Capacity for Preferences

Respecting Patients with Compromised Decision-Making

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Surrogate decision-making standards do not fully capture the significance of the patient's own preferences. The moral reasons for valuing a decisionally incapacitated patient's preferences are not reducible to either best interests or surrogate autonomy. They have to do with liberty and respect for persons.

When a patient lacks decision-making capacity, then according to standard clinical ethics practice in the United States, the health care team should seek guidance from a surrogate decision-maker, either previously selected by the patient or appointed by the courts. If there are no surrogates willing or able to exercise substituted judgment, then the team is to choose interventions that promote a patient's best interests. We argue that, even when there is input from a surrogate, patient preferences should be an additional source of guidance for decisions about patients who lack decision-making capacity.

Our proposal builds on other efforts to help patients who lack decision-making capacity provide input into decisions about their care. For example, "supported," "assisted," or "guided" decision-making models reflect a commitment to humanistic patient engagement and create a more supportive process for patients, families, and health care teams.[1] But often, they are supportive processes for guiding a patient toward a decision that the surrogate or team believes to be in the patient's medical best interests. Another approach holds that taking seriously the preferences of such a patient can help surrogates develop a better account of what the patient's treatment choices would have been if the patient had retained decision-making capacity; the surrogate then must try to integrate features of the patient's formerly rational self with the preferences of the patient's currently compromised self.[2] Patients who lack decision-making capacity are well served by these efforts to solicit and use their preferences to promote best interests or to craft would-be autonomous patient images for use by surrogates. However, we go further: the moral reasons for valuing the preferences of patients without decision-making capacity are not reducible to either best-interests or (surrogate) autonomy considerations but can be grounded in the values of liberty and respect for persons. This has important consequences for treatment decisions involving these vulnerable patients.

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Our proposal focuses on the difference between two kinds of patient capacity: decision-making capacity and what we call "capacity for preferences." We will avoid using "incapacitated" to refer to patients who lack decision-making capacity because such patients may possess capacity for preferences, which we argue is a morally relevant capacity. Additionally, while the term "preferences" is commonly used to refer to the choices of a patient with decision-making capacity, we will argue that patients can have capacity for preferences even if they lack decision-making capacity. Accordingly, we will use "preferences" in a broader way, to refer to the health care wishes and desires of all patients, even those without decision-making capacity.

A Confounding Case

As members of an academic hospital's ethics consultation service, both of us consulted on the following case, which confounded the typical framework for adjudicating clinical ethics dilemmas. This case illustrates the need for a broader account of the moral value of the preferences of patients who lack decision-making capacity.

The patient was a forty-one-year-old male who at age twenty-five had been involved in a car accident that left him paralyzed from the waist down and with a traumatic brain injury, including damage to the ventromedial prefrontal cortex. As a result of the brain injury, and perhaps compounded by an underlying organic psychiatric illness, the patient behaved erratically. He had a court-appointed guardian and had lived in group homes since becoming paralyzed. He was admitted to the hospital for stage 4 decubitus ulcers on his legs resulting from lack of hygiene and refusal of wound care. During the hospitalization, the patient consistently refused wound care, dressing changes, medications, and other interventions, though many of these were provided against his will, with the permission of his guardian. The patient was frequently abusive toward staff members and was once put in restraints for twenty-four hours following a violent outburst. He denied that he was paralyzed.

The health care team identified three options for treating advanced infection in his legs: a six-week course of intravenous antibiotics, amputation below the knee, or no curative action but comfort care in the hospital and then hospice once he became septic. The patient refused to accept any of these options. However, multiple physicians, including a psychiatric consultant, determined that he lacked the capacity to make this treatment decision. He did not appear to understand his condition or the implications of his options for treatment or nontreatment.

The patient's court-appointed guardian deferred entirely to the health care team and offered no insight into the ways that the patient's values, beliefs, or life narrative might inform a decision. An infectious disease consultant favored the first option, which would be best practice under ordinary conditions. However, treatment with antibiotics likely would have required six weeks of prolonged restraint because of the patient's consistent refusals and his propensity for agitation. A consultant from surgery favored the second option. Including postoperative wound care, this option would have required approximately two weeks of prolonged restraint. No one from the ethics consultation service seriously advocated for the third option, although it was acknowledged as likely to be the least coercive.

This case was very challenging from the standpoint of the traditional decision-making hierarchy, even though the health care team followed many institutional best practices for so-called unfriended patients, including drawing on a diverse group of consultants from multiple specialties and the clinical ethics consultation service, the hospital's team of social workers, and a court-appointed guardian.[3] As noted, the standard view of clinical decision-making in the United States counsels that the health care team should rely on a hierarchy of successive standards.[4] First, the team should look to the patient, if he or she possesses decision-making capacity, or to relevant directives the patient might have given when possessed of decision-making capacity. If the first standard cannot be met, then health care teams should look to a surrogate decision-maker, ideally one who knows the patient well and who can make decisions that there are good reasons to believe are similar to the decisions the patient would have made if he or she had decision-making capacity. If this standard cannot be met, then the team is to treat the patient in accordance with what they believe to be in the patient's medical best interests.[5]

In the case at hand, the patient could not make a decision, the surrogate could not or would not speak on his behalf, and the patient's best interests were not clear, in light of the conflicting recommendations from the consulting services whose relative expertise could not be ranked. Best-interests considerations counted strongly against the third option, but there was no clear way to adjudicate between the first and second options. While amputation would require less time in restraints, it was irreversible. In contrast, intravenous antibiotic therapy would require more time in restraints, and its likelihood of long-term success was relatively low, given the high risk of reinfection; it might only delay amputation.

When we discussed this case with other members of the ethics consultation service, we realized that no one had asked the patient whether he had a preference between the first or second options. This was a difficult patient; he had attempted to refuse almost all interventions, and he resisted when the health care team provided many of these interventions against his will. Even so, we argued that it mattered morally how he would have responded if he had been presented with a bounded choice, such as, "One of two treatments *is* going to happen to you: amputation or antibiotics. Which would you prefer?"

Some other members of the ethics consultation service replied that the patient's possible preferences regarding amputation and antibiotics could have no moral value, since he lacked decision-making capacity relative to those treatment options. They suggested that we might treat his preferences as a something like a coin toss, in other words, as a morally neutral means of resolving the dilemma between those two options. We disagreed. This article is our attempt to explain why and, in so doing, to develop a more broadly applicable account of the ethical responsibility of health care teams to elicit and respond to the preferences of patients without decision-making capacity.

Capacities, Preferences, and Decision-Making

Our case illustrates an important distinction between two kinds of patient capacity relevant to clinical decision-making. The first is decision-making capacity. There are many different accounts of the criteria necessary and sufficient for patients to possess a capacity for clinical decision-making—and a wide variety of clinical instruments for assessing decision-making capacity—but a widely used account is articulated by Thomas Grisso and Paul Appelbaum:

1. the ability to express a choice;

2. the ability to understand information relevant to treatment decision-making;

3. the ability to appreciate the significance of that information for one's own situation, especially concerning one's illness and the probable consequences of one's treatment options; and

4. the ability to reason with the relevant information so as to engage in a logical process of weighing treatment options.[6]

Even profound cognitive dysfunction or deficit need not undermine a patient's decision-making capacity for a particular intervention. What matters is whether the patient's dysfunction or deficit prevents the patient from understanding and reasoning about information relevant to that intervention. For example, the mere fact that the patient in our case suffered from the delusion that he could walk would not suffice to demonstrate that he lacked decision-making capacity for all interventions. However, this delusion was decisive in determining that he lacked the capacity to decide how to treat his infected legs.[7]

Capacity for preferences is distinct from decision-making capacity. A person has a preference when there is something the person likes better, would sooner have, or would select over something else. A preferred option need not be one's favorite option among all imaginable options; it need be favored only among the options actually on the table. One might argue that the patient we discuss could not have a preference for amputation or antibiotics, since he did not want either outcome (he was, after all, refusing all treatment and even wound-dressing changes). But expressing a rank ordering for bounded choices is consistent with the notion of preference. In fact, hospital patients are nearly always faced with options that exclude their most favored outcomes, since few people like being sick or injured. Further, even patients who possess decision-making capacity (should) experience restricted treatment options, since health care teams should not offer medically inappropriate (for example, nonbeneficial) interventions. Treatment preferences are always relative rank orderings between options that are bounded by empirical realities and clinical judgments.

Research shows that there are many patients who possess capacity for preferences, even if they lack decision-making capacity.

A patient can possess capacity for preferences without possessing decision-making capacity: a patient may be able to identify a preferred treatment option without drawing on relevant facts, appreciating the significance of the decision, or understanding the consequences of his or her decision. These two kinds of capacities are related, however. Capacity for preferences is necessary, but not sufficient, for decision-making capacity. (In Grisso and Appelbaum's account of decision-making capacity, capacity for preferences is the first necessary condition of decision-making capacity.)

When patients possess capacity for preferences but lack decision-making capacity, we think health care teams should grant significant moral weight to patients' preferences among treatment options, even when doing so will neither better inform surrogate decision-making nor better promote the patient's best interests. As we will argue below, such a patient's preferences have moral value given the demands of respect for persons and liberty, beyond what is instrumental for informing surrogates or promoting their best interests.

In practice, clinicians often are averse to treating patients over their refusal, even when patients lack decision-making capacity. Treatment over objection, even in cases of profound psychiatric diagnosis, is a challenging ethical and legal issue that is not taken lightly by practitioners or the state.[8] Indeed, the more invasive the procedure, the less willing practitioners are to coerce patients. Our position accords with physicians' reluctance to use coercion, but it diverges both from well-established perspectives in bioethics and from clinical practice. The bioethics literature has not fully explored the inherent moral value of preferences (a value irreducible to autonomy qua surrogacy or best-interests considerations), while clinicians still tend to disregard the preferences of a patient who lacks decision-making capacity as psychopathological noise, even while they shy away from providing treatment over patient refusal.

Empirical Prerequisites

Patient preferences would be of no use in decisions for patients who lack decision-making capacity if such patients could never reliably express preferences. Recent research, however, provides evidence that the preferences of many such patients are neither arbitrary nor unstable (though future studies may support a more nuanced account of the preference stability of these patients). Indeed, there is an implicit recognition in various parts of the bioethics and clinical literature that such preferences are reliable enough to be useful in health care decision-making. For example, the concept of pediatric assent presupposes that even young children can express preferences about their health care and that pediatricians should grant moral weight to those preferences.[9] Children may not be competent to make their own decisions—they may lack decision-making capacity—but they can often express opinions and perspectives that are widely acknowledged to be relevant for medical decision-making. We might say, in other words, that there are defeasible reasons to grant the treatment preferences of children. In contrast, the ethical guidance for clinicians working with cognitively impaired adults does not usually emphasize the moral significance of such a patient's preferences, even though research suggests that preferences among adults without decision-making capacity can be robust.

Older adults with severe dementia often exhibit preferences about treatment options. A decision to satisfy some of those preferences can motivate compliance with other therapeutic behaviors.[10] Javier Virues-Ortega and colleagues note that "individuals with intellectual or developmental disabilities are able to reliably express their likes and dislikes through direct preference assessment."[11] A literature review by Christopher A. Tullis and colleagues summarized findings along these lines from more than fifty published studies.[12]

More germane to the case with which we began, John F. P. Bridges and colleagues showed that individuals with schizophrenia could reliably make conjoint decisions and that they based those decisions on stable underlying preferences.[13] When given a bounded choice between two options, participants in this study made decisions that were consistent, purposeful, and meaningful—not chaotic and not random assertions of an underlying psychopathology.

The research literature provides evidence that both patients with progressive diseases, such as dementia, and those with chronic psychiatric, cognitive, or developmental impairments can express deliberate and relatively stable preferences. In terms of clinical decision-making, however, these patient populations have important differences. In particular, patients with progressive ailments often have a history of decision-making capacity, even during early stages of their diseases, and they therefore may provide advance directives about future courses of treatment. Their past autonomous preferences may or may not align with the preferences such patients express once their cognitive faculties become impaired. In contrast, individuals with chronic or lifelong impairments to decision-making capacity may have no such history of autonomous decision-making or advance directives.

Potential conflicts between the autonomous preferences of former selves and the nonautonomous preferences of current selves who lack decision-making capacity present pressing moral problems. Nancy Berlinger, Bruce Jennings, and Susan Wolf note that it is particularly challenging when patients with progressive neurological deterioration have contemporary preferences that conflict with their advance directives.[14] Berlinger and colleagues suggest that we should usually give greater weight to the preferences a patient expressed when he or she retained decision-making capacity. This does not mean, however, that the patient's current preferences lack moral significance but only that those preferences have been defeated by overriding concerns. Our intent here is to explain why the preferences of patients who lack the capacity to make decisions are not devoid of moral weight and might therefore guide or at least influence treatment decisions when they cannot be defeated by other considerations.

Similar conditions attend the patient with intermittent loss of capacity from mental illness. A patient in the midst of a psychotic episode may have stable preferences that conflict with the stipulations of a Ulysses contract (an advance directive in which someone with a history of psychoses precommits to undergoing appropriate medical treatment should he or she lack capacity to make decisions about medical care in the future). The contract may ultimately be decisive, but this does not mean that such a patient's contrary preferences have no moral weight at all. Rather, it means that such preferences are not decisive under those conditions, even though they may be decisive under other conditions.

Another important empirical consideration is how stable a patient's assertion of a wish or desire must be to be accurately characterized as "the patient's preference." We doubt that a persuasive general account can be provided for a threshold stability level for patient preferences. However, it seems clear that more stable preferences have greater moral significance than less stable preferences.

And when a patient without decision-making capacity expresses a set of constantly changing and contrary preferences in the days or weeks in which the health care team is deliberating about treatment choices, these expressions provide no reasons for favoring a particular treatment option. In such a case, a patient cannot meaningfully be said to have preferences about treatment.

We have provided evidence that patients who have significant mental and cognitive impairments may be able to assert stable preferences. This is true for those with intermittent, chronic, and progressive impairments, even though questions about how to weigh their preferences and whether their preferences are defeated by countervailing considerations may differ across the types of patients commonly presenting these challenges. Our case is useful for examining the moral value of preferences because it does not involve some of these further complexities of application. For our purposes, it is enough to note that the research shows that there are many patients who possess capacity for preferences, even if they lack decision-making capacity. This empirical finding has significant moral consequences for clinical ethics.

Why Preferences Matter Morally

According to the standard view, the preferences of a patient who lacks decision-making capacity matter morally only if satisfying those preferences would promote the patient's best interests or if those preferences provide surrogates with clues about what the patient would have wanted if he or she possessed decision-making capacity. In this framework, the moral value of such a patient's preferences are reducible to the moral value of best interests or surrogate autonomous decision-making. In contrast, we argue that the values of respect for persons and liberty ground irreducible, though defeasible, reasons to value patient preferences. And we argue that these reasons for valuing patient preferences can be decisive in clinical decision-making.

A patient's preferences are functionally independent from his or her best interests, since patients can prefer things that do not promote their best interests. In turn, the reasons to morally value a patient's preferences are distinct from the reasons to morally value the patient's best interests. Consider that the reasons that count in favor of granting decision-making authority to patients with decision-making capacity—including autonomy, respect for persons, and liberty—are deontological counterweights to the consequentialist considerations of best interests. The reasons to value the preferences of patients who lack decision-making capacity are also deontological counterweights to consequentialist considerations of best interests.

Respect for persons. To respect persons, you must recognize that there is something about persons that constrains your practical reasoning about what may be done to or for them.[15] In particular, respecting persons requires you to identify their preferences as necessary considerations in your practical reasoning about how you may treat them. This is because part of what it means to be a person is to possess the desires, drives, and commitments that inform our preferences. And to respect a person, you must treat the constitutive features of his or her personhood as relevant considerations in your deliberations about how to treat the person. Accordingly, one reason to grant moral weight to a patient's preferences is because doing so is a requirement of respecting that patient as a person.

If we go on to say that the only preferences that matter morally are the preferences of fully autonomous patients, then we are in effect asserting that only fully autonomous patients are moral persons. That would be an extreme view, however, and it is almost certainly not what mainstream clinical ethicists really hold. We suspect that many clinical ethicists and health care providers think that patients without decision-making capacity can be persons and that they agree with us that the preferences of such patients ought to count for something in health care decision-making. Therefore, our arguments in this section give voice to what we hope is a common discomfort with the ways in which mainstream clinical ethics valorizes autonomy at the cost of other conceptions of moral personhood.

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We are tempted to engage in a direct assault on the hegemony of autonomy in bioethics, and our arguments have some affinity with critical or constructivist views of mental illness. However, this article's arguments require less radical claims. Even if autonomy were the paradigmatic feature of moral personhood, there might be reasons to embrace a more expansive and pluralistic conception of the ways in which someone can be a person. Perhaps we should think of the grounds of moral personhood as falling on a kind of continuum, with autonomous humanity at one end and other kinds of agency and quasi-agency occupying other positions. And even if we thought autonomy were the sole basis of full moral personhood, we might think that beings who possess something resembling autonomy should be entitled to a degree of respect that corresponds to the degree of similarity between their agency and autonomy. Therefore, even if decision-making capacity were the paradigmatic (or sole) criterion for fully authoritative patient decision-making, patients who possess something less than decision-making capacity (such as capacity for preferences) may possess a moral claim to participate in their medical decision-making to the degree that their agency resembles decision-making capacity.

On a more informal note, it is striking to us that members of health care teams and ethics consultation services sometimes talk about patients who lack decision-making capacity as if they were bystanders to their own care. This seems unnecessarily dehumanizing. It can be avoided by recognizing that the preferences of patients with capacity for preferences have moral significance, given that such patients are moral persons.

Liberty. A person's freedom from bodily coercion is normatively basic, such that deviations from liberty rights require justification. The fact that a coercive act promotes a person's interests is not sufficient to justify coercion, even when a person would otherwise make a less-than-fully-autonomous decision. In daily life, we make decisions of all kinds that are not well-informed and whose consequences we do not well understand, especially when we make decisions about dramatically new experiences.[16] In short, we likely lack the nonmedical equivalent of decision-making capacity for many of the most important choices we make in our personal and professional lives. But these facts about our imperfect forms of everyday rationality do not, by themselves, warrant interference in our decision-making, either by the government or by private actors. Instead, liberty rights entitle us to make many kinds of decisions that are bad for us and to do so in ways that are not fully rational. Indeed, we suspect that a commitment to liberty also may explain many providers' aversion to treating patients who lack decision-making capacity over their objections.

When a health care team treats a patient against his or her stable preferences, it violates the patient's liberty rights in ways that demand justification. This remains the case for patients who lack decision-making capacity. As we discuss below, the presumption of liberty—and the presumption against bodily coercion—can be overcome and may be more easily overcome when a patient lacks decision-making capacity than when a patient possesses it. But even to put the point that way is to concede what we assert: the preferences of a patient who lacks decision-making capacity have moral weight in medical decision-making and can be overridden only in the face of more powerful countervailing reasons. It should therefore be clear that considerations of liberty provide moral reasons to value patients' preferences, even in the absence of decision-making capacity.

Addressing Practical Problems

Cases with undetermined best interests. Let us apply the arguments of the previous sections to the case with which we began. Our arguments for the moral significance of patient preferences provide good reasons for the health care team to have asked the patient whether he preferred amputation or antibiotics to treat the stage 4 decubitus ulcers on his legs. Recall that the patient's surrogate was unable or unwilling to make substituted judgments on his behalf. At the same time, it was difficult, if not impossible, to determine which course of action was in his best interests, not only given the conditions and undetermined prognoses attached to each treatment option, but also because two expert consultant services supported different options. The best-interests standard could be effectively leveraged against the third option (not treating the wounds and providing comfort care only) because the outcome of death from preventable disease fell short of this patient's best interests to a dramatic degree. However, choosing between the other two options presented a more difficult challenge.

Suppose the patient had been offered a bounded choice between IV antibiotics or amputation, and suppose he had selected the former. (This is the choice we would have expected, since the patient did not believe himself to be paralyzed and, on that basis, may have preferred to avoid amputation.) If the patient had demonstrated a consistent preference for this option (over the days or weeks during which deliberation about treatment options occurred), then there would have been a sufficiently weighty moral reason for the medical team not to amputate. After all, no other recognized standard (autonomy, surrogacy, best interests) could have effectively discriminated between amputation and IV antibiotics, and, as we have contended, there are moral reasons to treat patients in accordance with their preferences. Even if the patient's preference would have been based on a delusion (as it likely would have been, since he denied that he was paralyzed), attention to capacity for preferences should have revealed a decisive reason for a particular treatment option in the absence of a compelling reason to the contrary.

Cases with determined best interests. The argument so far suggests that capacity for preferences has greater moral value than flipping a coin (as one member of our ethics consultation service suggested be done in the early stage of the case we have discussed). However, we are willing to go further to say that even when best-interests considerations tell in favor of one potential intervention over another, a health care team may sometimes have a moral obligation to follow a treatment option that is suboptimal with respect to the best interests of a patient who lacks decision-making capacity, on the grounds that the patient prefers the suboptimal option. Recall that the case we discuss faced an impasse between consultants from surgery and infectious disease about whether amputation or antibiotics would best promote the patient's best interests. However, as more information about the patient and his living situation emerged, the infectious disease consultants acquiesced to the surgical option, largely because the chances for future reinfection were high in the absence of amputation.

At this point, the health care team agreed that amputation was most aligned with the patient's best medical interests, but they agreed that amputation was likely only marginally better than antibiotics. While amputation would have prevented reinfection in the legs, it would not have resolved other infectious disease risks that the patient faced, and it would have involved increased risks of infection during and after surgery. Additionally, amputation would have been irreversible, and amputating the patient's legs against his wishes would have required a significant degree of coercion, although not for as long as would be required for IV antibiotics.

Even though it became reasonably clear that amputation would better promote the patient's medical interests, we think that the patient's preferences (had they been solicited) would have been sufficiently morally important to decide in favor of antibiotics (had the patient preferred antibiotics), as this treatment was not thought to be significantly worse than amputation. We are not claiming that the preferences of patients who lack decision-making capacity always provide sufficient reason for the health care team to implement treatment options that do not best promote the patient's interests. For example, in our case, we do not think that the team would have been obligated to pursue the third option—comfort care in the hospital and then hospice—even if the patient had expressed a stable preference for that option. This option arguably was too contrary to the patient's best interests for his preferences to have generated a moral obligation for the team to implement it.

Mitigating error in assessing decision-making capacity. Our arguments about the moral value of preferences cohere with broader discussions in biomedical ethics that seek to deemphasize the role of assessments of decision-making capacity and, more generally, critically evaluate the role of patient autonomy in clinical decision-making.[17] A fortunate consequence of increasing the moral weight given to the preferences of patients who lack decision-making capacity is that doing so will mitigate the effects of these assessments, which have many well-documented problems. For example, the assessments are often not revisited, a lack of decision-making capacity for one intervention is often assumed to demonstrate a lack of decision-making capacity for another intervention, a patient's possession of a mental or cognitive deficit is assumed to be sufficient to indict the patient's decision-making capacity for particular decisions, noncompliant patients are disproportionately determined to lack decision-making capacity, and even the best decision-making-capacity assessment tools involve significant discretion for subjective judgment.[18] We advocate efforts to directly address these problems. However, given the apparent intractability of some drawbacks of decision-making-capacity assessment, it would be a welcome consequence of our approach that patients who were wrongly determined to lack decision-making capacity would nonetheless be recognized by health care teams as retaining a moral claim to meaningful participation in decision-making about their care.

The criteria for decision-making in clinical ethics is often conceptualized as a simple hierarchy of successive standards: patient autonomy, surrogate decision-making, and best interests. Reality is more complicated.

Complicating the Hierarchy of Decision-Making Criteria

The set of criteria for decision-making in clinical ethics is often conceptualized as a simple hierarchy of successive standards: patient autonomy, surrogate decision-making, and best interests. The received view is that health care teams descend from one criterion to the next until they find a criterion that can inform their decision-making process. Reality is more complicated, even when we bracket the arguments this article introduces. For example, it is common practice even for a patient's autonomous medical decision-making to be constrained by best-interests considerations, as reflected in the set of options that the health care team believes to be medically appropriate. Mainstream clinical bioethics acknowledges that health care teams have a responsibility not to facilitate patient choices that would gravely compromise the patient's interests, such as elective suicide, amputation for otherwise healthy patients, or full-code status for patients who are very unlikely to survive resuscitation attempts. We can see that the scope for patient autonomy is ultimately constrained by the health care team's determination that some interventions are especially contrary to the patient's best interests, even while teams ought to act in accordance with autonomous patient choices made among the options that are offered. So, to say that autonomy (operationalized through assessment of decision-making capacity) has priority over best interests is to say that autonomous patients may choose some interventions that do

Options Permitted by the Health Care Team

Possible interventions, sorted by alignment with best interests	*If the patient has decision-making capacity*	*If the patient lacks decision-making capacity but has a capacity for preferences*	
		Standard view	Our view
Aligned with patient's best interests	Yes	Yes	Yes
Somewhat suboptimal	Yes	No	Yes
Highly suboptimal	Yes	No	No
Entirely contrary to best interests (futile or actively harmful)	No	No	No

not promote their best interests, even while best-interests considerations ultimately constrain the options that the patients may choose between.

We argue that patients with capacity for preferences should also be permitted to choose options that may not strictly promote their best interests. And, as in the case of autonomous patients, the scope of decision-making in which a patient who lacks decision-making capacity but possesses capacity for preferences is involved should be constrained to the range of medically appropriate options. Furthermore, because there are weightier reasons to respect autonomous preferences than nonautonomous preferences, the latter patients should have a smaller scope within which their preferences should be authoritative. That is, their preferences are morally significant enough to justify a smaller deviation from their best interests than can be justified by the preferences of patients with decision-making capacity.

These complexities are summarized in the table, in which the full range of possible treatment options are organized according to how well they are aligned with the patient's best interests. Our view is that for a patient who lacks decision-making capacity but can express preferences, there is a morally important distinction between options that are only moderately suboptimal with respect to a patient's interests (see the second row in the table) and those that are quite suboptimal, even though not so radically contrary to best interests that they would not be offered to a patient who had full decision-making capacity (the third row). By contrast, the standard view in clinical ethics is that there is no morally significant distinction between these options for any patients.

For the case we have discussed, amputation would be in the first row and antibiotics in the second, while comfort care would be in the third. The bottom row would include all options that the health care team would not have offered to a patient who possessed decision-making capacity, for example, active euthanasia. If the patient possessed decision-making capacity, he would have been permitted to decide between amputation, antibiotics, and comfort care. However, he did not, although he may have possessed capacity for preferences. The hospital ethics consultation service followed the received view for decision-making in the case of such patients, agreeing to allow coercive amputation without soliciting the patient's preference of amputation or antibiotics.

Preferences and Real-World Clinical Practice

We have left unanswered many questions about how the claims we have advanced should affect "real-world" clinical ethics, but we will conclude with some practical considerations. First, we advocate the use of preference assessments. Like capacity assessments, preference assessments could have many variations for use in different clinical settings. For example, assessments of capacity range from simple phenomenological evaluations to validated assessment tools (such as the MacArthur Competence Assessment Tool for Treatment, or MacCAT-T). Similarly, we would expect that assessment of preferences might vary. In some contexts, a patient's expressed preferences would have face validity, while in others, it would be necessary to use a validated tool, a structured preference assessment like the one discussed by Louis P. Hagopian, Ethan S. Long, and Karena S. Rush.[19] Capacity for preferences may be analogous to decisional capacity insofar as it is specific to both context and intervention, such that capacity-for-preferences assessments would need to be reevaluated as cases progress.

Often, cases present challenges because they are rare or have idiosyncratic features that may be interesting even though the cases are not broadly informative. Although the case we discuss in this paper emerged through a perhaps uncommon confluence of events, the issues it raises about the moral significance of patient preferences are widespread. Patients frequently have impaired decisional capacity, even while they retain the capacity for preferences. And while important moral problems attend both patients with progressive impediments and those who may have never had decision-making capacity, preferences ought to matter morally, though perhaps to different degrees, for both populations. Our analysis suggests that even when best-interests considerations dictate a clear direction, preferences ought to be taken seriously and may sometimes be decisive. Moreover, as we have articulated above, clear conceptions of best interests are often elusive, sometimes because projected outcomes appear equivocal, but even more often because of an inability to predict those outcomes, to reliably compare the outcomes of two different courses of action, or to discriminate between equally positioned experts who favor different options. There are idiosyncrasies in the case we present, yet its core features are broadly instructive.

We believe health care teams frequently involve patients who lack decision-making capacity in making decisions about their health care. As noted, there appears even to be widespread tacit recognition by clinicians that they should do so; for example, many clinicians are reluctant to (or refuse to) participate in coercive treatments against the wishes of patients who lack decision-making capacity. In practice, the more aggressive an intervention, the more reticent most clinicians are about forcing it on patients. It is common for such reluctance (or refusal) to be explained as a consequence of the necessity of patient compliance for good outcomes or as a response to the moral distress involved in coercion per se. But if patients without decision-making capacity have capacity for preferences, then clinicians who refuse to coercively treat them may be responding to a moral reason not to treat those patients contrary to their preferences.

We advocate the development of a broader framework to address the role of patient preferences in clinical decision-making, a framework that does not reduce the moral value of patient preference to considerations of autonomy, surrogate decision-making, or best interests. It is time to recognize the moral importance of capacity for preferences, even for patients who lack decision-making capacity.

Notes

1. L. B. McCullough, J. H. Coverdale, and F. A. Chervenak, "Ethical Challenges of Decision Making with Pregnant Patients Who Have Schizophrenia," *American Journal of Obstetrics and Gynecology* 187, no. 3 (2002): 696-702; T. M. Pope, "Making Medical Decisions for Patients without Surrogates," *New England Journal of Medicine* 396, no. 21 (2013): 1976-78.

2. E. R. Koppelman-White, "Dementia and Dignity: Towards a New Method of Surrogate Decision Making," *Journal of Medicine and Philosophy* 27, no. 1 (2002): 65-85.

3. N. Karp and E. Wood, *Incapacitated and Alone: Healthcare Decision-Making for the Unbefriended Elderly* (Washington, D.C.: American Bar Association, Commission on Law and Aging, 2003).

4. N. Berlinger, B. Jennings, and S. M. Wolf, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*, 2nd ed. (New York: Oxford University Press, 2013).

5. National Center for Ethics in Healthcare, *Life-Sustaining Treatment Decisions: Eliciting, Documenting & Honoring Patient's Values, Goals & Preferences* [VHA Handbook 1004.03] (Washington, D.C.: Department of Veterans Affairs, Veterans Health Administration, 2017).

6. T. Grisso and P. S. Appelbaum, *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals* (New York: Oxford University Press, 1998), 31.

7. Courts have made this moral distinction legally significant. They generally recognize a difference between a patient's mental health status, general competency, and capacity for making particular medical decisions, with the consequence that even patients who suffer from significant delusions, as in the case above, may have capacity for particular medical decisions, especially in nonemergent situations (Rogers v. Okin 1979, Mills v. Rogers 1982, Rogers v. Commissioner of Mental Health 1982).

8. J. Karagianis et al., "Too Sick for Freedom, Too Healthy for Treatment: Untreated Patients in a Forensic Psychiatry: A Literature Review," *Journal of Medicine, Law, and Ethics* 5, no. 2 (2017): 81-103.

9. A. L. Katz, S. A. Webb, and [American Academy of Pediatrics] Committee on Bioethics, "Informed Consent in Decision-Making in Pediatric Practice," *Pediatrics* 138, no. 2 (2016): e1-e16.

10. J. Cohen-Mansfield et al., "The Impact of Past and Present Preference on Stimulus Engagement in Nursing Home Residents with Dementia," *Aging and Mental Health* 14, no. 1 (2010): 67-73; L. A. LeBlanc et al., "Using Choice-Making Opportunities to Increase Activity Engagement in Individuals with Dementia," *American Journal of Alzheimer's Disease & Other Dementias* 21, no. 5 (2006): 318-25.

11. J. Virues-Ortega et al., "Clinical Decision Making and Preference Assessment for Individuals with Intellectual and Developmental Disabilities," *American Journal on Intellectual and Developmental Disabilities* 119, no. 2 (2014): 151-70, at 151.

12. C. A. Tullis et al., "Review of the Choice and Preference Assessment Literature for Individuals with Severe to Profound Disabilities," *Education and Training in Autism and Developmental Disabilities* 46, no. 4 (2011): 576-95.

13. J. F. P. Bridges et al., "Can Patients Diagnosed with Schizophrenia Complete Choice-Based Conjoint Analysis Tasks?," *Patient* 4, no. 4 (2011): 267-75.

14. Berlinger, Jennings, and Wolf, *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care Near the End of Life*.

15. S. Buss, "Respect for Persons," *Canadian Journal of Philosophy* 29 (1999): 517-50.

16. L. A. Paul, *Transformative Experience* (New York: Oxford University Press, 2014).

17. C. Schneider, *The Practice of Autonomy: Patients, Doctors, and Medical Decisions* (New York: Oxford University Press, 1998).

18. L. Ganzini et al., "Pitfalls in Assessment of Decision-Making Capacity," *Psychosomatics* 44, no. 3 (2003): 237-43.

19. L. P. Hagopian, E. S. Long, and K. S. Rush, "Preference Assessment Procedures for Individuals with Developmental Disabilities," *Behavior Modification* 28, no. 5 (2004): 668-77.