

CASE AND COMMENTARY

Should Dialysis Be Stopped for an Unrepresented Patient With Metastatic Cancer?

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Abstract

Unrepresented patients (also referred to as unbefriended, patients alone, patients without proxy, or isolated patients) are among the most vulnerable persons entering the health care system. Legislation concerning these patients varies across the United States, resulting in disparities in care. For example, the statutory definition of who is unrepresented varies. In some states, clergy or close friends may act as surrogates; in other states, they cannot do so. Available end-of-life options also differ, creating significant disparities in end-of-life care for these patients.

Case

Mr B, a 74-year-old man with a prior history of hypertension and mild dementia, was admitted to the hospital from his nursing home after experiencing swollen limbs, shortness of breath, and altered mental status. In the emergency department, due to hyperkalemia and acute renal failure, Mr B was emergently dialyzed and stabilized. Mr B was minimally communicative, unable to provide his own health history. The team admitted Mr B, obtained his records, and learned that Mr B was diagnosed with renal cell carcinoma one year ago and received a total left nephrectomy. One week following his admission, Mr B's mental status deteriorated. He continued dialysis, as his renal function showed no signs of improvement; a CT scan revealed brain metastases; and consultation with oncology confirmed no curative options were available to him.

Mr B remained unable to contribute to his treatment plan. He has no known relatives and has received no calls or visitors. Dani, a nurse caring for Mr B, shared that, following his nephrectomy, Mr B's dementia symptoms worsened and his memory and attention were poor. Dani also relayed that Mr B refused to complete his part of the medical orders for life-sustaining treatment form when he first entered a nursing home 5 years ago. Dani could not say what Mr B would choose today but shared that when Mr B was diagnosed with renal cancer, he said, "I'm going to fight this cancer so hard."

Dr A, Mr B's primary attending physician, who is committed to keeping Mr B comfortable and allowing him a natural death, suggests that Mr B's dialysis be stopped. Dani wonders

whether stopping dialysis would express disregard for Mr B's wishes. The team wonders how to proceed.

Commentary

Patients who lack the capacity to make medical decisions for themselves, have no advance directive, and have no one to speak on their behalf are known by several names—unrepresented, unbefriended, patients alone, or patients without proxy. In hospitals across the country, there are thousands of patients like Mr B who often face major medical decisions without the decisional capacity to navigate them and without a loved one to take the helm.¹ While some unrepresented patients without decisional capacity still retain the ability to articulate their preferences and share their values, many, like Mr B, cannot. Without an advocate at their bedside, they face increased risk of being overtreated or undertreated as well as receiving treatment that is inconsistent with their preferences.²

With neither an advance directive nor a surrogate decision maker to guide them—and often without any guidance from the patient—clinicians must make medical decisions without knowing how those decisions might align with the patient's values. Clinicians like Dr A face the challenging task of crafting a treatment plan, often with life-or-death consequences. The less a clinical team knows about who a patient is or what the patient's preferences might be, the harder it becomes to know how to “do right” by that patient.

States have taken very different approaches in drafting laws concerning decision making for the unrepresented, with some states granting complete authority to treating clinicians and others providing no mechanism for decision making whatsoever.^{1,3} Therefore, the end of Mr B's life could look very different depending on where he was admitted. Significant attention has been given to how the variability in state laws guiding decision making for unrepresented patients impacts timeliness of care, quality of care, and medical options available to this population.^{1,2,4} End-of-life options available to the unrepresented also differ, creating significant disparities. For example, hospice enrollment is not available by statute to the unrepresented in every state.⁵ Treatment of unrepresented patients within states can also vary due to hospital policy and practice.^{6,7}

The variability in available treatment options affects the ethicality and process of decision making as much as the final decision itself. It is through decision-making processes that promote careful deliberation that we are best able to honor the patient, even when the outcome might be the same whichever law is followed. New York and North Carolina are 2 examples of states with disparate approaches to end-of-life care options for the unrepresented. We will use these extreme cases to examine the ethical and clinical impact of state statutes on clinical practice and health care outcomes for patients such as Mr B.

North Carolina

North Carolina and Oregon are the only 2 states that, by statute, allow attending physicians to unilaterally terminate life-sustaining treatment under specific conditions.^{8,9} In North Carolina, if Dr A determined to a “high degree of medical certainty” that Mr B would remain incapacitated and she, along with a second concurring attending physician, reached the conclusion that Mr B had “an incurable or irreversible condition that [would] result in ... death within a relatively short period of time,”⁸ Dr A would be free to withhold or discontinue life sustaining treatment (LST). In Mr B’s case, this would mean she could unilaterally stop his dialysis. North Carolina does permit “an individual who has an established relationship with the patient, who is acting in good faith on behalf of the patient, and who can reliably convey the patient’s wishes” to act as a surrogate.⁸ However, there is no statutory guidance regarding what constitutes an “established relationship” or what might count as knowledge of the patient’s wishes, adding yet another level of subjectivity to this process. Some hospitals in North Carolina thus might determine that the nurse, Dani—if willing—has sufficient information about Mr B to serve as decision maker, and some might feel that his casual relationship with and limited knowledge of Mr B do not qualify him.¹⁰

Granting Dr A this decision-making power, while potentially efficient, is problematic. Other than Dr A’s consulting with a second attending physician regarding Mr B’s clinical status, there is no requirement that Dr A confer with any other clinician, interdisciplinary team, or ethics committee when deciding to terminate dialysis. She would not have to account for how she reached her decision, and any conflicts of interest or inherent biases about quality of life could go unchecked.¹¹ Dr A would not have to consider what Mr B’s values might have been when weighing the risks and benefits of terminating dialysis.

Although Mr B’s specific preferences are unknown, there is some information available, such as his statement about wanting to fight cancer. In order to honor Mr B, this information must be at least considered when making current medical decisions. A single physician might take the time to consider insights into unrepresented patients’ values when deliberating, but there is no guarantee that he or she will do so. Even if a clinician were to take the time, weighing risks and benefits of particular interventions in the light of a patient’s prognosis and values is a delicate process that becomes even more complicated when the information we have about a patient is scant. The risk of overvaluing or undervaluing information can be mitigated through a more deliberative process involving perspectives of an [interdisciplinary team](#). This approach can also decrease the chances that Mr B would receive different treatments depending on the attending physician on service.¹¹

The decision-making model used by Dr A not only lacks transparency, has potential for bias, and does not specify a process, but also places an unfair burden on the shoulders of the attending physician. Even though Dr A believes that allowing Mr B a natural death is

in Mr B's best interest, making that decision for him or a similar patient can take a toll on her. Deciding for others is a significant burden and can produce distress and burnout,¹² although these effects can be mitigated when decision making is done in conjunction with other health care professionals or using a team model. There is evidence that this approach—wherein clinicians unilaterally decide on the withholding or withdrawing of LST—is widely used though only authorized explicitly by North Carolina and Oregon.⁶

New York

If Mr B were receiving his care in New York State, Dr A would not have the authority to unilaterally stop dialysis. The New York Family Health Care Decisions Act states that LST can only be withdrawn if the treating attending physician and an independent physician agree that the treatment—in Mr B's case, dialysis—would offer “no medical benefit” because the patient would “die imminently, even if the treatment is provided” and that the treatment “would violate accepted medical standards.”¹³ With the nephrologist open to continuing dialysis, it would be challenging to argue that dialysis violated acceptable medical standards.

In 2015, New York State law was amended to provide hospice care as an option to patients like Mr B with the approval of a [hospital ethics review committee](#) (ERC).¹³ An ERC—composed of at least 5 people including an attending physician, a registered nurse, a community member, and 2 others, one of whom must be a health care professional—is tasked with reviewing the hospice recommendation and must give its approval before a patient can be enrolled. Prior to 2015, Dr A would have had little room to do anything other than maintain Mr B on what she viewed as unduly burdensome dialysis, keep him comfortable, and await his death. Now Mr B could be transferred to hospice care, and his dialysis could be discontinued with approval of an ERC. The criteria for withdrawing LST for the purpose of hospice enrollment allows for withdrawal in situations in which the treatment would be an extraordinary burden to the patient and provided that the patient has an illness or injury that could be expected to cause death within 6 months, whether or not treatment is provided.¹³ Members of the ERC would have the opportunity to hear from Dr A, the nephrologist, the bedside nurse, and any other clinician engaged in Mr B's care. The ERC would then weigh the benefits and burdens and would need to reach consensus regarding whether hospice would be in Mr B's best interest.

An ERC does not guarantee that Mr B's values will be unearthed and honored, but it provides a space for stakeholders with different perspectives to come together, share what they know about Mr B, and try to decide whether hospice enrollment and potential withdrawal of LST for that purpose is in his best interest. As the person with the greatest knowledge of Mr B, Dani would also be welcomed to share insights.

A Different Fate From State to State

In North Carolina, Mr B might no longer be receiving dialysis. In New York State, Mr B might be in hospice care. In states where the law is silent, he might still be in the hospital receiving dialysis, or the hospital might be engaged in the often-unwieldy process of seeking guardianship for him.¹⁴ Regardless of whether dialysis is terminated, Mr B will likely die in the next few days to months. However, the process by which his treatment options are decided upon is as important as the outcome itself. It is both a profound privilege and a profound responsibility to be the de facto advocate for a patient's best interest. A statute that demands a deliberative, interdisciplinary process is more likely to honor the patient.

In a society that prizes autonomy, making decisions—especially end-of-life decisions—for those who have no voice is inherently a fraught process. Several states have developed legislation to address this problem, but there is no perfect system for making end-of-life decisions for unrepresented patients. Every unrepresented patient deserves an individualized assessment of his or her needs, taking into consideration not only medical facts but also his or her values and wishes. This task can feel impossible when so little is known about who the patient is and what he or she values. The most effective means of ensuring that patients like Mr B receive care consistent with their values is by preventing them from becoming unrepresented patients.¹ While these patients often come from growing marginalized populations such as the [homeless and elderly](#), we should not automatically assume that they are without connections.¹⁵ Clinicians should proactively identify patients at risk for becoming unrepresented and support them in identifying potential surrogates and documenting their wishes. When Mr B was first hospitalized for renal cancer, his oncologist might have asked him: “Whom do you trust?” “Who knows you best?” No statute can replace the astute clinician's ability to care for the whole patient.

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