Comments on the Case of Mrs. L.

Steven Levenson, MD

Primary responsibility for managing ethics issues in nursing home residents and patients falls to the attending physician in conjunction with the patients, families, and staff. The medical director is responsible for (a) helping establish and implement appropriate care systems and for (b) helping ensure that physicians and nursing facility staff apply appropriate care processes and practices to the care of individual residents and patients. Therefore, these comments on the cases in this series will consider (a) how the medical director can help nursing facilities develop and implement relevant systems and processes to manage ethics issues in their residents and patients; (b) the attending physician’s role in helping a facility manage individual cases; and (c) potential medical director interventions in individual cases to help the attending physician and facility fulfill their responsibilities more effectively.

OVERVIEW OF ISSUES REPRESENTED BY THIS CASE

This case concerns Mrs. L., a 97-year-old nursing home resident with advanced dementia and multiple comorbidities. The family was asking the facility to limit the scope and extent of treatment, with the expectation that she would die. The case is complicated because some of her care providers did not believe that the patient was suffering or experiencing excess emotional distress and disagreed with the request for palliative care, withholding supplemental oxygen and medications, and providing medications that could have hastened this patient’s death.

Several issues relevant to medical directors are illustrated. Ethics decision making involves several distinct steps (Table 1).1 Medical directors can be involved successfully in several ways: (1) ensuring that the process is followed effectively, in order to optimize decision making capacity in individual cases, (2) intervening effectively in case of disagreements or need for clarification, and (3) evaluating the quality of the facility’s decision making by evaluating the performance of those steps.

ESTABLISHING CONDITION AND PROGNOSIS

To make effective ethics decisions, patients and families need information about medical condition and prognosis.2 This case illustrates several related issues.

First, how did the staff and attending physician draw conclusions about this patient’s prognosis? Agreeing on patient prognosis facilitates agreement on appropriate treatment options. Generally, different starting premises are likely to lead to different conclusions.

It appears that the family did not “trust” the current attending physician. But the concept of “mistrust”—like “miscommunication” and “personality conflict”—should be analyzed procedurally. The medical director should examine the factual and conceptual basis for differences and ensure that the physician followed the appropriate processes before drawing conclusions.

In this case, the family and the staff were interpreting the patient’s behaviors and condition differently. As a clinician, the medical director should be a resource and referee in case of disputes; for example, to speak with the parties and try to ascertain the basis for their disagreements. The medical director should ask the attending physician and staff about the grounds for their conclusions, and may point out things that they failed to consider.

Also, when a situation arises as in this case, in which a patient has qualified his or her wishes, the medical director should help review the criteria that are used to establish that the qualifying condition exists. For instance, in this case there was a disagreement about whether the patient was truly “terminal.” That was relevant because she had used the term in her advance directives.

In this case, it is unclear whether and how well the physician addressed the patient’s condition and prognosis with the family. Sometimes, families do not wish to accept a physician’s realistic appraisal or do not understand the significance of what they are told. But that does not appear to apply in this case.

Using basic management techniques, the medical director should ask the physician why he or she did or did not do certain things before reaching a conclusion. There may be various answers, including fear of negative consequences (“I didn’t want to be sued”), not knowing the evidence, not agreeing on the significance of various signs and symptoms, and so on.

For instance, did this attending physician evaluate all relevant factors influencing this patient’s condition, and consider the evidence in the medical literature regarding likely survival of a 97-year-old with progressive dementia, a recent acute illness, and a subsequent decline in condition? Is the attending physician focusing on his or her own values as a basis for judging others’ requests? Or, does the physician believe that people should not refuse artificial nutrition and hydration?

IDENTIFYING PATIENT WISHES

The medical director should help the facility ensure that patient wishes are determined effectively.3 This may be done by consulting a capable patient, identifying the previously expressed or documented wishes of an incapacitated individ-
Table 1. Steps in Making Ethics Decisions

<table>
<thead>
<tr>
<th>Step</th>
</tr>
</thead>
<tbody>
<tr>
<td>Establish medical condition and prognosis</td>
</tr>
<tr>
<td>Identify patient values and wishes</td>
</tr>
<tr>
<td>Determine decision-making capacity</td>
</tr>
<tr>
<td>Identify primary decision maker</td>
</tr>
<tr>
<td>Identify treatment options</td>
</tr>
<tr>
<td>Present options and obtain decisions</td>
</tr>
<tr>
<td>Evaluate results of interventions and modify accordingly</td>
</tr>
</tbody>
</table>

The patient’s wishes were expressed primarily through her daughter. Generally, the primary goal was comfort over life prolongation. The daughter had previously approved some limited medical interventions and had authorized orders for “do-not-hospitalize” and no diagnostic tests. As recently as a month before the current episode, the daughter had allowed blood work and oral antibiotics for an acute illness.

The instructions in many advance directives are general. When situations requiring substitute decision making arise later, these instructions may not offer enough clear or specific guidance. In this case, the patient's instructions were relatively specific. She apparently rejected life-sustaining measures under several circumstances, including terminal illness and an “end-stage” condition (a situation of progressive decline with no significant likelihood of regaining it).

Subsequent disagreements between the family and the staff appeared to hinge not only on the interpretation of her current condition but also on the implications of her advance directive. When situations arise for which advance directives are not explicit, it is appropriate to consider the general tone of a patient’s wishes. In this case, the patient was inclined towards rejecting life-sustaining treatments that were unlikely to improve her overall status and quality of life. The medical director should help the attending physician and facility staff apply a patient’s general wishes to specific circumstances.

**ESTABLISHING DECISION-MAKING CAPACITY**

The medical director should help ensure that decision making capacity is determined appropriately, and that someone with partial decision-making capacity is allowed to participate in considering treatment options to the extent of their capacity. Identifying decision-making capacity is particularly challenging when capacity fluctuates or may be adequate for some situations but not for others. In such cases, participation may need to be identified for each situation that arises.

This patient lacked significant decision-making capacity to provide any further useful input into the discussion. However, she had expressed her wishes previously when she still had decision-making capacity.

**IDENTIFYING PRIMARY DECISION MAKER**

The medical director should help ensure that the appropriate substitute decision maker is selected and consulted, in accordance with state laws. Most states give appointed substitute decision makers considerable latitude to make decisions for incapacitated individuals, even when a patient's written wishes may not be explicit. State laws may be more restrictive concerning unappointed or default substitute decision makers.

Often, family members disagree about what should be done. They may contest the requests of another family member or even threaten the staff or physician for trying to accommodate another family member’s requests. In such cases, the medical director may help the facility clarify the rights of the primary decision maker and try to reconcile disparate opinions. Most state laws about substitute decision making specify a sequence of decision-making authority and contain some instructions about the level of agreement required before the provider can institute requests to withhold or withdraw treatments.

In this case, the patient had appointed her daughter as the substitute decision maker. Additionally, the grandchildren agreed substantially with the daughter’s conclusions and requests for limited care. Therefore, the authority of the primary decision maker was clear, and there was no significant conflict among other family members.

The medical director can help the facility influence a substitute decision maker to focus on the resident’s “best interests” in making treatment requests. There is no evidence in this case to suggest that the daughter stood to gain financially or otherwise from her decisions. If she had, greater concern about her request may have been warranted. But, it appeared that the daughter was trying to focus on this patient’s best interests based on the patient’s expressed wishes and values.

**PRESENTING AND OBTAINING DECISIONS ABOUT TREATMENT OPTIONS**

Presenting treatment options should flow from the appropriate application of the preceding steps. The medical director should help ensure that the attending physician and staff do not reach conclusions prematurely, and that they offer relevant treatment options so that a substitute decision maker can understand the underlying rationale.

This case was referred to the facility ethics committee because Mrs. L.’s treatment team did not agree with the daughter’s request for palliative measures only, including no artificial nutrition and hydration. Additionally, they disapproved of the daughter’s request that the physician authorize significant doses of morphine to try to hasten her death.

In this individual, artificial nutrition by feeding tube would have been highly unlikely to materially prolong her life and would probably have caused significant unpleasant complications. Offering her food and fluids as tolerated seemed to be a reasonable compromise.
The facility staff and physician appropriately rejected the daughter’s request to provide a high dose of morphine. In this situation, limited treatment in a 97-year old medically unstable patient was enough to allow her to die quickly. It is almost always possible to find a legally and ethically acceptable approach to allowing an elderly patient to die comfortably without having to cross the line into the illegal and ethically sticky territory of euthanasia.

The issue of whether it is appropriate to withhold a patient’s long-term medications can be controversial in many situations. Some physicians and nursing home staff are adamantly opposed to stopping medications even in clear situations of terminal illness. Occasionally, medications can be an effective palliative measure; for instance, giving a diuretic may allow someone with end-stage heart disease to die without struggling with pulmonary edema.

But, adverse drug reactions are a major problem in the institutionalized elderly. Many medications given to nursing home residents are either irrelevant or excessive. Ironically, some individuals considered to be in irreversible decline improve significantly—at least temporarily—when multiple medications are tapered or stopped. So, there were several good reasons in this case to stop the patient’s medications, including the potential for a more comfortable death by reducing possible adverse drug reactions.

SUMMARIZING THE ISSUES

Many approaches to managing ethical issues in long-term care emphasize the philosophical, social, and cultural aspects of ethics decision making. The medical director should certainly consider these issues. But the medical director should also emphasize the management and procedural aspects of ethics decision making.7–11 While often overlooked, the successful application of basic management principles and clinical principles can do much to enhance good decision making in nursing homes.

For example, the alleged lack of awareness of this patient’s advance directives in this case—which some of the ethics consultants identified as a “communication” problem—should be considered by the medical director as a procedural issue. Why did those taking care of this patient not know of her wishes? Were the documents not available in the chart? Had they been thinned? Or, were they not read? Or, were they read but interpreted in different ways by different individuals? Similarly, the medical director can help by analyzing issues of “trust” in terms of possible procedural shortcomings on the part of the attending physician, facility staff, and family.

Additionally, very few nursing homes around the country have access to bioethicists. So, they are unlikely to engage in extensive discussions of personhood or the nature of suffering. But the medical director can help staff and physicians at least to consider and discuss openly the criteria they are each using to draw conclusions, and help them identify and accommodate the patient’s and family’s perspectives rather than imposing their own viewpoints.

REFERENCES