respondents coped with the phenomenon of relying on a deceased donor in order to get a transplant while they were on the waiting list. The number of coping methods did not differ based on gender (females = 2.89, males = 2.81, $t = +.17$, df 75, p.43). However, there were some differences in the types of methods used (see **Table 1**). Females were significantly more likely to engage in pleasurable pastimes ($\chi2 = 6.78$, df 1, p.009); 31% of all female respondents did this but only 5% of males did so. Speaking with clergy was an activity completed by 13% of females and 26% of males, though it was not a statistically significant difference ($\chi2 = 1.46$, df 1, p.22). Additionally, females more frequently responded with trying not to think about their donors' death (25% vs. 13%) though this was not significant ($\chi2 = 1.2$, df 1, p.27). Overall, the use of

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prayer/faith/religion was the most commonly cited method of coping. It was noted by 62% of all respondents, including 64% of females and 60.5% of males. 56% of the respondents rated this as being moderate-to-extremely important as a form of coping. There was a difference based on gender, with females rating it as being more important (*t* = +1.88, *df* 75, *p*.03). There was a mild negative correlation based on age (*r* = -.26); however, female respondents were much younger at the time of their transplant age (47 (*SD* 12.9)), as compared to males (56 (*SD* 9.8)), so the influence of gender could be even greater. Talking with family/friends and speaking with others waiting for a transplant were the second and third most common forms of coping. Passive methods of coping including doing nothing, sleeping/napping, being in denial and trying not to think about it (18% of females and 15.5% of males, with no statistical difference χ2 =.14, *df* 1, *p*.70).

The second group of research questions dealt with waiting for a transplant. Fifty-five percent of respondents noted that the fact they were on a deceased donor waiting list for a transplant was moderately-to-greatly on their minds. There was no statistical difference based on gender (*t* = +.71, *df* 75, *p*.23). There was a minimal negative correlation based on age (*r* = -.18). The level of distress experienced thinking about the donor's death was rated as moderate-to-severe by 39%, and there was a significant difference, based on recipient gender, with females experiencing more distress (*t* = +1.75, *df* 75, p.04). A mild negative correlation based on age was noted (*r* = -.22).

On average, the respondents in this study were nearly nine years post-transplant. The majority of them (77%) still frequently thought about their donor and a there was a difference based on gender, with females more likely to do so (*t* = +2.24, *df* 75, *p*.01). Age at time of transplantation appeared to have no correlation (*r* = -.07). After transplantation, 60% of all respondents experienced moderate-to-great sorrow/mourning for their donor's death with no gender difference noted (*t* = +1.16, *df* 75, *p*.12). Age at the time of transplant had only a minimal effect (*r* = -.18). Interest in learning about their donor's lives was experienced by 80.5% of all respondents, with no difference based on gender (*t* = +.55, *df* 75, *p*.29).

People waiting for a transplant come into contact with many medical professionals. Respondents were asked if they spoke with any of them about coping with the death of their donors. Results show that they were most likely to have spoken with mental health professionals, particularly social workers and counselors. This was noted by 25% (19), including 26% of females and 22% of males, with no noted difference between genders (χ2 =.23, *df* 1, *p*.63). There were disparities in speaking with mental health professionals, based on the type of organ received: 35% of all lung recipients had done so, as had 30% of heart recipients, 22% of liver and only 4% of kidney recipients (none of the multi-organ recipients). The second most common professionals spoken to were physicians/nurses, which was noted by 21% (16), with 15% (6) of females and 26% (10) males doing so (χ2 = 1.4, *df* 1, *p*.23).

Four overarching themes were identified in the ways that respondents coped with the deaths of their donors: (1) resolving an inner conflict as to whether or not the donor "died for" the recipient; (2) seeing death as random; (3) the role of religious faith and belief in God for both support and acceptance; and (4) a profound sense of gratitude and a desire to somehow repay the donor or their family.

DISCUSSION

The respondents to this survey used a variety of coping methods to deal with the deaths of their donors, most of which were active efforts to improve mood or to self-distract. The primary method for both genders was faith/prayer/religion. Though there was no difference in the frequency of it being cited, females rated it as being more important to them in the coping process. Prayer and faith are noted to provide various benefits for people with chronic illness. They can be sources of solace, a way to bring about a sense of control over ones' life, and a resource of strength and perseverance (Gordon et al., 2002). Being able to appeal to a "higher power" has the potential to be a mental "safety net." That is to say, that when the abilities of medical interventions (medications, surgeries, professionals, etc.) are found to have limits, there is a power that a person can turn to that transcends all of them. Research has noted that people often want their physician to inquire, or know about, their religious and spiritual beliefs especially in the face of life-threatening situations (Ehman et al., 1999; MacLean et al., 2003). A study of kidney recipients who had survived over 25 years found that many attribute their longevity to faith in God (Matteson-Kome et al., 2016). An examination of liver recipients noted that those with high levels of religious faith had longer survival rates than those who did not (Bonaguidi et al., 2010). Though the frequency of faith/prayer/religion was not significantly different between females and males in this study, females rated it qualitatively as being more important.

The only coping method found to have a significant difference in frequency, based on gender, was that females were more likely to engage in pleasurable pastimes as compared to males. This is a beneficial approach, since its influence can be global (Pressman et al., 2009).

After faith/prayer/religion and social supports, including speaking with other candidates, the most commonly cited coping method was humor. Like faith, it too provides various benefits to those who are dealing with chronic or life-threatening illnesses. It has been noted to be a source of empowerment and relaxation, and can allow for altering perceptions of negative situations (Herth, 1990). It has also been identified as a buffer in patient-physician relationships. An analysis of interactions found that humor acts in many different ways in this regard (Schöpf et al., 2017). It allows people to vent frustrations, to deal with negative emotions, and express disagreement with and criticism toward their physicians, while also increasing rapport.

Passive coping methods were used by a minority of respondents (20%). Active methods have been correlated with lessened depression, lessened anxiety and greater overall well-being for those waiting for lung transplantation (Taylor et al, 2008), whereas a study of people waiting for heart transplants identified a strong connection between the use of passive denial and depression (Burker et al., 2005). Similar negative correlations have been identified between denial and its impact on physical functioning, along with quality of life (QOL) for those awaiting a new heart (Burker et al., 2009).

There were four primary overarching themes that arose from this study. The first, one of the most common, was a developmental hurdle that not all were able to resolve, which was to distinguish between the view that ”the donor died,” versus “the donor died for me.” Those who made this distinction in a positive manner made comments such as, “I came to an understanding that I was not responsible for my donor’s death,” or as another eloquently stated, “I distinguished between the thought that my donor died to give me life, versus my donor died and gave me life.” Those who did not reach this understanding expressed “survivor guilt,” and a sense that transplantation was a zero-sum process, in that one person lived (+1) and another died (-1), thus zero lives saved. Denial seemed to be linked to guilt for a small number of respondents as in, “I couldn’t cope with it (the donor’s death). I tried to push it into the back of my mind; otherwise, it made me feel guilty.”

The second theme was that death is part of life and the common nature of it, along with the ensuing organ-matching process, provides a sense of equal chance for one to obtain a needed transplant and not the sense that some died specifically for that recipient. As with the first theme, this seems to provide a defense against the thought that someone “died for me.” As a recipient noted, “My donor would have died whether I got his liver or not” and, “I took solace in knowing that I am not in control. People die every day and I have no say in that,” along with, “It was simply that my donor’s liver was most suitable for me.”

A third theme was thanks for and faith in God for both receiving a transplant and for getting through the process. There were numerous comments such as, “I relied on God to give me strength and peace,” along with, “I prayed that God’s Will be done.” This was also frequently directed as a sentiment toward the donor family, as in, “I prayed for their family,” and, “My thoughts and prayers were with the family who was going to lose a loved one.”

Throughout the many comments made by respondents, the word “honor” was often used, and it is linked to the fourth theme of gratitude. This was frequently cited as giving meaning and purpose to one’s extended life. For example, “I focused on how to honor my gift of life, to care for it….When I received it, I wanted to show my respect to my donor by sharing my story,” and, “I am deeply grateful for this gift of life. I am inspired to live life to the fullest to honor him.” Several reported that they had gotten involved with promoting organ/tissue donation. Again, “honor” was often cited with regard to becoming active in donation awareness efforts. For example, “I strive to honor my donor by promoting organ and tissue donation,” and, “I use my donor’s death as motivation to make the most of my life now by reaching out to help others, in order to honor my donor.” Additionally, as one respondent succinctly stated, “I think of him [donor] as my hero.” This altruistic desire to somehow repay/acknowledge the donor or their family has been noted as a transformative anthropological construct in transplantation and a common desire amongst recipients (Conway et al., 2013; Evangelista et al., 2003; Sharp, 1995). A total of 76% of all respondents stated that they were involved in organ donation promotion programs, many as a means of repaying the donor or their family. Along with “gratitude,” the majority of respondents stated that their donors are still frequently in their thoughts, and most experienced a period of mourning/sorrow regarding their donors’ deaths.

One of the most surprising findings was that, even though coping with the death of the donor appears to be a concern for many recipients, it was rarely discussed with transplant professionals. Though it cannot be assumed that all of the respondents who received kidneys had been on dialysis, it is surprising that only one recipient stated that they had discussed this topic with a social worker/counselor. Under Medicare regulations (Conditions for Coverage (CfC)), there is a social worker available in every dialysis clinic in the United States, and they are there to help people deal with a multitude of psycho-emotional concerns (Callahan, 2011; DHS, CMS, 2008). Respondents were even less likely to discuss donor death with physicians, nurses, and clergy. The question arises as to whether or not transplant candidates fail to raise this concern or if professionals don’t ask about it. It is known that discussing death-related issues differs among health professionals and that their attitudes, along with experiences, regarding death affect how they approach this topic with patients (Black, 2007). There were also differences, based on organ type, regarding whether respondents had broached the subject of donor death with their medical professionals. Heart and lung recipients more frequently had done so, as compared to liver and kidney, which is unique, since respondents had received their transplants at a variety of hospital programs across the nation. It is possible that this is due to the qualitative difference of the organs themselves. As has been noted in the literature, the heart is particularly different, in that it is constantly perceptible—there is a pulse that one can be aware of—as compared to other organs that work silently (Rauch & Kneen, 1989). That is to say, that the beating heart and the constant perception of breath might lead to someone being more aware of the life and death nature of donation and transplantation.

Most of the results from this study point to the common human need to find meaning in loss, which is particularly salient in a population who would most likely have died without transplantation. Research in related fields has noted that this need is often the most pertinent variable in post-loss adjustment (Keesee et al., 2008). It has been postulated that coping with death can lead to personal growth on various levels, such as becoming more appreciative of life and loved ones, and a general increase in resilience (Neimeyer et al., 2002).

Though this study had a relatively small number of respondents and cannot be considered generalizable, it appears that coping with the death of one's donor may be a common experience for transplant recipients. The study had the potential risk for self-selection bias within the sample population, in that respondents were from transplant support groups—which might attract people who are either coping well, or poorly, with the transplantation process. Finally, there is a multidimensional quality to coping methods that was not explored. For example, simply noting that transplant candidates used religious faith to cope does not provide in-depth understanding of how they used it or the specific benefit received.

A variety of coping methods were used, most of which were psycho-emotionally beneficial. Four primary themes were identified with regard to coping. Of particular note, the task of separating that "the donor died for the recipient" versus "the donor died and benefited the recipient" appears to be exceptionally important. Failing to successfully distinguish between the two seems to lead to feelings of guilt. Faith/prayer/religion, the random nature of death, and gratitude toward donors and their families were also commonly noted themes in the coping process. Even though coping with the death of the donor appears to be a frequent issue, it is not commonly discussed with transplant professionals. Further research into this dichotomy is recommended, especially with regard to differences noted based on the type of organ received.

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Table 1. Types of methods used to cope with pending death of organ donor

Method	Overall	Females	Males	χ2
Faith/prayer/religion	62% (48)	64% (26)	60.5% (23)	.01 ns
Talked with social supports	58% (45)	56% (22)	60.5% (23)	.02 ns
Spoke with others waiting for a transplant	35% (27)	31% (12)	39% (15)	.32 ns
Sense of humor	26% (20)	28% (11)	24% (9)	.04 ns
Spoke with clergy	19% (15)	13% (5)	26% (10)	1.46 ns
Slept/napped	19% (15)	23% (9)	16% (6)	.22 ns
Tried not to think about it	19% (15)	25% (10)	13% (5)	1.2 ns
Did pastimes that I enjoy	18% (14)	31% (12)	5% (2)	6.78*
Talked to mental health professional	15% (12)	13% (5)	18% (7)	2.14 ns
Did nothing	13% (10)	7.5% (3)	16% (6)	.56 ns

ns = not statistically significant
* = statistically significant

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Application of the Family Resilience Framework to Dyadic Shared Decision-Making in Dialysis: An Interpretive Phenomenological Inquiry

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Nephrology social workers are trained to assess and address the ecosystemic splits in nephrology care that threaten the resilience of dialysis patients and their families. Given this training and skills, nephrology social workers are ideally positioned to help center the patient and their decision partner in modality decisions that are increasingly influenced by provider incentives to promote home dialysis and transplant utilization. The Family Resilience Framework provides a paradigm for social work assessment and intervention during the iterative process of dyadic dialysis decision-making to develop an individualized care plan that promotes resilience through attunement to dyadic processes.

INTRODUCTION

The social work role in nephrology care has shifted from being a guest in a medical host setting to a Medicare-mandated member of the interdisciplinary team (Centers for Medicare & Medicaid Services (CMS), 2008; Dane & Simon, 1991). The role of social work interventions in improving patient outcomes, including quality of life, vocational rehabilitation, and treatment adherence, is well established (Browne, 2019). Nephrology social workers, whose training is informed by the National Association of Social Workers (NASW) Code of Ethics (NASW, 2017), continue to describe and report professional value discrepancies within the interdisciplinary team, leading to role ambiguity and marginality in treatment planning and patient care. As the dialysis industry responds to increasingly incentivized measures to promote positive patient outcomes (Mendu & Weiner, 2020), the nephrology social worker's commitment to service, social justice, the dignity and worth of the person, importance of human relationships, integrity, and competence are necessary to center the patient and their partners in treatment decision-making (Browne, 2019; NASW, 2017; Sledge et al., 2020).

The dialysis interdisciplinary team (IDT) generally, and nephrology social workers specifically, have essential roles in reducing dialysis burden by promoting patient- and family-centered care. While the physician, dietitian, and nurse must focus on the patient's body, the nephrology social worker ensures that the patient's personal, familial, and cultural characteristics are considerations in treatment planning. Each nephrology social worker has the training to attend to ecosystemic splits that influence nephrology care in the United States, including: (i) mind-body dualism; (ii) individual vs. the family; (iii) individual and family vs. institutional settings; (iv) clinical, operational, and financial issues; and (v) separation of the community from their clinical health care facilities (McDaniel et al., 2014). The nephrology social worker is challenged to address these competing demands in ways consistent with their training and compatible with the healthcare setting in which they are hosted. For example, nephrology social workers balance assisting patients with travel/transportation and insurance while supporting patients in pursuing their personal and family goals.

Dialysis modality selection provides an opportunity to evaluate ecosystemic splits inherent in medical care and the subsequent nephrology social work response. Dialysis decisions are often explored in research as episodic choices of access placement (Almasri et al., 2016; Loiselle et al., 2016), treatment modality (Finderup et al., 2018; Fortnum et al., 2015), advanced-care planning (Goff et al., 2015; Harwood & Clark, 2014; Vig et al., 2006), and end-of-life care (Davis & Davison, 2017; Eneanya et al., 2015; Maurizi Balzan et al., 2015). In practice, dialysis modality discussions are triggered by algorithms informed by regulation (DHS, CMS, 2008) or clinical recommendations (Rocco et al., 2015). This episodic paradigm of decision-making may explain why patients initiate dialysis modalities that are not consistent with their goals and values (Amar et al., 2018; Davis & Davison, 2017; Morton et al., 2010; Visser et al., 2009).

The ecosystemic splits, competing systemic demands, modality-focused treatment discussions (rather than person-focused), complicated diets, and treatment schedules increase the burden and threaten the resilience of families of people on dialysis. This build-up of stressors, combined with the chronic nature of end-stage kidney disease (ESKD) further test family resilience when unresolved emotions

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and stressors from earlier stages of kidney disease influence current family processes (Walsh, 2016). Not incorporating families in treatment decisions leads to an increased risk for conflict when surrogate treatment decisions are required (O'Hare et al., 2017).

Family resilience framework

Medical care is, by nature, a problem-focused practice about one patient. The Family Resilience Framework (FRF) offers a strengths-based, systems-focused perspective for identifying and targeting family processes that will buffer stress and encourage healing (Walsh, 2002). The FRF can be used to better understand patients, in both their family environments and medical settings, by assessing resilience ecosystemically. Through the integration of developmental theory and research about family stress, coping, adaptation, and transactional processes, the framework provides an ecological and developmental perspective, informed by the biopsychosocial model and the individual, family, and illness life cycles, that addresses the ecosystemic splits of healthcare (Rolland & Walsh, 2005; Walsh, 2004). The framework recognizes the impact of family histories, and the pile-up of stressors and crises on the entire family system (Rolland & Walsh, 2005).

Family resilience is the "capacity of the family, as a functional system, to withstand and rebound from stressful life challenges-emerging strengthened and more resourceful" (Walsh, 2016, p. 315). The FRF highlights adaptation and coping by describing three key processes:

- belief systems;
- organization patterns; and
- communication and problem-solving activities.

These processes promote resilience within the system (**Figure 1**). Family belief systems foster resilience through meaning-making and a positive outlook that shapes a transcendent or spiritual perspective. Organizational patterns, characterized by flexibility, connectedness, and mobilization of resources, can adapt to meet the challenges presented during adversity. Clear and honest communication, open emotional expression, and collaborative problem-solving help the family transition from a crisis-reactive to a proactive response (Walsh, 2004). A focus on family strengths (rather than deficiencies) and attunement to the influence of close relationships on personal outcomes shape both the processes and outcomes of family resilience (Martin et al., 2015).

Families collaborating as functional units with these key resilience-promoting processes (e.g., belief systems, organizational patterns, communication) mediate the risk of maladaptation and encourage the potential for growth when a crisis or stressful change occurs, thereby promoting family resilience (Martin et al., 2015; Walsh, 2004; Walsh, 2016). Psychological distress is more likely when family organizational patterns are disrupted by complicated diets, polypharmacy, treatment schedules of dialysis, patient morbidity, and vocational disruption (DePasquale et al., 2019). The disruption of normative nodal events of the family life cycle (e.g., graduation and retirement) and unexpected events occurring because of the chronicity of ESKD further tests family resilience, especially when emotions and stressors from earlier in family life and the disease process remain unresolved (Walsh, 2016). The lack of attunement to family resilience processes and decision partners early in ESKD treatment increases the risk of conflict with providers in later treatment decisions (O'Hare et al., 2017).

A family resilience perspective considers people within relational networks that manage the complicated demands of treatment. A relational perspective in research can clarify how dyadic interdependence shapes the decision-making experience (Meyer & Sledge, 2020, 2021). This interpretive, phenomenological study investigated how dialysis patients and their decision partners experience dialysis decision-making by uncovering the meaning and activities of dyadic dialysis decision-making episodes. Three interrelated themes were identified and are described in detail elsewhere:

- Their body, but not their life;
- Seeking semi-liberation; and
- Decision-making is caring (Sledge et al., 2021).

These themes collectively suggest dyads experience dialysis modality discernment activities as an intentional process that shifts according to their developing experiences with treatment and is informed by their relationship history. Three paradigm cases illustrating these themes and processes are described below with the Family Resilience Framework presented as an orientation consistent with nephrology social work values, while meeting patient and family needs.

METHOD

Participants

This purposive sample included 13 ($N = 26$) dialysis patient and decision partner dyads. Both dyad members were over 18 years old, spoke English, and were recruited from dialysis clinics and patient advocacy organizations in the U.S. The patients and their decision partners were involved with their current dialysis team for at least six months to ensure that the patient, decision partner, and current healthcare providers had participated in treatment-related decisions. Data collection and analysis occurred concurrently throughout the study, and recruitment continued until achieving thematic saturation. Each member of the dyad was offered \$15 (total \$30) as compensation for time spent participating in the study. Thirteen dyads were interviewed for 60–90 minutes (**Table 1**). Patients represented four dialysis modalities, including: in-center hemodialysis (ICHD; *n* = 6), peritoneal dialysis (PD; *n* = 3), home hemodialysis (HHD; *n* = 2), and nocturnal HHD (NHHD; *n* = 2). Decision partner relationships included romantic partner (*n* = 9), either parent, sibling, or friend (*n* = 4). Fifty-seven percent of participants were White, 46% of patients were women, and 76% of decision partners were women.

Study Procedures

Patient and decision partner dyads participated in in-depth, semi-structured interviews that lasted between 60–90 minutes in person or on Zoom. These dyadic interviews, consistent with the study's aims, are recommended in interpretive phenomenology when investigating how processes and relationships inform daily activities (Wilson et al., 2016). An interview guide was developed, based on a thorough review of the literature and piloted with dialysis patients and decision partners. A professional transcriptionist transcribed the interviews, and the transcriptions were reviewed by the principal author to ensure accuracy. A comprehensive field note journal that included a description of the setting, actors, role, events, and interviewer reflections on her beliefs and judgements was maintained. All participants were encouraged to respond, correct, and corroborate the transcript, summary, and initial interpretations.

Crist and Tanner's (2003) five-step iterative process of data analysis guided interpretation. This process includes:

- an investigation of early focus and lines of inquiry;
- developing central concerns, exemplars, and paradigm cases;
- identifying shared meanings;
- final interpretations; and
- dissemination of the results.

Rigor was ensured in data collection and analysis through adherence to strategies to maintain credibility, transferability, dependability, and confirmability (Krefting, 1991). Triangulation during data analysis and peer evaluation of interpretive analysis was completed to achieve credibility. The investigators' experience as nephrology social workers and psychotherapists increased the potential of securing rich descriptions from participants. An audit trail, field notes (i.e., reflexivity journal), and detailed analysis plan increased dependability and confirmability. The reader is referred to earlier publications for a complete description of the sample, procedure, and analysis (Sledge et al., 2021). Pseudonyms are used for each of the participants below. Potentially identifying information within each of the quotes has been replaced with bracketed words.

RESULTS

Their body, but not their life

The dyads' treatment goals shifted from individual survival to the family system's well-being throughout the dialysis treatment trajectory. Dialysis decisions were thus nested and interrelated decisions about the body, self, and family. Dyad partners were in a shared fight to preserve life, preserve *individual* roles and goals, and maintain *family* well-being. These nested decisions were situated within the dyads' shared meaning of family, organizational patterns, and intentional communication activities.

Gary (patient; **Table 2**) and Pam (decision partner) had been married for 23 years; both were previously married, and at the time of their union, Pam was an empty nester, and George had children still at home. The couple described their marriage as shaped by intentional organizational patterns focused on flexibility (e.g., Pam choosing to mother again) and connectedness (e.g., working together to raise his children), founded on a shared meaning of partnership shaped by their previous marriages. Gary has type 2 diabetes (T2D), managed with an insulin pump, and began peritoneal dialysis (PD) 18 months before the interview. Five years before starting dialysis, Gary had an arteriovenous fistula placed. While dialysis felt inevitable, the fistula placement reinforced the dyad's positive outlook that they were actively managing his chronic kidney disease (CKD) as best they could. When dialysis became imminent, the dyad's optimism was threatened by its realities.

Gary: And I had a rush of emotion while we were sitting there. I remember this. But we were looking at diagrams, and they'd just started the spiel. And it just, it hit me all of a sudden that, wow, this is for real. This isn't…we're not planning for the future anymore. This is happening in the next couple [of] months. And so, I did get a little emotional then…

Interviewer: So, you went out and took a break. And what did you do, Pam, when he stepped out?

Pam: I just stayed there. And I think I knew that he just needed some time. It was overwhelming—it really was—to hear all this stuff, and know that, wow, we have to make some decisions here pretty soon of what are we going to do. What's going to be best for him?

Despite Gary's history with CKD education, the modality education class was a disruptive transition that challenged the dyad's resiliency processes. Their previously established organizational patterns allowed them to shift focus to considering the modality that provided flexibility, thereby allowing Gary to maintain his role within the family. Based on their initial research and the context they sought from others' stories, they shifted their positive outlook to evaluating modality, based on their previously established roles and the impact of dialysis on Gary's daily activities and habits.

Gary: We went to lunch afterwards and just kind of sat there in a stupor.

Pam: Yeah, with all the folders that we got…[we began] looking at things immediately. Whereas driving in, I don't think we had any idea of what—now, the doctor may have talked about these options, but it was like talking in a different language to us. But after the class, we were much more informed, had a lot of material to read, and a lot of homework to do in order to make the decision. Okay, [on] what path are we going to go? Because even with PD, you could do a daytime PD. You could do a drip PD. There were just so many different options that we were completely unaware of.

Gary: And by the time we left the [modality] class, I was leaning toward PD already because I like the flexibility of it. And they did emphasize that it was much more flexible. And some of the drawbacks, the peritonitis and so forth, that hasn't been an issue.

Pam: I think it was, even though we were sitting in the restaurant looking over that material…I think that when we got home, he went online and looked up even more information and especially from people who were either using one [mode] or the other or both or something. And I think that information, I think it helped him make a better decision on what he wanted to do. And I think flexibility was probably [a priority] because he's still a young man. He's pretty active, and we just [laughter about Gary being young]—I think that's probably what guided us to doing the PD and, ultimately, the nighttime PD rather than doing it every—what was it, three times, four times, every other…?

Gary: Every other day, basically, yeah, three times a week for hemo.

In the daily activities and skilled management of dialysis, the values of the dyad and their family were made most explicit. The dyad's central concern was choosing a modality that provided flexibility to maintain Gary's role in the family, as being young, healthy, and active. Through their collaborative problem-solving and goal setting, the dyad recognized that a young, healthy, and active Gary would promote family well-being. The flexibility of the dyad in adapting to PD's daily activities facilitated their goals of traveling and parenting. PD was the means to maintain shared functioning of the family.

Pam: Yeah, but we knew that at some point, when he started this, how much it would change and be a part of any decisions that we do going forward. So, I think that we kind of knew that. We knew that the decisions we made were going to be able to effectively keep our lives and his life as normal as possible. And it has, even to the point of right now. We're watching a movie, and it's past ten o'clock; he's in a position where he can hook up the machine, bring a chair, and sit out in the living room and finish watching that movie, if it's something that we're watching on-demand. Or he can go to the bedroom if it's just a regular program and watch it in bed and finish watching it there. So yeah, the whole process has been, I think, we knew…I think we knew which way we were going to go. And our decisions were, I think, based on those…how is this going to affect our life? What is the best—well, first of all—what is the best procedure or process that we can do, and how will it or will not affect our normal life? What would minimize the impact on those and still get the end result?

Int.: And were those questions that you asked yourselves? Or are those questions you asked each other?

Pam: I think we asked them…I think we asked them ourselves at first, and then we talked about it together, don't you?

Gary: Yeah.

Pam: You were talking about decisions and looking up information and trying to figure all of this out. I think if we had a question that came in our minds, we also talked about it.

The dyad acknowledged that to maintain their family priorities, they would need to adapt their daily habits and activities, including their physical space, schedule, and routines to meet their larger family goals. Through their intentionally established collaborative problem-solving processes and the organizational patterns of connectedness and flexibility, the dyad pursued their family goals, shaped by their underlying belief systems.

Seeking semi-liberation

Dyads also used their organizational patterns, belief systems, and communication activities to find semi-liberation in a situation bound by knowledge, language, and resources. These processes were shaped by making smaller micro-decisions and applying "stubbornness" in response to limitations of choice. Jen (patient) and Rob (decision partner) were married for 12 years and are raising two young children. The couple had historically made meaning of adversity through a shared identity as survivors, shaped by their oldest child's extended stay in a neonatal intensive care unit and their experiences with surviving two natural disasters. Jen had been on dialysis for two years and had type 2 diabetes (T2D). Jen started dialysis emergently, which balanced their experiences between the family's needs and the limitations imposed by the healthcare system.

Jen: So, when I got discharged, they put me in-center because they wouldn't let me leave without having that. And they were like, "Okay, well you're in acute kidney injury." I was like, "All right." And they're like, "Well, you can recover from that." Okay. So, this was in October [that year]. So, November and December passed, and they told me, "If you want to do home hemo [dialysis], you can't be AKI [acute kidney injury]. You have to be ESRD [end-stage renal disease; end-stage kidney disease (ESKD); kidney failure]." And I just view that as a term, as words on paper. I said, "That's cool. Then make me ESRD so that I can move on with my life." Because when I was in-center, I woke up at 5 o'clock in the morning Monday, Wednesday, and Friday. My chair time was 5:30. I was done by 9:30 and at work by 10:00.

Rob: I mean, yeah, first off, she was doing that. But I mean, that's the thing. That's the whole thing. They went from saying she had an acute kidney injury [AKI] and she'll recover to she's on dialysis. And they also were supposed to do a biopsy for her kidney, and they were supposed to explore other reasons why something might be happening. They never even pursued any of that.

Jen: So as far as chronic kidney disease, I never had that. I was never treated for that. It's just all of a sudden—boom—your kidneys are dead. And no matter what I do, I can't get a doctor to understand that and say, "Well, let's try to figure out what went wrong here." It seems they are just like, "Well, you're on the program. Keep doing it." And that was beyond frustrating.

Ultimately, the dyad responded to the crisis of ambiguity regarding her diagnosis by collaboratively problem-solving to address barriers to their daily activities. The dyad's previous experiences with adversity shaped their belief that they could find semi-liberation through home hemodialysis's daily micro-decisions, despite the limitations imposed by the healthcare system.

Jen: So, I knew for a long time you could…do it at home. But I didn't know the difference between home hemo and peritoneal, and then I started asking questions. That's the thing—you have to ask questions. What sucks is nobody sits there and lays it out in front of you and says, "This is your choices. These are your options. This is what you can do."

Rob: You're only supposed to be just fitting in a box.

Jen: I mean, they treat me like that too, because I'm like, "Could I do this differently or could I do that?" I'm on four days a week, and I wanted to do every other day just because that will fit my lifestyle a lot better…

Rob: But I mean, either way, try to do something so you can be semi-liberated from having to just go and—

Jen: Be on somebody else's schedule…I don't, and that's part of the reason I wanted to go home hemo because I thought it was a more personalized care experience. And in some ways it is, but in other ways, it still is just…it's a different box. It's the same box, different shape.

While home hemodialysis provided a "differently shaped box" for the dyad to manage together, transcendent interpretation of survivorship established through tenacity provided a context for their interpretation of living with ESKD (end-stage kidney disease). While other dyads frequently described this tenacity as "stubborn" (Sledge et al., 2021), Rob and Jen framed their shared approach to thriving in spite of the limitations with dialysis as a strength that is shaped by experience.

Rob: Right. I mean, for me, I mean, it's the way that I view things. And I'm saying I always try to—even if I have down points or sad things—I always try to focus on the positive aspects of the things about Jen that not only make it so we are married, but I'm just saying, in terms of the dialysis, how strong she is about it, the fact that she still works. You know what I mean? Thinking of things in an appreciative way instead of focusing on the negative side of it all the time and letting it weigh in to where…Everybody's in different situations is what I'm saying, but still, there's other people who are there and they're being teammates with each other. But I'm just saying the way things work with relationships and stuff in general because, I mean, we know people who've been married, they were married whenever we first got married. They're already divorced or who knows what.

Jen: They make problems when they don't even have problems. We've been through real problems, and we worked through them and deal with them. I mean, it's not like we're never frustrated or mad about anything or whatever.

Rob: But like Jen said, I mean, I'm [an artist] and stuff so I have some type of outlet to go and do things. And I mean, she's still supportive of me doing that stuff. She doesn't sit there and say, "Oh, I have to do this, and you have to be here at my beck and call every day." In terms of that, you know what I mean? And, "I'm so downtrodden because I'm on dialysis." We don't treat the situation like that.

Jen's emergent start to dialysis shaped the dyad's early experience in searching for adequate dialysis knowledge to make informed decisions and achieve semi-liberation through home hemodialysis. The family's previous experiences with adversity contributed to organizational patterns that allowed the dyad to respond to the stress of dialysis initiation. The dyad's transcendent identity as survivors informed their interpretations of the limitations imposed by the healthcare system, and their organizational patterns and communication patterns shaped their responses.

Decision-making is caring

Dyadic shared decision-making was characterized in both the patient and decision partner as an act of caring that was intentional and shaped by relationship history and the evolving understanding of living with dialysis. Chuck (patient) and Rita (decision partner) were married for 41 years. Chuck started in-center hemodialysis three years ago after an emergent start, despite several years of CKD care. Rita was not active in Chuck's pre-dialysis nephrology appointments, and did not understand the physical changes he experienced before dialysis initiation. In addition to in-center hemodialysis, Chuck was blind and dependent on others for mobility. At the first crisis point of dialysis initiation, the dyad's organizational patterns established that Rita's role was to support Chuck's autonomy.

Rita: And then he called me. And he told me, he…and he said he's heading to the hospital. Because he was like—before then, he would just sit up at night. We would sit and prop him up in a chair because he couldn't breathe.

Chuck: Well, yeah, I couldn't. No, I couldn't lay back because I had too much fluid going in my lungs and [it was] drowning me.

Rita: And at the time he was seeing, so he would just jump up and run down the hall at the other house. He'd just jump up and run trying to—

Chuck: Well, I had to…I had to throw up to get some air. I had to get all of the liquid out of my lungs. So, I was [sic] killing me, so.

Int: Yeah. Yeah. So, when you were saying that you didn't want to do dialysis, how did you two talk about that?

Chuck: We actually didn't, because I didn't know what it was, and I don't think she knew what it was.

Rita: And to us, it was just a scary word.

Chuck: Right. I'm like, I had no idea what he was talking about.

Rita: And so, I was like…so as soon as he was going outside, he said…so whatever he had said, he didn't want to do. And I said, "Well, okay, I'll just leave it alone because that's your body. Whatever you decide to do is fine."

Chuck: Well, it really didn't matter what she said, because I'm an old country boy. I'm like, "I ain't doing it. I ain't doing it." That stubborn will kill you.

While the couple initially described much of their decision-making process as intuitive, they described a shared spiritual purpose to partnering, shaped by their marriage vows that structure their organizational patterns. Chuck's "stubbornness" relaxed to allow for more collaborative problem-solving, which facilitated their resilience, demonstrating organizational patterns of flexibility and connectedness. Thus, dyadic decision-making activities were purposeful and an extension of their commitment, and changed according to the dyad's understanding of their situation.

Rita: So, he was like, "Rita…" he said, "…well, I'll tell you later." And I was like, "How you doing?" Then I said, "Okay, all right. I'll show it." I'm sitting there saying, "Now, how am I going to do this? How am I going to do this?" [show support].

Chuck: But then, I was fine.

Rita: And so, it's like we got strength from each other. We just started talking.

Chuck: Yeah. I just wanted to get home.

Rita: And then we started talking. And he started telling me. I said, "Okay, yeah. And this is what happened with me." And I was like, "Okay. All right." Then he said, "The only thing I really need," he said, "at this time—I just need a hug." Okay, so I went and hugged him.

Chuck: Sometimes that's all you need.

Rita: Then I got one too.

As the dyad adjusted to living with dialysis, the decision partner's voice in shaping the micro-decisions of daily living and larger treatment decisions became more pronounced, demonstrating flexibility in organizational patterns. This increasingly collaborative problem-solving process was framed as both caregiving and partnering by the dyad. Ultimately, these activities were essential in coping with dialysis.

Rita: Well, first, you have to communicate with people. He had to learn this, and he's still learning this at the time. Even though you are still married as one, and you're learning to be one, if I'm afraid about something and you're strong about something, you can't assume that I'm strong because you're strong.

Chuck: Right, yeah, we definitely went through that.

Rita: Okay? You can't do that. You can't.

Chuck: Because it won't work; you're right. You can't make a person—because fear will make you stop. And if you push a person to something that they're afraid of, it ain't going to end well.

Rita: Now this is what I told him about dialysis, and I got tough on him about his days on dialysis: I said, "Look, honey. This is not school where you can take a GED. This is not a job where you can go get on the temporary service and go get a job." I said, "This is life. So, you got to do this every day whether you like it or not."

DISCUSSION

Families living with ESKD manage complicated treatment demands and schedules, polypharmacy, and symptom burden, which further affect the family system through caregiver distress, financial toxicity, and disruptions in work, school, and home life (Browne, 2019). These three dyads illustrate how the chronic nature of living with ESKD necessitates shifting priorities, activities, and roles throughout the modality decision-making process. Dyads shifted focus from the patient's body to family well-being, and worked to achieve semi-liberation as they learned more about living with dialysis. Dyads adjusted the extent of decision partner involvement in modality discernment, along the treatment trajectory. As the communication and problem-solving processes became opened, the dyads adapted organizational patterns and belief systems, shaped by the nested decisions of ESKD disease management, to promote family resilience.

Systems-level assessment and intervention that is framed by the Family Resilience Framework (FRF) may help the dialysis interdisciplinary team (IDT), including the patient and decision partner dyad, identify resources to respond to ecosystemic splits in healthcare that present threats to resilience (Walsh, 2004). Promoting the key processes of family resilience empowers the family to take proactive steps, to buffer disruptions, reduce risks of dysfunction, and support positive adaptation and resourcefulness to meet future challenges (Martin et al., 2015). While partnering with patient/decision partner dyads in modality discernment, the nephrology social worker should attend to the linkage between the presenting symptoms and family stressors. Family coping and adaptational pathways should be considered processes that change over time (Walsh, 2002). The FRF does not add an assessment to the already regulated dialysis patient assessment process (DHS, CMS, 2008). Instead, it provides a lens to engage dyads in assessment and intervention (Walsh, 2016).

The ecosystemic and developmental perspective of the FRF recognizes the evolving adaptational pathways of families living with chronic illness. Gary and Pam's example of shifting from physiological wellness to a family well-being perspective is consistent with research describing the evolving considerations in modality selection (Bezerra et al., 2018; Senghor, 2020; Winterbottom et al., 2014). The reassessment activities in dialysis clinics provide nephrology social workers with the opportunities to lead the IDT in exploring the changes in a family's resilience-promoting processes to consider modalities that are most meaningful, value-consistent, and beneficial to dyads and their families (Olthuis et al., 2014; Vranceanu et al., 2009).

The systemic orientation of FRF recognizes that families are situated within contexts (e.g., relationships, roles, spirituality, daily routines) and structures (e.g., social norms, socio-political, economic) that influence modality decision-making (Oshana, 2006). Jen and Rob were acutely attuned to the limitations of choice imposed by their limited knowledge of ESKD, medical language, and resources. Their belief systems and positive outlook shaped the organizational patterns and problem-solving that informed their modality selection. Rob and Jen demonstrated how the inherent power asymmetry imposed by lack of knowledge inhibited their opportunities to engage in shared decision-making with the nephrologist (Murray et al., 2013; Sledge et al., 2020). Exploring the dyad's organizational patterns, particularly their social and economic resources, can facilitate nephrology social worker attunement to the family's adaptative pathways to counter the power differentials that impede shared decision-making (Peek et al., 2016). Acknowledging and understanding the larger social structures that influence the dyad's key resilience processes facilitates modality selection consistent with the dyad's resources, values, and goals (Williams-Reade et al., 2014).

Rather than considering resilience individually, a family resilience perspective acknowledges that patients are embedded in relational networks that engage in caring practices through managing diagnostic, prognostic, and treatment-related information (Martin et al., 2015; Sledge et al., 2020). Chuck and Rita demonstrated engagement in modality decision-making discussions as an expression of caring and partnering that was intentional and responsive to treatment demands. While the influence of informal caregivers in dialysis patient outcomes is generally accepted in ESKD Care (Green et al., 2020; Renal Physician Association (RPA), 2010), family members are generally not engaged by the IDT in dialysis mode decisions until the end of life (O'Hare et al., 2017). A nephrology social work assessment that recognizes how dyads adapt roles according to their changing belief systems, organizational patterns, and communication may be more sensitive to the decision partner's influence in modality discernment (Kim et al., 2019).

Future research can provide opportunities to address the limitations of this study. The inclusion of only English-speaking participants limits the transferability of findings. Future research should explicitly explore the impact of culture on interpretation, health, illness, and care in dialysis modality decision-making. Additionally, racial and ethnic disparities in dialysis modality are well documented (Braun et al., 2021; Mehrotra et al., 2016). Given these disparities and interpretive phenomenology's goal to uncover commonalities and differences in experiences, future studies should focus on Black/African-American dyads' experiences. This study adds to the literature demonstrating that dialysis decisions are iterative and would be strengthened with a longitudinal design. The inclusion of active dialysis patients, rather than conservative care or transplant patients, does not address the full spectrum of ESKD treatment. The inclusion of the clinician perspective would provide a richer relational context to the experience of shared decision-making.

CONCLUSION

The dialysis interdisciplinary team balances patients' needs with the increasingly incentivized measures to promote positive patient outcomes, including home modality selection. Nephrology social workers are trained to facilitate dialysis modality decisions from a perspective that promotes resilience and attunement to the relational context of the patient.

This interpretive phenomenology study identified three interrelated themes:

- Their body, but not their life;
- Seeking semi-liberation;
- Decision-making is caring.

The chronic nature of living with ESKD necessitates shifting priorities, activities, and roles throughout the modality decision-making process. Dyads intentionally adjusted their decision-making activities as they shifted focus from the patient's body to family well-being and worked to achieve semi-liberation as they learned more about living with a family member undergoing dialysis treatments. The Family Resilience Framework provides a paradigm for nephrology social workers to assess the iterative process of dyadic dialysis decision-making to develop an individualized care plan that promotes resilience through attunement to dyad processes.

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Figure 1. **Family Resilience Framework** (Walsh, 2004)

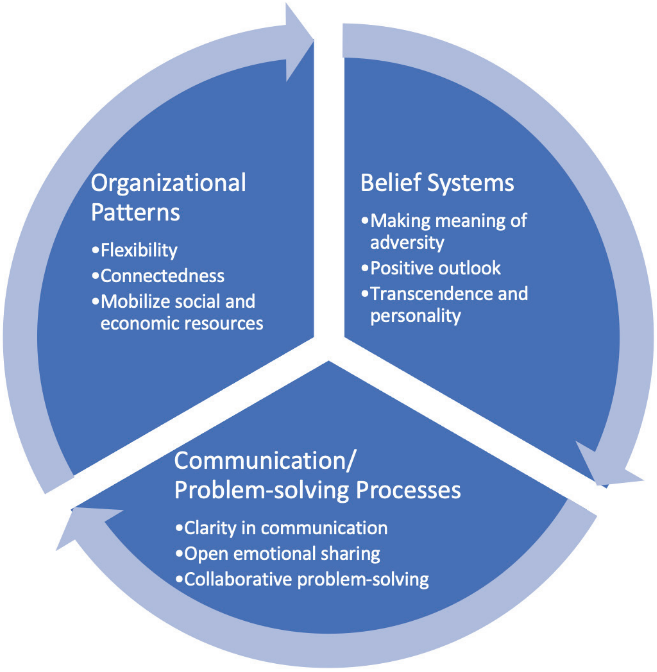

Table 1. Participant demographics

	Patient (*n* = 13)	Decision partner (*n* = 13)
Gender identity		
Male	7	3
Female	6	10
Race/ethnicity		
African American/Black	3	2
Hispanic/Latino	1	1
White/Caucasian	7	8
American Indian/Alaska Native	1	1
Asian American	1	1
Age		
20–29	1	0
30–39	3	3
40–49	1	1
50–59	4	1
60–69	1	4
70–79	2	4
80–89	1	0
Education		
High school diploma/GED	0	3
Some college	4	3
College diploma	5	6
Graduate school	4	1
Technical degree		
Employment status		
Employed	4	5
Unemployed	2	2
Student	1	0
Retired	6	6
Partner type		
Romantic partner	9	
Parent	2	
Friend	1	
Sibling	1	
Dialysis modality		
ICHD	6	
PD	3	
HHD	2	
NHHD	2	

Abbreviations: HHD: home hemodialysis; ICHD: in-center hemodialysis; NHHD: nocturnal home hemodialysis; PD: peritoneal dialysis.

Table 2. **Paradigm case demographic characteristics**

	Patient				Decision partner		
	Age	**Gender**	**Modality**	**Emergent start**	**Age**	**Gender**	**Relationship**
Gary and Pam	50–59	Male	PD	No	60–69	Female	RP
Jen and Rob	30–39	Female	HHD	Yes	30–39	Male	RP
Chuck and Rita	60–69	Male	ICHD	Yes	50–59	Female	RP

Abbreviations: HHD: home hemodialysis; ICHD: In-center hemodialysis; PD: peritoneal dialysis; RP: romantic partner.

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