

***ETHICAL ASPECTS OF THE RELATIONSHIP BETWEEN
CLINICIANS & SURROGATE DECISION MAKERS***

***A Report by the National Ethics Committee
of the Veterans Health Administration***

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***National Center for Ethics in Health Care
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Department of Veterans Affairs***

Founded in 1986, the National Ethics Committee (NEC) of the Veterans Health Administration (VHA) is an interdisciplinary group authorized by the Under Secretary for Health through the National Center for Ethics in Health Care. The NEC produces reports on timely topics that are of significant concern to practicing health care professionals. Each report describes an ethical issue, summarizes its historical context, discusses its relevance to VHA, reviews current controversies, and outlines practical recommendations. Previous reports have been useful to VHA professionals as resources for educational programs, guides for patient care practices, and catalysts for health policy reform. Scholarly yet practical, these reports are intended to heighten awareness of ethical issues and to improve the quality of health care, both within and beyond VHA.

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Executive Summary

When patients are not able to make health care decisions themselves, we look to surrogates to make decisions for them. This report by VHA's National Ethics Committee discusses the surrogate's role and responsibilities in making decisions for an incapacitated patient. It explores critiques of prevailing ethical standards for surrogate decision making and arguments that a more nuanced interpretation is called for, particularly with respect to substituted judgment. It examines more closely the surrogate-patient relationship to better understand its implications for thinking about how clinicians should work with surrogates to jointly make decisions on patients' behalf. Finally, it offers guidance for clinicians when surrogates and health care professionals disagree.¹

The National Ethics Committee recommends that VHA clinicians strive to identify opportunities to build relationships with prospective surrogates and family members of patients who are most likely to lose decision-making capacity, whether on the wards, in the ICU, or in nursing homes. The committee further urges VHA clinicians to adopt practices to promote shared decision making and foster a more collaborative relationship with surrogates:

Before a patient loses decision-making capacity

- Clinicians should clarify with the patient (and ideally with the surrogate) the patient's values relating to health care, preferences regarding treatment under different circumstances, and preferences about who should serve as surrogate in the event the patient loses decision-making capacity.

Clinicians should also clarify the patient's preferences about who should or should not be involved in the surrogate decision-making process (such as other family members), and how closely the patient wants the surrogate and treatment team to adhere to previously expressed treatment preferences (if any).

Once a patient has lost capacity

- The treatment team, surrogate, and family members involved in making decisions on the patient's behalf should jointly clarify the surrogate's role as partner in the process of shared decision making and underscore parties' mutual commitment to making decisions with which the patient would most likely agree.

The grounds for such decisions may be that they follow the patient's expressed wishes, or take account of values that would be important to the patient (which might include the patient's interest in the well-being of family members), or are in the patient's best interests. Clinicians should also make clear that as health care professionals, they have an obligation to serve as the patient's advocate.

- Clinicians should communicate effectively with the surrogate and family as the patient's situation changes. The treatment team should be candid but sensitive in discussing the patient's prognosis, and should provide regular, timely updates. It is important that information be consistent—the team should attempt to reach consensus *before*

¹ Making treatment decisions for patients who lack decision-making capacity raises distinct ethical and practical challenges in different contexts—e.g., when patients have never had capacity, when no surrogate can be identified, or when decisions are made by a court-appointed guardian. The present analysis intentionally focuses narrowly on decision making by authorized surrogates for patients who once had, but at the time health care decisions must be made have lost capacity.

communicating with the surrogate and family. Ideally, a member of the treatment team will be designated as the primary point of contact for the surrogate and family.

We encourage clinicians to seek—and VA medical centers to provide—specific training in communication skills, especially around end-of-life decisions.

- Clinicians should respect the decisions of the patient’s authorized surrogate. The presumption should be that the surrogate’s decision reflects the patient’s values and is one with which the patient would agree. Clinicians should challenge only those decisions that appear to be seriously inconsistent with the patient’s previously stated preferences, values, and/or best interests—for example, if there is convincing evidence of malevolent intent toward the patient, or blatant disregard for the patient’s wishes or interests.
- When there is disagreement about a treatment decision, clinicians should make every reasonable effort to resolve the situation, including acknowledging that patient preferences are subject to interpretation and that the patient’s surrogate is usually best able to interpret them. Clinicians should also recognize that patients may want surrogates to consider their own interests (including financial interests) as well as the interests of others who will be affected by a treatment decision. They should also remember that many patients prefer that clinicians follow the surrogate’s decision because that is the individual they want to have make decisions on their behalf.

The reasons for a decision with which the treating clinician/treatment team disagrees should be explored with the surrogate (and family) in order to clarify the decision-making process and seek shared understanding of the interests at stake for the patient, the surrogate and family, and health care professionals. The goal should be to help all parties refocus on their shared commitment to respecting the patient—for example, by asking, “Looking at this situation, given everything that’s happened, how do you think [the patient] would want this resolved?” or “Now that [the patient’s] condition has changed, what do you think [he or she] would want?”

Introduction

When patients are not able to make health care decisions themselves, we look to surrogates to make decisions for them. In the ideal scenario, the surrogate is someone who has a close, loving relationship with the patient; someone who has intimate knowledge of the patient's preferences and values; someone who has the patient's best interests at heart; someone the patient chose or would choose to make health care decisions on his or her behalf; and someone with whom the patient has discussed preferences for care.

All too frequently, however, real world interactions among patients, surrogates, and clinicians fall short of this ideal. Surrogates often are not well prepared to take on decision-making responsibility, especially around care at the end of life. They are thrust into the position of having to make extraordinarily difficult decisions with little warning, in an unfamiliar institutional environment, and with little guidance from health care professionals about what is expected of them. [Dubler 1995; Abbott 2001; Rabow 2004; Back & Arnold 2005; Lederer 2005] The result is strained relationships and even open conflict when surrogates and clinicians disagree about treatment decisions.

This report by VHA's National Ethics Committee discusses the surrogate's role and responsibilities in making decisions for an incapacitated patient. It explores critiques of prevailing ethical standards for surrogate decision making and arguments that a more nuanced interpretation is called for, particularly with respect to substituted judgment. And it examines more closely the surrogate-patient relationship to better understand its implications for thinking about how clinicians should work with surrogates to jointly make decisions on patients' behalf. Finally, it offers guidance for clinicians when surrogates and health care professionals disagree.²

PREVAILING ETHICAL & LEGAL STANDARDS FOR SURROGATE DECISION MAKING

Prevailing ethical and legal theory views surrogates almost exclusively in terms of the decisions they are asked to make. It sees the surrogate's role narrowly as a task of applying one of three standards in making decisions on the patient's behalf: precedent autonomy (i.e., the patient's previously stated preferences, oral or written), substituted judgment, or best interests. Briefly, on the *precedent autonomy standard*, when the patient has expressed clear treatment preferences, particularly in a written directive, the surrogate is expected to make health care decisions according to those previously stated preferences. This standard firmly "locates decision-making authority in the formerly competent individual." [Buchanan & Brock 1989] On this account, the surrogate serves simply as the bearer of the patient's wishes.

When the patient does not have a treatment directive, or it is not clear how to interpret an existing directive, the *substituted judgment standard* requires the surrogate to use general knowledge of the patient's values to decide as the patient would in the given circumstances, if he or she were able to. That is, the surrogate should "choose as the patient would choose if the patient were competent and aware of the facts of his or her condition, including the fact that he or she is incompetent." [Buchanan & Brock 1989; cf. *Quinlan*] Under this standard, the surrogate is not the direct bearer of patient preferences. Rather, the surrogate functions as an interpreter of the patient's

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likely preferences, who draws on his or her knowledge of the patient as a unique individual in a good faith effort to determine what the patient's own decision would be.

When the patient's wishes cannot be known—there is no guiding directive, the surrogate does not have sufficient personal knowledge of the patient's values to predict what his or her treatment preferences would be, and there is no other reasonably available evidence from which to infer the patient's wishes—the *best interests standard* instructs surrogates to make the decision that will best promote the patient's interests. Under this standard, the surrogate must “try to determine the net benefits to the patient of each option, after assigning weights reflecting the relative importance of various interests affected when subtracting the ‘costs’ from the ‘benefits’ for each option.”[Buchanan & Brock 1989] The surrogate is not called on to articulate the known or inferred wishes of the patient as a unique individual, but to make the kind of judgment that a “reasonable person” would be expected to make in similar circumstances.

Although theory sees each of these standards as distinct and in principle takes them to be mutually exclusive, as a practical matter decision making by surrogates is actually likely to involve all three. In making treatment decisions, surrogates don't look only to the patient's stated preferences, but also draw on their own knowledge of the patient's values and goals and their understanding of what would be in the patient's interests. This has led some to argue for a more “context sensitive” standard for surrogate decisions:

the stronger and more decisive the evidence of the patient's wishes, the more weight should be given to advance directive and substituted judgment reasoning; the weaker and less decisive the evidence, the more weight must be given to best interests reasoning.[Brock 1994]

VA policy on informed consent for clinical treatments and procedures subsumes the traditional precedent autonomy and substituted judgment standards within a single standard. By policy, substituted judgment is:

the standard to be used by surrogate decision makers who have specific knowledge of the patient's values and wishes pertaining to health care choices. This standard requires that the surrogate decide based on what the patient would have wanted if he or she were capable of expressing those preferences. That decision may not necessarily coincide with what the surrogate and health care team otherwise would consider optimal for the patient.[1004.1, 3.]

When the patient's preferences are not known, policy mandates that surrogates' decisions be made based on the patient's best interests.

THE REALITIES OF SURROGATE DECISION MAKING

Although these decision-making standards offer some guidance, in the real world the task of making specific decisions for actual patients can be quite difficult. One challenge is that none of these standards is purely objective; each involves an exercise of judgment. Treatment directives have been promoted as a way for patients to give concrete directions for care, but are often problematic.[Buchanan & Brock 1989; Lynn 1991; Myles et al. 1996; Teno et al. 1997; Fagerlin & Schneider 2004; Tulsky 2005; Shalowitz et al. 2006] Since they are never fully self-explanatory, interpretive judgments are frequently required. For example, judgments may be required as to

whether the patient's particular clinical situation matches the conditions set out in his or her directive.

Moreover, this kind of anticipatory decision making has inherent limitations. Treatment directives ask individuals to identify and articulate preferences for care with respect to their own future health states, but most patients have no actual experience of the health conditions and decisions that are typically addressed in such directives.[Malloy et al 1992] Numerous studies have shown that patients' preferences change with their experience of illness and disability, raising questions about the authoritativeness of advance treatment instructions.[Emanuel et al. 1994; Danis et al. 1994; Patrick et al. 1997; Fagerlin & Schneider 2004]

Substituted judgment is also problematic. Surrogates are asked to infer the patient's preferences with respect to specific treatment decisions from their general knowledge of a patient's values, goals, and way of life. Neither health care professionals nor surrogates are very accurate in predicting patient preferences.[Hinkka et al. 2002; Fagerlin et al. 2001; Dresser 2005; Shalowitz et al. 2006] Further, evidence concerning preferences doesn't carry "the same moral weight as the actual choice of a patient when he or she is competent." [Buchanan & Brock 1989]

Not even the best interests standard is as objective or straightforward as some might imagine it to be. Although clinical considerations clearly have a role to play in such judgments, they are neither the sole considerations nor the definitive ones. Determining what is in a patient's best interest necessarily involves also a judgment about quality of life preferences from the patient's perspective.[Buchanan & Brock 1989] A further complicating factor is that this determination is typically made by a (relatively) healthy individual on behalf of a patient who is vulnerable and impaired.[Dresser 2005]

Furthermore, in most clinical situations the prevailing model, which presumes a simple one-to-one relationship between a single surrogate and a single clinician, maps poorly onto the realities of surrogate decision making. In fact, decision making frequently involves other family members in addition to the surrogate and multiple health care professionals, especially in hospital settings.[Heyland 2003] We also know that conflict—among family members, between families and clinicians, and among clinicians themselves—is not infrequent when surrogates are called on to make decisions for incapacitated patients with life-threatening illnesses.[Back & Arnold 2005; Abbott 2001] Families are especially concerned about not receiving information about the patient's condition in a timely manner.[Abbott 2001] And clinicians too often fail to take into account the burden on surrogates of the "awesome moral responsibilities" they take on when they are asked to make life or death decisions for a loved one and the emotional costs of such decisions.[Dubler 1995; Pochard et al. 2001; Azouley et al. 2001; Ditto 2006]

TOWARD A BETTER UNDERSTANDING OF SURROGATE DECISION MAKING

As the challenges of surrogate decision making have become more and more apparent, there has been growing concern that prevailing theory has significant weaknesses. Notably, critics charge that prevailing theory misconstrues the surrogate's role and that it rests on too thin a notion of autonomy. If we are to help clinicians and surrogates better navigate the troubled waters of making treatment decisions for incapacitated patients, we need a richer account of autonomy, as well as a better understanding of patients' relationships with and expectations for their surrogates. And we must take surrogates more seriously as moral agents themselves.

Surrogates as Partners in Decision Making

The prevailing theory of surrogate decision making is rooted in the ethical values of self-determination and commitment to the patient's well-being. When a patient is unable to exercise his or her rights to participate in making treatment decisions because he or she lacks decision-making capacity, the patient's surrogate is empowered to exercise those rights on the incapacitated patient's behalf.³ The surrogate "speaks with the patient's voice" with respect to treatment decisions, and clinicians have a *prima facie* professional obligation to honor the surrogate's decisions as if they were the patient's own, including decisions to refuse life-sustaining treatment.[See, e.g., Buchanan & Brock 1989; Pres. Comm. 1983; *Quinlan*; *Cruzan*; cf. Arnold & Kellum 2003] Yet despite the fact that relationships between surrogates and health care professionals can affect the quality of decision making and patient care,[Back & Arnold 2005] traditional legal and ethical theory gives little explicit consideration to clinician-surrogate relationships.

If we take the surrogate to be exercising the patient's right to participate in health care decisions, as the traditional view does, it is reasonable to look to the ethical ideal of shared decision making to understand the roles and relationships at stake in surrogate decision making. Where patients and clinicians are concerned, the model embodies a robust view of their relationship as one of mutual respect and engagement, to which both parties bring knowledge and values that are essential to well-considered health care decisions.[E.g., Emanuel & Emanuel 1992; Quill & Brody 1996; Brody 2005] Shared decision making goes beyond the clinician simply providing information and obtaining consent. It requires that clinicians and patients actively engage in a joint process of weighing the implications of that information *for this patient as a unique individual*, whose values and preferences may differ from those of the physician, to craft a treatment decision with which they mutually agree.[Brody 1989; Emanuel & Emanuel 1992; Quill & Brody 1996; Charles et al. 1997; Brody 2005] Not all patients want to participate fully in decision making themselves, of course, and clinicians should in principle respect patients' preferences for participation in decision making. For example, patients may wish to delegate primary responsibility for decisions to a family member.[E.g., Freedman 1993; Gostin 1995; Brody 2005]

Clinicians' responsibility to adhere to shared decision making does not end when the patient loses decision-making capacity. Rather, when patients are no longer able to participate themselves, their surrogates "stand in" for them in this process. More than being merely the bearers or interpreters of patients' autonomous preferences surrogates should be understood as taking on the role of *partners* in decision making.

There is certainly evidence to suggest that patients view the surrogate's role in this way. Many want to have their surrogates and clinicians collaborate in making the best decision for them when they can no longer participate in decision making themselves.[Seghal et al. 1992; refs] As one informant in a recent study noted:

Well, . . . professionally my doctor . . . I would trust him . . . and my husband for what would be best for me. . . . my doctor would use his head and my husband would use his heart.[Rosenfeld et al. 2000]

³ Generally, if the patient has not formally named a surrogate (e.g., through a durable power of attorney for health care), the presumption is that a family member or other intimate associate of the patient will be approached to play that role.[E.g., B&B 1989; *Quinlan*] In keeping with federal regulations, VA policy establishes the following priority order for surrogates: health care agent; legal or special guardian; adult next of kin (i.e., spouse, child, parent, sibling, grandparent, grandchild); or close friend.[VHA Handbook 1004.1]

If surrogates are to carry out the responsibilities of shared decision making effectively, certain conditions must prevail. Clinicians must acknowledge surrogates as moral agents and recognize their moral and legal authority. Clinicians must also engage surrogates early and often over the patient's course of care, not only "at the moment of deciding whether the patient should live or die." [Dubler 1995] And they must communicate effectively, help surrogates understand what is expected of them as participants in shared decision making on behalf of the incapacitated patient, and involve surrogates (and families) meaningfully in the decision making process. When clinicians fail to attend to these aspects of their relationships with surrogates they not only fall short of their professional responsibility to engage in shared decision making; they also set the stage for conflict and dissatisfaction with care. [Dubler 1995; Rabow et al. 2004; Lederer et al. 2005]

Effective communication plays a critical role in helping to avoid, or resolve, disagreements. To help ensure smooth communications between surrogates (and family members) and clinicians, discussions about the patient's treatment preferences under various circumstances should take place *before* the patient loses capacity if at all possible. And patients should be encouraged to include surrogates and perhaps even other family members in these discussions. For some patients and surrogates, of course, this ideal cannot be met—e.g., when the loss of capacity is sudden and unanticipated.

Communicating effectively can be difficult when clinicians do not have an established relationship with the patient or surrogate, as is often the case when a patient is admitted to the ICU. In such situations, the patient's primary care provider (or other clinician who knows the patient) may be a valuable resource in helping the critical care team understand and open channels of communication with the patient, surrogate and family.

Surrogates who experience conflict with the health care team often indicate that their communication needs have not been met—such as the need for timely communication, the need for honesty, the need for clear information, and the need to be listened to. [Norton 2003]. There is a growing body of evidence which suggests that proactive, multidisciplinary approaches such as family conferences, daily team meetings, palliative care team conferences, and routine ethics consultation improve communication and reduce conflict. [Azoulay 2004, Boyle 2005, Curtis 2004] Particularly intriguing are controlled trials showing that routine ethics consultation on high risk patients leads to better communication, quicker resolution of conflicts, and decreased lengths of stay [Dowdy 1998; Schneiderman 2000; Morgenstern 2005; Boyle et al. 2005; Danis 2005; DuVal et al. 2001]

Consistency in communication is also important. Whether information is provided by a single spokesperson or by multiple members of the treatment team, clinicians should strive to communicate with one voice and provide consistent information. In all situations, clinicians must be both candid and compassionate, striving to create a trusting environment that will support open, honest interactions. [Tulsky 2005] A variety of literature and resources are available to help clinicians develop and improve their communication skills. [See, e.g., Lang & Quill 2004; Curtis et al. 2002; Wenrich et al. 2001; Back & Arnold 2005; Rabinow et al. 2004; Tulsky 2005] Several training programs are available through VA's Employee Education System, including training on clinician-patient communication offered by the Institute for Healthcare Communications. [IHC] In addition, the Education for Physicians on End-of-life Care curriculum contains several modules relating to clinician-patient communication. [AMA]

Finally, although not generally recognized as important in interactions between clinicians and surrogates, some have argued that the notion of loyalty or fidelity central to clinician-patient relationships is also appropriate to the clinician-*surrogate* relationship. And thus that the patient's surrogate should inherit "not only the obligation of the patient to decide, but also the right of the patient to be treated with compassion and respect." [Dubler 1995]

Patient-Surrogate Relationships

In addition to critiques of the theoretical framework for surrogate decision making, there is growing concern that prevailing ethical theory rests on an inadequate understanding of autonomy, one that erroneously views “autonomous individuals as separate from all of their essential moral relationships.”[Jecker 1990] And when we misunderstand autonomy, critics charge, we misunderstand the relationship between patients and their surrogates.

By overlooking “the social network that helps define the patient’s core identity”[Levine & Zuckerman 1999], it is argued, prevailing ethical theory—and law—profoundly mistake the moral world that patients and surrogates inhabit together. They fail to take adequate account of the fact that family members are advocates, caregivers, and trusted companions, as well as surrogate decision makers.[Jecker 1990; Levine & Zuckerman 1999; Collopy 1999] This is not to contend that all families or intimate associations provide loving, nurturing environments for their members; we know that the relationships between some patients and their surrogates or prospective surrogates are dysfunctional and potentially dangerous to the patient.[Nelson 1992] We raise this issue only to underscore the point that we have too often failed to appreciate the patient-family-surrogate nexus.

That failure has repercussions for surrogate decision making. Importantly, critics charge, a theory that sees surrogates as mere extensions of patient autonomy misses the relationship of trust that is the moral and emotional basis of patients’ relationships with their surrogates. What we may most want from our surrogates is not so much that they make a given decision in a particular way, as that *they* be the ones who make the decision on our behalf.[Seghal et al. 1992; High 1994; Puchalski et al. 2000;] We choose our surrogates, that is, “not to be some clone of our autonomy, but to be the trusted *other* who will bring to fruition a journey that we cannot map in advance or control through its final stages.”[Collopy 1999]⁴

OVERCOMING THE LIMITS OF SURROGATE DECISION MAKING

Given the complexity of surrogates’ role, prevailing ethical theory and law create unrealistic expectations for surrogate decision making and demand of surrogates an impartiality and objectivity that ignores or denies the real moral ties between intimates.[Jecker 1990; High 1991; Hardwig 1993; Dresser 2005] What is needed are standards that harmonize and balance *all* the interests at play in a decision.[Hardwig 1993]

Standards better attuned to the realities of decision making and to the moral character of the surrogate-patient relationship would help to reduce the moral and practical tensions experienced by patients, surrogates, and clinicians. Instead of requiring surrogates to act as if they could be *morally neutral channels* for conveying patients’ preferences, more ethically astute standards would support surrogates as moral agents and *decision makers*. Empirically, there is evidence that many patients are more concerned that decisions be made through a collaborative process than that a treatment directive be strictly adhered to.[Ayers Hawkins et al. 2005] Indeed, some recent research suggests that individuals may want less to state specific treatment preferences than to make known their general values and goals for care and allow their surrogates to exercise judgment in making decisions on their behalf.[Ayers Hawkins et al. 2005] Even when patients express specific treatment preferences in advance, they often wish for their surrogates to have considerable leeway in deviating from their stated preferences. For example, among certain populations of patients, including elderly

⁴ Cp. similar analyses of surrogates as “continuers” of the patient’s life story, the one who carries the patient’s narrative forward when the patient no longer can.[Blustein 1999; Dubler 1995]

hospitalized patients and those undergoing dialysis, about half would want their surrogate to be allowed to make decisions that were inconsistent with the treatment preferences they had explicitly communicated in advance.[Seghal et al. 1992; Puchalski et al. 2000]

A Fresh Look at Surrogate Decisions

With respect to substantive standards, some have argued that the substituted judgment standard should permit surrogates to take account of interests beyond those of the patient in making treatment decisions—within reasonable limits. For example, it has been suggested that surrogates consider others' interests when the patient him- or herself would have been expected to do so, so long as the surrogate does not give “undue” consideration to interests beyond those of the patient.[Hardwig 1993] Others have suggested a principle of “harm prevention” to set boundaries on the acceptable range of treatment decisions surrogates may make. Such a principle would permit decisions that give significant weight to the interests of others and thus are not strictly in the best interest of the patient so long as those decisions do not impose clear harm on the patient.[Dresser 2003]

Still others proposed a “not unreasonable” standard for surrogate decision making. On this standard, a surrogate's decision to refuse a recommended treatment should be considered “not unreasonable” as long as the decision is based on universally recognized reasons.[Rhodes & Holzman 2004] (In contrast, a patient with decision-making capacity may refuse a recommended treatment for any reason, even an idiosyncratic one.) These scholars would argue that we need not require “full blown commitment to the patient's best interest” so long as the surrogate demonstrates a “minimally appropriate level of concern” for the patient's well-being.[Rhodes & Holzman 2004]

As moral agents, surrogates cannot reasonably be expected to completely subordinate their own interests when important interests will be significantly affected by the treatment decision.[Brock 1996; Arnold & Kellum 2003; Dresser 2005] The individuals whom we prefer to have serve as surrogates are often the very individuals most likely to have strong personal interests in the patient's clinical outcome. As one commentator has noted, “many treatment decisions inevitably and dramatically affect the quality of more than one life.”[Hardwig 1993] The mere fact that a surrogate has a potential conflict of interest—even a financial interest in the outcome—in itself does not lessen his or her decision-making authority.

These critiques open the way to a more ethically compelling understanding of substituted judgment. Such an understanding takes better into account the moral realities of patients' lives, the kind of relationship most patients desire to have with their surrogates, and the complex considerations at play for surrogates grappling with ethically and emotionally challenging decisions.

Contested Decisions

Surrogate decisions that appear to be inconsistent with a patient's stated preferences or best interests can be troubling. However, in all but exceptional cases, the moral authority to make decisions on behalf of the patient should remain with the surrogate decision maker.

Health care professionals should take care not to impose their own subjective interpretations of the patient's preferences, values, and best interests on the authorized surrogate decision maker. Respecting the surrogate as a moral agent requires that clinicians not simply dismiss what they see as problematic decisions as wrong or evidence of bad faith on a surrogate's part. Rather, respect requires that they explore with the surrogate the reasoning behind a decision that seems inconsistent with the patient's treatment preferences, values, or best interests.

Ultimately, clinicians' primary obligations are to the patient, not to the surrogate or family. But overriding the decision of an authorized surrogate is a serious matter—for the patient, for the

surrogate and family, for individual clinicians, and for the institution. Clinicians should make reasonable efforts to negotiate an ethically justifiable decision acceptable to both the surrogate and the treatment team. If a resolution cannot be reached and in the best professional judgment of the treating clinician the surrogate's decision is inconsistent with the patient's previously stated preferences, values, and/or best interests, the clinician should seek guidance from the local ethics consultation service, and if necessary, legal counsel, in accordance with local and national VA policy.

RECOMMENDATIONS

Surrogate decision making is a mainstay of ethical practice when patients are no longer able to make health care decisions themselves. However, serving as a surrogate is a challenging undertaking, the more so when individuals are poorly prepared for that responsibility. To fulfill their primary ethical and professional responsibilities to patients, clinicians and health care organizations have an obligation to provide resources and support to help ensure that surrogates are able to participate in shared decision making.[Dubler 1995; Lang & Quill 2004; Rabow 2004; Back & Arnold 2005; Lederer 2005] Clinicians need to remember that while the patient is always at the center of decision making, he or she is also usually at the center of trusting relationships that may rightly affect what decisions are ultimately made.

A robust process of shared decision making will best respect the moral nature of the bonds between patients and their surrogates. Recognizing the surrogate as a partner in shared decision making will help clinicians to temper the power and authority they wield in the clinician-surrogate relationship. The National Ethics Committee therefore recommends that VHA clinicians strive to identify opportunities to build relationships with prospective surrogates and family members of patients who are most likely to lose decision-making capacity, whether on the wards, in the ICU, or in nursing homes. The committee further urges VHA clinicians to adopt practices to promote shared decision making and foster a more collaborative relationship with surrogates:

Before a patient loses decision-making capacity

- Clinicians should clarify with the patient (and ideally with the surrogate) the patient's values relating to health care, preferences regarding treatment under different circumstances, and preferences about who should serve as surrogate in the event the patient loses decision-making capacity.

Clinicians should also clarify the patient's preferences about who should or should not be involved in the surrogate decision-making process (such as other family members), and how closely the patient wants the surrogate and treatment team to adhere to previously expressed treatment preferences (if any).

Once a patient has lost capacity

- The treatment team, surrogate, and family members involved in making decisions on the patient's behalf should jointly clarify the surrogate's role as partner in the process of shared decision making and underscore parties' mutual commitment to making decisions with which the patient would most likely agree.

The grounds for such decisions may be that they follow the patient's expressed wishes, or take account of values that would be important to the patient (which might include the patient's interest in the well-being of family members), or are in the patient's best interests. Clinicians should also make clear that as health care professionals, they have an obligation to serve as the patient's advocate.

- Clinicians should communicate effectively with the surrogate and family as the patient's situation changes. The treatment team should be candid but sensitive in discussing the patient's prognosis, and should provide regular, timely updates. It is important that information be consistent—the team should attempt to reach consensus *before* communicating with the surrogate and family. Ideally, a member of the treatment team will be designated as the primary point of contact for the surrogate and family.

We encourage clinicians to seek—and VA medical centers to provide—specific training in communication skills, especially around end-of-life decisions.

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- When there is disagreement about a treatment decision, clinicians should make every reasonable effort to resolve the situation, including acknowledging that patient preferences are subject to interpretation and that the patient's surrogate is usually best able to interpret them. Clinicians should also recognize that patients may want surrogates to consider their own interests (including financial interests) as well as the interests of others who will be affected by a treatment decision. They should also remember that many patients prefer that clinicians follow the surrogate's decision because that is the individual they want to have make decisions on their behalf.

The reasons for a decision with which the treating clinician/treatment team disagrees should be explored with the surrogate (and family) in order to clarify the decision-making process and seek shared understanding of the interests at stake for the patient, the surrogate and family, and health care professionals. The goal should be to help all parties refocus on their shared commitment to respecting the patient—for example, by asking, “Looking at this situation, given everything that's happened, how do you think [the patient] would want this resolved?” or “Now that [the patient's] condition has changed, what do you think [he or she] would want?”

Following these recommendations will go a long way toward ensuring effective communication, and less stressful, more respectful and productive relationships between clinicians and surrogates. We also encourage the National Center for Ethics in Health Care to further clarify the role of surrogates in decision making, in keeping with this Committee's analysis and recommendations, when it undertakes its planned revision of policy on informed consent for clinical treatments and procedures (Handbook 1004.1).

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