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

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3) Text
4) References
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"I don't want it to be left up to anybody else."— A Qualitative Study of Patient Experiences with Advance Care Planning in a Chronic Kidney Disease Clinic Employing the MY WAY Intervention

Adriana D. Glenn, PhD, MA, MN, RN, FNP-BC, CNE, George Washington University; Nadine Marchi, BSN, MSN, DNP, CRRN, CHSE, CNE, George Washington University; Elizabeth Anderson, DSW, LCSW, MSW, Pacific Institute for Research and Evaluation; Annette Aldous, MPH, George Washington University; Dale Lupu, MPH, PhD, George Washington University

Evidence-based practice requires input of patient preferences and values to improve patient outcomes and support their desired quality of life. Advance care planning (ACP) is used to coordinate care, and motivational interviewing (MI) can facilitate this process. This study, part of a larger randomized clinical trial, provides insights emerging during ACP discussions with chronic kidney disease (CKD) pre-dialysis patients. Data generated from 33 recorded patients were analyzed using qualitative content analysis. One overarching theme emerged prominently from the data: eliciting conversations. Four themes and ten sub-themes contributed to the overarching theme. ACP discussions with patients who have CKD are beneficial when starting predialysis. Use of an MI approach provides focus on the patient's narrative and guides the patient toward a more productive ACP discussion.

Keywords: Advance care planning, kidney diseases, supportive care, interpersonal relationships, motivational interviewing, coordination

INTRODUCTION

According to the National Kidney Foundation (2022), people with chronic kidney disease (CKD) experience comorbidities, such as stroke, dementia, and heart disease, and more than 125,000 patients go on dialysis each year creating complex end-of-life (EOL) decision-making issues. Patients with CKD who go on dialysis often express that dialysis was presented as a necessity, rather than a treatment option (Song et al., 2013). Davison et al. (2015) recommend in the Kidney Disease Outcomes Quality Initiative (KDOQI) that advance care planning (ACP) conversations occur upstream, prior to dialysis initiation. Currently, about one in three adults in the U.S. have completed an advance directive (AD) (Yadav et al., 2017). Yet, people with kidney disease are much less likely to have an ACP (Davison, 2010; Ladin et al., 2018; Luckett et al., 2014). As many as 90% of dialysis patients state they have not spoken with their nephrology team about EOL care (Davison, 2010). Additionally, almost 90% of kidney patients wanted to discuss EOL care and found supportive care valuable when they received accurate information (Davison et al., 2016). Davison (2022) notes that as the CKD disease trajectory progresses, patients' goals-of-care align with a focus on quality of life (QOL) , as opposed to simply survival; their support network and emotional/social health also become more important to address. The issue of nephrologists not broaching supportive care conversations when patients desire these conversations is concerning because ACP increases patient satisfaction (Amro et al., 2016), improves QOL (Wright et al., 2008), and reduces costs associated with overly aggressive EOL treatment (Moses et al., 2013; Song et al., 2015; Wright et al., 2008).

Advance care planning (ACP) is a preventative intervention allowing people to plan their future healthcare in case of incapacity (Sudore et al., 2018). ACP is one avenue for facilitating and structuring goals-of-care conversations. An AD, the result of this planning, is a legal document used to communicate the person's healthcare values and preferences. ACP research on populations with late-stage diseases, including CKD dialysis patients, is well documented (Arora, 2022; Bowling et al., 2017; Fahner et al., 2019; Lee et al., 2018; Song et al., 2009; Wong et al., 2019). There is a paucity of literature on the initiation of ACP conversations with CKD patients, predialysis. The prominent barriers to provider-initiated ACP conversations are: inadequate training of nephrology providers (Combs et al., 2015; Schell & Lam, 2017); fears of upsetting patients or destroying hope (Wasylynuk & Davison, 2016); lack of provider knowledge and insufficient time (Haras et al., 2015); low health literacy of patients (Yadav, 2017); as well as unfamiliar terminology, providers' reluctance to engage in conversation, patients conforming to social constructs, differing expectations of in-treatment, and alignment of EOL with the patient's preferences and values (Ladin et al, 2018).

To address this disparity, an ACP intervention specifically for CKD clinics, Make Your Wishes About You (MY WAY), was designed and grounded in motivational interviewing (MI)

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(Anderson et al., 2018). MI is a person-centered counseling style which focuses on eliciting patient motivations and exploring and resolving ambivalence (Rollnick & Miller, 1995). Research by García-Lanna et al. (2014), supports that MI can be used in the early stages of a chronic illness to facilitate ACP discussions.

To better understand the motivations and challenges arising during ACP dialogues, using MI a qualitative analysis was conducted of the audio-recorded interviews at one CKD clinic, guided by Story Theory. Story Theory, a middle-range nursing theory, is quite useful for understanding what is most important to a person with a health problem (Smith & Liehr, 2005). Underlying assumptions include: 1) people change connection with varied dimensions; 2) they live in an expanded present encompassing past and future events transformed into the present; and 3) they experience meaning via awareness of their story facilitating their ability to address challenges (Smith & Liehr, 2005). A few studies have used Story Theory as a framework to develop effective intervention programs (Crogan et al., 2008; Liehr et al., 2006). In this study, Story Theory complements MI because one views the patient's story emerging from guided, casual conversation which provides understanding of what is most important to the patient's goals-of-care and a foundation for knowledge development. This theory is very helpful in providing a working foundation for nephrology staff, including nurses and social workers who most likely would work with patient's ACP in the clinic setting.

The MY WAY approach combined MI skills with ACP conversation best practices, including eliciting patient values, life goals, and preferences regarding future healthcare, including establishing a healthcare agent (Wong et al., 2019). Using a randomized control trial approach, the study tested the effectiveness of a MY WAY trained coach with CKD patients, versus previously published literature and resources on ACP.

METHOD

This qualitative study used data generated from interviews facilitated by an ACP coach trained in MI by this study's author (EA). Data yielded reveals CKD patients' conversations, motivations, and challenges with ACP. The consolidated criteria for reporting qualitative health research (COREQ) was followed, addressing necessary components of the research design (Tong et al., 2007).

Study Population

The study was part of MY WAY, a larger randomized clinical trial of ACP in patients with CKD, which was approved by the George Washington University Institutional Review Board (Anderson et al., 2018). Three CKD clinics in different states participated. The larger multi-site study, conducted from May 2018 to October 2019, involved 254 participants. Eligible patients were 55 years or older, had stage 3–5 CKD (**Table 1**), and were English speaking. The study tested a model intervention to increase ACP. Using MI, a trained ACP coach met in person with patients assigned to the intervention arm, discussing their goals and preferences. One clinic site invited participants for audio-recorded coaching sessions for qualitative analysis and monitoring of adherence to the intervention protocol. Of 43 participants assigned to receive coaching sessions, 41 consented to recording, 37 completed at least one coaching session, and 33 were actually recorded. Reasons for non-recording of 4/41 sessions were technical and logistical, unrelated to patient preference. This study examines data generated from the 33 recorded participants. The demographic characteristics of the participants were similar to the overall sample (**Table 1**).

The trained ACP coach used the *Curriculum Guide for Advance Care Planning (Item Supplement 1)* (Western Carolina University, n.d.), which contained suggested prompts. Additional materials included a checklist to assess participants' readiness for ACP engagement. Participants received a scheduled 60-minute in-person coaching session and proceeded at their own pace. Coaching sessions averaged approximately 47 minutes with a range of 19–75 minutes. Audio recordings were sent for professional verbatim transcription.

Data Analysis

Qualitative Content Analysis (QCA) (Saldaña, 2021; Schreier, 2012) was performed on the data. QCA is a systematic and flexible approach to analyzing qualitative data. An initial reading was performed by the first author (AG), identifying potential codes, topics, patterns, and initial thoughts. Transcripts were then reread using the lens of Story Theory to reveal and interpret the meaning of the participants' narratives and to discover potential personal challenges.

The first author developed a coding frame based on the initial and subsequent readings. The coding frame was uploaded by a study author (AA) into Dedoose Version 8.0 software web application (2019). The first and second authors (AG & NM) performed coding independently in Dedoose. Once coding of all the responses was complete, codes were sorted into categories. Categories ultimately contributed to the development of themes based on how codes co-occurred.

Reliability of the QCA process was ensured through intercoder reliability. The first author was experienced in qualitative methods. During the data analysis process, discussions among the first and second authors addressed alternative interpretations and interconnectedness between codes and theme development. Categories and themes were then discussed with the additional authors with agreement reached on analysis and final representations of the data which supported consistency regarding data meaning and interpretation.

RESULTS

Overview of Participants

The 33 participants recorded during coaching sessions ranged in age from 55 to 85 years, with most being 65 to 74 years (42%). Most of the participants were White (76%) with slightly more females (54.5%) than males (45.5%) and the majority had a CKD diagnosis of stage 3 or 4 (94%). Participants were pre-dialysis and had no history of kidney transplantation. Most participants rated their health by the Patient-Reported Outcomes Measurement Information System (PROMIS) as fair to very good (90.9%) (Cella et al., 2007) (**Table 1**).

Themes

The Story Theory framework was critical for understanding the importance of story to motivate and frame conversations on ACP. Story Theory illuminates the intentional dialogue around the story created by the ACP coach. The ACP coach's expertise helped patients connect to and understand their ACP choices, which led patients and their families to greater awareness of motivators and challenges in the process of ACP and successful completion of documentation. **Figure 1** represents how the story ultimately helps form the AD.

We identified five themes, including an overarching theme: *Eliciting Storytelling, Conversation Connections, Barriers to ACP, Spirituality and Religion*, and *Knowledge*. ACP conversations require motivation and *Eliciting Storytelling* overlaps with the other four themes. Ten subthemes were also identified. The 5 themes and 10 contributing sub-themes are presented in **Boxes 1–4** with illustrative quotes supporting each area.

Eliciting Storytelling

Eliciting Storytelling emerged as an overarching theme because it helped patients share their personal stories related to ACP. ACP coaches elicited story telling about ACP by encouraging patients to share narratives that reflected life stories about their experiences with serious or terminal illness. For example, an ACP coach initiated a goals-of-care conversation by directly acknowledging how a patient's life experiences may be driving their decisions and asking them to reflect on the connection.

> *A lot of times when you come to writing these wishes for yourself, you think about who, how in the family it happened…if someone in your family was terminally ill and dying, how it went for them and if you were a part of that, and if that is what is influencing what you're thinking now.*

Queries from the ACP coach often resulted in topics of trauma, death, spirituality and conflict, which provided context to then move to the patient's personal wishes regarding healthcare and ACP. Using MI, the ACP coach can take this type of information and knowledge to frame an ACP conversation and help the patient see that they are able to decide and plan for themselves.

Conversation Connections

The theme Conversation Connections captured the wide, but relevant topics present when participants had discussions about ACP using MI. Conversation topics included the sharing of lived experiences, humor, and motivators for engaging in ACP (**Box 1**).

Lived experiences. The lived experiences of participants were instrumental in providing reflection and guidance for the ACP process. Conversations about "what ifs" occurred organically and their lived experiences affected their thoughts on withdrawing treatment or planning for the future. Some participants shared their health history, providing context about the hesitancy to begin the ACP process, because they also desired a focus on living (**Box 1**).

Humor. Participants used humor to diffuse uneasiness, unpleasantness, and tension. Laughter was not out of place and helped to reduce the stress and connect with the ACP coach as she guided participants through ACP conversations (**Box 1**).

Motivators. Participants identified several reasons why they were motivated to complete ACPs, including retaining a sense of control over one's fate. Participants were motivated by sensational cases of people who did not have an ACP. Participants shared stories and observations about other family members' lives and the impact of not having an ACP.

Reducing Burden. Participants expressed concern that, without an ACP, their families may prolong life, possibly leading to financial worries or concerns. Several patients brought up the need to have a plan because they did not have family.

Barriers to ACP

The barriers described in interviews ranged from healthcare provider trustworthiness, patient and family comfort levels with discussions, uncertainty about physical being at the end-of-life, to defining physical being in the context of QOL (**Box 2**). Being cognizant of these potential challenges patients face is critical when using MI during the ACP process.

Trustworthiness. Several patients expressed worries that healthcare providers might be callous in their recommendations of EOL. These thoughts are common, with many citing this as a reason not to participate in organ donation when developing an ACP.

Comfort level with ACP discussion. Participants shared the challenges of discussing their EOL wishes. Many participants shared that the topic is considered taboo because these conversations evoke feelings of discomfort in their families. Participants shared that an additional hurdle is the identification of someone whom they appoint as their decision maker.

The issue involving the appointment of a decision maker largely relates to participants' concerns about placing undue stress on their loved ones. Participants identified immediate family (spouse, children), followed by extended relatives and, in the absence of family, close friends as decision makers. Many participants echoed sentiments like, "I don't want to put that on my decision maker," or "I feel just awful. That puts a lot of stress on her." Participants attempted to balance capturing their EOL wishes and ensuring that the ACP was not too restrictive for their decision maker. The presence of family member(s) during the interview posed additional concerns regarding trust because some patients did not feel they could freely express themselves and wishes to the ACP coach. Additional concerns included their decision maker's ability to carry out their wishes.

Burden in QOL context: Participants identified being a burden to loved ones as a QOL issue. Participants reported concerns about asking family to make important healthcare decisions that could create an emotional or financial burden, while also acknowledging that undocumented wishes may not be followed or result in potential legal challenges among family members. Several participants noted concerns about potential family and legal conflicts in the plan of care.

Physical being (uncertainty of physical being at the end of life). Participants voiced concerns about how to capture their EOL wishes in a document. They struggled with defining their physical being's impact on having a meaningful life, and then simplifying it for an AD form. Some participants viewed some machines as providing QOL for physical well-being, while other machines were viewed as inhibiting QOL. For instance, life support or dialysis machines were viewed as having a purpose, but participants expressed uncertainty regarding their quality of life and physical well-being after removal from machines. Some viewed a ventilator as extending a poor QOL but did not view a dialysis machine as life extending and had the notion that a dialysis machine offered a "better" QOL.

Several participants reported experiencing constant pain and questioned their ability to have a meaningful life due to their physical condition. They also questioned how to address pain in the ACP form because they were already experiencing constant pain. The ACP coach would remind them of the context of the ACP and that responses to forms are designed to be "when you are very sick" and notes if the patient does not acknowledge this on the form, "Docs [doctors] look at these in a total picture." Sometimes, the ACP coach simply affirmed the patients' statements to let them know she heard them and reminded them of their goals as well as, "No matter how sick you are or where you are, the doctors and nurses should always be working on keeping you comfortable."

Spirituality and Religion

"Higher power" is not exclusive to religion. Spirituality was an important part of ACP conversations for most participants. Spirituality is defined as a connection with something called a "higher power" or something larger than the patient's life and is usually focused on a sense of peace or purpose (**Box 3**). Religion is seen as more of a specific set of organized beliefs/practices. Participants often connected God to descriptions of spirituality. The ACP coach took cues from the patients and explored their beliefs and connections by asking for clarifications and specifics related to those beliefs and in the context of desires they may want included in their ACP or AD document. Some participants provided specific information regarding religious beliefs while others described their religious practices (e.g., rites, rituals associated with the physical body) and how they aligned with their wishes.

Knowledge

Knowledge of ACP is needed to have meaningful interactions. Participants' knowledge varied widely. Some participants struggled with common medical terms, while others with ACP experience were more comfortable navigating terms, forms, and language (**Box 4**).

Terminology and legal confusion. Terms, forms, and concepts were sources of confusion. Many participants did not understand the meaning of "comatose." When participants were unfamiliar with the terms used, ACP appeared less productive, as evidenced by the need for multiple sessions. Participants were perplexed by some of the questions healthcare providers viewed as basic, such as, "You wanted to give total flexibility to your decision maker?" Some participants appeared to have communication challenges and were unable to express themselves.

Experiential knowing. A few participants had a strong sense of ACP terms and processes. Participants who had prior, direct experience and knowledge of AD were more comfortable during the interviews. Their wide range of knowledge displayed underscores the need to evoke the stories of participants to understand their knowledge, comfort, and health literacy prior to beginning ACP conversations. The use of MI helped to draw out the personal experiences essential to guiding patients in developing the ACP.

DISCUSSION

Quality content analysis (QCA) was used to explore the content of conversations patients had with an ACP coach who used MI. By using MI, the ACP coach evoked stories to understand patients' motivations and concerns which is helpful while engaging in ACP. It is critical to frame these conversations within the context of the individual's experiences to reflect the patients' comforts, desires, and knowledge. An ACP coach using MI and facilitating the patient's storytelling helped to bring meaning to the ACP process, which optimally concluded with creation of an AD. Patients' varied conversations during ACP related their life stories and lived experiences with death and dying. Using MI, the ACP coach facilitated patients' life sharing and supported beliefs aligning with person-centered care, mutual goal attainment, and positive patient outcomes. Patients were motivated to participate in ACP by: 1) the need/desire for autonomy and QOL they viewed as acceptable, and 2) the desire to reduce distress for their loved ones. The most difficult conversations identified by the patients related to: 1) the comfort level of the patient's family when the patient attempted to initiate ACP discussions, and 2) how to effectively convey their holistic experience of physical being in written documentation within the context of complex healthcare technology.

The patients were comfortable, reflective, and able to connect their stories to the development of an ACP, with most patients being able to voice their ACP in one session. During the ACP process, humor appeared to be a coping mechanism in addressing emotionally laden conversations. Also noteworthy was patients sharing with the ACP coach the specific spiritual/religious rites/rituals associated with the physical body that may be important for some, so the spirit can move freely to the "next plane." Extracting personal stories could be time consuming, but patients' lived experiences provided a bridge connecting the past with the future.

The use of MI was an effective communication approach because it provided an organized method toward creating a narrative and foundation for the ACP dialogue leading to an AD document.

This research adds to findings on the importance of ACP with CKD patients. However, this study brings novel information regarding ACP in pre-dialysis patients and how MI can enhance ACP. Despite the benefits of starting ACP discussions early in the CKD illness trajectory, most ACP conversations are delayed until a crisis or the patient's health is severely compromised (Hutchison et al. 2017; Miller et al., 2019; Owen & Steel, 2019). Patients prefer, and will wait for, providers to initiate ACP conversations (Owen & Steel, 2019). Patients are motivated to engage in ACP discussions and value the opportunity when it is introduced by providers (Owen & Steel, 2019). One study noted 60% of patients would not start ACP discussions (Owen & Steel, 2019). This delay in discussions affects potential QOL concerns patients may have but are not able to express. Patients and families value ACP and share that it is important for providers to begin ACP conversations earlier (Hutchison et al. 2017; Miller et al., 2019; Owen & Steel, 2019). Patients' satisfaction and comfort with ACP discussions with their providers are supported by relationship and psychosocial components (Hutchison et al., 2017).

The conversations evoked by MI during ACP, including illness, loss, and death, emerged in this study and aligned with prior research (Molzahn et al., 2019). This research also identified topics, including spirituality/religion and the selection of a decision maker, as important in ACP conversations. The patients' stories were an important impetus for framing their conversations and providing comfort in moving toward ACP discussions. Using MI, patients were more receptive and engaged in discussing their health desires and wishes when ACP was discussed within the context of health, illness, and lived experience (Simpson, 2012).

As previous findings suggest, the ACP motivators for patients in this study largely centered on prior observations of close family/friends who faced EOL situations and a strong desire to reduce the decision-making burden and conflict among the family left behind. Patients expressed a genuine desire for autonomy over their lives and bodies in the event of significantly diminished QOL or death.

This research also identified patients' barriers during the ACP process. These topics included: worries regarding trustworthiness of the healthcare providers, broaching the conversation of ACP with family, selecting a decision maker who would uphold the patient's wishes, ACP knowledge, and defining levels of comfort in the context of death (i.e., use of life-sustaining machines/technology). These topics have been well documented in ACP literature (Hutchison et al. 2017; Johnson, 2016; McLennan et al., 2015; Molzahn et al., 2019; Owen & Steel, 2019). The distinct perceptions of the different types of life-sustaining machines is an interesting issue that emerged from this study and has not been described elsewhere. It is possible these thoughts reflect a patient's level of understanding of a machine's purpose as well as awareness of its impact on one's QOL and may factor prominently in the selection of which machine is seen as palatable to them for selection in ACP. A dialysis machine still allows for an acceptable level of independence and QOL, while a ventilator requires a much greater physical dependence, limiting awareness or enjoyment of life. However, lower health literacy could be responsible for unrealistic views of the purpose of a dialysis machine (Ladin et al., 2018). These findings merit further exploration.

Consistent with prior research, our data suggests challenges with ACP discussions stemming from patients' health literacy. Patients value honest and understandable discussions with enough information regarding their prognosis for them to engage in ACP. Lower health literacy impedes the effectiveness of EOL conversations, affects the patient's ability to use basic health information in decision making, and interferes with a patient's ability to understand complex medical concepts (Ladin et al., 2018). Lower health literacy also contributes to distrust of healthcare providers which has implications for the facilitation of productive ACP conversations. It is evident patients need more guidance from providers as well as help in formulating and documenting preferences.

There are two clear findings of this study. The first highlights the need for nephrology social workers in the ACP process. Social workers as ACP coaches are uniquely qualified to facilitate important ACP conversations and document the patient's wishes. Social workers' professional ethics include respect for an individual's right to self-determination (National Association of Social Workers, 2023), which aligns with the patient-centered focus prominent in today's healthcare settings. Social workers in the nephrology space work with diverse populations and possess knowledge specific to understanding the disease trajectory and the significant comorbidities associated with CKD. Nephrology social workers (NSWs) recognize the importance of ACP, as well as the need for trust, relationship building, and good communication (Nedjat-Haiem et al., 2023), and that patients' decisions can and do change based on the clinical findings. Thus, NSWs are ideal brokers of the ACP process. Furthermore, as ACP coaches, they are well equipped to "broker communication between the patient, doctors and family members about the documents [AD]" (Nedjat-Haiem et al., 2023, p. 5), which is instrumental in supporting the patient's expressed wishes to their family and healthcare team. NSWs are essential to the interprofessional team because they improve communication and promote AD completion. Another finding of this study was the data reflecting ACP in the setting of CKD with pre-dialysis patients. Prior ACP work for patients with CKD occurred through dialysis treatment. An important aspect of this work was understanding how patients respond to ACP at an earlier point in their illness, as well as the value of having structured conversations with a dedicated ACP coach.

A notable limitation of this study is that patients' narratives were from one site and one person conducted all MI sessions. The findings may not be transferable to other settings or capture additional nuances that might emerge resulting from use of a more experienced ACP coach or a higher level of interprofessional collaboration. Additional research is needed to explore matters of trust, as well as defining patients' comfort levels in the context of life-limiting illnesses and healthcare technologies, and the written documentation of their preferences.

In conclusion, ACP discussions with patients who have CKD are beneficial when started pre-dialysis and when integrating the patient's personal story. The process becomes more meaningful when patients incorporate their lived experience into ACP. MI allows the provider to comfortably evoke the patient's goals and values for inclusion in the ACP discussion and mitigate some of the barriers identified in the literature. The use of MI provides focus on the patient's narrative and guides them towards a more productive ACP discussion and increases the likelihood of completion of an AD document.

Author Note: *All authors declare that they have no conflicts of interest. No external funding was used in the preparation of this manuscript. Address correspondence to the primary author, Dr. Adriana D. Glenn, George Washington University, at* **adrianaglenn@gwu.edu**.

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Table 1. *Participant Characteristics*

	All	Interviewed (recorded)
N	254	33
Age Group, *n* (%)		
55–64	65 (25.6)	9 (27.3)
65–74	118 (46.5)	14 (42.4)
75–84	60 (23.6)	9 (27.3)
85+	11 (4.3)	1 (3.0)
Gender, *n* (%)		
Female	134 (52.8)	18 (54.5)
Male	120 (47.2)	15 (45.5)
Race, *n* (%)		
White	161 (63.4)	25 (75.8)
African American/Black	92 (36.2)	8 (24.2)
Asian	1 (0.4)	0 (0.0)
CKD Diagnosis, *n* (%)		
Stage 3	136 (53.5)	21 (63.6)
Stage 4	102 (40.2)	10 (30.3)
Stage 5	16 (6.3)	2 (6.1)
eGFR, mean *(SD)*	31.58 (11.86)	34.64 (12.67)
Comorbidities, median [IQR]	2.00 [1.00, 3.00]	3.00 [3.00, 5.00]
PROMIS Overall Health*, *n* (%)		
Excellent	8 (3.1)	1 (3.0)
Very good	45 (17.7)	4 (12.1)
Good	88 (34.6)	12 (36.4)
Fair	89 (35.0)	14 (42.4)
Poor	24 (9.4)	2 (6.1)
IPOS-Renal Score, mean *(SD)*	16.28 (9.98)	17.52 (9.56)
ACP Engagement Score, mean *(SD)*	35.61 (7.61)	35.76 (6.89)
ACP Barriers, median [IQR]	1.00 [0.00, 2.00]	1.00 [0.00, 2.00]
ACP Facilitators, median [IQR]	5.00 [4.00, 6.00]	5.00 [4.00, 6.00]

ACP: advance care planning; CKD: chronic kidney disease; eGFR: estimated glomerular filtration rate; IPOS: Integrated Palliative care Outcome Scale; IQR: interquartile range; *N*, *n*: number; PROMIS: Patient-Reported Outcomes Measurement Information System; *SD*: standard deviation

*Where percentages do not add to 100%, the difference is attributable to rounding.

Boxes 1–4. Overarching Theme—Eliciting Storytelling: *"...did you see things that made you want to shape your own wishes?" (ACP Coach)*

[Note: Edited for grammar and punctuation.]

Box 1: *Conversation Connections*

Lived experiences

"…what we feel and that's been shaped by events that have happened watching other people." (Participant 39, patient)

"…we would just sit at the table and have these discussions and I always remember, I had one…I have this brother who, when we were having these discussions, he was in seminary and he was always out there saying, 'No, no, no you don't pull the plug,' and we would always argue at the table. No, if you know it's your time and you want somebody to pull the plug, I'd pull the plug." (Participant 30, patient)

"Yeah, I even got shot one time. It went through my small intestine, big intestine, hit my left kidney, chest bone, and my lumbar vertebrae. I had a colostomy for over a year." (Participant 13, patient)

"I am at peace with myself. I am at peace with God, and I am happy. I mean I've got high blood pressure, vasculitis, neuropathy, stage 4 kidney disease. I am looking at some dialysis. I got to go next week to the doctors. They are going to put another needle in my eye because I have bleeds in my eyes. But—You know what?—I am happy. I am alive." (Participant 13, patient)

Humor

"Comedy usually helps." (Participant 9, patient)

"I will just wait until he gets to the other side and then I will get him. I am not going to come back and haunt him; I am just going to wait until he gets there." (Participant 35, patient)

"If I am unable to communicate, but I am lucid and cognizant and can listen and watch television…I would want to die if they don't put FOX® News on. If there were only MSNBC®—that is an end-of-life decision. If I can't have that [a sense of humor] then it's not worth it." (Participant 85, patient)

Motivators

"…the one case we always studied in school was the Karen Ann Quinlan case [A controversial 1975 right-to-die case.] and so, I don't want anything like that to happen to me." (Participant 30, patient)

"On the day of her bridal shower she [her cousin] stopped at a yard sale and she was hit by a car and [she suffered] a head injury and her parents kept her alive for, I want to say, 25–30 years. They [family] can hang onto you for a long time. You don't know how people will respond…they are stuck on you and want you to survive." (Participant 67, patient)

"I would just rather go home [to die] instead of everybody come[-ing] every week and cry and waste a bunch of money on a 'vegetable.' It's not good. Let God, let Him, do what He needs to do." (Participant 13, patient)

"I don't have anybody else, so if I don't make the plans, there is nobody. I don't want it to be left up to anybody else." (Participant 29, patient)

"My grandmother suffered, emotionally, terrible at the end. She was not at peace when she died, and I was young, so I did not understand. It took me years to understand that, at the end, you have to be at peace with something at the end, and she wasn't. She fought it clean to the end. She jerked and twisted and fought. There was no peace to that. I think in your life you have to find peace because you are going to die." (Participant 9, patient)

"I've been talking with the minister for the last couple of weeks, because I am not sure whether I want to go on dialysis now at all. I mean everybody's got a different opinion, if it's suicide or not, because I don't want that." (Participant 29, patient)

Reducing burden

"I wouldn't want to burden anybody." (Participant 33, patient)

"…a drawn-out ordeal and I know it was stressful for my mom, my brother, and of course, for myself—for all the family." (Participant 35, patient)

"If I cannot be revived in as far as being on life support, and I am going to be in there the rest of my life, I don't want to be like that." (Participant 13, patient)

"We had this [experience of not having an AD] with my mother-in-law. There were times where my husband was just stuck in neutral and couldn't come to a decision about something." (Participant 37, patient)

"…you see fights sometimes with the children having one belief, you know." (Participant 30)

"[ACP is] …useful in a legal sense…" (Participant 49, patient)

"…there are certain things that are going to be touchy points with the family that are going to be left, and that is one of the things we want to use a living will for." (Participant 49, patient)

Box 2: *Barriers to ACP*

Trustworthiness

"…you know I have this dilemma of wanting to donate stuff, but not trusting the doctor's incentives." (Participant 71, patient)

"I would prefer that you did not sign that one [ACP]. I am worried that I would get someone who doesn't know your history and doesn't know you…I just would rather you did not do that." (Family member)

"…but I also don't want somebody else to walk in the room who has no ties with you and say, shut her off." (Family member)

Comfort level

"It's [conversations about ACP] more difficult when it's an intimate person in your life…" (Participant 81)

"…in some circumstances, I want one person to be the decision maker and then in other instances, I want someone else to be the decision maker." (Participant 11)

"I have two children, twins, very capable but I don't know which one of them to choose because the other one might get upset about it." (Participant 20's family member)

"When it comes time [to], excuse the expression, 'pull the trigger,' can she do it?" (Participant 30, patient)

Physical being

"I don't think [surrounding physical] conditions are important because you are not all that concerned about your surroundings. The environment has very little to do [sic] when things become that intense". (Participant 65, patient)

"…I don't understand the one [question] about pain because to me you have pains and you live with them." (Participant 60)

"You may want to fight no matter what. I mean I don't want to be hooked up to machines, but if there is a possibility to go beyond the machines where I could be taken off the machines…if I have all my senses you know, like my dad did because he was alert when it came time to start turning everything off. He was still alert." (Participant 53, patient)

"Although that one [pain question; to be free from pain] is so subjective. I mean, I have been through so much pain over the years." (Participant 80, patient)

"I'm just not ready to spell out every scenario because I don't think that's easy to do. As I look at this question, I think it's some degree of vanity—it's only worth living if you can feed, bathe and take care of myself. There are so many circumstances where there [that] is not, you know, a factor, so I would dismiss that point. Be free from pain? I'm in pain now, so what the heck!" (Participant 51, patient)

"…it all depends on my condition. If I've had a heart attack or stroke, I would. I would not want aftercare. When I was a child, my father had a series of strokes, and I remember he was incapacitated for about eight years." (Participant 33, patient)

Box 3: *Spirituality and Religion*

"Higher power" is not exclusive to religion.

"My relationship with God is the most important to me." (Participant 65, patient)

"God has a plan for you and a reason for it." (Participant 49, patient)

"Sometimes you get to a point and you are so emotional, you can't think straight, and you need that [spiritual] guidance." (Participant 87, patient)

"We have Bible directives about extreme measures that prolong life, and we have respect for life but, ultimately, we know the condition of ourselves, being who we are in this world. With death, [considering] how it impacts everybody around, we use reasonable, but not extreme means." (Participant 65, patient).

[Religious beliefs (e.g., rites, rituals associated with the physical body) and practices and how they align with their wishes.] "The ritual of washing and preparation of the body… so that the soul is comforted. It doesn't have so much anguish and the soul doesn't really leave the body until the body is actually in the ground, which is why we bury so quickly. We don't embalm, we get the body in the ground, and once it's in the ground, then the soul can go up and go to its next journey…" (Participant 87, patient)

Box 4: *Knowledge*

Terminology and legal confusion

"Can you educate me on that? What's going on when you're in a coma?" (Participant 51, patient)

"How specific do you get?" (Participant 67, patient)

"When I write in there that my son has all the 'yeses' or 'nos,' and he is stuck with it, okay so he is my medical decision maker? I wasn't sure about filling in anything." (Participant 60, patient).

"When they say you are intubated, does that mean they are feeding you too?" (Participant 80, patient)

"So, I suffer from depressions and I don't apprehend a lot of stuff." (Participant 6, patient)

"You know what? We did something, and it's in the bank. In fact, it's in the bank down here, but I don't know if it's the same thing." (Participant 37, patient)

Experiential knowing

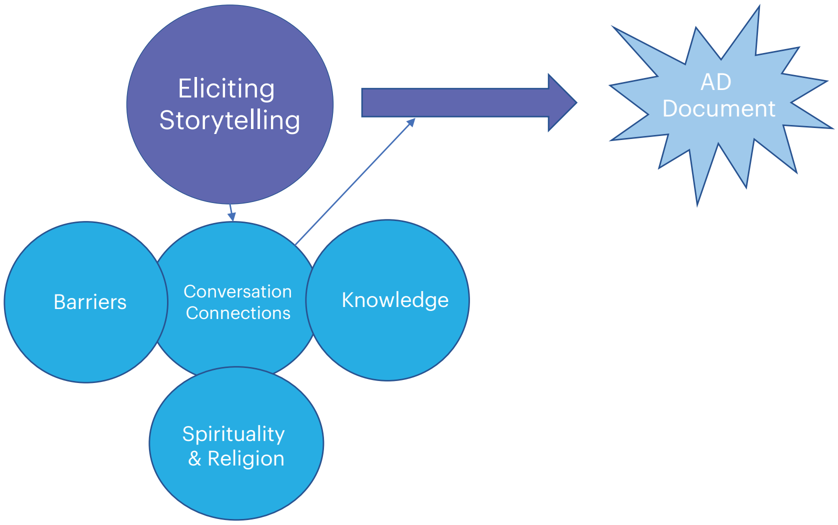
"…more of an advance directive…but it was not a situation where it was a crisis situation." (Participant 51, patient)

"I went through my father passing away, my wife passing away, and my mother passing away. I took care of a lot. I was an administrator of a nursing home, assistant administrator of a nursing home." (Participant 76, patient)

"'Medical power [of] attorney' is a legal term whereas 'agent' is not a legal term. So, since this is not being made out by an attorney, it's important to use the term 'agent.' So, based on their decision making [nursing home residents], it was my job to talk to each one of the residents and find out what they wanted or [to] talk with the family members…and to get the paperwork if they had it and arrange for them to meet with an attorney if they didn't have paperwork. I was there for the meetings, but I was not part of the decision making." (Participant 84, patient)

Figure 1: *What emerges in conversations about advance care planning?*

When an ACP coach elicits story telling, themes about ACP relating to *Barriers, Spirituality and Religion* and *Knowledge* of ACP or EOL, conversation occurs. The *Conversation Connections* theme captures relevant topics present in ACP discussion which help facilitate progress and guidance of patients toward the desired behavioral change—discussion leading toward eventual completion of an AD.



APPENDIX

Clinical Resources

Center to Advance Palliative Care: https://www.capc.org/

Coalition of Supportive Care for Kidney Patients; Implementing the MyWay Approach to Advance Care Planning into CKD Practice: https://kidneysupportivecare.net/resources-for-providers/

Standardized Outcomes in Nephrology (SONG) Initiative: https://songinitiative.org/

Dialysis Social Work, Professional Practice, and Social Work Education

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The purpose of this study is to identify tasks, setting characteristics, and practice barriers encountered by dialysis social workers in order to inform social work education. Through convenience sampling, 62 dialysis social workers from the United States completed a 31-item survey. Findings revealed that 45 of the 62 respondents (72.5%) indicated that they had minimal or no supervision, and only six (9.7%) had supervisors who were social workers. Respondents reported high caseloads, role confusion, and role ambiguity in this setting. Recommendations for social work education include: strengthening content on healthcare social work in all specializations, and emphasizing leadership and autonomy in practice, ethical decision making, professional advocacy, and policy practice.

Keywords: dialysis, education, nephrology, social work

INTRODUCTION

The purpose of this research is to identify the roles and tasks performed by social workers in dialysis clinics to inform and strengthen healthcare social work, education, supervision, and professional clinical practice.

Social workers are key members of the interdisciplinary team in dialysis and nephrology settings (Jackson, 2014), and since 1976, Medicare regulations have required that these specialty settings have qualified and licensed social workers on staff (National Archives and Records Administration, 1976). There are more than 7,500 dialysis clinics throughout the United States (Levin, Lingam, & Janiga, 2020), yet the number of social workers in dialysis settings is hard to determine. Although there is not an exact number of how many dialysis social workers there are in the United States, dialysis social work is a popular specialty and employment setting for social workers (Craig et al., 2016; Jackson, 2014; Spigner, 2017).

The Council of Nephrology Social Workers (CNSW) provides valuable resources and materials for dialysis social workers, such as standards of practice, professional networking, and webinars. In addition, two health social work textbooks (Dziegielewkski & Holliman, 2020; Gehlert & Browne, 2019) include sections on dialysis and nephrology social work. Other health social work texts (Allen & Spitzer, 2016; Cowles, 2003; Heyman & Congress, 2018; McCoyd & Kerson, 2016) do not explicitly cover dialysis social work, but these texts present examples and models that could be applied to social work in dialysis settings.

Because of the importance of dialysis social work, we were perplexed by the dearth of content and literature on the specialty in health social work textbooks and social work education. This led to our interest and further exploration of the specialty to learn more about the roles of social workers in dialysis settings.

METHODOLOGY

Survey

To assess the perceptions and work environment of dialysis social workers, a 31-item survey titled “Clinical Opportunities for Dialysis Social Workers” (CODSW) was developed. The CODSW consisted of closed-ended and open-ended questions that explored the work setting of dialysis centers (e.g., tasks completed in dialysis centers and social work supervision) and dialysis social work characteristics (e.g., the number of hours worked and the number of patients). The CODSW also assessed the demographics of the research participants. To access this online survey, the participants were informed of the purpose of the survey, the number and categories of survey items, and the amount of time it may have taken to complete the survey, and that their participation was strictly voluntary. In addition, the survey introduction explained that data from the survey would only be reported in aggregate form and that the survey was constructed using the ethical guidelines of the National Association of Social Workers (NASW) Code of Ethics (2021). The survey and study were approved as Exempt after full review by the Institutional Review Board of the authors' institution.

Sampling Strategy and Data Analysis

The survey was created using Qualtrics XM (2019) and disseminated to dialysis social workers. Dialysis social workers were identified through the personal and educational contacts of the investigators. The CODSW was sent to dialysis social workers through their personal emails to avoid work oversight and conflicts of interest. The survey was also advertised on Facebook groups for social workers, such as the Net-

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work of Professional Social Workers, Hospice Social Work Support Group, and our university's MSW alumni page. In addition, the CODSW was sent to the Listserv of the National Kidney Foundation Council of Nephrology Social Workers twice—initially in January 2020, and then two weeks later. Data was collected over a two-month period.

The data from the closed-ended questions were entered into IBM® SPSS (Statistical Package for Social Sciences)(2023) to calculate the means, standard deviation, frequencies, and percentages, while the data from the open-ended questions were transferred to a spreadsheet in Microsoft® Excel for analysis. A content analysis, as described by Cummings and Worley (2018), was used to analyze the open-ended questions for emerging themes. The content analysis method involved having three dialysis social workers (i.e., Georgia Licensed Master Social Workers with at least two years of work experience in dialysis settings) as subject matter experts to sort each statement into domains (i.e., themes) that they perceived to emerge throughout the sorting process. Inter-rater agreement of the three professionals was utilized to ensure accuracy of the sorting process. A statement was not sorted into a theme without consensus from all raters during the sorting session. If the three raters could not come to a consensus, a fourth rater (i.e., a social work professor with at least five years of clinical experience) would settle the dispute. However, there were no disputes among the three dialysis social workers. The thematic labels were created to allow for more meaningful interpretation of the data.

RESULTS

Participants

Sixty-two social workers (all of whom identified as female) responded to the survey. Of the 62 participants, 44 (71%) identified as White, 11 (17.7%) identified as African American/Black, three (4.8%) identified as Hispanic/Latino, two (3.2%) identified as more than one race, one (1.6%) identified as Asian, and one (1.6%) individual did not indicate their race or ethnicity. The survey participants were employed in 18 different U.S. states. Of the 62 participants, 16 worked in Georgia; seven from Texas; six from Illinois; five from California; three were working in each of these states: Florida, Pennsylvania, New York, Minnesota, and Michigan; two respondents worked in each of these states: Hawaii, Virginia, and Indiana; and one respondent worked in each of these states: Tennessee, Wisconsin, Arkansas, Connecticut, Oklahoma, and Louisiana. One respondent did not identify their location. This demographic and locational information is also found in **Table 1**.

Table 1. *Survey Respondents' Demographic and Locational Information*

Survey Respondents (*N* = 62)	**Number (*N*) and % of respondents**
Sex/Gender	
Female	62 (100%)
Male	0 (0%)
Race/Ethnic Identifiers	
African American/Black	11 (17.7%)
Asian	1 (1.6%)
Biracial/Multiracial	2 (3.2%)
Hispanic/Latino	3 (4.8%)
White	44 (71.0%)
Did not indicate race/ethnicity	1 (1.6%)
Location of Respondent	
Arkansas	1 (1.6%)
California	5 (8.1%)
Connecticut	1 (1.6%)
Florida	3 (4.8%)
Georgia	16 (25.8%)
Hawaii	2 (3.2%)
Illinois	6 (9.7%)
Indiana	2 (3.2%)
Louisiana	1 (1.6%)
Michigan	3 (4.8%)
Minnesota	3 (4.8%)
New York	3 (4.8%)
Oklahoma	1 (1.6%)
Pennsylvania	3 (4.8%)
Tennessee	1 (1.8%)
Texas	7 (11.3%)
Virginia	2 (3.2%)
Wisconsin	1 (1.6%)
Not reported	1 (1.6%)

All of the participants held an MSW degree. All but one social worker indicated that they were licensed in social work. The job positions held by the research participants included job titles such as social worker, dialysis social worker, renal social worker, and nephrology social worker.

As shown in **Table 2**, the participants' mean number of patients was 106.20 (*SD* = 32.28) and the range of patients served by a social worker was from 30 to 150. Participants worked an average of 38.4 hours per week (*SD* = 8.46), with a range of 8 to 50 hours per week. The social workers surveyed worked in their current position for an average of 89.73 months (*SD* = 107.10), just over seven years. One social worker stated they had worked at their center for 1.5 months, and the one with the longest tenure had worked in dialysis settings for 34 years. The average number of centers covered by the social work respondents was 1.65 (*SD* = 0.83) or one to two centers. More than 80% of the participants stated they worked in private/for-profit dialysis centers, compared to 17.7% in private/non-profit and 1.6% in city or county.

Table 2. *Participant Work Setting Characteristics*

Characteristics of participants' work settings (*N* = 62)	**Mean (*SD*) or *n* (%) or range (lowest to highest)**
Number of patients	106.20 (*SD* 32.28)
Lowest to highest number of patients (range)	30–150
Hours worked	38.40 (*SD* 8.46)
Lowest to highest (range)	8–50
Months/years in current position	89.73 months (*SD* = 107.10), approx. 7.5 years
Lowest to highest (range)	1.5 months to 34 years
Number of centers covered by workers	1.65 (*SD* = 0.83)
Lowest to highest (range)	1–2
Dialysis center ownership	
Private/for-profit	50 (80.7%)
Private/non-profit	11 (17.7%)
City/county	1 (1.6%)

Job Skills
To gain an understanding of how often social workers use the skills they acquired during their social work education and field placements, survey participants were asked to rate on a 1 ("Never") to 5 ("Always") Likert scale the frequency at which they used their social work skills on their job. The average response was 3.23 (*SD* = 1.12), indicating most of the time they use their social work skills. See **Table 3** for frequencies and percentages. Examples of social work skills most often utilized were psychosocial assessment, depression and suicide risk screening, supportive counseling, and cognitive behavioral therapy (CBT).

Table 3. *Frequency of How Often Respondents Indicated They Used Professional Social Work in Dialysis Settings*

Survey question: How often are you able to use professional social work skills in dialysis social work? *N* = 62. (Likert Scale (1 Never, 2 Rarely, 3 Sometimes, 4 Very often, 5 Always))	**Number (percentage)**
Always	11 (17.7%)
Very often	14 (22.6%)
Sometimes	15 (24.2%)
Rarely	22 (35.5%)
Never	0 (0%)

Avg. 3.23% (*SD* = 1.12)

Regarding the tasks these social workers performed, most indicated they occasionally performed clerical tasks, such as greeting those who entered the center, answering the center phone, and copying/scanning/faxing documents along with other center personnel. Approving work hours/time off and scheduling patients was typically done by the charge nurse and/or administrators. When it came to addressing insurance concerns and education, 60 (97%) of social workers indicated they performed that task in their center. Forty-nine (79%) of social workers indicated they arranged transportation, and 61 (98%) of social workers indicated they linked patients and caregivers with community resources.

Stress and Supervision on the Job
To assess the stress levels experienced by social workers, a 1 ("not stressful") to 10 ("very stressful") Likert scale was used. The average response among the social workers was 6.28 (*SD* = 2.16), indicating they experienced moderate stress levels.

To examine factors that can cause stress for social workers, the type of supervision and the frequency of the interruptions experienced by social workers was explored. A 1 ("I really don't have supervision. I almost never see my supervisor.") to 5 ("I have extreme close supervision in which my supervisor checks my work all the time.") on The Likert scale was used to assess the social workers' supervision. The average response of the social workers was 1.10 (*SD* = 0.76). Forty of the 62 respondents (64.5%) indicated that they had minimal or no supervision at work. See **Table 4** for frequencies of types of supervision of dialysis social workers. When asked about the discipline and background of the respondents' supervisors, 45 of the 62 (72.5%) respondents stated that their supervisor had a nursing background, six (9.7%) stated their supervisor was a licensed social worker, two (3.2%) reported their supervisor had an MBA or a business background, and other responses included a dialysis technician, a registered dietitian, a physician assistant, and someone with a BS in Criminal Justice. Four respondents did not include the professional or educational background of their supervisor. To assess how frequently social workers got interrupted when working with a patient, a 1 ("never") to 5 ("always") Likert scale was used. The results showed the average response was 3.19 (*SD* = 0.92), indicating that many of the social workers do get interrupted while interacting with patients.

Table 4. *Frequency of Supervision*

Describe the supervision you have in your present job? ***N*** **= 62**	**Number and percentage of respondents indicating this frequency of supervision**
I have extremely close supervision in which my supervisor checks my work all the time.	2 (3.2%)
I have moderate supervision in which my supervisor occasionally checks my work	15 (24.2%)
I have minimal supervision in which my supervisor rarely checks my work.	32 (51.6%)
I really don't have supervision. I almost never see my supervisor.	13 (20.9%)

The respondents were also asked an open-ended question to discuss what they believed were the barriers in their settings to using professional social work skills, such as doing psychosocial assessments and clinical and behavioral interventions with patients who are living on dialysis and with end-stage kidney disease and their caregivers. Fifty-eight of the 62 (93.5%) respondents wrote about these challenges in the survey; two stated that there were no barriers to providing these services, and two left this item blank. From the 58 written responses, a content analysis was performed with the barriers organized into the categories of: *client characteristics, social worker characteristics, setting/facility/organizational characteristics,* and *procedural and policy characteristics*.

Client Characteristics

Client characteristics are described as factors or qualities of patients and caregivers that may make it challenging for social workers to perform psychosocial assessments and interventions in dialysis settings. From our content analysis of the barriers, appointment fatigue (i.e., clients being exhausted due to multiple medical appointments and long treatments), clients not feeling well, stigma of receiving psychosocial services, and transportation schedules affected the client's willingness and ability to participate in psychosocial treatment from social workers.

Social Worker Characteristics

"Social worker characteristics" are defined as limitations that social workers identified in themselves or other social workers as barriers or weaknesses in conducting clinical assessments and performing social work interventions in dialysis settings. These limitations and barriers stem from their beliefs about their lack of clinical skills, language barriers between themselves and clients, or not seeing dialysis social work as clinical social work. **Table 5** lists responses from the survey respondents that implied that some social worker characteristics were limitations/barriers in providing clinical and therapeutic services to dialysis clients.

Table 5. *Limitations and Barriers of Social Workers to Provide Clinical Social Work*

Social worker characteristics identified by survey respondents as potential barriers to providing clinical mental health and therapy interventions:	
Response 1	"Because I've been doing case management so long, I am out of practice with my clinical skills."
Response 2	"New social workers need extended training and continuing education to provide clinical treatment. They don't often have this in dialysis social work."
Response 3	"There are language barriers between many of the patients and the dialysis staff, and it is not fair to ask the family members to interpret, and in therapy there may be things the patient doesn't want their family members to hear and interpret."
Response 4	"There is not enough consensus among social workers to do therapy with dialysis patients. Some social workers don't want to do therapy with patients."
Response 5	"This job doesn't pay enough for me to do therapy as well."
Response 6	"Providing clinical social work would be a conflict of interest for clinic social workers. We know their families and if they are compliant or not. It is a conflict because we are often the ones to tell them what they should be doing or what they can't do rather than being their therapists."
Response 7	"Dialysis social work is a task-oriented job, not a clinical job."

Setting/Facility/Organizational Characteristics

Work setting, facility, physical, and organizational characteristics are factors within the work environment that affect the delivery of services. In the survey results, these characteristics were most commonly listed as barriers to providing professional social work interventions. Twenty-one (33.9%) reported that physical work setting factors, such as lack of privacy and quiet (e.g., people talking and machines making beeping noises), in dialysis settings were barriers for social workers to engage in in-depth therapy with clients. **Table 6** provides responses from participants describing setting/facility and organizational barriers.

Table 6. *Setting/Facility and Organizational Barriers to Providing Clinical Social Work*

Setting/facility and organizational barriers to providing clinical social work in dialysis settings as identified by survey respondents	
Response 1	“Treatment floor is not quiet or private. There are lots of interruptions, including taking patient vitals, responding to the machines, and checking on how the treatment is going.”
Response 2	“It is difficult to get into deeply personal information chairside.”
Response 3	“Private office space is not available where I work.”
Response 4	“Lack of space to have confidential discussion; lack of time when patient is present; physical issues that superseded dealing with psychosocial issues."

Procedural and Policy Barriers

Forty-eight respondents (77.4%) identified procedural and policy barriers, such as large caseloads, not having enough time to provide longer term interventions with patients/caregivers, lack of understanding of the competencies and professional skills of MSWs, and the corporatization of dialysis and healthcare. See **Table 7** for responses describing these barriers.

Table 7. *Procedural and Policy Barriers to Providing Clinical Social Work*

Procedural and policy barriers to providing clinical social work in dialysis settings as identified by survey respondents	
Response 1	“At my clinic it seems like they look at me when there is a problem or when pt’s [sic] need help with transportation or insurance.”
Response 2	“Micromanaging by telling SWs how to do every aspect of their job, totally misunderstanding what an MSW is trained for and capable of.”
Response 3	“After 34-plus years in dialysis, I can tell you that the actual quality of time a social worker is able to spend with a patient has drastically deteriorated due to the clerical tasks placed on the social worker by the company they work for, the Network, the government, etc.”
Response 4	“When dialysis became corporate, the paradigm changed. It became all about checking the box for annual transplant education, advanced care [sic] planning, screening for depression—redundant and rote—not much time to find out about family stressors or address what was going on or needed at home—too much focus on missed treatments—outcome[s] driven; forced, structured social work program—like the programs they want us to implement—to the point of harassment and almost threatening if you don’t get the numbers—not about quality—no flexibility/freedom to do what would be helpful; also too much time spent on insurance issues; high caseload and unrealistic expectations for social workers.”
Response 5	"...medical staff don't understand what social workers do."

CONCLUSION

The results of the Clinical Opportunities for Dialysis Social Workers (CODSW) survey yielded an array of data to describe characteristics of dialysis social workers, their work environments, and barriers to their work with patients. For this study, we examined the components of social work practice and barriers to providing professional services. For the dialysis social workers surveyed, setting, facility and organizational characteristics were reported to be the most burdensome for them as they engaged in social work practice with patients. In dialysis centers most of the social workers' time—approximately 25 to 30% per week—is allocated for administrative tasks, such as addressing insurance and financial concerns, implementing center initiatives and projects, documentation, setting up transportation, risk management, answering the phone, copying/faxing, and scheduling transportation (S. Chambers, B. Hebert, & P. Murphy, personal communication, November 3, 2021). Social workers also reported that, in dialysis settings, licensed social workers addressing insurance concerns and patient financial and transportation issues had been more common than in other medical settings where they have worked, such as hospice, inpatient care, or transplant services (B. Hebert, personal communication, November 3, 2021, & P. Murphy, personal communication, June 19, 2023).

The average caseload size for the social workers surveyed was 106.20 (*SD* = 32.28). Roughly this could mean that, in a 40-hour week, each social worker had three minutes to spend with each of their patients. However, this did not include time for documentation, addressing insurance and financial concerns, participating in center initiatives, setting up transportation, risk management, administrative meetings, and more. High caseloads and the amount of time spent doing indirect social work practice made it difficult, if not impossible, to provide individualized and in-depth services to patients and caregivers.

The results of this survey led to recommendations for direct and macro social work practice and education. Dialysis social workers face challenges similar to those faced by medical social workers, as well as social workers in settings where they may be considered "guests" in host settings. Dane and Simon (1991) describe how social workers have been "guests" in host settings, such as hospitals, medical clinics, schools, psychiatric settings, and juvenile courts since professional social work was first formalized in the early 20th century. Dane and Simon (1991) define "host settings" as organizations whose mission, structure and authority are defined by those who are not social workers.

Professional guests in host organizations, as social workers are in dialysis settings, are confronted with role ambiguity, role strain, professional tokenism, and isolation (being the only social worker in a setting), as well as discrepancies between their own social work values and ethics and institutional values and requirements (Dane & Simon, 1991).

Furthermore, practicing dialysis social workers become acutely aware of the social inequities faced by their patients and gaps in the healthcare system that interfere with providing quality patient care. Advocacy is an important tool for social workers. Joining organizations such as the National Association of Social Workers (NASW) and the National Kidney Foundation (NKF) as a social worker are ways to join with others to advocate for systemic and structural changes in policies, communities, and organizations to provide early, accessible, and high-quality services for people with kidney disease.

Other startling findings from this survey were that only six of the 62 social work respondents (9.7%) had social work supervisors, and that 45 of the 62 respondents (72.5%) stated that they had minimal or no work supervision. From these findings, it is recommended that all MSW specializations strengthen their content on health and healthcare social work and emphasize leadership and professional autonomy in social work practice, ethical decision making, advocacy, and policy practice. The NASW Code of Ethics (2021) and Peace's (2016) standards of practice provide a foundation for nephrology social workers for ethical practice and leadership.

Knowing when and how to seek supervision and consultation from social work colleagues, the interdisciplinary team, professional networks, and advocacy organizations is also critical. Furthermore, implications from this survey may include professional development and continuing education specific to dialysis centers, providing language interpreters in settings, and further qualitative studies of dialysis social workers to provide more detail about social work practice and barriers in dialysis centers.

As dialysis social work can be considered a subspecialty of health social work, content from health social work texts is clearly applicable to dialysis social work. This content includes human biology; medical diagnosis; treatment and terminology; social workers and role ambiguity and role confusion; working on multidisciplinary and interdisciplinary teams; documentation and technology in healthcare settings; and clashes between social work values and those of the host settings. In addition, topics from macro social work and policy—the development and structure of the U.S. healthcare system, Medicare, Medicaid, private and managed payor sources, and the corporatization of human services—are also pertinent to dialysis social work practice.

The limitations of this research are that the data for this survey was collected through convenience and network sampling, and this is not as robust as random sampling. Also, the data were collected in January and February 2020, before the COVID-19 pandemic and restrictions came to the United States. This may have affected the sample size. Additionally, starting March 2020, medical settings changed dramatically. Staff and patients were required to wear and use personal protective equipment and dialysis centers required that all have their temperature taken before entering the dialysis center. In some dialysis centers, the social worker was the professional required to do the additional tasks of taking temperatures and doing a short questionnaire to screen for COVID-19 risks and symptoms (S. Chambers, personal communication, March 30, 2020).

Despite the sample size and convenience and network sampling, the researchers were impressed with how quickly completed surveys were returned and how detailed some of the written responses were to the open-ended questions. We concluded that this showed interest and enthusiasm for dialysis social work. We see potential for dialysis social workers to become powerful advocates for those with kidney disease, and to work for changes in the healthcare system to promote more comprehensive psychosocial care for those with chronic illnesses.

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APPENDIX

Clinical Opportunities for Dialysis Social Workers

1. Gender: ______________________________
2. Ethnicity or race: ________________________
3. Location of employment (city/state): __________
4. Educational background (major/field of study & degree):

   ____

5. List all professional licenses or credentials you currently hold: ________________________

   ____

   ____

6. What type of dialysis patients do you work with? Check all that apply:

   ___ In-center/clinic

   ___ Home

   ___ Other: ______________________________

7. On average, how many patients do you serve?________

8. What is the title of your present job?

   ____

9. Auspice of dialysis center:

   ___ Private/for-profit

   ___ Private/non-profit

   ___ Federal (VA or military)

   ___ State

   ___ City or county

   ___ Other______________________________

10. How long have you worked in your current position?

    ______ Months ______ Years

11. In a typical week, approximately how many hours do you work at this job? ____

12. How many dialysis centers do you cover? ____

13. On a scale of 1 to 10, with 1 being not stressful at all and 10 being extremely stressful, how stressful is your workload? ____

14. At your center, who carries out the following? List the position title of the person who most often completes the following tasks:

    Greeting those who enter the center _______________

    Answering the center telephone _______________

    Copying/scanning/faxing _______________

    Approving work hours and time off _______________

    Scheduling patients _______________

    Addressing insurance concerns _______________

    Education on insurance _______________

    Community resources for patients _______________

    Arranging transportation _______________

15. How would you describe the type of supervision you have in your present job?

    ___ I have extremely close supervision in which my supervisor checks my work all the time.

    ___ I have moderate supervision in which my supervisor occasionally checks my work.

    ___ I have minimal supervision in which my supervisor rarely checks my work.

    ___ I really don't have supervision. I almost never see my supervisor.

16. What is the professional background/discipline of your supervisor? ______________________________

17. How do you assess for depression in your patients?

    ___ PHQ-2 (Patient Health Questionnaire 2)

    ___ PHQ-9 (Patient Health Questionnaire 9)

    ___ The Beck Depression Inventory

    ___ Other: ______________________________

18. How often do you screen for depression in dialysis patients? ______________________________

19. If a patient scores positive for depression, how often do you refer to or recommend outpatient mental health therapy?

    ___ Always

    ___ Very often

    ___ Sometimes

    ___ Rarely

    ___ Never

20. If a patient scores positive for depression, how often do you inform the medical doctor?

    ___ Always

    ___ Very often

    ___ Sometimes

    ___ Rarely

    ___ Never

21. If outpatient therapy is recommended for a patient, how often do they agree to participate in outpatient therapy?

___ Always

___ Very often

___ Sometimes

___ Rarely

___ Never

22. If you answered "Sometimes," "Rarely," or "Never" to Question 21, why do you think patients decide not to receive outpatient mental health therapy?

____

____

23. If antidepressants are recommended to the patient by the medical doctor, how often does the patient agree to take them?

___ Always

___ Very often

___ Sometimes

___ Rarely

___ Never

24. If you answered "Sometimes," "Rarely," or "Never" to Question 23, why do you think patients respond negatively to taking anti-depressant medications?

25. How do you treat or address depression in your dialysis center? (Check all that apply.)

___ Groups

___ Psychoeducation

___ Self-care (Discuss exercise, walking, yoga)

___ Family support (talk to family to address and get family involved)

___ Supportive counseling

___ Cognitive behavioral therapy

___ Other (Please describe.) __________________

____

26. How often are you able to use professional social work skills in dialysis social work?

___ Always

___ Very often

___ Sometimes

___ Rarely

___ Never

27. Describe the professional social work skills that you use.

____

28. What are the barriers to using professional social work skills in dialysis social work?

____

29. How often do you get interrupted when trying to use social work skills with a patient?

___ Always

___ Very often

___ Sometimes

___ Rarely

___ Never

30. What do you see as some of the potential interventions that dialysis social workers could use in treating/addressing depression with patients?

____

31. After completing this survey, do you have additional comments or feedback about social work in dialysis settings?

____

____

____

____

____

National Kidney Foundation 2023 Spring Clinical Meetings Social Work Abstracts

CKD/ESRD—Otherv

1 In a National Survey—Nephrology Social Workers' Opinions on the Use of Acceptable Humor in Conversations with Advanced Illness Patients

Kevin Caeckowski, Christina Yuan, Dustin Little. Walter Reed National Military Medical Center, Bethesda, MD, United States

2 Low Utilization of Outpatient Social And Behavioral Services Among Patients with Documented Problems (ICD-10-CM Z-Codes)

Yun Han[1], Tiffany Veinot[1], Brenda Gillespie[1], Jennifer Bragg-Gresham[1], Yoshihisa Miyamoto[2], Meda Pavkov[2], Hal Morgenstern[1], Rajiv Saran[1]. [1]University of Michigan, Ann Arbor, MI, United States; [2]Centers For Disease Control and Prevention, Atlanta, GA, United States

3 COVID-19 Vaccine Perspectives And Experiences Among Patients with Kidney Failure in the Southeastern U.S.

Megan Urbanski, Laura Plantinga, Emma Blythe, Monique Hennink, Stephen Pastan, Rachel Patzer. Emory University, Atlanta, GA, United States

4 Applying the KDQOL Survey in Ethiopia

Niya Ahmed[1,] Wubshet Jote[1,2], Tigist Demisse[1], Biruh Workeneh[3]. [1]King Menelik II Hospital, Addis Ababa, Ethiopia; [2]St. Paul Millennium Medical College, Addis Ababa, Ethiopia; [3]University of Texas MD Anderson Cancer Center, Houston, TX, United States

TRANSPLANTATION

5 Barriers in Access to Transplantation in Central Texas in the Setting of a New Transplant Program

Gloria Chen[1], Brindha Anantharam[2], Cindy Hu[2], Sofia Jimenez[2], Anderson Slack[2], Arnold Kuk[2], Brian Lee[2], Nicole Turgeon[2], Joel Adler[2]. [1]Dell Seton Medical Center at the University of Texas at Austin, Austin, TX, United States; [2]Dell Medical School At the University of Texas at Austin, Austin, TX, United States

6 Barriers And Facilitators of Transplant Listing for ESKD Patients with Limited Health Literacy

Colleen Satarino[1], Karen Crampton[1], Deb Manderachia[2], Silas Norman[1]. [1]University of Michigan Health, Ann Arbor, MI, United States; [2]Veterans Administration, Ann Arbor, MI, United States

7 Deliberate Delay in Transplant Education for "Overwhelmed" Dialysis Patients

Jenny McDonnell, Megan Urbanski, Stephen Pastan, Janice Lea, Kimberly Jacob-Arriola, Cam Escoffery, Rachel Patzer, Adam Wilk. Emory University, Atlanta, GA, United States

8 How Dialysis Providers Assess and Refer Patients For Kidney Transplant Evaluation: A Process Model

Adam Wilk, Jenny McDonnell, Megan Urbanski, Stephen Pastan, Janice Lea, Kimberly Jacob-Arriola, Cam Escoffery, Rachel Patzer. Emory University, Atlanta, GA, United States

1. IN A NATIONAL SURVEY—NEPHROLOGY SOCIAL WORKERS' OPINIONS ON THE USE OF ACCEPTABLE HUMOR IN CONVERSATIONS WITH ADVANCED ILLNESS PATIENTS:

Kevin Ceckowski[1], Christina Yuan[1], Dustin Little[1]. [1]Walter Reed National Military Medical Center, Bethesda, MD, United States

By using acceptable humor, defined as "a smile, a laugh or a joke," do social workers experience less burnout on their own lives? Do they believe that humor alleviates perceived pain or discomfort in advanced illness patients? Smiling, laughing, and a kind joke is a part of many social workers lives and no less important for those patients with advanced illness. Social workers frequently encounter patients with advanced illness in the end-stage renal disease (ESRD) setting. They assess for depression, anxiety, pain, and suicidality. Death is all too frequent in this population, and this contributes to burnout. In multiple studies on palliative care, the use of humor allows providers, patients, and caregivers to be connected, provide them hope, decrease their agitation, and improve their own unique perspectives.

This study was a cross-sectional, 33-item anonymous online survey. It was sent out by the Executive Directors from the 18 ESRD Networks. Permission to proceed from the Centers for Medicare & Medicaid Services (CMS). No identifiable information was collected, all questions were optional and the survey could only be taken once.

Over 6,100 surveys were e-mailed with a rate of return of 21% (1,018) over three weeks in May-June 2022, with a 100% completion rate.

The survey used a Likert scale. A majority of social workers (92%) strongly agreed or agreed that they engage in acceptable humor and (80%) use humor in their practice 26-100% of the time. These social workers experienced burnout (80%) and (67%) felt that humor decreased this burnout and enhanced their personal connection(s) (95%) with their patient. Most did not use humor until the patient initiated (83%). A majority (60%) felt that their cultural background influenced positively their ability to engage in humor. Humor was also useful in allowing for the patient to cope with grief (72%), emotional distress (84%) and their overall well-being (95%). There was no difference in the use of acceptable humor by gender, ethnicity or region of the country. However, the use of acceptable humor slightly increased as the provider's age and the number of years in practice increased in white respondents (*N*=753).

2. LOW UTILIZATION OF OUTPATIENT SOCIAL AND BEHAVIORAL SERVICES AMONG PATIENTS WITH DOCUMENTED PROBLEMS (ICD-10-CM Z-CODES):

Yun Han[1], Tiffany Veinot[1], Brenda Gillespie[1], Jennifer Bragg-Gresham[1], Yoshihisa Miyamoto[2], Meda Pavkov[2], Hal Morgenstern[1], Rajiv Saran[1]. [1]University of Michigan, Ann Arbor, MI, United States; [2]Centers for Disease Control and Prevention, Atlanta, GA, United States

ICD-10 Z-codes were launched in 2015 to record health-related social needs and behavioral health issues. Social and behavioral services may be important to improve care, especially for conditions like chronic kidney disease (CKD). We assessed whether patients received appropriate social and behavioral services following records of selected Z-code concerns.

Patients insured by Medicare Advantage (MA) or Commercial (COM) plans with 5 Z-code concerns were extracted separately: 1) dietary, 2) tobacco use, 3) primary support group, 4) social environment, and 5) upbringing problems (Optum data 2015-2020). Outpatient social and behavioral services—dietary counseling visits, smoking and tobacco use counseling visits, and social worker visits—were captured using CPT codes or provider ID. Patient demographics, CKD, and other conditions that predict social and behavioral services were assessed using logistic models.

More COM patients than MA patients received appropriate services when they had records of problems related to dietary (32.4% vs 5.7%), primary support group (18.8% vs 12.1%), and social environment (15.7% vs 6.6%), while less COM patients received such services when they had records of tobacco use (7.1% vs 11.4%) and upbringing problems (23.5% vs 35.8%). Younger age and male sex were associated with less use of social and behavioral services after adjusting for patient factors (Tab). CKD patients with COM plans and dietary problems were less likely to receive dietary counseling.

Use of social and behavioral services was low in patients with Z-code concerns. The inverse association between CKD and receiving dietary counseling suggests missed opportunities in health-care delivery tailored to nonmedical problems.

2. (*continued*) LOW UTILIZATION OF OUTPATIENT SOCIAL AND BEHAVIORAL SERVICES AMONG PATIENTS WITH DOCUMENTED PROBLEMS

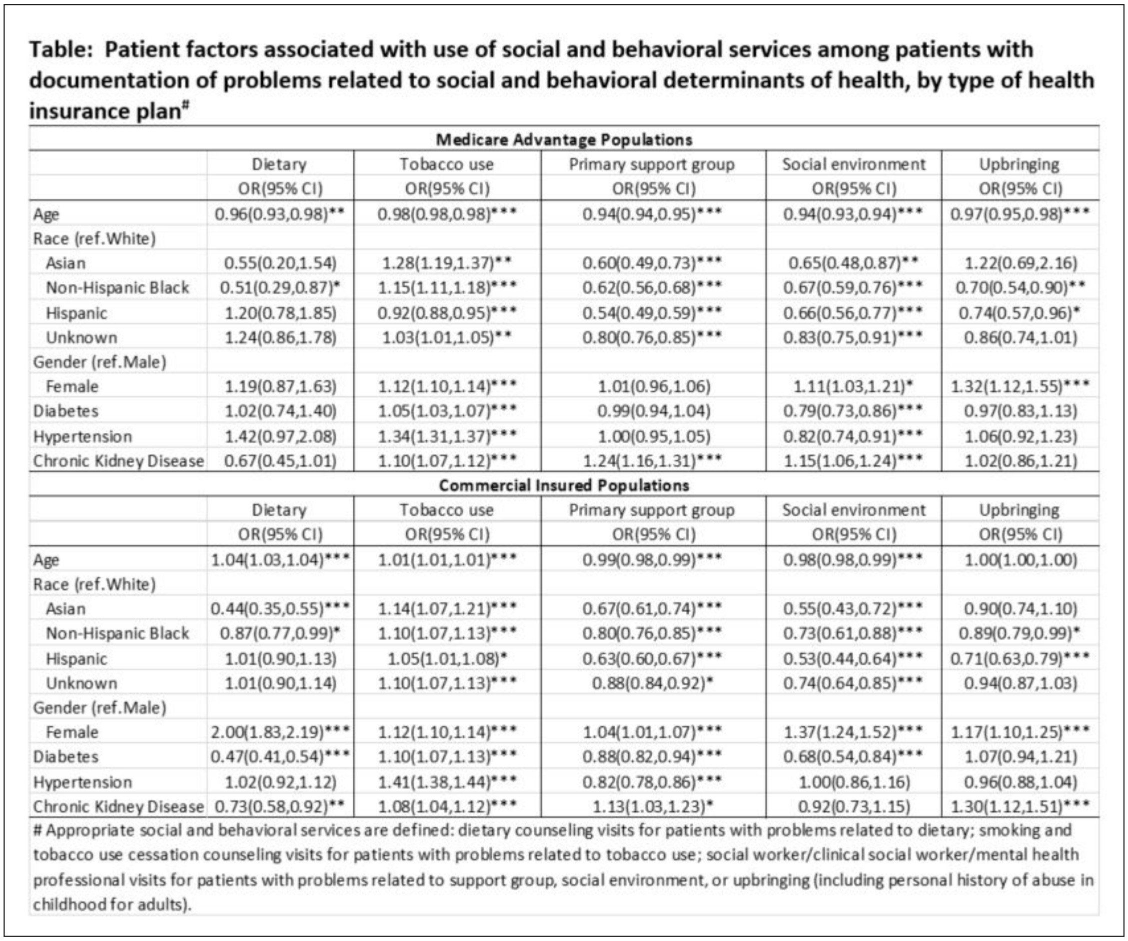


Table: Patient factors associated with use of social and behavioral services among patients with documentation of problems related to social and behavioral determinants of health, by type of health insurance plan#

Medicare Advantage Populations					
	Dietary	Tobacco use	Primary support group	Social environment	Upbringing
	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)
Age	0.96(0.93,0.98)**	0.98(0.98,0.98)***	0.94(0.94,0.95)***	0.94(0.93,0.94)***	0.97(0.95,0.98)***
Race (ref.White)					
Asian	0.55(0.20,1.54)	1.28(1.19,1.37)**	0.60(0.49,0.73)***	0.65(0.48,0.87)**	1.22(0.69,2.16)
Non-Hispanic Black	0.51(0.29,0.87)*	1.15(1.11,1.18)***	0.62(0.56,0.68)***	0.67(0.59,0.76)***	0.70(0.54,0.90)**
Hispanic	1.20(0.78,1.85)	0.92(0.88,0.95)***	0.54(0.49,0.59)***	0.66(0.56,0.77)***	0.74(0.57,0.96)*
Unknown	1.24(0.86,1.78)	1.03(1.01,1.05)**	0.80(0.76,0.85)***	0.83(0.75,0.91)***	0.86(0.74,1.01)
Gender (ref.Male)					
Female	1.19(0.87,1.63)	1.12(1.10,1.14)***	1.01(0.96,1.06)	1.11(1.03,1.21)*	1.32(1.12,1.55)***
Diabetes	1.02(0.74,1.40)	1.05(1.03,1.07)***	0.99(0.94,1.04)	0.79(0.73,0.86)***	0.97(0.83,1.13)
Hypertension	1.42(0.97,2.08)	1.34(1.31,1.37)***	1.00(0.95,1.05)	0.82(0.74,0.91)***	1.06(0.92,1.23)
Chronic Kidney Disease	0.67(0.45,1.01)	1.10(1.07,1.12)***	1.24(1.16,1.31)***	1.15(1.06,1.24)***	1.02(0.86,1.21)
Commercial Insured Populations					
	Dietary	Tobacco use	Primary support group	Social environment	Upbringing
	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)
Age	1.04(1.03,1.04)***	1.01(1.01,1.01)***	0.99(0.98,0.99)***	0.98(0.98,0.99)***	1.00(1.00,1.00)
Race (ref.White)					
Asian	0.44(0.35,0.55)***	1.14(1.07,1.21)***	0.67(0.61,0.74)***	0.55(0.43,0.72)***	0.90(0.74,1.10)
Non-Hispanic Black	0.87(0.77,0.99)*	1.10(1.07,1.13)***	0.80(0.76,0.85)***	0.73(0.61,0.88)***	0.89(0.79,0.99)*
Hispanic	1.01(0.90,1.13)	1.05(1.01,1.08)*	0.63(0.60,0.67)***	0.53(0.44,0.64)***	0.71(0.63,0.79)***
Unknown	1.01(0.90,1.14)	1.10(1.07,1.13)***	0.88(0.84,0.92)*	0.74(0.64,0.85)***	0.94(0.87,1.03)
Gender (ref.Male)					
Female	2.00(1.83,2.19)***	1.12(1.10,1.14)***	1.04(1.01,1.07)***	1.37(1.24,1.52)***	1.17(1.10,1.25)***
Diabetes	0.47(0.41,0.54)***	1.10(1.07,1.13)***	0.88(0.82,0.94)***	0.68(0.54,0.84)***	1.07(0.94,1.21)
Hypertension	1.02(0.92,1.12)	1.41(1.38,1.44)***	0.82(0.78,0.86)***	1.00(0.86,1.16)	0.96(0.88,1.04)
Chronic Kidney Disease	0.73(0.58,0.92)**	1.08(1.04,1.12)***	1.13(1.03,1.23)*	0.92(0.73,1.15)	1.30(1.12,1.51)***

Appropriate social and behavioral services are defined: dietary counseling visits for patients with problems related to dietary; smoking and tobacco use cessation counseling visits for patients with problems related to tobacco use; social worker/clinical social worker/mental health professional visits for patients with problems related to support group, social environment, or upbringing (including personal history of abuse in childhood for adults).

3. COVID-19 VACCINE PERSPECTIVES AND EXPERIENCES AMONG PATIENTS WITH KIDNEY FAILURE IN THE SOUTHEASTERN U.S.:

Megan Urbanski[1], Laura Plantinga[1], Emma Blythe[1], Monique Hennink[1], Stephen Pastan[1], Rachel Patzer[1]. [1]Emory University, Atlanta, GA, United States

Patients with kidney failure are at an increased risk for morbidity and mortality from COVID-19 infection making vaccination a priority for this population. However, patients' perspectives regarding the COVID-19 vaccine have not been fully explored.

A cross-sectional survey and semi-structured interviews were conducted in 2022 with hemodialysis patients in the Southeastern U.S. Surveys included Likert scale items [range 1 (strongly disagree) to 5 (strongly agree)] informed by the Health Belief Model that assessed participants' perceived susceptibility to and severity of COVID-19 infection, barriers to and benefits of the COVID-19 vaccine, and cues to action; interviews explored accessing dialysis during the pandemic and reasons for accepting or refusing the vaccine.

A total of 24 hemodialysis patients completed the survey [median age 57 years; 50% female; 87.5% Black]. Most (87.5%) respondents had received at least one vaccine dose. Domain scores for perceived susceptibility, severity, barriers, benefits, and cues to action [median (IQR)] were 2.3 (2.0-3.0), 4.5 (4.0-5.0), 1.9 (1.4-2.4), 4.0 (3.5-4.5), and 3.9 (3.3-4.5). The news/other media (61.3%), nephrologist (58.1%), and dialysis staff (58.1%) were the most reported vaccine information sources. The dialysis clinic (38.7%), community vaccine clinic (19.4%), and local pharmacy (13.0%) were the most reported locations for receiving the vaccine. Preliminary analysis of interviews (*n*=7) revealed a conflict between attending dialysis as life sustaining vs. life-threatening due to possible COVID-19 exposure, vaccination as an opportunity to take control over one's health, and desire for vaccine information from dialysis providers because of longstanding trusting relationships. Our findings suggest that the outpatient dialysis center may be an advantageous setting for the provision of COVID-19 vaccine-related resources and inform interven-tions in the dialysis setting aimed at improving vaccination rates for dialysis patients.

4. APPLYING THE KDQOL SURVEY IN ETHIOPIA:

Niya Ahmed[1], Wubshet Jote[1,2], Tigist Demisse[1], Biruh Workeneh[3]. [1]King Menelik II Hospital, Addis Ababa, Ethiopia; [2]St. Paul Millennium Medical College, Addis Ababa, Ethiopia; [3]University of Texas MD Anderson Cancer Center, Houston, TX, United States

Little is known about the disease burden of patients with ESRD in Ethiopia. The kidney disease quality of life (KDQOL) survey is essential to managing psychological health and safety in dialysis patients in the United States and beyond. However, it is challenging to apply in countries where very little English is spoken. Aided completion of KDQOL may affect the validity, particularly questions patients may find sensitive, which was the case after administering the survey to an initial cohort of 19 patients. Ethiopia's dialysis population is underserved, and there is an acute need for a validated tool in the local language to assess disease burden and target improvement.

YeAbe Dialysis at Menelik II Hospital is a comprehensive dialysis care center with a psychologist and social worker on the staff. Partnering with the RAND Corporation, which developed and managed the KDQOL-Complete, we sought to develop an Amharic version of the survey. Language experts formally translated the survey.

After several rounds of review, including the social worker, the tool was validated and is nearing completion. The KDQOL Amharic version will be available to administer using the online platform.

This experience demonstrates the difficulty of administering the currently available KDQOL and shows that adding a context-appropriate KDQOL is feasible and achievable in developing countries that have the appropriate conditions and resources to develop it.

5. BARRIERS IN ACCESS TO TRANSPLANTATION IN CENTRAL TEXAS IN THE SETTING OF A NEW TRANSPLANT PROGRAM:

Gloria Chen[1], Brindha Anantharam[2], Cindy Hu[2], Sofia Jimenez[2], Anderson Slack[2], Arnold Kuk[2], Brian Lee[2], Nicole Turgeon[2], Joel Adler[2]. [1]Dell Seton Medical Center at The University of Texas at Austin, Austin, TX, United States; [2]Dell Medical School at The University of Texas at Austin, Austin, TX, United States;

Barriers in accessing kidney transplantation remain poorly understood. The founding of a new transplant center provides an opportunity to identify local disparities and build solutions. We sought to better understand the barriers to accessing kidney transplantation among our first evaluated patients.

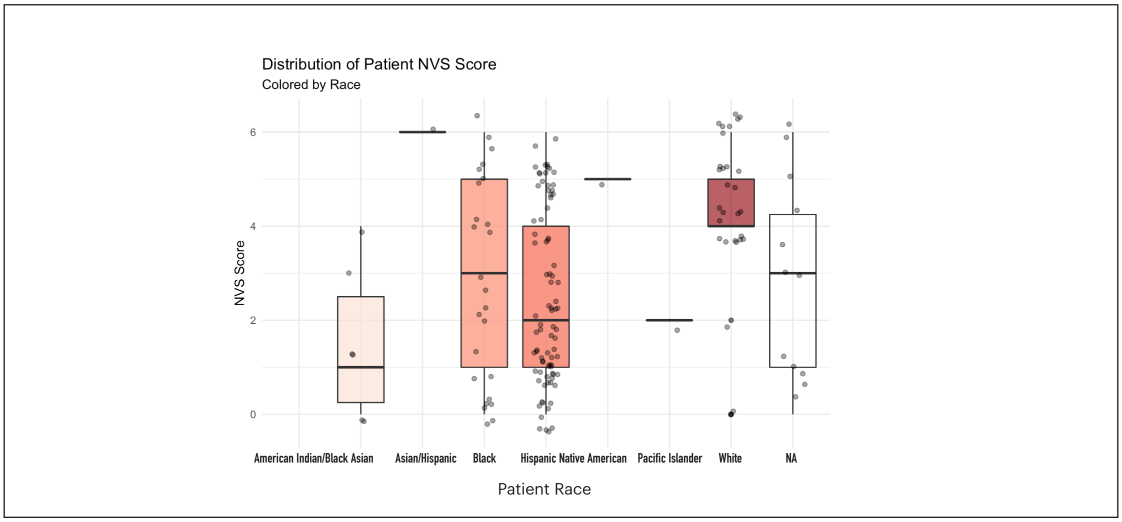
We employed a parallel mixed-methods design, inviting all patients undergoing evaluation to collect demographics and measure health literacy (Newest Vital Sign), mood (PHQ9 and GAD7), social needs (AAFP SDOH Screening Tool), and quality of life (KDQOL). Results were analyzed descriptively.

134/170 patients (78.8%) participated in the study. Median age was 53 years (IQR 43-63 years), and 54.6% male. 45.2% were Hispanic, while White and Black patients were equally represented (19.2%). 50.8% had Medicare and 22.3% had employer insurance. 67% held a high school diploma or higher. 45.9% had been previously evaluated at another center.

Identified barriers were an annual personal income of <$25,000 for 46.7% of patients. 55.1% had a Newest Vital Sign score of ≤3, indicating limited health literacy (figure). 31.5% had mild-moderate depression and 14.9% reported mild-moderate anxiety. Identified social needs were not having enough money to pay bills (35.1%), food insecurity (17.7%), housing and living environment (14%), and personal safety (3.1%). The median kidney symptom score was 67 (IQR 55.5-79.9), indicating a lower burden of disease.

We identified key barriers of lower income, limited health literacy, and multiple social determinants of health. These suggest potential barriers that can be targeted for future research.

5. (*continued*) BARRIERS IN ACCESS TO TRANSPLANTATION IN CENTRAL TEXAS IN THE SETTING OF A NEW TRANSPLANT PROGRAM



6. BARRIERS AND FACILITATORS OF TRANSPLANT LISTING FOR ESKD PATIENTS WITH LIMITED HEALTH LITERACY:

Colleen Satarino[1], Karen Crampton[1], Deb Manderachia[2], Silas Norman[1]. [1]University of Michigan Health, Ann Arbor, MI, United States; [2]Veterans Administration, Ann Arbor, MI, United States

Equal access to kidney transplantation for all patients with end-stage kidney disease (ESKD) is imperative as kidney transplant is the best treatment for ESKD. The literature has established that ESKD patients with limited health literacy (LHL) make up at least 30% of the ESKD population and are less likely to attend their transplant evaluation, less likely to complete their evaluation, and less likely to be placed on the waiting list. This phenomenological study focuses on a cohort of pre-kidney transplant patients with LHL to identify barriers and facilitators to achieving listing and transplantation.

Semi-structured phone interviews were conducted with 37 participants who were evaluated for kidney transplant between August 2018 and October 2019. Eligible participants had no previous transplants and scored 6 or lower on the Rapid Evaluation Assessment of Health Literacy – Short Form. Participants were asked to provide their own definition of 9 common kidney transplant terms. Other variables such as informal and formal support, self-efficacy and knowledge of their listing requirements were discussed.

Among the 37 interviewed, 19 participants were eligible for listing after their initial evaluation. 9 participants were listed at 6 months and an additional 2 participants at 12 months. Patient transplant status was reviewed after 2 years, and 11 participants received a transplant. Several transplant terms were misunderstood by the participants. Potential facilitators include support, knowledge of listing requirements and self-efficacy. Potential barriers include difficulty in reading their evaluation requirements by over 30% of the participants.

Knowledge of the barriers and facilitators of LHL ESKD patients to listing and transplant are critical when designing interventions to improve access. Assistance by family and friends, the dialysis and transplant communities, and beliefs about self-efficacy contribute to listing and transplantation. Identifying LHL remains crucial for dialysis clinics and transplant centers to provide the necessary support to achieve listing and transplantation.

7. DELIBERATE DELAY IN TRANSPLANT EDUCATION FOR “OVERWHELMED” DIALYSIS PATIENTS:

Jenny McDonnell[1], Megan Urbanski[1], Stephen Pastan[1], Janice Lea[1], Kimberly Jacob-Arriola[1], Cam Escoffery[1], Rachel Patzer[1], Adam Wilk[1]. [1]Emory University, Atlanta, GA, United States

Access to timely transplant education at a dialysis facility increases patient interest in transplant, likelihood of waitlisting, and transplant receipt. Evidence shows some dialysis patient groups are less likely to receive appropriate transplant education than others. It is unclear how dialysis providers’ transplant education practices may differ for patients who initiate dialysis unexpectedly (e.g., following hospitalization for ESRD).

We conducted 39 in-depth interviews during June-August 2022 with dialysis clinic providers in Georgia, North Carolina, and South Carolina about their processes leading up to referral or non-referral to a transplant center. We recruited dialysis social workers, nurse managers, nephrologists, and administrators using purposive sampling to capture diversity by participants’ role, years of experience, and county median household income. Semi-structured telephone interviews were recorded and transcribed. We managed textual data using MAXQDA software. We used thematic analysis to identify themes, with multiple coders developing the codebook and interpreting data.

Some dialysis providers described providing uniform transplant education to all patients, yet most providers described 3 types of transplant education practices for ESRD patients who initiate dialysis unexpectedly. In Type (1), these patients need time to stabilize and “settle into dialysis” *before* providers share any transplant education. In Type (2), patients who initiate dialysis unexpectedly receive transplant education best when it is limited and provided slowly over many weeks or months. In Type (3), these patients have greater transplant knowledge deficits compared to patients who had prior nephrology care; identifying and filling these patients’ knowledge gaps takes more time.

Despite recognition that ESRD patients who initiate dialysis unexpectedly often require more extensive transplant education than patients who had prior nephrology care, providers often delay or limit discussing transplant with these patients. Promoting equitable transplant education practices will require accommodating diverse patient needs as well as diverse provider perspectives on best practices in transplant education for all patient groups.

8. HOW DIALYSIS PROVIDERS ASSESS AND REFER PATIENTS FOR KIDNEY TRANSPLANT EVALUATION: A PROCESS MODEL:

Adam Wilk[1], Jenny McDonnell[1], Megan Urbanski[1], Stephen Pastan[1], Janice Lea[1], Kimberly Jacob-Arriola[1], Cam Escoffery[1], Rachel Patzer[1]. [1]Emory University, Atlanta, GA, United States

For most patients with kidney failure, transplant is the preferred treatment modality, yet they receive dialysis first. Referral to a transplant center is a key early step toward receiving a transplant, but only 34% of patients are referred within 1 year of dialysis start. Efforts to mitigate any provider and clinic-level barriers to referral are hampered by the absence of a process model to characterize how dialysis clinics approach the decision of whether to refer patients for transplant.

We conducted 39 in-depth interviews during June-August 2022 with dialysis clinic providers in Georgia, North Carolina, and South Carolina about their processes leading up to referral or non-referral to a transplant center. We recruited dialysis social workers, nurse managers, nephrologists, and administrators using purposive sampling to capture diversity by participants’ role, years of experience, and county median household income. Semi-structured telephone interviews were recorded and transcribed. We managed and analyzed transcripts using MAXQDA software. We used a phenomenological approach to identify key constructs, including discrete steps and decisions, with multiple coders developing the codebook and interpreting data.

Most participants described a 4-step process preceding any transplant referral decision. (1) At patient intake, providers assess whether the patient has a non-modifiable contraindication to transplant, in which case referral does not proceed. (2) Providers engage in parallel dialogues with the patient (including transplant education) and within the care team about the patient’s likely eligibility, culminating in asking the patient “Are you inter-ested?” If the patient demurs, step 2 is repeated. (3) If the patient assents, a lead provider (e.g., nephrologist) or the care team collectively judges whether to make the referral then or to wait and intervene with the patient to improve their chances of waitlisting. (4) On the specified timetable, providers carry out the referral.

Qualitative interviews with dialysis providers revealed a 4-step process for approaching transplant referral decisions. This model can be used to inform interventions on dialysis clinics’ assessment and referral processes.

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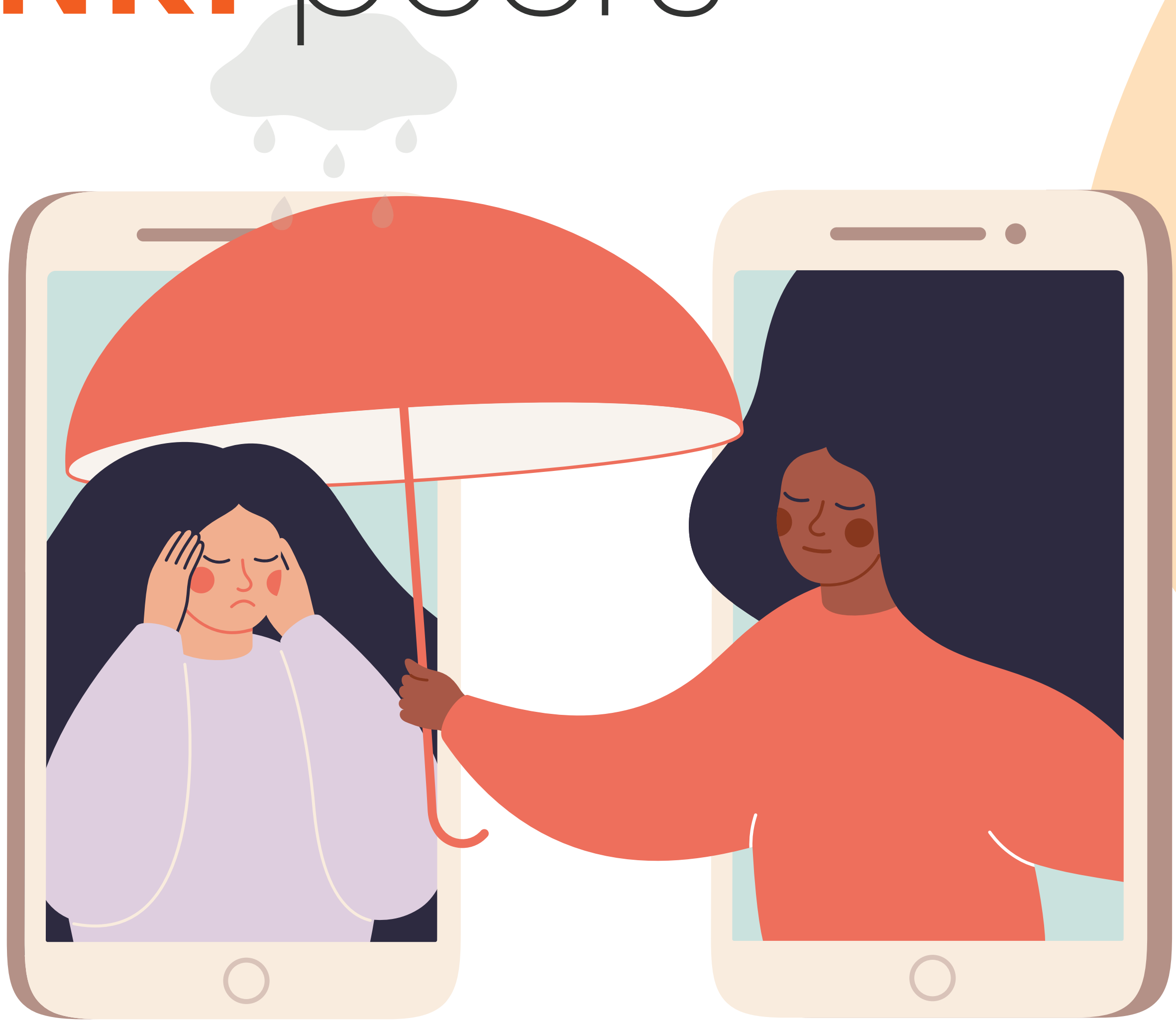

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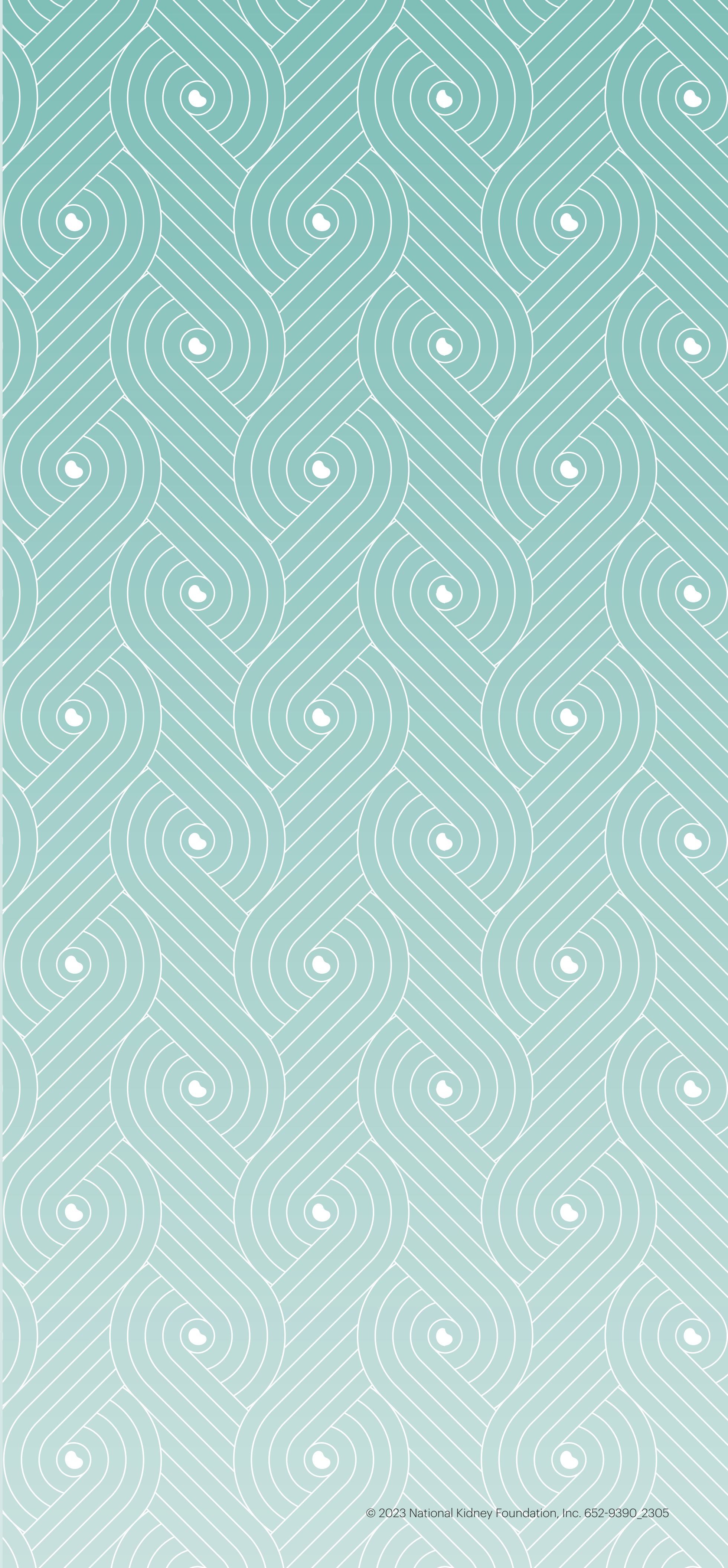

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