


Older Patients with Advanced Chronic Kidney Disease and Their Perspectives on Prognostic Information: a Qualitative Study



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BACKGROUND: Prognostic information is key to shared decision-making, particularly in life-limiting illness like advanced chronic kidney disease (CKD).

OBJECTIVE: To understand the prognostic information preferences expressed by older patients with CKD.

DESIGN AND PARTICIPANTS: Qualitative study of 28 consecutively enrolled patients over 65 years of age with non-dialysis dependent CKD stages 3b-5, receiving care in a multi-disciplinary CKD clinic.

APPROACH: Semi-structured telephone or in-person interviews to explore patients' preference for and perceived value of individualized prognostic information. Interviews were analyzed using inductive content analysis.

KEY RESULTS: We completed interviews with 28 patients (77.7 ± SD 6.8 years, 69% men). Patients varied in their preference for prognostic information and more were interested in their risk of progression to end-stage kidney disease (ESKD) than in life expectancy. Many conflated ESKD risk with risk of death, perceiving a binary choice between dialysis and quick decline and death. Patients expressed that prognostic information would allow them to plan, take care of important business, and think about their treatment options. Patients were accepting of prognostic uncertainty and imagined leveraging it to nurture hope or motivate them to better manage risk factors. They endorsed the desire to receive prognosis of life expectancy even though it may be hard to accept or difficult to talk about but worried it could create helplessness for other patients in their situation.

CONCLUSION: Most, but not all, patients were interested in prognostic information and could see its value in motivating behavior change and allowing planning. Some patients expressed concern that information on life expectancy might cause depression and hopelessness. Therefore, prognostic information is most appropriate as part of a clinical conversation that fosters shared decision-making and helps patients consider treatment risks, benefits, and burdens in context of their lives.

KEY WORDS: shared decision-making; dialysis risk; prognosis; palliative care; communication.

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INTRODUCTION

Patients often perceive that they have no choice but to start dialysis when they reach end-stage kidney disease (ESKD).^{1,2} Yet there are significant concerns about the equipoise of benefits to harms of dialysis for certain sub-populations such as frail older patients.^{2–4} Guidelines and position statements have long called for increased shared decision-making around the appropriate initiation of dialysis or other forms of renal replacement therapy (RRT); however, research indicates that there has been limited positive change in this direction.^{5–9} Prognostic information is important for patients with chronic kidney disease (CKD) to facilitate shared decision-making and support patient autonomy.^{10,11} Multiple tools exist for prognostication in ESKD¹², but research on prognostic communication in nephrology is limited.¹³ Surveys and tradeoff studies have suggested that the majority of patients with advanced CKD desire prognostic information but few perceive that this information is shared with them.^{1,7,14,15}

Nephrologists are hesitant to share prognostic information,^{7,16–18} voicing concerns about upsetting patients, uncertainty of predictions,¹⁹ time constraints, fear of litigation, and economic pressures to keep dialysis units full.²⁰ To address these concerns and to inform the design of a clinical decision aid that makes intellectual, practical, and emotional sense to patients, we sought insight into how older patients with advanced CKD value individualized ESKD risk and life expectancy prognostic information. We explored differences in their desire for and value of these two different types of prognostic

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information, any perceived harms, and how they would use the information if it was offered.

METHODS

We conducted semi-structured interviews of patients with advanced CKD seen at a multi-disciplinary CKD clinic at a tertiary referral center in the USA serving local and referral patients. The qualitative data collection was embedded in a larger mixed-methods study, *CKD Journeys*, to design a decision aid (DA) for treatment choice in ESKD. We developed our DA drawing on data from preparatory focus groups with patients and multi-disciplinary clinicians, direct observation of patient-clinician encounters with and without DA prototypes, and secondary data analysis of survival with and without dialysis. Prior to our study, the clinic was using the kidney failure risk equation (KFRE) to guide treatment recommendations but not consistently sharing these findings with patients. Once we had developed a DA, 12 of the patients were exposed to various prototypes of the DA that included expected time to ESKD (in months). The Mayo Clinic Institutional Review Board approved this protocol (16–005,457). The Consolidated Criteria for Reporting Qualitative Research (COREQ) framework was used to guide study planning and reporting.²¹

Recruitment

Eligible patients were adults (≥ 65 years), living with an advanced CKD diagnosis (stage 3b or higher), and able to speak English. Exclusion criteria included prior dialysis, kidney transplant, and moderate or severe cognitive impairment, as determined by the Montreal Cognitive Assessment (MOCA) < 21 .²² We sampled purposively, using consecutive screened patient appointment lists, to recruit a diverse cohort with respect to age, stage of kidney disease, sex, and ethnicity. We called patients the day before their scheduled appointment to inform them of the study and met interested patients before their appointment to explain the study aims. Patients provided oral consent to undergo the MOCA: patients who scored 21 or more provided written consent for the interview, which was scheduled within 48 h of their clinic appointment. Family members were present during some interviews per patient's preference and gave oral consent.

Data Collection

Between July 2017 and July 2019, three trained qualitative interviewers (AB, SC, NES) conducted the interviews in person or by telephone, according to patients' preference. Interviews lasted between 30 and 60 min in length. We used a semi-structured interview guide developed with guidance from experienced qualitative researchers (AK, ES), as well as input from a multi-disciplinary group of clinicians and a patient advisory group. The questions elicited patient experience with prognostic information, perspectives on receiving

prognosis of the risk of progression to ESKD and life expectancy, the perceived value of such information, and the perceived barriers of engaging in prognostic discussions with their clinicians (see Appendix 1 for interview guide). Interviews were audio-recorded with permission, transcribed verbatim by a professional transcription service, compiled with field notes written by interviewers, and anonymized for analysis. Data collection ceased once we reached data saturation. All participants received a \$25.00 gift card.

Analysis

Interview data and field notes were analyzed concurrently using inductive content analysis procedures.^{23,24} Four research team members (AB, SC, NES, BT)—including social scientists and physicians—trained in qualitative research methods developed an inductive codebook based on team discussion around the first four interviews and coded all interview transcript data line by line. The codebook was refined as necessary throughout the coding process and transcripts were recoded accordingly. Each transcript was double coded and consensus on all codes was achieved: coders met with the principal investigator (BT) to resolve outstanding coding disagreements. Analysis was done concurrent with interviews and continued until thematic saturation. All transcripts and coded excerpts were entered into NVivo Version 11 (QSR Intl Inc; Burlington, MA) to assist with data management and analysis. Researchers (SC, NES, BT) then examined the coded data for patterns using memory cards and mapping analysis, engaged in aggregate analysis of coded excerpts, and identified overarching themes for each prognostic category which were then compared and contrasted to clarify any overlap and identify sub-themes. The senior analysts (ES, AK, IH) reviewed the themes for reliability and credibility using triangulation through multiple analysts. We did not do formal member checking; however, the findings were shared with both patient and clinician focus groups who concurred with the findings. After the peer review process, we returned to the data to revisit and refine our themes.

RESULTS

Of the 39 potential participants presented with study information, 28 completed interviews, 8 participants declined, 2 had MOCA scores below 20, and 1 withdrew before the interview. Two participants had a hard time engaging with the interviewers resulting in scant data. Most (69.9%) patients had adequate health literacy, as assessed by a single item from the health literacy scale about comfort filling out forms.²⁵ Participants' baseline characteristics are described in Table 1.

We identified three themes, summarized in Table 2: (1) preference for information in the information vacuum, (2) managing prognostic uncertainty, and (3) the tradeoffs of receiving prognostic information, as summarized in Table 2.

Table 1 Patient Demographics

	Patient <i>n</i> = 28
Sex (F)	9
Age mean (SD)	77.7 (6.8)
Age range	66–90
White race (%)	25 (89.3)
Health literacy adequate	18 (64.3)
Marital status	
Married	13
Divorced	2
Widowed	8
Never married	2
Residence	
Minnesota	18
Non-Minnesota	10
CKS stage	
Stage 3	6
Stage 4	15
Stage 5	7

5 of the 28 did not return the pre-visit survey

Preference for Information in the Information Vacuum

Patients and their family members expressed lack of information about their disease stage: “We knew for quite a period of time that his kidneys weren’t functioning normally, but we had no information other than that. We knew nothing” (spouse of patient 11, 79). In this information vacuum, many patients perceived a binary choice between dialysis and quick decline toward death: “Obviously, if your kidneys quit functioning, it’s a choice of going on dialysis or dying, right? Except a kidney transplant” (patient 32, 74). Prognosis had rarely been discussed with patients in our study and only 7 of the patients indicated they had been given estimates of their risk of disease progression to ESKD. Instead, patients relied on their creatinine trends to glean how they were doing or what to expect, although this did not satisfy their desire to assess their current health or know what to expect: “I don’t know what parts- what they’re looking for in the blood that says, ‘Hey you better get in there right now’” (patient 10, 77). Almost all participants expressed that they would want to know ESKD risk information: “Well, I definitely want to know what’s going on. I don’t want them to not tell me. You know, if things are just really, really bad and things, they should definitely tell a person” (patient 02, 85). Some patients even framed this forcefully as a “right to know” (patient 08, 89) this information. Others were more indifferent on the subject: “I guess I’ve had more people ask me if anybody has given me a timeframe as far as when I would need to go on dialysis versus me worrying about it” (patient 17, 67). A few patients were explicit in their preference not to receive such information. While they could imagine it being helpful for others, for them, it represented an added burden. As explained by one participant, “I think that just living day by day is a good challenge” (patient 18, 67).

Patients were also interested in knowing their life expectancy prognosis and only two had discussed it with their treatment team. Sixteen of our participants explicitly expressed wanting to know their life expectancy prognosis and how that number

Table 2 Themes and Quotes

Theme	Subtheme	Representative quotations
Preference for information in an information vacuum	Dialysis vs. death	Eventually, probably gonna have it [dialysis] or die. (patient 11, 79 years)
	Preference	Well, the more information you can get, the more your mind is eased. That’s the way I look at it, you know? (patient 10, 77) To me it’s gonna happen and you can’t really say. It doesn’t matter to me. (patient 34, 94) Uh, I think I’d rather not know and just-just live my life as it is (patient 18, 67)
Managing prognostic uncertainty	Acceptance	I guess I just kinda go with the flow. I’m one of them that just go. It happens. When it happens, it happens. (patient 29, 71) I would rather not be told that I would live three years then live three years over the predictions. (patient 22, 73) I think they’re kinda going by what they have seen in the past with other people. Maybe I’m different. Maybe my body is different. (patient 16, 76) I really do. I just feel like if I can follow what they’re telling me to do, well, then I can continue maybe a little longer. (patient 16, 76)
	Leveraging uncertainty	I think you should just always know so you can do what you can do to make things better. (patient 2, 85) I would probably stop worrying about the little things and worry about somethin’ that really matters. (patient 21, 79) Well, it gives us a pause to think about treatment and stuff somewhat down the road. (patient 11, 79)
Tradeoffs of prognosis	Motivation	I think it would be good to give ‘em an option they can—they can choose themselves whether they—how they wanna go ahead with their treatment if they—if they knew (patient 18, 67)
	Planning and prioritizing	Some people couldn’t handle it. Some people I’m talking about they just would collapse mentally (patient 23, 76)
	Treatment decisions	
	Harm	

was reached, even if it might be “scary” (patient 21, 74) or reveal bad news. One patient explained, “oh yeah, I’m sure if it can be predicted, I mean, it’ll give me that opportunity to make definite decisions if it could be predictable” (patient 4, 81). Three patients, however, expressed either indifference to receiving such information or a preference not to know: “I’ll tell you, when your number’s up, your number’s up [...] I guess it

would be up to them [the clinician], 'cause it don't make a damn difference to me [...] uhhhhhhh, yeah, I'd rather not know actually" (patient 12, 78). No patients expressed a strong negative reaction to the suggestion of learning prognostic life expectancy from their clinician.

Managing Prognostic Uncertainty

Participants expressed uncertainty about their disease process and indicated that they knew things could turn for the worse any time: "I realize that any time I can have problems, so-[hand gesture]" (patient 4, 81). When asked specifically about concerns related to the inherent uncertainty of prognostic tools, most participants expressed acceptance: "How do you predict those things? You don't. Life is life" (patient 16, 76). Patients incorporated such uncertainty into a broader philosophical understanding of life and death independent from their disease: "nothing is gonna be 100%" (patient 21, 74). As one participant shared, "well, the doctors aren't God." (patient 30, 70). Patients also realized that their kidney disease was not the only threat to their survival, foreseeing other health or life events that could interfere with life expectancy prognoses: "It's hard to predict. He might die of a heart attack. Yeah but you know- how would you predict kidney issues where could be other issues that would be life expectancy?" (patient 33, 79). One patient did feel less interested in life expectancy information due to its uncertainty and the possibility the information could be wrong: "I would rather not be told that I would live three years then live three years over the predictions" (patient 22, 73).

Patients expressed a belief that individual differences in their body and approach to managing their disease could make a difference in their health outcomes: "Your body is not the same as mine. Treatment for you cannot be exactly as treatment for me. I understand that" (patient 4, 81 years). Some participants leveraged this uncertainty of prognostic information to allow them to hope that they were different or that their behavior and lifestyle choices around "things that you can control" (patient 32, 74) might improve their outcomes and let them "continue maybe a little longer" (patient 16, 76):

Then I realized the two years are always a bell-shaped curve. There's another side out on the bell-shaped curve. I thought well by gosh. I don't plan on being out on the other one. Again, there are things that I know influences outcome like medicine compliance and diet. (patient 34, 90)

The Tradeoffs of Receiving Prognostic Information

Many patients indicated that getting prognostic information would be helpful to motivate them to work on their health and prioritize the important things in life. Participants underscored the importance of receiving risk of progression to ESKD early and with "ideas of how we're going to fix it" (patient 20, 69),

"make things better" (patient 2, 85), or "improve" (patient 6, 84) their health. Individualized prognostications were also interpreted by our participants as a source of motivation to "follow the rules" (patient 32, 74) and "do whatever it takes" (patient 23, 76) to effect a change in their medical outcomes. One participant even framed the value of knowing one's life expectancy as a direct challenge to prove the prognosis wrong: "It might give them [patients] the [thought], 'Two years? I'm gonna outlive that.' It might give them the energy to move forward better and live a little bit longer, as a challenge that, 'Two years? Absolutely not!'" (patient 30, 70).

Additional perceived value of prognostic information centered on patients' ability to wield some control over their future. Whether talking about individualized risk of progression to ESKD or life expectancy, participants articulated that knowing such information would allow them to plan and prepare for their future: "It looks a little scary, but this is an idea for you and it gives you enough time that you can sit down, talk to your family, your friends, get your evaluation from the dialysis team, and let them give you an idea if you're qualified" (patient 20, 69). Patients explained that if they had a sense that they would need additional services, they could plan accordingly: "Then we could kinda schedule, okay, you know, in two years we're going to have to, you know, make sure somebody's around all the time and stuff like that. Yeah. In that sense it would be prob'ly very helpful." (patient 18, 67). Patients also emphasized the importance of discussing the potential for dialysis with patients early to avoid being overwhelmed by a precipitous dialysis start:

...bring it up to the possibilities that this is gonna happen, then a patient gets prepared for it in the back of his mind. It's there and it's gonna happen but it's not an urgent thing. When they wait until it becomes an urgent thing, then you get so many things going around in your mind. What do you got to do? What do I have to get ready? It's a life changing thing when you go on dialysis. (patient 21, 74)

When asked about potential harms of receiving ESKD prognostic information, most had no concerns and felt that most CKD patients would want to know: "No I don't think so. Everybody that I know would wanna know" (patient 13, 81). However, one participant recalled getting upset when presented with her ESKD risk, as she had misinterpreted the information as a veiled threat of what would befall her if she did not work harder on maintaining her health. "I guess I don't want anybody shoving it in my face that you just better watch out or else this is gonna be you" (patient 7, 83).

Similarly, having a sense of one's life expectancy was perceived as an opportunity to allow patients to get their financial and personal affairs in order: "I think people need to get their life in order. I think they need to have their wills made out. All of this stuff" (patient 32, 74). Life expectancy prognoses were considered by some participants as "a chance

to correct some wrongs” (patient 21, 74) and “tie up your loose ends” (patient 39, 82). Others suggested that prognostic information might help them to not worry about the small things in life, but rather focus on the important things, such as their bucket list: “it would somewhat give me a goal. Okay. I need to get this done before I can't do it anymore” (patient 17, 67). One patient even suggested that knowing such information could make them a better person: “Oh make me a better person, I guess. Oh, learn not to worry about the little stuff, yeah, yea, things I can't control. Instead of getting' all worked up about it, just slough it off” (patient 21, 74).

Life expectancy was also perceived useful for treatment decision-making, to help weigh the perceived burden of dialysis against a potential survival benefit. For example, if life expectancy was short, they might opt out of dialysis; otherwise, they were likely to pick the treatment option that would prolong their life:

“If I'm not gonna be here in six months why start it [dialysis]? You know, why do it type of thing, you know? I guess that's the scary part about it. It's a big thing to start. But if it's gonna prolong my life I feel it's worth it” (patient 18, 67 years). One patient, planning to do home based dialysis, said life expectancy would not influence their choice: “I would say that my life expectancy wouldn't change my opinion of going to some place for dialysis. I prefer to do it at home” (patient 23, 76). Another patient recognized that it was hard to forecast decisions about treatment and ultimately, “You really don't know until you're right in the midst of it and it's happening in real time” (patient 38, 76).

Most participants acknowledged that discussing life expectancy is uncomfortable and can be “scary.” Several patients maintained that the potential drawbacks of learning life expectancy information were likely more of a concern for other patients rather than themselves: “I don't see any (harms) for us, but I think some people would get depressed” (spouse of patient 11, 79). Potential harms of being informed of one's life expectancy focused predominantly on the concern that life expectancy could lead to those “who don't like the word death at all” (patient 24, 88) to “worry themselves to death” (patient 10, 77), “collapse mentally” (patient 23, 76), or “give up” (patient 16, 76).

DISCUSSION

Our findings show that many, but not all, patients with advanced CKD desire and value prognostic information. More patients wanted to know their risk of progression to ESKD than their life expectancy, although they tended to conflate the two. Patients both acknowledged and accepted the limitations of prognostic tools. When weighing the tradeoffs of

prognostic information, patients reported that it could provide them with some feeling of control over their disease and destiny. They also suggested that prognostic information could influence treatment choice. While some participants suggested prognostic information could cause depression and hopelessness, this was expressed as a possibility for others, rather than a personally relevant concern.

Our findings add nuance to contemporary understandings of how patients with advanced CKD perceive the value of prognostic information and how they would integrate and use such information to manage their disease and live their lives. We confirmed existing survey and qualitative findings that suggest most patients want information about prognosis and they want it earlier in the course of their disease.^{14,15,19,20,26} Our unique contribution to this growing literature is our in-depth qualitative exploration of patients' perceptions of two distinct types of prognostic information: risk of progression to ESKD and life expectancy. Most other studies did not distinguish between the two. Through our dialogues with patients, we unpacked patients' understandings of these two distinct end points.

Like others, we found frequent conflation of the time of reaching ESKD with quick decline and death^{2,27,28} which may underlie a common misunderstanding that dialysis is the patient's “only option.”² Knowing that this misperception is present earlier in the disease trajectory allows for savvy counter messaging, as comparative survival studies suggest this belief is misguided.^{29–32} If patients learn to associate palliative care with several months of remaining life, they may be less likely to view dialysis as their “only option.” This in turn may strengthen their resolve when negotiating with clinicians or family members who may be less comfortable with conservative goals of care⁹.

Our results suggest that concerns about prognostic uncertainty and diminishing hope should not dissuade clinicians from sharing this information. Most of our participants were quite accepting of the inherent inaccuracy of prognostic estimates, some even suggesting they could leverage this uncertainty to nurture hope or feel empowered. Other qualitative studies among ESKD patients have similarly suggested that life expectancy information to facilitate advance care planning may have the potential to enhance, rather than rob, patient's hope and that when left in the dark patients cope through avoidance and false hope.^{19,26} The tendency to interpret prognostic uncertainty in their favor is also consistent with previous studies that have shown a strong optimism bias, both among dialysis patients and others.^{33,34} Unfortunately, such optimistic bias has been shown to correlate with lower engagement in advance care planning.^{7,35} While a certain level of denial may be protective for patients with life-limiting illness, it can be helpful to engage patients in a “hope for the best, plan for the worst” dialogue to promote realistic expectations while allowing for the pursuit of important life goals. The variability of patients desire for prognostic information and ambivalence expressed in a study of conservatively

managed patients highlights the complexity of how different individuals desire and use prognostic information to manage their disease and everyday life.³⁶ Therefore, asking patients what they value and how much they want to know before sharing prognostic information is critical. Our findings also support the importance of engaging patients in a dialogue early in their disease course to foster choice awareness and shared decision-making about the many health, treatment, and life decisions they must make as a patient living with CKD, as highlighted by Muscat et al.²⁸ Emphasizing treatment choices and implementing a shared decision-making approach are especially important among older patients and individuals with limited English proficiency, as they often perceive a steep hierarchy difference between patient and physician and may not volunteer much information or ask important questions about physician's treatment recommendations.²⁸ Nephrologists need more training in how to elicit and understand their patients' preferences and circumstances so that they can help identify the treatment option that best aligns with their patients' goals and values.³⁶

More research is needed on how to incorporate prognostic information in conversations between patients with CKD and their clinicians. We need better understanding of how patients and clinicians relate to prognostic information at different times across the disease trajectory and whether it influences clinician's treatment recommendations and patients' participation in shared decision-making, modality choice, and quality of life. The insights gathered in our study have informed the design of our decision aid *CKD Journeys* that provides individualized prognosis to patients with CKD and is currently undergoing pilot testing.

Our study has a robust sample size and followed rigorous qualitative research methods. It has some external validity, as similar themes emerged in previously reported studies. Limitations include the racially homogenous white population receiving care at a tertiary referral center, and thus may not translate to patients of other race/ethnicity, disease stage, or social status. As recommended by our patient focus group members, we interviewed participants before dialysis was imminent. Their preferences may change over the disease trajectory. Our interpretation that patients differed in the level of desire for estimates of ESKD and life expectancy is complicated by patient's conflation of ESKD risk and death. However, since the same themes arose for both categories this lack of distinction is less concerning. Finally, since most of our patients had not previously been presented with prognostic information, their thoughts and feelings were hypothetical. Patients often choose differently in reality than when presented with a hypothetical scenario.^{37,38}

CONCLUSIONS

Patients with advanced CKD are more interested in their risk of developing ESKD than information about life expectancy,

although this distinction is confounded by patients' tendency to perceive a binary choice between dialysis and imminent death. While our data suggest that clinicians' fear of taking away patients' hope seems unfounded, it is important to ask for permission before sharing prognostic information, as not all patients want to know. Patients indicated that prognostic information could give them the ability to plan and wield some control over their disease trajectory by motivating them to better manage their disease. Patients were also accepting of prognostic uncertainty and suggested it could be leveraged to nurture hope. More research is needed on how clinicians and patients relate to bedside translation of prognostic tools and how it influences shared decision-making and treatment choice.

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Declarations:

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REFERENCES

- Ladin K, Lin N, Hahn E, Zhang G, Koch-Weser S, Weiner DE. Engagement in decision-making and patient satisfaction: a qualitative study of older patients' perceptions of dialysis initiation and modality decisions. *Nephrol Dial Transplant*. 2017;32(8):1394-401. <https://doi.org/10.1093/ndt/gfw307>
- Russ AJ, Kaufman SR. Discernment rather than decision-making among elderly dialysis patients. *Semin Dial*. 2012;25(1):31-2. <https://doi.org/10.1111/j.1525-139X.2011.01047.x>
- Thorsteinsdottir B, Swetz KM, Albright RC. The Ethics of Chronic Dialysis for the Older Patient: Time to Reevaluate the Norms. *Clin J Am Soc Nephrol*. 2015;10(11):2094-9. <https://doi.org/10.2215/cjn.09761014>
- Thorsteinsdottir B, Swetz KM, Tilburt JC. Dialysis in the Frail Elderly - A Current Ethical Problem, an Impending Ethical Crisis. *J Gen Intern Med*. 2013;28(11):1511-6. <https://doi.org/10.1007/s11606-013-2494-1>
- Moss AH. Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis. Clinical Practice Guideline. Rockville: Renal Physicians Association. 2010.
- Williams AW, Dwyer AC, Eddy AA, Fink JC, Jaber BL, Linas SL, et al. Critical and honest conversations: the evidence behind the "Choosing Wisely" campaign recommendations by the American Society of Nephrology. *Clin J Am Soc Nephrol*. 2012;7(10):1664-72. <https://doi.org/10.2215/CJN.04970512>

7. Wachterman MW, Marcantonio ER, Davis RB, Cohen RA, Waikar SS, Phillips RS, et al. Relationship between the prognostic expectations of seriously ill patients undergoing hemodialysis and their nephrologists. *JAMA Internal Medicine*. 2013;173(13):1206-14. <https://doi.org/10.1001/jamainternmed.2013.6036>
8. Wong SPY, Hebert PL, Laundry RJ, Hammond KW, Liu C-F, Burrows NR, et al. Decisions about Renal Replacement Therapy in Patients with Advanced Kidney Disease in the US Department of Veterans Affairs, 2000–2011. *Clinical Journal of the American Society of Nephrology*. 2016;11(10):1825-33. <https://doi.org/10.2215/cjn.03760416>
9. Wong SPY, Boyapati S, Engelberg RA, Thorsteinsdottir B, Taylor JS, O'Hare AM. Experiences of US Nephrologists in the Delivery of Conservative Care to Patients With Advanced Kidney Disease: A National Qualitative Study. *Am J Kidney Dis*. 2020;75(2):167-76. <https://doi.org/10.1053/j.ajkd.2019.07.006>
10. Michel DM, Moss AH. Communicating prognosis in the dialysis consent process: A patient-centered, guideline-supported approach. *Advances in Chronic Kidney Disease*. 2005;12(2):196-201. <https://doi.org/10.1053/j.ackd.2005.01.003>
11. Schell JO, Cohen RA. A Communication Framework for Dialysis Decision-Making for Frail Elderly Patients. *Clin J Am Soc Nephrol*. 2014. <https://doi.org/10.2215/CJN.02190314>
12. Anderson RT, Cleek H, Pajouhi AS, Bellolio MF, Mayukha A, Hart A, et al. Prediction of Risk of Death for Patients Starting Dialysis: A Systematic Review and Meta-Analysis. *Clin J Am Soc Nephrol*. 2019;14(8):1213-27. <https://doi.org/10.2215/CJN.00050119>
13. Thorsteinsdottir BGM. The Role of Estimating and Communicating Prognosis in Kidney Supportive Care, in *Palliative Care in Nephrology*. First Edition ed. 198 Madison Ave, New York, NY 10016, United States of America: Oxford University Press; 2020.
14. Fine A, Fontaine B, Kraushar MM, Rich BR. Nephrologists should voluntarily divulge survival data to potential dialysis patients: a questionnaire study. *Perit Dial Int*. 2005;25(3):269-73.
15. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol*. 2010;5(2):195-204. <https://doi.org/10.2215/CJN.05960809>
16. Combs SA, Culp S, Matlock DD, Kutner JS, Holley JL, Moss AH. Update on end-of-life care training during nephrology fellowship: a cross-sectional national survey of fellows. *Am J Kidney Dis*. 2015;65(2):233-9. <https://doi.org/10.1053/j.ajkd.2014.07.018>
17. Davison SN, Jhangri GS, Holley JL, Moss AH. Nephrologists' reported preparedness for end-of-life decision-making. *Clin J Am Soc Nephrol*. 2006;1(6):1256-62. <https://doi.org/10.2215/CJN.02040606>
18. Holley JL, Carmody SS, Moss AH, Sullivan AM, Cohen LM, Block SD, et al. The need for end-of-life care training in nephrology: national survey results of nephrology fellows. *American journal of kidney diseases : the official journal of the National Kidney Foundation*. 2003;42(4):813-20.
19. Schell JO, Patel UD, Steinhäuser KE, Ammarell N, Tulsy JA. Discussions of the Kidney Disease Trajectory by Elderly Patients and Nephrologists: A Qualitative Study. *American Journal of Kidney Diseases*. 2012;59(4):495-503. <https://doi.org/10.1053/j.ajkd.2011.11.023>
20. Ladin K, Pandya R, Kannam A, Loke R, Oskoui T, Perrone RD, et al. Discussing Conservative Management With Older Patients With CKD: An Interview Study of Nephrologists. *American Journal of Kidney Diseases*. 2018;71(5):627-35. <https://doi.org/10.1053/j.ajkd.2017.11.011>
21. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349-57. <https://doi.org/10.1093/intqhc/mzm042>
22. Nasreddine ZS, Phillips NA, Bédirian V, Charbonneau S, Whitehead V, Collin I, et al. The Montreal Cognitive Assessment, MoCA: A Brief Screening Tool For Mild Cognitive Impairment. *Journal of the American Geriatrics Society*. 2005;53(4):695-9. <https://doi.org/10.1111/j.1532-5415.2005.53221.x>
23. Thomas DR. A General Inductive Approach for Analyzing Qualitative Evaluation Data. *American Journal of Evaluation*. 2006;27(2):237-46. <https://doi.org/10.1177/1098214005283748>
24. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77-101. <https://doi.org/10.1191/1478088706qp0630a>
25. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med*. 2004;36(8):588-94.
26. Davison SN, Simpson C. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. *BMJ*. 2006;333(7574):886. <https://doi.org/10.1136/bmj.38965.626250.55>
27. Kaufman SR, Shim JK, Russ AJ. Old age, life extension, and the character of medical choice. *J Gerontol B Psychol Sci Soc Sci*. 2006;61(4):S175-84.
28. Muscat DM, Kanagaratnam R, Shepherd HL, Sud K, McCaffery K, Webster A. Beyond dialysis decisions: a qualitative exploration of decision-making among culturally and linguistically diverse adults with chronic kidney disease on haemodialysis. *BMC Nephrol*. 2018;19(1):339. <https://doi.org/10.1186/s12882-018-1131-y>
29. Foote C, Kotwal S, Gallagher M, Cass A, Brown M, Jardine M. Survival outcomes of supportive care versus dialysis therapies for elderly patients with end-stage kidney disease: A systematic review and meta-analysis. *Nephrology*. 2016;21(3):241-53. <https://doi.org/10.1111/nep.12586>
30. Verberne WR, Geers AB, Jellema WT, Vincent HH, van Delden JJ, Bos WJ. Comparative Survival among Older Adults with Advanced Kidney Disease Managed Conservatively Versus with Dialysis. *Clin J Am Soc Nephrol*. 2016;11(4):633-40. <https://doi.org/10.2215/CJN.07510715>
31. Chandna SM, Da Silva-Gane M, Marshall C, Warwicker P, Greenwood RN, Farrington K. Survival of elderly patients with stage 5 CKD: comparison of conservative management and renal replacement therapy. *Nephrology, Dialysis, Transplantation*. 2011;26(5):1608-14. <https://doi.org/10.1093/ndt/gfq630>
32. Thorsteinsdottir B, Montori VM, Prokop LJ, Murad MH. Ageism vs the technical imperative, applying the GRADE framework to the evidence on hemodialysis in very elderly patients. *Clin Interv Aging*. 2013;8:797-807. <https://doi.org/10.2147/CIA.S43817>
33. Zier LS, Sottile PD, Hong SY, Weissfield LA, White DB. Surrogate decision makers' interpretation of prognostic information: a mixed-methods study. *Ann Intern Med*. 2012;156(5):360-6. <https://doi.org/10.7326/0003-4819-156-5-201203060-00008>
34. Hole B, Salem J. How long do patients with chronic disease expect to live? A systematic review of the literature. *BMJ Open*. 2016;6(12):e012248. <https://doi.org/10.1136/bmjopen-2016-012248>
35. O'Hare AM, Kurella Tamura M, Lavalée DC, Vig EK, Taylor JS, Hall YN, et al. Assessment of Self-reported Prognostic Expectations of People Undergoing Dialysis: United States Renal Data System Study of Treatment Preferences (USTATE). *JAMA Internal Medicine*. 2019. <https://doi.org/10.1001/jamainternmed.2019.2879>
36. Selman et al BMC nephrology. The views and experiences of older people with conservatively managed renal failure: a qualitative study of communication, information and decision-making. 2019. <https://doi.org/10.1186/s12882-019-1230-4>
37. Nemiroff L, Marshall EG, Jensen JL, Clarke B, Andrew MK. Adherence to "No Transfer to Hospital" Advance Directives Among Nursing Home Residents. *Journal of the American Medical Directors Association*. 2019;20(11):1373-81. <https://doi.org/10.1016/j.jamda.2019.03.034>
38. Gurmankin AD, Baron J, Hershey JC, Ubel PA. The Role of Physicians' Recommendations in Medical Treatment Decisions. *Medical Decision Making*. 2002;22(3):262-71. <https://doi.org/10.1177/0272989x0202200314>