

Making Medical Decisions for Patients without Surrogates

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People who are decisionally incapacitated but haven't provided advance directives for their health care and have no health care surrogates — sometimes called the “unbefriended” or “unrepresented” — are some of the most powerless and marginalized members of society. Most of the unrepresented are elderly, homeless, mentally disabled, or socially alienated. Yet medical decision making for these vulnerable patients often lacks even minimally sufficient safeguards and protections. Consequently, health care decisions made on their behalf are at risk of being biased, arbitrary, corrupt, or careless.

Most U.S. states have similar processes for making treatment decisions on behalf of patients without capacity (see table).¹ In an emergency, clinicians can treat patients without their consent. For nonemergency situations, patients may have completed a Physician Orders for Life-Sustaining Treatment (POLST) form or advance directive with instructions that clearly address their current circumstances, or they may have appointed a health care agent or durable power of attorney. But most patients have taken neither of these steps, so 43 states have “default surrogate” laws specifying who can make decisions. In most of these states, a spouse is designated first, followed by adult children, parents, siblings, and often other relatives and friends.

None of these decision-making mechanisms, however, can help the unrepresented. They

have no POLST forms, no advance directives, no agents, and no default surrogates. And the unrepresented are a big group — including some elderly and mentally disabled patients, as well as many who are homeless or socially isolated. In many states, lesbian, gay, bisexual, or transgendered patients may have same-sex partners who could serve as decision makers but are not legally recognized as surrogates. Experts estimate that 3 to 4% of the 1.3 million people living in U.S. nursing homes² and 5% of the 500,000 per year who die in intensive care units³ are unrepresented.

Who can consent to treatment on behalf of these unrepresented patients? In almost every state, the only legally authorized decision maker is the court-appointed guardian.² But that solution is usually inadequate, for several reasons: the judicial process is too slow and cumbersome relative to the need for treatment decisions, it's expensive, and guardians often lack time, given their heavy case-loads, to learn about the patient. The biggest problem, though, is that guardians are often unavailable.² Most court-appointed guardians are family members, but unrepresented patients have no available family. Professional guardians are unwilling to serve if the patient has no resources. In many states, not even the use of public guardians is practicable. For example, in 2010, Georgia enacted a new medical-guardian statute specifically to help the unrepresented, but a recent sur-

vey of Georgia probate judges indicates that the law is ineffective because there's a shortage of people willing to serve.⁴

So what happens to unrepresented patients when there is nobody authorized to consent to medical decisions? Clinicians exercise substituted judgment to the extent that that's possible. Otherwise, they aim to make decisions that are in the patient's best interest. But when clinicians do not hear the “voice” of the patient, they may provide treatment discordant with his or her preferences, values, and best interest.⁵

We can do better. Most model and institutional policies start with prevention, by promoting measures that aim to keep patients from becoming unrepresented in the first place. That means, first of all, protecting and promoting patients' ability to make their own health care decisions to the greatest extent possible. Capacity is not all or nothing; it fluctuates and can often be preserved through “supported decision making,” such as assisting the person to make and communicate preferences and choices. Second, while patients still have capacity, they should be helped to complete an advance directive appointing an agent and an alternate agent, so that when they really do lose capacity they will have someone to make treatment decisions. Third, in cases in which no agent or default surrogate is initially available, a thorough and diligent search should be conducted. Often, a surrogate can eventually be found²

Mechanisms and Sources of Authority for Substitute Decision Making.	
Mechanism or Situation	Source of Authority
Emergency	Implied consent
Instructional advance directive (living will)	Decided by the patient
Physician Orders for Life-Sustaining Treatment (POLST) form	Decided by the patient or surrogate
Proxy advance directive (durable power of attorney)	Appointed by the patient
Default surrogate	Appointed by the clinician
Guardian or conservator	Appointed by the court

— and even if that turns out not to be the case, casting a wide net to include friends and pastors can at least provide evidence of the patient's values and treatment preferences.

But for many patients, even improved preventive measures won't work. If we can't keep the patient from becoming unrepresented, who should make treatment decisions? Who should play the role of surrogate and apply the substituted-judgment and best-interest standards? Today, most decisions for the unrepresented are made by physicians alone, with no hospital oversight.³ This practice is understandable. Physicians appreciate the risks, benefits, and alternatives of various treatment options. And they can make quick decisions.

But their responsiveness and expertise notwithstanding, physicians often do not make good surrogates.⁵ Indeed, most states specifically prohibit patients from selecting their physicians as surrogates. Without a separate surrogate, the clinician's conflicts of interest and biases related to disability, race, and culture all remain unchecked.⁵ In addition, when physicians don't need to explain their treatment decisions to another decision maker, the bases for those decisions are less clearly articulated and more

susceptible to the physician's idiosyncratic treatment style. In short, I believe that the risks associated with unilateral decision making by physicians outweigh the benefits.

We must strike an appropriate balance between a decision maker who is responsive and can make timely decisions and a decision maker who is independent from the treating clinicians. Occupying this middle ground, I would argue, is the ethics committee. These committees are typically composed of at least a physician, a nurse, a social worker, a bioethicist, and a community member. The ethics committee applies the same decision-making standards as the individual physician decision maker. But the committee has greater ability to discover and diligently represent the patient's wishes, to offer and consider various perspectives, and to weigh both medical and non-medical considerations.

Ideally, this ethics committee would be external to the health care facility, like the committees used for unrepresented patients in the New York and Texas mental health systems. Many areas of the country already have city-wide or regional ethics committees that could assume this role. But even an intramural committee would be a substantial safeguard, at least until novel solutions are

developed. This solution should not be resource-intensive, since almost all hospitals already have an ethics committee.

Unfortunately, only five states have formally empowered existing institutional multidisciplinary committees to make treatment decisions for unrepresented patients. The remaining states have no clear legislative or regulatory guidelines,² so in order to ensure transparency and fair process for unrepresented patients, it is up to facilities to develop their own institutional policies. So long as legally sanctioned mechanisms are nonexistent or inadequate, I believe that providers have both the duty and the discretion to design these policies.

The best approach would carefully balance due process and efficiency. Clearly, we need a decision-making process that not only is accessible, quick, convenient, and cost-effective but also provides the important safeguards of expertise, neutrality, and careful deliberation. Ideally, the mechanisms we develop would not only increase the quality of decisions but also provide a greater sense of social legitimacy.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

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DOI: 10.1056/NEJMp1308197

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HISTORY OF MEDICINE

Railways, Industry, and Surgery — The Introduction of Risk Management

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Trains sometimes derail, planes crash, factories collapse — yet we take trains and planes and keep building factories. We have learned to live with risk. The notion of risk is so common that it has been described as a defining feature of modern societies. Modern risk management has made risk calculable and to some extent controllable. It is also a central feature of medical intervention, most notably in surgery. But when risk management was initially introduced into surgery, in the 1870s, it was not only because of developments in medicine (such as antisepsis) but also because of precedents in the railroad and manufacturing arenas. This new attitude toward risk led to greater use of surgical interventions and, I would argue, was at least as important as antisepsis for the development of the field.

Before the late 19th century, surgeons had engaged in what might be called the “management of chance.” A particularly instructive example of this approach is encapsulated in an 1854 essay by the Russian surgeon Nikolay Pirogov, aptly titled “On Luck in Surgery.” As Pirogov knew, surgeons had always been particu-

larly vulnerable to being blamed for bad outcomes, since the link between an operation and the death of a patient is normally obvious and hard to deny. Pirogov assumed that the reason why surgeons had always had to cope with this problem was that outcomes in surgery were essentially beyond the practitioner’s control. Surgeons needed a certain “practical tact,” explained Pirogov, to judge whether or not to operate in a situation in which the odds could neither be completely known nor influenced. Such decisions had to take into account a whole economy of risk, involving the influences of both medical and nonmedical factors. Surgeons incurred particularly high risk to their reputations and future work, for example, when operating on a patient of high social standing. Some patients, Pirogov advised, should therefore be referred to colleagues. Others should be dissuaded from undergoing surgery altogether. Involving several doctors in a given case could disperse responsibility. One could also try to perform as many safe operations as possible so that the occasional failure would not spoil one’s mortality statistics. How-

ever, at the end of the day, all these strategies had their limitations. The power of hidden factors and pure chance was too strong. Pirogov explicitly rejected the idea of using statistical calculations to deal with this uncertainty because, he explained, the chance element in probability calculations made them inapplicable to the surgeon’s day-to-day work.

In 1881 the German surgeon Richard von Volkmann suggested that the traditional surgeon resembled a farmer who could only cultivate his land and wait to see how his harvest turned out, whereas the modern surgeon, with antisepsis at his disposal, resembled a manufacturer from whom the public expected consistently high-quality products.¹ Volkmann had adopted Joseph Lister’s antisepsis a decade earlier and had become Germany’s most influential proponent of the antiseptic method, an innovation that had engendered an unprecedented expansion of surgery. Operations whose performance would have been considered insane or criminal just 15 years earlier were now performed routinely. The decisive advantage of antisepsis, however, was the predictability of good results so