

Mark Yarborough, "Deciding for Others at the End of Life: Storytelling and Moral Agency," *The Journal of Clinical Ethics* 16, no. 2 (Summer 2005): 127-43.

Deciding for Others at the End of Life: Storytelling and Moral Agency

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PROLOGUE

Countless times every day, in hospitals across the United States, people must decide about how aggressively to treat others who are approaching the end of life. The routine occurrence of these life-and-death decisions ought not desensitize us to the awesome responsibility that falls upon those who are faced with making them. Nor should we lose sight of how vexing these decisions can be for family, friends, and healthcare providers. While these deaths no doubt occur when lives are judged to be waning and are accompanied by a host of signs of death's approach, they are also accompanied by deliberate decisions by family and friends, acting in concert with healthcare professionals, to decide the timing, manner, place, and other details of another's dying.

How are friends and family, namely, surrogate decision makers, to understand their part in this setting and in the decision-making process? I want to focus on how to go about making these decisions in many instances, as well as on the importance of fully acknowledging and embracing the substantive role that surrogates and others play in the process. Besides surrogate decision makers, the other parties include clinicians, such as physicians and nurses; ethicists; hospital chaplains; and many others. Try as hard as we collectively might to divorce or minimize the impact of our presence and participation in these moments of choosing more or less life and living for someone else, we unavoidably leave a moral residue. I want to describe and illustrate a narrative method that can help assure that this residue, our moral fingerprint if you will, reveals that we have done right by, and good for, those for whom we have chosen.

INTRODUCTION

Consensus emerged long ago regarding various aspects of decision making at the end of life: surrogates, rather than healthcare professionals, should make such decisions.¹ In addition, there is consensus that it is equally valid to proceed from the moral position of the sanctity of life, wherein one believes and acts upon a duty to save all life that can be saved; or the moral position of quality of life, wherein one believes and acts upon a duty to save only some lives that can be saved. Consequently, we generally accept surrogates' decisions that follow from either of these positions. By and large, surrogates tend to be at liberty to choose among all available medical treatment options.

These areas of broad consensus notwithstanding, it does not necessarily follow that all surrogates' decisions that fall within the range of viable treatment options are ethically sound. There are independent standards by which to judge the appropriateness of specific surrogates' decisions for medical treatment at the end of life. Consequently, clinical practices regarding surrogates' consent for adult patients should follow these standards, standards that have been established largely through case law.² These standards establish that surrogates' decisions should reflect the explicitly stated wishes of patients, when possible. This is known as the *subjective standard*. When surrogates do not have this knowledge, they should seek to have their judgments reflect and comport with the beliefs, values, and goals of the patient. This is known as the *substituted-judgment standard*. It is probably the most widely used standard, and will be the focus of this essay. Only when surrogates are not in a position to let judgments be guided in this manner either should they rely on the *best-interest standard*, and make clinical decisions that are seen as promoting the well-being of the patient. In the very broadest terms, the subjective and substituted-judgment standards derive their moral authority from the principle of respect for persons, but the best-interest standard is derived principally from those of beneficence and nonmaleficence.³ I want to explore a method that can assure that surrogates' decisions that utilize the substituted-judgment standard do so in a way that affords patients the full measure of dignity and respect that is their due. (What constitutes this full measure will be apparent in the pages to follow.) This exploration will describe why surrogates, much of the time, will need to be "responsibly creative" in their deliberations, and will highlight the central role that surrogates' discretion frequently plays in making ethically responsible substituted judgments.

Embracing surrogates' discretion as a mechanism to promote respectful treatment of patients does not always get as much attention in clinical bioethics as it may deserve. Perhaps this is because it is the principle of respect for persons that has done much to replace the discretion of third parties in clinical settings, primarily the discretion of healthcare professionals, with the discretion of the patient. Respect for persons has led the charge against the old paternalism in healthcare, helped usher in the era of informed consent and shared decision making, and made common the wisdom that people should be allowed to make their own decisions in the healthcare setting. Given the predominance of the patient's voice that respect for persons has established, what is the import of this principle when people lose their voices and cannot make their own decisions? The substituted-judgment standard is an attempt to preserve the guidance of this principle, and it does so by instructing that surrogates be guided by the goals, values, and preferences of patients. In so doing, the standard implicitly recognizes the necessity of, and authorizes the use of, multiple voices taking part in the process of discovering how we treat others with dignity and respect.

The practical clinical ethical question that confronts us is knowing how surrogate decision makers best derive guidance from this principle when they employ the substituted-judgment standard. Answering this question can be problematic, since the substituted-judgment standard is subject to various interpretations, both in case law⁴ and in bioethics,⁵ making the ethical responsibilities of surrogates who employ this standard of proxy consent a matter of dispute. The disagreement about the standard centers largely on the degree of discretion in decision making that the standard permits surrogates to exercise. Some bioethics commentators eliminate almost all surrogates' discretion by imposing a "pure-autonomy" standard, wherein the "only foundation" for substituted judgments is "the principle of respect for autonomy, which applies if and only if either a prior autonomous judgment itself constitutes an authorization or such a judgment supports a reasonable basis of inference for a surrogate."⁶ It is more typical, though, to interpret the standard as granting more discretion to surrogates so that they make decisions that are based not upon the patient's prior judgments, but rather based upon the patient's known values, goals, preferences, and the like. I will argue in favor of the latter "discretionary" view over that of the former "nondiscretionary" view, and justify and illustrate a method for knowing how we can judge whether the scope and intent of a surrogate's discretion is appropriate.

The discretionary view is consistent with laws in all of the states that grant broad discretion to surrogates whom patients have designated in advance to serve as their medical decision makers. It is also consistent with laws in some states that give broad discretion to surrogates who are identified, not by advance directive, but according to statutory processes triggered after the patient has lost decisional capacity. The discretionary

view is inconsistent, however, with laws in other states that, in the absence of a surrogate decision maker designated in an advance directive, impose a standard of clear and convincing evidence to support surrogates' decisions regarding treatment. The following discussion will reveal the extent to which a standard of clear and convincing evidence potentially disrespects and misserves those who are subject to them.

THE INTERFACE OF NARRATIVE, DISCRETION, AND SHOWING RESPECT FOR PARTICULAR PEOPLE

Using a life narrative, which is an authentic account of a person's life, can help illuminate substituted judgments by helping surrogates to think clearly about exactly how they can most respectfully treat those for whom they will make decisions. Thus, my central point will be that discretion is most responsibly exercised by grounding substituted judgments in the life narratives of patients. This method of application, much more so than nondiscretionary explications of substituted judgment, assures that patients are treated with the full degree of respect that is their due.

We show particular people who have lived particular lives that are reflected in particular narratives dignity and respect by making decisions for them that reflect their particularity, not just their humanity. The best-interest standard, along with nondiscretionary interpretations of the substituted-judgment standard, ground decisions out of respect for the humanity of the patient, thus treating the patient in a generic, rather than a particular, way. For instance, according to the best-interest standard, we want to do what is best with respect to the welfare of the patient, and we emphasize generic attributes of all persons, such as the need for comfort, warmth, and the like. While these considerations are certainly important, by no means does their satisfaction exhaust the duty to treat people with respect.⁷

The nondiscretionary interpretations of substituted judgments emphasize one's humanity, rather than one's particularity, by equating respectful treatment of previously competent persons with enforcement of prior autonomous decisions. If this cannot be done, then, as persons, patients are recognized as vulnerable, and thus needing to be protected in their time of vulnerability.⁸ This "default setting," in essence, charges surrogates with making decisions with what amounts to little more than a best-interest standard. By creating this dichotomy, wherein people are either fully autonomous or vulnerable, we fail to recognize that there is a morally rich middle ground, manifest in people's life narratives, between these two points on the spectrum. Robin Dillon, in recognition of this middle ground, has argued forcefully that when we wish to treat persons with respect, "What matters about each of us is not (only) some abstract capacity but the fact that we are the specific concrete individuals that we are."⁹ Our life narratives can reveal and illuminate the specific concrete people that we are, and thus inspire surrogates' judgments. For this to occur, however, surrogates must be granted sufficient discretion.

Contrasting the substituted-judgment standard with the subjective standard is instructive to our efforts to appreciate the significance of surrogates' discretion. The subjective standard, wherein the surrogate is literally the mouthpiece of the incapacitated patient and says what the patient would say if able to speak, reflects the patient in his or her full particularity, because his or her actual decisions are being spoken, heard, and deferred to by others. The surrogate is completely transparent in this decision-making process, exercising no discretion, but serving instead as a repository and reporter of the patient's prior decisions and instructions. Such transparency, out of deference to the principle of respect for persons, is a good thing. Precise acting upon the patient's prior decisions grants assurance that surrogates have acted according to the responsibilities stipulated by the subjective standard.

Although it may be our fervent desire that *all* surrogates should never be much more than the voices *of* patients, merely serving to report and replicate their prior decisions, the reality, as the empirical data that are reviewed below illustrate, usually is otherwise. The data indicate that surrogates most often must be the voices *for* patients. Consequently, precision is really the wrong benchmark by which to measure substituted judgments. What is needed in its place is a benchmark that recognizes that surrogates are rightly the voices

for rather than the voices *of* patients. Speaking *for*, rather than *as*, another introduces a greater degree of authority, and thus responsibility and accountability, into the surrogates' decision-maker role.

BACKGROUND CONSIDERATIONS

The rich moral agency that surrogates at times embody is apparent when we examine some telling empirical evidence regarding advance care planning, evidence that renders nondiscretionary interpretations of substituted judgment essentially inapplicable. First we ought to note that surrogate decision makers can be relied upon to accurately predict the treatment preferences of patients who lack decisional capacity, that is, surrogates are "invisible," as they should be under nondiscretionary interpretations of the substituted-judgment standard, only 66 percent of the time.¹⁰ This reliability is a function of patients having conversed with their surrogate about clinical situations that they later find themselves in, but this reliability quickly erodes once the seriousness of the medical condition or the invasiveness of the procedure lessens. (Of interest here is one study that indicates that patients value such conversations much less than their surrogates do.)¹¹ In the absence of explicit conversations about directly analogous clinical situations, surrogates are only slightly more accurate than a coin toss at correctly anticipating the decisions that patients would make for themselves regarding medical treatment preferences.¹² In other words, surrogates' decisions match those of patients only when the surrogates are in a position to correctly employ the subjective standard of surrogate consent, showing that surrogates' invisibility, or even limited transparency, truly is confined to this other standard of surrogate consent.

Evidence further indicates that less than 25 percent of the adult population have advance directives,¹³ suggesting that not as many explicit advance discussions about treatment preferences occur as we would ideally desire if our picture of a "good" substituted-judgment surrogate decision maker is one who mimics patients' decisions. Also complicating matters, though, is the following. Even if such conversations were routine and widespread, it is not clear to what extent such advance decisions would comport with the actual decisions people might make should they be able to make them while in a state of decisional capacity. It is difficult for most of us to anticipate in more than a general way the decisions that we would make in future, changed situations. Chances are we would later change our minds about our treatment preferences anyway, once we had experienced a situation, rather than merely speculated about it.¹⁴

The guidance that surrogates who must make substituted-judgment decisions often receive from clinicians, ethicists, and others does not always comport with this empirical record. Surrogates are often prompted in ways that mask, rather than acknowledge, their discretion and visibility. For instance, it is not uncommon for the instructions that surrogates receive to be limited to asking them to decide as they *presume* the patient would decide if she or he were only able to understand the pending choices and decide among them. Such guidance encourages surrogates to speculate about what the patient would say and/or what decisions she or he would make. While these are correct questions to ponder to see whether a surrogate can make a subjective-standard decision, as the empirical evidence indicates, the honest answers to such questions most of the time will be "I don't know." Rather than helping surrogates to move beyond this impasse by instructing them how to find something besides a patients' prior decision upon which to ground decisions, clinicians often allow surrogates to continue to engage in speculation about what the patient might say or do.

I call this the *presumptive-judgment* method of substituted judgment. Surrogates are expected to be able to presume to know what patients likely never considered and thus never knew. Here we see the inappropriate benchmark of precision, and the desire for an "only slightly adulterated" informed consent sneaking its way into the implementation of the substituted-judgment standard, and muddying the waters as a result. The surrogates' task ought not be to anticipate what the patient might decide if she or he were miraculously capable of deciding for herself or himself. That approach seeks the impossible from surrogates: knowing how another would decide a question she or he never decided, an exercise in little more than guesswork. The data indicate the problematic nature of this approach, and simultaneously reveal that surrogates play, by necessity, a substantive role in the life-and-death decisions they are called upon to make. Clinicians should

be cognizant of this substantive role, and understand how they can best guide surrogates to make ethically responsible decisions.

The data indicate that, on a routine basis, surrogates must exercise discretion in the decision-making process. This reliance on discretion is not an intrinsically good or bad thing. Rather, it is merely a fact of the decision-making process, one that highlights the importance of having the correct benchmarks and methodology to assess and employ substituted judgment. That is why the benchmark of precision, so appropriate to surrogate decisions based upon a subjective standard, is so ill-suited to typical substituted judgments.

In place of precise (or, as the empirical data suggest, imprecise) judgments by surrogates, I want to argue for *characteristic* judgments from surrogates. The use of what I call the *constructed judgment* method can lead to characteristic judgments, judgments inspired by life narratives. Such judgments can help assure that surrogates' choices comport with the responsibilities, set forth in the substituted-judgment standard, to have choices that are informed by patients' values and goals. In what follows, I hope to illustrate this method, indicate the benchmarks of good decisions embedded within it, and show how it preserves the appropriate weighing of the principle of respect for persons with those of beneficence and nonmaleficence.

Before turning to this method, however, two additional related and important aspects of surrogate decision making in the clinical setting need to be noted. First among these is the most obvious. As already noted in passing, surrogates' decisions affect the time, manner, place, and other aspects of another person's dying. So the stakes for both patients and decision makers could not be higher. Surrogates' decisions that opt for aggressive treatment may result in the patient living for many years in a physically and cognitively impaired state. Conversely, their decisions may result in an earlier death for the patient.

However, it is not just another's survival that is at stake, but his or her legacy. Aristotle's considerations about happiness illustrate this. Happiness "turns out to be activity of soul in accordance with virtue. . . . But we must add 'in a complete life'."¹⁵ In this view, happiness is a lifelong achievement that includes, to some extent, the circumstances of one's death and legacy. "For there is required [for happiness], as we said, not only complete virtue but also a complete life, since many changes occur in life, and all manner of chances, and the most prosperous may fall into great misfortunes in old age, as is told of Priam in the Trojan Cycle; and one who has experienced such chances and has ended wretchedly no one calls happy."¹⁶ Aristotle further mentions that, in the pursuit of happiness, there is a death that is "worthy of [one's] life."¹⁷

These passages from the *Nicomachean Ethics* remind us not to underestimate the importance of surrogates' decisions about life-sustaining treatment with respect to both the denouement of one's living and dying, as well as one's legacy and thus ultimate happiness. They also remind us of the extent of our interconnectedness with others, that is, the inescapable ties of family and friendship-based relationships. This brings us to the second important feature of surrogates' decision making that we should note, namely, the new status of the patient's moral agency. Previously autonomous adults are not the same as fully autonomous adults. Their independence that previously characterized them has now been replaced by dependency. Above all else, dependent patients lack their voices, their ability to make independent judgments, and therefore the power enjoyed by their fully autonomous counterparts. "[F]amilies gradually (and eventually completely) take on both the decision-making and care-giving needs of their [demented] relatives. . . ."¹⁸ To view, then, incapacitated persons as akin to someone for whom precise judgments exist and can be made or as someone who is (just) helpless and in need of protection is to misunderstand the nature of their current personhood. *Dependency* is now a central characteristic of theirs, meaning they are dependent on others not just for their physical care and well-being, but the subsequent unfolding of their lives, as well as their role and place in their larger community. What they do, what happens to them, the social role they fill, all of this and more *depends* on the judgments others make on their behalf. This dependence is a *brute fact* that cannot be wished away. Consequently, discretion is an unavoidable hallmark of many, if not most, surrogates' decisions about treatment near the end of life. All of these considerations show how crucial it is that we, especially those of us who have a clinical role with surrogates, recognize the central role of surrogates' discretion, and that we have a method by which to understand how that discretion is responsibly exercised.

THE CONSTRUCTED-JUDGMENT METHOD

The constructed-judgment method can responsibly guide surrogates' discretionary judgments. For those times when we must decide for those we know and there is no prior decision to replicate, yet we know enough about them that it would be wrong to view them as some generic person to whom our duty to treat with respect is fully captured by our duty to promote their welfare while avoiding undue harm—we know them well enough that there is a substantive difference between the duties that flow from respect for persons compared with beneficence and nonmaleficence—a constructed judgment is ethically preferable. Based on joining our knowledge of them—their past, their desires, their values, and their character—with our knowledge of their medical situation, knowledge that the patients are not privy to, we can construct *characteristic* judgments, that is, respectful decisions that comport with their life narratives. Employing this method of the substituted-judgment standard, being able to determine the extent to which a surrogates' decision is "in" or "out" of character for a patient, becomes the proper benchmark, rather than precise comportment with a prior decision, by which to measure surrogates' decisions.

Recalling the earlier point about the need to treat people as the concrete individuals they are, the value of using a narrative method is apparent. It is our life narratives that reveal our concrete characters. Narratives pertain to lives lived in relationship with family, friends, and others,¹⁹ and thus are constructed largely in public view. Our concrete subjectivity is manifest in our conversations, behaviors, dispositions, and attitudes, meaning there is a transparency to our subjectivity. It is our life narratives that also can "uncover" the concrete individuals we remain, even in times of dependency. The task of surrogate decision makers who use a constructed-judgment method is to do this uncovering.

In practice, the constructed-judgment method would establish the following. Surrogates would be obliged to recall the narrative unity of the patient's life revealed through the public dimensions of that life, since they are not privy to the purely private aspects of the other's life; learn what the various treatment options are; and then *judge*, that is, exercise discretion, regarding what type of treatment decision complements and helps complete the narrative or avoids creating dissonance within the narrative. Blustein has suggested that such a narrative surrogate decision-making process can be approached as an effort to write the last chapter of someone's life.²⁰

In effect, in writing the last chapter, surrogates would be called upon to reconstruct and employ the *authoritative voice* of the patient's narrative. What is the authoritative voice and where is it to be found? All narratives are constructed from a time and place. Within a narrative, one can look forward and backward, that is, read the narrative, from a *constructive vantage point* that gives the life contained in the narrative continuity and meaning. The existence of a constructive vantage point reflects the fact that a life is constructed by its author(s) in relation to its unfolding. Thus, there is embedded within any life narrative an authoritative voice, the voice that speaks from a constructive vantage point. The more that a surrogate's decisions "ring true"²¹ with the authoritative voice of the patient's narrative, the more respectful those decisions are. Surrogates' decisions "ring true" to the extent that they not just complete, but also *continue*, the patient's life narrative in a way that *compliments* the portions of it that have gone before. Complimentary portions of the narrative are those that are characteristic of the subject of the narrative. So the benchmark by which to judge that last chapter is the extent to which it is characteristic. Employing the authoritative voice to speak from a constructive vantage point can help assure that this benchmark is attained.

Given the brute fact of dependency, we must acknowledge that there are times when the authoritative voice is spoken not by the subject of the life, but rather by those who choose on behalf of the subject. Dependency produces multiple authors for a narrative.²² Taking this inescapable consequence of dependency into account reminds us of the immense power to decide the course of life for others that is naturally inherent in the surrogates' decision-making role. Tempering this power with the responsibility to treat patients with dignity and respect is the purpose of surrogate consent, regardless of which standard of surrogate consent is employed. Joining power with the moral responsibility of authorship is what sets the constructed-judgment method of the substituted-judgment standard apart from the other standards. Recalling the empirical data discussed in a previous section, responsible authorship is a reasonable constraint to place on the

discretion that surrogates inevitably enjoy. Accordingly, clinicians must not just grant surrogates power; they must hold them accountable for the manner in which they exercise their power. The constructed-judgment method is a responsible, and, as I hope to show, an intuitive and thus feasible manner by which to exercise power.

CHALLENGES TO CONSTRUCTED JUDGMENT

The criterion of my proposed constructed-judgment method of surrogate consent, characteristic completion of a life narrative, that is, an episode that complements rather than creates dissonance with the preceding episodes, is not as precise as some may desire. Recalling Aristotle, however, precision is not always possible in our reasoning about moral courses of action.²³ What is possible and appropriate with respect to the criteria is that they are ethically sound and achievable in practice, not that they are precise. And I think the criterion for the constructed-judgment method is both sound and achievable.

Perhaps a criterion's suitability is best appreciated by turning to some obvious criticisms of the constructed-judgment method. For instance, will surrogates know patients' life narratives well enough, and if so, will those narratives adequately portend the judgments that ought to be constructed? In many instances, narratives will contain very explicit prods to surrogates, such that their decisions will come close to comporting with the subjective, as opposed to the substituted-judgment method. As the empirical evidence noted earlier suggests, however, this will be the unusual rather than the normal circumstance. So most narratives will contain suggestions rather than explicit prods to surrogates.

Does it follow from this that respectful judgments therefore cannot be constructed in these instances? It is true that constructed judgments require an element of responsible "play" and interpretation, since the decisions that surrogates must make are constitutive, that is, determinative, of how the individual's life subsequently unfolds. But prior chapters of the patient's life narrative can serve as useful prompts, that is, constraints, on surrogates. As Dillon notes, surrogates must seek to "promote what the other person regards as important; or where that is not possible or where we cannot bring ourselves to do that, then we at least have to take account of her conception of her own good. And that, too, requires informed understanding."²⁴ Presumptive judgments, which attempt instead to anticipate patients' hypothetical, that is, nonexistent, decisions, obfuscate the need for constitutive decisions, as they hide behind these hypothetical presumptions and act as if they were other than hypothetical.

Acknowledging the need for these constitutive exercises of discretion, while recognizing their moral legitimacy, should be acceptable, first, because the judgments are grounded in the patient's particularity and individuality. Second, being dependent forecasts that the unfolding of our lives during times of full dependency are constituted largely by the decisions of others. There is nothing disrespectful about this recognition, unless those who have the power over that unfolding fail to take inspiration and direction from the dependent person's life. This direction, limited though it is, is better than the "direction" afforded by presumptive judgments. As noted previously, the surrogates' task is not to guess what the patient might decide if he or she were miraculously capable of deciding. Surrogates cannot possibly *know* how another would decide a question she or he never decided.

Taking the full import of dependency into consideration, we should recognize that surrogates' decisions are not a search for knowledge, of having surrogates' decisions correspond with patients' decisions. Such correspondence is an elusive dream; there are no prior decisions with which surrogates' decisions can possibly correspond. Rather, surrogates need to seek information to inform and inspire their judgments; life narratives are the richest source for both. Thus, reliance upon life narratives can best assure that surrogates' discretion is exercised responsibly. Surrogates who know the patient well have a broad understanding of both the patient and his or her current lived context. They are in a position to decide the action consistent with the patient's narrative, that is, the *characteristic* course of action. Thus, constructed judgments do not emerge from guesswork, but emerge from the understandings and within the trust that are the hallmarks of close relationships. Therefore, these judgments, more than others, are characterized by responsiveness and responsibility. They are *responsive to*, that is, informed and inspired by, the subject's life narrative, and they

are *responsible* for the continuation and completion of that narrative in a manner worthy of the prior chapters in the narrative.

Consider a hypothetical example of an adult brother and sister who are faced with the decision to discontinue life-preserving medical treatments for their father, who has at least temporarily lost his decisional capacity because he has suffered a serious stroke. The neurologist is very guarded about their father's prospect for a full recovery, but she states that there is a chance that their father can be discharged home, and that, with appropriate rehabilitation, can recover what many people would consider a meaningful quality of life. There is also a strong chance that he will experience little or no further recovery. This inability to be sufficiently confident in the extent of recovery is what creates the need to decide about continuing life-preserving medical treatments.

As is frequently the case, let's also assume that their father has not completed an advance directive, but he has talked with his children about "his wishes." He has stated on numerous occasions, "I don't want to be a vegetable. I'd rather die than be a burden to others." This is not an unusual situation, in that there is no advance directive and no ability for either child to follow the subjective standard, that is, no one knows with any certainty what the patient would decide were he able to make his own decision. However, since they know their father well, they are able to employ the substituted-judgment standard rather than the best-interest standard. One can imagine that the children are conflicted. The patient's daughter might say, "Dad would never want to live like this because he always said he didn't want to be a vegetable. I know that if he could only see himself in the hospital bed, hooked up to so many tubes and needles and machines, that he would want us to just let him die." It is not difficult to imagine the son countering, "I had those same conversations with Dad. But don't you think if he could talk with the doctor and hear that there is a chance that he'll get better, that he would take that chance? I think it's too early to give up."

Such a case illustrates that frequently, even when surrogates have had conversations with patients about their treatment wishes, these conversations lack specificity to dictate certain decisions. In this case, neither the son's nor the daughter's view is directly at odds with the words spoken by their father. Rather, given that the father is not privy to his current situation and given that his comments were made without specific reference to what he would want were he to suffer a stroke and have an uncertain prognosis, both surrogates' views are plausible. No one can dictate that, based upon Dad's previous statements, the daughter is right and the son is wrong, or vice versa.

I think this brief hypothetical case is illustrative of the situation of many surrogates' decisions that must be made. Even in the presence of prior conversations, there frequently is no obviously *right answer* to the exclusion of all others. This means we are left with finding the *right method* that, when used, will produce a respectful answer. I am proposing the constructed-judgment method as the method for surrogate decision makers to use as they struggle to make ethically appropriate decisions that will determine, to a large extent, both the content and duration of their father's life narrative.

All the children can do in this instance is decide the denouement of their father's life, in light of the facts as they are known, their understanding of his values and preferences, how he has lived his life, and what kind of future for him is most characteristic of him. Their task is a challenging one, insofar as Dad never fully thought through and/or communicated anything to unambiguously decide the question to be decided. Thus, Dad's narrative, like those of all living people, is in continuous process and play, and is in "need of completion." It falls to his children to do that in a respectful manner. This is done by them, as they become his authoritative voice and find that constructive vantage point that lets them see more clearly than other vantage points, such as what they want for their father or what they think is best for their father: what constitutes respectful treatment of him.

I recognize that it can prove very difficult for surrogates to adopt the constructive vantage point, but it need be no more difficult than asking them to adopt the presumptive vantage point. The more they are asked by clinicians what they think *their father* would decide as they struggle to make *their* decision, the more likely they are to guess about what their father never decided. I am suggesting instead that they be instructed by clinicians to make "characteristic decisions" rather than say what they think "Dad would do." This will

afford surrogates the opportunity to think back on the other's life and living, and construct a remaining "living while dying" that is consonant with the patient's prior living.

In considering this recommended method of making substituted judgments, I think the field of bioethics needs to acknowledge the indeterminacy that is a hallmark of substituted judgments. If my reading of the empirical data is correct, most people never decide end-of-life matters, at least not beyond who they want their surrogate decision maker to be, or, if they do arrive at clear and specific decisions, they do not communicate their decisions accurately. As a result, others *must* decide for them, and the decision will be the surrogate's, not the patient's, decision. Try as we might to declare the decision to be the patient's—because "this is what we think Dad would say"—does not negate that the decision is a work of fiction. I think what the bioethics literature, and clinical ethics practices as well, have failed to fully appreciate is that all substituted judgments are fictions at some level. The challenge is to know how to discern the responsible fictions from the irresponsible ones. I have offered the constructed-judgment method as a way to make that determination. If a surrogate's responsibility is to make a decision that treats the patient with dignity and respect, surely a judgment that is explicitly inspired by the patient's life narrative is preferable to one based on speculation about an unmade decision.

Terms such as fiction, play, responsiveness, inspiration, and the like will no doubt be troublesome to many, prompting worries that the constructed-judgment method gives too much discretion to surrogates.²⁵ Perhaps it gives them license to selectively read a narrative and, rather than responsibly interpret it from the constructive vantage point, co-opt it according to the surrogate's desires on behalf of the subject. In other words, how can we trust that the surrogate's interpretation is correct?

There is no doubt that surrogates can make poor decisions. What makes for a poor decision, though? At one level, surrogates' decisions can be flat-out wrong because they fail to use an ethically and legally prescribed standard. For instance, a surrogate who is in a position to make a subjective-standard decision but who fails to do so would make a wrong decision. What we most need to concern ourselves with, however, are those instances in which the correct standard is misapplied. Thus, one could misapply the best-interest standard by making decisions that are contrary to others' assessment of the patient's well-being; one could misapply the presumptive method of the substituted-judgment standard by making decisions that do not match presumed hypothetical judgments; or misapply the constructed-judgment method by making decisions that would be out of character for the patient. The task of surrogates and clinicians, then, is first to make sure that the correct standard is used, and second to strive to assure that it is applied correctly. If we assume that respect for persons is to be the primary guide for surrogates' decisions, then we should use the best-interest standard only as a last resort. If my prior assessment of the faults of the presumptive method of substituted judgment stands, then the constructed-judgment method prevails.

No doubt, some readers will still be troubled by possible misapplication of this method, since one has to rely on the surrogate's interpretation of another's life narrative. After all, we cannot, nor should we, set aside all of our disquiet when one person makes life-and-death decisions about another. Some may experience more disquiet with the constructed-judgment method than other methods, since it sanctions more discretion on the part of the surrogates. If my defense of the need for more rather than less discretion is sound, then such readers are really questioning whether the principle of respect for persons should be the preferable ethical justification for surrogates' decision making in this setting. Other readers may accept the primacy of this principle, yet nevertheless question the wisdom of letting one person interpret, and thus dictate, how another person's life narrative should unfold. I would remind these readers to consider the true moral import of dependency. There is simply no escaping the fact that one person will determine the unfolding of another's life. Further, there is no escaping the fact that all life narratives, autobiographical ones as well as biographical ones, always merely suggest, and never decree, their own unfolding. So the play and indeterminateness of a narrative method like the one I am arguing for is inescapable. For those who remain unconvinced of the virtues of the constructed-judgment method, I ask to know what the alternative method is that is grounded, on the one hand, in respect for persons, but that, on the other hand, does not require interpretation and other kinds of discretion by the surrogate.

The foregoing considerations notwithstanding, I do not mean to suggest that we do not need to worry that surrogates will never make poor judgments. What I do mean to suggest is that worries about the frequency of poor judgments can be mitigated when we remember that the method will likely be very familiar, rather than foreign, to surrogates, because the decisions produced by the method frequently will be similar to the kinds of decisions surrogates are already making for those who are dependent on them. We are called upon to judge for others all of the time, and we do not typically require that when we judge *for* another that we judge *as* another would, as required by the presumptive standard of consent. So this proposed method, even though it lacks the illusory "precision" of the presumptive method, is consistent with prevalent social practices in both family life and friendship, wherein we act on behalf of those close to us, especially when their ability to act on their own behalf is compromised.

There are other considerations that support confidence in this narrative method's ability to promote responsible surrogate decision making. First, the value of the narrative method in bioethics is well-established.²⁶ Second, the constructed-judgment method comports well with a bioethics theme that has been sounded elsewhere, which is that people's moral status, and thus the key to knowing how to assure their respectful treatment, is fully understood only if we account for their familial and other social status as persons.²⁷ We cannot presume to know how to treat another who is previously well-known to us with respect in our interactions, consensual or non-consensual, if these interactions are not informed by our understanding of who that individual is, based upon how that individual lived his or her life. This level of understanding, and hence respect, cannot be achieved if the social nature and features of subjects that are contained in and revealed by their narratives are ignored.

Even in light of the preceding discussion, some readers may still ask whether use of the constructed-judgment method would make any substantive difference to the decision making of surrogates when compared with use of the presumptive-judgment method. I think the answer is both yes and no. At one level, since both methods involve speculation, application of either will provide for a range of possible decisions. Thus, it is reasonable to assume that there may be a broad overlap of decisions arrived at by thinking about "What would Dad do?" versus "What decision would be most characteristic of Dad?"

What, then, is the principal value of the constructed-judgment method? Its value resides in the fact that this method is firmly, rather than merely peripherally, grounded in the principle of respect for persons. While I would not go so far as to say that thinking about "What would Dad do?" could be "wild speculation," it is not *necessary* that it be very disciplined speculation either. Surrogates who speculate about what Dad would do might draw upon his values, past behaviors, and the like, but they also might just engage in guesswork. In contrast, one cannot answer the question about the most *characteristic* course of action without formulating an answer that is grounded in Dad's *character*. Thus, surrogates' decisions that are made with the constructed-judgment method *necessarily* are *disciplined by* and *focused in* the particular life narrative of the person whose fate is at stake. Surely this discipline and focus guarantees respectful treatment of the patient in a way that presumptive judgments do not. And if respect for persons is the ethical principle that provides justification for substituted judgments, then surely the method of applying that principle should be one that assures, rather than merely permits, that surrogates' decisions are in fact grounded in the principle. Thus, the greater ethical soundness that emerges from use of the constructed-judgment method lends greater moral authority to surrogates' decisions than do presumptive judgments.

However, these important benefits cannot be realized unless clinicians and others correctly guide surrogates throughout their decision making, highlighting the need for clinicians to correctly understand the responsibilities of surrogates. I stated earlier that clinicians sometimes guide surrogates in ways that mask rather than acknowledge the need for discretion, when they ask surrogates to decide as they presume the patient would decide. This too-common tendency of clinicians poorly reflects and frames the extensive responsibilities of surrogates. Equally problematic in this regard is the tendency for some clinicians to only get surrogates to answer questions about procedures. They want to know whether to continue a therapy, institute a new one, or the like, and thus ask, "If your father's heart were to stop, do you want us to try to resuscitate him?" or "Should we begin dialysis to treat your father's kidney failure?" Surrogates are asked

"What to do?" when in reality, if we want assurance that the morally responsible thing will occur, clinicians need to engage surrogates about "How to be clear about how to decide what to do."

In other words, one cannot appropriately determine what to do if one is not clear about how to decide what to do. It is not ethically adequate to just get an answer to the question, "What should we do?" Surrogates can answer that question in any number of ways, but they have both an ethical and legal responsibility to answer it in the correct, that is, ethically and legally justified, way. It is the role of the various standards of surrogate consent to arrive at justified answers. Only when clinicians are clear with surrogates about *how they should decide* can we have any assurance that answers about what should be done are morally justified. I think I have made clear why people should decide using constructed judgments, rather than presumptive ones, when their responsibility is to make substituted judgments. Even though both methods of applying this standard may produce identical outcomes in many instances, constructed judgments will possess a moral authority and reflect a degree of dignity and respect that presumptive judgments may lack.

CONSTRUCTED-JUDGMENT CONSENT AND RESEARCH

Constructed judgments need not be limited to clinical decision making. They can be just as useful in the research setting, when surrogates are called upon to decide whether to enroll a dependent person in a research protocol. To show the value of constructed judgments in this setting, I will limit the discussion to considerations of nontherapeutic research, since surrogates' decisions to enroll participants in nontherapeutic research contrasts most from surrogates' clinical treatment decisions. In this context, what constitutes respectful and dignified treatment of these subjects? The constructed-judgment method can shed light on two matters: one is practical and the other more theoretical. I will begin by addressing the practical matter.

It has been documented that surrogates make decisions to enroll persons in research even when the surrogates believe the research participants themselves would not agree to be in the research.²⁸ Such findings, along with additional findings that report that researchers themselves believe that surrogates require more preparation for their role of proxy decision maker,²⁹ demonstrate that a practical way to instruct surrogates on how to make surrogate decisions is needed. The regulations that govern research involving human subjects in the U.S. that is federally funded, the "Common Rule,"³⁰ stipulate only that surrogate consent be obtained in research that involves minimal risk, but they do not stipulate what standard of consent should be used. Some defend the use of the best-interest standard,³¹ even though, as I have argued here and elsewhere,³² the use of that standard permits less than fully respectful care and participation in research, even when the research poses no or minimal risk.

Many recommendations exist, most notably from the National Bioethics Advisory Commission, that call for the use of the substituted-judgment standard by surrogates.³³ If we opt for nondiscretionary interpretations of substituted judgments, we have to recognize that very few surrogates can ethically grant consent to participate in research. People are much less likely to discuss in advance whether they would want to participate in nontherapeutic research once they lose their decision-making ability than they are to discuss which clinical treatment decision they would want in the same circumstances. So few, if any, surrogates would be aware of prior autonomous agreements to enroll in such types of research. Since constructed judgments do permit more discretion to surrogates, it allows the opportunity to enroll more participants, provided that such enrollment constitutes respectful care for and participation by the research participants.

Deciding whether enrollment in research characteristically or uncharacteristically compliments and helps conclude a life narrative can be an accessible and intuitive way for surrogates to exercise their discretion. Surrogates can judge, for instance, that participation in a purely observational study related to palliative care would be uncharacteristic, even though it would pose no risk or inconvenience to the research participant. On the other hand, some surrogates would also recognize that participation in nontherapeutic research that poses significantly more than minimal risk would be characteristic with the participant's life narrative, suggesting that enrollment is the more respectful decision. This brings us to the more theoretical matter.

Should Institutional Review Boards (IRBs) and regulatory bodies permit surrogates to use the constructed-judgment method to consent to research that presents greater-than-minimal risk? Answering this

question requires us to determine how best to strike a balance between protecting dependent people from unnecessary harm and permitting them to make appropriate sacrifices in the name of progress, when their surrogates are persuaded that is what respectful treatment condones, at least—if not requires. Knowing how best to strike that balance is contentious; for example, commentators disagree whether adults with dementia—and presumably, by extension, many other adults as well, who are thought to have irretrievably lost their decisional capacity—can be enrolled in nontherapeutic research that presents more-than-minimal risk, even in the presence of explicit advance consent, such as a research advance directive.³⁴

The thrust of my argument thus far would require, out of respect for subjects, that we permit the use of advance explicit consent to enroll in research that presents more-than-minimal risk. The loss of decisional capacity ought not deprive one of the opportunity to engage in altruistic actions when one assumes risk, albeit only with general knowledge, in advance. For example, if we consider a case study that required a bronchoscopy for research, rather than for diagnostic or treatment purposes, I see no good reason why people could not consent to such a procedure in advance, even though, as others have noted,³⁵ the consent might be granted in the absence of detailed knowledge about the investigative procedures and the kinds of risk they pose. Others disagree because of the vulnerability of the population, and to respect the directive of *The Belmont Report* that we treat vulnerable people with respect by offering them protection.³⁶ I would argue that advance consent essentially negates their current vulnerability and justifies their enrollment.

If one grants this point for the sake of argument, could a surrogates' decision based upon a constructed judgment, rather than an advance directive, also suffice? On one hand, I see no good reason why it could not. After all, the source of the justification for surrogate enrollment is the degree of comportment with one's life narrative, not the degree of risk. But herein lies a problem, because this manner of justification is at odds with how IRBs assess such questions. Regulations of research categorize research by risks, with different levels of risk triggering different considerations by IRBs and other regulatory bodies. Thus, despite the merits of the criterion of narrative comportment for determining what constitutes respectful participation and treatment of adult research subjects, adoption of such an approach across the categories of research risk does not seem possible, given the regulatory constraints to which IRBs are currently subject.

Consequently, from a practical standpoint, we are left at the point where respect for persons sways us to require non-enrollment in minimal risk research when enrollment does not constitute respectful treatment, even though current regulations would permit enrollment. At the same time, the regulations require non-enrollment in research that presents more-than-minimal risk, even though we know there are times when surrogates are persuaded that such enrollment would, in fact, constitute respectful treatment. We can tolerate this inconsistency when we consider that IRBs and the institutional research they sanction must satisfy obligations to more than just individual research subjects. They must be accountable to their communities, as well as those who sponsor and regulate research. Thus, until such time as the regulations permit more flexibility, it seems that constructed judgments permitting enrollment in nontherapeutic research will have to be limited to research that poses minimal risk.

We need not abide this inconsistency permanently, however. The scope of nontherapeutic research involving adults who lack decisional capacity, to which surrogates can consent, is a topic worth reconsideration for a host of reasons, not least of which are prudent, given demographic trends. If we are satisfied that we know what respect for persons means for this population of research participants, and if we are satisfied we know how surrogates best provide this respect in the research setting, then we will know how best to weigh respect for persons with the principles of beneficence and justice in the research setting.

MISCELLANEOUS MATTERS

There are two remaining substantive matters related to constructed judgments, whose full exploration remain beyond the scope of this essay. First, there surely will be specific times when we ought not give full decisional authority to a patient's life narrative. For instance, characteristic completion of some narratives may be unjust, because this may require an inappropriate use of resources, while characteristic completion of

others may be callous or uncaring, because this may continue hurtful family dynamics. It is not clear that surrogates or healthcare professionals are duty-bound to implicate themselves in such injustice or malfeasance. So we must be clear to recognize the limits of narratives; they do not constitute or replace, in and of themselves, normative deliberation.³⁷ While reliance on narrative can surely enhance surrogate decision making, and thus clinical decision making,³⁸ it will not settle substantive debates in bioethics.

The second remaining issue is more anthropological than it is bioethical, as it has to do with whether surrogates can be motivated to use constructed judgment or any other method of substituted judgment. Surrogates may wish to eschew constructing life-and-death judgments for others. Instead, they may feel duty-bound to instruct clinicians to continue treatment to preserve life until and unless they become persuaded that a patient is unavoidably dying. These surrogates would not accept that they are responsible for or complicit in the living and dying of another, clinical realities notwithstanding.

CONCLUSION

I have explored how we show an appropriate degree of respect for persons when their dying is at stake and there is no prior informed-consent or other explicit decisions to guide surrogates in their decision making. I have suggested that the way we treat patients with the degree of respect that is their due is to have surrogates ground and constrain their discretionary judgments by delving deeply into patients' life narratives, so that they do all they can to assure that patients' narratives are completed in a characteristic fashion. Although there is always the risk that this method of surrogate consent, like any, can be misused, the risk is less for constructed judgments than it is for other prevalent approaches. The method seeks to produce surrogates' judgments that grant patients dignity and respect, and that its manner of application is consistent with widely accepted social practices that permit friends and loved ones to exercise discretion and respectfully judge for those who can no longer judge for themselves.

EPILOGUE

We must be careful that the routine occurrence of decisions to withhold and withdraw life-sustaining medications and technologies does not numb us to their moral significance. Not only do such decisions orchestrate³⁹ the dying of people, but they can also have a lasting impact on those who have the awesome responsibility to make such choices. In the absence of clear directives or statements that give us instructions we know we must follow, how do we know, in a given situation—whether it is a decision to withhold medication for a life-threatening infection or to withdraw mechanical ventilation—if this is an instance when we should try to save a particular life in a particular time? The family and friends who are responsible for making these most intimate of decisions must ground their decisions in something. That something can be, indeed ought to be, the patient's life narrative. Such grounding can generate good—that is, characteristic—decisions for patients and grant assurance to surrogates that they have made right decisions—that is, that they have appropriately acquitted themselves of their responsibilities. We should not expect, nor can we achieve, a more fitting moral residue when we make decisions for others who are near the end of their lives.

ACKNOWLEDGMENTS

I would like to thank Philip Candilis, MD, Rebecca Dresser, JD, Sally Gadow, PhD, Jacqueline Glover, PhD, and anonymous reviewers for providing many useful comments and suggestions on earlier versions of this essay. I would especially like to thank Dawson Schultz, PhD, for his many conversations about the focus of this article. His familiarity with Charles Taylor, Alisdair MacIntyre, Paul Ricoeur, and others helped me better understand the nature and philosophical significance of narrative and interpretation.

NOTES

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4. See note 2 above.

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16. *Ibid.*, p. 1100a.

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20. J. Blustein, "Choosing for Others as Continuing a Life Story: The Problem of Personal Identity Revisited," *Journal of Law, Medicine & Ethics* 27, no. 1 (1999): 20-31.

21. J. Marta, in "Toward a Bioethics for the Twenty-First Century: A Ricoeurian Poststructuralist Narrative Hermeneutic Approach to Informed Consent," employs a similar insight when she speaks of the cachet of truth in narratives, in *Stories and Their Limits*, ed. H.L. Nelson (New York: Routledge, 1997): 207.

22. A. MacIntyre, *After Virtue* (Notre Dame, Ind.: Notre Dame University Press, 1984), 213-4. MacIntyre describes how life narratives always exist in relation to and are embedded within multiple narratives; see also note 3 above, p. 148, wherein the author states that "our characters come attached to others."

23. See note 15 above, p. 1094b.

24. See note 9 above, p. 125.

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