REIMAGINING THE QUALITY OF LIFE

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ABSTRACT: In recent papers, I defend the intrinsic value of the interesting, and the intrinsic disvalue of the boring. My arguments introduce two claims with important implications for discussions of the quality of life. The first is that when it comes to experiences, there’s more value at stake than pleasure alone. The second is that there is value to cognitive engagement itself, even when it is unstructured by desires or reasons. This paper explores the important consequences these conclusions have for how we appraise the quality of life of subjects with dramatically impaired cognitive capacities (such as patients with advanced Alzheimer’s and patients in a persistent vegetive state). I examine whether such groups are capable of experiencing the interesting and, by extension, what degrees of self-awareness are required to experience the kind of cognitive engagement at stake in interesting experiences.

I. INTRODUCTION

Traditional frameworks for evaluating the quality of one’s life rely on two standards. The first concerns the degree of agency exhibited by the patient, while the second concerns the degree of pain or suffering the patient experiences. Respectively, these frameworks prioritize a patient’s capacity to exercise agency and her capacity to experience pain. In cases where a patient’s cognitive impairments afflict both capacities, leaving her incapable of exercising agency or experiencing pleasure, most would support a decision to end a patient’s life on the grounds that her continued existence would fail to be of prudential value to her. In cases where one of these capacities is absent, there is spirited debate about how to decide whether the patient’s life is worth living.

Defenders of the agency framework stress the priority of agency over sentience, illustrating the common view that the human capacity to exercise agency is more important to the quality of life than is our sentience. This position drives the current focus on advance directives. When a competent person forms an advance directive, the expectation is that respect for their agency warrants following an advance directive, even when doing so means ending the life of someone capable of experiencing pleasure and pain (e.g., Dworkin 2011). The agency framework so
prioritizes agency over sentience. In contrast, the sentience framework holds that if a patient has the capacity to experience pleasure and is not in pain, her life still benefits her, regardless of whether she has agency (e.g., Dresser 1995).

These debates regarding the quality of life, especially at the margins, test and explore the notion of prudential value. They press us to consider, at root, what prudential value is and wherein its threshold lies. Because these debates often arise in the context of needing to make decisions on behalf of those who lack competency or are otherwise unable to communicate, they tend to focus on the basic capacities it takes to experience prudential value or to be the bearer of prudential value. The agency framework holds that prudential value is realized by or derivative from an agent’s cognitive faculties, while the sentience framework holds that prudential value must be experienced by the subject.

While within and in between these central frameworks there are many important nuances and divisions, I focus here on the basic assumptions driving each way of assessing the quality of life, which are two: the first is that cognitive activity is valuable only when it reflects agency (the agency claim); and the second is that sentience exhausts the range of experiential values (sentience claim).

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<th>Agency-centered approach</th>
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<td>Prudential value is realized through or derives from an agent’s cognitive faculties.</td>
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<td>Essential Capacity: Agency</td>
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While these two assumptions pervade discussions of the quality of life, recent arguments call into question both the agency claim and the sentience claim. The plausibility of these arguments show it is time to re-imagine the quality of life.

In earlier work, I argue that there is intrinsic value to interesting experiences, and disvalue to boring experiences (Besser 2023; forthcoming). My view maintains that cognitive engagement is prudentially valuable independently of whether it demonstrates agency, and holds that pleasure is not the only intrinsic experiential value. In this paper, I explore the implications of these arguments for how we assess the quality of life in patients with severe cognitive impairments. I argue that given the plausibility that even those with severe cognitive impairments can experience the interesting, we ought to take this capacity into consideration when we evaluate life at the margins.

There are three parts to the paper. First, I revisit my earlier arguments in defense of the value of the interesting and the disvalue of the boring, and show how
these arguments complicate the agency and sentience claims. Second, I examine whether two groups of patients with significant cognitive impairments—patients with Alzheimer’s disease and patients in a minimally conscious state—have the capacity to experience the interesting. Through this analysis, I develop a deeper understanding of the nature of the cognitive activity that is distinctive to the interesting and of the difference between cognitive activity and cognitive engagement. Third, I explore how we can begin to invoke the value of the interesting into our assessments of the quality of life.

II. BROADENING THE CATEGORY OF EXPERIENTIAL VALUE

The notion of “experiential value” refers to the prudential value(s) experienced by a subject independently of their connection to further ends and values. Pleasure is the most recognizable experiential value: it is something good for the subject to experience. It might be bad all-things-considered, such as when a subject takes pleasure in the failure of others, but the pleasuring quality of the experience is experienced as valuable by the subject.

In contrast, non-experiential value derives from outside of the subject’s experience. Non-experiential prudential value still benefits the subject but does so in ways that go beyond her experiences. Perfectionist value is an example of a prudential, non-experiential value. Perfectionist value refers to the value of developing and using our cognitive faculties in ways that are distinctive to human beings (e.g., Hurka 1993). This value derives from the proper use of these faculties, where “proper use” is defined independently of the subject’s subjective experience. That is, the perfectionist maintains that there is prudential value to developing one’s cognitive faculties that can be determined objectively, without reference to the subject’s experience. As my discussion here is limited to quality of life analyses, which gauge a subject’s experiences, my focus is on experiential value.

The central, distinguishing feature of experiential value is thus that it is experienced as a value and that its value does not derive from the nature of the activity (e.g., whether or not the activity involves rationality), or from the products of the activity (e.g., whether or not the activity produces good consequences). Experiential value and non-experiential value may very well overlap: using reason can be experientially valuable, just as acts that produce good consequences can be experientially valuable, but the categories themselves are different.

In Besser (2023), I propose to expand the category of experiential value to include the value of the “the interesting,” which I define as a qualitative feature of our experience of being cognitively engaged. I argue that the interesting arises from a place of resonance and derives from the ways in which the activity engages our minds and stimulates further engagement. Exactly what we find interesting depends on a range of factors about ourselves, such as our past experiences, our emotional responses, our beliefs, and our values. There is no one set of conditions that gives rise to the interesting, and it can be challenging to predict what we will find interesting on any given occasion.4

We experience the interesting whenever we find that what we are doing stimulates cognitive engagement that triggers new thoughts and new feelings, which
themselves trigger further engagement. For example, consider the last time you read an article that caught your mind and stimulated your curiosity, leading you to think both “wow” and “why?”. We experience the interesting when we allow ourselves to pause on the “wow,” and let the “why?” implicitly or explicitly guide us. Almost any activity can prompt an interesting experience: reading books, traveling, casual banter with a friend, or a chance encounter with a stranger. The key is that our minds need to be open to the engagement, and that we allow our minds to be stimulated. It’s all about how we cognitively engage with whatever we find ourselves doing.

The interesting describes a qualitative aspect of our experience of a robust form of cognitive engagement that we experience as valuable, in much the same sense in which we experience pleasure as a value. Just as the value of pleasure does not derive from the massage but from our experience of the massage, the value of the interesting does not derive from what we are doing or thinking about, but from our experience of it. In broadening the category of experiential value to include the interesting and the pleasant, my argument thus challenges the sentience claim, which holds that pleasure is the only experiential value. It suggests that it is a mistake to evaluate the quality of a patient’s life solely by the amount of pleasure she can experience, and that we ought to consider, as well, the amount of interest she can experience.

While my analysis of the interesting pokes holes in the sentience claim, my parallel analysis of the boring introduces doubt into the agency claim (Besser forthcoming). The agency claim, remember, holds that cognitive activity is valuable only when structured by reason—what I’ll call “agentic thinking.” Agentic thinking allows us to plan, to shape our lives, and to make decisions about how we want to live. It’s the form of cognitive activity that philosophers have long held to be the important one, such that its loss may warrant a decision to end one’s life. Appreciation of the experiential value of the interesting implies that other forms of cognitive activity bear prudential value.

Reflecting on the nature of boredom brings to light the prudential value attached to the experience of cognitive engagement. Drawing on psychological discussions of boredom, I define boredom as a lack of cognitive engagement that is experienced as an aversive state by the subject, in light of her need or want to be engaged (Besser forthcoming). My analysis explains why boredom is [prudentially] bad in a way that also makes clear its resolution, which is that any form of cognitive engagement resolves boredom. Whether it is structured by means and ends, plans and purposes, or whether it is unstructured, cognitive engagement resolves boredom.

This is not only true to our experience, it also shows a clear value attached to cognitive engagement, which renounces the agency claim. If there’s value to cognitive engagement itself, then our cognitive activity isn’t valuable only when structured by means-end reasoning, and this ought to inform our quality-of-life assessments. This means that we should neither limit our analysis of a patient’s quality-of-life to her sentience or discount a patient’s cognitive activity even if that patient is unable to structure her cognitive activity through reason. This suggests that a complete evaluation of the quality of life ought to include a patient’s capacity for cognitive engagement of any sort. Her ability to experience any kind of cogni-
tive activity is prudentially valuable insofar as it provides her with the capacity to experience the interesting and to avoid the boring.

But who has the capacity to experience the interesting? How do we determine when a patient’s cognitive impairments impair her ability to experience the interesting? I’ll now consider how broadening of the category of experiential value to include the interesting impacts the most complicated cases in which we must evaluate the quality of life. Two categories of patients stand out: people with Alzheimer’s disease, and those in a Minimally Conscious State (MCS). Individuals in both categories present severely impaired cognitive faculties that compromise their capacity for agentic thinking. Because these individuals are not able to engage in higher-order cognitive activity, quality of life assessment for both groups tends to focus primarily on sentience. But if these groups can experience the interesting, this ought to influence our assessments.  

III. PATIENTS WITH ALZHEIMER’S DISEASE

People with Alzheimer’s disease suffer from damage to their hippocampus, which is the area of the brain responsible for transforming short-term into long-term memories through the acquisition and processing of thoughts. These individuals are deemed incompetent because their capacity for agentic thinking is limited. Of particular concern for these subjects is that they seem to lack a sense of continuity typically provided through memory. Absent the ability to create new memories, the minds of people with Alzheimer’s seem to be stuck continually in the present, floating from impression to impression, in a fashion similar to what Oliver Sacks describes as “Humean froth” (1998: 39). The loss of continuity, or the sense of time, seems to inhibit people with Alzheimer’s from imagining their future experiences. To plan and pursue, we need to be able to anticipate the effects of our current actions on our future selves. But if we are, indeed, stuck in the present, then we can’t make this kind of cognitive leap.

Philosophers such as Ronald Dworkin (2011) have drawn on this limitation to argue that patients with Alzheimer’s lack agency. He holds that imagining the impact of future experiences on oneself is essential to competent decision-making about the shape of one’s life. The exercise of agency involves being able to connect the past to the future, which requires a sense of continuity.

On the surface, that the course of Alzheimer’s may preclude the exercise of agency does not entail that people suffering from Alzheimer’s lack the ability to experience the interesting, for the interesting invokes a different form of cognitive activity than the one requisite for agentic thinking. Given the independence of the interesting from desires, interesting experiences are not always the kinds of things we can predict. And it’s plausible that planning and predicting might interfere with our experiences of the interesting, for it invokes cognitive processes that lead one to constrain and direct one’s attention on a goal and its pursuit, thereby potentially filtering out stimuli and modes of thought that invite interesting experiences. Just as children are more apt to experience the interesting, so too may be those with limited agential capacities.
Prima facie, thus, that people with Alzheimer’s disease cannot imagine themselves in the future and may be stuck in the present does not seem to impair their capacity to experience the interesting. This observation doesn’t close our question, however, for to experience the interesting one does need the capacity for cognitive engagement. Dworkin’s fundamental worry with respect to the cognitive limitations that Alzheimer’s incurs over its course is not so much about planning and predicting as it is about a person’s ability to appreciate the impact of one’s experiences upon one’s sense of self; or, in Dworkin’s terminology, the self-awareness one has of the extent to which one’s experiences serve one’s critical interests. If a person’s cognitive limitations are such that they cannot connect their experiences to themselves, or that they cannot process them as their own experiences, then those experiences fail to serve their critical interests.

Do these limits also suggest that the subject’s ability for cognitive engagement is limited, too? With respect to the project of analyzing whether those with Alzheimer’s can experience the interesting, their limited self-awareness is important not insofar as self-awareness is critical to a subject’s critical interests, but only to the extent that it implies a limited ability for cognitive engagement more generally. As experiencing the interesting involves not just cognitive activity but a robust form of cognitive engagement, our concern focuses not so much on Alzheimer’s impact on a person’s agentic thinking and critical interests, but on its impact on her capacity for cognitive engagement and her capacity to experience cognitive engagement as valuable.

Two pressing questions arise, which I consider in turn. First, to what degree does cognitive activity need to engage the subject for her to experience it as valuable? Second, to what degree does a subject need a developed sense of self to benefit from the engagement?

There is an intuitive distinction between cognitive activity and cognitive engagement. We know that even very high levels of cognitive activity can and often does occur beyond our conscious awareness (Bargh and Chartrand 1999). Such cognitive activity impacts both our thoughts and our behavior, but we wouldn’t describe it in terms of engagement. Cognitive engagement requires conscious awareness—at a minimum, it requires conscious awareness of one’s cognitive activity.

We see this point illustrated in the shifts newborns make as they come to develop conscious awareness. There’s some kind of cognitive activity happening from birth, yet we wouldn’t begin to describe it as engagement. When they begin to focus their eyes, watching Mom while she nurses, or watching the colorful objects hanging from their mobile, it is clear they are beginning to engage. Their eye contact and eye movements more generally produce a clear signal of their engagement, enhanced even more by their emerging coos and smiles, further evidencing the impact of their engagement.

We find evidence of cognitive engagement through these kinds of behavioral clues. And we see right away that most patients with Alzheimer’s display similar evidence of engagement. Even if limited to the present moment, they have conscious awareness of themselves and their environment. They respond and react to their activities in ways that suggest engagement.
There are countless stories that report the ability of subjects with Alzheimer’s to display the enthusiasm we associate with engagement. A friend describes his grandmother, Grummy, who suffers from Alzheimer’s. She reads the same book every day. And every day Grummy expresses enjoyment at the delight of the new book. Every day she gets to re-live the experience. This experience is not an anomaly.

Consider, as well, Sacks’ description of an early conversation with a 49-year-old patient named Jimmie, who had been hospitalized for memory loss. Sacks’ line of questioning clearly engages the patient, albeit in a different fashion than might be expected from you and me. Sacks describes Jimmie as animated when asked to share details of his childhood. Interestingly, when Jimmie began to describe his childhood in the expected past tense, he quickly moved to speaking in the present tense. Sacks’ questioning seemed to have engaged Jimmie to the point that he was able to relive the past. Full of animation, Jimmie began using the “actual present tense of immediate experience” (Sacks 1998: 24).

This is remarkable. Previous doctors described Jimmie as “helpless, demented, confused, and disorientated” (1998: 24). And if we are examining Jimmie from the perspective of his capacity to be an agent, perhaps this is apt. But setting aside this lens, Sacks found Jimmie to be “cheerful, friendly and warm” (1998: 24).

Jimmie’s experience of his past in the present reflects the impaired sense of time we know to be associated with the progressions of Alzheimer’s disease. Yet it also reflects a robust sense of engagement. The cognitive activity prompted by Sacks’ questioning took on a life of its own, and, unbounded by a sense of time, Jimmie begins to re-live the experience, just as Grummy re-lives the experience of reading a book for the first time, every day. This suggests that patients with Alzheimer’s disease can experience cognitive engagement and that the way they experience cognitive engagement may be more robust insofar as it is not constrained through our typical lenses of space and time.

This example reinforces the idea that cognitive activity doesn’t need structure for it to be engaging, nor does it need to be anchored within a conceptual framework that preserves either a subject’s sense of self or of her values. A subject can experience the interesting without being aware that it is she who is having an interesting experience in that moment. What separates activity from engagement is not the conscious processing of the experience as one that is beneficial to the subject but is rather the way in which a subject’s cognitive activity stimulates her mind. A subject needs conscious experience of her engagement to experience the interesting, yet there is no reason to think cognitive impairments that alter the ways in which a person processes her cognitive activity prevent her from experiencing the interesting.

IV. NON-COMMUNICATIVE PATIENTS

While the cognitive impairments incurred through the progression of Alzheimer’s may not preclude a person from experiencing the interesting, surely some deeper degree of cognitive impairment does inhibit a subject’s ability to experience cognitive engagement. There must be a point at which one’s impairments leave one unable to experience the interesting even if one’s minds may be active.
Following Giacano et al. (2002), we can view the range of cognitive impairment on a spectrum. At one end are patients in a coma, who present no signs of consciousness and whose motor functions are limited to reflexive and postural responses only. At the other end are patients in “locked-in syndrome,” such as patients at the end stages of ALS, whose consciousness remains intact yet whose motor skills are severely impaired such that most cannot communicate at all, while those that can do so through eye movements only.

We can safely presume that patients with locked-in syndrome do have the capacity to experience the interesting (along with the capacity for agentic thinking), and that patients in a coma do not. There is nothing to indicate that patients in a coma are capable of cognitive engagement. They lack consciousness, sleep and wake cycles, and emotions. While they show motor functions in response to stimuli, the rudimentary nature of these reflexive responses suggests that their responses bypass cognition.

As always, it is murkiest in the middle of this spectrum, where patients in a “minimally conscious state” lie. Patients in this state show brain activity, which demarcates them from those in a vegetative state, yet they are not capable of intelligible communication. Because they can’t express their wishes, essential decisions must be made by others on their behalf.

These decisions are often very difficult to make. In contrast to patients with Alzheimer’s, from whom we can glean the impact and nature of their cognitive activity through our interactions with them, to determine the quality of life of patients in MCS, we must rely on our third-person assessment of what we imagine their experiences to be.

This limitation may explain the dominance of the “best interest” standard in the context of quality-of-life assessments in non-communicative patients, which embraces the sentience claim. We are used to gauging a person’s experience of pleasure and pain through their behavioral responses. These assessments are relatively non-controversial given the shared physical basis of our experiences of pleasure and pain. But it is much more difficult to assume anything about the life of the mind for someone not capable of communicating.

Patients in MCS do show some evidence of cognitive activity through their behavior. They can reach for objects and fixate on them, which suggests internal motivation and control. They smile and cry, which suggests experiences of emotion. And they can interact with others, albeit inconsistently: sometimes following commands, sometimes making an intelligible gestures or uttering some intelligible words (Giacino et al. 2002).

As its name indicates, distinctive to MCS is the partial preservation of consciousness, which indicates impaired cognitive activity. Our question is whether there is any prudential value attached to the cognitive activity of patients in a minimally conscious state. We can grant that they lack any kind of sophisticated capacity for agentic thinking and so should be viewed as incompetent. Yet, if agentic thinking is just one form of valuable cognitive activity, losing this ability shouldn’t entail that there is no value to the cognitive activity that patients in MCS can experience. More exploration into the nature of their cognitive activity.
is warranted. We need to consider whether it is reasonable to think their cognitive activity can become engaging and take the shape of the interesting.

Monti et al. (2010) used fMRI to explore cognitive activity amongst patients in MCS. They looked for evidence of brain activity in a subject in response to questioning and prompts. They found evidence of cognitive activity that signaled “yes” responses and “no” responses, suggesting awareness and responsiveness. They also found that a small but significant percentage of patients displayed the ability to imagine themselves in a past environment, such as their former bedroom. Whatever exactly the nature of their cognitive activity, it is becoming increasingly clear that MCS allows for cognitive activity and that behavioral observation of cognitive activity does not tell the fully story.

Cognitive activity is not cognitive engagement, though. Engagement requires experience and experience seems to require consciousness, which is severely compromised in MCS. Nonetheless, the limited awareness patients in MCS show of their environment suggests engagement and presents the possibility that they can experience the interesting. Patients in MCS do exhibit behaviors that reflect awareness of their environments. They can focus on moving stimuli, they can hold objects, and they show emotional responses appropriate to the context (Giacino et al. 2002). And while they may not be able to engage verbally, there is evidence that their minds can process and react to commands (Monti et al. 2010). This is all minimal cognitive functioning, for sure, but it supports the claim that they experience their cognitive activity and that their activity can engage them.

This analysis of patients suffering from severe cognitive impairments affirms that such impairments limit primarily the shape that one’s cognitive activity can take and the structure a person might impose on their cognitive activity. It doesn’t limit cognitive activity or engagement per se, but it limits what a person can do with it. It limits their capacity to be an agent. Yet, it doesn’t seem to limit their experience of the interesting.

We can tentatively conclude that the capacity to experience the interesting requires only the capacity to experience cognitive activity, such that the activity can become engaging. To experience the interesting, a person thus minimally needs the capacity to experience cognitive activity. It’s evident that patients in MCS have this capacity, although it may not be always active. They may not have the capacity to process their cognitive activity, but sometimes at least, they have the capacity to experience their cognitive activity. This gives them the capacity for cognitive engagement, which allows them to experience the interesting.

V. IMPLICATIONS

I’ve argued that the capacity to experience the interesting is one available even to those suffering from the most severe cases of cognitive impairment, such as patients with Alzheimer’s and patients in MCS. This entails that quality-of-life assessments ought to take into account the prudential value this capacity affords them.

It is hard to determine just how much value the interesting contributes to a life, especially when we try to do so from the third-person perspective. After all, the value of the interesting is experienced, just like pleasure, and without first-person
testimony, our assessments are rudimentary and basic, focusing on the subject’s potential to experience value. And the skeptic amongst us can push: just how much value derives from a person’s experience of the interesting? Does the value that Grummy finds in reading the same book every day make her life worth living? Does the value that a patient in MCS might experience when imagining herself in her home make her life worth living? It is hard, in our position, to say. Given all that we are capable of experiencing, these aren’t enough values for you and me, but they very well might be enough for the person experiencing them. That is, they might seem inconsequential to those of us with a full range of capacities to experience the interesting, but to the cognitively impaired, they might very well be enough.

Here we hit against a concern parallel to the one we face when trying to weigh the value of pleasure for a non-communicative patient. Are the small pleasures they can experience enough to give their lives value overall?

The US Supreme Court Case of Claire Conroy, one of the first to explore third-party standards of assessments for patients in a minimally conscious state, highlights the following as examples of her experiences of pleasure and pain:

- she was able to scratch herself, and had pulled at her bandages, tube, and catheter; she moaned occasionally when moved or fed through the tube, or when her bandages were changed; her eyes sometimes followed individuals in the room; her facial expressions were different when she was awake from when she was asleep; and she smiled on occasion when her hair was combed, or when she received a comforting rub.  

The court settled on (and established) the best interest standard, according to which we weigh the patient’s experience of pleasure against the continued burdens of life. And let’s face it: the pleasures at stake here are small. Conroy’s sources of pleasure revolved around being taken care of: having her hair combed or her shoulders rubbed. These small pleasures wouldn’t add up to much for a healthy person, but they do add up for a person whose cognitive capacities are limited.

Just as the pleasure Conroy takes in having her hair brushed should count towards the calculation of her best interest, so too the interesting experiences she might be capable of having should count. Even if extremely limited, if there’s value there, it should count. We shouldn’t cast it aside, for the reality is that, for many people, it might be the primary source of life’s value and is worth considering as such.

Exactly how we weigh the value of the interesting against other values is a question I will not broach. This is a personal, individualized decision. Interesting experiences are valuable to all, but whether or not someone prioritizes them over pleasure (or over autonomy) seems an individual choice. The degree to which people value the interesting varies considerably between people, just as the degree to which people value pleasure varies. Both are intrinsic prudential values, as evidenced by the fact that they resonate with most people, but the degree to which they resonate, and so the degree to which they define any one person’s quality of life, varies.

Perhaps down the line we can gain better insight into how to calculate the value of the interesting, how to weigh it against pleasure, and how to determine whether its small occurrences are enough to sustain a life. I’m inclined to think that the first
step in developing this insight is to begin to talk more about the value of interesting experiences and how we can enhance our lives and others’ by prioritizing them.

Values are, in a sense, contagious. They spread through appreciation and awareness. When we visit a loved one suffering from Alzheimer’s disease, our understanding of the value of their life shapes their experience. If we find ourselves tormented by their cognitive impairments, they will sense our torment. They will sense that their lives are lacking. But if we can set this concern aside and come to appreciate the value their lives do have, this will help them value their lives as well.

My husband’s mother suffered from dementia for years before she passed away. His reaction to this baffled me for a long time. He loved being around her. He laughed at the nonsense words that came out of her and would thoroughly enjoy himself as she rambled on and on about nothing whatsoever. Thinking through this, there’s no question in my mind that his ability to find value in their interactions enhanced her life and allowed her to take more enjoyment from it. The more he engaged with her, the more she was able to engage herself, and to experience the interesting along with him. It prompted her to keep engaging her mind, in whatever way. And I’m sure his experience of the interaction as interesting helped her do the same. Values spread.

The more we talk about and highlight the value of the interesting, the greater understanding we will have of the role it plays in each other’s lives. We’ll learn whether our loved ones would choose to have an interesting experience over a pleasant one; and we’ll learn whether a life whose only positive value might be the interesting is one that our loved ones would want. In this way we can begin to incorporate this knowledge into our third-party assessments and the treatment decisions we might need to make. This is a small but important step towards reimagining the quality of life.

ENDNOTES

1. Following the well-being literature, I take “prudential value” to refer to that which benefits the subject’s welfare.

2. These frameworks track, but in no way exhaust, philosophical theories of well-being. I address the question of which theories of well-being are most apt for evaluating the well-being of a patient with severe cognitive impairments in my reply to critics, “Engagement, Experience, and Value” (this volume).

3. Dworkin (2011) differentiates between critical interests, which reflect agency, and experiential interests, which reflect the interests subjects have at a particular moment, for an experience. His account of experiential interest is broader than most, insofar as he includes, in addition to sentience, mental states such as contentment and enjoyment. Nonetheless, his position is that the agent-based critical interests can override these experiential interests.

4. An important aspect of my analysis is that the interesting is independent of desire. Having a desire to do something is neither necessary nor sufficient to experience the interesting. For example, we’ve all desired to find something (a book, a class, a movie) interesting and yet have been disappointed. In this respect, the value of the interesting is distinct from the value of desire-satisfaction. See Besser (2023) for further discussion.
5. This suggests a plurality of experiential value, for there are at least two. But—and this is just conjecture—I don’t expect a proliferation of experiential values, and my intuition is that most experiences will be valuable in virtue of being interesting or pleasurable. I return to this question in my reply to critics, “Experience, Engagement, and Value” (this volume).

6. As I discuss in the final section, exactly how it ought to influence our assessments is a question that depends largely on the individual at stake, so it is a question for which there may be no uniform answer.

7. Dworkin develops this point to argue for respecting a patient’s advance directives over and above their current interests. His argument emphasizes the priority of “critical interests,” which are the interests we have in shaping our lives, over “experiential interests,” which are the interests we have in experiences that satisfy or feel good. For the purposes of this discussion, my use of the term “experiential value” tracks what is at stake in “experiential interests,” while my use of “agentic thinking” tracks what is involved in “critical interests.”

8. Sacks asks “what sort of a life (if any), what sort of a world, what sort of a self, can be preserved in a man who has lost the greater part of his memory and, with this, his past, and his moorings in time?” (1998: 23).

9. Both Jaworska (1999) and Craver et al. (2014; 2016) present research suggesting grounds for attributing more agency to patients with Alzheimer’s than we currently do. Jaworska argues that people with Alzheimer’s display behavior and attitudes indicative of valuing; Craver and colleagues explore how people with Alzheimer’s make decisions about the future. Both lines of research provide further grounds for thinking that Alzheimer’s disease does not preclude the ability to experience cognitive engagement.

10. Indeed, consider the first known description of locked-in syndrome, by Alexandre Dumas in The Count of Monte Cristo: “Sight and hearing were the only senses remaining... It was only, however, by means of one of these senses that he could reveal the thoughts and feelings that still occupied his mind, and the look by which he gave expression to his inner life was like the distant gleam of a candle which a traveler sees by night across some desert place and knows that a living being dwells beyond the silence and obscurity. In his eyes, shaded by thick black lashes, was concentrated, as it often happens with an organ which is used to the exclusion of the others, all the activity, address, force, and intelligence which were formerly diffused over his whole body; and so although the movement of the arm, the sound of the voice, and the agility of the body, were wanting, the speaking eye sufficed for all” (Dumas 2005: 257).

11. Of course, there are increasing examples of those declared to be in a coma who turn out not to have been. I take this as a sign of our limited ability to diagnose the existence of brain activity in noncommunicative patients rather than as a defect with the classification itself.


13. This is so even if, as Jaworska (1999) might argue, they have preferences and values. Agentic thinking requires not only the ability to value but to plan and act on the basis of those values. MCS deprives patients of the latter, even if there are grounds for thinking it does not deprive them of the former.

REFERENCES


