

“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

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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, pre-dialysis. 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 (Wasylynyuk & 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 pa-

tients 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 posi-

tive 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.

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Table 1. Participant Characteristics		
	All	Interviewed (recorded)
<i>N</i>	254	33
Age Group, <i>n</i> (%)		
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, <i>n</i> (%)		
Female	134 (52.8)	18 (54.5)
Male	120 (47.2)	15 (45.5)
Race, <i>n</i> (%)		
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, <i>n</i> (%)		
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 (<i>SD</i>)	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*, <i>n</i> (%)		
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 (<i>SD</i>)	16.28 (9.98)	17.52 (9.56)
ACP Engagement Score, mean (<i>SD</i>)	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

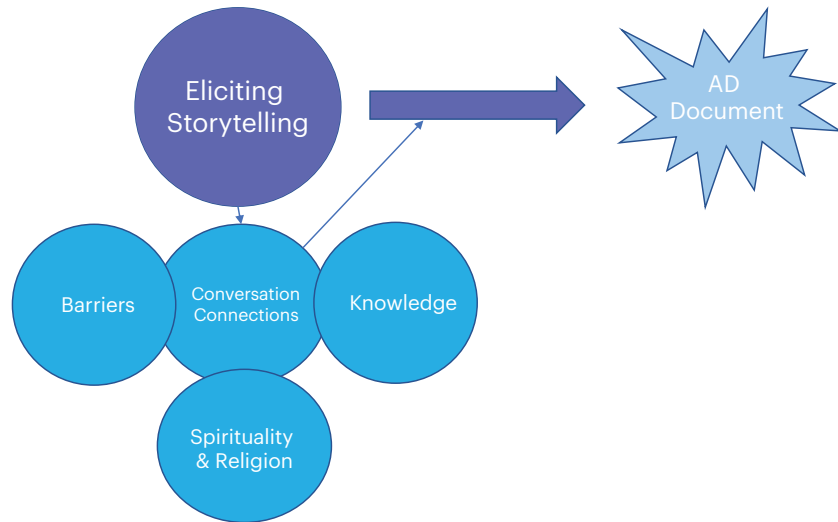
“...more of an advance directive...but it was not a situation where it was a crisis situation.” (Participant 51, patient)

“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/>