

Ditching Decision-Making Capacity

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1. Introduction

Decision-making capacity (DMC) plays an important role in clinical practice – determining, on the basis of a patient’s decisional abilities, whether they are entitled to make their own medical decisions or whether a surrogate must be secured to participate in decision-making on their behalf.¹ And assessments of DMC are ubiquitous – while adult patients are presumed to have DMC unless there is good evidence indicating otherwise, there often is such evidence. A meta-analysis by Sessums et al. [2], for instance, found significant prevalence of incapacity across different patient populations, including 2.8% of healthy elderly adults, 20% of patients with mild cognitive impairment, 26% of medicine inpatients, 44% of nursing home residents, and 68% of patients with learning disabilities.²

So assessing DMC is both important and commonplace. As a result, it’s critical that we get things right – that our conceptual framework be well-suited to the task of helping practitioners systematically sort through the relevant ethical considerations in a way that reliably and transparently delivers correct verdicts about who is and is not entitled to make their own medical decisions – or, as we’ll often put it, about who should and should not have *decisional authority*.³ To overly circumscribe decisional authority would risk systematically violating patients’ autonomy, and to grant it too broadly would fail to protect and support vulnerable patients who aren’t in a position to decide for themselves [3–5].

¹ Of course, a surrogate’s involvement in medical decisions need not (and very often should not) preclude the patient’s participation in decision-making to at least some extent. But, even still, patients with decision-making capacity retain an authority to *on their own* accept or decline offered treatments that incapacitated patients lack. For a recent, insightful discussion of supported decision-making for incapacitated patients, see McCarthy and Howard [1].

² Specifically, the metaanalysis covered “English-language articles that studied instruments assessing medical decision-making capacity...for treatment decisions and were feasible to use in the office or bedside.” For more on the prevalence of incapacity see Kim [3 (pp.37-54)].

³ Here and in what follows, we have in mind a *non-normative* notion of decisional authority whereby a patient has decisional authority over some choice if and only if their decision will *in fact* determine which option prevails. This is in contrast a *normative* reading on which a patient has decisional authority over some choice if and only their decision *should* determine which option prevails. In our (non-normative) sense, then, decisional authority is something that we can grant or withhold, and the normative question – which DMC is meant to answer – is ‘who should (and should not) have decisional authority?’

Unfortunately, however, “the standard approach” (as we characterize it) to DMC does not get things right. The commitments of the standard approach result in a conception of DMC that is of little use for sorting through the relevant ethical considerations and obfuscates the underlying ethical justification for granting or withholding decisional authority. And there’s no easy fix; variations on the standard approach do not adequately address these problems.

Of course, we’re not the first to offer a critique of DMC. There’s an extensive literature.⁴ But while some existing critiques echo some of the concerns we raise below, proposed solutions typically preserve key features of the standard approach.⁵ What sets our project apart is that we argue that the problems that plague the standard approach can’t be solved by tinkering around the edges. Instead, a more radical reconceptualization is needed of both how we measure patient autonomy and its role in determinations of decisional authority. More pithily: we should ditch DMC, and replace it with something better suited to our needs.⁶

In what follows, we’ll begin (in §2) by sketching (what we take to be) DMC’s characteristic role within the prevailing anti-paternalist paradigm. We’ll then (in §3) home in on DMC itself, describing several core commitments of the standard approach. With the standard approach clarified, we proceed (in §4) to identify three problems with it and argue (in §5) that in light of these problems, we should “ditch” DMC and replace it with a reengineered measure of patient autonomy and approach to determinations of decisional authority that together help practitioners identify and sort through relevant ethical considerations while avoiding the problems that plague DMC.

2. The Anti-Paternalist Paradigm

To start, it’ll be helpful to tell an (admittedly caricatured) story about the history of medicine.

⁴ One much too extensive to fully engage with here (though points of contact will be noted along the way). For a helpful overview of the relevant philosophical literature, Hakwins and Charland [5]. For a more general overview (including historical and legal context), see Kim [3].

⁵ To take just one recent notable example, Navin et al. [6] argue that the standard (“comparative”) account of DMC fails to capture an important range of cases in which a patient should have the authority to refuse medical intervention, proposing to replace it with a tripartite account that distinguishes between *burdens-based*, *goals-based*, and *comparative* DMC. We’re sympathetic with Navin et al.’s concerns. But although their tripartite account might initially appear to constitute a radical departure from the standard account, it’s in fact a rather conservative extension of it: all three kinds of DMC belong to the broadly Appelbaumian framework according to which DMC is binary, risk-relative, authority-entailing, and constituted by the abilities to understand, appreciate, reason, and communicate. What distinguishes the three kinds is merely the type and degree of understanding, appreciation, and reasoning required.

⁶ Here it’s worth emphasizing that we’re concerned with DMC’s purported role in helping practitioners sort through *ethical* considerations relevant to determining whether patients should have decisional authority. We acknowledge DMC’s *legal* importance in determining who *legally* is entitled to make their own medical decisions. But while we suspect that the existing legal apparatus could be modified to accommodate a more (ethically) useful measure of patient autonomy (apart from the standard approach to DMC), we won’t speak directly to this point.

Once upon a time, medical practice was *thoroughly paternalistic* – treatment was guided by concern for patients’ well-being, but largely unconstrained by concern for patients’ autonomy. Then, some bioethicists descended from their ivory towers and helped medical practitioners appreciate the importance of respecting autonomy – patients, typically, are autonomous agents and, as such, are entitled to exercise (at least some degree of) control over their medical treatment.⁷ In response, medical practice has become *anti-paternalistic*. The anti-paternalist thought is that it’s always (or at least almost always) wrong to fail to respect a patient’s autonomy, even if doing so is in the patient’s best interests. The reason to respect patient autonomy is, in this sense, *decisive* – when in play, it trumps other normatively relevant considerations such that if some treatment fails to respect a patient’s autonomy, that alone is enough to make that treatment ethically inappropriate. On this model, a patient’s well-being remains important, but it is to be promoted only within the confines created by the demand to respect patients’ autonomy, and if an autonomous patient autonomously chooses among (or declines) offered treatments, their choice should determine which treatment option (if any) is pursued. Autonomous patients, in other words, should have decisional authority.⁸

Despite the overriding importance of autonomy in the anti-paternalist paradigm, however, it’s clear that sometimes autonomy concerns simply don’t arise – or at least not in the way they usually do for typically functioning adult patients. Sometimes a patient can’t decide. Perhaps, for example, they arrive at the Emergency Department in a coma. Or they have a severe intellectual disability. Or they’re an infant. In such cases, respecting the patient’s autonomy by doing as they decide is not an option because, again, they *can’t* decide. Instead, treatment is aimed – typically in consultation with a surrogate – at promoting the patient’s well-being in a way that is consistent with their preferences and values, if such there be.⁹

So, to summarize, according to the anti-paternalist paradigm, there is an inviolable obligation to respect patients’ autonomous decisions that, when present, entitles a patient to decisional authority. Oftentimes whether this obligation is present (as in the case of a healthy, sober, typically functioning adult) or absent (as in the case of a coma patient, or a severely intellectually disabled patient, or an infant) is obvious. But sometimes it’s not obvious. And in

⁷ Note that respecting an individual’s autonomy (in the relevant sense) only requires ensuring or allowing that they exercise control over choices within their *sovereign domain*, rather than over anything whatsoever (see Feinberg, ch. 19 [7]). Although the boundaries of one’s sovereign domain are subject to dispute, it’s relatively uncontroversial that choices to accept or decline offered medical treatments lie within them.

⁸ Katz [8] and Faden and Beauchamp [9] tell versions of this history. For a more nuanced take, see Kim [3]. For a prominent defense of the anti-paternalist paradigm (though not under that description), see Gillon [10] who characterizes the principle of respect for autonomy “as *primus inter pares* – first among equals – among the four principles [of bioethics].”

⁹ Although treating a patient in a way that is “consistent with their preferences and values” might reasonably be characterized as a way of respecting their autonomy (and applies to capacitated and incapacitated patients alike), it’s distinct from respecting a patient’s autonomy by *deferring to their decision* or *ensuring they exercise control*. It’s the possibility of respecting autonomy in this latter sense that DMC is meant to track and that will therefore be relevant in what follows. For more on the distinction between these two ways of respecting autonomy, see Brudney and Lantos [11], Enoch [12,13], and Schwan [14].

such cases we need a way of distinguishing patients who (in the relevant sense) *can* decide, and hence for whom the obligation to respect autonomy arises, from patients who *cannot* decide, and hence for whom this obligation is silent.¹⁰

This is the characteristic role of DMC: to determine which patients should have decisional authority by gauging patients' autonomy.¹¹ But whether any given account of DMC is well-positioned to play this role depends on both the particular features of the account proposed and on the underlying normative considerations.

Before moving on, it's worth pausing for some terminological housekeeping. We characterize DMC's "characteristic role" as we do because, despite competing conceptions in the literature, DMC is almost universally employed in the clinical setting as a mechanism for determining decisional authority in part on the basis of decisional abilities linked to autonomous agency. "DMC", in this sense, should be treated as a term of art – one that picks out the concept that plays this practical role. That said, there are various ways one might approach DMC, so understood. In the next section we'll characterize what we take to be "the standard approach" to DMC, and in the following sections we'll criticize the standard approach and variations of it.

3. The Standard Approach to Decision-Making Capacity

What we'll be calling the standard approach to DMC – first sketched by Grisso and Appelbaum [17] – consists of two main parts: one concerning the *nature* of DMC and one concerning the *role* of DMC. We'll discuss each in turn.

3.1 *The nature of DMC*

According to the standard approach, DMC is binary – a patient either has DMC or lacks it – and is constituted by the following four core abilities:

Understanding: the ability to understand the relevant information provided.

Appreciation: the ability to appreciate one's medical condition and situation.

Reasoning: the ability to reason about one's options.

Communication: the ability to communicate one's preferences and decisions.

Appelbaum [18] helpfully provides the following table describing the four criteria and how they can be assessed:

¹⁰ Why "in the relevant sense"? Because to merely decide doesn't take much. There's a sense in which even a patient suffering from persistent systematized delusions can still make decisions on the basis of their delusions. But such a patient clearly can't make decisions in the sense that DMC is meant to track. Indeed, such a patient is a paradigmatic example of *lacking* DMC (see, for instance, Grisso et al. [15]).

¹¹ This is true at least in the context of the United States. To the extent that a similar approach is used elsewhere, our arguments will apply to those too (see Kim [3, Ch. 1] and Berg [16]). To the extent that an approach to DMC posits a different nature/role, however, our arguments simply won't apply.

Table 1. Legally Relevant Criteria for Decision-Making Capacity and Approaches to Assessment of the Patient.

Criterion	Patient's Task	Physician's Assessment Approach	Questions for Clinical Assessment*	Comments
Communicate a choice	Clearly indicate preferred treatment option	Ask patient to indicate a treatment choice	Have you decided whether to follow your doctor's [or my] recommendation for treatment? Can you tell me what that decision is? [If no decision] What is making it hard for you to decide?	Frequent reversals of choice because of psychiatric or neurologic conditions may indicate lack of capacity
Understand the relevant information	Grasp the fundamental meaning of information communicated by physician	Encourage patient to paraphrase disclosed information regarding medical condition and treatment	Please tell me in your own words what your doctor [or I] told you about: The problem with your health now The recommended treatment The possible benefits and risks (or discomforts) of the treatment Any alternative treatments and their risks and benefits The risks and benefits of no treatment	Information to be understood includes nature of patient's 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
Appreciate the situation and its consequences	Acknowledge medical condition and likely consequences of treatment options	Ask patient to describe views of medical condition, proposed treatment, and likely outcomes	What do you believe is wrong with your health now? Do you believe that you need some kind of treatment? What is treatment likely to do for you? What makes you believe it will have that effect? What do you believe will happen if you are not treated? Why do you think your doctor has [or I have] recommended this treatment?	Courts have recognized that patients who do not acknowledge their illnesses (often referred to as "lack of insight") cannot make valid decisions about treatment Delusions or pathologic levels of distortion or denial are the most common causes of impairment
Reason about treatment options	Engage in a rational process of manipulating the relevant information	Ask patient to compare treatment options and consequences and to offer reasons for selection of option	How did you decide to accept or reject the recommended treatment? What makes [chosen option] better than [alternative option]?	This criterion focuses on the process by which a decision is reached, not the outcome of the patient's choice, since patients have the right to make "unreasonable" choices

* Questions are adapted from Grisso and Appelbaum.³¹ Patients' responses to these questions need not be verbal.

Importantly, each of these abilities comes in degrees. One can understand information better or worse and appreciate one's situation more or less well. Likewise, one can reason about one's options more or less fully and communicate one's choice more or less clearly. Possession of DMC thus requires more than just the possession of each ability to *some* degree – it requires the possession of each ability to a *sufficiently high* degree. The need for determining (what we'll call) *ability thresholds*, however vague or indeterminate they may be, follows from the fact that each of the abilities constitutive of DMC – which we'll sometimes refer to simply as 'decisional abilities' – comes in degrees while DMC itself does not.

DMC is also *decision-relative*. As Hawkins and Charland [5] put it,

Decision relativity refers to the now almost universally accepted idea that [DMC] should be assessed relative to a specific decision, at a particular time, in a particular context.¹²

To better understand decision-relativity, it'll be helpful to introduce a distinction commonly drawn in the philosophical literature on abilities – namely, between *general* and *specific* abilities. Mele [21] illustrates the distinction as follows:¹³

Although I have not golfed for years, I am able to golf. I am not able to golf just now, however. I am in my office now, and it is too small to house a golf course. The ability to golf that I claimed I have [is] a *general* practical ability. It is the kind of ability to *A* that we attribute to agents even though we know they have no opportunity to *A* at the time of attribution and we have no specific occasion for their *A*-ing in mind. The ability to golf that I denied I have is a *specific* practical ability, an ability an agent has at a time to *A* then or to *A* on some specified later occasion.

To have a general ability to *A* is, roughly, to have the capacity to *A* should the opportunity arise. It's the kind of ability we might ascribe to Serena Williams when we see her driving a car and say "She is able to serve a tennis ball", or to a sleeping Yo-Yo Ma when we say "He can play the cello". General abilities like these are largely a function of the relevant person's traits and talents and the nature of the relevant task.

Having the specific ability to *A*, on the other hand, requires having the general ability to *A* together with the opportunity to exercise it. You might possess the general ability to kick a soccer ball, for example, without ever having the opportunity to do so. Perhaps it just so happens that you go through life without coming across a soccer ball. Or perhaps you do come across one but can't kick it because the kids with the ball won't give it to you, or because you recently broke both of your legs. These are all obstacles, whether internal or external, that rob you of the opportunity – and hence the specific ability – to kick a soccer ball.

Of course, not all opportunities are created equal – some are better or worse than others. Perhaps you have a soccer ball but it's flat, and you're so sleep-deprived you have trouble seeing straight. You may still be able (in the specific sense) to kick the ball, but doing so will be more difficult and require more skill or effort than it would under normal circumstances. So having an obstacle-free opportunity to exercise a given ability is not the only thing that matters – the *quality* of the opportunity also makes a difference to whether and how well we can exercise our general abilities. The quality of opportunity thus impacts one's specific abilities without impacting one's general abilities – the latter are relatively stable and not directly impacted by one's fluctuating circumstances.

The distinction between general and specific abilities helps tease apart two ways in which DMC is decision-relative. First, since general abilities depend, in part, on the nature of the relevant

¹² Hawkins and Charland in turn cite Buchanan & Brock [4], Culver & Gert [19], and Zapf & Roesch [20].

¹³ For similar distinctions, see Honoré [22], van Inwagen [23] and Maier [24], among others.

task, whether a patient has the general ability to understand and appreciate relevant information, reason about their options, and communicate their decision will depend on the *content* of the choice they face. Just as you might have the general ability to kick a soccer ball but not to solve a Rubik's cube, so a patient might have the general ability to reason about discharge plans, but not about goals of care. So one way DMC is decision-relative is that it's *content-relative* – the extent of a patient's (general) decisional abilities depends (in part) on the content of the choice they're facing.

Second, since specific abilities are a function of general abilities plus opportunity, whether a patient is specifically able to understand, appreciate, reason, and communicate depends (in part) on their circumstances and the quality of opportunity those circumstances provide. It makes a difference, for example, how well-rested and alert one is, how much time one has to process information, whether there are any internal or external distractions, and so on. So another way DMC is decision-relative is that it's *circumstance-relative* – circumstantial factors help determine whether and how well a patient is able to understand, appreciate, reason, and communicate with respect to the particular choice they face in the particular circumstances they're in.

It's unsurprising that DMC is decision-relative in these ways – DMC is constituted by (specific) decisional abilities, and *all* (specific) abilities are content-relative and circumstance-relative. But in addition to these unsurprising ways, there is another, much more peculiar way in which DMC is treated as decision-relative: it is *risk-sensitive*. To understand what this amounts to, recall that because DMC is binary we must (at least implicitly) posit thresholds on the constitutive decisional abilities above which a patient qualifies as having DMC and below which a patient qualifies as lacking it. And it's commonly thought that the relevant thresholds *change* depending on the stakes of the choice at hand. For instance, a patient facing a very high-stakes choice – say, one in which they must decide between a life-prolonging treatment accompanied by significant suffering and a more comfortable but life-limiting treatment – must demonstrate *robust* decisional abilities to qualify as having DMC, whereas a patient facing a comparatively low-stakes choice – say, one in which they must decide between a slightly less powerful painkiller with no side effects and a slightly more powerful painkiller with a risk of nausea – need only demonstrate (comparably) modest decisional abilities to qualify as having DMC. The threshold(s) required for DMC are thus standardly taken to be risk-sensitive: the riskier a choice is, the greater the degrees of decisional abilities required for DMC.

We say 'standardly', though it's worth noting that risk-sensitivity is contested.¹⁴ We nonetheless include it as part of the standard approach for three reasons. First, risk-sensitivity is often endorsed by DMC assessment guidelines, including from authorities such as the American Bar Association and American Psychological Association (jointly) [37] and the American Psychiatric

¹⁴ For early critical discussions, see Culver and Gert [19], Wicclair [25–27], Saks [28], Elliott [29], and White [30], among others. For early defenses see Brock [31], Skene [32], Winick [33], and Wilks [34,35], also among others. For further references, see Berens and Kim's [36] excellent systematic review of arguments for and against risk-sensitivity.

Association [38]. Second, in practice, DMC assessments are significantly influenced by assessors' perception of risk, as evidenced by a study by Kim et al. showing that "clinicians with experience in capacity evaluations are clearly influenced by the risk/benefit profile of the patient's decision-making situation" [39]. Third, most theorists seem to favor a risk-sensitive approach as well, as evidenced by Berens and Kim [36] in their systematic review of arguments for and against risk-sensitivity.¹⁵ That said, it would be a mistake to ignore those who reject risk-sensitivity. And we don't. We'll consider a modified version of the standard approach that eschews risk-sensitivity in §4.1.

3.2 *The role of DMC*

In §2, we sketched the DMC's characteristic role: helping practitioners determine which patients should have decisional authority by gauging patients' autonomy. Here, we'll say more about *how*, according to the standard account, DMC plays that role.

First, DMC is standardly taken to be *autonomy-tracking* in the sense that it tracks whether a patient is capable of making an autonomous decision (in a given choice context). To be autonomous, roughly put, is to be self-governing – to have the capacity to act according to one's beliefs, values, aims, intentions, and so on (which we'll collectively refer to as one's "commitments").¹⁶ And it's very plausible that the abilities that constitute DMC are also central to self-governance – our abilities to understand, appreciate, and reason are part of the explanation for *how* our actions and decisions accord with our commitments (when in fact they do).¹⁷ Given this, DMC is well-positioned to track whether a patient (or their decision) is autonomous. This is important because, as emphasized in §2, autonomy demands respect – when a patient makes an autonomous decision about some choice within their sovereign domain, others have a strong reason to allow (or perhaps even help ensure) that the decision determines which option prevails.

Second, DMC is taken to *justify decisional authority*. According to the standard approach, *if and because* a patient has DMC regarding some choice, their decision should determine their treatment; whereas *if and because* they lack DMC, it's not the case that their decision (alone)

¹⁵ Because Berens and Kim examine *arguments* for and against risk-sensitivity, they may actually overstate the extent to which risk-sensitivity is controversial (both in the literature and in practice) since their review omits literature and guidelines (like those cited above) that endorse risk-sensitivity without arguing for it.

¹⁶ There are of course many competing accounts of autonomy on offer in the philosophical literature. This very rough sketch is very rough precisely because it's meant to be ecumenical. The points in what follows should go through for any plausible account of autonomy.

¹⁷ We omit the ability to communicate because it isn't plausibly central to self-governance. The reason it's an element of DMC is that without it, we have no way of *knowing* the extent of a patient's other decisional abilities. See Hawkins and Charland [5]. We set this complication aside in what follows.

should determine their treatment.¹⁸ Beauchamp and Childress [40] summarize this role as follows:

Obligations to respect autonomy do not extend to persons who cannot act in a sufficiently autonomous manner. (p. 108)

Competence or capacity judgments in health care serve a gatekeeping role by distinguishing persons whose decisions should be solicited or accepted from persons whose decisions need not or should not be solicited or accepted. (p. 114)

The *way* in which DMC is thought to justify decisional authority falls out of the anti-paternalist paradigm in which DMC operates. Since, according to the standard approach, DMC tracks whether a patient's decision is autonomous and hence generates a reason to respect their autonomy, and since, according to the anti-paternalist paradigm, the reason to respect a patient's autonomy is decisive, if a patient has DMC then we have a decisive reason to respect their autonomy by deferring to their decision.

Here's the justificatory schema, a bit more formally:

1. If a patient has DMC (regarding some set of options within their sovereign domain), then to respect their autonomy is to do as they decide. (*DMC is autonomy-tracking*)
2. If to respect a patient's autonomy is to do as they decide, then we (all things considered) ought to do as they decide. (*Anti-paternalism*)
3. So, if a patient has DMC, then we ought to do as they decide – i.e. they should have decisional authority (regarding the relevant choice). (*DMC justifies decisional authority*)

Similarly, lacking DMC justifies *withholding* decisional authority given that DMC is *autonomy-tracking* and the common thought that when a patient's decision does not generate a reason to respect their autonomy, that patient should be treated in whatever way best promotes their well-being (and is consistent with their commitments).¹⁹

3.3 Taking stock

So DMC is standardly taken to be *binary* and *constituted by decisional abilities* (to understand, appreciate, reason, and communicate) that come in degrees, thus requiring *thresholds*; it's *decision-relative* in both unsurprising (*content-relative* and *circumstance-relative*) and surprising (*risk-sensitive*) ways; and it's commonly thought to *track autonomy* and *justify decisional authority* within an *anti-paternalist paradigm*.

¹⁸ This isn't to say that the treatment should be *contrary* to their decision, just that their decision isn't sufficient by itself to justify the treatment they decided upon.

¹⁹ Again, while the reason to treat an incapacitated patient in a way that is consistent with their values and commitments is plausibly construed as an autonomy-based reason, it's distinct from the autonomy-based reason to *do as a patient decides* (see fn. ix).

That’s a lot of italics. So here’s a summary (*table 1*):

<i>The Standard Approach to DMC</i>	
<i>Nature</i>	Four abilities: DMC is constituted by the decisional abilities to understand, appreciate, reason, and communicate.
	Binary: DMC is binary (and hence requires thresholds for the constitutive abilities).
	Decision-relativity: whether a patient has DMC is relative to the choice context, including the content of the relevant choice (<i>content relativity</i>), the circumstances of the relevant choice (<i>circumstance relativity</i>), and the potential risks and benefits of the choice (<i>risk sensitivity</i>).
<i>Role</i>	Autonomy-tracking: DMC tracks whether a patient (or their decision) is autonomous.
	Justifies decisional authority: A patient should have decisional authority if and only if (and because) they have DMC.
	Anti-paternalist: The reason to respect a patient’s autonomy is decisive.

Table 1

The upshot of all this is that, in clinical settings, assessments of DMC are enormously consequential, determining whether a patient is entitled to make their own medical decisions. As a result, it’s especially important to ensure that the presence or absence of DMC—as standardly conceived—tracks the underlying normative considerations sufficiently well that it does in fact justify granting or withholding decisional authority.

Unfortunately, it does not.

As we see it, the standard approach to DMC is plagued by at least three serious problems: first, DMC does not just track autonomy; second, DMC fails to deliver on the promises of the anti-paternalist paradigm; and third, the presence and absence of DMC cannot justify granting and withholding decisional authority. Moreover—as we’ll argue—there’s no quick and easy fix for these problems. The most natural strategies for solving them raise other, equally serious concerns. For this reason, we argue, it would be best to ditch DMC.

4. Three Problems

To begin to get a grip on the problems with DMC and to identify their sources, consider Hansel and Gretel:

Hansel. Hansel is a 40-year-old male with a history of moderate paranoia and mania, diabetes, and respiratory disease, hospitalized with sepsis caused by an infection in his big toe on his left foot. Antibiotics have resolved the sepsis, but the medical team is recommending amputating the toe as the only way to guarantee the infection is cleared. Given Hansel's medical history and significant comorbidities, without amputation, another septic episode would almost certainly be deadly. Hansel is skeptical of the medical team – in part due to his paranoia – and doesn't believe that amputation is really necessary to clear the infection. And, regardless, he doesn't like the idea of someone cutting off his toe. So he refuses the amputation.

Gretel. Gretel is a 40-year-old female with a history of moderate paranoia and mania, hospitalized with sepsis caused by an infection in her big toe on her left foot. Antibiotics have resolved the sepsis, but the medical team is recommending amputating the toe as the only way to guarantee the infection is cleared. Without amputation, it's likely that the infection will spread and trigger another (treatable) septic episode. Gretel is skeptical of the medical team – in part due to her paranoia – and doesn't believe that amputation is really necessary to clear the infection. And, regardless, she doesn't like the idea of someone cutting off her toe. So she refuses the amputation.

On a natural way of fleshing out the details of these two cases, it seems that we should *not* accept Hansel's refusal but we *should* accept Gretel's. And this is so even if we stipulate that Hansel and Gretel face choices of equal complexity and have identical (specific) abilities to understand, appreciate, reason about, and communicate their respective decisions. The stakes of Hansel's choice are just too high. To allow him to refuse would very likely be to ensure his death. And, given his impaired abilities to understand, appreciate, and reason about his situation (in part symptomatic of his paranoia and mania), we shouldn't allow him to take such a risk. Gretel, on the other hand, faces a comparatively low-stakes choice. So we lack a similar justification for overruling her decision.

As it happens, the standard approach to DMC is well-positioned to secure these intuitive verdicts. Since DMC is *risk-sensitive*, and since the stakes of Hansel's decision are significantly higher than the stakes of Gretel's, Hansel must have commensurately greater abilities to understand, appreciate, reason, and communicate in order to qualify as capacitated. So it's very plausible that Hansel does not meet the decisional ability thresholds relevant to his choice and hence lacks DMC, while Gretel does relative to her

choice and hence has DMC. And since lacking DMC entails one should lack decisional authority while having DMC entails one should have it (recall the justificatory schemas sketched in §3.2), we should *not* allow Hansel to refuse amputation, but we *should* allow Gretel.

Again, this strikes us as the correct verdict. But perhaps you don't share our intuitions. So let us pause to say a few words more generally about the *kind* of cases we take Hansel and Gretel to represent. Given DMC's risk-sensitivity, there are at least some patients lacking DMC who, holding fixed the complexity of their choice and their specific decisional abilities, would have DMC *were the risks lower*. Likewise, there are at least some patients with DMC who, holding fixed those same factors, would lack DMC *were the risks higher*. This is just what it means for DMC to be risk-sensitive. And we take Hansel and Gretel (respectively) to be instances of these sorts of patients – were the risks of Hansel's choice (sufficiently) lower and all else were equal, he would have DMC; and were the risks of Gretel's choice (sufficiently) greater and all else were equal, she would lack DMC. But we don't want to hang our hats on the details of their cases. So if you don't share our intuitions about Hansel and Gretel or feel that their cases are too underdescribed, you can construct your own pair of cases from this template. Our arguments in what follows will still apply.

What cases like Hansel's and Gretel's help show is that although the standard approach to DMC is often well-positioned to secure intuitive verdicts about what we all-things-considered ought to do in such cases, the *way* it does so is problematic. And these problems have important downstream consequences for a much broader class of patients and for how we justify granting or withholding decisional authority more generally.

4.1 *The First Problem: DMC does not track autonomy*

The standard approach secures the intuitive verdicts in the case of Hansel and Gretel by insisting that Hansel lacks while Gretel has DMC. But recall that, stipulatively, Hansel and Gretel are facing equally complex choices and have identical abilities to understand, appreciate, reason, and communicate. So the only thing that can explain their differing DMC-statuses is what's at stake in their respective circumstances. DMC's *risk-sensitivity* is thus the mechanism by which the standard approach is able to count Hansel as incapacitated and hence appropriately *lacking* decisional authority, and Gretel as capacitated and hence appropriately *having* decisional authority.

The problem, though, is that it's deeply implausible that what's at stake in their respective situations render Hansel's refusal *nonautonomous* and Gretel's *autonomous*. More generally, facts about what's at stake in a decision are just not relevant – at least not in any direct way – to whether, or to what extent, that decision is autonomous.

As noted above, to be autonomous is to be self-governing – to have the capacity to act in accordance with your commitments. And to act autonomously is to exercise this capacity – for your commitments to combine in the appropriate way to determine what you do. This is, admittedly, a thin gloss. But it should be enough to make clear that whether a decision is autonomous is – at least primarily – a matter of whether the relevant agent has the required internal states and capacities and whether their action bears the right relation to those states and capacities. The *risks* of a decision thus fail to play any direct role in whether a decision is or is not autonomous.

Importantly, this isn't to say that the stakes of a decision are never relevant to whether a decision is autonomous. For instance, it's plausible that Parker, the especially poor poker player who compulsively folds whenever a bet is high, finds the autonomy of his decisions undermined or eliminated whenever his opponent bets big. Here, the autonomy of Parker's decisions to fold (or not) is in part a function of what's at stake. But, first, note that it is only *indirectly* and *contingently* so – the stakes are autonomy-relevant in virtue of a contingent connection between the stakes and what's directly relevant: Parker's ability to exercise his rational capacities and act in accordance with his commitments. Second, there's nothing special about stakes in this respect. Any feature of one's circumstances might bear some indirect and contingent connection to one's capacity for self-governance with respect to some decision or another. The ways in which one's environment can hamper or enhance individuals' autonomy is important. But there's little reason to suspect that there's something special about the stakes of a decision that would make it the case that *in general* autonomy is undermined or eliminated when the stakes are high.

Hansel and Gretel are a case in point. Setting aside questions about what we should do, all things considered, and about what respecting autonomy demands, and focusing solely on the question of whether Hansel's decision is more or less autonomous than Gretel's, it becomes hard to see how their decisions could be anything other than on a par.

So, the standard approach to DMC is able to secure the intuitive verdicts in Hansel's and Gretel's cases only by insisting that DMC is *risk-sensitive*, but since the autonomy of a decision is not plausibly a function of the stakes, this means that DMC is *not autonomy-tracking*.²⁰

One natural response to this challenge is to simply jettison risk-sensitivity. And this may appear to be an attractive strategy given (as mentioned in the §3) that risk-sensitivity is the most contested feature of the standard approach to DMC to begin with. This straightforward revision would plausibly preserve DMC as (at least roughly) autonomy-tracking, which is good – we

²⁰ This shouldn't be a huge surprise. For as Hawkins and Charland [5] note, "although many philosophers and bioethicists continue to equate [DMC] and the capacity for autonomous decision-making, it is really not true that our current notion of [DMC] has been derived from the notion of autonomous decision-making. Instead, [it] has been built from the ground up, largely (though not entirely) independently of philosophical theory. And this means that it is an open question whether a competent decision is an autonomous decision."

don't deny that the abilities constitutive of DMC are correlated with autonomy. But abandoning risk-sensitivity requires us to posit *risk-independent* thresholds on what levels of decisional abilities are sufficient for DMC. And, absent further revisions, this leaves us with an approach to DMC that cannot secure intuitive verdicts in cases like Hansel's and Gretel's. Since the only difference between Hansel and Gretel is the risks of their respective decisions, a risk-independent approach must classify either both or neither as having DMC. And since DMC determines decisional authority, this means that either both or neither are entitled to refuse amputation. But, again, this seems incorrect. There's too much at stake to allow Hansel to make such a harmful decision, especially in light of his impaired decisional abilities. And there's too *little* at stake to justify overriding Gretel's refusal. More generally, on a risk-independent approach, setting the ability thresholds low enough to explain why we should defer to the decisions of decisionally-impaired patients in low-stakes contexts will prevent us from protecting such patients when the stakes are high; and setting the ability thresholds high enough to explain why should protect impaired patients in high-stakes contexts will prevent us from deferring to such patients when the stakes are low. Given that DMC determines decisional authority, there's no place to draw the ability thresholds on a risk-independent approach that can capture the full range of cases in which patients should and should not have decisional authority.

4.2 *The Second Problem: DMC is not anti-paternalistic*

In response to the first problem, one might simply admit that DMC tracks more than just autonomy, and revise the standard approach accordingly. But such an admission highlights the second problem with the standard approach to DMC: it does not deliver on the promise of the anti-paternalist paradigm.

As Hansel and Gretel's cases illustrate, given the standard approach to DMC, it's possible for two patients, faced with identical choices, to make equally autonomous decisions, but for one (e.g. Hansel) to lack DMC and the other (e.g. Gretel) to have it. But if what justifies granting Gretel decisional authority is that doing so respects her autonomy, and Hansel's and Gretel's decisions are equally autonomous, then to deny Hansel decisional authority is to *fail to respect his autonomy*. What this shows is that the standard approach sometimes – surreptitiously – issues the verdict that it is all-things-considered permissible to deny authority to a patient despite that patient making an autonomous decision that is worthy of respect. And this, you may notice, *just is* to treat the incapacitated patient paternalistically.

This should be worrisome regardless of whether you're inclined to accept the anti-paternalist paradigm. (We ourselves are not, and will say more about it in §5). If you are, then the standard approach to DMC is problematic simply for failing to be anti-paternalistic. But if you (like us) are not so inclined – if you think that paternalism is sometimes justified – then the standard approach remains problematic not for being paternalistic, but rather for *obscuring* the paternalistic justification (when present) for denying a patient decisional authority. Presumably, if we think that treating patients paternalistically is sometimes justified, we should say so and

we should be explicit about why such treatment is justified. But the standard approach to DMC treats patients without DMC as though autonomy considerations do not apply, even when they do. This is deeply misleading.

In response, a proponent of the standard approach might insist that decisional authority is only withheld when a patient's decision is *not autonomous enough* (though perhaps still to some degree autonomous) to warrant respect.²¹ Such a response can account for the autonomy of Hansel's decision (and the decisions of patients like him) while still preserving the central commitments of the anti-paternalist paradigm. The thought is that, as the anti-paternalist insists, the reason to respect autonomy remains decisive – i.e. it trumps other morally relevant considerations – but it is only generated by decisions that are *sufficiently* autonomous; and the decisions of Hansel and his ilk fall below the relevant threshold.

While this response preserves (something like) the core commitments of the anti-paternalist paradigm, it raises additional worries. First, by insisting that Hansel's decision fails to generate a reason to respect his autonomy (since if it did, the reason would be decisive), this response risks significantly circumscribing the range of cases in which autonomy concerns arise. Generally, and especially in the clinical setting, the reason to respect autonomy seems to be ubiquitous. And this response can't account for this ubiquity.²² Second, and relatedly, given the basis for denying Hansel decisional authority, it's not clear what justification could be given for granting Gretel such authority. Recall that it's in Gretel's best interest to have the amputation. So we have a reason to perform the amputation. And recall that Gretel's decisional abilities are equal to Hansel's, and thus their respective decisions are equally autonomous. Given the story on offer, however, Hansel's decision is not autonomous enough to generate a reason to respect his autonomy. And so the same must be true of Gretel. But if we don't have a reason to respect Gretel's autonomy, then it's not clear what *other* reason(s) we could have that would compete with the reason to promote her best interests. In sum: if we deny that there's a reason to respect Hansel's autonomy, then we must say the same of Gretel, in which case it becomes unclear what the basis for respecting Gretel's decision could be.

The standard approach to DMC thus faces a dilemma: either it fails to deliver on the promises of the anti-paternalist paradigm or else it fails to explain why we should grant decisional authority to a wide range of patients whose decisions intuitively demand respect, and demand it on the grounds that our reason to respect their autonomy outweighs the other morally relevant considerations.

²¹ In the passage quoted above, for instance, Beauchamp and Childress emphasize that a patient's decisions must be "sufficiently autonomous" to warrant respect. [40, p. 108]

²² For a related point, see Schwan [14].

4.3 *The Third Problem: DMC cannot justify authority*

So far we've argued that the standard approach to DMC is surreptitiously paternalistic and fails to (just) track autonomy. These first two problems reveal a third: DMC cannot justify granting or withholding decisional authority.

It's not difficult to see why. Recall the justificatory schema sketched in §3.2—the first premise claims that DMC is autonomy-tracking while the second states the central commitment of anti-paternalism (namely, that our reason to respect a patient's autonomy is decisive). The two problems sketched above show that the standard approach to DMC is inconsistent with these premises. So having or lacking DMC can't justify granting or withholding decisional authority in this way.

The underlying problem is that assessments of DMC *themselves* encode commitments about whether, in light of the autonomy and well-being considerations at stake, a patient's decision should or should not determine her treatment. This is a version of the familiar concern raised by Wicclair [25,26] and Elliot [29], among others.²³ Since DMC is risk-sensitive, assessments of DMC require making tradeoffs between concern for promoting patients' well-being and concern for respecting their autonomy. This tradeoff is baked into the capacity assessment. So rather than DMC *itself* playing a role in justifying the granting or withholding of decisional authority, DMC assessments represent the *conclusion* of our reasoning about whether, in light of the patient's decisional abilities and the stakes of the choice, our reason to respect the patient's autonomy outweighs our reason to promote their well-being, or vice versa. To judge that a patient has DMC with respect to a particular choice, in other words, *just is* to judge that that patient should have decisional authority with respect to that choice. What this means is that, on the standard approach, we lack a good explanation for why DMC should play its characteristic role in determining decisional authority.

5. **Ditching DMC**

In the previous section we argued that, taken together, the core commitments of the standard approach—in particular, the assumptions that DMC (a) is autonomy-tracking, (b) justifies decisional authority (within an anti-paternalist paradigm), and (c) is risk-sensitive—generate serious problems. To begin with, autonomy is not (in any direct or systemic way) risk-sensitive, so risk-sensitivity is incompatible with DMC being autonomy-tracking. While the most natural solution to this problem is to simply jettison risk-sensitivity, doing so is problematic in its own right—in particular, a risk-*insensitive* conception of DMC (absent further changes) generates the wrong results about who should (not) have decisional authority by either requiring an implausibly high degree of decisional abilities to have decisional authority over mundane medical choices or implausibly granting decisional authority to individuals with impaired decisional abilities making momentous or risky decisions. If we instead admit that DMC does

²³ See also Culver and Gert [19], Maclean [41], DeMarco [42], and den Hartogh [43].

not (just) track autonomy while attempting to preserve the other elements of the standard approach, we're likewise in trouble – in particular, a non-autonomy-tracking conception of DMC cannot justify granting or withholding decisional authority within the anti-paternalist paradigm. And once we jettison DMC's justificatory role, it's no longer clear what exactly DMC is for – it has lost its *raison d'etre*. So there's no easy fix for the problems that plague the standard approach to DMC. And these problems – and lack of solutions – are serious enough, in our view, that they warrant ditching DMC.

We don't say this flippantly. After all, as noted at the outset, there's a problem of decisional authority that is ubiquitous in the clinical setting. And much is at stake, especially for patients with impaired decision-making abilities. In treating such patients, providers must consider the risks and benefits of available treatment options while grappling with the uncertainties that surround them; they must balance their obligations to promote well-being and avoid harm against their obligations to ensure patients exercise appropriate control over their course of care and to treat patients in ways consistent with their commitments and values; and they must navigate these waters all while avoiding perpetuating existing social injustices. Making ethically justifiable decisions about decisional authority among so many competing considerations is hard work.

Given this, one might worry that abandoning the standard approach to DMC will somehow remove important safeguards that protect patients' autonomy and protect vulnerable patients from making harmful decisions. Moreover, given how integrated capacity assessments are in the delivery of clinical care (especially in the hospital setting) one might wonder procedurally how we could determine decisional authority if we were to ditch DMC.

For the record, we're not especially moved by this worry. It seems to us that the current DMC regime (for all the reasons discussed above) is also prone to violating patient autonomy, and failing to protect vulnerable patients. We do, however, grant that the standard approach to DMC is helpful in one respect: it draws assessors attention to the main ethical considerations relevant for determining decisional authority – namely, decisional abilities and the risks/benefits of the available options. But even if the *process* of determining DMC can be helpful – because of its component parts – there is no sense in which the judgment or determination *itself* that a patient has or lacks DMC contributes to a case for or against granting decisional authority over and above the case that might be made by considering the relevant facts about the patient's abilities and the moral considerations *directly*. So it's not obvious why, procedurally speaking, a physician, in consultation (when appropriate) with a psychiatrist or ethicist, couldn't simply document their reasoning about why a patient should or shouldn't have decisional authority – appealing directly to relevant well-being considerations and

relevant facts about a patient’s decisional abilities – without any intermediate reference to DMC.²⁴

So there is little – if anything – that is gained, ethically speaking, from DMC assessments themselves. And there’s a cost. As discussed in §4.2, the standard approach to DMC obscures the paternalistic justification at work in cases in which a patient with certain decisional abilities lacks decisional authority in part because the stakes of their choice are sufficiently high. It is our view that paternalism is sometimes justified. And, insofar as they endorse a risk-sensitive approach to DMC (again see [37–39]), we take this to be – at least implicitly – the prevailing view among clinical practitioners. But if we think that sometimes we all-things-considered ought to treat patients paternalistically, we should be explicit about the reasoning we take to justify doing so. The current DMC regime obscures this justification while donning a mask of anti-paternalism.

So the standard approach to DMC provides little benefit while obscuring important trade-offs we must make between considerations of beneficence, non-maleficence, autonomy, and justice. These problems are significant enough that they call for more than merely tinkering and fine-tuning. We should ditch DMC.

Crucially, however, simply ditching DMC isn’t the only alternative to maintaining the status quo. We could, in addition, replace DMC with an alternative measure of patient autonomy that better tracks the normatively relevant considerations while also playing a genuine role in justifying the granting or withholding of decisional authority.

In future work, we hope to reengineer a measure of patient autonomy that can do this work. In the meantime, here’s what we take to be the most important desiderata of a reengineered approach, followed by brief explanations of each:

1. *A measure of patient autonomy should (just) track (the relevant sense of) autonomy.*²⁵
2. *A measure of patient autonomy should be scalar rather than binary.*
3. *A measure of patient autonomy should be psychometrically validated.*
4. *The measure of patient autonomy alone should not (necessarily) determine decisional authority.*

Regarding (1): one of the main insights of the standard approach to DMC is that the decisional abilities to understand, appreciate, and reason (at least roughly) track whether – and to what

²⁴ Again, as mentioned in footnote vi, our point here is about DMC’s utility (or lack thereof) for sorting through the ethical considerations relevant to determinations of decisional authority in the clinical setting. We don’t presume to know how such a strategy would be perceived legally.

²⁵ The parenthetical qualification concerning the “relevant sense of” autonomy is meant to demonstrate sensitivity to the distinction, noted in footnote ix, between respecting *autonomy-as-sovereignty* by deferring to a patient’s decision and respecting *autonomy-as-authenticity* by ensuring that treatments are consistent with a patient’s commitments. It’s important that we re-engineer a measure of patient autonomy that allows us to (just) track our reason to respect *autonomy-as-sovereignty*, which will in some cases conflict with our reason to respect *autonomy-as-authenticity*.

extent (see just below) – a patient’s decision is autonomous. And it’s certainly true that facts about a patient’s autonomy are relevant to whether that patient is entitled to make their own medical decisions. So it’s reasonable to want a measure of patient autonomy – one that *just* measures patient autonomy – to use as an input into determinations of decisional authority without packing in any other normatively relevant considerations as, for example, the standard risk-sensitive approach to DMC does by factoring in well-being concerns.

Regarding (2): autonomy – both of persons and their actions – comes in degrees. And, very plausibly, the weight of our reason to respect a patient’s autonomy by deferring to their decision is, in part, a function of *how autonomous* that decision is. So the degree to which a patient’s decision is autonomous matters in determining whether that patient should have decisional authority. We want a measure of patient autonomy, then, that reflects this: one that is explicitly scalar (rather than binary) and tracks the *degree* to which a patient’s decision is autonomous, thereby indicating the weight of our reason to respect it.

Regarding (3): the extent to which a patient’s decision is autonomous is largely a function of their mental states and dispositions. And these are best assessed using a psychometrically validated tool (ideally, at least in the difficult cases, by a psychiatrist or psychologist). A reengineered measure of patient autonomy should thus include measurable and standardized means of assessment, even if this comes at the expense of perfectly tracking our best philosophical account of the nature of autonomy. Trade-offs between theoretical accuracy and practical utility should be minimized, but are ultimately unavoidable.

Regarding (4): perhaps most fundamentally, it’s important to pull apart questions about the extent to which a patient’s decision is autonomous from questions about whether the patient should have decisional authority. As illustrated by the case of Hansel (in §4), it is sometimes ethically appropriate to deny decisional authority to a patient even though that patient’s decision is (to some degree) autonomous. The determination of the extent to which a patient’s decision is autonomous should thus be independent of – and come prior to – the determination of decisional authority. Doing so allows us to be much more explicit about the justification for granting or withholding decisional authority. For instance, in Hansel’s case, the *degree* to which his refusal was autonomous did not generate a reason strong enough to outweigh our reason to save his life. But in Gretel’s case, since there was less at stake, the reason to respect her refusal was weighty enough to justify granting decisional authority. Importantly, this is compatible with there being a (perhaps vague) threshold on our measure of patient autonomy above which decisional authority is granted regardless of the other considerations at play, and for the threshold to be achievable by most adult patients. The thought is that once a decision is autonomous to a sufficiently high degree, the reason to respect it is – for practical purposes, anyway – genuinely decisive. Such an approach would have much the same practical effect as the standard approach to DMC for typical adult patients, but it would do so without the undesirable consequence of denying the relevance of autonomy considerations for patients that fall below that threshold.

In summary, the overarching goal in reengineering a measure of patient autonomy is for determinations of decisional authority to be *accurate* – such that, to the extent possible, all and only patients who should have decisional authority do have decisional authority – as well as *principled* – such that they’re grounded in a clear, systematic assessment of the various ingredients that determine what all-things-considered ought to be done. So a reengineered (i.e. non-binary, autonomy-tracking) measure of patient autonomy must be weighed alongside other considerations relevant to decisional authority, including, at least, (i) the extent to which each treatment option is consistent with the patient’s values and commitments, (ii) the well-being implications of each treatment option, (iii) constraints against any relevant harms that the treatments might impose, and (iv) the extent to which treatment options promote fairness or mitigate unfairness. In addition to being accurate and principled, then, an approach to patient autonomy and determinations of decisional authority should be *transparent*: the tradeoffs made between the above mentioned considerations should be made explicit, rather than obscured or baked in from the outset. As we’ve argued, the standard approach to DMC is none of these things: it is neither accurate nor principled nor transparent. We can and should do better.²⁶

²⁶ For helpful feedback, we would like to thank audiences at the ASBH 2022 Annual Conference, the NYU Bioethics WIP Workshop, the College of Wooster Philosophy Roundtable, and MetroHealth’s Bioethics@Noon, as well as two anonymous reviewers and an anonymous associate editor for the *Journal of Medical Ethics*.

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