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A New Standard for Incapacitated Patient Decision Making: The Clinical Standard of Surrogate Empowerment

Marc Tunzi

ABSTRACT

Founded upon the primacy of the principle of respect for autonomy, three methods of surrogate decision making traditionally have been promoted to help the family and friends of incapacitated patients. Unfortunately, the standards of advance directives, substituted judgment, and best interests are often inadequate in practice. Studies report that few patients have formal, written advance directives; that patients often change their minds about treatment over time; that many patients are simply not ready or willing to plan ahead—in part, because some patients and families simply don't believe in autonomy; that those patients who do plan ahead often do not communicate their plans; and that while some patients want their directives followed strictly, many prefer that their surrogates use judgment in making decisions. After reviewing articles describing a variety of alternative approaches, a new clinical standard of surrogate

empowerment is proposed to reconcile and integrate these observations and concepts. The "procedure" for this clinical standard is presented.

INTRODUCTION

People are different. We are different sizes, shapes, and colors. We espouse different values, beliefs, customs, cultures, and religions. We exhibit different personalities. We have different experiences of health, wellness, and illness.

And yet we throw patients and their surrogates all together into one big box, giving them only a couple of choices to facilitate complex medical decision making. It is time for a new standard to help widely diverse patients and families make these difficult, often life-and-death determinations: the clinical standard of surrogate empowerment.

Founded upon the primacy of the principle of respect for autonomy, three methods of surrogate decision making traditionally have been promoted to help family and friends evaluate medical options for patients who become inca-

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pacitated.¹ The standard of advance directives states that surrogates should follow the previously documented, clearly written wishes of individual patients. This standard is usually viewed as a subset of the standard of substituted judgment, which states that surrogates should make choices in the same way the patient would make them if the patient were not incapacitated. The standard of best interests states that when a patient has not previously documented clear wishes, and when the surrogate does not know what the patient would decide under the current circumstances, the surrogate should make decisions that he or she believes are in the patient's best interests.

There are two very significant general problems with these standards. First, not every patient and family endorse the primacy of the principle of respect for autonomy, but may instead prefer to balance autonomy with beneficence, nonmaleficence, and justice, based on the family and community consequences of the decisions to be made. Second, even when patients and families do endorse the primacy of autonomy, it is not clear that these standards always support autonomous decisions in practice, relying instead on guesses or on opinions expressed in the past.

This article will examine the shortcomings of the standards of advance directives, substituted judgment, and best interests. It will then review the alternative decision-making methods of substituted interests, therapeutic interests, narrative, and covenants, and the process of shared decision making. Finally, it will suggest a clinical standard of *surrogate empowerment*, a model that better reflects the diversity of the patients and families we serve and the diversity of medical decisions we ask them to make in real life.

THE INADEQUACIES OF THE STANDARDS OF ADVANCE DIRECTIVES, SUBSTITUTED JUDGMENT, AND BEST INTERESTS

The growth of contemporary bioethics over the last 50 years has been based largely on the principle of respect for autonomy.² People have the right to control their own bodies and to make

their own medical decisions. Advance care planning and advance directives (ADs) were developed to provide individuals the capability to make future healthcare decisions in the event they were to lose real-time decision-making capacity. The 1990 Patient Self-Determination Act endorsed the notion of future autonomy by promoting advance directive documents through legislation. The well-publicized cases of Karen Ann Quinlan and Nancy Cruzan highlighted the need for patients and families to have control over themselves and their loved ones if they wished to avoid the false beneficence of continuing life-sustaining treatment when there is no chance of meaningful recovery.

Bioethicists have encouraged the development and implementation of ADs as the most practical way to honor the two standards of surrogate decision making that best support autonomy—the standard of advance directives and the standard of substituted judgment.³ The annotated durable power of attorney for healthcare has been promoted as the best of these AD documents. This type of AD does two things:

1. They respect autonomy by honoring a patient's carefully considered and clearly documented wishes regarding prospective medical care, noting particular treatments and interventions that the patient will accept or decline, and
2. They enable a patient to appoint a specific surrogate agent or proxy to make future medical decisions in the event the patient were to lose medical decision-making capacity—hopefully, a surrogate who will make decisions in the same manner that the patient would for him- or herself, based on discussions of the patient's clinical condition, medical values, and thinking processes that the patient and surrogate had together before the patient's incapacitation.

Unfortunately, despite their theoretical appeal, the standard of advance directives and the standard of substituted judgment are often inadequate in practice.⁴ The standard of advance directives suffers from three problems:

1. Only a few U.S. adults have ADs,
2. Over time, many people change their minds

- about their advance planning decisions, and
3. Many individuals who do clearly document their wishes about specific interventions actually prefer that their surrogates use judgment in making future medical decisions, rather than follow their previously documented directives strictly.

Studies of the rates at which advance directives are completed suggest that 18 percent to 36 percent of all Americans have an AD.⁵ The large, national SUPPORT study performed at academic medical centers demonstrated a 21 percent AD rate.⁶ A more recent, smaller study at four community hospitals in California, however, indicated that only 7 percent of patients had completed an AD, varying from <1 percent at a public county hospital to 12 percent at an urban community hospital.⁷ Both the SUPPORT and California studies suggest that patients with ADs don't use them to their fullest potential, and that ADs do little to specifically guide hospital treatment.

Studies of the stability of patients' life-sustaining treatment preferences indicate that somewhere between 15 percent and 50 percent of patients change their minds about future medical decisions.⁸ Stability varies by individual, by changes in patients' health status, and by clinical scenario. Some people exhibit more stability in medical decisions, overall, than others. Both positive and negative changes in health, illness, and disability are associated with changes in decision making that are difficult to predict, with better or worse states of future health influencing decisions in different ways for different people. And some clinical scenarios are more stable than others. Generally, initial decisions to decline care are more stable than initial decisions to accept care, and decisions related to the most serious and least serious conditions are more stable than decisions related to intermediate clinical scenarios. Patients with ADs exhibit more stability than patients without ADs—although this is probably related to the fact that more people with ADs decline aggressive future treatment than people without ADs. No groups of patients are completely stable, however: patients with and

without ADs, patients who initially accept or decline care, and patients who are healthy, ill, or disabled all change their minds.

One reason people change their minds about medical decisions over time is due to what Lachlan Forrow calls "The Green Eggs and Ham Phenomena": until an individual has thought about a situation at some length—or better yet, has experienced it—that individual can't make a truly informed decision.⁹ Thus, an individual's initial response may not be that individual's ultimate response. The nameless Seussian fellow in the book tells Sam-I-Am, "I do not like green eggs and ham"—until, of course, he finally tries them.

These phenomena may also explain why several studies report that many people who have previously expressed specific preferences about life-sustaining treatment prefer that their surrogates use judgment in making future decisions, rather than to follow their previously expressed preferences strictly.¹⁰ These studies do not analyze the differences between those patients who want their preferences followed strictly and those who want their surrogates to use judgment, however. They simply group patients into two broad categories and note that patients who want their surrogates to use judgment in medical decision making cite *trust* as their primary reason for doing so.

The standard of substituted judgment suffers even more from a lack of clinical utility. Studies suggest that agreement among what most people would consider to be the best patient-surrogate pairs (a surrogate appointed via a power of attorney; a longtime spouse) is only about 66 percent when they are presented choices for care in various clinical scenarios.¹¹ Indeed, evidence suggests that agreement between patients and surrogates is not necessarily influenced by patient appointment, in contrast to "default" surrogates,¹² or by whether patients and surrogates have engaged in prior discussion about future decisions.¹³ Studies have not assessed whether differences in patient-surrogate agreement vary by the patient appointment process (that is, do some appointments result in more agreement than others?) or by the quality of prior discussions between

patients and surrogates (that is, is agreement better if a specific set of issues and topics is covered?).

In practice, future medical scenarios are difficult to predict, and personal values and thought processes are difficult to discuss. Further, since individual patient's choices regarding complex treatment preferences often change over time, it is not surprising that surrogate decisions are also imperfect.

Moreover, not all patients and families believe in planning ahead or in picking one specific surrogate.¹⁴ In fact, not all patients and families believe in the primacy of the principle of respect for autonomy. Some people simply don't plan: it's not their personality, it's too stressful, or they are too uncertain about their situation and their choices to think about any kind of medical issue in advance.¹⁵ Others simply realize that once they lose capacity it won't be their problem. Many patients and families from minority cultural and ethnic groups do not believe in picking one surrogate.¹⁶ Instead, they believe that all of life's complex decisions—especially medical decisions—are family decisions that can only be made in the context of family consensus. Because the outcomes of these decisions affect everyone in the family, individual autonomy makes no sense to them. Decision making must balance autonomy with beneficence, nonmaleficence, and justice in the family context, honoring the patient's role as a member of a larger, loving family community. Outcomes, too, can only be evaluated in the family context—outcomes that are necessarily influenced by the ongoing care patients receive from family members.

One family issue that often influences end-of-life decision making is that of family burden.¹⁷ Patients often make decisions based on a personal value of wishing not to burden their families. And yet it is their families who will ultimately determine whether the consequences of a decision are burdensome to them or not, not the patient. Autonomy, beneficence, nonmaleficence, and justice: who decides?

This question of "who decides?" is also the basis for the practical inutility of the standard of best interests.¹⁸ "Best" according to whom,

using what criteria, under what circumstances? In practice, "best" usually means beneficence, and "doing good" usually means doing more, as if every unknown situation requires the default, emergency response of providing treatment unless it is clear that an individual would not accept it or should not receive it. Applying this line of thinking to advanced chronic illness and end-of-life care makes no sense. Very often, patients are provided more care than they would likely choose and accept for themselves. Elsewhere in medicine, physicians are admonished to "first, do no harm," honoring the principle of nonmaleficence. Somehow, this admonition is forgotten with incapacitated patients who, as attested to by their very incapacity, are the patients most in need of our compassion and practical wisdom to know when to quit and not be held hostage by misguided beneficence.

Surrogates who do not have the benefit of clearly expressed prior patient wishes, and who do not know a patient well enough to make decisions in the same manner that the patient would make them, are forced to make decisions based on their best guess of the right thing to do. Unfortunately, the four great goals of medicine—to prevent disease, to cure illness, to ameliorate pain, and to prolong life—are often in conflict with each other.¹⁹ Surrogates often have an impossible choice—a choice that leads to uncertainty, anxiety, guilt, and personal distress.²⁰ And it is often a choice that provides no guarantee that the right decision has actually been made.

ALTERNATIVE CONCEPTS AND ADJUNCT RECOMMENDATIONS

A number of authors have presented alternative approaches to surrogate decision making, offering various insights into the process of preparing for, supporting, and fulfilling that difficult role. Several have written about the general process of shared decision making.²¹ Some have described surrogacy as the process of continuing an individual's narrative when that person can no longer do so him- or herself.²² Fins and colleagues have suggested that the role of a surrogate is to fulfill a covenant

with the patient.²³ Sulmasy believes that the concept of “substituted interests” is more helpful than that of substituted judgment.²⁴ Kapp recommends decision making based on “therapeutic interests” rather than best interests.²⁵

“Shared decision making” refers to the process of negotiating how large a role patients or their agents play in making medical decisions. Kon describes a five-point continuum of participation, ranging from a 100 percent patient-driven process at one end, to a 100 percent physician-driven process at the other, with three steps in between.²⁶ Because surrogates are often unable to apply the standards of advance directives and substituted judgment, and because they are able to apply the standard of best interests only with difficulty, sharing the process of decision making with the clinical team is necessary in practice.²⁷ A study by Johnson and colleagues suggests that surrogates vary in their desire to participate in decision making, but tend to prefer more authority in value-sensitive decisions, such as those involving futility or quality of life, than in technical-medical decisions, such as those involving which specific interventions to accept or decline.²⁸ Clinical practice guidelines written by the American College of Critical Care Medicine endorse a partnership model of medical decision making in the intensive care unit, assisted by early and frequent family meetings to review the patient’s and the family’s understanding of the clinical situation, assess emotional needs, and provide information and support, as needed.²⁹

The process of narrative has also been promoted as a means of directing surrogate decision making.³⁰ Narrative advocates assert that what surrogates are called to do is to help patients live/write/tell the next part of their personal story at a time when they cannot do it for themselves. Surrogates are advised to honor the personal identity of the patient and to make choices that “fit” or “hang together” with the choices that the patient previously made and the manner with which the patient has conducted his/her life. Indeed, such an approach can be helpful even when the patient’s specific medical preferences and medical values are not known. The surrogate’s task is simply to con-

tinue the patient’s story to the best of her or his ability to do so.

Fins and colleagues believe that the traditional *contractual* standard of surrogate decision making should be replaced by a *covenantal* patient-proxy relationship.³¹ In this model, a surrogate is not simply “a sterile instrument who accurately conveys patient preferences,”³² but someone who can think “inductively and contextually” on the patient’s behalf.³³ That is, a surrogate is someone who is responsible for faithfully representing the patient to the health-care team by means of being an active and committed interpreter of the patient’s interests and wishes. According to Fins and colleagues, patients and proxies favor a judgment-based covenantal approach over strictly following a patient’s instructions—with one exception: negative instructions to withhold care are expected to be followed closely.

This notion of interpreting the patient’s interests is also the basis of Sulmasy’s approach to surrogate decision making.³⁴ Indeed, Sulmasy labels his approach “substituted interests,” to emphasize that what surrogates are asked to do is to apply what is known about the patient’s specific preferences to what the surrogate knows generally about the patient’s values and interests, in order to make decisions for that person. For Sulmasy, the principle of *authenticity* is more important than the principle of *autonomy*, and the right question for surrogates is not “What would the patient choose if he or she could tell us?” (a theoretical question that is not usually answerable), but “What can you, the surrogate, tell us about the patient—about his or her values, beliefs, moral commitments—and how you can use that knowledge to make the right decision now?”

Kapp labels his approach to surrogate decision making “therapeutic interests,” seeking the best action by balancing what is possible for patients with what is therapeutically indicated under the current clinical circumstances.³⁵ In effect, Kapp re-introduces the primacy of “do no harm” into clinical decision making—emphasizing the avoidance of unnecessary, painful interventions in order to determine what should be done.

All of these alternative surrogate decision-making approaches start by noting that the traditional standards are inadequate in many situations. Kapp, for example, specifically promotes “therapeutic interests” rather than “best interests” to balance beneficence with nonmaleficence and prevent futility. Kuczewski and the other narrative authors, Fins and colleagues, and Sulmasy all seek more practical alternatives to substituted judgment. In clinical practice, narrative, covenant, and substituted interests appear quite similar: all seek to engage surrogates in a way that builds on their relationship with the patient, rather than their knowledge of specific treatment directives by the patient, or their knowledge of the patient’s specific views about clinical treatments.

In addition to these authors who have presented alternative concepts and philosophical approaches to surrogate decision making, others have discussed a wide variety of adjunct recommendations to augment and better inform all surrogate processes. For example, Emanuel and Emanuel have long advocated that patients and their surrogates discuss possible future medical scenarios and the kinds of treatment decisions that might be associated with them.³⁶ According to this recommendation, which directly supports the standard of substituted judgment by enabling surrogates to make the same treatment choices that patients would make in specific clinical situations, the more detailed the discussions patients and surrogates have together, the better. However, evidence that scenario-driven discussions make a significant impact in practice is weak: they do not address the issue of patients changing their minds over time, and they cannot possibly cover all future medical events.³⁷ One recent study, however, does suggest that disease-specific scenario discussions are helpful for patients with advanced illness.³⁸

Doukas has proposed that detailed discussions of medical and personal values are more helpful than discussing a set of theoretical clinical scenarios.³⁹ This recommendation also directly supports the standard of substituted judgment—the more a surrogate knows about a patient’s values, the better he/she can think like

the patient regarding treatment decisions—but it also informs other approaches. Like scenario-based discussions, however, these discussions do not address how a patient’s values may evolve over time, nor do they necessarily account for the harsh reality of care in the intensive care unit or care at the end of life. Indeed, some values develop only in the face of real-life choices. For example, a patient who values mental alertness over pain control or values “fighting until the end” over “quality of life” might have never considered what it’s like to experience accelerating cancer pain or long-term ventilator support.

Some authors, most notably Pearlman and colleagues at the Veterans Administration, have attempted to combine scenario- and values-based discussion planning to help patients plan more broadly.⁴⁰ They have also encouraged other kinds of end-of-life preparations, such as organ donation, funeral arrangements, financial planning, and so on. Unfortunately, their monograph, *Your Life, Your Choices*, is no longer available from the VA.

The “5 Wishes” document, available from the organization Aging with Dignity, is another means to integrate scenario- and values-based planning.⁴¹ This document asks individuals to consider:

1. The person they wish to be their surrogate decision maker,
2. The kind of medical treatment they want or don’t want,
3. How comfortable they wish to be,
4. How they wish for others to treat them, and
5. What they wish their loved ones to know.

A menu of examples and choices for all five wishes is listed for consideration within the document.

Smucker and Houts and colleagues propose a non-patient-centered means of assisting surrogate decision making.⁴² Based on a study of geriatric outpatients and their self-selected surrogates, these authors believe that an actuarial model of decision making using statistical analysis is just as accurate as surrogate decision making in predicting what patients would choose for care. Modal preferences are also just

as stable over time as surrogate decisions. Whether most patients would be comfortable with this kind of decision making is not clear, but community standards can certainly inform surrogate decision making. Such a process is consistent with concepts of community morality and the reflective consensus of communitarian ethics proposed by Kuczewski as the best approach to highly complex public medical policy issues.⁴³ It may also meet Dresser's quest for a "community mission" to address what she views as the "social problem of medical decision making for incompetent patients."⁴⁴

Still, in the absence of alternative preparatory activities, reviewing scenarios, discussing values, and having an advance directive are better than nothing. After all, even community modal preferences must be based on *something*. Indeed, Silveira and colleagues have empirically demonstrated that patients with ADs receive care more consistent with their preferences than patients without ADs.⁴⁵ At the same time, discovering what makes some discussion and planning activities better than others remains open for continued study.

The POLST (physician orders for life-sustaining treatment), also known as the MOLST (medical orders for life-sustaining treatment) in New York, is a new advance care planning document designed for individuals with terminal illness or actively progressive chronic disease (for example, congestive heart failure, chronic obstructive pulmonary disease, chronic renal disease, cirrhosis, Alzheimer's disease).⁴⁶ Taking the idea of disease-specific planning one step further, the POLST is essentially an intensity of care document that enables an individual to choose: in Section A, CPR (cardiopulmonary resuscitation) or no CPR; in Section B, comfort measures only, limited additional interventions (for example, intravenous fluids, antibiotics), or full treatment; and in Section C, no artificial nutrition (that is, tube feeding), a trial of artificial nutrition, or long-term artificial nutrition.

Once signed by a patient—or surrogate—and by the patient's physician, the POLST is a legal physician order that travels with the patient from clinical site to clinical site (that is, from home to hospital to skilled nursing facil-

ity and back, et cetera). In this way, the POLST is the ultimate end-of-life advance directive. Patients and physicians are advised not to sign the document, however, unless the patient's clinical situation and prognosis are clear and they have had an opportunity to discuss the stability of the patient's choices, the likelihood of anticipated scenarios, and the role of surrogate judgment and shared decision making. The patient (or the surrogate) and the physician should make a commitment to review the POLST at least once a year, and they should also review it every time the primary site of clinical care changes.

INTEGRATION AND THE NEW PROCEDURAL STANDARD OF SURROGATE EMPOWERMENT

Reconciling what is known about surrogate decision making and advance care planning and integrating this information into a holistic, practical approach that honors our pluralistic society is not straightforward. Several authors have attempted to do this from a variety of perspectives.

Sabatino takes a distinctly legal approach to the process, beginning with a discussion of the legal history of proxy decision making, in general, and the legal history of medical surrogacy, in particular.⁴⁷ He then reviews the current status of diverse state laws on the topic, emphasizing the tension between what he terms the "legal transactional approach" of tools and forms and the "communications approach" of discussion and conversation. Finally, he makes five recommendations that he believes will improve physician-surrogate relationships:

1. Allow the appointment of immediately effective proxies, who would serve as official patient advocates or advisors for patients still having capacity and who would become legal surrogate decision makers when patients lose capacity.
2. Require medical providers to identify proxies as early as possible for patients "suffering from chronic or acute illness or condition that could lead to death."
3. Require medical providers to provide writ-

ten information and counseling to surrogates.

4. Define a method of informed consent that emphasizes the physician-surrogate discussion process.
5. Recognize the authority of proxies over written living will directives.

Pope also presents a legal review of medical surrogacy, starting by identifying five distinct types of surrogates:

1. Surrogates designated by patients via ADs,
2. Surrogates designated by patients via oral directives to their physicians,
3. Court-designated surrogates such as guardians and conservators,
4. Default surrogates such as family members who are identified by physicians and/or who follow hierarchical guidelines according to state law,
5. Special surrogates such as temporary guardians, hospital ethics committees, regional surrogate committees, et cetera, for patients who do not have family or friends able to serve as surrogates.⁴⁸

He then outlines problems with surrogate decision making and suggests several general solutions to these problems, including a recommendation for surrogate education—although he does not clearly define what this education should comprise in practice.

Torke and colleagues, in contrast, take a very different approach to integration, describing a conceptual model of surrogate decision making founded upon “information processing” and “relationship building” between surrogates and clinicians that leads to “high quality medical decisions.”⁴⁹ While the authors describe the theoretical steps to their communication-based approach, they do not provide a detailed description of how to apply these steps in practice.

Vig and colleagues describe five “actual processes of surrogate decision making” based on conversations with individuals who previously served as surrogates.⁵⁰ These surrogates based their decisions on the following primary factors:

1. Past conversations with patients (66 percent),
2. The surrogates’ own beliefs, values, and preferences (28 percent),
3. Consensus-building discussions with patients’ other family members and friends, clergy, and clinicians (18 percent),
4. Past life experiences shared with patients (16 percent), and
5. Patients’ written documents (10 percent).

Vig and colleagues do not conclusively describe *why* surrogates chose the primary basis they did for their decision-making process.

Braun and McCullough outline a very detailed set of algorithms summarizing what they see as the current, common “best interests” practice of providing life-sustaining treatment by default.⁵¹ They write that a combination of three factors leads to continuing life-sustaining treatment:

1. The presumption of preserving life when a patient’s preferences are unknown or when the prognosis is not absolutely certain,
2. Surrogates’ requests to “do everything” out of fear, guilt, and so on,
3. The path of least resistance, in which clinicians do not really engage surrogates to think through what “doing everything” means.

Their suggestion for how to address these complex scenarios is actually fairly simple: clinicians must actively encourage patients and surrogates to discuss and communicate preferences and decisions early and often, both orally and in writing. They do not describe in detail, however, *how* to make this happen.

In a manner fairly similar to the argument made at the beginning of this article, Berger, DeRenzo, and Schwartz note that the bioethical hierarchy of the three traditional standards of surrogate decision making—advance directives, substituted judgment, and best interests—are often inadequate in practice.⁵² In response they propose a multidimensional approach that honors our society’s complex and pluralistic patient population and reconciles ethical theory with clinical practice. In preparation for the future, they encourage physicians to assist their

patients in completing ADs by discussing prognosis, broad goals of care, and the role of their directive either “as binding, as weighty but not binding, or as merely informative.” Clinicians should also assist patients in identifying their best proxy and best decision-making process. Once a patient with an AD becomes incapacitated, Berger and colleagues believe that clinicians should:

1. Review the patient’s previously written specific directives in light of a current assessment of benefits and burdens,
2. Assess who the patient’s best surrogate might be, and
3. Review with that surrogate how to implement the patient’s advance directive, including whether it should be followed strictly or whether there is reason to diverge from it.

When caring for a patient without an AD, clinicians should assist the surrogate in constructing a narrative for that patient that includes the patient’s preferences and values.

Sudore and Fried emphasize preparation for “in-the-moment decision-making” by patients and surrogates rather than the completion of advance directive documents.⁵³ They write that the first part of this preparation is to assess a patient’s readiness to engage in advance planning and then, when the patient is ready, to help him/her execute three steps:

1. Choose an appropriate surrogate decision maker,
2. Clarify and articulate personal values, and
3. Establish leeway in surrogate decision making.

They conclude their article with brief sample language for clinicians wishing to engage in this process.

In a systematic review of empiric studies on the effects of surrogate decision making, Wendler and Rid assert that at least one-third of surrogates in the studies experience emotional stress and burden due to a variety of factors, including uncertainty regarding patients’ preferences, uncertainty regarding prognosis, and poor clinician communication.⁵⁴ Noting

that preparation and prior discussion decrease surrogates’ stress, the authors propose three general behaviors to promote the surrogate process:

1. Identify treatment consistent with patients’ preferences,
2. Respect patients’ preferences regarding how decisions should be made, and
3. Protect family and loved ones.

In a separate systematic review of studies evaluating individual patient goals for surrogate decision making, Kelly, Rid, and Wendler⁵⁵ note that most patients want three things:

1. The involvement of their family members,
2. To be treated in accord with their stated preferences (although the authors acknowledge that patients vary greatly with regards to how much leeway they wish their surrogates to have), and
3. To minimize the burden of their situation on their families.

In a policy paper on how to improve the surrogate process, Rid and Wendler advocate shared decision making between surrogates and clinicians, and they encourage identifying and incorporating patients’ preferences in as detailed and specific a manner as possible.⁵⁶ They strongly promote future research on how to integrate patients’ treatment preferences into shared surrogate-clinician decision making, as well as research on the development of an instrument to survey these preferences.

Meanwhile, although several general advance care planning resources are available,⁵⁷ there remains a need to develop practical clinical tools to assist patients in planning for the future and to assist surrogates—indeed to empower them—to handle their role when called upon. What we know is this:

- Documenting specific advance directives is good, but many patients change their minds over time.
- Clear decisions not to want certain types of treatment are more stable than other decisions.
- Patient-surrogate agreement on specific treatment decisions, in the best situations, occurs only about two-thirds of the time.

- Patient-surrogate discussions of values and scenarios do not necessarily improve agreement. Discussion does appear to decrease surrogates' stress. Disease-specific scenario discussions may improve agreement more than generic discussions do.
- Some patients want their directives followed strictly. Many patients want their directives to inform their surrogates' decisions, but they prefer that their surrogates use judgment in decision making.
- Narratives, interest-based conversations, and covenantal relationships might help some patients and surrogates prepare for and fulfill their respective roles and duties.
- Shared decision making is central to all approaches.

A new clinical standard of surrogate empowerment is therefore proposed to reconcile and integrate these observations. Surrogates must be empowered—by preparation as well as by explicit endorsement by patients and clinicians—to fulfill their role thoughtfully, responsibly, and with the respect and support of patients' other family members, friends, and the healthcare team. This clinical standard acknowledges the stress of the surrogates' role, the strengths and limitations of current standards, the need to incorporate patients' preferences for treatment and decision-making style, and the need for a process that has practical clinical utility. It both honors societal diversity and the pluralism of patients, and it addresses real-life clinical situations. Finally, it is open to be the focus of empiric research and future refinement.

The procedure for this clinical standard is outlined here.

PROCEDURE FOR HEALTHCARE PROFESSIONAL WITH THE PATIENT

The healthcare professional can use this "script" in discussions with patients on planning.

1. I think that all patients [or all patients in certain categories: terminal illness, advanced chronic disease, any chronic disease, patients who are older than 65 . . .] should think about

advance care planning. How should medical decisions be made for you, if you were not able to make them for yourself because of illness or because of the effects of medication or other treatments?

2. Who could or should make decisions for you? Can you identify one or two best substitute or "stand-in" decision makers? Doctors usually use the word "surrogate" or "proxy" for this person. If several possible surrogates come to mind—for example if you have several children or several siblings—would you like help in identifying which one or two would be the best surrogate(s) for you? Would you like help in talking to your family about who your surrogate(s) should be?

3. Or is your family one in which everybody makes important life decisions together? If so, can you identify one or two family members who might be best able to pull your family together and be the best spokesperson(s) for you? Please remember that surrogate decision making is often very stressful for family and friends. The more you are able to plan ahead, the better you will be able to take care of them and keep your family and friends from feeling guilty and stressed when the time comes for them to make decisions for you.

4. Are there specific treatments or interventions that you are *completely certain* you want to have done, if medically indicated, or that you are *completely certain* you would never want done, even if they might be options for care? For example, undergoing cardiopulmonary resuscitation (CPR), being intubated and put on a breathing machine, having a feeding tube placed, [et cetera].

5. Are you comfortable discussing specific medical scenarios with your surrogate or family and talking about what you might want or not want done under particular circumstances? What if you developed Alzheimer's and had no memory and couldn't recognize people? Or what if you developed terminal cancer and had a prognosis of only six to 12 months? Or what if you had a severe stroke and couldn't talk or eat? Or what if you developed severe lung disease and needed long-term ventilator treatment? What might you want or not want in those situ-

ations? Talking about these situations is very difficult, but it will help your surrogate to make decisions, as much as possible, in the same way that you would make them for yourself if you could.

Would you like help on how to have these kinds of conversations?

5.A. [For patients who have a specific terminal illness or a very serious/advanced chronic illness.] Given your current medical situation, there are a couple of disease-specific scenarios that are very possible. Would you be comfortable discussing those scenarios and the kinds of decisions that will likely need to be made should they occur?

6. Are you comfortable discussing your medical and personal values with your surrogate and family? Some people, for example, really want to avoid pain—even if that means that they might die sooner or be “drugged up” a lot of the time because of pain medication. Others, often for religious reasons, want to live as long as possible regardless of how or where they live (for example, on a breathing machine in the hospital). Some people want to live only if they can be awake, talking, and thinking clearly. Still others want treatments only if those treatments will help them get out of the hospital and back home. Some people want to be certain that they do not become a burden to their family.

What kinds of things are important to you?

Would you like help on how to have these kinds of conversations?

7. Many patients prefer not to be too specific in stating prior wishes, however, because: (A) They are too uncomfortable—or simply too uncertain about medical care in general—to discuss their medical and personal values. (B) They know their medical situation might change and they just can’t predict the choices they might have to make. Or (C) like lots of patients, they know they might change their minds as their situation develops over time. Many of these patients would like their surrogates simply to follow community standards about medical decision making—that is, what most people want in these situations. Would you like us to discuss with your surrogate what most people in your situation usually want done?

8. Other patients prefer that their surrogate [or their family, if the patient has expressed interest in a family-consensus style of decision making] simply use his or her judgment in making decisions. Does this sound like what you would like?

9. If you would like your surrogate to use his or her judgment in making decisions for you, would you be comfortable telling him/her that? That is, would you be comfortable telling your surrogate to do his/her best with whatever happens? In a sense, you are empowering your surrogate to write a part of your story, because you trust them to do so.

10. Another way to prepare your surrogate to make decisions for you is to empower him/her to make decisions the same way he/she would for him/herself in the same medical situation. Does it sound like something you would be comfortable telling your surrogate to do?

11. If you are able to be specific about these areas, you should document your wishes in an advance care directive document:

A. Name your surrogate(s).

B. List specific treatments about which you are completely certain you would accept or decline in particular situations.

C. List the medical and personal values that are most important to you.

D. Give direction to your surrogates about whether you want them to follow your directives strictly or whether they should use their judgment, including the judgment to make decisions for you the same way they would make decisions for themselves.

E. Write down any other guidance for your surrogates.

12. [If the patient has a terminal illness or a serious, advanced chronic illness, and if the POLST is available in your state, provide the patient a copy and review it with him/her.]

PROCEDURE FOR HEALTHCARE PROFESSIONAL WITH THE SURROGATE

The healthcare professional can use this script in discussions with surrogates.

1. Thank you for helping us make medical decisions for your friend or loved one because

of your special role/relationship in his/her life. [If the surrogate is a “default” decision maker, mention his or her relationship to the patient. If the surrogate was appointed, mention the fact that the patient must trust him/her a great deal in order for the patient to have appointed him/her to perform this special, difficult duty.] We know that this can be difficult and stressful, and we know that you will do your best. We would like to help you make the best decisions you can by asking some questions that usually help people who serve this role for their friends and loved ones.

2. Did you know that you would be making these kinds of decisions for your friend or loved one? Have you discussed advance care planning together at all?

3. Many surrogates want to share decision making with the doctors and staff caring for the patient. Would you like to make decisions independently? Or would you prefer to talk about how we can work together to make decisions?

4. Has your friend or loved one given you specific directions or expressed specific wishes about what he/she would want done in this situation? Does he/she have an advance directive, and, if so, have you discussed it? Do you have a copy? Have you discussed the kinds of medical scenarios or situations that might arise for him/her? Have you discussed the kinds of things that might be important to him/her—special values or interests—that might help you make decisions?

5. If your friend or loved one has not expressed clear wishes about what he/she would want done, and if you have not discussed specific scenarios or specific medical values, do you feel like you know him/her well enough, overall, to make decisions in a way that simply “fits with” what you do know about him/her? Do you think you can tell the story of what should happen now?

6. If you do not have a clear idea about exactly what your friend or loved one would want done in this situation, and if even the idea of “telling his/her story” seems awkward or too hard, or just not right, would you be comfortable making decisions for him/her the same way you would make them for yourself in this situ-

ation? After all, you are the person he/she asked to make decisions for him/her [or: After all you are the person with the closest relationship to him/her], so he/she must trust you a great deal.

7. Is there anything that I or anyone else on the healthcare team can do to assist you serve as the surrogate for your friend/loved one? We are here to share information with you and to share in the decision-making process as much as you need us. Is there specific information that you think would be helpful? Would you like to speak to a social worker or a chaplain or a member of the hospital’s palliative care team or ethics committee to help you understand what is going on and to help you make decisions?

8. [If the POLST is available in your state, provide the surrogate a copy and review it with him/her.]

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