

# Dialysis or Death: A Qualitative Study of Older Patients' and Their Families' Understanding of Kidney Failure Treatment Options in a US Public Hospital Setting



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**Rationale & Objective:** Conservative management (medical management without dialysis) may be an appropriate treatment option for some older patients with advanced chronic kidney disease or kidney failure. Patients' and family members' perspectives about conservative management in the United States have been relatively unexplored.

**Study Design:** Qualitative study with individual semi-structured interviews.

**Setting & Participants:** We recruited patients 65 years and older and their family members from a public hospital system in the United States.

**Analytical Approach:** Participants were asked about perspectives of kidney failure treatment options. Interviews were audiotaped, transcribed, and analyzed using an iterative approach to thematic analysis.

**Results:** Among 15 patient and 6 family member interviews, we identified 3 themes. Participants: (1) do not view conservative management as a viable personal option for their own (or their family members') care, (2) understand the realities of dialysis only abstractly, and (3) consider dialysis the only treatment option for kidney failure and any alternative as death.

**Limitations:** Single site, public hospital setting. Included patients younger than 75 years for whom dialysis likely has survival benefit. Changed the definition of conservative management partway through the study.

**Conclusions:** Older patients and family lack full understanding of kidney failure treatment options and are therefore unable to make truly informed care decisions.

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By 2030, an estimated 5.4 million people globally will be receiving kidney replacement therapy (KRT) for the treatment of kidney failure.<sup>1</sup> Although increasing numbers of adults 65 years and older are initiating KRT, there is a growing body of literature suggesting that a subset of patients, particularly those older than 75 years who have serious illnesses such as dementia or ischemic heart disease in addition to advanced chronic kidney disease (CKD), may not live longer with dialysis and may have worse quality of life and functional status after initiating dialysis.<sup>2-9</sup> Conservative management is a nondialysis option that encompasses a planned holistic approach incorporating symptom management, treatment to delay disease progression, advanced care planning, and spiritual and psychological support for patients and their families. A recent systematic review concluded that patients with kidney failure who receive conservative management may have improved mental health–related quality-of-life scores compared with those who receive dialysis.<sup>10</sup>

Although a few studies have explored why patients opt for conservative management, all have taken place in countries outside the United States, where conservative management has become more established as a practice.<sup>11-15</sup> In this study, we explore the understanding of and attitudes toward kidney failure treatment options among older patients and their family members in a US public hospital setting.

## METHODS

### Study Design and Conduct

We used a qualitative descriptive design using semi-structured interviews to explore older patients' and their family members' knowledge, awareness, and perspectives about their treatment options. We developed an interview guide using practical knowledge of the clinical area and an existing interview guide from Tonkin-Crine et al.<sup>16</sup> The interview guide was not pilot tested given that these questions were successfully used in the prior study. A definition of conservative management for use in this study was devised with an advisory board that included hospital leadership, palliative care and nephrology experts, and patient and family member representatives.

After a third of the interviews were completed, results were reviewed with the advisory board, and after discussion with the board, the “dialysis or death” theme that was emerging could have been attributed to the definition. As such, the board suggested altering this definition out of concern that it was too negative and was possibly leading participants to equate conservative management with an end-of-life decision (Box 1). The second definition included reference to research that has been done rather than focusing on conservative management as an individual decision.

The University of California, San Francisco Institutional Review Board approved the study (14-15272).

**Box 1.** Definition of Conservative Management**Definition for First One-Third of Interviews**

Conservative management is treatment of symptoms without dialysis. With conservative management, patients are kept as comfortable as possible with medications, but are allowed to pass naturally from their kidney failure or other medical problems. Some people with kidney failure, along with their doctor and family, make this choice because they believe their age and other serious medical problems will mean dialysis would make them feel worse and would not help them feel better, have a better quality of life, or live longer.

**Definition for Remaining Two-Thirds of Interviews**

Research shows us that for older people with serious health problems other than kidney failure, dialysis may not allow them to live any longer than they would have if they never started dialysis at all. And for these people, dialysis may actually decrease their ability to feel good and enjoy life because dialysis can take time away from being with family, it can cause symptoms like cramping and tiredness, and it can mean more procedures and stays in the hospital. Therefore, some patients, along with their doctor and family, decide to focus on comfort and quality of life. They decide to have their symptoms of kidney failure treated with medications and diet changes and allow nature to take its course. They choose to not start dialysis. This treatment option is sometimes called conservative management.

## Participant Selection

Using clinical databases within the San Francisco Department of Public Health, we identified potential participants who met basic study criteria, including aged 65 years or older, were receiving dialysis for less than 3 years or had an estimated glomerular filtration rate  $\leq 20$  mL/min/1.73 m<sup>2</sup>, and spoke English, Spanish, or Cantonese. We expected those within 3 years of dialysis would recall KRT options education and those with glomerular filtration rates  $\leq 20$  mL/min/1.73 m<sup>2</sup> would have received it. After obtaining permission from primary care or nephrology providers, potential participants (excluding assaultive or completely nonverbal patients) were mailed an invitation letter and then contacted by telephone. Patient participants were asked to identify a family member involved in their care. Each was interviewed separately and given \$40 in cash for their time.

## Data Collection

One Spanish/English and 1 Cantonese/English bilingual, female, bicultural, nonphysician research coordinator conducted all semi-structured interviews after undergoing basic training with 2 coauthors (V.G. and C.A.C.). The research coordinators had no relationship with the participants before the interviews and no previous expertise

regarding treatment options for kidney failure. All interviews were conducted in person between August 2015 and August 2016 at a time and location convenient for each participant and in their preferred language. Thirteen interviews were conducted at the research facility, and 8, at participants' homes. No one besides the participant and researcher were present during the interview. Patient participants were asked to complete the Montreal Cognitive Assessment (MoCA) in their preferred language. Participants were reminded that the goal of this research study was to learn about their knowledge, understanding, and perceptions of treatment options for kidney failure. After providing written informed consent (from a surrogate decision maker for patients with MoCA scores  $< 10$ ), participants were asked to provide demographic and basic life and health information and then were interviewed.

Interviews focused on participants' understanding about treatment options for kidney failure, specifically asking about conservative management and/or dialysis. We did not explore transplantation because most would have been ineligible due to age. Participants unaware of conservative management were read a prepared definition (Box 1). For those with severe cognitive impairment (MoCA score  $< 10$ ), an abbreviated guide intending to capture the participant's understanding and experience with treatment was used. Interviews were recorded, translated as needed, and transcribed verbatim. No interviews were repeated. However, there was 1 follow-up interview for purposes of clarification.

Data collection was terminated due to exhaustion of the list of potential participants who met the inclusion criteria. Transcripts were not returned to participants for comment and feedback from participants on findings was not elicited.

## Analysis

Interview transcripts were entered into Atlas.ti for qualitative data analysis. Narrative and thematic analyses were systematically conducted by 2 investigators (J.K. and V.G.) using comparative analysis of text within and between interviews. Codes regarding central themes were decided by consensus after independent analysis of 5 interviews, then applied iteratively to subsequent interviews until we reached analytic saturation and 85% intercoder reliability, indicating agreement about the definition of each code. Theme sufficiency was achieved after analysis of 15 interviews and all remaining interviews were examined, providing confirmation of our findings.

## RESULTS

### Participant Characteristics

We identified 47 potential participants from the clinical database. We were unable to reach 17 patients, 11 declined to participate (5 Cantonese and 6 English speaking), and 4

had died. A total of 21 interviews were completed in person with 15 patients and 6 family members. The average interview duration was 47 (range, 8-91) minutes. One patient with a low MoCA score had the shortest interview.

Most patient participants were English speaking, were receiving dialysis, described themselves as religious, and had 12 years or less of schooling (Table 1). Table 1 indicates patients' current state (8 receiving dialysis) and that 10 would choose dialysis when clinically indicated.

Under the options about choice, foregoing dialysis did not indicate that the patient had actually chosen conservative management. The average age of patient participants was 72.4 (range, 65-93) years, with a median age of 70 years. All but 2 identified themselves as nonwhite. Only 6 identified a family member involved in their health care decisions. All family member participants were women, nonwhite, and modally older than 55 years. Half were foreign born and did not speak English. No family member rated the patient's health as poor.

### Thematic Findings

Three themes emerged from analysis of the interviews with patients and their family members: (1) not viewing conservative management as a viable personal option, (2) understanding realities of dialysis only abstractly, and (3) considering dialysis the only treatment option for kidney failure (see Tables 2 and 3 for representative quotes).

### Patients and Family Do Not View Conservative Management as a Viable Personal Option

Seven patient participants attended nurse-led KRT options education and 1 author (V.G.) recalls providing a detailed explanation of all treatment options, including conservative management, to 4 patients and 1 family member in the sample. Despite this, none of the participants understood conservative management as a personal treatment option, suggesting that the option either was not presented at all or was presented in a way that participants could not fully understand. When prompted with the definition for conservative management, patients and their families were not able to perceive conservative management as a treatment to choose, even when it aligned with their stated goals of care. For example, a 75-year-old man foregoing dialysis (but not choosing conservative management per se) said:

So what is the point of having a longer life when you can't do and eat what you want? I will be exhausted and so will my family members. Regardless, my kidney disease will not be cured. As for dialysis, it is just trying to extend my life a little.... If my life will only shorten a couple years, I'd rather have that than going back and forth to the hospital.

After being prompted with our conservative management definition, the patient still only understood his

**Table 1.** Participant Characteristics

	Patients Not on Dialysis (n = 7)	Patients on Dialysis (n = 8)	Family Member (n = 6)
Mean age, y	73.6	71.4	
Male sex	3 (42.9%)	6 (75%)	0 (0%)
Female sex	4 (57.1%)	2 (25%)	6 (100%)
Race			
White	1 (14.3%)	1 (12.5%)	0 (0%)
Black	1 (14.3%)	5 (62.5%)	3 (50%)
Hispanic	3 (42.8%)	1 (12.5%)	2 (33.3%)
Asian	1 (14.3%)	1 (12.5%)	1 (16.7%)
Other	1 (14.3%)	0 (0%)	0 (0%)
Primary language			
English	3 (42.8%)	6 (75%)	3 (50%)
Spanish	2 (28.6%)	1 (12.5%)	2 (33.3%)
Cantonese	1 (14.3%)	0 (0%)	1 (16.7%)
Other	1 (14.3%)	1 (12.5%)	0 (0%)
US born	3 (42.9%)	6 (75%)	3 (50%)
Current dialysis state			
Not on dialysis	7 (100%)	NA	NA
On in-center hemodialysis	NA	6 (75%)	NA
On peritoneal dialysis	NA	2 (25%)	NA
Received treatment options education	3 (43%)	4 (50%)	
Chosen option			
Dialysis	1 (14.3%)	8 (100%)	NA
Undecided	5 (71.4%)	0 (0%)	NA
Forego dialysis	1 (14.3%)	0 (0%)	NA
Education			
<5 y	2 (28.6%)	1 (12.5%)	2 (33.3%)
Some high school	2 (28.6%)	2 (25%)	1 (16.7%)
Completed high school	1 (14.3%)	1 (12.5%)	1 (16.7%)
>High school	2 (28.6%)	4 (50%)	1 (16.7%)
Importance of religion			
Very	4 (57.1%)	5 (62.5%)	4 (66.7%)
Somewhat	1 (14.3%)	1 (12.5%)	1 (16.7%)
Not at all	0 (0%)	1 (12.5%)	0 (0%)
No answer	2 (28.6%)	1 (12.5%)	1 (16.7%)
How sure understand patient's medical condition			
Very sure	4 (57.1%)	5 (62.5%)	3 (50%)
Somewhat sure	2 (28.6%)	2 (25%)	3 (50%)
Unsure	1 (14.3%)	1 (12.5%)	0 (0%)
How see patient's current health			
Very good/excellent	1 (14.3%)	3 (37.5%)	1 (16.7%)
Fair/good	5 (71.4%)	5 (62.5%)	5 (83.3%)
Poor	1 (14.3%)	0 (0%)	0 (0%)
How see patient's health in 1 y			
Better	1 (14.2%)	6 (75%)	2 (33.3%)
No change	3 (42.8%)	1 (12.5%)	2 (33.3%)
Worse	3 (42.8%)	1 (12.5%)	2 (33.3%)

Note: All values are number (percent) unless otherwise noted. Abbreviation: NA, not applicable.

**Table 2.** Representative Quotes From Patients

Theme	Quotes From First 1/3 of Interviews With First Definition of Conservative Management	Quotes From Second 2/3 of Interviews With Second Definition of Conservative Management
Theme 1: Conservative management not viewed as a viable personal option	<i>Interviewer:</i> “Do you know about the alternative of not doing dialysis?” <i>Patient:</i> “Yes. It’s called death.” –80-year-old patient on PD	<i>Patient:</i> “Well, [conservative management] sounds like a dead end. Again, if the blood isn’t clean, one dies. So is it even worth talking about?” –73-year-old patient on HD
Theme 2: Understanding the realities of dialysis only abstractly	<i>Patient:</i> “Honestly, I don’t like it [dialysis] neither here nor at home. I don’t want anything.” <i>Interviewer:</i> “And when did you change your mind?” <i>Patient:</i> “I came once and they told me that only 5% of my kidneys were working and they told me that if I didn’t receive it there would come a time when dialysis wouldn’t be an option.” –72-year old patient on HD	<i>Patient:</i> “What is the benefit [of dialysis]? Maybe prolonging my life when they tell me I need dialysis. Maybe when the time is here, maybe I will live another 20 years?” –66-year-old patient, undecided
Theme 3: Considering dialysis the only treatment option for kidney failure	<i>Interviewer:</i> “Anything good about dialysis?” <i>Patient:</i> “No good.” <i>Interviewer:</i> “Then why do you choose to do dialysis?” <i>Patient:</i> “Because the only choice is go to the dialysis.” –70-year-old patient on HD	<i>Patient:</i> “I didn’t agree to nothing. They made me. They forced me [laughter].” –70-year-old patient on PD

Abbreviations: HD, hemodialysis; PD, peritoneal dialysis.

choice as to have dialysis or do nothing, rather than choosing conservative management affirmatively.

This finding persisted when the conservative management prompt was changed to improve understanding. When posed with the question about choosing conservative management, an 80-year-old man on peritoneal dialysis therapy stated, “I call it death.” When asked who he thought conservative management was appropriate for, a 73-year-old man who had chosen hemodialysis but considered himself in poor health responded: “Well, if a person is of an advanced age and...” Interviewer: “What do you consider to be advanced age?” Patient: “Anything a few years beyond mine.”

This humorous comment highlights that even when conservative management is understood, patients do not think of it as an acceptable option for themselves, most likely because they equate it with death.

### Understanding the Realities of Dialysis Only Abstractly

Most participants who were still undecided about kidney failure treatment presented an abstract and fairly minimal appreciation of what dialysis entailed, framing it only in terms of hope for a longer life: Interviewer: “And what does receiving dialysis mean to you?” Patient (74-year-old woman, undecided): “According to what they told me I would live longer.” Interviewer: “What else have they told you?” Patient: “That’s all.”

Others misunderstood the benefits of dialysis. A 70-year-old man recalled, “I was hoping that [my kidneys would] get better and improve [after starting dialysis], but

apparently that’s not the way it works.” Still others had a reductionist, but solely negative, understanding of dialysis. For example, the only patient who had chosen to forego dialysis may have done so for inaccurate reasons. This 75-year-old explained:

Because if I am on dialysis, I will become an invalid. I still feel I am like a healthy person now.... Everyone wants to live a long life. Long and happy life is okay, but long and difficult like dialysis is very exhausting. You can’t even eat! What’s the point then?

Only 2 patients appeared to have an accurate understanding of dialysis before initiation. A 65-year-old woman receiving hemodialysis explained, “I’m doing this to be able to survive a little bit longer. This is not for people to get better. It’s a lie. Nobody is going to get cured here.” A 69-year-old man also receiving hemodialysis concluded:

I was explained all this before it happened. If they had snuck up on me or something and then I didn’t know what to expect, then that would’ve been something different, but I was explained in detail by detail and everything I went through or had to go through. I was very familiar with it because they told me very well.

These 2 patients express that they feel comfortable having chosen dialysis although it will not cure them and dialysis would be inconvenient. We recognize that a subset of patients will choose dialysis based on patient preferences and are reassured that these 2 patients felt well informed to make their choice to pursue KRT.



**Table 3.** Representative Quotes From Family Members

Theme 1: Conservative management not viewed as a viable personal option	<p><i>Interviewer:</i> “And if the person is feeling bad and he still doesn’t want to receive dialysis, what do you think about that?”</p> <p><i>Respondent:</i> “I would need to consult my children and we would do what they said. I am the first one, but my children... if he really needed it... at that point we would have to decide... I would have to decide. I have already spoken to my children, and he would accept it. But, now we see he is fine... I can’t force him to have it unless his doctor told him he needed it.”</p> <p><i>Interviewer:</i> “And what if he says he doesn’t want to have it?”</p> <p><i>Respondent:</i> “If his doctor told him he should have it, then I would tell him to do so.”</p> <p><i>Interviewer:</i> “But what if he doesn’t want to receive it?”</p> <p><i>Respondent:</i> “If he doesn’t want it, there is nothing we can do about it.”</p> <p><i>Interviewer:</i> “How would you feel if the doctor recommended it and he doesn’t want to have it?”</p> <p><i>Respondent:</i> “Bad because if his doctor is telling him, it is clear that he needs it, so I would consult with my children and he would have to receive it. If it’s a direct order from the doctor, then I would force him to have it. If his doctor told me, ‘Look, your husband needs it now’ [then I would say] ‘It’s the doctor’s order, not mine, and you need it!’”</p>
Theme 2: Understanding the realities of dialysis only abstractly	<p><i>Interviewer:</i> “What do you think would help both of you in terms of deciding what choice X actually ends up with?”</p> <p><i>Respondent:</i> “I think if she’s not doing so bad, I don’t want her to suffer.”</p> <p><i>Interviewer:</i> “How do you think she would suffer, by going through dialysis or by not having dialysis?”</p> <p><i>Respondent:</i> “She’s not going to suffer from dialysis. It might help her and it might not because you can’t be too sure that dialysis won’t help you. That’s the way I feel about it now. If it can help you, let it help. If it’s no good for her, she doesn’t need it. She might be too old for it. I don’t know. I don’t know. I would know what I would say to myself when I get too old for stuff, I wouldn’t want it.”</p>
Theme 3: Considering dialysis the only treatment option for kidney failure	<p><i>Interviewer:</i> “What do you think about people who choose not to go on dialysis?”</p> <p><i>Respondent:</i> “I think they’re crazy.”</p> <p><i>Interviewer:</i> “Why?”</p> <p><i>Respondent:</i> “Because that’s for you. You have to go because your kidneys are failing.”</p>

### Considering Dialysis the Only Treatment Option for Kidney Failure

Ultimately, most patients and their family members did not actually think that they had a choice about treatment options and instead viewed their options as “dialysis or death”; that is, if a patient did not choose to do dialysis, he or she would die imminently. For most participants, this perception appeared to be imparted by health care providers. For example, when the patient who had chosen to forego dialysis was asked, “Your doctor asked you to do dialysis every time [you went to the clinic] without offering you another option?” the patient responded, “No other options.” His wife agreed. Interviewer: “The doctor has not discussed with him about his other options?” Wife: “I don’t know. I don’t really feel like he did.”

When recalling the specifics about how he “chose” to do peritoneal dialysis, a 70-year-old man on peritoneal dialysis therapy stated:

I really didn’t want to do it and the nurse here—bless her heart. When I told her, I said, “I’d rather die,” she started crying.... She said, “You got things to live for,” and then she said, “How many kids you got? How many grandkids you got? You got all these people to live for.” [I said], “Yes, well, you’re right, but I don’t have many years.”

Although this participant describes some of the details of his options education, the content for most participants

is unknown, with the exception of a subset in the care of 1 coauthor (V.G.) for whom she provided a detailed explanation of conservative management, dialysis modalities, and the realities of each. Still, dialysis or death was viewed as the bottom line, as exemplified by a 72-year-old man on hemodialysis. Interviewer: “How did you decide to start dialysis?” Patient: “Dr. [ ] brought me to the front of realizing that I had to deal with dialysis, or die.” Interviewer: “That’s what she said?” Patient: “Pretty much.”

This perception of “dialysis or death” influenced not only decisions to start dialysis but also to stop it. Most of the patients who were receiving dialysis could not envision a time when they would stop dialysis, even when their own goals were not being fulfilled. When asked under what circumstances he would consider stopping dialysis, a 70-year-old man on hemodialysis therapy who was confined to a wheelchair and dependent on his wife for his activities of daily living responded:

No, I don’t think so.... Because I like living... [Living] means everything to me. It means being able to do things that you want to do and being able to do things, support yourself.... All I can tell you is that I want to live, and dialysis is the only way I can live. To discontinue is a tragedy.

In this quote, we hear a patient who is able to express his desire to live longer, but unable to recognize the other

alternative of conservative management, which might allow him to live just as long.

## DISCUSSION

This is the first US study to focus on the knowledge, attitudes, and perceptions about kidney failure treatment options for older patients with advanced CKD or kidney failure in a US public hospital setting. Given that initiation and continuation of dialysis for patients in the United States with poor prognosis is common and conservative management programs are not, we wanted to better characterize how individuals with kidney failure understand their treatment options.<sup>17,18</sup>

We found that participants had a limited, often reductionist, understanding of kidney failure treatment options. They equated conservative management with death and viewed dialysis as their only real option for treating kidney failure. Even patients who ostensibly expressed a desire during the interviews for less active care did not believe that conservative management was an option for them.

Undoubtedly health care providers are central to this “dialysis or death” perception. Either providers are not presenting conservative management as a viable treatment option or they are not conveying conservative management in a way that patients and their family members perceive it as such. In a qualitative study of documentation in electronic medical records, Wong et al<sup>19</sup> found that providers did not themselves perceive foregoing dialysis or conservative management as an acceptable option and thought that they had little to offer patients who did not accept dialysis. This was suggested in our study by the patient who recounted the nurse crying in response to his desire to forego dialysis. In a qualitative study by Ladin et al,<sup>20</sup> many nephrologists reported that they saw conservative management as “no care” or did not bring it up as an option. Tonkin-Crine et al<sup>16</sup> found that older patients in British renal units with more established conservative management programs were more aware of conservative management and less often believed that dialysis automatically conferred a survival benefit.<sup>16</sup> Unlike in England, conservative management programs specifically and outpatient palliative care services in general are uncommon and not established at our study site.<sup>17,21</sup> In our study, we had the benefit of knowing that at least 1 nephrologist discussed conservative management. Nonetheless, patients and their families were still unable to understand the benefits of choosing that option.

That most participants believe that patients’ health status will either remain the same or improve in the future may also factor into their inability to perceive conservative management as an option for themselves. This is likely, at least in part, due to clinicians inadequately explaining the realities of advanced CKD trajectory and prognosis throughout the disease course, which would be needed to help dispel such misperceptions.<sup>22</sup> Additionally, low

health literacy in our particular population likely serves as a barrier to communication about end-of-life choices, as Ladin et al<sup>23</sup> found in their study of end-of-life discussions among dialysis patients 75 years and older.

Strengths of this study are its racial/ethnic diversity and inclusion of family members. A limitation of this study is that it is a single site and may not be generalizable to a more educated, higher socioeconomic status group. Although this may seem like a limitation, it should be noted that the vast majority of patients with kidney failure are similar to our cohort. Additionally, we were surprised by how similar our findings were to the 2017 analysis by Ladin et al<sup>24</sup> of a mostly white English-speaking population of dialysis patients in the Boston area that also found that patients held unrealistic beliefs about their prognosis, were not engaged in decision making, and were unaware that dialysis initiation was voluntary. This suggests that our findings may be generalizable to the population of patients 65 years and older who meet criteria for dialysis initiation.

Another limitation is the inclusion of patients younger than 75 years because research suggesting that dialysis may not confer a survival benefit is limited to those older than 75 years. Further, this age group (and their providers and family members) may have considered themselves too young to consider foregoing dialysis. Finally, the interview script definition of conservative management was altered to a more positively worded definition, which pointed out research supporting the choice of conservative management, but this did not appear to change how participants perceived conservative management as an option. This may be because research may not inform their decisions as much as patient narratives or trust in their individual health care providers.

Despite these limitations, our study demonstrated that older patients with advanced CKD, including several currently receiving dialysis, and their family members have little or no understanding of conservative management and do not consider it a viable personal option. Conservative management programs need to become an established aspect of kidney failure care for patients who may not attain improved quality of life or longevity with dialysis. Providers involved in their care—nephrologists, primary care physicians, and ancillary staff—need to embrace conservative management as a realistic option for the treatment of kidney failure and learn how to communicate it effectively. Only then can we be sure that patients and their families are making truly informed decisions.

## ARTICLE INFORMATION

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