

# Treatment Decisions for Patients Without Surrogates: Rethinking Policies for a Vulnerable Population

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Contemporary medical and ethical guidelines have stressed the importance of a dialogue between the physician and patient as the basis for making treatment decisions. When patients are too ill to decide for themselves, physicians must rely on an advance directive or on family members or others close to the patient for consent to treatment and for decisions to forgo life-sustaining measures. Some patients, however, have no family members or others available and willing to decide about treatment on their behalf. In the voluminous literature on bioethics, the special needs of this patient population have received little attention.

To our knowledge, no data exist regarding the number of individuals in nursing homes or hospitals who have no available and willing surrogate decision-maker, nor have any studies examined how decisions are currently made for these individuals. In one study of the Do-Not-Resuscitate (DNR) law in New York State, all but 3% of the nursing home residents in the study had a family member or other potential surrogate who could be identified, but 45% of the potential surrogates did not respond to attempts to obtain a decision about a DNR order during the 3-month period of the study.<sup>1</sup> This study suggests that the population of individuals in long-term care who lack capacity and have no person available and willing to serve as surrogate may be a substantial subset of long-term care residents.

Physicians face significant obstacles in securing treatment decisions for hospital and nursing home patients who lack decision-making capacity, have not signed an advance directive, and have no family member or other person available to decide on their behalf. In most states in the country, the only legally recognized avenue to decide about treatment for these patients involves court proceedings, either to appoint a guardian or to seek judicial approval for a particular treatment decision. Judicial proceedings provide public accountability for decisions and an explicit examination of the basis for the decision. However, reliance on judicial proceedings as the only avenue for treatment decisions presents clear disadvantages for both patients and physicians. For patients, the proceedings may delay access to needed treatment and increase the cost of treatment. The need to seek judicial review as an alternative to informed consent by the patient or

a family member may also make some physicians and health care facilities reluctant to treat patients who have no surrogate. Judicial proceedings may also create a barrier to appropriate decisions to forgo life-sustaining measures. In addition, the courts are not a preferred forum for physicians; judicial proceedings are more formal, adversarial, and time-consuming than the clinical model of decision-making at the bedside.

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This article discusses existing law governing treatment decisions for patients without surrogates and explores the alternatives that have been proposed to facilitate decisions for these patients. Those options include authorizing physicians to decide for patients, an approach taken in Arizona, North Carolina, and Oregon. The article also considers methods for reviewing decisions outside healthcare facilities, such as the state ombudsman program that exists in New Jersey, and a quasi-judicial system of committees composed of community volunteers, which operates in a limited form in New York. Finally, the article explores a hybrid of these approaches, based on a proposal by the New York State Task Force on Life and the Law, under which decisions would be made within facilities by doctors and other health care professionals with review by a multidisciplinary committee in the facility.

## THE NEED FOR POLICIES ON TREATMENT DECISIONS FOR PATIENTS WITHOUT SURROGATES

Physicians routinely seek substitute consent to treatment for patients who lack decision-making capacity and who have not left advance directives reflecting their treatment wishes. In the acute care setting, older patients may lack capacity only temporarily, following an acute crisis or surgery. In long-term care, many patients have diminished decision-making capacity that is irreversible as a result of illnesses associated with old age, including dementia. These patients may have the capacity to make some decisions and not others. In one study of long-term care facilities, 47% of patients lacked all decision-making capacity, and 26% had only partial capacity.<sup>2</sup>

Advance directives, such as a living will specifying treatment wishes or a health care proxy appointing someone to decide about treatment, are recognized widely as important options for all patients, including long-term care residents. Clinical studies show that approximately 15% of the general population has signed a directive, with completion rates

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varying depending on the interventions used to facilitate completion of the documents.<sup>3,4</sup> Typically, however, patients who have no surrogate lack the social support that would prompt use of advance directives or generate evidence of their wishes. Patients without surrogates are among those whose medical records most frequently lack documentation of advance directives.<sup>5</sup>

For patients who have no advance directive, family members and others with a close personal relationship to the patient can be a valuable source of information about the patient's wishes, values, and goals for health care. Although family members called upon to act as surrogates do not always approximate the patient's wishes, they are generally more knowledgeable about the patient's treatment preferences than others, including health care professionals.<sup>6-9</sup> In addition, family members are relied upon as surrogates because of the value society places on family relationships and the presumption that family members will be committed to the patient's well-being. For these reasons, physicians have long turned to family members for consent to treatment. State statutes and court decisions have also granted family members the authority to forgo life-sustaining treatment for patients who lack decision-making capacity in accord with standards that require surrogates to make decisions that are consistent with the patient's wishes or, if those wishes are not known, the patient's best interests.<sup>10</sup>

Shared decision-making between the physician and an appointed or unappointed surrogate has been recognized as a critical aspect of treatment decisions for incapacitated patients.<sup>11-14</sup> Without a surrogate, decisions may be less open, less clearly articulated and more susceptible to judgments about the patient's social and individual worth. Studies have shown that some physicians make treatment decisions based on their own values or on criteria independent of the patient's medical needs, including age, race, and mental disabilities.<sup>15-21</sup>

These risks are particularly pronounced for patients without surrogates. This group includes some of society's most marginalized members, such as older people who have outlived family and friends, and the mentally ill or homeless, who have lost contact with their family and other social connections. These patients may face additional risks as managed care arrangements become more common for the Medicare and Medicaid populations, given the financial incentives under managed care to underutilize services or limit access to care.<sup>22</sup> Indeed, the rapid shift to managed care underway for older and low income patients lends an urgency to the concerns posed by this vulnerable population.

#### GUARDIANSHIP AND JUDICIAL APPROVAL OF TREATMENT DECISIONS

Most states require judicial proceedings, either to appoint a guardian or to seek judicial approval for a particular decision, when treatment decisions arise and patients have no surrogate. Guardianship is a judicial procedure that transfers decision-making responsibility from an incapacitated individual (the "ward") to another person (the "guardian"). In appropriate cases, this responsibility includes the power to decide about medical treatment. Because guardianship divests the ward of significant decision-making authority, strict procedural and substantive guidelines apply to the entire guardianship process. These guidelines generally require notice of pending proceedings, the right to be represented at a

hearing before a judge, and a requirement that guardians file regular reports about their activities with the court. Patients without surrogates, who are alone and especially vulnerable, may benefit from these aspects of judicial decision-making. They cannot speak for themselves, nor do they have a person close to them who can serve as an advocate and evaluate their treatment options.

Unfortunately, despite the potential benefits of an ongoing relationship between the guardian and ward and the guardian's accountability to judicial authorities, these ideals are often not realized in practice.<sup>23</sup> According to one widely publicized study, "due process rights are often lacking; the standard used to determine incapacity is often unclear; guardians generally have little or no training, and often institutionalize their wards; [and] many probate courts lack the resources to adequately monitor the activities of the guardian."<sup>24</sup>

Frequently, guardianship is not even an option for patients without surrogates because of the shortage of individuals willing to serve as a guardian for patients without family or friends. This problem is most pronounced for patients without sufficient assets to compensate the guardian for his or her services; under these circumstances, the judge must find someone willing to serve as guardian on a pro bono basis. In some states, courts are authorized to appoint the local Commissioner of Social Services, public guardianship agencies, or private social service agencies to serve as guardian when no one else is available.<sup>24</sup> However, these organizations generally lack the resources to serve as guardian in more than a small number of cases.

Even when it is possible to find a guardian for a patient without family or friends, applying for a guardianship order is expensive and time-consuming. According to a recent study of guardianship petitions brought by local departments of social services, the shortest time for obtaining a guardianship order was approximately 1 month, and more than one-third of the reported cases took 6 months or longer.<sup>25</sup> Such delays, as well as the attendant expenses — estimated at \$4000 to \$6000 for older people with modest assets<sup>26</sup> — make guardianship an impractical option for treatment decisions. As a result of these problems, hospitals and long-term care facilities are generally reluctant to seek guardians for patients without family or friends. Typically, a guardianship proceeding will be initiated only if the patient explicitly objects to a proposed treatment or, more commonly, if the patient objects to being transferred from an acute care facility to a nursing home.

Judicial proceedings to obtain approval for particular treatment decisions are usually less expensive and time-consuming than guardianships. However, the time and expense associated with the proceedings still present a significant deterrent. According to one study, courts in New York took an average of 135 days to hear a petition for authorization of medical treatment and to render a decision.<sup>23</sup> Moreover, a judicial hearing may add little to decisions already made by physicians, because judges have no personal knowledge of the patient and generally lack medical expertise.

#### STATE OMBUDSMAN OFFICE

Another approach to treatment decisions for patients without surrogates is the creation of a centralized state program to oversee decisions made within hospitals and nursing homes. This approach, which would rely on an individual or

office to investigate problems or resolve difficult cases, has severe shortcomings. First, it leaves all decisions subject to the values and judgments of a single person or office that is removed from the clinical setting. Second, it vests the office with the responsibility of overseeing treatment decisions for thousands of patients in each state.

This approach was instituted for long-term care residents in New Jersey in 1985 in response to a court ruling involving an older demented woman, Clair Conroy.<sup>27</sup> The courts authorized the decision to forgo a feeding tube for her and mandated the creation of a state-wide ombudsman's office to oversee decisions to withdraw or withhold life-sustaining treatment for all long-term care residents in the state who lacked decision-making capacity. Once appointed, the ombudsman required every decision to forgo life-sustaining treatment to be reported as a potential case of patient abuse. This policy was rejected by both healthcare professionals and advocates for patients, leading ultimately to the ombudsman's resignation.<sup>28,29</sup> The current ombudsman's office generally limits its review of decisions to forgo life-sustaining treatment to cases involving a conflict between the patient's surrogate and healthcare providers. According to representatives of the office, few cases are reported that involve decisions to forgo life-sustaining treatment for incapacitated patients without family or friends.

### PHYSICIANS AS SURROGATES

Another alternative for treatment decisions for patients who have no surrogate would authorize physicians to decide for these patients. Three states, Arizona, Oregon, and North Carolina, have adopted this approach.<sup>30</sup> Under Arizona law, the attending physician must consult with an institutional ethics committee, if one exists, before deciding about treatment for incapacitated patients without surrogates although the physician is not required to follow the committee's recommendations. In addition, the law does not require facilities to establish ethics committees, nor does it specify standards or procedures that the committees must follow. If the healthcare facility does not have an ethics committee, the attending physician is authorized to decide about treatment after obtaining a concurring opinion from another physician.

Oregon authorizes the attending physician to consent to treatment and to refuse life-sustaining measures for patients who have not signed an advance directive, have no adult relative or friend available to decide for them, and are incapable of deciding for themselves. The attending physician, identified as the person with primary responsibility for the patient's care, determines if the patient is capable of deciding about treatment and has sole authority for decisions to consent to and to forgo treatment for these patients. The attending physician, like other surrogates, must decide about treatment in accord with the patient's wishes and best interests and has the authority to forgo life-sustaining treatment for patients who meet certain criteria: those who are terminally ill, permanently unconscious, facing permanent or severe pain from the administration of life-sustaining procedures, or who have a progressive, debilitating illness and who lack the capacity to communicate with and recognize others. The physician is not required to consult a second physician about the patient's diagnosis or the decision to stop or withhold treatment. North Carolina law is similar, although a second physician must confirm in writing that the patient has one of the medical conditions required in order to discontinue treat-

ment. North Carolina's law states explicitly that the decision will be at the "discretion" of the attending physician.

This approach, especially as adopted in Oregon and North Carolina, presents several serious drawbacks. These drawbacks are particularly severe in light of ongoing changes in the healthcare system. Although financial incentives in a fee-for-service system may harm patients by encouraging overtreatment, the national shift to managed care has created widespread incentives to undertreat.<sup>22</sup> Under managed care, physicians' judgments will be influenced not only by the cost of care, but by concern that palliative care and other treatments that would enable patients to live longer and more comfortably may not be available to their patients. Moreover, unless the treatment is futile, in the sense that it offers no physiological benefit, decisions to forgo life-sustaining treatment are social and ethical, not medical judgments. They are often deeply personal decisions and, if left to individual physicians, will inevitably reflect the physician's own views and values.<sup>15-21</sup> Finally, patients are usually well served by a decision-making process that involves more than one person. When family members or friends decide for patients, the physician performs a vital role in recommending treatment options, reviewing decisions, and challenging those that seem clearly wrong. This safeguard is lost if one person acts as both surrogate and physician. Without some additional review, decisions about life-sustaining treatment will remain largely private choices at the discretion of each physician.

### COMMUNITY-BASED COMMITTEES

One novel approach for making treatment decisions for incapacitated patients without surrogates is the system of surrogate decision-making committees for the mentally disabled established by Article 80 of New York's Mental Hygiene Law.<sup>23,31</sup> This system relies on multidisciplinary committees, comprised of volunteer health care providers, consumers, and attorneys, to decide about treatment for mentally ill and developmentally disabled individuals who reside in mental hygiene facilities and lack natural surrogates. Committees are required to hold hearings, which the patient and others, including an attorney for the patient, can attend. The committee process was designed as a quicker process than the courts. Moreover, because the panels are composed of healthcare providers and others knowledgeable about the concerns confronting persons with disabilities, they are uniquely qualified to evaluate the risks and benefits of treatment. They are also less likely to harbor biases against individuals with disabilities, or to undervalue the quality of life of these patients.

It is unlikely, however, that the Article 80 system could be expanded to cover treatment decisions for all patients, including older patients, who lack surrogates in hospitals and nursing homes. Given the volume of cases likely to arise, committees comprised of volunteers would be difficult to establish and administratively complex to manage. In addition, whereas the committees can render decisions in much less time than courts, delays of several weeks to schedule hearings are not uncommon.<sup>23</sup> Finally, data on the Article 80 program show that the committees have followed physician recommendations in all but a few cases,<sup>23</sup> suggesting that review of decisions by an outside committee may not substantially improve decisions reached at the facility level.

## A MODEL FOR DECISIONS WITHIN HEALTH CARE FACILITIES

Another alternative for making treatment decisions for patients without surrogates would involve a hybrid of the above approaches: relying on physicians to initiate the decision-making process and propose a course of treatment but providing review of decisions within the healthcare facility. In a 1992 report proposing policy for treatment decisions for patients who lack capacity and have not signed an advance directive, the New York State Task Force on Life and the Law recommended policies for patients without surrogates. Those policies would facilitate access to treatment and establish a process of review for decisions to forgo life-sustaining measures.<sup>12</sup> The proposed policies would cover only patients who lack decision-making capacity, as determined by the attending physician and one other healthcare professional. All treatment decisions would have to be consistent with the patient's wishes, if known, or a good faith judgment about the patient's best interests.

### *Decisions About Major Medical Treatment*

For decisions about major medical treatment, defined to include those treatments that entail significant risk, discomfort, debilitation, or invasion of bodily integrity and for which physicians ordinarily seek informed consent, the attending physician would decide about treatment in consultation with other health care professionals involved in the patient's care. Treatments such as major surgery, diagnostic procedures such as a spinal tap, and the provision of drugs with substantial side effects, like chemotherapy, would fall in this category. Consultation about these decisions with other members of the care team, especially nurses and social workers, may provide important personal information about the patient, including perhaps some indication of the patient's preferences and health care goals. The attending physician would also be required to consult with and obtain the concurrence of a second physician selected by the healthcare facility before proceeding with major medical interventions. This approach would give the incapacitated older patient in a hospital or long-term care facility the benefit of the second opinion that he or she is unable to request.

In a fee-for-service system, allowing physicians to act as gatekeepers and to provide consent for incapacitated patients without surrogates raises the possibility of overtreatment. Review by a second physician and a written record of the decision would minimize but not eliminate that risk. As capitation becomes more common, the greater risk for patients without surrogates is that they will not receive needed treatment. Allowing two physicians to consent to treatment removes a barrier to care but does not in itself assure that needed treatment will be provided. More vigorous enforcement of existing professional standards and the common-law duty of care owed to patients, including those who are under or uninsured, will be needed to protect this vulnerable patient population. Ultimately, as safeguards are designed to protect patients' interests in the evolving environment of managed care, special consideration must be given to this patient population to prevent the use of financial incentives to deny major medical treatment.

### *Decisions About Life-Sustaining Treatment*

Under the Task Force's proposal, the attending physician would also initiate decisions to forgo life-sustaining treat-

ment. The physician must determine, in consultation with other health care professionals caring for the patient, that the decision accords with the patient's wishes and interests. In addition, decisions to forgo life-sustaining treatment would be authorized only if the treatment imposes an "excessive burden" on the patient and the patient is terminally ill or permanently unconscious, or if the patient has an incurable or irreversible condition and the treatment would "involve such pain, suffering, or other burden that it would reasonably be deemed inhumane or excessively burdensome under the circumstances."<sup>32</sup> These are the same standards that would guide decisions for patients who have family members or others to decide on their behalf.

If these standards are satisfied, the attending physician must consult a second physician who independently decides whether to concur in the recommendation to withhold or withdraw treatment. In addition, the decision must be reviewed and approved by a multi-disciplinary committee within the healthcare facility. The committee would seek to determine if the standards for the decision have been met. Is any information available about the patient's wishes and is the decision consistent with those wishes? Does the patient meet the medical standards for the decision? In evaluating the physician's recommendations, the committee would in effect provide the kind of consideration that a surrogate would offer, if available.

The membership of the committee would include physicians, nurses, social workers, and individuals with training or expertise in ethics or theology, similar to the composition of many existing hospital ethics committees. However, the committee would have the authority to review and approve or disapprove treatment decisions, a role not generally assigned to ethics committees. Under the proposal, the committee's function could be fulfilled by an existing ethics committee or by a subcommittee of the ethics committee. A healthcare facility could also create a new committee to fulfill this responsibility or participate in a committee that serves more than one facility. Committees in long-term care facilities would be required to include at least one resident or family member of a resident and one individual not affiliated with the facility with a demonstrated commitment to older people or nursing home residents. Similar community or family representation would be required in the acute care setting.

Several commentators have emphasized the importance of clear procedures to assure confidentiality as well as patient and family access for ethics committees involved in case consultation or mediation.<sup>33,34</sup> This is especially critical for committees that will have the authority to review and approve decisions. As proposed by the Task Force, committee guidelines would require that members keep information confidential and would grant access to the committee proceedings to individuals connected with the patient, including health care professionals who wish to be heard. The committees would also be required to keep a record of their decision in each case and a statement of the reasons for the decision. This will promote consistency in the response to cases over time and will also create a record that would allow further review by the court or other public bodies. As long as the committee members act in good faith, they would be protected from liability for decisions or actions taken in accord with their responsibilities under the law.

Committee review of decisions to forgo treatment would create a decision-making process that is open and informed

by diverse professional perspectives. This approach would support doctors in their role as advocates for patients by creating a process that is accessible to them and closer to a clinical model than judicial review. At the same time, it would avoid the problems posed by allowing doctors to decide on their own and provide a safeguard for sensitive decisions for a highly vulnerable patient population. Committees within healthcare institutions would also offer an alternative that is less bureaucratic and administratively complex than committees comprised of community volunteers.

Granting committees within hospitals and nursing homes this authority does raise important questions. This approach is untested. Apart from institutional review boards, no other committees have decision-making authority over treatment decisions for patients. Indeed, some commentators have urged that ethics committees should remain advisory only because they will otherwise diminish or supplant the role of the physician.<sup>35</sup> However, except in three states, physicians currently have no authority to decide about treatment for patients who have no surrogates. The policy proposed by the Task Force would, therefore, increase the physician's role in treatment decisions, authorizing physicians to propose a course of treatment, seek a second opinion, and engage in a dialogue with a committee at the facility.

Another potential concern about relying on committees is that committee decisions and the quality of the committees would vary from one facility to the next. However, judicial rulings and decisions by individual doctors, as permitted in Oregon, North Carolina, and Arizona, are subject to an even broader range of personal views and expertise in making ethical judgments. The committee process will minimize, although not eliminate, the possibility that decisions will be driven by the views of one individual because the committee members must reach agreement. Finally, the committee system will require the commitment of time and resources by health care professionals and institutions. The costs of such a system, however, are likely to be less than the current legal options, which rely principally on judicial proceedings. The committee process is also likely to yield better decisions because the committee will have more expertise than an individual judge who must rely on health care providers for insight, clinical information, and guidance.

## CONCLUSION

No data are available about the number of patients who have no surrogate, their personal circumstances, or how decisions are made for them. The scarcity of data itself reflects the lack of public attention to the needs of these patients. The small number of court cases seeking guardians to decide about medical care or judicial approval for particular treatment decisions for patients who have no family or other surrogate, in comparison with the potentially large population of these patients, especially in the nations' nursing homes, suggests that physicians often decide about treatment for these patients without legal authorization. This leaves a significant gap between law and practice. It also undermines the well-being of patients, some of whom may receive unnecessary treatment while others may not receive treatment they need. For many, decisions will be made without the consultation or explicit guidelines that shape decisions for other patients.

The proposal by the Task Force on Life and the Law offers a useful model for healthcare providers and policymak-

ers. If implemented, it would require careful study and evaluation, but it holds out the possibility of removing legal barriers to needed care and providing a sound facility-based approach to decisions about life-sustaining treatment for socially isolated patients. Whether state policymakers adopt this approach or consider other options, the challenges presented by caring for elderly patients without surrogates must be publicly explored and debated, especially as our health care system becomes increasingly cost conscious. The fact that incapacitated patients who have no surrogate are often voiceless makes public debate about their needs more, not less, critical.

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