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Decisional Capacity After Dark: Is Autonomy Delayed Truly Autonomy Denied?

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Abstract

The model for capacity assessment in the United States and much of the Western world relies upon the demonstration of four skills including the ability to communicate a clear, consistent choice. Yet such assessments often occur at only one moment in time, which may result in the patient expressing a choice to the evaluator that is highly inconsistent with the patient's underlying values and goals, especially if a short-term factor (such as frustration with the hospital staff) distorts the patient's preferences momentarily. These challenges are particularly concerning in cases, which arise frequently in hospital settings, in which patients demand immediate self-discharge, often during off-hours, while faced with life-threatening risks. This paper examines the distinctive elements that shape such cases and explores their ethical implications, ultimately offering a model for such situations that can be operationalized.

Keywords: Capacity; against medical advice; psychiatry; consult-liaison psychiatry

“What at night seems oh so scenic May be cynic by and by.”
– *The Fantasticks*

Introduction

Self-discharges from hospital settings, also known as discharges “against medical advice,” account for between 1 and 2 percent of all discharges from American hospitals.¹ As a result, physicians—and particularly emergency medicine specialists and psychiatry consultants—are frequently called upon to determine whether patients possess the decisional capacity to leave the hospital before their medical needs have been addressed fully. Often the risks of such premature departures are significant—including potential death. In fact, multiple studies have shown increased rates of mortality among patients who opt for self-discharge.² Often, these patients come disproportionately from historically marginalized communities, including racial minority groups and those of lower socioeconomic status.³ Physicians must be confident that their capacity assessments in such cases are accurate and that the outcomes reflect the authentic autonomous decisions of the patients being evaluated.

Since the 1980s, a relatively standardized model of capacity assessment has become widespread in the United States. This model relies upon four skills delineated by Paul Appelbaum and Thomas Grisso in their seminal 1989 article: communicating a consistent choice, understanding relevant information, appreciating the situation and the risks and benefits of various responses, and logical reasoning.⁴ In addition, the level of scrutiny applied during capacity assessments may be shaped by such factors as the stakes of the decision and the deviation from recommended care.⁵ Although the four-skills model has faced recent challenges, no alternative approach has yet been operationalized, and elements of this model have been codified into statute in many jurisdictions—so, at present, clinicians can generally be expected

to work within its framework.^{6,7,8} Unfortunately, existing standards offer limited guidance on how to address a distinctive yet frequent category of requests for self-discharge: those requests that occur outside business hours, often late at night or on weekends, in which a patient expresses a desire for immediate self-discharge for reasons that do not appear urgent to the evaluator while remaining in need of potentially lifesaving treatment. Such cases, which arise all too frequently, implicate competing notions of autonomy, as discussed below, and may require a somewhat different approach to capacity assessment than that advanced by the dominant model.

A Clear, Consistent Choice

Communicating a choice is generally not regarded as sufficient for medical providers to ascertain a patient's wishes; rather, that choice must be "clear and consistent."⁹ Yet consistency can be afforded a range of interpretations. Appelbaum and Grisso define consistency rather narrowly, arguing that capacity merely "requires the ability to maintain and communicate stable choices long enough for them to be implemented" and that "the stability of the choice can be examined by repeating the question a few minutes later."¹⁰ However, if the goal of capacity assessment is to ensure a decision that reflects the patient's authentic beliefs and preferences, such pinpoint evaluation may capture the patient's will at a given moment but still be highly inconsistent with their past and future preferences, values, and goals. Repeating the same questions a few hours later may produce a very different choice, one that is far more concordant with the patient's underlying beliefs. In other words, the fleeting preference of the moment may stand in contrast to a preference measured over time—each reflecting a different form of autonomy.

A hypothetical case may prove useful in clarifying these tensions:

Mrs. A is a 55-year-old widow without any known family who presents to the hospital with severe chest pain at 3 am on a Sunday. The emergency medicine physician orders routine labs, cardiac-specific labs, and an EKG, suspecting that this might be a case of myocardial infarction. Before these interventions can occur, Mrs. A says to the nursing aide, "If I have to stay here a long time, I need to make sure somebody feeds my cat, Cheshire." This nursing aide responds, "You have more important things to think about right now than your cat." This upsets Mrs. A greatly. She now refuses to accept an EKG or lab work and demands self-discharge, stating that she intends to go home to arrange to have her cat fed by a neighbor and will then seek care at a different, "feline-friendly" hospital. When the consult-liaison psychiatrist on duty assesses her for capacity to self-discharge against medical advice, she states, "Sure, I know I could die, but at least I'll have peace of mind that Cheshire is looked after." Even an offer to have a social worker and the fire department check upon her cat does not satisfy her concerns. "They don't know Cheshire like I do. They will scare him."

A narrow interpretation of the requirement for a *consistent* choice would merely require ascertaining whether Mrs. A meets the four skills of Appelbaum and Grisso's model at the very moment when she wishes to self-discharge. If she does display these abilities—and most likely, she will do so—then this narrow interpretation will demand permitting immediate self-discharge as no ethical basis exists for curtailing Mrs. A's autonomy. However, the discerning clinician may note several reasons why Mrs. A's expressed wish at this precise moment may conflict with her core values and goals, both what her preferences were at the time of initial presentation and also what they may likely be a few hours hence. An emotional response to a perceived slight may be distorting her wishes. This slight may have also triggered overvalued concerns regarding the welfare of her cat. Of course, Mrs. A may sincerely wish to leave the hospital as a result of this slight, even at the risk of imminent death, and the possibility certainly exists that these preferences will persist over time. If Mrs. A continued to express these wishes the next day, honoring her request for self-discharge would appear in line with her authentic preferences and be both an ethical and a legal obligation. Yet one can easily imagine Mrs. A remaining in the hospital for an hour, calming down, possibly receiving an apology from the nursing aide, and deciding that she now does want

a cardiac workup after all. The challenging ethical question for clinicians is whether a patient's communicated request for self-discharge can be refused in the short term under such circumstances, that is, until that patient has a meaningful opportunity to reflect upon the situation and, in some circumstances, for the medical or psychiatric team to gather additional information about her underlying values that may help clarify the capacity assessment.

The need to gather additional information about a patient's underlying beliefs may be highly relevant in such requests for immediate self-discharge. For instance, in the example above, ascertaining whether Mrs. A, at her baseline, is a person who would accept an increased risk of death to secure transient comfort for her cat may help clarify whether her current demand is consistent with her underlying values or, alternatively, is an impulsive, fleeting wish, not consistent with those values and thus a preference that will likely change within a short period of time. Unfortunately, gathering such information rapidly in the hospital setting, particularly during off-hours, often proves difficult. Obviously, these issues can arise at 3:00 pm as well as at 3:00 am, but common sense—as well as the experience of this author—suggests that such collateral information may prove harder to obtain outside of regular business hours. How long a patient should be held against her wishes after a request for immediate self-discharge, so that the care team can attempt to obtain information to clarify underlying values, is another question left largely unresolved in the literature.

Competing Notions of Autonomy

Debates surrounding the values of autonomy and paternalism in medicine have been occurring for centuries and are beyond the scope of this paper.¹¹ What is relevant here is that, even if one places priority upon autonomy, tensions exist regarding what it means to strive to maximize such autonomy. Discussions of temporality regarding decisional capacity usually focus either upon advance directives, which only come into full force once patients lose capacity, or upon the issue of patients binding their future, still-capacitated selves through so-called “Ulysses pacts.”¹² In both of these cases, the medical decision to be rendered is usually chronologically distant from the execution of the authorizing document or authority. Whether or not one should be permitted to bind one's distant future self remains controversial, complicated by such considerations as the evolution of preferences and the phenomenon of bargaining down.¹³ However, the complex ethical issues raised by advance directives and Ulysses pacts are fundamentally different from those relevant to immediate demands for self-discharge. Four of these distinctive features are discussed below. An effective capacity evaluation for this specific class of cases must account for these phenomena.

Suffering from the Process of Autonomy Denial

The act of limiting a patient's autonomy, independent of the consequences of the specific liberties curtailed, can be detrimental to a patient's well-being. Such restrictions can be psychologically taxing and demoralizing. A patient who presents to a hospital of her own free will and is then informed that she cannot leave on the same terms may make future choices that are less optimal for her overall welfare, such as avoiding physicians or medical facilities when ill. In Mrs. A's case, even a temporary restriction upon her autonomy may result in deleterious decisions; for instance, if she maintains her desire for self-discharge into the following day and is ultimately permitted to leave without a cardiac workup, these brief limitations upon her autonomy may render her reluctant to seek medical care elsewhere, even after securing the well-being of her cat. Limiting her autonomy may also impact the behavior of other patients: if Mrs. A returns home and tells her neighbors of her experience, they too may be reluctant to pursue medical care—and soon, the perception will spread through the community that doctors are actively engaged in denying fully capacitated patients the right to immediate discharge. One can easily imagine how this perception could have a chilling effect upon the choices of future patients. Enforcing her ongoing detention may also prove traumatic, especially if the presence of security officers or even the threat of physical force must be deployed.

Suffering from Absence of Autonomy

If the act of limiting autonomy can prove detrimental to the patient's well-being, the loss of the specific liberties curtailed may also prove psychologically damaging. Whatever reason is motivating the patient to depart immediately, even if this motive seems inconsequential to the evaluating physician, is clearly of considerable importance to the patient. In Mrs. A's case, no evidence suggests that her concerns for her cat are not genuine. In addition, the existential suffering of being forced to remain inside a hospital setting against her will—in essence, to remain a short-term captive of the institution—cannot be underestimated. This distress may be increased by the perception that the duration of such detention is uncertain and may be long, a fear which might prove difficult to dispel once the care team has already revoked the patient's right to leave. Telling Mrs. A, "We're not going to let you leave now, but we will tomorrow if you still want to depart," is unlikely to sound convincing in a setting where she did not anticipate the prospect of such involuntary detention at all.

Present Delay Versus Future Delay

One purpose of delaying discharge in order to further evaluate capacity is to allow the patient time to reflect upon her decision. In an ideal situation, such reflection may lead to reconsideration that vindicates deeper values and goals. At the same time, allocating additional time before discharge may make less time available to the patient after discharge—a concern in clinical conditions requiring urgent care. For instance, Mrs. A may be persistent in her desire for immediate self-discharge so long that such a discharge eventually becomes legally and ethically obligatory. She may also be sincere in her intention to seek care elsewhere once she had arranged for the well-being of her cat. But if she does not leave the first hospital until noon on Monday, as a result of the decision to delay discharge, then she will not receive care at the second hospital until later that day—when, had she been discharged earlier, she would have had the opportunity to address her feline concerns and obtain time-sensitive, potentially lifesaving care at the second hospital more quickly.

The Kabuki Request for Self-Discharge

Another phenomenon that pits the patient's stated wishes against her underlying beliefs arises when a patient expresses a desire to leave—often as a result of a perceived or actual slight—while fully expecting the hospital to refuse the request. Patients who have been denied immediate self-discharge in the past under similar circumstances may voice their requests out of frustration with the goal of conveying their exasperation to the care team—not with any intent of actually being allowed to depart with their medical needs unaddressed. In theory, calling such a patient's bluff might persuade her to retract her request. Far more likely, such a patient will find herself acting against her own unspoken preferences to save face in a form of metaphorical *kabuki* theater in which each actor has a stylized role to play from which she must not deviate. Requests for immediate self-discharge may also mask subconscious desires to remain hospitalized, which will become manifest within a short interval of time. Patients who make such requests may often retract on their own once they have received sufficient attention and concern from their care teams, suggesting different psychological forces at play from those consistent with an autonomous desire to turn down care and depart.

A Working Model for Immediate Self-Discharge Requests

In light of the issues raised above, this paper proposes a working model for addressing issues of capacity in requests for immediate self-discharge that balances the need to respect patient autonomy in the moment with concerns regarding the authenticity of fleeting choices. In low-stake cases, such as when the risk of significant morbidity or mortality is limited, a strong argument exists for deferring to the patient's momentary preferences in all cases where she meets established capacity criteria. In high-stake cases, where a substantial risk of death or debility exists, this model proposes three situations in which

immediate discharge should be permitted without indication for additional reflection or information-gathering. These are outlined below.

Presence of Collateral Confirmation

In many cases, the evaluator will be able to establish concordance between the patient's choice in the moment and her underlying goals and values. For example, if the psychiatrist evaluating Mrs. A spoke to her neighbor, who confirmed that Mrs. A frequently stated she would sacrifice her own life to make sure her cat was comfortable, then the perceived slight from the nursing aide and the evaluator's perception that Mrs. A's preferences seemed disproportionate to the risks might appear far less like distortions of her underlying values than they might seem in the absence of those additional data. Instead, her preferences in the moment would appear consistent with her underlying values and unlikely to change in a short time frame. In the presence of such concordance, holding the patient in the hospital against her will any longer would not appear to increase the likelihood of a more authentic autonomous choice, so immediate self-discharge would be indicated.

Dissenting Religious or Cultural Values

Even in the absence of such collateral information, some patients may voice religious or cultural objections to proposed care that leads them to seek immediate discharge. For instance, a Christian Scientist may fall in the street and hit her head, resulting in her being transported to a nearby hospital for a concussion workup. As Christian Scientists generally reject medical interventions in favor of prayer on religious grounds, this patient will wake up and demand immediate self-discharge against medical advice. The evaluating physician has no doubts that the patient, who appears well-versed in her religious beliefs, is indeed a devout Christian Scientist. Holding such a patient in the hospital to ascertain whether she will accept medical care several hours later is a fruitless endeavor, as the likelihood that the patient will abandon deeply held religious convictions in a short period of time seems low and certainly not probable enough to justify the concomitant loss of autonomy. In short, patients who are religious or cultural dissenters at sunset are highly likely to remain religious or cultural dissenters at dawn.

Limited Life Expectancy/Poor Prognosis

A third category of patients who seek immediate self-discharge are those suffering from terminal diagnoses or extremely poor quality of life independent of the presenting illness. For example, a patient who wishes to turn down an emergency appendectomy at 3:00 am on a Sunday may explain to the capacity evaluator that she is dying of pancreatic cancer or glioblastoma and that she would prefer to have nature take its course quickly. In such situations, assuming the underlying diagnosis is confirmed, a short interval of additional time is unlikely to alter the patient's prognosis or preferences. Rather than altering the inevitable outcome, declining care merely speeds up a process that is already looming and unavoidable. No additional time is likely to alter these underlying facts, so whatever benefit is gained by additional reflection is likely outweighed by the psychological costs of delay. In fact, some patients may view the prospect of an accelerated death as preferable and even experience distress at the prospect of having this option delayed or denied to them by their caregivers.

Residual Cases

In cases that do not fall into these three categories, the clinician should give greater consideration to balancing the immediate wishes of the patient against the benefits of reflection and additional information. In particular, capacity evaluators should ascertain the motivation for seeking immediate self-discharge. When the risks of discharge appear highly disproportionate to the stated reasons for seeking discharge, the evaluator should ensure that the patient's views remain consistent over a reasonable period

of time. In addition, obtaining additional information about the patient's underlying values is likely in order, which often will require contacting family members or outpatient clinicians for collateral information. If such requests occur during off-hours, holding patients overnight for reassessment in the morning may be indicated and ethically justified. That does not mean that *all* patients should be held for additional assessment under such circumstances. Rather, medical providers should balance the need for additional reflection and information against the negative effects of short-term limitations upon acceding to patient self-discharge requests in order to achieve outcomes that most reflect patients' authentic values without undermining their psychological well-being.

Bias

The decision to hold a patient in a hospital against her will is a serious one with significant implications for autonomy, justice, and human rights. Convincing evidence shows considerable racial bias already exists in such assessments.¹⁴ Steps must be taken to ensure that decisions to delay requests for immediate self-discharge do not reflect or exacerbate such biases. At the same time, patients from marginalized and low-income communities are more likely to request immediate self-discharge. These requests are likely tied to some combination of baseline distrust of the healthcare system and perceived or actual slights that occur during care delivery. Providers may demonstrate a different form of bias in acceding too readily to such patients' requests for immediate self-discharge in cases where either brief reflection or additional information-gathering is far more appropriate, because these marginalized patients are too often regarded as difficult or less deserving. Systemic measures must be established to avoid such premature discharges as well. Avoiding such bias requires, among other factors, examining each patient's case in depth to ascertain the patient's authentic wishes.

Conclusions

The dominant method for assessing capacity in the United States is designed to assess patients whose skills and preferences are static over short periods of time. Appelbaum and Grisso's approach also recognizes "repeated reversals of intent" or vacillation, "particularly if they can be linked to a diagnosable psychiatric disorder and can prevent the implementation of any consistent approach."¹⁵ Yet in clinical practice, cases of individuals who demand immediate self-discharge in the setting of sudden emotional distress, frustration, or concerns for extraneous matters far out of proportion to the medical risks they face prove highly frequent—and the pinpoint approach to temporality characteristic of the four-skills model may require some modification. An overly formalistic or rigid approach to the definition of consistency in communicated choices might achieve the superficial appearance of vindicating autonomy but may actually prevent patients from achieving outcomes consistent with their underlying beliefs, values, and authentic goals.

Competing interest. The author declares no competing interests.

Notes

1. Alfandre DJ. "I'm going home": Discharges against medical advice. *Mayo Clinic Proceedings* 2009;**84**(3):255–60.
2. Glasgow JM, Vaughn-Sarrazin M, Kaboli PJ. Leaving against medical advice (AMA): Risk of 30-day mortality and hospital readmission. *Journal of General Internal Medicine* 2010;**25**(9):926–9.
3. Ibrahim SA, Kwok CK, Krishnan E. Factors associated with patients who leave acute-care hospitals against medical advice. *American Journal of Public Health* 2007;**97**(12):2204–8.
4. Appelbaum PS, Grisso T. Assessing patients' capacities to consent to treatment [published correction appears in *New England Journal of Medicine* 1989 Mar 16;320(11):748]. *New England Journal of Medicine* 1988;319(25):1635–8.

5. Buchanan AE, Brock DW. *Deciding for Others: The Ethics of Surrogate Decision Making*. New York: Cambridge University Press; 1989.
6. Appel JM. A values-based approach to capacity assessment. *Journal of Legal Medicine* 2022;**42**(1–2):53–65.
7. Garrett WS, Verma A, Thomas D, Appel JM, Mirza O. Racial disparities in psychiatric decisional capacity consultations. *Psychiatric Services* 2023;**74**(1):10–6.
8. Mirza O, Appel J. Capacity reconceptualized: From assessment tool to clinical intervention. *Cambridge Quarterly of Healthcare Ethics* 2023;1–5.
9. Palmer BW, Harmell AL. Assessment of healthcare decision-making capacity. *Archives of Clinical Neuropsychology* 2016;**31**(6):530–40.
10. See note 4, Appelbaum, Grisso 1988.
11. Kassirer S, Levine EE, Gaertig C. Decisional autonomy undermines advisees' judgments of experts in medicine and in life. *Proceedings of the National Academy of Sciences of the USA* 2020;**117**(21):11368–78.
12. Spelley R. Reviving Ulysses contracts. *Kennedy Institute of Ethics Journal* 2003;**13**(4):373–92.
13. Appel JM. "Some people in persistent vegetative states have working minds. Does keeping them in limbo amount to torture?" *Stat* 2020 Jan 9; available at <https://www.statnews.com/2020/01/09/working-mind-body-vegetative-state/> (last accessed 19 December 2022).
14. See note 7, Garrett et al. 2023.
15. See note 4, Appelbaum, Grisso 1988.