

# When Patients Make Unexpected Medical Choices

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**Background:** In the United States, about 500,000 patients are receiving maintenance dialysis for end-stage renal disease. The decision to discontinue dialysis and receive hospice care tends to be more difficult than to withhold or forego dialysis.

**Observations:** Supporting patient autonomy is an important health care priority that is recognized by most clinicians. However, some health care professionals are conflicted when patient autonomy

varies from their treatment recommendations. This paper describes the case of a patient on kidney dialysis who chose to discontinue a potentially life-prolonging treatment.

**Conclusions:** Respecting a patient's autonomy to make informed decisions about their end-of-life care is a fundamental ethical and legal principle. Medical opinion should not and cannot overrule the wishes of a competent patient who refuses treatment.

Due to advances in medicine, people are living longer with the aid of increased options for life-prolonging treatments. These treatment options may improve the quantity but not necessarily the quality of life.<sup>1</sup>

Kidney failure can be treated with renal replacement therapy (dialysis or renal transplantation) or supportive care.<sup>2</sup> In 2017, the global prevalence of kidney failure was about 5.3 to 9.7 million.<sup>3</sup> In the United States, about 500,000 patients are receiving maintenance dialysis for end-stage renal disease (ESRD), and about 1 in 4 will stop dialysis before death, coupled with hospice enrollment.<sup>4</sup> ESRD is 2 times more prevalent among veterans than in nonveterans, which can be due in part to high rates of comorbid predisposing conditions, such as diabetes mellitus, hypertension, and advanced age, among others.<sup>5</sup> The decision to discontinue dialysis and receive hospice care tends to be more difficult than choosing to withhold or forego dialysis.<sup>6</sup>

A study conducted among patients who were taken off hemodialysis before death reported that the 2 most common reasons for the withdrawal were acute medical complications and frailty.<sup>7</sup> A retrospective study among patients with ESRD receiving hemodialysis highlighted the underutilization of hospice care in this patient population.<sup>8</sup> The study also found that those patients who were aged > 75 years, had poor functional status, and had dialysis-related complications, such as sepsis and anemia, were more likely to elect withdrawal of hemodialysis. There was no difference in overall survival or

quality of life among patients who were aged ≥ 75 years with multiple comorbidities and functional impairment who elected conservative management vs those who started dialysis.<sup>8</sup> Long-term continuous dialysis has been associated with a lower quality of life, increased dependence on others, and a variety of symptoms, such as pain, nausea, insomnia, anxiety, or depression.<sup>9</sup>

## CONSERVATIVE CARE VS MEDICAL PATERNALISM

In the United States, it is unusual for patients with ESRD to choose conservative care, and supportive services are less available for those who do compared with patients with ESRD in Europe, Asia, Australia, and Canada.<sup>10</sup> A study looking at a small number of US nephrologists has shown they may have limited experience in caring for patients who forego dialysis and they are not comfortable offering conservative management over dialysis.<sup>10</sup> Another small study from Sweden also showed that many nephrologists do not feel prepared for end-of-life care and conversations.<sup>11</sup>

Patients often rely on knowledgeable recommendations from medical experts. However, medical paternalism occurs when a physician makes decisions deemed to be in the patient's best interest but are against the patient's wishes or when the patient is unable to give their consent.<sup>12</sup> Hard paternalism occurs when the patient is competent to make their own medical decisions, while soft paternalism occurs when a patient is not competent to make their own medical decisions.<sup>13</sup>

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*Fed Pract.* 2023;40(1).  
Published online January 11.  
doi:10.12788/fp.0350

Patient autonomy is widely recognized as an ethical principle in medicine. It recognizes patients as well-informed decision makers who may act without excessive influence to make intentional determinations on their own behalf.<sup>14</sup> Autonomy can be exercised at any point during the health care process.<sup>12</sup> Although ethical and legal guidelines encourage physicians to recommend appropriate treatment, medical opinion cannot overrule the wishes of a competent patient who refuses treatment.<sup>12</sup>

### CASE PRESENTATION

Mr. S presented to the emergency department at a US Department of Veterans Affairs (VA) medical center with abdominal pain from recurrent pancreatitis. The patient aged > 65 years had a history of depression, ESRD, and was receiving hemodialysis. A computed tomography scan revealed a new pancreatic mass, and he was referred to the palliative care (PC) department nurse practitioner (NP) for a goals-of-care discussion. PC was informed to assist with hospice care initiation: The patient elected a do-not-resuscitate (DNR) code status and hospice care.

At the consultation, Mr. S stated that he had decided to forego life-prolonging treatments, including hemodialysis, and declined further evaluation for his pancreatic mass. He shared a good understanding of concerns for malignancy with his mass but did not wish to pursue further diagnostics as he knew his life expectancy was very limited without dialysis. He had been dependent on hemodialysis for the past 10 years. He had briefly received hospice care 5 years before but changed his mind and decided to pursue standard care, including life-prolonging dialysis treatments. He reported no depression, suicidal ideation, or intentions of hastening his death. He stated that he was just physically tired from his ongoing dialysis, recurrent hospitalizations, and being repeatedly subjected to diagnostic tests. Mr. S added that he had discussed his plan with his family, including his son and sister-in-law who is married to his brother. Mr. S previously identified his brother as his surrogate decision maker.

Mr. S shared that his brother had sustained a traumatic brain injury and was now unable to engage in a meaningful conversa-

tion. He shared that his family supported his decision. He also recognized that with his debility, he would need inpatient hospice care. On finding out that Mr. S's brother was no longer able to act as the surrogate decision maker, the PC NP asked whether he wanted her to contact his son to share the outcome of their visit. The patient declined, adding that he had discussed his care plans with his family and did not feel that his health care team needed to have additional discussions with them.

Mr. S also reported chronic, recurrent right upper quadrant pain. He was prescribed oxycodone 10 mg every 4 hours as needed; however, it did little to control his pain. He also reported generalized pruritus, a complication of his renal failure.

After 1 week, Mr. S was transferred to the inpatient hospice unit. At that time, he allowed the hospice team to contact his son for medical updates and identified him as the primary point of contact for the hospice team if the need arose to reach his family. Due to the restrictions imposed by the pandemic, Mr. S had virtual video visits with his family. Mr. S developed intermittent confusion and worsening fatigue over time. His son was informed of his deteriorating condition and visited his father. Mr. S died peacefully 2 days later with his family present.

### Multidisciplinary Inputs on the Case

**Medicine.** In discussing the case with medicine, the PC NP was informed that the goals the patient had for his care, which included stopping dialysis, having a DNR code status and pursuing hospice care, along with the patient's pain symptoms prompted the PC consultation. The resident also shared concerns about the patient's refusal to have his surrogate decision maker and family contacted regarding his decisions for his care.

**Palliative care.** After meeting with the patient and assisting in identifying goals for care, the PC NP recommended initiation of hospice care in the hospital while the patient awaited transfer to the inpatient hospice unit. The PC NP also recommended a psychiatric evaluation to rule out untreated depression that might influence the patient's decision making. A follow-up visit with nephrology was also recommended.

Optimal management of his distressing physical symptoms was recommended, including prescribing hydromorphone instead of oxycodone for his pain and starting a topical emollient for pruritus.

**Nephrology.** The patient's electronic health records (EHR) showed that he informed nephrology of his desire to pursue hospice care and that he decided against further dialysis, including as-needed dialysis for comfort. The records also indicated that the patient understood the consequences of discontinuing dialysis.

**Psychiatry.** The patient's EHR also showed that during his psychiatric visits, Mr. S reported he had no thoughts of suicide, and it was against his spiritual beliefs. He said he made his own medical decisions and expressed that his health care team should not attempt to change his mind. He also said he understood that stopping dialysis could lead to early death. He stated he had a close relationship with his family and discussed his medical decisions with them. He was tearful at times when he talked about his family. Mr. S shared his frustration about repeatedly being asked the same questions on succeeding visits.

After evaluation, psychiatry diagnosed Mr. S with mood disorder with depressive features and he was prescribed methylphenidate 5 mg daily and sertraline 25 mg daily. They also recommended continuing to offer dialysis in a supportive manner since the patient had changed his mind about hospice in the past. However, psychiatry followed the patient daily for 5 days and concluded that his medical decisions were not clouded by mood symptoms.

## DISCUSSION

Patients who are aged > 65 years and on dialysis are more likely to experience higher rates of hospitalization, intensive care unit admission, procedures, and death in the hospital compared with patients who have cancer or heart failure. They also use hospice services less.<sup>15</sup> Often this is not consistent with a patient's wishes but may occur due to limited discussion of goals, values, and preferences between physician and patient.<sup>15</sup> Many nephrologists do not engage in these conversations for fear of upsetting patients, their perceived lack of skill in

prognostication and discussing the topic, or the lack of time to have the conversation.<sup>15</sup> It is important to have an honest and open communication with patients that allows them to be fully informed as they make their medical decisions and exercise their autonomy.

Medicare hospice guidelines also are used to help determine hospice appropriateness among veterans in the VA. Medicare requires enrollees to discontinue disease-modifying treatment for the medical condition leading to their hospice diagnosis, which can result in late hospice referrals and shorter hospice stays.<sup>16</sup> Even though hospice referrals for patients with ESRD have increased over time, they are still happening close to the time of death, and patients' health care utilization near the end of life remains unchanged.<sup>16</sup> According to Medicare, patients qualify for hospice care if they are terminally ill (defined as having a life expectancy of  $\leq 6$  months), choose comfort care over curative care for their terminal illness, and sign a statement electing hospice care over treatments for their terminal illness.<sup>17</sup> A DNR order is not a condition for hospice admission.<sup>18</sup>

The VA defines hospice care as comfort care provided to patients with a terminal condition, a life expectancy of  $\leq 6$  months, and who are no longer seeking treatment other than those that are palliative.<sup>19</sup> Based on his ESRD, Mr. S was qualified for hospice care, and his goals for care were consistent with the hospice philosophy. Most families of patients who elected to withdraw dialysis reported a good death, using the criteria of the duration of dying, discomfort, and psychosocial circumstances.<sup>20</sup>

## Role of HCPs

Health care practitioners (HCPs) are expected to help patients understand the risks and benefits of their choices and its alternative, align patients' goals with those risks and benefits, and assist patients in making choices that promote their goals and autonomy.<sup>21</sup> Family members are often not involved in medical decision making when patients have the capacity to make their own decisions.<sup>22</sup> Patients will also have to give permission for protected health information to be shared with their family members.<sup>22</sup> On the other hand, families have

been shown to provide valuable emotional support to patients and are considered second patients themselves in the sense that they can be impacted by patients' clinical situation.<sup>22</sup> Families may also need care, time, and attention from HCPs.<sup>22</sup>

Mr. S was found capable of making his own decisions, and part of that decision was that his family not to be present for the goals-of-care discussion. He added that he would discuss the care decisions with his family. At the time of registering for VA health care services, Mr. S had provided his health care team with his brother and sister-in-law's emergency contact information as well as named his brother surrogate decision maker. As Mr. S's condition was expected to rapidly decline without dialysis, the HCPs would be able to notify family members once his condition changed, including death.

Neuroplasticity changes can contribute to chronic pain that may also lead to depression.<sup>23</sup> Chronic pain and depression may involve the same brain structures, neurotransmitters, and signaling pathway.<sup>23</sup> Factors leading to chronic pain and depression include decreased availability of monoamine neurotransmitters, such as serotonin, dopamine, and norepinephrine in the central nervous system, decreased brain-derived neurotrophic factor, inflammatory response, and increased glutamate activity.<sup>23</sup> Depression and hopelessness have been associated with the desire to hasten death among patients with a terminal illness.<sup>24</sup> Worse mental health has been associated with the desire to hasten death among patients who are older and functionally impaired.<sup>25</sup> It was important to optimize Mr. S's treatment for pain and depression to ensure that these factors were not influencing his medical decisions.

With increasing recognition of the need to improve quality of life, health care utilization, and provide care consistent with patients' goals in nephrology, the concept of renal PC is emerging but remains limited.<sup>26</sup> The need to improve supportive care or PC for patients starting on dialysis for ESRD is high as these patients tend to be older (aged > 75 years), have high rates of cardiovascular comorbidities, can have coexisting cognitive impairment

and functional debility, and have an adjusted mortality rate of up to 32.5% within 1 year of starting dialysis.<sup>26</sup> Some ways to enhance renal PC programs include incorporating PC skill development and training within nephrology fellowships, educating patients with chronic and ESRD about PC and options for medical management without dialysis, and increasing the collaboration between nephrology and PC.<sup>26</sup>

### Outcomes and Implications

Respect for the ethical principle of autonomy is paramount in health care. Patients should be able to give informed consent for treatment decisions without undue influence from their HCPs and should be able to withdraw that consent at any point during treatment. Factors that may influence patients' ability to make medical decisions should be considered, including untreated or poorly treated symptoms. The involvement of PC helps optimize symptom management, provide support, and assist in goals-of-care discussions. Advanced practice PC nurses can offer other members of the health care team additional information and support in end-of-life care. Family involvement should be encouraged even for patients who can make their own medical decisions for emotional support and to assist families in what could be a traumatic event, such as the loss of a loved one.

The desire to pursue a comfort-focused approach to terminal illness and stop disease-modifying treatments are criteria for hospice care. An interdisciplinary approach to end-of-life care is beneficial, and every specialty should be equipped to engage in honest communication and skillful prognostication. These conversations should start early in the course of a terminal illness. Multiple factors contribute to poor clinical outcomes among patients with ESRD even with renal replacement therapy, such as dialysis. There is a need to improve PC training in the field of nephrology.

### CONCLUSIONS

Mr. S was able to choose to withdraw potentially life-prolonging treatments with the support of his family and HCPs. He was able to continue receiving high-quality care and treatment in accordance with his wishes and

goals for his care. The provision of interdisciplinary care that focused on supporting him allowed for his peaceful and comfortable death.

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### Author disclosures

The author reports no actual or potential conflicts of interest or outside sources of funding with regard to this article.

### Disclaimer

The opinions expressed herein are those of the author and do not necessarily reflect those of *Federal Practitioner*, Frontline Medical Communications Inc., the US Government, or any of its agencies.

### Ethics and consent

The author was unable to obtain a written consent from the patient who died before this manuscript was prepared. Some details have been changed to protect patient anonymity.

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