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Decision-Making Capacity, Memory and Informed Consent, and Judgment at the Boundaries of the Self

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Momentous decisions with uncertain futures impel us towards deliberation about the best next move. But most often we make decisions without conscious reflection about the process of doing so. As is the case with many features of our mental life, we find no need to scrutinize them until they malfunction.

Analogous to the famous and equally tragic cases of the American patient H.M. and of the British composer Clive Wearing, in the case before us anterograde amnesia has so swiftly dissociated the capriciously modular components of the mind.[1] The unfortunate circumstances present a number of multifaceted questions about treatment decisions at a time when even the word "decision" is called into question. And so we must ask and dissect things that, under non-pathological circumstances, arise routinely from prodded introspection.

WHAT IS IT LIKE TO BE AN ANTEROGRADE AMNESIAC?

The philosopher Thomas Nagel reminds us of the difficulties of penetrating to the depths of another person's first-person subjectivity in his thought experiment about attempting to imagine what it is like to be a bat, an animal with an entirely different apparatus of perception.[2] Thus the amnesiac's inner world could be effectively closed to us. We cannot know the intricacies of his waking moments, of his thoughts and feelings, and elaborate tricks of compensation employed to survive the day. What is it to be without the very features of mental life that keep our continuous personal identity intact? Nagel counsels modesty rather than claiming certainty of knowledge about such irreducibly subjective and private states of consciousness.

However, an amnesiac is not a bat, but an impaired human. He is someone with whom we were wired to empathize. It therefore is no surprise that, although difficult to create, good art and creative imagining can at least hint to us at what it must be like. For example, in Christopher Nolan's screenplay *Memento,* the amnesic protagonist tells us of anterograde amnesia: "It's like waking. Like you just woke up."[3]

He gives us a few glimpses of his anxieties and struggles, and some that can help provide perspective as we discuss the ethical features of the case before us. Here, the protagonist describes waking in the morning to find his previously deceased wife not present:

> I don't even know how long she's been gone. It's like I've woken up in bed and she's not here . . . because she's gone to the bathroom or something. But somehow, I know she's never gonna come back to bed. If I could just . . . reach over and touch . . . her side of the bed, I would know that it was cold, but I can't. I know I can't have her back . . . but I don't want to wake up in the morning, thinking she's still here. I lie here not knowing . . . how long I've been alone. So how . . . how can I heal? How am I supposed to heal if I can't . . . feel time?[4]

DECISION-MAKING CAPACITY AND SUBSTITUTED JUDGMENT

Mr. G has lost all of his recent long-term memory but retains remote long-term memory, and cannot form new memories, with memories lasting less than one hour. The etiology of these problems is uncertain but began some time after a truck crash two weeks prior to evaluation, and included seizures.

It is important to remember that even in the face of selective incapacity in a cognitive domain, decisions about treatment may well be possible. We believe this may be the case with Mr. G. Although the mini-mental status exam is not especially useful for assessing decision-making capacity except in extreme forms of impairment, this situation may qualify.[5] It is uncertain what his exam results demonstrated as they are not detailed.

In the window of time in which Mr. G does live — something less than one hour we are told — he has a very selective deficit, however, and all signs indicate that his registration (allegedly follows commands, able to use visual cues in room and hallway), orientation (knows where he is), insight (he acknowledges his memory problems), judgment (appropriate reaction to news of illness), language, concentration, and short-term memory are intact. He shows some mild retrograde memory loss since the accident (not remembering where he lives), but in general his long-term and remote memory (from which he might derive access to his lifelong values and goals) are intact as demonstrated by recognition of family pictures, and relational bonding ("very interactive and comfortable") with even estranged daughters.

From what we have read in the case, Mr. G is able to reason, communicate, understand the proposed treatment and its alternatives, understand the risks and benefits of the proposed treatment and the risks and benefits of declining treatment, and his mental state seems to be stable over time, if selectively impaired in terms of memory consolidation, all the hallmarks of decision-making capacity.[6] He does not seem to have a complicating mood disorder that might thwart his judgment, even if he were assessed to have decision-making capacity on purely cognitive grounds.[7]

Regardless, Mr. G's inability to remember his diagnosis would not necessitate that he is unable to foresee or appreciate benefits and risks of treatment, but only that he would not be able to do so continuously in time, and only when prompted. The questions were raised, "Would we have been more willing to accept his choice if he said 'yes' to treatment, without involving a surrogate?" and "Was he asked often enough to provide a consistent pattern?" These seem to us to be the central ethical questions of the case. Was Mr. G able to make choices based on his values and his assessment of his situation, however brief? It would have been helpful for the case to detail more of the attempts to elicit Mr. G's thoughts about treatment and its risks and benefits, considering the centrality of this question, his lack of global impairment, and the impression that he made on staff, that he was often "quite lucid and capable of decision-making."

Complicating the decision to treat Mr. G is the vital question of the likelihood of recovering or improving his memory, which cannot be ruled out based on one neurological evaluation with little follow up. We have no confirmation of ruling out metastases or other possible causes, since no mention is made of any imaging studies of the brain. We don't know for certain if this is permanent bilateral destruction of the medial temporal lobes (as in patient H.M.) or something else entirely. Although we are uncertain of the etiology of his memory impairment, we can — given his history — reasonably suspect that it is secondary to traumatic brain injury (TBI), which commonly causes problems in the acquisition of new information, especially episodic memory.[8] Recovery of memory after TBI represents a heterogeneous recovery curve, and

some studies show three subtypes: slow progressive recovery, dramatic linear recovery, and initial dramatic recovery followed by significant decline at one year.[9]

Even in the face of a severe memory incapacitation, Mr. G may still retain his autonomy. But can his wishes be ascertained? That the consultant seems vaguely familiar is a hopeful sign. Making decisions about his future with the expectation of little to no changes in his cognitive functioning would be premature. His preliminary responses to a hypothetical situation of treatment, that he "would have to think about it, it's a lot to consider," and later, after shaking his head at the thought of the side-effects, that "it [is] a lot to think about," seem to be an appropriate response to a momentous, potentially uncertain but certainly painful, life-saving decision. Expecting moderate improvement in the months or years ahead may have provided incentive to probe Mr. G to make a decision about treatment rather than relying on the proxy. These considerations are even more complex, given his unexplored statement on another occasion that "I have always said I didn't want to go through all of that."

INFORMED CONSENT

That Mr. G was transiently unaware of his cancer made it difficult for him to consent to treatment on his own. Might he have been able, however, to consent with help? We do not get a sense of whether he actively forgot during the consenting process, or whether he was able to be informed, stabilized, and then brought at least partially through the informed consent process before he lapsed with unconsolidated memories. When Mr. G's daughters visited, the second ethics consultant found Mr. G quite lucid and capable of decision making, but we are unsure whether this means he was able to remember his cancer diagnosis, or whether this represented an improvement from his previous mental state? That staff was putatively able to provide information about Mr. G's condition and proposed treatment (either by a reasonable-person standard or subjective standard) and was able to check for understanding (asking him to summarize what had just been said) was a helpful sign. Involving a surrogate would have been necessary if this process failed or if Mr. G actively forgot too quickly, but it is unclear that either of these things occurred. Our concern is that this process should have been exhausted before the substituted judgment was instituted.

SURROGATE DECISION MAKING

That a healthcare proxy was obtained upon Mr. G's admission and reconfirmed thereafter has been confirmed. One need not doubt that Mr. G was capable of such an appointment. The question arises — on what basis was Mr. G said to be capable of giving permission to others to have access to his medical records (daughters), and said to be capable of appointing another person as the bearer of his autonomy (brother) — including all that these decisions imply about present and future continuity of personal identity and medical care — and yet not able to consent to treatment? If capacity is task-specific, why were there markedly different evaluations of capacity, given the similar cognitive mechanisms and requirements? Again, to us, the central ethical issue mentioned above requires reflection on the question of whether a surrogate was necessary. After all, any estimation on the part of the proxy as to what Mr. G might have desired in potentially life-saving treatment is superseded by even a modestly capable decision by Mr. G about attempts to save his life or avoid unnecessary suffering.

Even if Mr. G was grossly incapacitated by his amnesia (for example, if he could not hold a thought for more than 45 seconds) and no doubt existed about the need for a surrogate, the bar in this case for allowing a deferral of potentially life-saving evaluation and treatment might have been higher than others we may encounter. New York is one of the states that specifically declared a strict interpretation of substituted judgment: it requires that the decision of the surrogate about treatment is based on "clear and convincing evidence" that the patient had "a firm and settled commitment" about the decision under examination.[10] This standard would require not only that Mr. G had on some occasion mentioned a general wish against continuing life by artificial means. Rather, it would require that Mr. G expressed not wanting the particular treatment

in question (chemotherapy) in the particular circumstance in question, or some other very similar expression.

On a separate matter, there seems no reason to suspect a conflict of interest or coercion concerning the surrogate chosen or the manner in which it was accomplished.

TREATMENT DECISION

We know that physicians, compared to their patients, have a tendency to underestimate patients' present quality of life, and are thus more likely to balk at life-sustaining treatments.[11] Similarly, the ability of physicians and nurses to predict patients' future quality of life and outcome is regularly lacking, especially in the most sick patients.[12] Predicting outcomes in cancer patients is notoriously difficult, even among specialists.[13] It is also important to be aware of the influence, or even bias, of one's own preferences on the perception of a patient's wishes for life-sustaining treatment.[14] Mr. G is 58 years old and, with significant family supports, potentially able to endure chemotherapy. One wonders if a compromise position would have been to at least stage his cancer to better contextualize any deferral of treatment?

Although it is true that, as Nietzsche says, "the advantage of a bad memory is that one can enjoy the same good things for the first time *several* times," the converse is also true.[15] The concern about waking up to nausea and vomiting, all the while unaware of even having cancer, is obviously legitimate. If Mr. G had consented, could a sympathetic system to provide information and symptomatic support overcome the hesitation to treat, based on side-effects? As we mentioned, Mr. G's post-TBI anterograde amnesia would probably have improved somewhat over time, and he already had signs of residual consolidation to long-term memory (that is, the consultant was consistently not a novel stimulus). On one view, all non-physiologic futility is normative futility, entailing a confluence of value judgments and probability estimates.[16] Upon potential improvement, who among us, at 58 years, would not look back and yearn for a 15 percent chance (or possibly better, after accurate staging) of cure, and 60 percent (or better) chance of one more year of life with friends and family?

Finally, a question exists as to whether intermediate care options were explored other than only comfort measures versus chemotherapy. Were palliative surgery or other medical treatments explored?

FAMILY AND CAREGIVER CONFLICT

The conflicts between Mr. G's brother and daughters seems to have been resolved, as all parties eventually agreed with the brother's estimation of Mr. G's wishes to forego therapy. There seem to have been no known family conflicts of interest or financial incentives or secondary gain. We cannot know whether subtle, indirect conflicts of interest were considered regarding the caregivers. For example, there is the possibility that administering cancer chemotherapy to a complicated memory-impaired patient such as Mr. G. could well have been a money-losing proposition, given the amount of non-reimbursable time such care would have required.[17] Moreover, the medical treatment of any neuropsychiatrically impaired patient can pose a problem for overworked medical careproviders when there can be an unspeakable — and thus unexamined — undercurrent of *de facto* triage in the life of hospital-based care.[18] Yet, giving Mr. G's caregivers the benefit of the doubt, the priority given to relational proximity of the brother seems appropriate, given Mr. G's estrangement from his daughters and their enthusiastic attempts to reconcile with him.

CONCLUSION

There are no easy answers in the case before us, only more questions . . . and more sadness.

Primo Levi, in his story "In the Park," creates an imaginary world in which others' memories of you congeal together and somehow provide a semblance of a self, but it is one that is as easily lost — as easily

unmade, as made. In this excerpt from the story, the protagonist describes what it feels like to have one's sense of a (social?) self dissolve — traumatic brain injury in slow motion, if you will:

> Some three years after his arrival, Antonio noticed a surprising fact. When he raised his hands, as a shield against the sun, say, or even against a bright lamp, the light filtered through them as if they were wax. Some later time, he observed that he was waking earlier than usual in the morning, and he realized that this was because his eyelids were more transparent; in fact, in a few days they were so transparent that even with his eyes closed Antonio could distinguish the outlines of objects.
>
> At first he thought nothing of it, but toward the end of May he noticed that his entire skull was becoming diaphanous. It was a bizarre and alarming sensation: as if his field of vision were broadening, not only laterally but also up, down, and backward. He now perceived light no matter what direction it came from, and soon he was able to distinguish what was happening behind him. When, in mid-June, he realized that he could see the chair he was sitting on, and the grass under his feet, Antonio understood that his time had come: the memory of him was extinct and his testimony complete. He felt sadness, but neither fear nor anguish. He took leave of James and his new friends, and sat under an oak to wait for his flesh and his spirit to dissolve into light and wind.[19]

DISCLAIMER

The authors note no conflict of interest.

NOTES

1. Patient H.M. suffered from intractable epilepsy. In 1953, William Beecher Scoville resected H.M.'s temporal lobe structures, markedly decreasing the frequency of H.M.'s seizures, but with the unfortuate side-effect of immediate anterograde amnesia that continues to present. S. Corkin, "What's new with the amnesiac patient H.M.?" *National Review of Neuroscience* 3 (February 2002): 153-60.

Clive Wearing was a conductor widely renowned as an expert on early classical music. He developed a herpes simplex infection that caused a severe case of encephalitis, resulting in severe brain damage and anterograde amnesia. Although his short-term memory is nonexistent and his recall of both prior life events and general knowledge is impaired, he has shown a remarkable retention of his musical skills, including being able to conduct choirs and sight-read keyboard music at a level approaching his former functioning. A. Baddeley, *Essentials of Human Memory,* part of the Cognitive Psychology series (East Sussex, U.K.: Psychology Press Ltd., 1999).

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15. F. Nietzsche, *Human, All Too Human: A Book for Free Spirits,* ed. R.J. Hollingdale, (Cambridge, U.K.: Cambridge University Press, 1996), 188.

16. D.B. Waisel and R.D. Truog, "The cardiopulmonary resuscitation-not-indicated order: futility revisited," *Annals of Internal Medicine* 122, no. 4 (February 1995): 304-8; S.J. Youngner, "Who defines futility?" *Journal of the American Medical Association* 260, no. 14 (October 1988): 2094-5.

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