

*Possible Limits to the Surrogate's Role:
When a Patient Lacks Decisionmaking
Capacity, Is the Surrogate's Role Absolute?*

PAUL B. HOFMANN, GUEST EDITOR

Question

Our ethics committee is revising the organization's policy on forgoing life-sustaining treatment. The current policy now includes the statement, "When life-sustaining treatment is forgone, supportive care will be provided to relieve pain and ensure the patient's comfort, unless the patient or surrogate refuses those measures." Is it reasonable, however, for the surrogate to have the authority to refuse consent for pain medication and/or other supportive care?

Commentary

Paul B. Hofmann

Like some ethical dilemmas, this question has an obvious answer that may not be right. On first reflection, it seems entirely unreasonable and inappropriate to expect staff members to withhold supportive care. Legally, a designated surrogate has the authority to refuse pain medication on the patient's behalf, but is it ethically defensible? A patient lacking decisionmaking capacity is crying out in pain; can we really imagine just closing the door? What do we say to other patients, visitors, and staff members, such as physicians, nurses, housekeepers, and dietary workers, who might hear the patient? Do we place a sign on the door, one noting that the surrogate has refused, on behalf

of the patient, to authorize the administration of pain medication and that the hospital or nursing home must comply with the surrogate's decision?

Important Considerations

Before suggesting some options for addressing this dilemma, we should acknowledge that there are legitimate differences in treatment preferences among patients, their families, and staff members. Healthcare professionals often unconsciously assume that the patient shares their values and, by extension, so do the patient's family and surrogate decisionmakers. Innumerable studies have found, however, that values and attitudes about healthcare are highly variable, particularly among different cultures, so we should remind ourselves that, although the

rationale for pain relief may be self-evident to us, perhaps others do not share it.

Autonomy is a widely accepted ethical principle. Respect for the patient's right of self-determination regarding treatment and nontreatment options does not mean that we support the principle only when the decision of a patient or patient surrogate agrees with our own personal preference, regardless of how compelling it may be to us.

In this case, let us assume that the patient (a) is terminally ill, (b) recently consented to forgo life-sustaining treatment, (c) now lacks decisionmaking capacity, (d) is experiencing severe pain, and (e) has clearly designated someone to make decisions on her behalf. Let us also assume that her physician has recommended that morphine be given as an analgesic, but her surrogate has refused to give permission because it may depress the patient's respirations and make the patient less clear minded should she recover her decisionmaking capacity. As a second scenario, the same situation exists, but the surrogate has withheld consent for cultural reasons that are difficult to discern and understand. For a final scenario, the patient is a child, and both parents are unwilling to consent because they object to any intervention that might hasten death.

Possible Options

It is impractical to anticipate every reason or set of circumstances leading to disagreement between a patient's surrogate and healthcare professionals. Therefore, an organization's policy on forgoing life-sustaining treatment could contain a section, "Consultation in the Event of a Disagreement," that provides generic guidance. Among the subheadings of this section might be brief paragraphs such as the following:

- a. Role of the Ethics Committee. In the event of an unresolved disagreement between the patient, the patient's family, the designated decision maker(s), or members of the healthcare team over the decision of whether to forgo life sustaining treatment or supportive care, consultation with the ethics committee is recommended.
- b. Role of the Risk Management and Legal Services. If consultation with the ethics committee does not resolve the conflict, then it shall be determined by the physician in consultation with the risk management department, which will consult with legal counsel, whether the case shall be brought to court.¹

This approach will not be appropriate for every institution. Some organizations have ethics consultation services rather than ethics committees. In either case, consultation could be stipulated as required instead of being optional. Other organizations may not specify a role for the risk manager or risk management department. Similarly, the use of legal counsel and the judicial system can vary from one institution to another.

Forgoing life-sustaining treatment is difficult for healthcare professionals, as well as for patients and their families. By recognizing the surrogate's pivotal role when the patient lacks decisionmaking capacity, anticipating areas of disagreement, and developing options for resolution, the organization will demonstrate sensitivity to the needs and expectations of all participants in decisions near the end of life.

Notes

1. Rubin SB. *Template Foregoing Life Sustaining Treatment Policy*. Berkeley, Calif.: The Ethics Practice; 2002.

Commentary

Susan B. Rubin

Whether surrogate decisionmakers have the authority to refuse pain and symptom management measures on behalf of incapacitated patients is a particularly timely question to ask in this era of growing commitment to ensuring appropriate pain and symptom management measures for all patients.

Evidence of the current trend toward aggressive pain and symptom management is abundant: Clinicians are told that pain is the fifth vital sign. Accrediting bodies are insisting that pain-management standards be met. Palliative care units and services are opening in hospitals across the country. Palliative care certification programs are inundated with inquiries of interest. One of the unspoken assumptions behind these developments is that all patients want their pain to be carefully assessed and maximally addressed and that we need to work harder to respond to this pressing need. So, when we confront a patient or surrogate decisionmaker who is disinclined to accept the state-of-the-art pain and symptom management techniques, it can give us pause.

It is far too easy to mistakenly assume in our clinical practices and policies that all patients desire whatever state-of-the-art pain and symptom management techniques we have to offer. But in point of fact, as Paul Hofmann so astutely notes, the desire for aggressive pain and symptom management is far from universal. There may well be patients who have a different relationship toward pain and suffering. They are patients for whom pain is not the thing to be most avoided, for whom there are worse things than being in pain, or for whom suffering

may hold particular meaning and/or the promise of redemption. Although they may be in the minority, they are patients who remind us that, on a fundamental level, whether it is appropriate to treat pain and symptoms is ultimately an open question that turns inevitably on one's values, goals, and perspective. There are certainly patients who want nothing more than to be kept out of pain, and for these patients, bringing the best of what pain management has to offer is certainly appropriate. Yet there are other patients who, if given the choice of remaining conscious, alert, and present in the dying process or being sedated and pain free, would clearly choose the former.

Is one choice better or worse than the other, more or less right? We would be hard pressed to make that case. Let us consider, for example, a dying Buddhist patient who consistently said that her goal was to remain as alert as possible, despite her pain. If she reported that the pain meds made her thought process cloudy and interfered with her ability to engage thoughtfully with her children in her final hours, would we medicate her against her will? Certainly not. As long as she was making a fully informed choice and had the capacity to do so, one would hope that we would honor her wishes and not impose treatment on her to facilitate our own comfort.

Why then would we consider overriding the same refusal of medications made by her surrogate decisionmaker on her behalf once she became incapacitated? Part of the confusion at the heart of this question stems from a confusion about what surrogate decisionmakers are doing when they make decisions on behalf of incapacitated patients. In their capacity as surrogates, such individuals are bound to

make decisions based first on their knowledge of the patient's wishes, values, goals, and priorities. We call this substituted judgment. They are substituting their voice for the patient's, or more literally, they are using their voice to give voice to the patient who can no longer speak for himself. Only if nothing is known about the patient's preferences are surrogate decisionmakers to make a decision based on what they think would be best for the patient. We call this best interest. But even in a best-interest context, the surrogate is still bound to take into account the kind of person the patient was, weighing the potential benefits and burdens of potential treatments from the perspective of the patient.

There might be reason to probe a little further with a surrogate decisionmaker who is refusing pain medications on behalf of a patient. We would want to be clear why she thought the patient would refuse pain medications, or why it would be best for the patient to not be medicated. We would certainly want to have protections in place to assure that the patient was being well cared for and well thought of. But we shouldn't reject out of hand the request of a surrogate decisionmaker to forgo pain medications just by virtue of his standing as a surrogate. In other words, unless there are exceptional circumstances, the surrogate should be presumed to have the same rights and authorities that the patient would have if the patient had decision-making capacity. Refusal of pain medications should be considered the same as refusal of any other medications.

What, then, can a treating team do if confronted with this kind of treatment refusal? Paul Hofmann asks whether we can really just close the door to a patient crying out in pain. Surely, that is not the only option. It is necessary to understand that what we have to offer in pain and symptom

management is not all or nothing; the choice to be made is not an either/or proposition—that is, either we give you meds and are therefore present and supportive, or we essentially abandon you and leave you moaning behind closed doors. There are numerous other ways that we can and should remain present with patients while still honoring their rights to refuse medications. We can sit quietly at their side, stroke their skin, play soft music, breathe deeply with them, keep the lights low. Most of all, we can ask them what they need us to do and what would be helpful to them. Too often, care providers abandon patients who make treatment choices that are difficult to understand or choices with which they disagree. The abandonment can be as overt as discharging a patient from one's practice or as subtle as closing the door or failing to round as regularly on the patient. Tending to our own feelings about the patient's choices is one way to ensure that one can be more genuinely present, no matter what the patient decides.

Sometimes, though, a patient or surrogate might make a decision to forgo pain medications that not only would we not choose for ourselves but that makes us acutely uncomfortable or that we think is wrong. Institutions need to create opportunities for such stark differences of opinions to be voiced, taken account of, and discussed. In my practice as an ethicist, I always encourage the establishment of mechanisms to get such conversations going within the team and between the team and the patient or surrogate and other involved parties. Often, concerns surface in the regular ethics rounds I conduct. Care conferences can be another good way of facilitating conversation between the stakeholders. In the event that a disagreement persists, I am a strong proponent of ethics consultation (see Paul Hofmann's reference to

The *Ethics Practice* template policy text on “Consultation in the Event of a Disagreement”).

Whatever the level of concern, when it comes to responding to the surrogate decisionmaker who is refusing pain medications on behalf of the incapacitated patient, we need to remember that our ideas about pain and suffering,

even our ideas about what makes for a good or bad death, are fundamentally influenced by our values, goals, and priorities. Our growing presumption in favor of pain relief, although wholly appropriate for most patients, needs to be tempered with the recognition that relief from pain is neither the only goal nor a universal goal.

Commentary

Robert V. Brody

All treatments, even those labeled as supportive, have burdens as well as benefits. Patients and their surrogates have the right to finally decide whether the offered treatment’s cost-benefit calculation is acceptable.

The issue is a little different if it is the patient refusing or a surrogate refusing for a patient. In general, a competent, informed adult patient has the right to refuse any offered treatment. So, a patient’s “no” is, in general, binding. Then, the clinical challenge is to

come up with another supportive measure that would be acceptable. The surrogate, on the other hand, has a duty to decide consistent with the patient’s wishes, not her own, or, in the absence of evidence of the patient’s wishes, consistent with the patient’s best interest. We might try to find another supportive measure, but a “no” from a surrogate must be backed by evidence of the patient’s wishes to not receive supportive care or by an argument that being supported would not be in the patient’s best interest. The first would be hard to imagine; the second impossible.

Commentary

Ben A. Rich

Background on Refusal of Treatment

The “right to die” litigation that dominated American healthcare jurisprudence in the last three decades of the twentieth century, culminating in the Supreme Court decisions in *Cruzan*,¹ *Glucksberg*,² and *Quill*,³ confirmed the almost unqualified right of competent patients to refuse any and all medical

interventions, for any reason or no reason, even when those interventions may be absolutely essential to preserve life. Although the courts acknowledged certain “countervailing” interests of the states that must be taken into account when patients directly, or indirectly through designated surrogates, refuse “medically indicated” treatment, only rarely have those interests been deemed of sufficient weight to override the clearly articulated wishes of patients.⁴

The hospital policy considered in this installment of “Ethics Committees

at Work" constitutes an effort to institutionalize this well-recognized constitutional, common law and, in some states, statutory right to refuse treatment. Treatment characterized as "life-sustaining" usually refers to such medical interventions as mechanical ventilation and artificial nutrition and hydration. However, depending on the patient's diagnosis and the extent of disease progression, treatment might also include medications to manage such conditions as congestive heart failure and chronic obstructive pulmonary disease, or renal dialysis for patients with renal failure. The institutional policy addresses situations in which treatment is "forgone," which might conceivably encompass both withdrawing interventions currently provided and withholding measures that might otherwise be indicated. An example of the latter would be the entry of a "do not resuscitate" order and hence the withholding of cardiopulmonary resuscitation in the event of a cardiac arrest. In the case of patients with advanced malignancy, such procedures as chemotherapy, radiation therapy, and in some instances surgery may be considered life-prolonging rather than curative.

There is a general presumption that forgoing life-sustaining treatment relates only to disease-directed (curative) or life-extending interventions and not those intended to make the patient comfortable and relieve physical or mental distress (palliative). This presumption is based on a reasonable belief that, whereas many patients may no longer wish to prolong what has come to be recognized as their inevitable death, one rarely encounters a patient who does not seek the relief of suffering. Hence the policy under consideration establishes a basic premise that "supportive care will be provided." The policy goes on to provide, however, that this presumption may

be rebutted by a statement to the contrary from "the patient or a surrogate." For purposes of discussion and analysis, it may be helpful to consider separately patients with and without decisional capacity.⁵

Patients with Decisional Capacity

When a patient possesses decisional capacity, the clinical and nonclinical implications of forgoing treatment can be fully explored in discussions between physician and patient. Curative and palliative measures can be described and distinguished as to their nature and purpose. If a patient who clearly has decisional capacity declines measures that would be provided solely to maintain comfort, it is very important to be clear about the basis for that refusal. Initially, the physician should seek to verify that the patient understands both the nature and the purpose of the measures, as well as the consequences of not providing them. The patient's refusal may be based on the mistaken assumption that they are life-prolonging or that their side effects may impose burdens that exceed whatever benefits might be anticipated. Such discussions should not focus excessively on particular comfort measures (means) but rather on the patient's goals (ends). Quality care at the end of life is care that is consistent with and promotes the patient's goals and values.

Because comfort measures for dying patients often include the administration of opioid analgesics to control pain and relieve other distressing symptoms, it is critically important that patients, and family members who are close to and may influence the patient, be educated about these medications. Opiophobia is not restricted to healthcare professionals.⁶ Quite understandably, many lay persons do not comprehend the distinction be-

tween addiction and physiological dependence on opioid analgesics to relieve severe, persistent pain. Patients and family members may also have exaggerated concerns about severe, unmanageable side effects from opioids. Pain management remains one of the vast wastelands of informed consent because a lack of physician knowledge quite naturally yields the perpetuation of myths, misinformation, and groundless fears among patients and families.⁷

If the patient's refusal does not appear to be based on ignorance or unfounded fears (his own or those of close family members) concerning opioid analgesics, then psychological, social, cultural, or religious factors should be taken into account. Good end-of-life care often requires an interdisciplinary team effort, and members of that team, or consultants readily available to it, should ideally include social workers, psychologists and/or psychiatrists, and chaplains or pastoral counselors. The patient may believe, erroneously, that particular cultural norms or religious doctrines demand or promote the experience of pain or suffering as an essential element of the dying process. Given the general disinclination of people of many different social and cultural backgrounds to discuss death and dying, one should not assume that discussions of this nature have previously taken place and hence inform the patient's perspective. If the patient has any association with a faith community, it is important to encourage that a leader of that community (e.g., minister, priest, rabbi, imam) provide spiritual guidance and counsel if the patient agrees.

In the unlikely event that, after exploring all of these factors, the patient continues to decline comfort measures, then the patient's wishes must be respected, just as they must when curative measures are declined. In some instances, healthcare professionals may

seek to be relieved of the responsibility to provide further care to the patient because they do not wish to participate in what they consider to be the infliction or the tolerance of unnecessary suffering.

Patients without Decisional Capacity

The ethical standards for surrogate decisionmaking reflect a primary objective of respecting the wishes, goals, and values of the patient who has lost decisional capacity. If a patient has provided clear written directives that indicate the circumstances under which she would or would not wish certain types of treatment to be provided, the responsibility of the surrogate is to make decisions consistent with such directives. Regrettably, such comprehensive and unambiguous directives rarely exist.⁸ At best, there may be one of two common types of advance directive. The first, a living will, provides that once a patient has lost decisional capacity and has been determined by two physicians to be in a terminal, irreversible condition, life-sustaining measures should be withdrawn. The second, a durable power of attorney for healthcare, designates a specific individual as the patient's proxy and confers on that person the authority to make medical decisions on behalf of the patient. Often a durable power of attorney contains no specific guidance on how such decisions, in the face of a terminal or serious, irreversible condition, are to be made. Sometimes the term "substituted judgment" has been used to describe the basis on which such a proxy is to make decisions that most closely approximate how the patient would make them if he had not lost decisional capacity.⁹ Substituted judgment presupposes some minimal level of knowledge about the patient as a unique individual, his val-

ues, and how he might make decisions in similar circumstances. It is a subjective standard, but the subjective view is that of the patient, not the proxy.

When the patient has provided no written directives, the ethical standard for surrogate decisionmaking is that of the patient's best interests.¹⁰ At least in theory, the best-interests standard is what a proxy must resort to for guidance when no information is available on which to base a substituted judgment. Traditionally, it has been considered an objective standard, based on what a reasonable person in the patient's circumstances might be expected to prefer. However, some recent state legislation has sought to impart a quasi-subjective tone to best-interests determinations by proxies. Consider, for example, the following language from the California statute regulating healthcare decisions by a conservator:

The conservator shall make health care decisions for the conservatee in accordance with the conservatee's individual health care instructions, if any, and other wishes to the extent known to the conservator. Otherwise, the conservator shall make the decision in accordance with the conservator's determination of the conservatee's best interests. In determining the conservatee's best interest, the conservator shall consider the conservatee's personal values to the extent known to the conservator.¹¹

One particularly salutary feature of such a provision is the recognition that best interests cannot, in any intrinsic sense, be a generic concept. Two patients with very similar diagnoses and prognoses might still have radically different perspectives on what, clinically, is in their best interests. One might view a high-risk surgical procedure or experimental treatment as in

her best interests, whereas another would not. Those acting as surrogates for patients who lack decisional capacity have an ethical obligation to make a good-faith effort to apply the "best interests" criterion from that particular patient's perspective.

We come, once again, to the situation addressed by the policy in question. The decision to discontinue or not provide life-sustaining treatment has been made by the appropriate proxy. Presumably that decision is consistent with the patient's directive, values and priorities, or best interests and is not inconsistent with the diagnosis, prognosis, and current clinical status of the patient. The critical issue is whether it would ever be appropriate for a surrogate to refuse comfort measures on behalf of a patient. The policy rightly posits that comfort measures are the standard of care when life support is withdrawn. There is a developing literature on how to manage patients as they are taken off of a ventilator or artificial nutrition and hydration are discontinued.¹² Carefully managed, the suffering of all involved, but particularly the patient, can be prevented or alleviated. However, there are also data suggesting that often "best practices" elude us and dying in the intensive care unit becomes an ordeal, especially for patients and their families.¹³

Just as I earlier conceded that there might well be circumstances, however rare, when a patient with decisional capacity declines comfort care when life support is discontinued, so too there might be circumstances in which a surrogate is authentically respecting the values of a patient by declining comfort measures. Nevertheless, an institutional policy that simply gives a surrogate carte blanche to decline measures that are intended only to prevent patient suffering seems deeply flawed. Patients who prefer to receive no comfort measures whatsoever are

extremely rare. More common are those who wish to accept a certain level of discomfort rather than be completely deprived of an opportunity to be present with those closest to them in the final days or hours of life. However, patients whose conditions afford them no real opportunity to experience the presence of others may still have the capacity to feel pain and suffering. In such instances, there is no meaningful trade-off available between comfort and engagement.

The healthcare team can responsibly challenge surrogates who are unable to provide some independent, credible basis for a judgment that a patient would not wish to receive appropriate comfort measures. In the absence of reasonably persuasive evidence to support the surrogate's decision to decline comfort measures, the question can legitimately be raised whether the surrogate is acting in the patient's best interests. Such situations warrant consideration by the institutional ethics committee. Ultimately, judicial review of the surrogate's position may well be required, and the institutional policy should recognize and provide for it.

Notes

1. *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261 (1990).
2. *Washington v. Glucksberg*, 521 U.S. 702 (1997).
3. *Vacco v. Quill*, 521 U.S. 793 (1997).
4. Rich BA. The assault on privacy in health-care decisionmaking. *Denver University Law Review* 1991;68:1-55.
5. I use the term "decisional capacity" advisedly to carefully distinguish it from "competence." Decisional capacity is a determination by the treating physician, based on an appropriate assessment and the application of sound clinical judgment, that a patient lacks the ability to make decisions for herself regarding medical treatment. Competence is a more global determination, made by a judge, after a hearing in which medical (often psychiatric) and other forms of testimony are provided.
6. Morgan JP. American opiophobia: customary underutilization of opioid analgesics. *Advances in Pain Research and Therapy* 1989;11:181-7.
7. Rich BA. An ethical analysis of the barriers to effective pain management. *Cambridge Quarterly of Healthcare Ethics* 2000;9:54-70.
8. Rich BA. Advance directives: the next generation. *The Journal of Legal Medicine* 1998; 19:63-97.
9. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. *Deciding to Forego Life-Sustaining Treatment: Ethical, Medical, and Legal Issues in Treatment Decisions*. Washington, D.C.: U.S. Government Printing Office; 1983:132-4.
10. Buchanan A, Brock D. *Deciding for Others: The Ethics of Surrogate Decision Making*. New York: Cambridge University Press; 1989:93-6.
11. Cal. Probate Code sect. 2355.
12. See, generally: Wilson WC, Smedira NG, Fink C, McDowell JA, Luce JM. Ordering and administration of sedatives and analgesics during the withholding and withdrawal of life support from critically ill patients. *JAMA* 1992;267:949-53; Brody H, Campbell ML, Faber-Langendoen K, Ogle KS. Withdrawing intensive life-sustaining treatment: recommendations for compassionate clinical management. *New England Journal of Medicine* 1997;336:652-7; Faber-Langendoen F, Lanken PN. Dying patients in the intensive care unit: forgoing treatment, maintaining care. *Annals of Internal Medicine* 2000;133:886-93.
13. SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients. *JAMA* 1995;274:1591-8.