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Independent Articles

Difficulties in Honoring Patient Requests for Hospice when Relying on Surrogate Decision-Makers: A Case Study

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Abstract

Honoring a patient's wishes for end-of-life care can be challenging if the patient loses decision-making capacity and the identified alternate decision-maker will not respect the patient's wishes. This article discusses how to proceed ethically and legally when the alternate decision-maker and care team disagree about respecting a patient's end-of-life preferences.

Keywords: surrogate decision making; alternate decision making; patient preference; ethics

Introduction

When a patient has medical decision-making capacity, clinicians typically demonstrate respect for autonomy through the practice of shared decision-making, a collaborative process in which patients, families, and health care professionals work together as partners, engaging in open dialogue and mutual respect. However, if the patient loses decision-making capacity, the clinician still must respect the patient's autonomy and uphold their goals and values.[1] Typically, this duty is fulfilled by adhering to a patient's previously expressed wishes, as expressed through advance directives or advance care planning (ACP) notes, or through alternate decision-makers (aka surrogate decision-makers)[2] who step in to make decisions on a patient's behalf. When an alternate decision-maker disagrees with advance directives and, in the case of patients nearing the end of life, requests interventions that lack utility or are not consistent with a patient's previously expressed wishes for a comfort-focused approach to care, substantial moral distress may ensue for the care team. This case discussion reviews how to proceed with decision-making, both ethically and legally, when such an impasse occurs.

Case

Mr. Andrews, a 75-year-old man with metastatic non-small cell lung cancer on home oxygen, was admitted to the hospital internal medicine service with shortness of breath, weakness, and failure to thrive after an initial chemotherapy treatment. He was diagnosed with sepsis caused by pneumonia. Antibiotics and high-flow oxygen therapy were initiated. His primary oncologist relayed to the hospital internal medicine attending and the patient that no additional cancer-directed treatments could be offered. In response, Mr. Andrews expressed a preference for a do not resuscitate/do not intubate (DNR/DNI) order and a transfer to an inpatient hospice program.

The hospital internal medicine attending determined through a formal capacity assessment that the patient, despite being ill, had the capacity to make this decision per the criteria outlined by Appelbaum and Grisso.[3] The patient expressed that he understood the relevant information regarding his medical condition, prognosis, and treatment options. He was aware of the severity of his illness, the limited treatment options available, and the implications of choosing a DNR/DNI order and hospice care. He appreciated the implications of his choices for his comfort and remaining life expectancy. He could relate his choices to his personal values, preferences, and goals. And, finally, Mr. Andrews consistently expressed his preference for a DNR/DNI order and hospice transfer throughout the assessment process. This was documented in the patient's electronic medical record. Unfortunately, before the patient was transferred to an inpatient hospice facility, his respiratory status worsened, and he became confused. He could no longer make any decisions for himself.

Mr. Andrews was a widower and did not have a medical power of attorney or a formal advance directive. His son, with whom he had had little contact over the past ten years, was the surrogate decision-maker of highest priority under state law, and the clinical team contacted him. (There were no other family or friends to assist.) He and the patient had never discussed end-of-life preferences or care. Upon learning of his father's wishes, Mr. Andrews's son

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disagreed with a comfort-based approach, demanded that "everything be done," and became verbally abusive. Additional attempts to engage him in discussion were not successful, and he left the hospital. He did not answer calls or messages from the clinical team. Given this conflict, the patient was not accepted into hospice care. The hospitalist was unsure of how to proceed. He questioned whether transitioning the patient to comfort care in the hospital was ethically and legally permissible without the surrogate decision-maker's direct consent. The clinical ethics service was consulted.

Considerations for Patient Autonomy and When to Override Advance Care Planning

One of the prominent ethical concerns in these circumstances is ensuring that the patient's goals and values are upheld despite the lack of decision-making capacity. Achieving this can be increasingly challenging without an advance directive. Although formal documentation is preferred, the verbally expressed and medically documented wishes of a patient with capacity can carry the same moral weight as an advance directive. Indeed, the American Medical Association *Code of Medical Ethics* indicates that verbal advisories are ethically valid and should be documented in the medical record.[4] Thus, as Mr. Andrews had decision-making capacity during his prior ACP conversation, his medical decisions ought to have been interpreted literally to respect his autonomy *unless* his son demonstrated clearly and convincingly that his father's expressed wishes should be disregarded. Medical ethics decisions are strongly context dependent; although ACP documentation can appropriately reflect a patient's wishes and produce preference-aligned outcomes, there are limited circumstances in which diverging from the ACP is ethically permissible and enhances patient-centered care.[5]

When determining the ethical permissibility of overriding patients' previously expressed wishes, clinicians should consider the *medical appropriateness* of the override request, the degree of *discretion* the patient afforded to the alternate decision-maker, whether the patient misunderstood the nature of their expressed wishes, and, most importantly, whether the alternate decision-maker is using *qualitative, evidence-based, substituted judgment*.[6] Although these principles are not weighted equally, clinicians ought to consider them in tandem to ensure ethical delivery of care.

Medical appropriateness seeks to ensure that the risk of harm does not outweigh the intended benefits.[7] Care teams are not ethically obligated to offer interventions that lack utility, even if the alternate decision-maker insists upon them. Conversely, clinicians are not obligated to inappropriately limit interventions (e.g., if an alternate decision-maker requests to prematurely transition an incapacitated patient to comfort care, contrary to the patient's previously expressed wishes or the care team's assessment that the patient will recover to baseline). In the case of Mr. Andrews, one may argue that interventions outside the scope of palliative care lacked medical utility and exposed the patient to the risk of incremental harm, including injury to bodily integrity and well-being, for little clinical benefit. The patient's son, however, had a different perspective.

Clinicians should also consider whether the patient empowered the alternate decision-maker with a degree of *discretion*, or flexibility, in decision-making.[8] For example, if Mr. Andrews had expressed, "My son knows me best and I trust him to make the right decisions for me," then that could have been an indication that an override may have been permissible. Grounded in relational autonomy, shared decision-making recognizes that end-of-life decisions are shaped not only by individual preferences but also by the patient's relationships, values, and broader social context. A persistent challenge in practice, however, is safeguarding patients from potential abuses or undue influence, as collective pressure can sometimes lead to futile treatment or therapeutic obstinacy. This holistic approach was attempted with Mr. Andrews's son, but his belligerent and uncooperative stance prevented meaningful dialogue. As a result, the team was unable to determine whether his decisions reflected a combination of his family's and father's values or were driven primarily by self-interest.[9]

The strongest foundation for permissibly overriding a patient's previously expressed wishes, however, is whether the alternate decision-maker can demonstrate *corroborated evidence of substituted judgment*.[5] If an alternate can rationalize their request in context of the patient's life story and prior choices, elucidating what mattered most to the patient, then a permissible override may be supported. An override would be supported further if the alternate's decision is corroborated by accounts from family or friends, chart notes, or historical, narrative examples. Suppose Mr. Andrews's son had clarified with the care team that he wanted them to "do everything" because his father had always expressed life-prolonging goals of care in the past and "wasn't ready to give up yet." Alternatively, if Mr. Andrews had had other children who agreed with the surrogate's request and indicated similar reasons, that too could have influenced decisions in favor of overriding Mr. Andrews's ACP. As facilitators of the decision-making process, care teams need to understand both the patient and the family in context, which requires sincere engagement. The *four-box method of ethical analysis* explains "contextual features" as an essential part of ethical deliberation, establishing that these relational factors are ethically relevant to care.[10]

It is also important to acknowledge that ACP documentation does not ensure goal-concordant care.[11] As such, advance directives and ACP notes should be considered within the contexts of limitations, especially if the patient's medical experience or situation may have influenced a change to goals and values. Although this possibility should be considered, there was no evidence in Mr. Andrews's case that such dynamic decision-making was at play. The surrogate indicated no prior father-son conversations, there were no historical care decisions that conflicted with the patient's most recently discussed wishes, and no other ACP notes were documented in the medical record. Moreover, Mr. Andrews's ACP conversation with the hospital internal medicine attending physician was the most recent goals-of-care discussion and was grounded in the patient's prevailing situation (as opposed to a hypothetical scenario). There was no subsequent conversation between Mr. Andrews and his son during which Mr. Andrews indicated that he had changed his mind about his DNR/DNI order or transferring to a hospice facility. Nor was there any indication that Mr. Andrews misunderstood the gravity of his decision. Therefore, *ethically*, it was permissible to follow Mr. Andrews's ACP preferences.

Legal Considerations

State laws regarding what constitutes an advance directive, as well as who ought to serve as an alternate decision-maker,[12] differ materially and, regardless of the permissibility from a medical ethics standpoint, may heavily influence decisions about whether care teams adhere to an alternate's request. Many states have laws

delineating requirements for a document to be considered a legally valid advance directive or living will, and fourteen states specify that an oral advance directive carries equal legal weight to a written one.[13] Therefore, in some states, Mr. Andrews's statements to his physician regarding his DNR/DNI order and hospice discharge would have the same legal standing as a formal advance directive. Clinicians are advised to familiarize themselves with local statutes and consult their department of legal affairs when questions arise.

With respect to decision-making, seven states have adopted laws specifying that either the designated health care agent appointed by the patient or the statutorily designated surrogate *should* make decisions in accordance with the patient's known preferences or wishes.[14] Some states are more specific about whether a designated health care agent *cannot act against* a patient's expressed wishes. For example, in Georgia, state law specifies that an appointed health care agent *does not* have the authority to make health care decisions contrary to a patient's prior capacitated written or expressed wishes.[15]

Some states also draw distinctions between decisions that can be made by appointed medical powers of attorney and default surrogates. In Arizona, for example, surrogates who are not a health care agent or court-appointed guardian cannot make decisions to withdraw artificial nutrition and hydration.[16] Given that states are more likely to limit the decision-making authority of statutory surrogates than of appointed health care agents, it might be expected that courts would interpret the law such that a surrogate's decisions (compared to those of an appointed health care agent) are more aligned with a patient's prior expressed wishes.[17]

In the absence of a valid advance directive, courts have generally used a clear and convincing evidence standard for determining whether a particular decision is in line with patient wishes and values, particularly when the proposed decision would result in the patient's death.[18] Some courts have even determined that statements made by a patient to a friend (months and years before hospitalization) expressing that they would not want their life prolonged by mechanical ventilation were sufficient evidence to meet the burden of proof.[19] In the case described herein, the attending physician's documentation of Mr. Andrews's capacitated, expressed preference for a DNR/DNI order and hospice transfer would likely meet the standard of clear and convincing evidence.

Practically, however, given that few hospitals have the desire (or resources) for prolonged legal battles, many do not engage the courts in disputes when alternate decision-makers go against a patient's expressed wishes, unless those wishes are in writing and state law already clarifies alternate decision-maker duties.

The mechanisms designed to protect incapacitated patients risk being misused if care teams alienate families and thereby render patients "unrepresented." Technically, the issue is not simply whether such abuse is possible, but which safeguards distinguish legitimate from illegitimate invocation of this authority. Legally, most "unrepresented patient" statutes and hospital policies require multiparty review (ethics consultation, concurrence of two physicians, or legal oversight), which makes it procedurally difficult for a single team to act unilaterally. Ethically, professional duties of loyalty and respect for persons demand that clinicians pursue dialogue with surrogates in good faith, even when those relationships are strained. If communication deteriorates, the burden is on the care team to demonstrate that the surrogate's disengagement was not manufactured by the team but arose despite reasonable efforts at inclusion. Thus, the safeguard is less about trusting clinicians not to misuse power than about embedding decision-making in transparent, multiagent processes that minimize the risk of coercion.

Next Steps

The conflict between alternate decision-makers and care teams can be morally distressing, and navigating these situations, challenging. This is particularly the case when the care team believes diverging from the ACP would be impermissible, but the alternate is adamant. Several steps to mitigate moral distress and support clinician-alternate communication can be considered.

Firstly, it is advised that clinicians work jointly with hospital resources, such as clinical ethics consultation services or an ethics committee and legal and risk management departments, to elucidate the ethical and legal nuances in determining a path forward. It is important to recognize, however, that family members and alternate decision-makers, like Mr. Andrews's son, are likely experiencing anticipatory grief, tremendous stress, and "may be so overwhelmed by their own emotional needs that they [act] in their own interests rather than those of the patient," which may manifest in difficult behaviors.[20] Moreover, the more the clinician-alternate relationship is neglected, the more isolated and misunderstood the alternate decision-maker may feel, perpetuating behaviors, disagreement, and decision-making barriers.[21] In circumstances such as these, it is necessary to reinforce a positive clinician-alternate relationship through open-ended questions and empathetic listening and responses. It may be beneficial to seek support from a clinical ethics consultant separate from the primary treatment team, who can maintain a neutral position and who is trained to facilitate conversations to improve value-based decision-making.[22]

Case Resolution

Mr. Andrews's son was unable to provide evidence-based reasons why his father's previously expressed wishes should be disregarded. A clinical ethics consultant recommended adhering to the patient's expressed wishes unless another surrogate in the state-established hierarchy could corroborate Mr. Andrews's son's request. At that point, the patient's son refused to engage with the clinical team and did not respond to multiple phone calls and messages.

Given the son's lack of engagement, and with no other surrogate identified, the clinical team chose to move forward with their hospital policy and state law, which mandate that two physicians and a clinical ethics consultant can jointly make decisions on behalf of an unrepresented, incapacitated patient.[23] Although the conflict with Mr. Andrews's son precluded his acceptance to a hospice facility, the decision-making team determined that providing in-hospital comfort care would best uphold the patient's autonomy and align with his goals of care. Mr. Andrews died comfortably in the hospital.

Conclusion

Complex decision-making and conflict among alternate decision-makers and clinicians can be a source of tension and moral distress in the hospital. This case analysis aimed to exemplify and elucidate the ethical and legal considerations when such disagreements arise, and no formal advance directive is available.

Ethically designated health care agents and alternate decision-makers have an obligation to uphold a patient's previously expressed wishes; only under limited conditions and with a high

burden of proof is it ethically permissible to accept an alternate's divergence. If the alternate's request is medically appropriate, uses evidence-based substituted judgment, and the patient afforded the alternate a degree of decision-making discretion, then departing from previously expressed wishes may be ethically permissible. When conflict arises, it is recommended that both ethical and legal resources are engaged to ensure the appropriate delivery of care.

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14. These state laws are based on the 1993 Uniform Health-Care Decisions Act model law, which provided a legal framework for states to adopt and clarify their laws regarding health care decisions. In 2023, a revised version was created that offered further clarity about agents and surrogates complying with patient wishes (https://www.uniformlaws.org/viewdocument/final-act-168). Since the publication of the revised version, one state (Nebraska) has proposed legislation based on the 2023 version to address surrogates making decisions in accordance with patients' known preferences and wishes. L.B. 1168, 108th Leg., 1st Sess. (Neb. 2024) (indefinitely postponed). See also Alaska Stat. § 13.52.030(g) (2024); Del. Code Ann. tit. 16 § 2507(8)(b)(1) (2023); Haw. Rev. Stat. § 327E-5(g) (2024); Me. Rev. Stat. Ann. tit. 18-C, § 5-803(5) (2017); Miss. Code Ann. § 41-41-211 (6) (2024); N.M. Stat. Ann. § 24-7A-5(F) (2024); Wyo. Stat. Ann. § 35-22-406(f) (2024).
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23. State laws and institutional approaches regarding the care of an unrepresented patient vary widely, and local state statutes and hospital policies should be considered before providing medical decision-making for such patients.