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## Three Kinds of Decision-Making Capacity for Refusing Medical Interventions

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### ABSTRACT

According to a standard account of patient decision-making capacity (DMC), patients can provide ethically valid consent or refusal only if they are able to understand and appreciate their medical condition and can comparatively evaluate all offered treatment options. We argue instead that some patient *refusals* can be capacitated, and therefore ethically authoritative, without meeting the strict criteria of this standard account—what we call *comparative* DMC. We describe how patients may possess *burdens-based* DMC for refusal if they have an overriding objection to at least one burden associated with each treatment option or *goals-based* DMC for refusal if they have an overriding goal that is inconsistent with treatment. The *overridingness* of a patient's objections to burdens, or of their commitment to a goal, can justify the moral authority of their refusal, even when a patient lacks some of the cognitive capacities that standard accounts of DMC involve.

### KEYWORDS

Decision-making capacity; patient rights; surrogate decision making

## INTRODUCTION

Whether a patient possesses decision-making capacity (DMC) is one of the most consequential ethical considerations for clinical care. Patients who lack DMC are not able to consent to or refuse treatment, but instead must have surrogates designated to make decisions on their behalf (Berlinger, Jennings, and Wolf 2013). Some of the most ethically challenging clinical cases involve patients who lack DMC, but who continue to express preferences about their care, especially when their preferences are contrary to the recommendations of physicians or the decisions of their surrogates. Treating patients over their objection is ethically fraught and distressing for those involved (Rubin and Prager 2018).

It is widely acknowledged that the preferences of patients who lack DMC should have *some* moral weight because satisfying those preferences may promote patients' best interests (Joosten et al. 2008; Pope 2013; Shay and Lafata 2015), facilitate surrogate decision making (Koppelman 2002), or protect patients' liberty and personhood (Wasserman and Navin 2018). But this paper makes a stronger claim. We argue that some patients who lack DMC (on its standard, comparative interpretation) may still possess two other kinds of DMC, which we call *burdens-based* and

*goals-based* DMC. If patients possess either of these kinds of DMC, then they may have as much moral authority to make healthcare decisions as patients who possess DMC on the standard account. Here, we focus our arguments on cases in which patients *refuse* proposed interventions, while bracketing the possibility that these other kinds of DMC may also apply to *consent*.

Importantly, our claims about DMC are not instances of the widely accepted idea that DMC thresholds are decision-specific, nor are we invoking the common claim that the requisite capacity to make decisions must be considered on a sliding scale, such that less risky or less consequential patient decisions require lower levels of capacity (Buchanan and Brock 1989; Drane 1985). Our arguments about goals-based and burdens-based DMC do not hinge on whether possible interventions are more or less consequential for the patient. Rather, our arguments about the capacity to refuse treatment derive their moral authority only from the relevance of a patient's overriding goal or of their overriding desire to avoid at least one burden associated with their treatment options. As a consequence, our view may sometimes have implications that are the opposite of what the "sliding scale" model suggests: patients who lack the standard (comparative)

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kind of DMC may still have a moral right to refuse treatment, even if such refusals will likely lead to serious debility or death. In the next section we describe such a case.

## A CASE

Mrs. P is a 77-year-old female who has experienced a difficult medical course in recent months, including complications from chronic kidney disease, COVID pneumonia, dementia, meningioma, and a middle cerebral artery aneurysm. She was admitted to the hospital from her nursing home with altered mental status, acute kidney injury, and abnormal labs following five days of refusing to eat or take medications, and repeatedly stating that she “just wants to die.” The patient is likely to survive to discharge with regular dialysis, medication, nutrition, and hydration. However, Mrs. P strongly refuses any treatment, stating “I don’t want to be tied up here any longer; I don’t want any more procedures or tubes in me. I just want to go home.”

The attending physician and a consulting psychiatrist determine that Mrs. P lacks DMC because she is not able to demonstrate sufficient understanding of her treatment options or to reason through the risks and benefits of those treatment options. Following generally accepted views about the sliding-scale nature of DMC, they require Mrs. P’s capacities to reach a high threshold to determine that she possesses DMC, since she would likely die if she were allowed to refuse treatment. The attending physician states that the patient clearly lacks DMC because her refusal will lead to her death, and because “she can’t even tell me the reason for the Quinton catheter in her chest.”

The patient’s daughter is acting as the surrogate decision maker because Mrs. P has no partner or other children. The daughter is often present at the hospital and demonstrates consistent concern for Mrs. P’s wellbeing and good understanding of the recommendations that physicians make about her mother’s care. Mrs. P’s daughter consents to all medications, as well as to dialysis and to the placement of a nasogastric (NG) feeding tube. Because Mrs. P continues to object to these interventions, both the NG tube and dialysis require sedation and restraints. Mrs. P subsequently dislodges the NG tube. The physicians offer to place a percutaneous endoscopic gastrostomy (PEG) tube and the daughter consents. However, Mrs. P continues to adamantly refuse treatment, and ethics is consulted to assist in determining how to proceed.

## THE STANDARD VIEW OF DECISION-MAKING CAPACITY (ABOUT REFUSAL)

Allen Buchanan and Dan Brock distinguish between three types of capacity standards:

- I. A *minimal* standard of decision-making capacity, which requires only that a patient express a choice;
- II. An *outcome* standard, which requires that a patient select options that a reasonable person would select; and
- III. A *process* standard, which requires that a patient have an appropriate process for making their decision, regardless of the content of what they choose (Buchanan and Brock, 1989, 48–51).

The dominant version of DMC that has been embraced in major guidance documents for clinical ethics is a *process* standard, according to which DMC requires patients to express a choice; understand information about their prognosis and proposed treatments; demonstrate appreciation of their condition; and reason about the relative risks and benefits of the treatment options, including the option of non-treatment (Appelbaum 2007; Drane 1985; Grisso and Appelbaum 1998). The thresholds for these component parts of DMC differ depending on the complexity and likely consequences of the interventions that patients must choose between, such that patients may lack DMC for some kinds of choices, but not others. On the standard view of DMC, either acceptance or refusal of an intervention requires patients to understand and appreciate *the entire range of options presented to them, including non-treatment, and to compare those options to each other*. This canonical conception of DMC emphasizes systematic comparative judgments about the details of each treatment or non-treatment option.

Consider, for example, Paul Appelbaum’s account of the *understanding criterion* for DMC. It requires that patients understand the “nature of [their] condition, nature and purpose of proposed treatment, possible benefits and risks of that treatment, and alternative approaches (*including no treatment*) and their benefits and risks” (Appelbaum 2007, 1836, emphasis added). Appelbaum’s description of the *appreciation criterion* similarly requires that patients “acknowledge [their] medical condition and likely consequences of treatment options” (Appelbaum 2007, 1836). Finally, the *reasoning criterion* emphasizes that patients must be able to “compare treatment options and consequences and to offer reasons for [their]

selection” (Appelbaum 2007, 1836). It is widely acknowledged in the clinical ethics literature that patients must have the ability to understand, appreciate, and compare all their treatment options, including non-treatment, in order to make informed decisions. For example, in his discussion of DMC, Bernard Lo writes that “[a] patient needs to understand the medical situation and prognosis, the nature of the proposed intervention, the alternatives, the risks and benefits, and the likely consequences of *each* alternative” (Lo 2015, 79, emphasis added).

On the standard account of DMC (which we will henceforth call the *comparative* view), Mrs. P seems to lack DMC to refuse the placement of a PEG tube because it appears very unlikely that she can understand, appreciate, or reason about the purpose, risks, and benefits of all of her options. She does not even understand why she is in the hospital or the purpose of her *current* interventions (e.g. the catheter). It seems unlikely that Mrs. P could understand the full set of medical interventions available to her or that she possesses the cognitive ability to compare their benefits and burdens. Therefore, Mrs. P seems to fall short of the criteria for the *comparative* account of DMC. Furthermore, the fact that the standard account of DMC is a sliding scale provides additional reason to suppose that Mrs. P lacks comparative DMC. As Appelbaum puts the point, a patient must demonstrate a “higher level of performance with respect to the relevant criteria” when decisions are especially risky or consequential (Appelbaum 2007, 1838). Mrs. P’s decision to refuse treatment will likely lead to her death and, therefore, she must have especially high levels of appreciation, understanding, and reasoning capacities to meet the requirements of comparative DMC.

We agree that Mrs. P lacks an important kind of decision-making capacity, but we argue that the comparative kind of DMC she lacks is *not the only kind* of DMC that is morally relevant to her authority to refuse interventions. Mrs. P may possess one or both of two other process types of DMC when it comes to her refusal of treatment.

Before proceeding, it may be helpful to note how we are diverging from existing accounts of both what DMC entails and how clinicians should respond to patients who lack DMC. As noted above, bioethicists recognize that there is often something ethically dubious about treating patients over their objection, and they acknowledge that even incapacitated patients should have some weight given to their preferences (Bruce et al. 2017, 11; Lo 2015, 83; Navin,

Wasserman, and Haimann 2019). But our point here is not that a patient’s mere preferences always matter morally (e.g. Wasserman and Navin 2018), but that patients who lack comparative DMC may possess *another kind of DMC*.

## THE CAPACITY TO REFUSE

We argue that there are three kinds of process standards that DMC patients can meet, which each qualify patients to make informed decisions to refuse interventions: (1) a comparative consideration of all available options, including non-treatment; (2) an overriding rejection of *burdens* associated with possible interventions (a *burdens-based* refusal); or (3) an overriding commitment to a *goal* that is inconsistent with treatment (a *goals-based* refusal). We argue that a patient possesses the kind of DMC required to make refusal decisions whenever they possess *at least one* of these three capacities, even when those refusals have serious consequences.

### *Burdens-Based Refusals*

Some patients can make informed decisions to refuse possible medical interventions if they have an overriding objection to the *burdens* of those interventions, even if they are not capable of more complex comparative judgments regarding the nature and potential risks and benefits of the interventions they refuse. Such patients object to *at least one* burden associated with *each* of the proposed interventions, and they object to this burden so strongly that no reasonably foreseeable benefits of potential interventions could compensate for such a burden. That is, these patients recognize some overriding *side constraints* on their treatment decisions. Consider a patient who demands “no more feeding tubes” and “no more surgeries,” and for whom these are *non-negotiable* demands. It does not matter to them that a PEG tube or additional surgeries may prolong their life; they have an overriding commitment to avoid additional tubes, surgeries, and rehabilitation. They do not need to know what the nature, benefits, and risks of various proposed surgeries are, or how a PEG tube differs from a nasogastric or jejunostomy tube, in order for them to have the capacity to make informed refusals of these options.

It appears as if Mrs. P may be making a burdens-based refusal of further medical treatments. Certainly, we would want to ask follow-up questions to clarify that she has an overriding objection to some of the

burdens associated with each possible intervention, but her statement that “I don’t want to be tied up here any longer; I don’t want any more procedures or tubes in me” is a good indication that there may be overriding *burdens* associated with possible interventions that she rejects. Of course, the healthcare team should do some further inquiry before they conclude that Mrs. P is making a burdens-based refusal of all interventions that involve “tubes.” They will want to confirm that Mrs. P’s refusal is based in her overriding objection to a burden associated with treatment options. This will require that she has consistently identified that burden as the reason for her refusal, that her refusal is not the result of a delusion or mental illness,<sup>1</sup> that she is not being coerced by others, and that she understands (in a general sense) the gravity of the potential consequences of her refusal. If the healthcare team can make these confirmations, then they should conclude that Mrs. P is making an informed *burdens-based* refusal even if she has not engaged in—and is not capable of—a *comparative* refusal, because she has an overriding objection to the burdens associated with the interventions available to her.

There are abundant examples of people making highly consequential decisions to refuse options based on an overriding rejection of one or more *burdens* associated with those options, even if they do not know (and have not reasoned about) other aspects of the options they have rejected. Consider someone who has decided that they do not want to find a new home, even though there are many other apartments, condominiums, or houses they could rent or purchase. Suppose the reason this person does not want to find a new home is that they find it extremely burdensome to move. We take for granted that such a person can make an *informed* decision to refuse to explore other properties for rent or purchase, even if they know *nothing* about those properties other than that there is one burden associated with making these properties their new home: the burden of moving. They do not need to consider the various details of all the properties they are rejecting, nor reason comparatively about how these other housing options would promote or undermine their goals (e.g. reducing commuting time, building wealth through home equity) for us to recognize that their decision was sufficiently informed. It is

enough that they overridingly reject at least one burden associated with each alternative housing option.

We can say something similar about informed decisions to refuse medical treatment that are based on a patient’s overriding rejection of some burdens associated with those interventions. This is not because choosing a new home (or moving) is somehow equivalent to life-prolonging medical interventions (or having tubes placed in one’s body), but because, in both cases, a decision to reject a set of options can be sufficiently well-informed if one overridingly rejects one or more burdens associated with each of the potential options. Accordingly, the fact that one does not know, or cannot know, more detailed information about the options one is rejecting does not undercut the rationality of that rejection.

Burdens-based refusals and comparative refusal are similar in that both involve patients considering the costs or burdens associated with potential interventions. The difference is that a patient can engage in a burdens-based refusal if they know only that proposed treatments involve at least one burden that they are unwilling to accept, while comparative refusal requires patients to know and reason about the various natures, risks, and benefits of potential outcomes for each proposed treatment. A patient who provides a comparative refusal, for example, may have to know about the nature (e.g., duration, iteration, rehabilitation) and aim of all proposed surgeries, what the likely complications would be, and how the expected risks and benefits of surgery compare to the expected benefits and burdens associated with other possible interventions. In contrast, burdens-based refusal requires *only one kind of knowledge* about each potential intervention, namely, that it involves a burden to which the patient has an overriding objection. Consider that Mrs. P does not know why she is in the hospital and does not (and likely can never) understand why she is being offered surgery. She does not and cannot engage in a comparative refusal. But she seems to be engaging in a burdens-based refusal, because she identifies that each proposed intervention has a burden she seems to overridingly reject (e.g. cutting, tubes, staying in the hospital). As such, her refusal ought to be as morally authoritative as are the refusals of patients who possess comparative DMC.

### Goals-Based Refusals

A second novel kind of DMC for refusal involves patients who are committed to the *goal* of non-treatment or to other goals that are inconsistent with

<sup>1</sup>There is much disagreement about the relationship between the preferences of mentally ill persons and their “true selves” (Davis 2018; Dresser 1995; Hope et al. 2011), but our view is neutral between positions in this debate.



possible medical interventions (e.g. going home). Some patients, for example, may want their disease to follow its natural progression. They may accept comfort measures, but they do not want to further prolong the course of their disease; they may have the goal of dying, or at least of no longer treating the disease. Importantly, a patient can make a goals-based refusal decision without understanding the details of their diagnosis and the nature and probable outcomes of possible treatments. It is enough that they know that they are being presented with possible medical interventions that interfere with their overriding goal.

Mrs. P may be making a goals-based refusal of further medical treatments. Of course, the mere fact that Mrs. P says she wants to die, or at least does not want any more treatment, is not sufficient evidence that she is refusing on the basis of an overriding goal. We would want to ask follow-up questions to confirm that she has an overriding goal that treatment would interfere with, but her statement that she “just wants to die” is an indication that any curative or life-prolonging treatment is inconsistent with such a goal. The healthcare team should attempt to confirm that Mrs. P has consistently identified an overriding goal as the reason for her refusal, that her refusal is not the result of a delusion or mental illness, that she is not being coerced by others, that she understands (in a general sense) the gravity of the consequences that could result from her refusal. If Mrs. P could meet these conditions, then she would have the capacity to refuse, even if she were incapable of comparatively analyzing each possible intervention that was being offered to her. If Mrs. P has an overriding goal (to be allowed to die), and if she recognizes that all possible medical interventions are incompatible with that goal (even if only because they *are interventions*), then her decision demonstrates sufficient understanding, appreciation, and reasoning for refusal of those interventions. A more detailed *comparative* analysis of her treatment options is unnecessary for her to possess a kind of capacity that gives rise to the moral authority to refuse medical interventions.

In non-medical contexts, we often think that people can make informed decisions to refuse entire option sets without being well-informed about the details of the options within those sets, when all those options are inconsistent with at least one of their overriding goals. For example, a person who is a committed celibate can make an informed refusal of all potential sexual partners even if they know nothing about the individuals who might be interested in having sex with them. A committed celibate does not need to

consider how their life might change if they were sexually intimate with each of the people with whom they have decided not to be intimate. It is enough for them to be overridingly committed to the *goal* of celibacy and for them to know that having a sexual partner would be inconsistent with that goal. Importantly, whether a person has good reasons for being celibate is a separate question from whether they understand what they are giving up by being celibate. For example, a person may choose celibacy because they want to emulate the model of Jesus Christ, and the reasonableness of this choice is not diminished by the fact that a celibate person has not conducted expected utility calculations for having intercourse with potential partners. A person can reasonably choose and pursue a goal—and can treat that goal as a relatively fixed point in their reasoning about how to live—even if they lack detailed information about the options and contingencies involved in not pursuing that goal in any particular moment.

We can say something similar about informed, goals-based refusals of medical treatment: A patient does not have to *know* any details about potential treatments—and they do not need to understand, appreciate, or reason about the relationship between each of those individual interventions—in order to make an informed refusal. They need only to know that those interventions are inconsistent with at least one of their overriding goals. While choosing celibacy seems likely to be less consequential than choosing to die, the importance of the analogy is to highlight that a very consequential choice to refuse an entire set of options can, in both cases, be based on a commitment to an overriding goal.

Both comparative and goals-based refusals involve reasoning about one’s goals, but the difference between them is that a goals-based refusal relies *only* on the recognition that possible interventions are incompatible with at least one overriding goal. Such a refusal need not involve comparative judgments about the nature and expected benefits and burdens of all possible interventions. Mrs. P seems to be engaging in a goals-based refusal, but she has clearly not engaged in comparative judgments about possible interventions. If the treatments that she has been offered are inconsistent with her overriding goal, then she has the moral authority to refuse those interventions.

## OVERRIDINGNESS: EVIDENCE OF A RATIONALE

Asking people to explain or to justify their core commitments can often feel like asking them to defend

their very identities. This is a good reason to usually grant patients the presumption that they have a rationale for their values. Consider how odd, and perhaps even insulting, it may sound to ask a patient “But why are you Christian?” or “But why do you love your grandchildren?” Philosophers may appreciate opportunities to respond to such questions, but most people do not. Their reluctance or inability to provide on-the-spot accounts of their deepest commitments does not undermine their claims to have reasons for those commitments. People can sometimes provide reasons for their most important values and projects, and such commitments are in some ways revisable, but very often their social identities are wrapped up tightly with their firmest commitments, such that it can sometimes be difficult for them to identify reasons for them, or to think of their most important goals as revisable. Accordingly, it is usually reasonable to treat a person’s statement that they have a value or a goal as good evidence that they have reasons for that value or goal.

In particular, we do not generally require that patients *who possess comparative DMC* provide evidence about how committed they are to the values they invoke. If a patient who has comparative DMC says that they want to follow the teachings of Jesus Christ, as interpreted by Mary Baker Eddy, even at grave risk to their life, then we largely take for granted that they do, in fact, possess this fundamental commitment. We act similarly if a patient says that the most important thing is that they stay alive long enough to see their first grandchild who will be born next month, even at the cost of invasive and painful medical interventions to sustain the patient’s life. We may want some confirmation that they are, in fact, Christian Scientists (e.g., we may ask them in private), or that a new grandchild is actually going to be born next month (e.g., we may confirm with a family member), especially if the stakes of the medical decisions are high. But, if a patient *has comparative DMC*, we generally accept that the religious beliefs or family commitments they cite are, in fact, real commitments they hold.

However, we should be somewhat less willing to grant a similar presumption when we are determining whether patients *who lack comparative DMC* have overriding reasons for their refusal of medical treatment. One reason is because these patients have already been determined to have substantial cognitive or epistemic deficits. Those deficits do not rule out the possibility of burdens-based or goals-based DMC, but their revelation somewhat shifts the burden of

evidence onto the patient. Another reason is that burdens-based and goals-based DMC require a special kind of reason: one that is *overriding* of other considerations. Because of the singular power of overriding reasons in burdens-based and goals-based refusals, we may ask for evidence that a patient who refuses treatment is doing so for a reason that they actually consider to be overriding. There are *three ways* a patient could provide such evidence.

First, a patient may be able to currently give an account of their overriding goal or objection to burdens. For example, if Mrs. P refuses treatment because she has the goal of a natural death, and if she explains that she is tired of living with the burdens of her illness, and that she has no other countervailing commitments, then that will be sufficient.

Second, a patient may not be able to currently explain how their refusal of medical treatment is based in an overriding goal or objection to burdens, but they may have previously provided such an account. Suppose that Mrs. P *can* currently express a preference to not be hooked up to a machine, but that she *cannot* currently explain whether this preference is overriding. Mrs. P might still have a capacity for a burdens-based refusal of treatment if she had a history of explaining that she *never* wanted to die in the hospital while hooked up to breathing and feeding tubes. A history of a patient’s statements about medical interventions is commonly understood to inform *substituted judgment* exercised by surrogates, in cases in which patients no longer have DMC. But, in the kinds of cases we are considering, historical evidence about patients’ statements can support the claim that their current refusal is based on an overriding reason. Here, historical evidence is not supporting a decision made by a *surrogate*, but it validates that the patient’s current preference is accompanied by the requisite capacity to refuse, in light of strong continuity between the patient’s current preferences and their historical behavior (Parfit 1984).

Third, a patient may not be able to currently explain how their refusal of medical treatment is based in an overriding goal or objection to burdens, but a patient’s life can sometimes provide evidence about their values. A history of living in consistent pursuit of a particular goal, or in avoidance of specific burdens—in the face of live alternatives—can provide good indirect evidence that a person values that goal, or values the avoidance of those burdens, above (almost) every other pursuit.

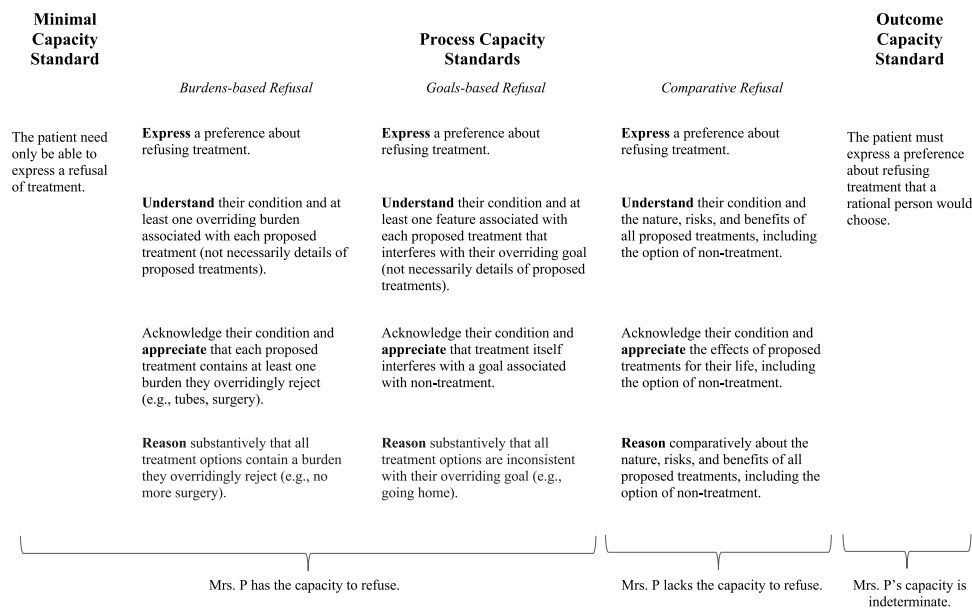


Figure 1. Types of decision-making capacity for refusal.

### CAPACITIES FOR COMPARATIVE, BURDENS-BASED, AND GOALS-BASED REFUSALS

We have described three types of decision-making capacity for refusing treatment. One of these, comparative DMC, requires understanding and appreciation of the patient's diagnosis and of the nature, benefits, and risks of treatment; it also requires the ability to comparatively reason about all the treatments being offered, including the option of non-treatment. We have argued that there are two other types of DMC for refusing treatment, and that neither requires a patient to possess the same thresholds of understanding, appreciation, or reasoning that comparative DMC requires. Patients need only enough understanding, appreciation, or reasoning to be able to recognize either that they are refusing a treatment because it has at least one burden they overridingly reject or because they have at least one overriding goal that is incompatible with offered interventions. Importantly, burdens-based and goals-based DMC have the same four criteria as comparative DMC (expression of preference, understanding, appreciation, and reasoning). But what makes these other two kinds of DMC different is that they require different kinds of these component capacities. By highlighting the different reasoning, understanding, and appreciation criteria of comparative, burdens-based, and goals-based DMC, we can identify formal differences between

these kinds of DMC for refusal, as we outline in Figure 1.

Figure 1 illustrates how the three process types of DMC we have discussed are situated between minimal and outcome standards and shows that burdens-based and goals-based DMC involve the same criteria (expression of preference, understanding, appreciating, and reasoning) as does comparative DMC. Table 1 summarizes how the three process types of DMC for refusal differ in their structure and content. Each involves a distinct combination of different kinds of understanding, appreciation, and reasoning.

A patient who has comparative DMC to select among treatment options knows details about their prognosis, as well as the nature and probabilities of various risks and benefits of all proposed treatments. In contrast, burdens-based or goals-based refusal can sometimes be fulfilled with more limited or even partial kinds of understanding, appreciation, and reasoning. Patients with these kinds of DMC know either that treatment is inconsistent with a non-treatment goal or that all possible treatments have at least one unacceptable burden. Patients who have burdens-based or goals-based DMC must demonstrate *some* kinds of understanding, appreciation, and reasoning, but the nature of the understanding, appreciation, and reasoning required for these other kinds of DMC is different than for comparative DMC.



**Table 1.** Summary of differences between three kinds of decision-making capacity for refusal.

| Burdens-based Refusal  | Goals-based Refusal   | Comparative Refusal  |
|--|---|--|
| A patient must have <i>partial</i> understanding and appreciation of all proposed treatments, such that they can recognize that their reason for rejecting treatment is that each potential treatment involves at least one burden they overridingly reject. | A patient must have <i>partial</i> understanding and appreciation of all proposed treatments, such that they can recognize that each potential treatment will not promote their overriding goal of non-treatment or other goals that are inconsistent with medical interventions (e.g. going home). | A patient must have understanding, appreciation, and be able to comparatively reason about their prognosis and the nature and likely risks and benefits of all proposed treatments (including non-treatment) in light of their goals and values. |

It follows that patients may have DMC to refuse treatments even if they have one or more of a wide set of impairments, including cognitive disabilities or mental disorders that prevent them from acquiring and synthesizing new information (e.g. about their diagnosis, prognosis, or possible interventions); impairments that prevent them from understanding probabilities associated with outcomes of interventions; or deficits in their ability to make comparative judgments about how different interventions may do more or less, on balance, to advance their interests. These kinds of impairments—and the consequent lack of comparative DMC—need not undermine DMC for goals-based or burdens-based refusals. To insist that comparative DMC is the only kind of DMC that makes refusal preferences authoritative is to ignore other ways that people can make informed refusals, both in medical and other contexts.

In ordinary life we rarely treat a person's capacity for detailed comparative judgments about all of their options as a necessary condition for being sufficiently informed about the choices they make. We should be similarly tolerant about decision-making capacity in clinical contexts: Patients who are capable of informed goals-based or burdens-based refusals have as much authority to refuse medical interventions as do patients who possess the capacity for detailed comparative judgments about treatment options.

Finally, we suspect that some people who disagree with our view are likely to be committed to conceptions of rationality or well-being that are unfriendly to the very idea of overriding goals or prohibitions. Indeed, it is common in some kinds of modern moral reasoning to think that (almost) all of one's commitments and convictions are potentially revisable, e.g. as when one relies on the contingencies of a utilitarian calculus or the fluid process of reflective equilibrium to identify or justify one's goals or prohibitions (Bentham 1996; Rawls 1999). However, there is a long tradition of reasoning in terms of one's teleological pursuit of overriding commitments (e.g. the pursuit of knowledge of the Form of the Good; the emulation of God as revealed by Jesus Christ), and there is a similarly long tradition of people living lives in which

some activities are overridingly rejected (e.g. Kosher dietary laws, deontological moralities). In a pluralistic society, it would be parochial and offensive to insist that there is something irrational about having overriding goals or rejecting some activities overridingly. Comparative means-ends reasoning, of the kind embraced by standard accounts of DMC, is just one way to live in accordance with reason.

## IMPLICATIONS FOR PEDIATRICS

There is significant upshot of our view for pediatric ethics. Older children can usually demonstrate (comparative) DMC, at least for some medical decisions, and this gives them a moral claim (though not generally a legal right) to make their own medical decisions (AAP Committee on Bioethics 2016; Hein et al. 2015; Partridge 2014). We think it is possible that some children could possess burdens-based or goals-based versions of decision-making capacity. If children had overriding goals that were inconsistent with possible treatments, or if they had an overriding desire to reject at least one burden associated with each possible treatment, then they could have goals-based or burdens-based DMC for refusal decisions, even if they lacked comparative DMC. Accordingly, we think that such children would have a moral claim (though not a legal right) to make these kinds of medical decisions.

Importantly, it does not follow from the fact that a child possesses DMC (on any of its formulations) that a child's refusal ought to be treated the same as an adult's refusal. In general, adults with decision-making capacity should be allowed to refuse any medical treatments and to leave the hospital for any reason, even if that decision would lead to serious disability or death. In adult clinical ethics there is usually a straight line from a patient's DMC to their authority to make medical decisions. In pediatrics the relationship between these two ideas is more complicated. In particular, parents and providers have ethical responsibilities (that often manifest as legal obligations) to promote children's best interests, even in contexts in which children have the cognitive capacities to make

their own decisions (Salter 2017). To meaningfully say that children have a “right to an open future” implies that their current preferences, even if well-informed, should not be allowed to undermine their options for future well-being, or at least not presumptively so (Feinberg 1980). This point is well established in the pediatric ethics literature, even in the context of standard (comparative) conceptions of DMC: While some older children generally have decision-making capacity, understood in its standard sense, it does not follow that physicians should allow older children to make their own medical choices, or that older children do not require surrogate decision makers. Notably, the American Academy of Pediatrics (AAP) affirms this point, when it argues that older children are often capable of exercising informed consent, but that parents usually have the legal and ethical rights and responsibilities to choose for them, even while physicians and parents have a moral duty to include children’s voices in the decision-making process (AAP Committee on Bioethics 2016).<sup>2</sup>

We endorse similar conclusions about children who possess burdens-based or goals-based DMC, even if they lack comparative DMC. Such children possess the capacity to make decisions to refuse medical interventions, and they therefore have a moral claim to have decision-making authority in those instances, but that moral claim is defeasible and not, by itself, sufficient reason in most cases for physicians to grant children the authority to make their own decisions. Parents’ rights and responsibilities—and clinicians’ obligations—play an important role here, too, even as the refusals of child patients with the relevant capacities should certainly receive substantial weight (Navin and Wasserman 2019; Wasserman, Navin, and Vercler 2019).

Furthermore, even as we acknowledge that it is *possible* for children to possess goals-based or burdens-based DMC, they are less likely to have these kinds of DMC than are adults. To possess goals-based or burdens-based DMC you must have an overriding goal or an overriding rejection of a burden. But an overriding goal or an overriding rejection of a burden involves a recognition and tolerance of a set of possible significant costs (e.g., death) associated with pursuing that goal or rejecting that burden. If you are not willing to suffer significant burdens for your goal (or to avoid a burden), then your goal is not overriding (and your

objection to that burden is not either). As we argue above, it seems likely that Mrs. P has an overriding goal or an overriding objection to burdens associated with treatment. She seems to recognize that serious debility or death is a possible outcome of refusing proposed treatments. In contrast, children—and especially young children—seem very unlikely to understand the kinds of costs they could incur from pursuing goals or rejecting burdens in an overriding manner. For example, a child may object to all vaccines because they hate needles, but that would not mean the child had burdens-based DMC unless we thought that the child understood the likely outcomes of an overriding rejection of needles, which seems unlikely. Of course, as we argue above, even children who do have burdens-based or goals-based DMC should not always be permitted by parents or providers to act on the basis of that capacitated refusal, just as a child’s possession of comparative DMC, by itself, does not justify a child’s decision-making authority.

We also are less likely to have historical evidence that children have overriding goals or rejections of burdens, in cases in which they are not able to provide contemporary accounts. Adults, by virtue of having lived longer lives, have had the opportunity to previously explain their overriding goals or rejections of burdens, or to have illustrated (through the choices they made in their lives) that they have overriding goals or overriding objections to burdens. As we argued above, this kind of historical evidence can often be sufficient to demonstrate the overridingness of a patient’s goal or objection to burdens, even if they now lack the ability to explain their commitments. But that means that adults are much more likely than children to be able to demonstrate that they have overriding goals or overriding objections to burdens, in cases when they are unable to give contemporary accounts.

## CONCLUSION: BROADER CONSEQUENCES OF OUR VIEW

We can now better assess how far this paper’s arguments and conclusions diverge from the standard view about DMC and refusal decisions. As we noted above, there is a widespread intuition that patient refusals matter morally, even when patients lack DMC. For example, the American Society for Bioethics and Humanities (ASBH) states that the objections of a patient who lacks DMC should be given “sometimes considerable or even definitive

<sup>2</sup>Notably, the AAP identifies three conditions in which children may have legal rights to make their own medical decisions: specialized consent statutes, emancipated minors, mature minors (AAP Committee on Bioethics 2016).

weight” (Bruce et al. 2017, 11). Along similar lines, Bernard Lo notes that:

Even if a patient lacks the capacity to make decisions, his or her stated preferences should be given substantial consideration... it would be morally and emotionally repugnant to force interventions on an unwilling patient who cannot understand how the interventions are helping him. (Lo 2015, 83)

Notably, Lo is focused on patients who lack the capacity to make decisions. But our point is that some patients who lack the (standard) *comparative* kind of DMC may still have the *capacity to refuse* treatment because they possess either goals-based or burdens-based DMC. Their preferences should not merely be given “substantial consideration,” but should generally be authoritative in the same way as are the preferences of patients who possess comparative DMC. This is not only because forcible treatment is “emotionally repugnant,” but because patients who have the capacity to make a choice should be permitted to make that choice. It is wrong to override them, since it violates a core commitment of clinical ethics: The right of persons to make decisions for themselves when they are able to make decisions for themselves.

Our view therefore has significant upshot for both the theory and practice of clinical ethics, beyond the immediate issue of whether and when patients have the capacity to refuse interventions. First, our account provides a richer understanding of the decision-specificity of DMC. It is commonplace in clinical ethics to observe that DMC is decision-specific, but we have illustrated that there are qualitative differences between kinds of DMC. And we suspect that there are other contexts of clinical decision making in which other *qualitatively unique* kinds of DMC apply. For example, we have recently argued elsewhere that a person could have the capacity to designate a surrogate, even if they lacked comparative DMC, since the decision to select a surrogate can be well-informed even if someone has little understanding of their diagnosis or proposed treatments (Navin et al. 2021).

Second, our account indicates that the use of surrogate decision makers could be better attuned to the different kinds of DMC that patients may possess for different kinds of choices. Patients who are determined to lack comparative DMC for most decisions are usually assigned surrogate decision makers to choose on their behalf. But patients who possess a capacity for *goals-based* or *burdens-based* refusal should be permitted to make refusal decisions, even if they lack the capacity for *comparative* selections among treatment options, and even if they already

have a surrogate appointed for them. The same patients who may need surrogates for some decisions may not require them for other decisions. It is therefore a consequence of our argument that some patients should not have surrogates, *in general*, but should have surrogates only for the particular kinds of interventions for which they lack the relevant kinds of DMC. Again, this conclusion is part of the existing consensus, but our view expands the scope of decisions that patients should be considered capacitated to make. Our view may have similar upshot for the emerging literature on supported decision making (Peterson, Karlawish, and Largent 2020).

Finally, this paper has focused on decision-making capacity for *refusal*, but there may be upshot for *consent*, though this paper has remained agnostic on that issue. Our inquiry here was motivated by our consultation on the case of Mrs. P. Patients like Mrs. P object to treatments and give reasons for refusing interventions, even while their valid surrogates often insist on treatments they believe will be beneficial. We think there is a kind of moral wisdom reflected in the distress and uncertainty with which clinicians often approach such cases, and we applaud clinicians who are reluctant to treat patients like Mrs. P over their objections. Such ethical insight is not yet well captured by standard guidance about DMC. One goal of this paper was to provide a philosophical defense of real-world practices that are inconsistent with standard guidance, but which seem to be morally justified.<sup>3</sup>

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## REFERENCES

- AAP Committee on Bioethics. 2016. Informed Consent in Decision-Making in Pediatric Practice. *Pediatrics* 138 (2): e20161484. doi: [10.1542/peds.2016-1484](https://doi.org/10.1542/peds.2016-1484).
- Appelbaum, P. S. 2007. Clinical practice. Assessment of patients' competence to consent to treatment. *The New England Journal of Medicine* 357 (18):1834–40. doi: [10.1056/NEJMc074045](https://doi.org/10.1056/NEJMc074045).
- Bentham, J. 1996. *The Collected Works of Jeremy Bentham: An Introduction to the Principles of Morals and Legislation*. Oxford, UK: Clarendon Press.

<sup>3</sup>We are grateful to an anonymous reviewer for suggesting this way to frame our paper.

- Berlinger, N., B. Jennings, and S. M. Wolf. 2013. *The Hastings Center Guidelines for Decisions on Life-Sustaining Treatment and Care near the End of Life: Revised and Expanded Second Edition*. New York: Oxford University Press.
- Bruce, C. R., G. E. Hardart, L. Wocial, S. Finder, B. Huberman, J. Jankowski, A. L. Katz, et al. 2017. *Addressing Patient-Centered Ethical Issues in Health Care: A Case-Based Study Guide*. Chicago, IL: American Society for Bioethics and Humanities.
- Buchanan, A. E., and D. W. Brock. 1989. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge, UK: Cambridge University Press.
- Davis, D. S. 2018. Advance directives and Alzheimer's disease. *The Journal of Law, Medicine & Ethics* 46 (3): 744–48.
- Drane, J. F. 1985. The many faces of competency. *The Hastings Center Report* 15 (2):17–21. doi:10.2307/3560639.
- Dresser, R. 1995. Dworkin on dementia: elegant theory, questionable policy. *Hastings Center Report* 25 (6): 32–38.
- Feinberg, J. 1980. The child's right to an open future. In *Whose Child? Children's Rights, Parental Authority and State Power*, ed. William Aiken and Hugh La Follette, 124–153. Totowa, NJ: Rowman and Littlefield.
- Grisso, T., and P. S. Appelbaum. 1998. *Assessing Competence to Consent to Treatment: A Guide for Physicians and Other Health Professionals*. New York: Oxford University Press.
- Hein, I. M., M. C. De Vries, P. W. Troost, G. Meynen, J. B. Van Goudoever, and R. J. L. Lindauer. 2015. Informed consent instead of assent is appropriate in children from the age of twelve: Policy Implications of New Findings on children's competence to consent to clinical research. *BMC Medical Ethics* 16 (1):76. doi:10.1186/s12910-015-0067-z.
- Hope, T., J. Tan, A. Stewart, and R. Fitzpatrick. 2011. Anorexia nervosa and the language of authenticity. *Hastings Center Report* 41 (6): 19–29.
- Joosten, E. A., L. DeFuentes-Merillas, G. H. De Weert, T. Sensky, C. P. F. Van Der Staak, and C. A. de Jong. 2008. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychotherapy and Psychosomatics* 77 (4): 219–26. doi:10.1159/000126073.
- Koppelman, E. R. 2002. Dementia and dignity: Towards a new method of surrogate decision making. *The Journal of Medicine and Philosophy* 27 (1):65–85. doi:10.1076/jmep.27.1.65.2971.
- Lo, B. 2015. *Resolving Ethical Dilemmas: A Guide for Clinicians*. 5th ed. Philadelphia, PA: Wolters Kluwer.
- Navin, M. C., J. A. Wasserman, D. Stahl, and T. Tomlinson. 2021. The capacity to designate a surrogate is distinct from decisional capacity: Normative and empirical considerations. *Journal of Medical Ethics*. Published Online First: 19 February 2021. doi:10.1136/medethics-2020-107078.
- Navin, M. C., and J. A. Wasserman. 2019. Capacity for preferences and pediatric assent implications for pediatric practice. *The Hastings Center Report* 49 (1):43–51. doi:10.1002/hast.980.
- Navin, M. C., J. A. Wasserman, and M. H. Haimann. 2019. Treatment over objection-moral reasons for reluctance. *Mayo Clinic Proceedings* 94 (10):1936–8. doi:10.1016/j.mayocp.2019.08.011.
- Parfit, D. 1984. *Reasons and Persons*. Oxford: Oxford University Press.
- Partridge, B. 2014. Adolescent pediatric decision-making: A critical reconsideration in the light of the data. *HEC Forum : An Interdisciplinary Journal on Hospitals' Ethical and Legal Issues* 26 (4):299–308. doi:10.1007/s10730-014-9250-8.
- Peterson, A., J. Karlawish, and E. Largent. 2020. Supported decision making with people at the margins of autonomy. *The American Journal of Bioethics*. doi:10.1080/15265161.2020.1863507.
- Pope, T. M. 2013. Making medical decisions for patients without surrogates. *The New England Journal of Medicine* 369 (21):1976–8. doi:10.1056/NEJMp1308197.
- Rawls, J. 1999. *A Theory of Justice*. Rev. ed. Cambridge, MA: Belknap Press of Harvard University Press.
- Rubin, J., and K. M. Prager. 2018. Guide to considering nonpsychiatric medical intervention over objection for the patient without decisional capacity. *Mayo Clinic Proceedings* 93 (7):826–9. doi:10.1016/j.mayocp.2018.04.005.
- Salter, E. K. 2017. Conflating capacity & authority: Why we're asking the wrong question in the adolescent decision-making debate. *The Hastings Center Report* 47 (1): 32–41. doi:10.1002/hast.666.
- Shay, L. A., and J. E. Lafata. 2015. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Medical Decision Making: An International Journal of the Society for Medical Decision Making* 35 (1): 114–31. doi:10.1177/0272989X14551638.
- Wasserman, J. A., and M. C. Navin. 2018. Capacity for preferences: Respecting patients with compromised decision-making. *The Hastings Center Report* 48 (3):31–9. doi:10.1002/hast.853.
- Wasserman, J. A., M. C. Navin, and C. J. Vercler. 2019. Pediatric assent and treating children over objection. *Pediatrics* 144 (5):e20190382. doi:10.1542/peds.2019-0382.