

American Medical Association Journal of Ethics

January 2016, Volume 18, Number 1: 12-17

ETHICS CASE

What's the Role of Autonomy in Patient- and Family-Centered Care When Patients and Family Members Don't Agree?

Commentary by Laura Sedig, MD

Dave's health is on the decline. Despite surgery, chemotherapy, radiation, and hormonal treatments, his prostate cancer has metastasized to his bones. When he's been in and out of the hospital for four months or visiting clinic for lab tests and treatments, he's often accompanied by his wife Jessica and one or both of his two children, Christine and Alex. Dave's family has remained optimistic, confident, and encouraging; they fully expected him to pursue aggressive treatment. Dave's physicians, however, now want to transition his care and incorporate hospice and palliative approaches to managing his illness.

The palliative care physician, Dr. Barelle, sits down alone with Dave to discuss his end-of-life wishes. Dave insists on pursuing aggressive acute care for his prostate cancer, but he also seems exhausted. As Dr. Barelle continues to describe what aggressive acute care would entail over the next months and begins to probe deeper into Dave's goals of care, Dave slowly confesses that he worries about aggressive treatment, states that it isn't what he wants, and also says, "I'm not the hero type." He goes on to express that he particularly values his independence and that he fears pain, suffering, impending loss of functioning, and loss of his autonomy. He finally admits that aggressive acute care seems to him to be excessive and futile at this point but that he doesn't want to let his family down by not "fighting." He fears that his family thinks of hospice and palliative care as capitulating and "giving up."

Dr. Barelle has suspected that Dave's wishes were diverging from his family's, and she wonders how to acknowledge this and how to advocate on Dave's behalf in ways that won't be divisive. What should she do? Should she downplay the potential of aggressive care to better persuade the family to respect the patient's wishes?

Commentary

In order to best care for Dave, Dr. Barelle must consider how to respect both his autonomy and the role of his well-intentioned and loving family in his care. She must also remain an advocate for his stated wishes without being paternalistic about his choice to follow his family's wishes. Furthermore, Dr. Barelle is in a challenging position as she is newly involved in Dave's care and does not have a long-standing relationship to serve as a foundation for these difficult conversations. So, we might wonder at this

point, what is the appropriate nature and scope of autonomy and the role of family members in a case like Dave's?

Patient Autonomy and Informed Consent

Expressing respect for patients' autonomy means acknowledging that patients who have decision-making capacity have the right to make decisions regarding their care, even when their decisions contradict their clinicians' recommendations [1]. Beauchamp and Childress remind us that autonomy requires both "liberty (independence from controlling influences) and agency (capacity for intentional action)" [2] and that liberty is undermined by coercion, persuasion, and manipulation [1]. The ideal of "informed consent" is a hallmark of Western medical ethics that came about following the horrors recounted in the Nuremberg trials and was codified in American law through *Canterbury v. Spence* in 1972 [3]. It requires physicians to respect patients' autonomy by giving them the information needed to understand the risks and benefits of a proposed intervention, as well as the reasonable alternatives (including no intervention), so that they may make independent decisions.

A patient's independence is traditionally the highest priority in American bioethics [1]. American bioethics circumscribes the role of others who might influence the patient to make a choice that does not put his own wishes or best interests first. Although this emphasis is intended to prevent patients from being coerced, especially by medical professionals, it ignores that a patient is part of a family. Patients often wish to take their family members' opinions into account when making medical decisions, as they would with many other important decisions. Respecting patient autonomy thus includes respecting both how patients wish to make a decision and the decision made, even if the decision is to allow their family's desires to supersede their own [4, 5].

Influence within Families

Reminders to respect a patient's liberty are generally directed toward clinicians, but family members [can](#) certainly coerce, persuade, or manipulate a patient. Agency, however, allows a patient to consider how a decision he or she makes might affect his or her family members. It is both common and socially acceptable for a patient to consult family members in order to aid in decision making. Focusing on the strict definition of autonomy and failing to recognize an individual as part of a family leads to an incomplete understanding of decision making for informed consent [2].

Despite the fact that most families offer suggestions with the best intentions, there are situations in which family members become unduly persuasive, manipulative, or coercive. For example, if family members are threatening to remove support, financial or otherwise, for patients if they do not make the decision desired by the family, the family would be manipulating the patient. Therefore, clinicians must be mindful of the potential for this dynamic and advocate for the patient to ensure that he or she feels free to make

an independent decision.

In this case, Dave has elected to make his decision based on the wishes of his family. He and his family have been presented with the relevant information to consider, and Dave appears to be making that decision without evidence of coercion by his family. Dave's decision therefore appears to be consistent with Beauchamp and Childress's description of the five components essential to informed consent: competence, disclosure, understanding, voluntariness, and consent [1]. In Dave's case, his competence is not in question. Dr. Barelle has disclosed what aggressive care and comfort care would be like and Dave appears to understand the differences between treatment options. He is making his decision without undue influence from his family or clinician, and he has given his consent to proceed with aggressive treatment.

Despite giving informed consent, he continues to struggle with the conflict between his desire to avoid further aggressive therapy and his desire not to cause additional pain to his family by refusing treatment that they wish him to undergo in hopes of prolonging his life. His conflict may cause discomfort for Dave and Dr. Barelle, but his decision is voluntary. Although it might be challenging to accept that Dave is choosing a course of treatment with a high chance of suffering for little chance of benefit, it is a reasonable decision to make. Some patients decide to do everything possible to prolong their lives, even if the treatment is harsh. The decision is acceptable as long as it is autonomous and the patient is aware of the risks and benefits of treatment.

If Dave's family were exercising undue influence, Dr. Barelle would be obligated to identify that as unacceptable and discuss it with Dave. In the case of undue influence from family members, Dr. Barelle would be obligated to follow the patient's wishes after discussion with his or her family.

Nourishing Family Relationships during High-Stakes Deliberations at the End-of-Life

There is research about how patients and family members think medical decisions should be made and which values they consider important. This information could help inform Dr. Barelle as she counsels Dave in hopes of achieving a treatment plan in accordance with Dave's stated wishes while maintaining his close family relationships. For example, Schäfer et al. [6] surveyed patients and family members about who should receive medical information and make medical decisions and how disagreements should be resolved. Ninety-three percent of respondents felt that both patients and family members should receive medical information; 70 percent of patients felt that family members should have a role in decision making, but only 54 percent of family members felt that they should. Most respondents (78 percent) thought it was important for patients, their families, and their physicians to resolve disagreements jointly. These findings suggest that Dave might be taking his family's wishes into account more than his family would want or expect, and that his family might wish to resolve the conflict

with a discussion involving Dave and Dr. Barelle.

Schäfer et al. [6] also asked patients and family members to rank their values at the end of their or their loved one's life. Both patients and family members ranked family, partner, children, and health in the top four, although in a different order. Freedom and independence were ranked seventh and eighth by patients and eighth and ninth by family members, with long life ranked eleventh by both groups. These results suggest that the values of patients and their family members are fairly closely aligned. Therefore, facilitating a discussion about Dave's underlying values might be a strategy for Dr. Barrelle to generate concordance between him and his family.

Knowing that patients might care more about incorporating their family's wishes into their decision making than family members themselves do might be helpful to physicians wanting to encourage Dave to discuss his desires with his family. Dr. Barelle can remind Dave that his family might be more open to his desired treatment option than he thinks. Even if their initial wishes are incongruent, patients and families usually have the same underlying values. This provides a basis for further discussion about overarching hopes for treatment outcomes and might help Dave and his family agree about how to approach his care at this stage of illness. Even if they do not agree, they might have a better understanding of each other's perspectives.

Decisions made in situations of high stress, such as treatment decisions when there is little hope of substantial benefit, are difficult for all patients, families, and physicians. It is even more difficult when the physician's relationships with the patient and the patient's family have not had time to develop. A new addition to the patient's care team, such as Dr. Barelle, must work to build her relationships with the patient and the patient's family for them to trust her and her recommendations. Additionally, when a patient's care is divided among multiple clinicians, it is ideal for all of the clinicians to discuss the case among themselves to minimize confusion for the patient and family. Having such a discussion does not mean that the clinicians come to a decision for the patient, but rather that they all agree on the available options and the potential risks and benefits of each in order to present a consistent interpretation of the current situation and the reasonable next steps. It is important for Dr. Barelle and Dave's oncologist to confer so that they are both presenting the same options to Dave and his family.

Resolution

The physician-patient relationship is a fiduciary relationship in which the physician is obligated to act in the patient's interests, with respect for the patient's autonomy. Physicians are also bound by patient-physician confidentiality. When an autonomous patient's stated wishes and actions are not aligned, the physician [must](#) both respect the patient's decision and keep his wishes confidential if he has asked her not to disclose them. However, Dr. Barelle can demonstrate her support for Dave by continuing to

advocate for his personal wishes, even if that advocacy is done primarily at appointments in which his family is not present. Dr. Barelle should discuss with Dave precisely which pieces of information he is comfortable having her disclose to his family so that she does not break physician-patient confidentiality in her attempts to advocate on his behalf. If he is comfortable with greater transparency, Dr. Barelle should discuss his values and hopes, as well as his family's values and hopes for him, as a foundation for setting care goals—prolonging life or minimizing suffering, for example—during another appointment at which a family member is present.

Prior to a conversation with Dave's family regarding the risks and benefits of pursuing aggressive therapy (or not) and goals and values, Dr. Barelle should work with Dave on how medical information and his values should best be presented to his family. He can provide insight into how his family would best understand the medical information, and they can discuss how to help his family understand his wish not to pursue aggressive therapy, even if he refuses to tell them directly. It is not acceptable for Dr. Barelle to downplay one option with the goal of persuading Dave's family to choose a different option without his express permission. However, after Dr. Barelle has ensured that Dave and his family all have realistic expectations for pursuing—or not pursuing—aggressive therapy and has held a discussion regarding their goals for the end of Dave's life, Dave and his family might be better able to come to a resolution with regard to his treatment. A deeper conversation with Dave and his family about broad goals and values at the end of his life—especially independence—might help them to find more common ground or some level of comfort agreeing to disagree.

A best result of this conversation would be that Dave and his family come to an agreement with regard to his future treatment. It could also happen that his family continues to disagree with his decision but supports him as an independent decision maker. Alternatively, Dave's family might continue to disagree with his wishes and Dave might continue to defer to his family, which is still acceptable provided these conversations have not demonstrated evidence of coercion, undue influence, or manipulation. Unfortunately, Dave and his family might continue to disagree, with growing tension in their relationship due to this disagreement. In this situation, enlisting social work and chaplaincy to help with [family dynamics](#) could be a good strategy for mitigating this tension and thus would likely be in everyone's best interest.

Whatever Dave's ultimate decision, Dr. Barelle will have respected Dave's autonomy and provided him and his family with all of the information needed for Dave to give informed consent for the next phase of care. She will also have laid the groundwork for continued discussions as Dave's cancer progresses and more decisions must be made.

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Acknowledgements

The author would like to acknowledge Dr. Raymond Hutchinson for his review of the manuscript, his edits, and his suggestions.

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ISSN 2376-6980**