



# Ethical Challenges When Caring for African American Older Adults Requesting to Withdraw From Dialysis

Debra J. Hain, PhD, APRN, AGPCNP-BC, FAAN, FAANP, FNKF    
 Mary S. Haras, PhD, MBA, APN, NP-C, CNN

The number of African American adults 65 years and older with end-stage kidney disease receiving maintenance hemodialysis is increasing. The high symptom burden (ie, pain, fatigue, depression) can make it challenging for many to continue dialysis, which can lead to request to withdraw from dialysis. This can present ethical challenges when someone has diminished decision-making capacity and no advance directives or family to assist with this complex decision. This article will provide a brief overview of ethical issues to consider when responding to an older adult's request to withdraw from a life-sustaining treatment such as dialysis. Suggestions for research to address the gaps in knowledge will be presented.

As the US population ages, there is an anticipated exponential growth of older adults receiving maintenance hemodialysis (HD). In 2018, there were more than 131 636 new cases of end-stage kidney disease (ESKD), an increase of 2.3% since 2017; approximately 1.7% of the population was African American (AA).<sup>1</sup> When a person has ESKD, he/she will require some form of kidney replacement therapy, such as HD, peritoneal dialysis, or transplantation, to survive. Utilization of peritoneal dialysis and transplant declines with age, and 87.6% of those 65 to 74 years old and 91.8% of those 75 years or older choose in-center HD. In 2018, there were 554 038 persons (70.7%) receiving dialysis and 229 887 persons (29.3%) with a functioning kidney transplant.<sup>1</sup> Approximately 30% of those starting dialysis are adults 75 years and older.<sup>2</sup>

**Debra J. Hain, PhD, APRN, AGPCNP-BC, FAAN, FAANP, FNKF**, is a professor (tenured), DNP Program director, Graduate co-coordinator AGNP Concentration, Christine E. Lynn College of Nursing, Florida Atlantic University, Boca Raton, FL.

**Mary S. Haras, PhD, MBA, APN, NP-C, CNN**, is an associate professor and chair, Department of Advanced Nursing Practice, School of Nursing & Health Studies, Georgetown University, Washington, DC.

Address correspondence to Debra J. Hain, PhD, APRN, AGPCNP-BC, AGNP Concentration, Christine E. Lynn College of Nursing, Florida Atlantic University, 777 Glades Rd, Boca Raton, FL 33431 (dhain@health.fau.edu).

The authors have no conflicts of interest to disclose.

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DOI: 10.1097/NJH.0000000000000862

Adults receiving HD have a high risk of mortality; however, older adults (≥65 years old) have a substantially higher risk compared with the general population living with cancer, diabetes, and cardiovascular disease.<sup>3</sup> Individuals, including older adults, receiving dialysis are faced with a high symptom burden related to a multitude of physical (ie, fatigue, pain) and psychological/emotional (ie, depression, anxiety) symptoms. On average, they have approximately 11 symptoms that contribute to poor health outcomes.<sup>4</sup> Patients in the United States Renal Data System Study of Treatment Preferences (n = 1000) endorsed a median of 5 symptoms, with the most prevalent being weakness or lack of energy (61%), pain (52.0%), difficulty sleeping (49.3%), and itching (47.5%).<sup>1</sup> Fatigue is a very common symptom for older adults receiving maintenance HD, and those with fatigue often suffer more than individuals without reported fatigue.<sup>5</sup> Ineffective treatment of pain adds to the high symptom burden and increases the risk of depression among older adults receiving maintenance HD.<sup>6,7</sup> The high symptom burden, morbidity, and mortality in older adults receiving dialysis may lead to withdrawal from maintenance HD as requested by the individual or family. Regardless of race, factors that contribute to the decision to withdraw from HD include having chronic kidney disease–associated pruritus,<sup>8</sup> being recently hospitalized (within 30 days), experiencing frailty,<sup>9</sup> and having biomarkers indicating malnutrition-inflammation-cachexia syndrome (high white blood cell count, low body mass index, low serum albumin, and low normalized protein catabolic rate).<sup>10</sup> Other factors related to withdrawal are age (≥70 years), diabetes as the cause for ESKD, renovascular disease, receiving in-center HD, and length of dialysis (time from the first dialysis treatment to present).<sup>11</sup> There are several things to consider before responding to a patient's request to withdraw from dialysis, such as ethical principles of stopping a life-sustaining treatment.

## WITHDRAWAL FROM DIALYSIS

According to the United States Renal Data System data,<sup>1</sup> in 2018, 24.3% of patients receiving maintenance HD or peritoneal dialysis discontinued treatment before death, with the highest percentage occurring in those 85 years or older.



Adults 75 years and older (37.1%) were more likely to discontinue dialysis before death compared with younger adults 21 to 44 years old (11.5%). Withdrawal from dialysis was more common in women and White adults versus men and other ethnic groups.<sup>1</sup> Geographical variations also seem to play a role in the decision to withdraw from dialysis. Adults from northwest regions were 2 times more likely to withdraw from dialysis than those living in the southwest.<sup>3</sup> The use of hospice for end-of-life (EOL) care among adults with ESKD is increasing; however, it is much lower compared with use among those with other life-limiting illnesses.<sup>11</sup> Hospice is often prescribed within the last 3 days of life (41.5%), which limits the opportunity to honor the individual's EOL wishes.<sup>12</sup>

### CASE STUDY

MJ, an 86-year-old AA woman with history of diabetes, heart failure, vascular disease, hypertension, and ESKD, receiving maintenance HD for 3.5 hours, 3 days a week (M-W-F), informed the dialysis nurse after 7 years of undergoing dialysis that she wanted to stop. The extreme fatigue and uncontrolled pain that she was experiencing led to a poor quality of life, where she could no longer engage in activities of daily living to the same degree she was able to a year ago. Her nephrologist recommended transitioning to a long-term care (LTC) facility where she could receive assistance with activities of daily living. She adamantly refused because she did not want to leave her home of 50 years and, like many older adults, she wanted to maintain her independence. The physician failed to involve MJ in the decision making but instead told MJ that the decision was made to keep her on dialysis because it was the best treatment option, and he was going to discuss LTC placement with the social worker. Eddie had been MJ's significant other for 6 years; she did not have any children and did not have advance directives. MJ disclosed not wanting Eddie involved in decisions regarding her care related to dialysis. She felt this was too much for him to deal with because he had his own health issues. So, despite her desire to withdraw from dialysis and not relocate to an LTC facility, MJ respectfully agreed to follow the physician's orders. In the nephrologist's attempt to provide the best care for MJ, he did not realize he may have violated several ethical principles related to withdrawal from dialysis.

### Ethical Issues

Autonomy, beneficence, nonmaleficence, and justice constitute 4 principles of ethics. These principles along with the Code of Ethics for nursing<sup>13</sup> apply to practice situations such as the one described in this case study. These fundamental principles support an individual's right to make an informed decision to withdraw from dialysis.<sup>14,15</sup> This article will discuss the ethical principles related to withdrawal from dialysis and evidence-based recommendations that support MJ's right to engage in shared decision making

regarding ESKD treatment options that include continuing dialysis or withdrawal from dialysis with hospice care.

### Autonomy (Self-determination)

Individuals have the right to determine what is best for themselves and to make an informed decision. This ethical principle was affirmed decades ago in a court decision and stated that "every human being of adult years and sound mind has a right to determine what shall be done with his/her own body."<sup>16</sup> Preservation of self-determination involves shared decision making where the older adult is provided accurate, complete, and understandable information about the risks and benefits of withdrawal from dialysis and available treatment options once dialysis is stopped (ie, hospice care).<sup>14</sup>

### Shared Decision Making

Before engaging in shared decision making, it is essential to evaluate MJ's decision-making capacity. The term "capacity" refers to a clinician's or other professional experts' judgment as to whether the person can perform a specific task or make health care decisions.<sup>17</sup> Although the terms "capacity" and "competency" are often used interchangeably, the context of use is different. Capacity is a medical term that is determined by the physician or nurse practitioner caring for the individual. Competency is a legal term that is established by the court system and refers to global decision making (eg, finances, advance directives).<sup>18</sup> Individuals with intact decision-making capacity, who are fully informed and making voluntary choices, have the absolute right to accept or refuse medically indicated treatment.<sup>14,15</sup> Decision-making capacity has 5 elements: (1) understanding of personal medical condition; (2) comprehending the benefits and burdens of various treatment options including nontreatment; (3) ability to judge the relationship between the treatment options and one's personal values, preferences, and goals; (4) ability to reason and deliberate about one's options; and (5) ability to communicate one's decisions in a meaningful manner.<sup>18</sup> Not having decision-making capacity is different from cognitive impairment, which is prevalent to some degree among older adults receiving maintenance HD. Lacking capacity can vary depending on the complexity of the health care decision. For example, someone can decide about taking a medication but may not have the capacity to make an informed decision about a high-risk cardiac surgery<sup>18</sup> or withdrawal from dialysis. Older adults with cognitive impairment may have the ability to make decisions related to daily care but lack capacity to make complex decisions.<sup>19</sup>

Commonly, decision-making capacity is determined when a health care professional interviews a patient. Once a relationship is established between the patient and a health care provider (HCP), the HCP is better able to assess capacity based on the 5 elements of decision-making capacity at each health care encounter. The first step is making sure



there are no communication barriers (eg, hearing, vision impairment, health literacy, language, dysarthria). Avoiding the use of medical jargon is essential to increase the patient's understanding and to reduce confusion. If there are no barriers, the next step is assessing the patient's medical status.<sup>18</sup> In the case of MJ, the HCP should evaluate for uremic symptoms and other metabolic conditions (eg, cerebrovascular disease, dialysis-related factors including adequacy of dialysis) that can impact cognitive function and decision making.<sup>20</sup> The last step to consider is the patient's wishes, values, culture, and spiritual beliefs. A valid and reliable instrument such as the Aid to Capacity Evaluation<sup>18</sup> tool can assist with determining decision-making capacity. This tool can be found at <https://www.healthcare.uiowa.edu/familymedicine/fpinfo/Docs/ACE.pdf>. Table 1 provides an adaptation of the tool that could be used with those withdrawing from dialysis. If the results of the Aid to Capacity Evaluation indicate impaired capacity to make an informed decision, the person should be assessed and treated for health conditions that may be reversible (eg, pain, depression, uremia, infection, drug toxicity). Once a reversible condition is identified and addressed, it is important to reassess decision-making capacity by administering the instrument again and/or asking questions (Table 2) that demonstrate the patient's understanding of the consequences of withdrawal. If the results of the assessment continue to support impaired decision-making capacity and the HCP is unsure about the individual's ability to comprehend proposed treatment options (what will happen if she withdraws from dialysis), then consultation with other health care professionals for a psychological evaluation (eg, psychiatry, psychiatric mental health nurse practitioner) should be considered. When evaluating decision-making capacity, it is important to acknowledge spiritual and religious beliefs. Spirituality can be defined as "the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness in the moment, to self, to others, to nature, and to the significant or sacred."<sup>21</sup> Religion has a much narrower focus, is often community based, and is frequently doctrine oriented. Spirituality is an important aspect within the AA population and is linked to EOL decision making. In some situations, an AA adult may continue a life-sustaining treatment such as dialysis to provide time for God to manifest healing.<sup>22</sup> After addressing all the issues related to shared decision making, it is essential to engage in discussions about advance care planning (ACP). If the individual lacks capacity to make informed decisions (evaluation discussed previously), then advance care plan documents can be initiated.

### **Advance Care Planning**

#### **Advance Directives**

The Conditions for Coverage for ESRD facilities state that patients have a right to execute advance directives and to

know the facility's policy regarding advance directives. The Centers for Medicare & Medicaid Services end-stage renal disease services (this terminology is now ESKD) for coverage of kidney replacement therapy were originally adopted in 1976 and have been updated for the past decades. In 2005, the Centers for Medicare & Medicaid Services published a proposed rule entitled "Conditions of Coverage for End-Stage Kidney Disease Facilities (CfCs)" in the Federal Register. In 2008, these rules went into effect. Dialysis facilities must meet Centers for Medicare & Medicaid Services requirements to be certified under the Medicare program, and dialysis facilities must focus on (1) improving the quality of care for patients, (2) establishing performance measures, (3) encouraging patient participation in their care and treatment, and (4) eliminating outdated requirements (available at [http://www.cms.hhs.gov/CfCsAndCoPs/13\\_ESRD.asp](http://www.cms.hhs.gov/CfCsAndCoPs/13_ESRD.asp)).

Although discussions related to ACP are mandated, the process of performing this task is plagued with several problems. Many nephrology providers are not comfortable discussing ACP because they may feel it would upset the patient and reduce their hope of recovery. In addition, many nephrologists lack the communication skills that are necessary to present information about palliative and EOL care.<sup>23</sup> Another issue is the process of discussing ACP with patients. Haras et al<sup>24</sup> developed a reliable and valid instrument, NephRN Perception Toward Advance Care Planning, to assess nephrology nurse structural and procedural perceptions toward ACP. Knowledge of and support for ACP were the structural factors assessed, and comfort with and attitudes toward ACP were the procedural factors assessed. Attitude and support were the strongest predictors of nephrology nurse perceptions toward ACP. This tool could be used for critical self-reflection of ACP to help identify areas of need for quality improvement projects aimed at increasing the number of AAs completing ACP.

In a busy dialysis center, the staff may not have the time to engage in an "intensely human process in which a vulnerable patient is invited to consider their own deterioration and death, and to make plans for navigating various threatening possibilities."<sup>25</sup> In addition, the staff may not have the training and skills to address patients' cultural and spiritual needs as they engage in ACP conversations. Discussing ACP early allows for personal reflection on wishes for EOL care while the person is able to make an informed decision,<sup>26</sup> so it is important to have a process with measurable outcomes in place.<sup>25</sup> There are other things to consider when engaging in ACP conversations with older adults with ESKD such as prognosis and health literacy.

### **Prognosis**

Starting with an evaluation of a person's knowledge of and previous experience with ACP can help guide conversations about ACP and withdrawal from dialysis. The conversation



**TABLE 1 ACE Tool (University of Toronto Joint Centre for Bioethics Aid to Capacity Evaluation)**

<p><b>1. Able to understand medical problem</b>                  What problems are you having today?                  What bothers you most at this time?</p>
<p><b>2. Able to understand proposed treatment</b>                  What treatment are you receiving for your kidney failure?                  Tell me about your dialysis treatment.                  What other treatment options do you have for dialysis?</p>
<p><b>3. Able to understand alternative to proposed treatment</b>                  What other care can you have if you stop dialysis?                  What options do you have?                  What will happen if you stop dialysis?</p>
<p><b>4. Able to understand option of refusing proposed treatment</b>                  Can you tell me the benefits of receiving dialysis? Are there changes to the treatment that help decrease your symptoms (eg, pain)?</p>
<p><b>5. Able to appreciate reasonably foreseeable consequences of accepting proposed treatment?</b>                  How can palliative care help you?                  How can hospice help you?</p>
<p><b>6. Able to appreciate reasonably foreseeable consequences of refusing proposed treatments (including withholding or withdrawing proposed treatment)</b>                  If you stop dialysis, what will happen?</p>
<p><b>7a. The person's decision is affected by depression</b>                  Assess for depression</p>
<p><b>7b. The patient's decision is affected by delusion/psychosis</b>                  Can you help me understand why you've decided to stop dialysis? Do you think anyone is trying to hurt/harm you? Do you trust the HCP and dialysis team? Did something happens in the Center to make you want to stop dialysis?</p>

Abbreviation: HCP, health care provider.  
 The questions have been adapted for patients receiving dialysis. The ACE tool may be copied by any person for noncommercial use. The ACE tool is available at <http://www.utoronto.ca>.  
 Instructions for scoring:  
 Domains 1-4 evaluate whether the person understands his/her current medical problem, proposed treatment, and other treatment options. Domains 5-6 evaluate whether the person appreciates the consequences of his/her decision.  
 Domains 1-6, if the person responds appropriately to open-ended questions, score "yes." If they need repeated prompting by closed-ended questions, score "unsure." If they cannot respond appropriately despite repeated prompting, score "no."  
 Domain 7, if the person appears depressed or psychotic, then decide if their decision is being affected by these conditions.  
 Domain 7a, if the person appears depressed, determine if the decision is affected by depression. Look for the cognitive signs of depression such as hopelessness, worthlessness, guilt, and punishment.  
 Domain 7b, if the person may be psychotic, determine if the decision is affected by delusion/psychosis.  
 Record observations that support your score in each domain, including exact responses of the patient.  
 Remember that people are presumed capable. Therefore, for your overall impression, if you are uncertain, then err on the side of calling a person capable.

between the nephrology provider, patient, and family should include prognostic information.<sup>26</sup> A prognostic model developed by Cohen et al<sup>27</sup> estimates 6-month survival for those receiving HD by considering 4 clinical variables (advanced age, hypoalbuminemia, and the presence of peripheral vascular disease and/or dementia). Santos et al<sup>28</sup> developed a simple 6-month mortality prediction tool for older adults starting dialysis based on the 5 criteria of age 75 years or older (2 points), coronary heart disease (2 points), time of nephrology care before dialysis (<3 months [2 points], ≥3 to <12 months [1 point]), cerebrovascular disease with hemiplegia (2 points), and low serum albumin (3.0-3.49 g/dL

[1 point], <3.0 g/dL [2 points]). Use of these tools can assist with ACP discussions with patients; however, it is essential to take time to pay attention to other possible reasons, such as health literacy, that may limit a patient's understanding of the importance of having advance directives.

**Health Literacy**

It is equally important to consider health literacy when engaging in ACP conversations. A qualitative descriptive study using semistructured interviews to evaluate health literacy, EOL conversations, and goals of care with older adults receiving HD (n = 31) revealed that although this population


**TABLE 2** Questions to Ask During Evaluation of Decision-Making Capacity

Assess ability to understand treatment and care options

- Can you tell me what you know about your dialysis treatment? What other options do you have? What are the benefits of your treatment options? What are the risks of your treatment options? What is your understanding of what will happen if you stop dialysis?  
Determine the person's ability to appreciate how the information provided applies to his/her situation
- Tell me about your dialysis treatment. Why do you think you started dialysis? Do you think dialysis is good for you? Why or why not? What has been done to address your pain? What else can be done to help reduce your pain?  
Determine the patient's ability to reason with the information provided in a manner that supports the facts and honors the person's wishes and values
- What is most important to you now? What made you think about stopping dialysis? Describe your relationship with your HCP and the dialysis team. What do you think will happen to you now?  
Determine the patient's ability to communicate and express a clear choice
- You have been provided a lot of information about stopping dialysis and things we can do, like palliative care, to reduce your pain if you stay on dialysis. You have been told that, if we stop dialysis, you can receive hospice care to help treat your pain and any other symptoms you may have as we try to make you as comfortable as possible. Can you tell me about these treatment options? What is best for you?

Abbreviation: HCP, health care provider.  
Adapted from Barstow et al.<sup>18</sup>

has a high risk for mortality, only 13% of the sample had not engaged in EOL conversations with their physician, approximately 50% had talked about EOL within their social network, and 25% stated they never even thought about EOL care.<sup>29</sup> This highlights that, despite the requirements for advance directives in dialysis centers, many patients are not discussing EOL care with anyone outside their personal social network. Ladin et al<sup>29</sup> also reported that approximately 30% of the sample had no idea what EOL care meant regardless of having been asked about ACP. Five themes emerged from the study data: (1) misunderstanding EOL terminology, (2) nephrologists' reluctance to discuss EOL, (3) patients conforming to socially constructed roles, (4) discordant expectations and dialysis experiences, and (5) reconciling EOL values and future care. The authors concluded that limited health literacy was related to patients' decisions to remain on dialysis mostly because they did not understand the available options.<sup>29</sup>

### Disparities in Completion of ACP

Health disparities among AAs are a substantial barrier to completion of ACP. A long-standing history of mistreatment of AAs has led to mistrust of the medical community. Many AAs believe they will be given poorer-quality health care and be treated differently if they complete ACP (eg, not receiving life-sustaining treatments).<sup>30</sup> African Americans with ESKD are less likely to have communicated EOL care preferences or have advance directives as compared with White adults.<sup>31</sup> In one study, less than 50% of individuals receiving maintenance HD (n = 808) had documented advance directives in their medical records, despite being asked about advance directives. Discussions about EOL care were rarely done.<sup>32</sup> The lack of advance directives can be very concerning especially when the per-

centage of Black adults with a documented surrogate decision maker (34.4%) was much less compared with that of White adults (56.6%).<sup>1</sup>

### Surrogate Designate

An important aspect of ACP is designating a health care surrogate. Determining who can serve as a surrogate decision maker is dependent on state statutes. The variability among states makes it important to identify the statutes for the state where the patient resides. Some adults live in one state and receive care in another, and approximately one-fifth of physicians have a medical license in multiple states. It is difficult to formulate a uniform plan for those with diminished decisional capacity because of variability in state statutes. One problem is the diversity in terminology as to who can be an alternative decision maker (court appointed, patient designated, or default).<sup>33</sup> The most common surrogate decision makers noted in many state statutes are spouses and adult children (in 40 states, the spouse is listed as the most appropriate surrogate decision maker). Many states do not permit unmarried partners or close friends to make decisions without being appointed.<sup>34</sup> State laws generally identify surrogate decision makers in 3 ways: (1) a court order (usually as guardianship), (2) a health care power of attorney document or health care representative, and (3) a default state surrogate decision-maker statutes.<sup>34</sup>

The other ethical principles of beneficence, nonmaleficence, and justice that guide medical decision making will be briefly discussed next.

### Beneficence

The principle of beneficence is the duty of the HCP to act for the benefit of the patient and supports several "moral



rules to protect and defend the right of others, prevent harm, remove conditions that will cause harm, help persons with disabilities, and rescue persons in danger.” The difference between this principle and nonmaleficence is this principle has positive language to ensure that the benefit of the treatment is recognized and not just avoiding harm. It is important to weigh the benefits versus the harm of each treatment decision; the benefit must outweigh the harm.<sup>35</sup> Older adults with ESKD have the right to the best available care when receiving HD and for EOL care when the decision is made to withdraw from dialysis.<sup>36</sup> Hemodialysis withdrawal can be defined as “HD discontinuation after an active decision to permanently stop dialysis by the patient, family, health care power of attorney, or health care team as documented in the electronic medical record.”<sup>37(p2)</sup> Once the decision is made to withdraw from maintenance dialysis, the health care professional has the responsibility to provide the older adults with the most comfortable death possible, which can be supported by a hospice referral.<sup>27</sup>

### **Nonmaleficence**

Nonmaleficence is the HCP's obligation to do no harm. This means do not cause death, pain, or suffering, and do not deprive the person of a good life.<sup>35</sup> This involves consideration of the burden a person may experience when receiving maintenance HD. In addition, this is important and relevant when making decisions to withdraw from a life-sustaining treatment<sup>35</sup> such as HD. Once decision-making capacity is determined, it is essential to perform a comprehensive physical and psychological assessment to develop strategies that alleviate symptoms such as fatigue, pain, and depression. Alleviating symptom burden and suffering may result in a change in the decision to withdraw from dialysis.<sup>38</sup>

### **Justice**

Justice is the fair, equitable, and appropriate treatment of a person. There are several categories of justice, but one that is important to clinical practice is distributive justice. Distributive justice is the equal distribution of health care resources regardless of socioeconomic status, race, sex, or age.<sup>35</sup> The Medicare program for ESKD has been in place since 1972 for individuals regardless of age who meet the eligibility criteria. The total amount for Medicare-related expenditures for beneficiaries with ESKD increased to \$49.2B in 2018, including the cost associated with hospitalizations. In 2018, the rates of 30-day readmissions among adults with ESKD and those 66 years or older were 31.1%, and 10.1% of patients died within 30 days of hospitalization. Black adults had the highest rates of hospitalizations due to cardiovascular disease and vascular-related infections.<sup>1</sup> Contemporary dialogue about the benefit of costly resources such as dialysis and the high risk for hospitalization

and 30-day readmission suggests that dialysis may not be the best treatment choice for some older adults. Although hospice may be a better choice for those who are experiencing high symptom burden, many patients receiving dialysis do not choose hospice because they do not want to shorten their survival.<sup>39</sup> Most people die within 7 to 10 days after withdrawal from dialysis. One option for adults is palliative care across the kidney continuum.<sup>40</sup> The paucity of evidence regarding the cost, consequences, and benefits of the various treatment options for ESKD and withdrawal from maintenance dialysis supports the need for more research and should be considered in shared decision making.<sup>9</sup>

## **OUTCOME OF CASE STUDY**

After assessing MJ's decision-making capacity, the dialysis team (nephrologist, nurse, social worker, and nurse practitioner) determined MJ had impaired decision-making capacity and did not have advance directives that named a health care surrogate decision maker (also referred to as proxy decision maker). Discovering that MJ did not have a health care surrogate decision maker presented even more challenges for the dialysis team.

MJ was a widow with no living children, and only had Eddie, her significant other—and they had lived together for many years. The ethical and legal question became “Could Eddie be the surrogate decision maker and determine the treatment that would be in MJ's best interest?” One concern was Eddie's cognitive capacity to make informed decisions. MJ had informed the dialysis staff 2 years ago that Eddie had been given a diagnosis of dementia. This added to the challenges related to his ability to making the best decision for MJ. When she first asked to withdraw from dialysis, she requested that Eddie not make decisions about her dialysis. In addition, there were concerns regarding any conflicts of interest that existed (eg, financial); Eddie had made several inferences about making sure MJ had life insurance. Eddie did not meet the criteria of having adequate capacity to be a surrogate decision maker.

The dialysis team had heard MJ, on many occasions, disclose that she did not want to receive dialysis if she could not care for herself, but when she made the request to withdraw, her dialysis team did not think it was the best option for her. However, they began to reflect on when MJ first started dialysis; she was ambulatory and independent of activities of daily living, but 7 years later, she was wheelchair dependent, experiencing multiple falls, and increasingly forgetful. After a lengthy discourse, the dialysis team (eg, nephrologist, nurse practitioner, nurse, social worker) finally decided to seek a court-appointed guardian for MJ. In the meantime, the dialysis team collaborated with a palliative care team for symptom management and alleviation of her suffering.

Guardianship was eventually granted by the courts. Upon further evaluation of MJ's current physical and psychological



health conditions and expressed wishes and preferences for care, the decision was made to withdraw her from dialysis and hospice services were implemented. MJ died about 7 days later in her home where she wanted to be. Eddie was present with her throughout the transition from withdrawal of dialysis to her death. The hospice nurses thought because Eddie seemed to be experiencing a moderate stage of dementia, it was no longer safe for him to live by himself, so they contacted his physician. Eddie relocated to an LTC facility with a dementia care unit.

## LESSON LEARNED

As the United States witnesses a growing AA older population receiving maintenance HD, nephrology HCPs, including nurses, are faced with patient requests to withdraw from dialysis. The ethical principles discussed in this article should be considered when engaging in shared decision making. Engaging in shared decision making that balances autonomy, beneficence, nonmaleficence, and justice while honoring the patient's wishes and preferences for care and subsequent withdrawal from dialysis is ethically and clinically appropriate. Impaired decision-making ability impacts one's ability for self-determination, which further highlights the critical need for awareness and implementation of ACP. Evidence supports that having interventions in place to support ACP can lead to better preparation for EOL decisions.<sup>9</sup> Therefore, having established systems/processes in place to ensure ACP is initiated when an individual begins dialysis and reevaluated on a regularly scheduled basis is essential.

Another lesson learned is the need to establish and evaluate the effectiveness of collaborative models of care that integrate both palliative care and nephrology expertise. Collaborating with a palliative care service may be a way to attend to unmet needs of older adults receiving dialysis, but more research is needed to demonstrate the effectiveness of this model of care.<sup>41</sup> Creation of a model of care that integrates palliative and nephrology care may result in improved clinical outcomes (reduced hospitalization and effective symptom management).<sup>42</sup> The absence of evidence showing the benefits of this model of care demands more attention through collaborative interprofessional research studies.

## CONCLUSION

It is important to consider ethical issues that may influence care of older adults with ESKD engaging in shared decision making regarding withdrawal from dialysis. Currently, there is little evidence discussing this process, and available evidence is mostly clinical in nature and lacks scientific rigor. Therefore, research is needed to provide guidance on how and when to discuss withdrawal from dialysis and how to support older adults on this journey. Despite the lack of adequate research, nurses can (1) advocate for comprehensive

ACP, (2) provide comprehensive symptom management, and (3) collaborate with palliative care experts when applicable.

In nephrology, the term *palliative care* is being replaced with *conservative care*. The Conservative Kidney Management Clinical Working Group, leadership of the Kidney Supportive Care Research Group, and Albert's provincial Conservative Kidney Management Steering Committee recommend a conservative kidney management pathway. This pathway has 4 steps (eg, making a choice, initiating care planning, using conservative kidney management, addressing grief and loss) but is focused on those with chronic kidney disease choosing a nondialysis care option.<sup>43</sup> There is a need for a similar pathway for older adults who choose dialysis as a treatment option. The Renal Physicians Clinical Practice Guidelines for Appropriate Initiation and Withdrawal from Dialysis<sup>44</sup> have been used for more than a decade but should be updated to reflect more recent evidence. The kidney community is focused on improving health outcomes for older adults, so there are many initiatives that will include older adults. One such initiative is the Kidney Disease: Improving Global Outcomes (an international organization whose mission is to improve care outcomes of patients with kidney disease) Controversies in Nephrology Conference in 2021. This conference addressed diagnosis and treatment of symptom-based complications of patients undergoing dialysis therapy, with the goal of developing a position statement. The Kidney Disease: Improving Global Outcomes has developed several clinical practice guidelines that are used in the care of individuals with kidney disease (acute and chronic) and ESKD. These initiatives are essential to improve health-related outcomes in a vulnerable population, as the number of older adults with chronic kidney disease and ESKD increases.

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