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Authors

Smith, Alexander K
Lo, Bernard
Sudore, Rebecca

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When Previously Expressed Wishes Conflict With Best Interests

Alexander K. Smith, MD, MS, MPH; Bernard Lo, MD; Rebecca Sudore, MD

Rising use of advance directives has made surrogate decision making both easier and harder. In many cases, these directives help guide decision making for patients who have lost decision-making capacity. In some cases, however, directives may conflict with what physicians or surrogates view as what is in the patient's best interest. These conflicts can place substantial emotional and moral burdens on physicians and surrogates, and there is little practical guidance for how to address them. We propose a 5-question framework for untangling the conflict between advance directives and best interests of a patient with a surrogate decision maker: (1) Is the clinical situation an emergency? (2) In view of the patient's values and goals, how likely is it that the benefits of the intervention will outweigh the burdens? (3) How well does the advance directive fit the situation at hand? (4) How much leeway did the patient provide the surrogate for overriding the advance directive? (5) How well does the surrogate represent the patient's best interests? We use 2 clinical cases with contrasting outcomes to demonstrate how this framework can help resolve common dilemmas.

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The existence of advance directives very often aids decision making for surrogates of patients who have lost decision-making capacity. However, these directives sometimes conflict with what physicians or surrogates view as the patient's best interest. We propose herein a 5-question framework for resolving this conflict and illustrate its use through 2 hypothetical case reports.

CASE 1

Dr Green, a physician on call for a nursing home is notified that Ms Stevens, an 85-year-old woman with moderate Alzheimer dementia and aortic stenosis, has fallen. The patient's right leg is shortened, externally

rotated, and cannot bear weight. The physician strongly suspects a hip fracture. Prior to the fall, Ms Stevens required personal assistance with dressing and bathing. Though she often did not recognize family, Ms Stevens enjoyed interacting with others and walking in the nursing home garden with a walker. Currently, her pain is well controlled with an increased dose of the oxycodone she had been prescribed for osteoarthritis. When Ms Stevens's daughter, her decision maker, is contacted by telephone, she reports that years ago, when still competent, her mother expressed strong preferences against going to the hospital if she were seriously ill and her Alzheimer had progressed. Ms Stevens stated, "When my time comes, just keep me comfortable; don't send me to the hospital." An advance directive signed by Ms Stevens when competent states a preference for "Comfort Measures Only" and asks that she not be transferred to the hospital.

Author Affiliations: Divisions of Geriatrics (Drs Smith and Sudore) and General Internal Medicine (Dr Lo), Department of Medicine, University of California, San Francisco; San Francisco Veterans Affairs Medical Center, San Francisco (Drs Smith and Sudore); and the Greenwall Foundation, New York, New York (Dr Lo).

1. Is the clinical situation an emergency that allows no time for deliberation? Is there a clear code status order?	Emergency and DNAR or specific code status order present	Nonemergency or emergency but no specific code status order*
2. In view of the patient's values and goals, how likely is it that the benefits of the intervention will outweigh the burdens?	Benefits weak or unlikely; burdens strong or likely	Benefits strong and likely; burdens weak and unlikely
3. How well does the advance directive fit the situation at hand?	Fits well	Poor fit
4. How much leeway did the patient provide the surrogate for overriding the advance directive?	No leeway	Leeway
5. How well does the surrogate represent the patient's best interests?	Poorly, or surrogate represents own interest	Represents patient's best interest well
Favors previously expressed preferences		Favors current best interest




Figure. A framework for weighing previously expressed preferences vs best interests. DNAR indicates do not attempt to resuscitate. *In the absence of an unambiguous order prohibiting life-sustaining treatment, in an emergency, the best interests of the patient are to prolong life until there is time for deliberation.

Dr Green believes that surgery, such as a pinning procedure, while presenting operative risk and requiring extensive rehabilitation, might provide better long-term pain relief than hospice care as well as the chance to maintain some mobility, such as walking in the garden. Dr Green and the surrogate agree on a goal of comfort but are not sure what plan is most likely to maximize the patient's comfort and quality of life.

CONFLICTS CREATED BY UNFORESEEN OCCURRENCES

When patients lack capacity for decisionmaking, physicians and surrogate decision makers often have to address situations that were never previously discussed. They must also balance potentially countervailing ethical guidelines: respecting the patient's previously expressed values and preferences and acting in her best medical interests in the present moment. Advance care planning can make these decisions easier. However, while advance directives have focused primarily on written forms documenting patient preferences about specific life-prolonging treatments ahead of time,¹ many clinical decisions for patients who have lost decision-making capacity arise in unforeseen circumstances. De-

spite our best efforts, no prior discussion or documentation can anticipate all scenarios.² And sometimes, advance directives, whether formal legal documents or, more commonly, conversations, can paradoxically make clinical decisions for patients who lack capacity both easier and harder.^{3,4}

Confusion and ambivalence about how to make the best decision can place a substantial emotional and moral burden on surrogates and physicians. One-third of surrogates experience negative emotional effects after making a decision for an incapacitated patient, with negative effects sometimes lasting for years.⁵ Ethicists and a Presidential bioethics commission have argued for an increased role of best interests standards in such decisions.^{6,7} Additional concepts, such as authenticity and substituted interests, also have been proposed to guide such decisions.^{7,8} However, clinicians lack practical guidance on how to consider the current best interests of a patient who lacks decision-making capacity and how to weigh them against her previously stated preferences in a particular clinical situation. Ethics consultants may also be at a loss as to how to weigh these competing ethical considerations for a specific patient and situation, and this may ex-

plain the concerning variation between recommendations.⁹ We present herein a practical conceptual framework to address this need.

AN ETHICAL FRAMEWORK TO WEIGH PREVIOUSLY EXPRESSED PREFERENCES VS BEST INTERESTS

In our framework of 5 factors (**Figure**), the importance of each factor will vary for each patient and situation. Herein, we analyze how each factor relates to the case presented. The framework is not meant to reduce complex decisions to a simplistic algorithm but rather to ensure that key issues are considered.

This framework relies on conversations between the physician and the surrogate to ascertain the patient's values and thinking during advance care planning, and as such it is most appropriate for cases where a surrogate is available. If a surrogate is not available, factors beyond the scope of this article, such as the clarity of previously expressed wishes or the presence of an appointed conservator, will need to be considered, and an ethics committee or consultant may need to be involved.

First, is the clinical situation an emergency that allows no time for deliberation? If so, as in a cardiopulmonary arrest, clinicians should immediately determine if the patient's previously expressed wishes have been translated into actionable orders, such as a *do not attempt to resuscitate* (DNAR) order. The *physician orders for life-sustaining treatment* (POLST) document, now legally recognized in 12 states including California and New York,¹⁰ was designed to provide physician orders to direct emergency responders, particularly for nursing home residents. This brightly colored form may contain DNAR orders that are valid across all health care settings. In the absence of a clear DNAR order or immediate, clear, and unambiguous input from the legally recognized surrogate decision maker, however, clinicians should initiate cardiopulmonary resuscitation (CPR). In contrast to orders such as the POLST or a DNAR, some advance directives or living wills may

contain vague language that requires time for interpretation. For example, an advance directive stating that life-sustaining measures are not desired in the case of a terminal illness does not imply that a patient would not want attempted resuscitation in all circumstances, and interpretations of the word “terminal” will vary. However, most clinical situations, such as with Ms Stevens, allow at least some time for deliberation and discussion.

Second, overriding previously expressed preferences should be considered in light of the benefits and burdens of the proposed intervention and its alternatives. The physician needs to ascertain key medical information and advice from specialists, discuss with the surrogate the clinical situation in terms she can understand, and invite questions. In this case, to consider overriding Ms Stevens’s wish not to return to the hospital, the benefits and burdens of hospital transfer and surgery need to be evaluated. On the one hand, the risks of surgery are increased owing to Ms Stevens’s age, aortic stenosis, and dementia. On the other hand, surgical options are likely to give her the greatest chance of resuming her walks in the garden, decrease pain after the postoperative period, and later allow daily care such as bathing and toileting without pain. To clarify the medical benefits and risks of surgery, Dr Green might ask a surgical consultant “What is the probability of restoration of function for Ms Stevens following surgery? What is her likelihood of perioperative death?” With this information, the physician and daughter can be guided by Ms Stevens’s underlying goals and values. For instance, if the possibility of restoration of function is low or if the patient’s aortic stenosis is critical, the burdens of surgery may outweigh the benefits for Ms Stevens. However, for some patients, a substantial risk of death is acceptable in light of the potential to maintain quality of life.

Third, the physician and surrogate must consider how well the previously expressed wishes fit the situation at hand and how clearly they were expressed. Dr Green should explore with the surrogate the values and goals behind Ms Stevens’s and the

surrogate’s preference for avoiding the hospital. Honoring Ms Stevens’s underlying values and goals may paradoxically lead to decisions that conflict with her previously specified treatment preferences. Yet respecting her values and goals may be more ethically defensible than following literally previously stated preferences in an advance directive that were meant to apply to different circumstances.^{2,8,11} In this case, Ms Stevens decided to stay out of the hospital after watching a close friend with severe Alzheimer dementia develop a bloodstream infection and spend a week on a ventilator before dying. Ms Stevens was clear that in such circumstances, being comfortable and avoiding a long stay in the intensive care unit (ICU) before dying was her top priority. Ms Stevens had never considered the possibility of a hip fracture. Dr Green can point out that after hip surgery, Ms Stevens’s hospitalization and ICU stay would likely be brief, in contrast to her friend’s experience. Dr Green could suggest that rather than following the exact words on her mother’s advance directive that concerned radically different circumstances, hospitalization and surgery may honor Ms Stevens’s underlying goal to remain comfortable and give her the best opportunity to maintain mobility. Should the surgery not turn out as hoped, the plan of care could be reassessed. If Ms Stevens were suffering, comfort care could be offered while she was allowed to die peacefully.

Fourth, the degree of leeway granted by the patient to a surrogate to override her previously stated wishes may help guide decisions. Because many patients want their loved ones to have some flexibility to adapt decisions to unforeseen circumstances,¹²⁻¹⁴ physicians should discuss leeway with patients during advance care planning.² In one study, 39% of patients would grant no leeway, while 31% would grant complete leeway.¹⁵ Currently, only a few advance directive forms capture patient preferences for leeway.¹⁶⁻¹⁸ Because all future clinical circumstances cannot be anticipated, it is desirable for patients to choose a surrogate they can trust to interpret their values and goals for clinical situations that had not previously

been considered, such as in the case reported by McMahan et al.¹⁹ However, the present article goes beyond the work of McMahan et al¹⁹ to suggest how prior decisions about leeway should be taken into account when a clinical decision needs to be made for a patient who has lost decision-making capacity.

To be sure, allowing leeway carries ethical risks as well as benefits. Advance directives were created to allow patients a form of extended autonomy in states of future mental incapacity. Leeway might be seen as an erosion of that autonomy and as unwarranted paternalism for a patient who cannot object. However, if a patient grants her or his surrogate leeway ahead of time, this decision can also be considered an extension of autonomy that should be honored.

Knowing the amount of leeway a patient has granted a surrogate can be very helpful. Consider if Ms Stevens had told her daughter “Don’t send me to the hospital, under any circumstances. I’ve been there enough, and I never want to go back. Please, please don’t do this, no matter what is happening to me.” The physician and daughter, guided by this preference, may decide to start a hospice approach in the nursing home. However, suppose Ms Stevens had allowed her daughter leeway by saying “I don’t want to go back to the hospital and die unconscious on a breathing machine, like my friend. But I trust you to make the right decision when the time comes.” In this situation, pursuing hip surgery would be consistent with the patient’s values. Having leeway, the daughter would not feel bound by the advance directive to withhold treatments that she believed to be in her mother’s best interest.

Unfortunately, until leeway is routinely incorporated into advance care planning conversations and advance directive forms, most patients will not have discussed leeway. Surrogates often cannot accurately describe how much leeway patients would want to grant surrogates if they lacked decision-making capacity.^{12,19} The absence of documented preferences for leeway does not necessarily close the door to overriding previously expressed

preferences if it is in the patient's best interest to do so. However, the reasons for doing so need to be stronger than if leeway had been previously granted. What is known about the patient's previous values and goals needs to provide a compelling reason to modify specific written directives. For Ms Stevens, a reasonable case can be made that surgery is in her best interest and is consistent with her goal of being comfortable and with her daughter's view that Ms Stevens would want her quality of life maximized by maintaining mobility under these circumstances.⁸

Finally, it is important to consider how well the surrogate is representing the patient's best interest. Ms Stevens's daughter might regard surgery and rehabilitation as much more burdensome than the clinician does³ because her mother often objects to routine nursing care, complains that her freedom is being abused, and calls the staff names.^{20,21} In some cases, the surrogates may be so overwhelmed by their own emotional needs that they may act in their own interests rather than those of the patient. Consider if the daughter had said, "I just can't bear losing my mother. I can't let her go." In this case, rather than trying to "convince" the daughter of what is in the patient's best interest, Dr Green would need to first address the surrogate's angst and anticipatory grief.²² Only after this acknowledgment would clinician then discuss how the patient's mother would want to be treated under her current circumstances. These 2 discussions might not be able to be completed in 1 conversation because the surrogate may need time to process emotions and all the clinical information.

In rare cases, the surrogate may have a strong conflict of interest, such as a stated desire to receive the patient's pension or an inheritance. In these cases the clinician might seek an ethics consultation or contact adult protective services, and depending on the situation, may need to seek a court order to authorize or withdraw treatments. Having mixed motivations alone does not warrant a call to adult protective services, however. There needs to be some evidence of biased decision making, such as not ac-

knowledging countervailing considerations or framing decision solely in terms of what is best for surrogate, not the patient.

There are helpful suggestions for words that physicians would use in these conversations.^{1,8,23} Physicians should use open-ended questions and empathic comments that respond to the emotional stress surrogates experience. Doctors should help surrogates deliberate by summarizing their statements about the patient's values and linking those values to the decisions at hand.²⁴ Furthermore, physicians should offer to make a recommendation based on the patient's values. About 40% of surrogates, however, prefer not to receive a recommendation.²⁵

CASE 2

Our proposed framework can also be used for patients who are "full code." For example, Mr Jones is a 42-year-old man with aggressive, widely metastatic lung cancer resistant to chemotherapy and worsening multi-organ failure. He is intubated and unconscious in the ICU and being treated with high-dose vasopressors. His advance directive states that he wants "life-sustaining treatments, such as CPR and mechanical ventilation in the case of serious or terminal illness." However, the directive also states that his wife can have leeway in medical decision making. His wife is torn between knowing what she feels to be in the patient's best interest now and his prior stated wishes, but she knows he does not want to suffer.

The Figure presents the framework of considerations the physician should consider. First, this situation is urgent but not an emergency with no time for deliberation. The physician has time to talk with Mrs Jones about the values and experiences that led her husband to express his preference for life-sustaining treatment under all circumstances. In this case, the patient wanted to stay alive to spend as much time with his wife and young children as possible before he died. Second, the benefits of continued ICU care are limited; Mrs Jones and the medical team agree that he is dying despite all indicated treat-

ments. He has little prospect of recovering enough to interact with his family. Alternatively, in combination with appropriate palliative care, discontinuing ventilator and vasopressor support will lead to a rapid but comfortable death.

Third, while one could argue that Mr Jones's advance directive regarding "serious or terminal illness" literally applies to the situation at hand, the clinician's conversations with the patient's wife reveal the underlying reasons behind this check-box determination—to spend as much time with his family as possible. In this regard, the underlying reasons for the determination on the advance directive do not fit the situation at hand because all appropriate treatments have been offered, and the patient is dying despite a trial of appropriate life-sustaining treatment. His goal to spend time with his family cannot be honored. In such situations, it may be helpful to offer a time-limited trial of intervention. If after a predetermined period, the patient's underlying goals cannot be achieved, or the patient is imminently dying or suffering, it may be easier for family withdraw the intervention feeling that they at least gave the patient a chance.

Fourth, because Mrs Jones was granted leeway, the doctors can remind her that her role is to use what she knows about her husband, to take his prior stated wishes into account, to weigh the physicians' recommendations, and to consider what she thinks is best for her husband at this time. She can be reassured that she does not have to literally follow his previous statements that didn't envisage his current deteriorating situation. The decision is difficult for Mrs Jones, but she is comforted by the fact that she can decide based on what she thinks is her husband's best interest. Fifth, during these discussions Mrs Jones is competent and caring.

If the facts of the case differed, the Figure might suggest a different conclusion. If Mr Jones's request for life-sustaining treatments resulted from a deeply held and longstanding religious belief, and no leeway had been granted in decision making, the balance would tip in favor of adhering to the patient's previously ex-

pressed preferences and maintaining the current clinical course. Emotional and spiritual support should be offered to Mrs Jones and family in conjunction with ongoing discussions.

CONCLUSIONS

Conflicts between a patient's previously expressed preferences and what is thought to be in his or her current best interest often create confusion, ambivalence, and substantial emotional and moral burden for surrogates and physicians. It is often difficult to know how best to proceed. While there are no absolute right answers that apply to all patients, we propose a new 5-question framework and shown how it can be applied in specific cases to help clinicians and surrogates think through the relevant issues and come to an ethically appropriate decision. Future research should test whether this approach is helpful in practice and whether it needs to be refined.

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Correspondence: Alexander K. Smith, MD, MS, MPH, University of California, San Francisco, 4150 Clement St (181G), San Francisco, CA 94941 (aksmith@ucsf.edu).

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