Ethics in Action

Sibling conflict over a parent's end-of-life care: A legal perspective

BY GRACE WANKIIRI ORSATTI, JD, AND ALISON M. COLBERT, PhD, PHCSN-BC, FAAN

Disclaimer: Clinical issues often have both legal and ethical dimensions. In order to help practicing nurses understand the complexities of end-of-life care, this Ethics in Action column is authored by a lawyer with experience in the preparation of advance directives. This article is intended for general information purposes only and does not constitute legal advice. Specific laws governing advance directives vary from state to state, and this article provides only an overview. You should not act or refrain from acting based on any information provided in this article. Please consult with your own legal counsel about your particular legal matter and all specific legal questions you have.

JORDAN* IS AN RN in the ICU. She is taking care of Mrs. H, 76, who was admitted for community-acquired pneumonia. Mrs. H had been living with her adult daughter after losing the ability to care for herself following a diagnosis of heart failure, likely due to earlier treatment for breast cancer. Her condition was deteriorating quickly due to the infection and her general poor health. A co-occurring cognitive decline has rendered Mrs. H unable to make her own decisions about her medical treatment. To discuss end-of-life care, Mrs. H's care team in the ICU reached out to her adult daughter, who reported that Mrs. H had told her she wanted support and comfort, and that she did not want "a lot of tubes or anything." During this conversation, an adult son arrived and stated to the care team that he knew his mother would want the team to do everything they could to save her life. The siblings openly and strongly disagreed. In discussions with the family, Jordan learned that Mrs. H and her two children had never formally discussed her end-of-life care and no advance directives had been written. What are the key considerations for Jordan and the team caring for this patient?

*Names have been changed to protect privacy.

The absence of advance directives can lead to indecision, helplessness, doubt, fear, and disagreement among the children left to make such difficult choices their own. The lack of guidance from the parent can increase the strain placed on a family already burdened by the stresses of a medical emergency or terminal illness, and it leaves the children at risk for dishonoring their parent's wishes. Additionally, as Mrs. H's circumstances reflect, the absence of advance directives leaves healthcare practitioners without clarity as to who is ultimately responsible for consenting to or refusing treatment on an incapacitated patient's behalf.

Many individuals like Mrs. H do not document their end-of-life care and treatment preferences, for reasons ranging from lack of awareness to simple unwillingness to confront a difficult task.[1] Despite the value of advance healthcare directives, only 37% of Americans had completed advance directives as of 2017.[2] While older adults are more likely than the average person to have prepared such documents, many still do not memorialize their end-of-life treatment and care preferences in a living will or select a healthcare agent to act on their behalf if they become incapacitated.[3]

The number of older adults who complete advance directives remains low despite the Patient Self-Determination Act, a 1990 federal law that requires many healthcare facilities to give patients information about their right to make their own medical decisions, accept or refuse medical treatment, and prepare advance directives.[4] As such, the problems facing Mrs. H and her family are quite common. Practitioners must be prepared for what can occur when sibling disagreements arise, particularly given that state laws may require the attending physician or NP to determine who the surrogate decision-maker should be.[5]

Where an incapacitated patient has no advance directive appointing a healthcare agent, state laws generally designate certain specified individuals to act as surrogate decision-makers for that patient. These laws seek to reflect what reasonable persons would naturally choose if they were able, recognizing that those closest to the patient are best suited to assume this critical role.

Generally, state laws designate a hierarchy of family members who can assume authority to make decisions as a surrogate. The incapacitated patient's spouse is commonly highest on the list of potential surrogates unless the couple is legally separated. Where no spouse is available, adult children are generally next to fulfill the surrogate decision-maker role. The

patient's parents often follow in the order of priority, and the patient's adult brothers or sisters are next. Other potential surrogates may include adult grandchildren, nieces and nephews, aunts and uncles, cousins, or any living relative.

Should no adult family member be willing or able to assume the role of surrogate decision-maker, many state statutes hold that any adult who has exhibited special care and concern for the patient, who is familiar with the patient's personal values, and who is reasonably available, may act as surrogate.[6-8]

In Mrs. H's case, her adult son and daughter have equal authority to assume surrogate decision-making authority. Where there is more than one potential surrogate of equal authority, state laws often require the surrogates to make reasonable efforts to reach a consensus. If both of Mrs. H's children were able to agree on treatment decisions, state statutes generally would allow them to act together as her surrogates.[9] Healthcare professionals should make an effort to identify and facilitate a consensus that would either permit joint decision-making between the siblings or help them agree on which of them should serve as sole surrogate.[10] From a practical standpoint, selecting a single surrogate may be more manageable for healthcare providers who might otherwise have to obtain consent from multiple surrogates before any treatment can be administered or withheld. Consultation with hospital ethics staff to help with assessing and resolving the reasons for the conflict is often beneficial if such services are available; some state laws specifically require consultation when family members cannot agree.[5,11,12]

Where agreement among siblings is not possible, state laws anticipating this sort of conflict vary in their approach. In cases in which no majority decision can be reached, no family resolution can be achieved, the ethics committee cannot mediate, or no other qualifying surrogate exists, court intervention in the form of guardianship or the intervention of a neutral third party as state laws allow may be required.[12,13]

However, some states grant healthcare providers the authority to choose the most qualified person among the conflicted siblings to act as a lone surrogate.[5] Healthcare providers can make this decision relatively quickly, but family members who are deprived of the ability to choose for themselves may disagree with the healthcare provider's selection. They may also object to the surrogate's decisions, which could escalate the family conflict and result in legal action, and healthcare providers may be reluctant to impose their decision on a disagreeing family. If state law allows, healthcare providers who choose to select a surrogate should consider factors such as the following before making their choice:

- how much regular contact with the patient the proposed surrogate has had prior to and during the incapacitating illness
- how much care and concern for the patient they have shown
- whether the surrogate appears better suited to make decisions in accordance with the known wishes or best interests of the patient
- whether the surrogate is available to visit the incapacitated parent during the illness to engage in face-to-face contact with healthcare providers at this critical time and to fully participate in the decision-making process.[5]

Articulating these decision-making factors to the family may help to address the concerns of dissatisfied family members. Here, the fact that Mrs. H lived with her daughter before her hospitalization might make the daughter a more appropriate candidate than her brother. Absent contradictory information, the daughter is arguably in a better position to know her mother's wishes because she spent time with her daily during her illness.

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Of course, before reaching such a determination, the healthcare provider or other designated person tasked with selecting the surrogate would be obligated to conduct a comprehensive assessment of all relevant factors. The fact that Mrs. H resided with her daughter may not alone be enough to tip the balance in the daughter's favor and the daughter's role as caregiver could in fact interfere with her ability to distinguish between her mother's preferences and her own, potentially making the son better suited to assume the surrogate role.

While some state statutes allow the healthcare provider to choose an appropriate surrogate where there is a conflict, others provide that a

simple majority of surrogates in the same class—meaning that they have equal authority—can make healthcare decisions, even if the minority objects. However, where there is an even divide or split decision between siblings as in Mrs. H's case and no majority can be reached, the entire class of disagreeing surrogates may be disqualified from assuming the role of surrogate decision-maker. Under those conditions, Mrs. H's two adult children would then both be disqualified from becoming surrogates for their mother.[14,15]

If both Mrs. H's daughter and son were disqualified because of conflict, it might seem to make sense to simply move down to the next category of potential surrogates on the priority list, such as grandchildren. However, where an entire class of surrogates is disqualified, in certain states the applicable law provides that everyone else with lower priority must also be disqualified.[8,15,16] This prevents more distant or remotely connected family members from overriding the wishes of a family member higher on the priority list—a situation that would be ripe for even greater family conflict and bitterness.[11,15]

Where no resolution can be achieved, court intervention in the form of a guardianship action may be required. Guardianship legal proceedings are potentially lengthy, costly, and complicated. The guardian, once appointed, may be granted authority to make medical decisions on the patient's behalf. In our case scenario, Mrs. H's children or a hospital staff member could petition for the appointment of a guardian for Mrs. H. The process of guardianship can be disruptive and traumatic for the family, who may be required to participate in intrusive legal proceedings that can strip them of any ability to participate in their loved one's medical care. It can also be traumatic for the patient herself, whose intimate medical decisions may now be made by a stranger.

To prevent often undesirable guardianship proceedings, healthcare providers can and should seek to facilitate agreement between potential surrogate decision-makers where possible. If this is achieved, state laws generally grant the designated surrogate(s) the authority to act in the manner the patient would if he or she were able.[17-19] If information about what the patient would want is not available, the surrogate is generally required to consider the patient's values (if they are known or can be determined) and to make decisions based on the surrogate's good faith belief as to what is in the patient's best interest. In considering the patient's values, the surrogate should reflect on the patient's personal, philosophical, religious, and ethical beliefs, as well as any reliable oral or written statements previously made by the patient, including statements made to family members, friends, healthcare providers, or religious leaders.[20,21]

In our case scenario, had Mrs. H prepared written advance directives, this dispute between her children might have been avoided. However, although Mrs. H did not memorialize her wishes in writing, she did articulate some preferences in "informal conversations" with her children. Therefore, any surrogate's decision about Mrs. H's treatment and care should first and foremost reflect any of the known wishes or preferences that she stated in those informal discussions.

Absent information about what Mrs. H would want, the surrogate would be required to make decisions that are in Mrs. H's best interests. State statutes may specify that practitioners need only comply with a surrogate's decisions to the extent they are within the bounds of responsible medical practice. If healthcare providers observe that a surrogate is not abiding by the patient's wishes, values, and best interests, they may decline to comply with the surrogate's decision and take certain actions to ensure proper documentation and resolution.[22] Moreover, if the primary healthcare provider is unable to comply with the surrogate's decision on professional grounds or because of moral, religious, or personal belief or conscience, state laws may relieve the healthcare provider of the requirement to comply with the surrogate's wishes. For example, physicians may not be required to remove the nasogastric feeding tube of a patient in a persistent vegetative state if doing so violates their personal or moral convictions.[23] In such cases, healthcare providers are generally required to take certain steps to notify the appropriate responsible parties and transfer the patient to another healthcare provider or facility.

As this article reflects, surrogate decision-maker laws do not seek to obstruct consensus-building and family agreement, or to enforce arbitrary rules when siblings disagree. Rather, in recognition of the personal nature of end-of-life decisions and their proper placement in the domain of healthcare professionals, the law seeks to mimic what a reasonable patient, healthcare professional, or family would do in any given situation and to ensure that a patient's rights to consent to or refuse treatment are honored and the patient's best

interests are upheld. Yet family members, healthcare professionals, and lawyers, even working together, cannot supplant the role of patients themselves, who are best able to make decisions about their own care. By having conversations about end-of-life preferences and documenting those preferences in advance directives, patients can preserve the right to decide for themselves the treatment they would prefer at the end of life. ■

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At Duquesne University School of Nursing, Grace Wankiiri Orsatti is an assistant professor of clinical legal education and Alison M. Colbert is an associate professor. Alison is also the coordinator of the *Nursing2020* Ethics in Action column.

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