

BACKGROUND

Hearing, a nephrologist say “You need dialysis” often conjures up images of a diminished life tethered to a machine until an imminent death.

No wonder that patients are devastated and nephrologists say talking about dialysis is the worst part of their job.

Thrice-weekly in-center hemodialysis (used by ~90%) has the highest rates of [1]:

- Costly infections and hospitalizations
- Sudden cardiac death
- Fatigue, cramping and other debilitating side effects
- Disruption of normal life activities (i.e., work and social participation)
- Depression among patients and their caregivers

There are better options.

Daily home peritoneal dialysis (PD, used by ~8%) or home hemodialysis (HHD used by ~1%), self-administered at the patient’s convenience [2]:

- Provide continuous kidney function with gentler treatments.
- Result in better physical, economic, emotional and social wellbeing,
- Allow for normal life activities, such as work and social participation.
- Have fewer costly hospitalizations.

Medicare, which pays for most dialysis and disability, promotes greater use of PD and HHD. **Why is ICHD still so common?**

Patient-centered, values-based, shared decision-making—the gold standard for choosing complex medical treatments—might support the use of frequent home home dialysis. [3]

Shared dialysis decision making rests on two pillars:

1. Nephrologist:

- Elicits and listens to the patient’s concerns, values and preferences.
- Provides expert advice tailored to the patient’s values.
- Encourages patient to actively participate in health decision-making.

2. Patient:

- Shares concerns, values, and treatment preferences
- Asks questions to home in on the best treatment.

Virtually nothing is known about how nephrologists and patients actually talk about dialysis.

OBJECTIVES

Understand how nephrologists and patients talk about dialysis, regarding:

1. Patient centered, values-based shared dialysis decision-making
2. Patient preferences for dialysis or other treatment
3. Patient participation in the dialysis segment of the conversation

METHODS

A mixed-method conversation study audio-recorded 62 patients (with <25% kidney function, eGFR <25) seen by 8 nephrologists from 3 Wisconsin clinics. Data included verbatim transcripts of clinic visits. In-depth analysis was performed on the 49 with a dialysis conversation. [4]

Demographics and decision-making preferences were collected by post-visit survey and analyzed with descriptive statistics.

RESULTS

Sample

NEPHROLOGISTS n = 8					
Age Mean (range)	39.43	(37-44)	Years of practice	7	(2-10)
PATIENTS n = 49					
eGFR Mean, SD	20.16	3.53	White	42	86%
Age	69.90	3.15	Married	25	51%
Age range	25-94		< College degree	32	65%
Female n, %	29	59%	Work fulltime	8	16%

Decision-making styles

Nephrologists primarily used autonomous decision-making; 2 used shared decision making (SDM)—when patients stated their values. Patients preferred SDM. Doctor-focused patriarchal decision-making was not used or preferred.

	Site A			Site B			Site C			Total
Nephrologists^a	1	2	3	1	2	3	1	2	8	
# Patients / Nephrologist	4	10	2	7	6	3	8	9	49	
Nephrologists’ Decision-Making Style										
Autonomous (give info patient chooses)	4	8	2	7	6	3	7	9	46	
Shared (team effort)	2						1		3	
Patients^b										
Autonomous (I want to decide)	2	5		3	2		1	1	14	
Shared (I want my doctor and I to decide)	2	5	2	4	6	1	7	8	35	
^a Conversation analysis					^b Patient Surveys					

Patients’ dialysis and treatment preferences

Nephrologists most often discussed ICHD, PD, and transplant, but hardly HHD. Nephrologists focused on the considerable benefits of PD. But more patients rejected than embraced PD—seemingly due to nephrologists’ use of didactic vs. dialogic communication methods, and emphasis on the need for a care partner (vs. optional) and rigorous training (vs. easy to learn). Nephrologists described transplant as the best option in 24 conversations, but then told 16 of those patients that they were not eligible—primarily due to being older than 75.

Number of conversations addressing dialysis, transplant or palliative option (49 total conversations)

In-center hemodialysis (ICHD)		Peritoneal dialysis (PD)	
Discussed	21	Discussed	20
Risks (<independence, >fatigue, heart)	17	Benefits (>independence, fatigue, heart)	10
Patient rejects	12	Patient rejects	11
Patient leaning toward	7	Patient leaning toward	4
Home hemodialysis (HHD)		Kidney Transplant	
Discussed	2	Discussed	24
Nephrologist encourages	1	Nephrologist then tells patient “Not eligible”	16
Patient leaning toward	1	Transplant planning underway	8
No Dialysis (Palliative)			
Patient initiated	9	Nephrologist initiated	4

Contact information: Meg Wise, PhD, Sonderegger Research Center, School of Pharmacy, University of Wisconsin-Madison 608-263-3959, mewise@wisc.edu

Patient participation in the full and the dialysis conversation

Nephrologist/Patient word count ratios	Mean ratio	SD	Range
Full conversation (rapport building, labs, lifestyle, medications)	3.35	2.35	0.63 - 13.33
Dialysis and treatment options segment of the conversation	7.75	9.42	0.61 - 44.20
Substantive dialysis conversation (removed um, uh huh, yeah, but...)	10.00	21.14	0.60 - 144.67

Nephrologists spoke ~8 times more than patients for the dialysis segment; 10 times more with filler words removed, perhaps overwhelming patients.

From the conversations

Patient (male >80 years) engages nephrologist in shared decision-making

P: “I read a study... where 3,000 patients that had dialysis, and, uh, 50% of them said they’d never do it again. ... And only 50% lived 6 months.”

N: “And they have shown that, ... some patients kind of lose their independence. ... They end up in a nursing home” ...

P: “I’m pretty active, and I just about do anything I want to do.”

N: “Good, that’s good. Yeah. That’s good... I, I, I hate, because hemodialysis will definitely tie you down. ...”

P: “We have a, a big fishing trip planned in . . . in July of next year in Alaska. And my boys have already bought their airline tickets.”

N: “Okay. But ... your kidney function is 11%. ...If you decide you absolutely do not want to do dialysis, there are doctors here. It’s called palliative care. ... They do everything to make sure that you have a good rest of [life].”

P: “Yeah, I’m, uh, I’m not into the long time, I’m into the good time.”

N: “Good time, okay. Let’s take each day as it comes.”

Patient’s (female <65 years) emotions acknowledged, but not addressed:

P: “Now, I be afraid of dialysis.”

PA: “Yeah, yeah. ... But, [your kidney function] is definitely lower than it’s been. P: [alone] “Lord, have mercy, please. Get my blood, my blood pressure, ... Nephrologist enters: “Hi!” How are ya?”

P: “Okay.”

DISCUSSION AND CONCLUSIONS

This is the first study to analyze real-life nephrologist/patient communication. Nephrologists established good rapport with their patients, aimed to forestall the need for dialysis They were uncomfortable talking about dialysis, which they overcame by avoiding emotions and using a script to deliver information so that patients could make their own decision. Shared decision-making occurred only when patients inserted their values into the conversation. Nephrologists are not trained to engage in shared dialysis decision making—and said they would welcome tools to help them do so. Our follow-up study is testing the effects of sharing the patient’s values and dialysis preferences after doing *My Life, My Dialysis Choice*, an online, interactive dialysis decision aid, on patient/nephrologist shared dialysis decision-making.[6]

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