The capacity to designate a surrogate is distinct from decisional capacity: normative and empirical considerations

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ABSTRACT

The capacity to designate a surrogate (CDS) is not simply another kind of medical decision-making capacity (DMC). A patient with DMC can express a preference, understand information relevant to that choice, appreciate the significance of that information for their clinical condition, and reason about their choice in light of their goals and values. In contrast, a patient can possess the CDS even if they cannot appreciate their condition or reason about the relative risks and benefits of their options. Patients who lack DMC for many or most kinds of medical choices may nonetheless possess the CDS, particularly since the complex means-ends reasoning required by DMC is one of the first capacities to be lost in progressive cognitive diseases (eg, Alzheimer's disease). That is, patients with significant cognitive decline or mental illness may still understand what a surrogate does, express a preference about a potential surrogate, and be able to provide some kind of justification for that selection. Moreover, there are many legitimate and relevant rationales for surrogate selection that are inconsistent with the reasoning criterion of DMC. Unfortunately, many patients are prevented from designating a surrogate if they are judged to lack DMC. When such patients possess the CDS, this practice is ethically wrong, legally dubious and imposes avoidable burdens on healthcare institutions.

INTRODUCTION

When a patient is judged to lack the capacity to make complex medical decisions, standard ethics guidance directs healthcare teams to locate a surrogate decision maker via the patient's durable power of attorney for healthcare decision making (DPOA-HC), through their next of kin, or, as a last resort, by seeking a court-appointed guardian.[1,2] In clinical practice, a patient who is determined to lack the capacity for complex medical decisions is often also treated as if they lack the capacity to appoint another person to make that decision for them. This is wrong and, importantly, it emerges not just from a misapplication of decision-making capacity (DMC) standards, but from a misunderstanding about the qualitatively different capacities required to make treatment decisions rather than to designate surrogates.

According to the standard view in clinical bioethics, a patient's capacity for decision making is always relative to a particular kind of choice at a particular time[3,4]; patients should not be declared globally 'incapacitated'.[5] It follows from this view that someone might lack the ability to make complex treatment decisions, but still possess the ability to designate a surrogate, as others have argued.[6,7] We agree with this rejection of global capacity determinations, and we acknowledge that it follows from this rejection that patients could have the capacity to designate a surrogate (CDS) even if they did not have the capacity to make complex medical decisions. But we defend a broader account of the capacity to designate surrogates rather than viewing that capacity as only an instance of the diversity of DMC.

In this article, we argue that many patients who lack the capacity to make complex medical decisions sometimes remain able to choose their own representatives. As we describe, the CDS does not require one of the core components of DMC: that a patient appreciates their clinical condition. Furthermore, the CDS requires only a minimal kind of reasoning about surrogate designations, and its reasoning criterion can be satisfied by rationales that are much more expansive and permissive than the kind of reasoning usually required for DMC. We conclude that patients who retain the CDS, even when they lack DMC, have a moral right to make surrogate designations and that healthcare teams generally have a moral obligation to allow such patients to designate their surrogates.

Importantly, we agree with others who have argued that patients' preferences (including about their surrogates) should always be considered, even if patients lack DMC.[1,8] But here we make a stronger point: Some patients who lack the capacity to make complex medical decisions nonetheless have the capacity to designate their surrogates. Therefore, patients with the CDS have not just a morally weighty preference, but one that should generally be authoritative.

A CASE

Let us ground our analysis in an illustrative case[i]:

Mr. Davis is a 74-year-old man with medical history of heart failure and COVID-19 pneumonia. He was brought to the hospital from his extended care facility because of abnormal labs and altered mental status. Psychiatry determined that Mr. Davis lacks medical DMC, in light of his altered mental status. Mr. Davis does not appear to understand why he is in the hospital or how and why he is being treated. In absence of DPOA-HC,

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[i]All identifiable information about this case has been removed or modified.

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the healthcare team sought to identify a surrogate decision maker, which they found in Mr.Davis's son, Darrell. Mr. Davis has consistently objected to his son making decisions for him, saying, 'I don't want him to have anything do with me. I don't trust him at all.' When asked if there is someone else that Mr. Davis would like to make decisions on his behalf, he says 'It should be my friend, Joanne. I trust her more than anyone.' Joanne has lived next door to Mr. Davis for approximately 10 years and is willing to serve as Mr. Davis's surrogate.

DECISION-MAKING CAPACITY

There are many accounts of the components of medical DMC and there are various DMC assessment tools, but they all possess a similar structure.[9] According to the standard view, a patient possesses DMC for medical interventions when they can:

1. Express a consistent choice about a preferred medical intervention.
2. Understand information about their condition and proposed treatments.
3. Demonstrate appreciation of their condition in light of their goals and values.
4. Reason about the relative risks and benefits of their options.[3 10]

DMC, therefore, requires the ability to absorb new medical facts, to make judgements based on likely outcomes of interventions, and to prioritise those outcomes in light of one's values. Patients who do not appreciate how their disease or their treatment decisions will likely impact their lives, who do not understand how various interventions may treat their disease, or who cannot reason about the risks and benefits of different possible interventions (ie, from the point of view of their goals of care) do not possess DMC for any kind of medical choices, even though they may retain strong preferences and other important forms of agency.

Importantly, a patient can lack DMC for some choices, but retain it for others, because of differences in how consequential those choices are, or because different choices require different amounts of understanding, appreciation or reasoning.[3] A patient may, therefore, lack the capacity to make a choice that is very consequential, or one that requires high levels of understanding, appreciation and reasoning; conversely, they may possess the capacity to make a choice that is less consequential, or for which lower levels of understanding, appreciation and reasoning are required. This account of the non-global nature of DMC provides one explanation for why a patient who lacks DMC for a complex medical choice may nonetheless possess the CDS: they lack DMC for the first choice, but they possess it for the second choice.

However, DMC always requires the abilities of choice, appreciation, reasoning and understanding, though it requires different threshold amounts of these abilities, depending on the kind of medical interventions in question. For example, decisions about the timing and order of different kinds of cancer treatments may require greater abilities for appreciation, reasoning and understanding than do decisions about delaying a hip replacement surgery. But, even for less complicated interventions, DMC always requires patients to have some ability for choice, appreciation, reasoning and understanding. Therefore, patients who entirely lack one or more of the constituent elements of DMC must lack DMC for all choices about treatments. For example, a patient who does not possess any appreciation of their clinical condition cannot possess DMC to make any treatment decisions. The same can be said of a patient who is entirely unable to reason about their medical options in light of their values and goals.

In the case above, Mr. Davis has trouble understanding new information and reasoning about his current options; he does not appreciate his clinical condition. Indeed, it seems possible that Mr. Davis is not capable of even low levels of reasoning or clinical appreciation and, accordingly, Mr. Davis likely lacks DMC for all medical treatment decisions. He likely needs a surrogate to make most or all consequential treatment decisions for him. We argue that a patient, like Mr. Davis, does not need clinical appreciation or means-ends reasoning abilities to make an informed decision to designate a surrogate. That decision is primarily about identification, relationship, affect and trust. It follows that Mr. Davis, and other patients like him, may have the capacity to appoint surrogates.

THE CAPACITY TO DESIGNATE A SURROGATE

On our view, a person possesses the CDS if they can:

1. Express a consistent choice about a preferred surrogate.
2. Demonstrate a basic understanding of what a surrogate does.

The first criteria for DMC and the CDS are similar: patients must express a consistent choice. Additionally, both DMC and the CDS require patients to possess a threshold of understanding (the second criteria for both the CDS and DMC). But these are different kinds of understanding. DMC requires patients to understand a set of medical facts about their condition, for example, diagnosis and prognosis, and the nature and mechanisms of possible interventions; it requires that a patient understands how their current medical condition will impact their future, especially in the absence of interventions.

The CDS requires only that patients understand that their surrogate will make decisions for them when they can no longer do so. There is a fundamental qualitative difference between knowing that someone will do something and knowing how they will do it. A patient with the CDS understands that a surrogate chooses for others, but need not know how the surrogate will choose, other than that they should choose as the patient would have chosen. DMC requires a patient to meet a threshold level of understanding about how the medical procedures they are consenting to will transpire and how these procedures will promote their goals of care and broader values. Of course, DMC does not require patients to share a physician's level of understanding of the relevant medical facts, potential interventions, and likely outcomes. But DMC does require that patients have some sense of why interventions are being offered, how those interventions will occur, and the likely outcomes of interventions. In contrast, the CDS does not require patients to have any understanding of the details of the decisions that surrogates will make, but only that surrogates will make such decisions.

The CDS also does not require appreciation (the third criterion of DMC), since the legitimacy of a decision to designate a surrogate does not require patients to appreciate details about their current medical condition, but only that they have a preference that someone choose for them when they need someone to do so. More generally, a person can make a well-informed decision about which person they'd like to do a job for them, even if they do not know the details about when they will need that person to do the job.

One could argue that a patient ought to appreciate one or both of the following in order to meaningfully designate a surrogate: (1) that they are not currently able to reason sufficiently about treatment decisions and therefore need a surrogate or (2) that a surrogate will make a particular decision for the patient. In reply, the kind of self-awareness specified in (1) should not be required for the CDS. If it were required, then the only people who would be permitted to designate a surrogate would be people who knew that their reason was sufficiently impaired that they needed a surrogate. But it is unreasonable to expect persons who have impaired reasoning to recognise that they have impaired reasoning. Moreover, their self-recognition of their cognitive deficits related to DMC is moot since such judgements are the responsibility of medical professionals, not patients. Furthermore, the appreciation required in (2) would demand that a patient understand what their surrogate would choose in a potentially limitless number of scenarios. Instead, the patient merely needs to understand that a surrogate will make decisions on their behalf; the patient does not need to appreciate how those decisions will be made or which decisions the surrogate will make.

Finally, the CDS also does not require patients to demonstrate a capacity for means-ends *reasoning* about their preferences for surrogates (the fourth criterion of DMC). Indeed, the CDS does not require that patients offer much of a rationale at all, other than a demonstration that they understand what a surrogate does and that they prefer someone to be their surrogate. The expression of a preference that a person be one's surrogate, in light of one's understanding that a surrogate makes decisions on one's behalf, inherently offers at least a thin reason for that designation, namely, that they want the person they have selected to be their surrogate because they want them to choose on their behalf. Additionally, there are many other kinds of more substantive reasons that one could provide for designating someone as their surrogate. Some of these would fit the parameters of reasoning required in the context of DMC. For example, patients might describe the likelihood that the surrogate would exercise substituted judgement or act in ways that decrease burdens on other family members. But we do not demand these kinds of reasons from fully autonomous patients when we ask them to designate a surrogate. Instead, the selection of a surrogate is commonly a matter of affection, of existing relationships, or of identification and trust. This common form of reason-giving in surrogate designations—for patients who possess DMC—also suffices for surrogate designations among patients who *lack* DMC.

Consider that Mr. Davis, above, merely invokes an affinity for Joanne as his reason for selecting her as a surrogate. On our view, this is a sufficient reason for selecting a surrogate, though it does not demonstrate the kind of comparative judgement required by DMC's reasoning criterion. For example, it should not count against Mr. Davis's designation of Joanne that he has failed to contrast the potential outcomes of Joanne's surrogacy with the potential outcomes of his son's surrogacy, or that he has not weighed the expected net benefits of these two options from the point of view of his goals and values. If we further stipulate that Mr. Davis understands that a surrogate is someone who will make decisions on his behalf, and that he has a consistent preference for Joanne, then we can conclude that Mr. Davis has the CDS, and that Joanne should be appointed as his surrogate.

It is worthwhile to clarify that it is possible for patients to fail to have the CDS, even if they are responsive to questions about potential surrogates. First, a patient who cannot express a consistent preference for a surrogate does not actually have a preference that could be fulfilled, and therefore, cannot be permitted to designate their surrogate. If Mr. Davis oscillated between naming Joanne and Darrell, when asked about who should be his surrogate, then he would fail to demonstrate that he has a preference. Second, a patient who cannot show that they understand what a surrogate does also lacks the CDS. Imagine that Mr. Davis consistently names Joanne when asked about his preference for a surrogate, but that he could not explain that Joanne would make decisions for him if she were his surrogate. While this requirement marks a low threshold—Mr. Davis needs only to say that he knows Joanne would make decisions on his behalf—if he cannot do that, then he does not have the CDS. Finally, a patient who meets the requirements both for having a consistent preference and understanding therefore also meets the reasoning criterion in at least a thin manner, as we note, above. (If you say that you want someone to be your surrogate, and if you demonstrate that you know that a surrogate will choose for you, then you have shown at least a baseline affinity for that person as your surrogate in that that you *want* them to fulfil that role.) Certainly, patients can provide additional (thicker) reasons. For example, they may describe their affinities in more detail ('he loves me') or even articulate something approximating the kind of comparative reasoning associated with DMC by articulating a belief that a potential surrogate will choose as the patient would have chosen. But even if patients identify mere baseline affinities of wanting a particular person as their surrogate, doing so would not undermine the reasoning criterion, if the person also understands the role of the surrogate.

Common practices surrounding surrogate designations for persons who possess DMC are consistent with the idea that the reasoning criterion for surrogate designation capacity can be easily met. That is, thin reasons are sufficient. Healthcare teams rarely interrogate patients who possess DMC about their reasons when they select surrogates. Someone who possesses DMC, and who selects a surrogate 'because she is my wife' or 'because I love him'—or even who provides no reason at all other than that they want the designated person to choose on their behalf—has acted in a routinely acceptable way, even though they have not demonstrated that they have 'reason[ed] about the relative risks and benefits of their options.' Mere statements of affinity count as valid reasons in the context of surrogate selections made by patients who possess DMC. They should also count as valid reasons for patient who lack DMC but possess the CDS. To do otherwise would be to unfairly judge DMC-lacking patients by a different standard.

By themselves, a patient's mere preferences have *some* moral weight.[1 8] Even if patients lack the capacity for reasoning, appreciation and understanding, the fact that they have preferences should be given substantial consideration, and treatment over objections are often morally fraught. Therefore, a patient's mere preferences about who should be their surrogate should always receive some consideration. However, patients who lack DMC, but who possess the CDS, have the moral authority to designate a surrogate. Their preferences should not merely be considered in balance with other considerations, such as best interests, but should be determinative unless there are strong countervailing reasons for rejecting the chosen surrogate (eg, the surrogate is unable, unwilling, or acts in ways that put the patient in harm's way). In this way, we can resolve the question of surrogacy for Mr. Davis by an appeal to the fact that he appears to possess the CDS, even though he likely no longer possesses DMC for most or all medical decisions. He should therefore be permitted to select his surrogate.

CLINICAL IMPLICATIONS

Developing criteria to assess the CDS would help align clinical practice with standards in human subjects research and the law and would have several benefits for current clinical practice. Many forms of progressive cognitive decline affect a person's ability to learn and appreciate new information, or to engage in complex means-ends reasoning, before they destroy a person's ability to recall or to reason about existing knowledge and relationships, or to identify and demonstrate affection for loved ones. Patients with mild to moderate cognitive impairments (eg, Alzheimer's disease), therefore, may lack DMC, but retain the ability to consistently identify persons they want to make decisions for them.[6 11 12] Such patients often lack the ability to provide informed consent to participate in research (ie, they lack the analogue of DMC), but many have argued that patients with mild to moderate AD retain the capacity to designate proxies who can make decisions about research participation for them; such patients are regularly enrolled in research.[6] The distinction between the capacity to consent and the capacity to designate a surrogate or proxy is even more consequential in the clinical context, because it bears directly on how patients will be medically treated and this distinction may even have implications for their end of life care. The choice of a surrogate is one of the most consequential decisions one can make in the clinical context.

Assessing patients for the CDS would also help to align clinical practice with current legal standards in some countries. Few countries provide clear guidance about the capacity a person needs to appoint a healthcare proxy, but healthcare institutions in many countries embrace higher thresholds for the capacity to make healthcare decisions than their legal systems identify for people to have legal rights to make decisions for themselves. For example, in the UK, the National Health Service identifies criteria for the capacity to consent to medical treatment[13] that are more stringent than the criteria the Mental Capacity Act (2005) identifies.[14] A similar mismatch is common in some other European countries[15] and across the USA.[16] For example, the state of Utah identifies three criteria for determining whether a person who does not have the capacity for medical treatment decisions retains the capacity to appoint a surrogate: (1) whether the adult has expressed over time an intent to appoint the same person as agent; (2) whether the choice of agent is consistent with past relationships and patterns of behaviour between the adult and the perspective agent, or, if inconsistent, whether there is a reasonable justification for the change and (3) whether the adult's expression of the intent to appoint the agent occurs at times when, or in settings where, the adult has the greatest ability to make and communicate decisions. (§105 (3))

These criteria express clearly that the standard for making decisions about proxies requires some of the elements necessary for determining DMC for medical treatment decisions (eg, expression of a consistent choice), but does not require all of those elements (eg, there is no expectation of appreciation and the reasons for one's decision matter only when the choice appears inconsistent with past behaviours). In jurisdictions that do not provide requirements for the CDS, the appointment of a healthcare proxy often requires an adult witness to attest that the person filling out the document appears to be 'of sound mind' and is not under duress (eg, MA 201 D §2, VT St T.14§ 3503, MI 700 §5506). There are no state statutes that define 'sound mind,' nor does case law provide additional guidance for the standard. The presumption, however, is that a lay witness attests that the person executing the document does not have obvious cognitive limitations or psychopathology.[17] Here again, there is some legal precedent that suggests the standard for designating a surrogate should not be equivalent to the capacity for medical decision making.

The recognition that the CDS is distinct from DMC has other practical implications for healthcare staff and organisations. In the absence of a patient-designated surrogate, clinical staff often spend time and effort identifying and contacting next of kin. Other times, in the absence of clear guidance from state law or family consensus, hospitals may go to court, which can be a costly and time consuming process and can sometimes delay treatments.[17] The process of choosing a surrogate or going to court can also be stressful and anxiety-provoking for families and caregivers and may result in the appointment of a surrogate that the patient would not have approved or whom they actively reject. Before engaging in these cumbersome and error-prone processes of surrogate identification, healthcare teams should appeal directly to those patients who still possess the CDS.

CONCLUSION

As populations age, as dementia becomes more pervasive, and as advance directives remain underused, it becomes even more pressing for healthcare facilities to have clear guidelines about when patients should be permitted to select surrogates for medical decision making. It is, therefore, essential to clarify the distinction between DMC and the CDS. Future research should focus on the creation and validation of instruments to assess the CDS as a distinct capacity.

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