

JANE SCHELL: Hi, my name is Jane Schell. I am a palliative care and nephrology physician at UPMC, and I'm very excited today to be talking to you about insights into managing kidney disease in older patients. In particular, I am hoping to send you off with some tools that can help you with managing your patients who have advanced kidney disease, and recognizing opportunities to talk about treatment decisions, and what that could look like. My disclosures are up to date, and I am also the palliative care advisor for Dialysis Clinic, Inc.

The goals of today's talks are threefold. The first is to describe the dialysis experience for older patients with kidney disease. I want to leave you with two tools that you can use to predict the risk of kidney progression in patients with kidney disease. And then we'll spend the majority of our time talking about conservative kidney management, what this is, the outcomes, and also which patients benefit, and who might be right for this treatment. I want to start with a picture. They say a picture is worth a thousand words, and I wonder what words come to mind when you see this picture? I know for me, the thoughts that came up were joy, laughter, family, resilience.

What if I told you that these two people were living with a serious illness? Well, for many of us, this is how we would imagine how, if we were living with any kind of chronic illness, that this life would be lived. And that is with quality of life, with joy, with laughter, with family, and resilience. I think it's important for us to think about this picture as we talk about how do we care for our patients and their families with chronic illness. For your knowledge, this is actually a picture that came from a family imprint. It was a book that Nancy Borowick actually did of her own parents, who were both living with cancer. And there's a series of beautiful photos that really capture that journey.

So how do we better prepare patients for living well with kidney disease? And why do I ask that question? Because it requires a change, a change in what we're doing now, and how we're caring for patients. So to start with that, I want to talk about what is the current state. Many of you care for patients on dialysis, and have seen and cared for many of the experiences that they go through. The average patient actually starting dialysis is older, and we know that they happen to be more frail. It's a three-fold higher incidence of frailty in patients on dialysis. Many of them have untreated symptoms. Untreated because they're under recognized despite being as great as those with cancer.

Many patients who start dialysis experience hospitalizations related to their dialysis or due to other comorbidities. Patients, especially those who are older, have dependency. And this dependency unfortunately gets worse after starting dialysis. There's a lot of literature that's looked at dialysis initiation in the nursing home setting and, actually, looking at one year mortality in a group of nursing home patients, 68% of them actually died in the first year. Only 13% of them maintained their level of function. And in addition, our patients are more likely to experience end of life in the hospital. Dialysis patients have half the incidence of hospice use at end of life compared to the general population. And so for many patients, when we think about living well, it always doesn't look like this.

And as I mentioned, the end of life experience for patients on dialysis is intensive. In fact, in this comparison between patients on dialysis compared to those with cancer and heart failure, dialysis patients are more likely to be hospitalized, they're more likely to go to an intensive care unit, and they're less likely to use hospice as I mentioned, and they're more likely to die in the hospital. This data is older, and yet it's still exist when we look at the data today.

This was a recent article that came out that actually looked at regret, and they noticed that regret is fairly high in patients on dialysis. About 20% of these patients who completed a standard regret tool actually reported high decisional regret, and they found that a lot of the regret was associated with why they started. If they didn't really make the informed decision themselves, they were more likely to regret the decision. Regret was less likely if the patient had had a prognostic conversation or completed some sort of document that thought about their goals of care.

And I think about this as a physician and researcher. When I was a fellow, I actually did an interview study of older patients on dialysis to really learn how they thought about their situation, and their life, and their future. One dialysis said a quote that I will always take with me. When he thought about his situation, he said, "The situation I'm in, I think about it a whole lot because that's no way to live. It seems like I'm going around in circles. I watch these people that come to dialysis, and I see that's the way I am." I hold that, and I think about what that experience must have been like for that patient. And I compare that to what patients tell us they want. Whether you have kidney disease, or cancer, or any kind of serious illness, people want quality of life. They don't want to be a burden to their families, they want to maintain their independence for as long as possible, they want to maintain social relationships, they want to have a sense of control, especially at end of life.

We've done a lot of these studies with patients, and in a survey of patients and caregivers on dialysis, when they talked about what they ranked as most important, they said survival, but they described it as living well. And interestingly, the clinicians were also surveyed, and they named mortality as number one. For patients and caregivers, mortality was number 14. And so it's really, how do we help our patients live well? And the reason we're having this conversation today is because right now, your patients are more likely to start dialysis than not. This was an article that was in the New York Times a couple of years ago, and it says "Dialysis is a way of life for many older patients. Maybe it shouldn't be." This idea of conservative management comes up a lot in the news, and yet we don't see many of our patients getting it, and it turns out that many of them don't know about it as an option.

And if you look at the literature from nephrology, many kidney doctors have never been taught about conservative management, and they aren't comfortable talking about it. So this is an opportunity for you, as the general physicians for your older patients, to really pick up the conversation and have a way of talking about it. And it's really important. Part of the Choosing Wisely campaign actually focused on kidney related issues, and one of them was that you cannot start dialysis without having a shared decision making conversation. And so we're going to focus the majority of our talk about conservative kidney management, what it is, and how to talk about it with your patients.

And we'll start with a case that's probably very similar to a patient you may have taken care of. An 83-year-old woman with stage four kidney disease due to hypertension. She has gout, she follows with nephrology. She's been hospitalized twice in the past six months, she's dependent, in her ADLs, and her daughter is her main caregiver. Her recent creatinine was 3.2, and her estimated GFR was 15. So she's someone that would be stage five kidney disease. So you look in the notes, and the nephrologist has referred her to vascular surgery twice for a fistula creation. But she didn't keep the appointment. She says, I don't want to do that right now. And the notes report that, however, she says that, and then she'll say, well I'll do dialysis when I'm ready.

And so many of us, if we think about what's the story that's likely going to happen with this patient, this is a patient who's going to get sick, she's going to end up in the emergency room, and she may very well likely end up on dialysis. So what about the other option? What about conservative management? What is conservative management? Conservative management is actually planned active medical management of advanced kidney disease without dialysis. I say planned because it's not in the hospital when someone's dying of acute kidney injury and just deciding to forego dialysis. This is when you have a true shared decision making conversation. And I put the word "active" medical management because it is very active, and it's very aggressive. We're aggressively managing comfort and quality of life. So its goals are to optimize quality of life, treat symptoms of kidney failure, and prepare for the future. And when appropriate, we do things to preserve residual renal function. It's intended for patients who may not meaningfully benefit from renal replacement therapies, and also whose goals really focus on quality of life rather than intensive treatments to prolong it.

And many of you understand shared decision making, you do it every day. In fact geriatricians have taught us how to do this best with older patients. But it's important to think about it in how we talk about kidney disease. So it's a process in which clinicians and patients work together to make decisions that balance the risk and benefits with patient preferences and values. It's relative for things that we call preference sensitive issues, that is decisions that really depend on the patient's values and priorities. If the one take away you take from this talk is that a doctor does not know if dialysis is right for a given patient, then you won the race.

Oftentimes I do not know the right answer for my patients. I really have to put it in the context of their values and preferences. And the three steps I'm going to focus on is determining the options in terms of the risks and benefits. Number two is eliciting the patient values and priorities, and three, making a shared plan based on those values and priorities. An important part of this is that, number one, it's kind of my job as a clinician, that's my expertise, is to make sure I can talk about the risks and benefits and what it looks like in my patient. And number two is the patient expertise. And that's where we find out what they know about themselves and how that informs how they want their life to look. And then we make a plan together. It's also important to know that not everybody wants to have a shared decision making process. The majority of people do, but there are people who still want to make their own decisions without the help of a clinician. And there's other people who depend completely on the clinicians recommendation, so it's having some space for that.

So the first step in my book is to determine how likely do I need to have this conversation. What is the risk of kidney progression, and what goes into it? I really like this graph because it's older data, but it really shows what we see clinically. This was basically a retrospective study looking at patients with different GFR, as you can see on the y-axis and on the x-axis, by age group. And what you found is that, for a given GFR, depending on your age, your risk of death versus ESRD is different. And so to put that a different way, if you look at older patients, say those over the age of 85, their likelihood of dying with their low very low kidney function is much higher than their risk of starting dialysis. And within this study, it was really interesting, they looked at the rate of progression of very low kidney disease by age group, and that patients who are over the age of 85 actually have slower loss of GFR over a year compared to younger patients. So that you could have a patient with very low GFR and it has a very good likelihood of remaining low. And so that's an important consideration as we think about conservative kidney management.

The other tool I want to show to you, and many of you know this, and that is the kidney heat map. Basically, what this shows is that it's not only about GFR that helps prognosticate about the risk of kidney or major outcomes in our patients, it's also looking at albuminuria. So that you could have a relatively mild, moderate GFR and yet, if you have significant proteinuria, you're actually at higher risk of progression. When we're thinking about our kidney risk, you need to look at the kidney number, and also put it in context with the proteinuria as well.

And then the other thing I look at is their rate of renal function decline. Looking at the loss of renal function across years tells me about their risk of progression. We say that about two milliliters per minute of loss a year is actually considered slow, compared to that of five, which would be more rapid. If I had a patient that was losing GFR this fast, it would make me want to have a sooner conversation. The final tool I want to alert you to is the kidney failure risk equation. And this is basically a tool that you can use at North America and Canada, it's been tested and validated, which actually shows the two and five year risk of kidney failure for your patients. And you put in age, sex, GFR, and albuminuria, and it gives you a risk based on short and long term outcomes. These are tools that you can use that give you a sense of "what is my patient's risk that we need to be having this conversation."

The next is talking about the risk and benefits of a given kidney treatment. And for your patients that are older, and especially those that are frail, it really is thinking about a trial of dialysis versus conservative kidney management. With a trial of dialysis, there's usually a goal, whether that's time, or whether that's trying to achieve some sort of benefit. They're willing to trade off quality and the option of setbacks in hopes for added time. And with conservative kidney management, the focus really is on quality of life. Patients are actually willing to trade off potential survival to gain better quality.

So how do patients with conservative kidney management do? For older patients, especially those over the age of 75 with high comorbidities, the survival can be quite similar to that of patients who choose to do dialysis. They are also more likely to spend their time out of the hospital compared to those that do dialysis. We do know that these patients tend to get better symptom management through services like palliative care and hospice, and in the limited data that we have on functional status, they tend to stay relatively preserved until near the end of life. These patients are more likely to get services such as hospice.

This is one retrospective study that looked at patients who elected dialysis versus conservative. RRT stands for dialysis. And essentially, they looked at only patients over the age of 75, and compared those with low comorbidity compared to high comorbidity. And what you'll notice from looking at these Kaplan-Meier curves is that the patients with low comorbidity, renal replacement therapy had a significant added months of life. But if you looked at the patients that had high comorbidity, there was no statistically significant improvement with dialysis. This is retrospective. These are small numbers. But it really helps us step back and think about it.

This is a slide that actually was shared with me by a researcher, Susan Wong, who really looked at the data. Looking at, specifically, patients over the age of 75 with high comorbidities. And what you'll notice is, first of all, these are all out of the United States. These are data that come from different countries. And again, many of them are retrospective, and it's a small number of patients on conservative management. But what you will see is that what we do know is these patients live about as long as they would have on dialysis. One thing you have to keep in mind besides all of the negatives that I told you about, the other thing is that many people will designate when survival begins at a different point. Some people use a GFR of less than 15, some use less than 20, and some have used less than 10. All of them define survival differently. But you'll see that nonetheless, it's relatively similar.

So who should you consider or want to talk to about conservative kidney management? We typically say patients over 75. As I just mentioned in the data, two or more of the following. Multiple comorbidities, especially cardiovascular disease, poor functional status, malnutrition, so frailty. And answering no to the surprise question, would I be surprised if this patient died in the next year? Patients who also have worsening of a non-kidney related condition, we should be having this conversation. And then patients whose quality of life, unrelated to their kidney disease, is poor and unlikely to get better. These are patients that doing a more conservative approach may make sense for them.

There's also some tools that you can use. I told you about the surprise question, that actually carries a lot of prognostic weight when it comes to looking at patients in CKD clinic, but also on dialysis. And the Charleston comorbidity index is another tool that has been fairly predictive. There are other tools that have been created. One of them is the dialysis score. All of them just give me a sense of how concerned I should be about my patient, not necessarily that I use this as the law in talking to patients.

The next step is OK, I know I need to have the conversation, well how do I have the conversation? And so the communication skills that we use are Ask-Tell-Ask. Again, shared decision making is based off two. Experts. It's not only the clinician speaking, but it's also trying to have a two way conversation where you get the patient or the surrogate perspective. And it's the sense that this is going to be hard conversation, so being ready and responding to emotion, so that patients can cope and hear the news.

I ask a number of questions when I am doing my first ask. The first is what have the providers told you about your kidney disease? That helps me know how much I need to fill in the gaps or how little they have heard. And it really helps me with where I need to go. I often ask my patients, how do you see your health? It helps me get a sense of do they see what I see. And oftentimes I am surprised by how much they do see that things are changing, and it helps us have a very different conversation. As I was mentioning before about decision making preferences, I will ask how people prefer to make medical decisions for their health.

And then the "tell," so the tell, in this sense, we call it a headline. It should be news that should be no more than one sentence, or two sentences, that gives the patient and the family member a sense of what the information is, and then what does it mean to them. And so one idea for a headline for a patient that might be in front of me is, "I'm worried that with your conditions, some of the kidney treatments actually may cause more harm than good." If I'm really clear that I'm not sure it's going to add time, I'm going to say it may not add time. It may be even less time. Excuse me.

And so when you give a really meaningful headline, how do you expect a patient to respond? Well, I think many of you are thinking they'll probably respond with emotion, and you're correct. It's important for me to respond to the emotion. Emotions are totally normal. In fact, if I don't see emotion after giving bad news, I'm worried I didn't give the news. And so when I see it, it actually helps me know that they are hearing what I'm hearing. What I do is I notice the emotion that I'm seeing, and I name it. So it might be, "this is hard, it sounds like you are overwhelmed." And then I just stop and let the patient respond.

We know that when patients or surrogates are emotional, they can't process more information. I have to respond to it to help them move to a place where we can talk further. And so how might you respond if a patient said, can't we just try it? You gave them the news, and they say "can't we just try dialysis?" Well if I looked at that as an information statement, I might just go to talking about, well there is dialysis, let me tell you about that. If I see it as emotion, which I know, if I gave bad news, 90% of what comes out of someone's mouth is going to be emotion, I'm going to respond to the emotion. I might say this is hard to hear. I might say it sounds like you're shocked. I wish things were different. What's the hardest part for you? So I might attend to his or her emotions and help them process what that means to them.

And then when things have quieted and their emotions have been better responded to, I want to make a deliberate shift to actually talking about their values. So this is deliberate because oftentimes with clinicians we go straight to what the options are. But for me, I can't think about those options until I know about what's important and what their priorities are. And so I am very clear in my conversation. I make a step back statement. So I say hey, to get a better sense of what's right for you, I'd like to learn about what's important, would that be OK? I even make it very clear. I say let's take a step back and find out what's important to you so we'll know the best way forward.

And then I ask open ended questions to learn about them. I ask about their hopes, what's important to them. And I also ask them about what their concerns are. I'll often spend and start with asking about prior conversations about their health, and if their health got worse. I can learn a lot from people from the work that they've already done, or the excellent conversations you've already had with them. And oftentimes what people say at first is not necessarily the most important value, and so I'm really going to sit and be a listener during this time. I'll often ask, what else? Tell me more. Because as people tend to talk about meaningful things, it gets deeper over time.

And there's a couple of websites that I find very useful to have some of the questions and frameworks. One is Vital Talk, and the other is the Serious Illness Conversation Guide, which some of you have seen before. There are other aides that can help your patients in making these difficult decisions. Patient decision aids are tools that convey options in terms of risk benefits and values. And they're often completed outside, or can be done within the clinical visit. They're really meant to be an aid to the conversation. They are not stand-alones. They help prepare patients for shared decision making.

I'm going to show you some examples in kidney disease that you could actually use with your patients, or share with them. The benefits are PDAs have been found to reduce decisional conflict. They engaged patients, and improve participation, and they improve values-choice concordance. There was a recent article in AJKD that looked at some of the PDAs that talk about conservative kidney management and how patients and families feel about it. And I think one of the take homes that I took away is that they don't want to feel like conservative kidney management is no care. They want to hear aggressive, they want to hear active, and so that's why I really make sure those are language I use when I talk about conservative kidney management.

And then once you feel confident, and that would be when I'm feeling that I'm hearing values that are quite strong and help me pick a certain bucket, whether that's more of a life prolonging bucket, or a trial of treatment bucket, or whether that's conservative care. So for conservative care, the goals really are I'm hearing more about quality of life and less about survival. They're not willing to go through more hospital, and more pokes and prods. They don't feel like it adds to their quality of time, and they're willing to trade that survival time off. Time limited trials, the goal is to focus on life extension. They're willing to undergo some of those burdens in exchange for more time or increased full function.

And so step 3 is really giving a plan that matches the patient's values. And we call this "showing our work" because the values actually inform the treatments. For conservative kidney management, it might sound like, "Given that spending time away from the hospital and your family is most important, I would recommend we treat your kidney disease medically with a focus on your symptoms, and not do treatments like dialysis that will not achieve these goals." So it's not that I just say let's not do dialysis, I tell them why it doesn't make sense. It's not going to help them stay out of the hospital, it's not going to keep them where they want to be and that's next to their family.

Frequently asked questions. A lot of people ask me, well what if they don't agree? What if I think that the patient is never going to do good on dialysis, and they ask for it? I step back and I turn it into a curiosity conversation. And I think to myself, is this emotion that I'm hearing from them, is it information needs? Do I need to make sure that I actually shared some of my worries? Is it that basically my values are different than this patient or family's values, and that maybe dialysis actually does make sense for this person? And so I really consider my own values. A helpful way to explore that is to just kind of say, help me understand. Help me help me understand what you're thinking. Help me understand what you're hoping dialysis might do for you.

And you often learn a lot. You may get more comfortable and confident in the values you're hearing and the plan that you're arriving to. And it may be that you want to consider a time limited trial. I think the majority of patients and people want to do a trial, and that's not wrong. I think what that means for us is we need to talk about what a time limited trial and actually set goals. What does success look like, and what does success not look like, and making sure you check in on the conversation. I might, after making a decision to do a trial of dialysis, I'll say, I hope that dialysis does help you get stronger. I wonder also if we can talk about if that doesn't happen. So then you start to set the stage for talking about when things don't go well.

Here are some tools that I would like you to put into your toolbox. One is Vital Talk, I told you about that. They also have an app called Vital Tips, which has a lot of these communication frameworks, videos, and some training opportunities if you'd like to learn more. Most of your faculty here at UPMC were all trained and teach actively with Vital Talk. We would love people who want to extend their communication skills. We created a curriculum called Nephro Talk that's all about conservative care. And so you can actually see some of this in a larger amount. And we also have some videos as well having some of these conversations.

The Serious Illness Guide actually provides language for clinicians to engage in serious conversations, and there's some training opportunities with them too. The patient decision aids, the one I really like and I've been pushing in my clinic, is My Kidneys, My Choice. It's out of Australia, it's printable, it's also online. It's really nice because it covers all of the modalities that one might be thinking about. And it really starts in a way that I feel is more friendly. It talks about the present, what makes their life worth living, what's meaningful to them, then talking about the options and then really focusing on values. The other one is the Conservative Kidney Management PDA, which is an online website that has a lot of different resources for patients, families, and clinicians. I don't use this one as much. I find the other one just seems to be a little bit more relevant and real, and includes more options than this one. But they're both good and it's something that you can check out and try yourself.

So as you think about incorporating conservative kidney management into your practice, we'll hear some pearls. I really talk about it early with a GFR of less than 30. If I'm seeing some of those risk factors that I talked to you about earlier in the talk, I'm going to bring it up. I really think it's important to bring up in the larger context of goals of care. And this is where it gets back to that shared decision making conversation, and really thinking about what does the kidney disease mean to this patient's life? Is it that we're dealing with heart failure, and the heart failure is so bad that now the kidneys are involved? And I'm worried that time is going to be shorter than we hope. Then it's talking about what kidney management looks like in that context

I would also consider referral for additional services and expertise. That might be doing some home programs like home palliative care, or even thinking about hospice in these patients when their symptoms do get worse, and time is looking less than six months. We also have a renal supportive care clinic that you can refer patients to. I'll show you that in a moment. The last thing is document, document, document. Document these conversations. If you're using EPIC, use the advanced care planning activity so that people, when they get hospitalized, can actually see that you've done all this work, and that we know exactly how that patient wants to be cared for.

This is the clinic we have. I do clinic with my colleague and friend, Amar Bansal. We see patients from PCPs, nephrologists, other subspecialties. We do a single consultation or we have ongoing care. We do symptom management goals of care, advanced care planning, definitely conservative care management, and help out with hospice referrals. So I'll conclude my case. This patient was referred by her geriatrician. She was having a lot of weight loss, poor appetite. Her goals were to be with her family and her grandkids, and avoid hospitalization. When it's my time, I just want to go she said to me. So she elected conservative kidney management and stayed home with no hospitalizations. Her daughter was right there with her. We ordered and managed her edema with Lasix and ordered home palliative care. And eventually, through actually conversations that included her PCP, virtually, thank goodness for COVID, we had a very good meeting and started hospice. And she died 10 months later with her family around her.

So in summary, treatment decisions for advanced kidney disease are preference sensitive decisions that require a shared decision making. Use Ask-Tell-Ask to gain a big picture information and elicit patient's values and preferences to reach a shared decision. And try patient decision aids, they're a great way to complement the great work you're doing in your conversations, and help different kinds of families make these difficult decisions. Thank you for your time. Please do let me know if you have questions, concerns, challenges, successes. I want to know. And I'd like you to just take 20 seconds to think about one thing that you learned from today that you will put into practice next week.