ETHICS ROUNDS

Can a Patient Designate His Doctor as His Proxy Decision Maker?

abstract

Most lawyers and bioethicists recommend that patients enact a durable power of attorney for health care designating somebody as their proxy decision maker should they become unable to make decisions. Most people choose family members as their agent. But what if a patient wants his or her doctor to be his or her proxy decision maker? Can the doctor be both physician and surrogate decision maker? Or should those roles necessarily be kept separate? We present a case in which those issues arose, and sought comments from Sabrina Derrington, a pediatric palliative care physician; Arthur Derse, an emergency department physician and lawyer; and Phil Black, a pulmonologist. *Pediatrics* 2013;131:986–990

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ethics, advanced directives, autonomy, end-of-life decisions, cystic fibrosis

ABBREVIATION

CF—cystic fibrosis

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THE CASE

Richard is a 20-year-old man with cystic fibrosis (CF). In spite of attentive treatment and good adherence to his medical regimens, his disease progressed. At age 15, he underwent a lung transplant. Recent recurrent infections and rejection have unfortunately led to deterioration in his lung function with the development of an oxygen requirement and exercise intolerance. Pulmonary function testing revealed worsening lung function.

Dr Andrews, the director of the CF center, has been Richard’s physician since infancy. Dr Andrews tells Richard that he might need a second transplant. Richard says that he would be willing if he could be guaranteed 5 to 10 years of a good quality of life. Dr Andrews honestly communicates his best guess that 5- to 10-year survival with a second transplant is unlikely and that, without a transplant, Richard might live another year or 2 with slowly worsening lung function. He discusses shifting the focus of Richard’s medical care to prioritizing comfort. They discuss do-not-resuscitate and do-not-intubate orders. Richard has several friends with CF. They have discussed advance directives before.

Richard then asks if Dr Andrews would be willing to be his health care agent and to continue to be his pulmonologist. Richard tells Dr Andrews that he trusts his judgment, that he would want excellent palliative care, and that he could not burden his mother with making a decision, because “she would never be able to let me go.”

Is It Ethical for Dr Andrews to Agree to be Richard’s Designated Proxy for Health Care Decisions?

Sabrina Derrington Writes

Dr Andrews must feel many emotions at the question posed to him by his young patient. He has probably cared for Richard during many medical crises. He has likely fostered Richard’s independence by helping him to understand how each one of his treatments work, to be responsible for maintaining compliance, and to participate more and more in making medical decisions. Richard has become a thoughtful, informed, and brave young man. Dr Andrews will certainly have mixed emotions if Richard decides to forego life-prolonging interventions.

As an adult of sound mind, however, Richard has the right to make decisions concerning his own health care, including the decision to accept or refuse medical or surgical treatment or to have life-sustaining therapy withheld or withdrawn. Completing an advance directive is a way for Richard to document these decisions ahead of time and so to extend his autonomy into an uncertain future. However, advance directive documents cannot capture the nuances of real clinical situations. The intentions of the patient in completing the directive must be interpreted to some degree. Therefore, Richard also has the right to name a proxy to interpret his stated wishes and to make health care decisions for him in the event that he becomes incapacitated. Although in many states Richard may be legally prohibited from designating his physician as his proxy, we will assume for the sake of this commentary that no such restriction applies. The question, then, is whether there are compelling ethical reasons for Dr Andrews to refuse to act as Richard’s proxy.

Bioethicists describe 3 standards for surrogate decision-making. To briefly summarize, in pure autonomy, also known as “precedent autonomy,” the proxy looks to an advance directive, or lacking that documentation, to previous autonomous actions of the patient to discern what the patient would want in the current situation. If this sort of evidence is not available, the standard of substituted judgment requires the proxy to make the decision that the patient would have made if he or she had not been incapacitated. The best interests standard is most helpful for patients who never had capacity, including children and the disabled, and requires that the proxy assess the risks and benefits of the relevant treatment options to make a decision that maximizes benefit to the patient and optimizes his or her quality of life. For a proxy decision maker to meet any one of these standards, he or she must have certain capacities. According to Beauchamp and Childress,1 proxy decision makers must have “(1) ability to make reasoned judgments, (2) adequate knowledge and information, (3) emotional stability, and (4) a commitment to the incompetent patient’s interests, free from conflicts of interest and free of controlling influence by those who might not act in the patient’s best interests.”

Does Dr Andrews meet these standards? There can be little question as to the adequacy of his knowledge and information. We can assume from his leadership role and from his professional and compassionate manner in which he has just finished communicating some difficult news to his young patient that he is also emotionally stable and able to make reasoned judgments. The question then hinges on the fourth standard: commitment to Richard’s interests and freedom from conflict of interest and controlling influences.

Rai et al2 analyzed the question of whether it made sense to prohibit physicians from acting as health care proxies. They addressed the following primary concerns underlying those restrictions: that physicians’ professional values would override patients’ personal values, and that conflicts of interest, financial or otherwise, would sway physicians’ judgment. Rai et al2 argued that restricting patient choice...
out of an undue fear of paternalism ignores the compelling reasons that some patients may have to choose their physician as proxy and takes an unnecessarily negative view of the physician-patient relationship. Dr Andrews has built a trusting relationship with Richard over many years of care. He has fairly presented Richard with options for treatment including pursuing a second transplant or focusing on maintaining comfort.

If he did not already, Dr Andrews now has an excellent opportunity to understand Richard’s opinions, values, and interests. If he has any conflict of interest due to his position as director of the CF center, or because of any personal or professional values, he has an obligation either to deny Richard’s request (with an honest explanation as to why), or to disclose those conflicts to Richard, and allow Richard to decide whether he still prefers Dr Andrews to be his health care proxy. Managing conflicts of interest by full disclosure and consent, rather than prohibition, is not without precedent, and acknowledges the ubiquitous and inextricable nature of these conflicts within the medical arena. Moreover, it is naive to assume that parents or other family members do not also have conflicts of interest or conflicting personal values that may keep them from acting in the interests of the patient. In fact in Richard’s case, his reason for choosing Dr Andrews as a proxy has to do with an anticipation of his mother being unable to “let him go.”

To insure that Richard’s designation of Dr Andrews as his health care proxy proceeds in an ethical fashion, there should be a full disclosure on Dr Andrews’ part of any potential conflicts of interests or values. Richard should formally acknowledge receipt of that information and have the chance to alter his decision. This could conceivably occur under the auspices of the hospital’s ethics committee, through a formal review process or consultation. A procedure should be put in place such that an independent physician is the one to evaluate and confirm Richard’s incompetence, when the time comes. If both patient and physician agree to these regulations, there is no reason that Dr Andrews cannot ethically act as Richard’s health care proxy.

Arthur Derse Writes

Yes, it is ethical for Dr Andrews to act as Richard’s proxy for health care decisions because of Richard’s long-standing relationship with Dr Andrews, the extent of their discussion about treatment options and end-of-life care, Richard’s independent discussions with friends about advance directives, and Richard’s consideration of his mother’s inability to let him go. Many patients with CF have been treated by only a few physicians and it is not uncommon for treating physicians to know their patients with CF and their families well. Though the boundaries of the physician-patient relationship should remain clear, the designation of the physician as proxy does not violate that boundary. The most common reasons cited for prohibiting a physician to act as proxy focus on paternalism and conflicts of interest. For these reasons, some state laws on end-of-life care prohibit patients from appointing their physicians as health care proxy unless they are related to them. However, the assumption that physicians will act paternally is no longer valid.

Paternalism may not be dead, but it is certainly a decrepit concept. Early benchmark cases in bioethics often featured physicians paternalistically overriding patients’ wishes to forgo life-sustaining medical treatment, and ethics commissions and task forces identified physicians’ proclivity to paternalism as a reason to prohibit physician proxies. However, a series of recent studies reveal just the opposite. In life support discussions with surrogates, for approximately half of the decisions that arise, physicians do not provide a recommendation, and even when families explicitly ask for a recommendation, only approximately half of physicians give one. The struggle in training physicians is not tamping down a burgeoning paternalism, but helping them understand their professional role to provide recommendations rather than offering treatment and nontreatment options as mere menu choices.

The other common reason for prohibiting physicians from acting as proxies is a fear that physicians may have conflicts of interest. Certainly there is a potential conflict of interest when a physician would be paid more for continuing life-sustaining medical treatment. But 2 points might be made. First, that conflict of interest is present whether the physician is proxy or not. Most proxies rely on physician recommendations about treatment. Second, there is no empirical evidence to reveal that physicians make choices that are against the patient’s wishes for financial reasons, nor is there evidence to reveal that salaried physicians are any more likely to stop life-sustaining medical treatment than are physicians who are paid on a fee-for-service basis.

Other possible proxies also have potential conflicts of interest. Family members may have financial conflicts of interest concerning treatment decisions (in matters of estate settlement or financial responsibility) and may also have conflicts of interest in asserting their own preferences about the patient’s treatment rather than asserting those of the patient. Court-appointed guardians who are paid have a conflict of interest tied to the patient’s continued life. Of course, a court-appointed guardian must not allow that conflict of interest to interfere with the appropriate
determination of what should be done for the patient. The same considerations should apply to the physician who cares for the patient. The presence of conflicts of interest should be identified, disclosed, acknowledged, and addressed through minimization when elimination is not possible.

Another reason to allow physicians to act as a proxy concerns the emerging understanding of the significant burden of surrogate decision-making in end-of-life care. A systematic review of studies of the effect on surrogates of making treatment decisions for others reveals that making those treatment decisions has a negative emotional effect on at least one-third of surrogates, including stress, guilt over decisions made, and doubt about whether the right decision was made. These negative emotional effects are often substantial and may last months or even years. It is not unreasonable for a patient to recognize this potential proxy burden as an important reason for the patient to choose a physician proxy. In the case presented, the patient may understand that one of the reasons his mother may not want to let him go may be because she cannot bear the burden of being “responsible” for allowing the patient to die, despite the proxy’s responsibility to implement the patient’s wishes.

The burdens of being a proxy decision maker might be even more difficult for a physician than for a family member. Before the physician, at the patient’s request, agrees to bear the burden of decision-making, the physician should weigh carefully the potential emotional toll this burden may take on his well-being, and also consider the attendant vigilance that will be necessary to maintain the appropriate boundaries of the doctor-patient relationship.

The patient might consider using a directive to physicians (“living will”) to forego specified life-sustaining medical treatments if the patient has a terminal condition and lacks decision-making capacity. However, many clinicians and ethicists recommend the use of a power of attorney for health care instead because these give the proxy decision maker more flexibility to make decisions in light of the current medical situation. In addition, a power of attorney for health care allows decisions whenever the patient becomes incapacitated and is not limited to situations in which the patient has a terminal condition.

The law of informed consent allows the patient to waive the physician’s obligation to disclose the nature of the treatment, as well as risks and alternatives, essentially allowing the physician to act as the patient’s informed decision maker. The recognition that the patient may defer decision-making to the judgment of the physician (based on the physician’s knowledge of the patient) should be extended to the ability of physicians to make those same decisions as the proxy when the patient has lost decision-making capacity.

In the case presented, the patient’s trust in his physician to act in accord with his wishes, his judgment about the inability of his mother to make a decision to withhold or withdraw treatment, and his understanding of his disease and advance directives (including his discussion with other patients) far outweigh concerns of paternalism and conflict of interest in his decision to appoint his physician as his proxy.

The discussion about the patient’s preferences should be documented in the chart, the patient’s decision should be disclosed by the patient to his mother, and then when the time comes, the physician should communicate with the mother and other family members and address their concerns in light of the patient’s wishes. If the physician is willing (at the request of the patient) to take on the burden of acting as a proxy, the physician should be allowed to do so.

Phil Black Writes

Upon first reading this case presentation, my immediate answer was “Absolutely not. It is a conflict of interest and absolutely unethical for Dr Andrews to be Richard’s designated proxy for health care decisions.” By the following morning, after further reflection during my drive home from the hospital and going over several actual and imaginary scenarios, my answer changed to “Yes, but…”

It is fairly clear from this case presentation that Richard is a competent adult and an experienced patient, gaining firsthand knowledge of many of the processes that would be present during his anticipated deterioration. At the same time, he is “only” 20 years old. Although this is full adulthood in the eyes of the law, it is a point in life in which his relationship with family and friends is fluid. Thereby, my first question would be the identification of a designated proxy. Has Richard actually had this discussion with his mother? Would their understanding of the specifics of designated proxy for health care decisions warrant further clarification from Dr Andrews or another provider? Are there considerations that Dr Andrews’ performance of this role would be hurtful to Richard’s family? How would that consideration influence Richard’s request? Are there other persons who have been considered for this role?

The second set of questions relates to Dr Andrews’ response to this request. For many physicians, pediatricians in particular, the patient’s family has been and may continue to be their “patients.” Dr Andrews likely has an established relationship with Richard’s family, and this request from Richard should be reviewed with them, ideally with Richard’s participation. (Should
Dr Richards accept this proxy roll, it would be hoped that this be taken for Richard and the family rather than for Richard and from the family.) The situation should be reviewed with his colleagues and coworkers, particularly those who have also known Richard and those who would potentially be involved in caring for Richard during his final days. The hospital council should also be asked for comment, as some sort of challenge related to real or perceived state laws or medical staff bylaws may arise. Depending on the practices of the institution, consultation with the hospital ethics committee may be helpful, as well. Dr Andrews should reflect on the potential conflict of roles; how would his or her physician’s wish for the right medication or therapy to add meaningful days to Richard’s life influence the much less technical role of deciding when to forgo such therapies?

In thinking through these questions and scenarios, I realized that my own role in former patients’ end of life processes could appear to an unbiased observer to have been precisely that of a designated proxy for health care decisions. I recall making statements such as “We are approaching the type of situation that Richard asked to be avoided” or “It is not necessary to keep the oxygen mask on at this point.” The nature of my relationship with family members was a strong determinant of this role.

Putting this all together, I think it is undesirable for Dr Andrews to function as Richard’s designated proxy for health care decision. However, I doubt that the perfect designee exists. The choice of Richard and Dr Andrews must be thoroughly weighed against other possibilities, and Dr Andrews may be the “better” choice.

John D. Lantos Comments

Medicine is, necessarily, a moral enterprise. Doctors necessarily and constantly make moral judgments. They do so when they decide what questions to ask patients as they take a history, what tests to order to establish a diagnosis, and which treatments to offer or to recommend. Health law and bioethics try to distinguish between the doctor as a value-neutral technician and the doctor as a moral agent. This is a futile task. The different roles of the doctor cannot be separated in practice as neatly as they can in theory. This case illustrates the ways in which attempts to do so become internally inconsistent.

When a competent adult patient wants to name his doctor as his proxy decision maker, it would be a violation of his autonomy to prohibit that choice. An autonomous person can make a reasonable and rational choice to delegate decision-making authority to another person, even if that person may have conflicts of interest and even if others think that the decision is not a wise one. That is, perhaps, what Richard is doing. So, although the concerns that each author has are valid ones, and although it is important to insure that Richard is aware of those concerns, it would be inappropriately paternalistic to curtail his freedom because we disagree with his choice of his doctor as his proxy decision maker and think we know better than he does what is best for him.

REFERENCES

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