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 min-

utes (**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, sociopolitical, 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)

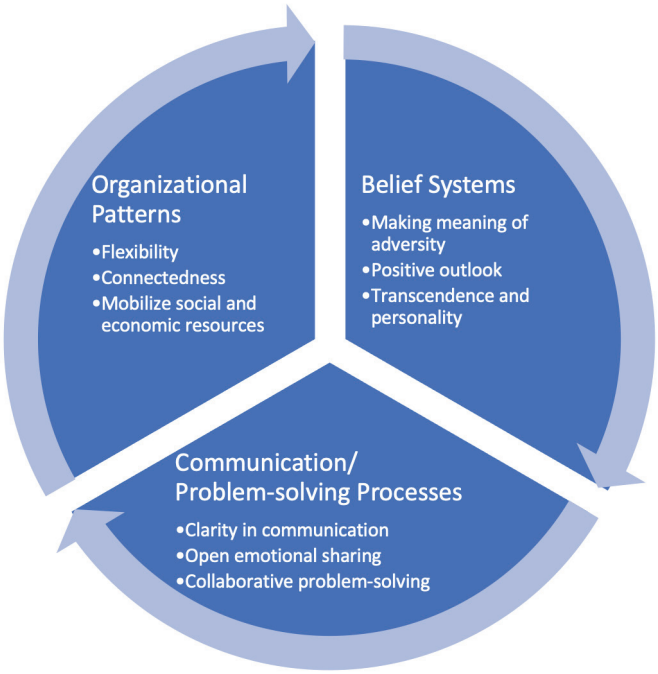

Table 1. Participant demographics

	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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