Kidney Medicine

Palliative Care Acceptability for Older Adults with Advanced CKD: A Qualitative Study of Patients and Nephrologists

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Rationale & Objective: Older adults in the United States often receive kidney therapies that do not align with their goals. Palliative care (PC) specialists are experts in assisting patients with the goals of care discussions and decision support, yet views and experiences of older patients who have received PC while contemplating kidney therapy decisions and their nephrologists remain unexplored. We evaluated the acceptability of CKD-EDU, a PC-based kidney therapy decision support intervention for adults ≥75 years of age.

Study Design: Qualitative study.

Setting & Participants: Two trained research coordinators interviewed patients and nephrologists participating in the CKD-EDU study.

Analytical Approach: Three coders analyzed the qualitative data using a thematic analysis approach to identify salient themes pertaining to intervention acceptability.

Results: Patients (n = 19; mean age: 80 years) viewed the PC intervention favorably, noting PC physicians' excellent communication skills, whole-person care, and decision-making support, including comprehension of prognostic information. Nephrologists (n = 24; mean age) welcomed PC assistance in decision making, support for conservative kidney management, and symptom management; a minority voiced concerns about third-party involvement in their practice.

Limitations: Single-center study.

Conclusions: Overall, patients and nephrologists generally found the PC intervention to be acceptable. Future testing of the current PC-based decision support intervention in a larger randomized controlled trial for older people navigating kidney therapy decisions is needed.

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The Institute of Medicine endorses goal-concordant decision making for individuals with serious illnesses, including those with advanced chronic kidney disease (CKD).[1] However, the kidney therapy decision-making process often lacks patient involvement.[2-4] Dialysis is commonly presented as a default option, and patient goals are frequently overlooked.[5] In addition, little information is provided about conservative kidney management (CKM) despite it being a goal-concordant option for some older people.[2-4,6,7] As a result, many patients experience dialysis regret.[4,8]

The emotionally taxing nature of kidney therapy decision making affects both patients and their families and also carries moral implications for nephrologists.[9-13] Therefore, there is an urgent imperative to improve the kidney therapy decision-making process, especially for older frail adults who often benefit less from dialysis and prioritize quality of life over longevity, preferring CKM.[6,7] However, interventions to support older adults about kidney therapy choices are scarce, and few kidney therapy decision aids include personalized coaching.[14] To fulfill this unmet need, palliative care (PC) could play a crucial role in aiding patients and families in kidney therapy decisions. However, despite calls for such research and emerging new PC interventions,[15,16] PC interventions have yet to be studied among older individuals with advanced CKD contemplating kidney therapy choices.[17]

To address this salient gap, we developed and pilot-tested the CKD-EDU intervention, a specialist PC-based decision support intervention for older patients with advanced CKD and their caregivers (when present). We assessed both patient and nephrologist perspectives of the intervention as well as nephrologists' general acceptability/perceived benefits of PC services. In conducting the study, we wanted to identify the positive and negative aspects of this pilot intervention to improve the intervention by amplifying the positives and mitigating the negatives and explore nephrologists' views about the acceptability or perceived benefits of PC services.

METHODS

Design and Participants

Overview of the CKD-EDU Study

The CKD-EDU trial (NCT03465449) was a PC-based pilot trial for individuals ≥75 years with advanced CKD (eGFR ≤25 mL/min) to aid in kidney therapy and end-of-life decisions. Caregivers ≥21 years, if nominated by a patient, were also invited to participate in the study. The primary goal of the pilot work was to assess the feasibility and acceptability of the CKD-EDU intervention. The control group received standard nephrology care and kidney therapy education from a clinic educator, whereas the intervention group received nephrology care from their

PLAIN-LANGUAGE SUMMARY

Literature on the acceptability of palliative care for kidney therapy decision making for older adults is scarce. This qualitative study establishes the acceptability of a palliative care (PC)-based kidney therapy decision support pilot intervention among older adults with advanced chronic kidney disease (CKD). Both patients and nephrologists found the intervention acceptable. Future testing of this PC-based intervention in an adequately powered randomized controlled trial for older individuals navigating kidney therapy decisions is needed.

nephrologist, a kidney therapy decision aid to assist with kidney therapy, and end-of-life planning[18] followed by up to 3 sessions with the same PC physician depending on patient's decisional needs as mutually decided by the patient and the PC interventionist. The PC intervention was adapted from the National Consensus Project for Quality Palliative Care[19] and a prior PC intervention for people with lung cancer.[20] The intervention visits focused on exploring hopes, goals, fears along with identifying and addressing sources of decisional conflict by answering questions and eventually firming up a kidney therapy decision and end-of-life plan. Two PC physicians delivered the intervention. They had access to a PC team (nurses, psychologist, social worker), but these services were not used as the intervention primarily focused on kidney therapy decision making. The intervention was not focused on symptom management; however, in a few patients in whom debilitating symptoms were reported by patients and families, recommendations for symptom management were provided. After each visit, the interventionist communicated their visit notes with the primary care physician and the nephrologist. Notably, we will report recruitment data and preliminary outcomes in a separate article.

Sampling Procedures

All participants provided written informed consent following University of Rochester institutional review board approval. The study enrolled older patients (with caregivers if consented) of participating nephrologists who consented to participate in the CKD-EDU intervention. Eligible patients were ≥75 years, had an estimated glomerular filtration rate of ≤25 mL/min, had not yet decided on kidney therapy option, and had not previously consulted a dialysis educator. Each patient nominated up to 3 individuals aged ≥21 most in a rank order list, but only one caregiver/patient was allowed to participate. Interviews with patients in the intervention group (and caregivers if present) were conducted by 2 research coordinators trained in qualitative interviewing after the final intervention visit.

Additionally, one research coordinator conducted interviews with nephrologists to understand their perspectives on the intervention's acceptability. We also examined the views of nephrologists whose patients did not partake in the intervention regarding the acceptability/perceived benefits of PC as a specialty. The audio-recorded interviews generally lasted approximately ∼30 minutes, with key questions detailed in Items S1 and S2. Notably, the PC intervention was administered by 2 male physicians, one with ∼27 years and another with ∼16 years of practice experience at the time of intervention delivery.

Data Analyses

Following Consolidated criteria for Reporting Qualitative research guidelines, we report analyses and results. The analyses process began with the transcription of interviews through a patient privacy compliant third-party vendor, followed by the utilization of MAXQDA software to assist in organizing the coding of the data. The coders came from medical and nonmedical backgrounds (F.N.H.: a PhD social worker, S.D.: a medical student, and A.J.: a physician with training in nephrology and PC). We employed modified framework analysis,[21] an approach often used for multidisciplinary teams; the focus of this approach lies in looking both common and unique elements, exploring relationships within the data to formulate theme-based conclusions, and streamlining comparisons across and within patients.[21] Concretely, after the transcription, each coder (F.N.H., S.D., and A.J.) conducted individual reviews of all transcripts to acquaint themselves with the data and identify emerging concepts. We then deductively coded the statements from the interviews as positive or negative toward the intervention so as to facilitate actionability of the findings[22]; we had a positive patients/caregiver category, a negative patients/caregiver category, a positive physicians category, and a negative physicians category. We then further sorted these 4 categories into subcategories, that is reasons why the intervention was deemed acceptable or not. The data were coded and interpreted collaboratively; to fortify data trustworthiness, the research team consistently convened to engage in discussions to reach an agreement.[22-24]

RESULTS

We present descriptive data on the demographic characteristics of the 19 patients (mean age 80 years) and 10 caregivers (mean age 70 years) who participated in qualitative interviews in Table 1. Table 2 presents the participating nephrologists' demographic characteristics (n = 24) with mean age of 43.1 years.

Patients' and Caregivers' Acceptability of the PC Intervention

Patients and caregivers deemed the intervention acceptable because they were satisfied with the communication skills of the PC clinician, the focus on whole-person care, the support of their goals, and the prognostic information they received (Table 3).

Table 1. Demographics of Patients and Caregivers

	*Patients[a], n = 19 (%)	Caregivers, n = 10 (%)
Age (y, mean ± standard deviation)	80.3 ± 4.6	70.2 ± 9.7
Gender		
Male	9 (47.4)	3 (30.0)
Female	10 (52.6)	7 (70.0)
Race		
White	14 (73.7)	8 (80.0)
Black or African American	3 (15.8)	2 (20.0)
Mixed	1 (5.3)	0 (0)
Other	1 (5.3)	0 (0)
Ethnicity		
Hispanic or Latino origin	3 (15.8)	1 (10.0)
Not Hispanic or Latino origin	16 (84.2)	9 (90.0)
Annual income		
50,000 or less	12 (63.2)	6 (60.0)
50,001 or more	5 (26.3)	3 (30.0)
Prefer not to answer	2 (10.5)	1 (10.0)
Education		
Grade 11 or below	4 (21.1)	0 (0)
Grade 12 or above	15 (78.9)	10 (100.0)
Caregiver's relationship to the patient		
Spouse		6 (60.0)
Child (≥21 years old)		3 (30.0)
Immediate family member		1 (10.0)

[a]Twenty-six patients received the intervention, but 7 patients were unable to participate in the interview for various reasons: placement in a nursing home after an injury (n=1), hospice admission (n = 1), audio failure (n = 2), withdrawal from the study because of a move (n = 1), loss of interest (n = 1), and death (n = 1).

Providing Information With Effective Communication Skills

Patients frequently expressed surprise at the contrast between their regular physicians' communication style and the information provided and communication skills of PC physicians. As one participant noted, "He [the doctor] was very congenial to work with because of his conversation, the knowledge he had, his answers to the questions, and he did it in a way that I could understand." This participant's caregiver also highlighted the intervention acceptability, stating, "The information and the personality, which combined made [the intervention] really effective." Another participant remarked, "I never got this kind of information from my nephrologist."

Providing Individualized, Whole-Person Care With Honesty and Attentiveness

Patients acknowledged the ability of PC physicians to address specific issues and provide whole-person care. One patient remarked, "the care that Dr. [name] provided was different from what my other team offers, because all the different explanations he gave and his suggestions to keep… the diet, the exercises, the spiritual care, that kind of thing." Caregivers also emphasized the physician's attentiveness and honesty, stating, "he listened and addressed every single concern. And he even did it honestly."

Table 2. Characteristics of Nephrologists Who Completed the Qualitative Interview

Demographics	Physicians n = 24 (%)
Age (y, mean, standard deviation)	43.1 ± 9.5
Sex	
Men	15 (62.5)
Women	9 (37.5)
Race	
White	14 (58.3)
Black or African American	0 (0)
Mixed	0 (0)
Other	10 (41.7)
Ethnicity	
Hispanic or Latino origin	1 (4.2)
Not Hispanic or Latino origin	23 (95.8)
Years of nephrology experience	
0-5 y	12 (50.0)
6-10 y	0 (0)
11-15 y	7 (29.2)
16-20 y	3 (12.5)
21-25 y	1 (4.2)
26 y or more	1 (4.2)
Participation in any Continued Medical Education communication training since completing internal medicine training	
Yes	11 (45.8)
No	13 (54.2)
Hours of credit-bearing courses in the social, behavioral, psychological, communication, or public health sciences over the course of academic career, beginning in college	
0 h	5 (20.8)
1-3 h	11 (45.8)
4-6 h	4 (16.7)
7 or more h	3 (12.5)
Unanswered	1 (4.2)

Supporting With Kidney Therapy Decision Making

Patient participants expressed their appreciation for the assistance with decision making. One reflected, "I think he made me come to grips with the fact that there are medical decisions that should be talked about." Another patient stated, "… I explained what I wanted, you know, how I would make the decision depending on my quality of life. I mentioned it more than once that I didn't want to prolong my death. It's not that I have a death wish. That's not what I'm thinking. I'm not afraid of it if it's my time..." Notably, a patient, despite appreciating the support, still felt uncertain about their kidney therapy decision, "I didn't really make any decisions [about dialysis initiation]." Another patient expressed ongoing uncertainty despite receiving the PC intervention, stating, "I am still, you know, uncertain in terms of decision-making ..."

Helping With Prognostic Understanding

Patients acknowledged the value of the opportunity to engage in prognostic discussions. One patient stated, "I

Table 3. Key Quotes of the Participants

Category	Title	Quotes
1. Patients' and caregivers' acceptability of specialist palliative care	i. Providing information with effective communication skills	"I understood what he [PC doctor] was talking to me about. Some people can outlay stuff to you and you don't understand but he put it in a form where I could understand where, what was going on."
	ii. Providing Individualized, whole-person care with honesty and attentiveness	"He [PC doctor] seems to be sympathetic. The way he explains things that are easy to understand and again he seems to be someone you can talk to."
	iii. Supporting with kidney therapy decision making	"It's normally you as a patient have to take whatever steps need to be taken to learn things. Here's a situation where a physician came to me and with an offer to inform me of something that affects me and that's unique in my experience."
	iv. Helping with prognostic understanding	"Well, just thinking about prolonging my existence and I was able to talk about that [ie, talk about prognosis with the PC clinician]."
2. Nephrologists' acceptability of specialist palliative care	i. Supporting with the kidney therapy decision-making process	" I think I'm good at preparing ahead of time. But I realize, like with [patient' name], I think I completely forgot that she was probably getting to a point to start talking about dialysis. And so having you in the clinic saying, wait, can I talk to this patient? It made me realize, oh, it's time, it's time to talk to that patient."
	ii. Supporting the adoption of the conservative kidney management pathway	"If it's just a dialysis decision making initially ahead of time when people have home support or when they don't need a lot of extra support, I feel comfortable offering conservative care. But if there are a lot of other needs, especially psychosocial mental health issues, it helps me to have other support, like for this patient and that family did get a lot of support."
	iii. Assisting with symptom management	"I think the other thing is there's a large symptom burden in patients that we don't know is going to [be addressed]."
3. Nephrologists' negative feedback on the PC intervention	i. Potential inappropriateness of conservative kidney management	"If the patient believes or comes to believe that you don't really want to care for them in the sense that you might consider that dialysis isn't appropriate for them or kind of maximum therapy isn't appropriate for them going forward [they may feel abandoned]."
	ii. Potential interruption of the therapeutic alliance	"I would have to call another [PC] educator to talk to my patients and that creates some confusion for the patients and then oh why, why do I need to see another one and it cause a lot of confusion because the more people getting involved with care with the elderly patient I think it harder for them." "You might argue that while they might feel that the physician is not sure of his decision and wants to reach out to more providers."
	iii. Possible lack of referral/less applicability to patients	A lot of the patients see multiple physicians and adding one more might be a bit of a burden.

think, first of all, get a good understanding, knowing your prognosis and working with the team." Another patient reflected on their better understanding of renal prognosis after the CKD-EDU intervention and expressed a relief that he does not have to do dialysis immediately, "I came home and said I must be again at the point that they're going to send me for dialysis. That's what I thought. That is very different from what he [the PC physician] said."

Patients' and Caregivers' Negative Feedback of the PC Intervention

Patients also provided reflections that could inform improvement of the intervention. One participant suggested "a video to support the decision-making process." Another wanted more detailed kidney therapy information, "My comment would be uh, I think that the (reading material) could be more comprehensive, depending on the patient." Another patient "didn't feel intervention was different from other nephrology care."

Nephrologists' Positive Feedback on the PC Intervention

Nephrologists reported that the intervention was helpful because it supported patients with decision making, particularly if choosing CKM, and assisted with symptom management (Table 3).

Supporting the Kidney Therapy Decision-making Process by Discussing Choices and Promoting Patient Action

The engagement of patients in the decision-making process and the support provided by the CKD-EDU study were recognized by nephrologists. One nephrologist stated, "And surprisingly, one guy had a firm decision, but he's not really from a medical background, and after he [participated in the intervention], he actually changed his decision and he has stuck with it, and I think he benefitted from it." The nephrologists also highlighted the limitations of other educational approaches that merely focus on dialysis modality without genuinely considering the patient's quality of life, stating, "We have had some patients get an education through [an educator], but their model really isn't dialysis, yes or no? Its dialysis—what modality do you want? So, I think [the PC intervention] is a much better approach because the bigger question whether dialysis is really right [or] not right? ….Versus just saying, OK, here's your four different choices for dialysis. Which one do you want to do?" Another nephrologist acknowledged that patients in the study were more active and had more questions than other patients, stating, "Of course, they had more questions than some other patients, but just because they were given more information."

Supporting the Adoption of the Conservative Kidney Management Pathway

Nephrologists recognized the valuable support they received regarding CKM, "I feel that [my patients] felt better about choosing not to use dialysis." Another nephrologist concurred stating, "I didn't feel that it was inappropriate for this person to consider conservative care, and I was happy that they had that support [from the study]."

Assisting With Symptom Management

Although the primary focus of the intervention was decision support, there were instances in which recommendations were made to address severe and distressing symptoms. One nephrologist said, "… the [PC] doctor, I believe, suggested a medication to prescribe for depression, and that is certainly something to think about in our CKD patients that maybe we as nephrologists don't think about as much but probably should...so, he [the PC doctor] suggested the medication to the primary care provider to prescribe…I think it helped the overall situation."

Nephrologists' Negative Feedback on the PC Intervention

Nephrologists generally felt positive about the intervention; however, some also pointed areas for improvement.

Potential Inappropriateness of CKM

One nephrologist expressed concern about the inappropriateness of CKM as one patient experienced decisional conflict as a result of the intervention. The nephrologist shared, "[A patient who] ended up choosing dialysis, was not somebody I would have actually pushed a conservative approach for her because she was otherwise pretty, you know, robust. But then she decided on a conservative care approach after she enrolled in this study." Another nephrologist remarked, "Yea, you know they're saying well why me, why wouldn't she just put me on dialysis and you know, continue to care for me. Um, again, just a theoretical concern. I would have very little concern about putting any of my patients in it."

Potential Interruption of the Therapeutic Alliance

Nephrologists expressed concern that the CKD-EDU intervention may interfere with the patient doctor relationship. One remarked, "I'm not sure, to be honest with you, about the outcome [of the intervention]; whether or not it necessarily will ultimately influence their decision-making with respect to dialysis. I think the premise is a good premise, but I think the assumption was that we providers do not give enough information about dialysis to begin with. The assumption isn't necessarily correct, and maybe it is, maybe it isn't." There was also a "worry" that "the relationship between the physician and the patient might be disrupted if the patient believes or comes to believe that you don't really care for them."

Possible Lack of Referral/Less Applicability to Patients

Another useful although not negative insight provided by a different nephrologist was that patients who strongly prioritize life extension and dialysis might immediately decline the intervention, leading to low referral rates. This nephrologist explained, "I think that many patients sometimes are attracted to our aggressive approach at wanting dialysis, and they are very hesitant to even look into palliative care." This quote may have an underlying patient misconception that PC may mean "no dialysis."

Nephrologists' General Views About Using PC in Clinical Settings

When exploring the general views of nephrologists regarding the utility of PC for individuals with kidney disease, several themes emerged.

Positive Views About PC

One nephrologist acknowledged "I think the reality of the issue on our end from the medicine side is not calling PC earlier in the patient's course….I cannot think of any time ever where palliative care was not helpful when they were consulted."

Managing Symptom Burden and Alleviating Suffering

One nephrologist stated, "I refer a few people here and there if they really have bad symptoms." Another nephrologist stated "I think that in general, the palliative

care docs and teams are able to break that down and explain that no one's trying to hurt your loved one. We're trying to help your loved one and ease their suffering."

Goals of Care and Kidney Therapy Decisions

Notably, nephrologists identified the importance of PC services in facilitating discussions related to goals of care and kidney therapy decisions. As one nephrologist explained, "I would refer someone to palliative care group when I think they were having trouble making that sort of [kidney therapy] decision. They didn't really know what the other options are, or what PC entails." Another nephrologist suggested PC as an integral part of the kidney therapy decision-making process: "Just like you would consult a vascular surgeon, you should probably meet with Palliative Care to decide if you want to do it in the first place." Similarly, another nephrologist reflected, "They're going to need dialysis or maybe they're too old, and they should not get dialysis. But I think that same sort of constant trust, if it is provided by, [the PC team], and sees the patient at different levels, might be a really good model to help patients make a good decision."

Conservative Kidney Management

Furthermore, some nephrologists sought PC involvement for patients opting for CKM, "I just couch it is as one of the multiple options of the patient and I emphasize it more in patients that have limited quality of life or comorbid conditions, where I'm not totally confident that they're going to have really great quality [of life] on dialysis."

Connecting Patients with Hospice Services

Physicians used PC to connect patients to hospice—"mostly, not having the conversations or making the decisions, more about the kind of navigating hospice and the medication part that I just don't do enough to feel comfortable advising. And how to get somebody into home hospice quickly."

DISCUSSION

In this study, we observed that older patients and nephrologists held positive views about the acceptability of CKD-EDU intervention, noting PC physicians' excellent communication skills, whole-person care, and decision-making support, including communication of prognostic information. Nephrologists welcomed PC assistance in decision making, symptom management, and support for CKM but a minority voiced concerns about third-party involvement in their practice.

The acceptability findings are broadly consistent with key skills and components of high-quality PC visits as reported in the literature[25,26] and align with the results of a prior pilot study on the acceptability of a joint kidney-PC clinical care model[16] and a telemedicine-based PC intervention for people receiving maintenance dialysis.[15] Nonetheless, our intervention is distinct from previous PC research interventions, as it exclusively focuses on older adults with advanced CKD contemplating kidney therapy choices. Further, as a result of patient/caregivers feedback and discussions among the study team, we made changes to the decision aid, including details of additional resources of reading for people wanting more information, and we also added a video to support the kidney therapy decision-making process.[18] Notably, those uncertain typically wished to continue their daily life, leading to a decision deferral. This inspired our proposal for the "Deciding Not to Decide" option.[27]

Nephrologists also found the CKD-EDU intervention to be useful and acceptable for kidney therapy decision-making; however, a few nephrologists expressed unease about patients considering CKM and concerns regarding the disruption of the doctor-patient relationship if a third party is involved. These concerns are broadly consistent with the prior literature.[28] For instance, a study by Metzger et al reported that low patient interest was a barrier to nephrology–PC collaboration.[29] Additionally, confusion between PC and hospice care among patients and family members is not uncommon.[30] Therefore, some have proposed using the term "supportive care" instead of PC.[31] We named our intervention the "CKD-EDU study" as it was a decision support intervention. Notably, patients' choices may change over time,[32] and decisional conflict is a natural part of the decision-making process.[9] However, given the current default to dialysis and a general lack of choice in kidney therapy decision-making process, it is understandable that nephrologists may be surprised if a patient considers CKM or changes their treatment choice after receiving more information or changing life situation or goal.[11] In such scenarios, clear interdisciplinary discussion (eg, a phone call between the providers) may be helpful in fostering consensus on a plan and mitigate "third-party involvement" concerns.

Clinicians' apprehensions regarding the potential disruption of doctor-patient relationships align with concerns previously noted among oncologists and nephrologists.[28,33] Some clinicians may wish to retain control over the referral process,[28] viewing PC referrals as professional vulnerabilities, potential turf intrusions,[34] or even as perceptions of patient abandonment, failure, or the loss of hope.[35] These concerns might be addressed by framing PC as a consult to elicit goals of care rather than reach final decisions as in some patients "Deciding Not to Decide" may be the best goal-concordant decision.[27] In future collaborations between nephrologists and PC physicians, it is imperative to educate individuals about PC services and proactively address the concerns articulated by nephrologists. This involves clarifying the roles of each specialty and inquiring whether their concerns pertain to a broader issue of third-party intrusion or are specifically related to PC involvement.

The present study has strengths, limitations, and implications. The study provides valuable insights into the

stakeholders' perceptions of acceptability of the PC intervention. Their feedback is a crucial initial step toward integrating PC into routine CKD care for kidney therapy decision making. The qualitative approach used in the study provides detailed information on the acceptability of the intervention. However, the intervention was administered by only 2 PC physicians. To mitigate this limitation and comprehensively assess PC acceptability among nephrologists, we also examined nephrologists' perspectives on PC as a broader concept. Some participants may be reluctant to provide constructive feedback because of social desirability bias.[36] Further, our sample is limited to patients consenting to participate, and although novel for kidney-PC literature, may not be generalizable to nonacademic settings with different cultural contexts. To address this limitation, future studies could be conducted in different settings (eg, nonacademic or other geographical locations) to validate the present findings. Our findings are consistent with growing research indicating that PC intervention for older individuals with CKD and will likely be welcomed by most nephrologists; however, concerns about a third-party involvement will need to be addressed.[15,16,29]

In summary, this qualitative study explored the acceptability of a PC intervention among older adults and nephrologists and found it to be acceptable. Further large-scale testing of the current intervention is needed.

SUPPLEMENTARY MATERIALS

Supplementary File (PDF)

Item S1: Examples of Qualitative Questions for Patients.

Item S2: Examples of Qualitative Questions for Nephrologists.

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