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RESEARCH ARTICLE

Suffering at the Margins: Non-Experiential Suffering and Disorders of Consciousness

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Abstract

Research suggests that caregivers of patients with disorders of consciousness such as minimally conscious states (MCS) believe they suffer in some way. How so, if they cannot experience sensations or feelings? What is the nature of their suffering? This paper explores non-experiential suffering (NES). It argues that concerns about NES are really concerns about harms (e.g., dignity-based harms), but still face problems. Second, it addresses the moral importance of bearing witness to suffering. It explores several possible accounts: epistemic (bearing witness generates important knowledge), consequentialist (witnesses' interests also matter), and deontological (there is a duty to bear witness). It argues that witnessing suffering creates epistemic advantages and disadvantages for determining a patient's interests; that clinicians' interests to not bear witness may have considerable moral weight; and that the obligation to bear witness to NES is unclear.

Keywords: consciousness; minimally conscious state (MCS); suffering; surrogate decision making; unresponsive wakefulness syndrome (UWS)

Introduction

Some years ago, my colleagues and I conducted an empirical study on how family members and clinicians caring for patients in a minimally conscious or non-conscious state conceptualized consciousness. We were interested in how their understandings of the nature and significance of consciousness mapped onto those articulated by philosophers, ethicists, and scientists. Readers who are interested in our findings on these issues and our study methods can find them elsewhere.[1,2] As part of that study, we preliminarily engaged the topic of suffering. Do patients who are not conscious ("unresponsive wakefulness syndrome"—UWS) or who are in a minimally conscious state (MCS) suffer? How so if they cannot (or do not often) experience sensations or feelings? What is the nature of their suffering? What is its significance? For example, does their suffering morally outweigh other considerations such as life-prolongation?

Many of the clinicians and family members that we interviewed believed that the patients they love and care for suffer in some way despite having no to low levels of consciousness.[3,4] There were various senses of suffering invoked, including physical pains (evidenced by grimacing, spasticity or posturing, a tear during a procedure, a rise in blood pressure, lying in wet or soiled clothing), emotional or psychological suffering (profound sadness and periodic crying), frustration of agency (patients have goals and aims that they cannot achieve, from moving an arm or basic communication to larger life goals), and suffering from "nothingness" (lying in a bed all day with nowhere to go). Most of our interviewees discussed how difficult it is to discern these patients' true level of suffering and thought it was better to err on the side of trying to prevent or alleviate it as much as possible—through keeping the patient physically comfortable, giving them positive mental and emotional experiences, and treating them with respect and dignity. Although clinicians and family members worked to minimize potential suffering, we found that clinicians worried more about the moral badness of suffering than family members, questioning whether it might be better to have no consciousness at all than minimal levels (as in the case of MCS). Family members were more inclined to view suffering as a necessary evil on the road to recovery of consciousness and/or a tradeoff that was "worth it." Some clinicians were particularly distressed by cases where family members did not visit their loved one and failed to "bear witness" to their suffering, even suggesting that in these cases loved ones should have less moral authority as surrogate decision-makers.

What I want to do in this paper is analyze some of the normative issues and claims emerging from these empirical findings. Although there are many rich issues to explore, the two that I am particularly interested in are: (1) the idea of non-experiential suffering, and (2) the moral importance of bearing witness to suffering when it occurs, especially in patients who are not conscious or only minimally consciously aware. These two issues are the focus of this paper. In Part 1 of the paper, I take up the idea of non-experiential suffering and argue that instances of non-experiential suffering of patients with brain death, UWS, and MCS are perhaps better described as harms or wrongs (e.g., dignity-based harms), but even then, these ideas face significant philosophical critique. In Part 2, I outline three reasons why bearing witness to patient suffering might be morally important: epistemic (to determine what is in the patient's interests), consequence-based judgments (assessing whose interests matter in such cases—balancing family, patient, and clinical team interests), and obligation-based views (ideas about the obligation or moral goodness to being present for and bearing witness to suffering when it occurs). I argue that witnessing patient suffering creates both epistemic advantages and disadvantages to determining what is in the patient's interests; that there may be rare cases where the clinical team's interests ought to be given considerable moral weight even compared to surrogate preferences; and that the moral importance or goodness (beyond epistemic) of presence in cases where patients are perceived to be suffering but are unaware is unclear.

Non-experiential suffering in patients with no or minimal consciousness

I think it is fair to say that the dominant view in bioethics and medicine is that it is something like a conceptual mistake to say that a patient with UWS or perhaps even an MCS is "suffering" since they cannot experience anything (or barely anything).[5] The thought is that suffering requires a subject, an *experience* of some negative or unpleasant mental or physical state.[6,7] As bioethics scholar and palliative care physician Tyler Tate writes, "Most modern theories of suffering consider suffering to be a species of negative subjective experience. A subjective experiential component of suffering is present, for example, in the theories of Eric Cassell, Jamie Mayerfeld, Michael Brady, Fredrik Svenaeus, David DeGrazia, Erica Salter, Laurel Copp, Steven Edwards, and James Davies, among others. For Cassell this experiential component is distress; for Mayerfeld negative feelings; for Brady undesired unpleasantness; for Svenaeus a negative phenomenological mood."[8]

In our empirical investigation, however, we found that families and clinicians who care for patients with UWS or MCS (who, by definition, experience nothing or very little) are very concerned about patient suffering. One way to make sense of this finding is to infer that the families and clinicians who we interviewed must have believed that these patients are experiencing more than we realize (i.e., are more conscious than we realize). However, there is a second way to make sense of this finding, and that is that *absent patients' ability to experience*, family members and clinicians think that there is an important way in which these patients suffer. In other words, we could see our results as a finding about a different *theoretical* view about the nature of suffering. While some of the kinds of suffering that the family members and clinicians were concerned about were essentially experiential in nature (e.g., pain, emotional distress, experienced frustration); others were not (e.g., nothingness, frustrated life goals, loss of dignity).

What sense, if any, are we to make of non-experiential suffering? Brent Kious, bioethics scholar, philosopher, and psychiatrist, has outlined a typology of theories of suffering which include sensation-based theories (the experience of something negatively valenced), flourishing-based theories (the frustration of some key aspect of our being), and values-based theories (the feeling that things we greatly value or care about are threatened)[9,10] While sensation-based theories and values-based theories have an experiential condition, flourishing-based theories do not necessarily. Tate has developed a flourishing-based (non-experiential, or objective) theory of suffering and has used it to analyze one way in which very young children, including ones with significant cognitive impairments, can be understood to suffer. In Tate's view, there are two dimensions to suffering: a subjective one and an objective one. Subjective (experiential) suffering involves negative affect, feeling, or mood, especially accompanied by a sense of loss of an important part of the self (e.g., one's relationships, roles, or narrative).[11] Objective (non-experiential) suffering, on the other hand, can be understood as "an objectively bad state of affairs," where a state of affairs refers to "the way in which something is placed, arranged, or constituted, especially in relation to other things." An objectively bad state of affairs is one where species-specific flourishing is absent.[12] For humans, according to Tate, species-specific flourishing involves the presence of conditions such as physical health, financial security, and social relationships.[13] Tate's view of flourishing allows for some further specificity as well—he says that a human *child's* flourishing might look somewhat different than a human adult's flourishing and that flourishing for each *particular* child might vary. Thus, Tate says, "In my view, child suffering is the absence of child flourishing. Child suffering is a state of affairs described in reference to an objective set of culturally embedded, species-specific conditions. To say that a child is suffering is to make an evaluative and judgmental claim about the child. It means that life is going poorly for her or him. However, because to say that some child is suffering is to make a claim about that particular child, pediatric suffering can be sensitive to the unique characteristics of each child. In pediatric medicine, for instance, each patient will have distinct medical needs and exist within a unique clinical and historical context. Hence what is necessary to prevent suffering and actualize flourishing will always differ from patient to patient."[14]

While I am not centrally concerned about child suffering in this paper, I have included this quote from Tate because it makes the theoretical point that non-experiential views of suffering may involve a mix of general assessments and patient-specific assessments. Interestingly, Tate applies his view to the case of a "brain-dead child," which is analogous to the case of a patient with UWS or MCS in the sense that they would all be cases of totally or mostly non-experiential suffering. He poses the question of whether such a child would be absent of flourishing, and as a result, suffering. In response, he writes "I think that the answer depends on how the situation is described. On the one hand, yes, the child is suffering. As Stan van Hooft observes, on a primitive level, suffering always connotes a 'departure from how things should be'. Within the claim that a brain-dead child is suffering is a normative evaluation that things are not as they should be for the child, and an implicit judgment that hospitals should not be keeping the molecules of brain-dead people in motion. This sentiment is expressed in hospital staff's frequent cries that a brain-dead child being maintained on a ventilator is suffering and worries that they are participating in something wrong. It feels like dead people ought to be allowed to die, and to keep them alive is to commit some kind of indecency, violence, or desecration."[15]

If we are to make sense of non-experiential suffering in cases where consciousness is absent (e.g., brain death, UWS) or mostly absent (e.g., MCS), it will need to involve something like a claim that the individual patient in front of us has a significant or complete absence of flourishing, that things are very far off from how or where they should be for that person, and perhaps as a result, that there is at least something wrong about putting them through such a state of affairs. All of this is irrespective of what they feel or experience about the state that they are in.

I must admit that I find the notion of non-experiential suffering to be a conceptual and linguistic stretch. Whereas Tate is motivated by the idea that the concept *reflects* ordinary language (e.g., we might say, "the forest is suffering drought") where we attribute suffering to entities that cannot experience pain or other negative physical, mental, or existential states; it seems to me that it betrays ordinary or important usage of the term. Most references to morally significant instances of suffering involve someone or something who *experiences* that suffering. Suffering is essentially phenomenological. Indeed, while we may want *some* way to capture the morally significant wrongs and harms that befall people beyond what they might be aware of or experience, there are ways to do this that do not involve attributions of suffering. For instance, there is a rich and large philosophical literature on "wrongs" and "harms" that do not necessarily involve negative experiential states (e.g., dignity wrongs or harms).[16,17,18,19] Perhaps the clinical team members and family members that we spoke with in our study are fundamentally worried about the "wrong" involved in keeping a person in a UWS or MCS alive, subject to various interventions and procedures, above and beyond what they experience. Moreover, even here, concepts like non-experiential "wrongs" or "harms" have faced significant challenges regarding how to make philosophical sense of them and their moral significance without a subject who experiences their negative effects.[20,21,22,23,24] What weight non-experiential harms or wrongs ought to have compared to experiential forms of suffering like pain or distress (mental, physical, existential) is an important question for those who are convinced of their existence and importance.

A second worry about non-experiential accounts of suffering is their susceptivity to smuggling in unsupported, hidden value judgments. As my co-authors and I have recently argued, the use of the concept of "suffering" in moral and clinical spaces is often vague—eliding between notions of physical pain, emotional distress, existential distress, goal-based considerations, value-based considerations, and flourishing-based considerations. This sort of pluralism is problematic because it can result in miscommunication and confusion if those involved in decision-making understand the concept differently. More worrisome is that clinicians could trade on the vagueness of suffering to unduly influence surrogate decision-making[25] and that vague claims about suffering can serve as a heuristic to smuggle in value judgments about the quality of life.[26,27] As Tate reminds us,[28] a recent analysis of 651 uses of the term "suffering" in pediatric articles over the past 10 years found significant variation in the use of the concept, but that suffering was used as a justification for a specific medical decision in over half of use cases and was three times more likely to be used to justify a life-ending decision than a life-extending one.[29] An example might be the case of Esther as Tate recalls, a baby with a type of lissencephaly who will never walk, talk, or feed herself, and will likely live for a few months or a couple of years.[30] Some might claim that Esther "suffers"—but in what way are her pain and distress controlled? Claims about non-experiential suffering are particularly vulnerable to misuse because the patient is not awake and aware enough to validate or refute them.

For these reasons, my colleagues and I have argued for greater specificity in appeals to patient suffering as a way of confronting these concerns, and proposed questions meant to guide discussion and specify the most ethically relevant elements of a patient's condition.[31] This is especially important for claims about non-experiential suffering.

The moral importance of bearing witness to the "suffering" of unconscious or minimally conscious patients

It is understandable that clinicians feel sadness and frustration when they care for patients with a disorder of consciousness whose family members do not regularly visit them.[32] We found, however, that some clinicians held the further belief that if family members do not visit and bear witness to the suffering of the patient, they ought to have less moral standing or moral authority to make decisions about that patient's life and care. Some even expressed the view that because in these cases, clinicians *do* witness patient suffering on a daily and long-term basis, they morally ought to have more authority or say in such cases than they typically do. This is an interesting normative claim, and there are several ways to make sense of it. Below, I outline and analyze three of them: epistemic, consequentialist, and obligation-based.

Epistemic importance and authority

One way to make sense of the moral importance of witnessing suffering and even the idea that those who witness a patient's suffering (e.g., the clinical team) ought to have more of a say or moral authority in terms of decision making than those who do not (e.g., a non-visiting family member/surrogate decision maker) is that those who see the suffering have important knowledge that those who do not witness the suffering do not have. Surrogate decision-makers have a moral obligation to make decisions that protect and promote the interests of the patient and to do that, they need knowledge about what the patient is going through and to communicate with the clinical team about how to contextualize that considering the patient's life and values. When clinicians express the view that those who *witness* the suffering of a patient in MCS/UWS deserve more moral authority regarding decisions about their care, they might be making an epistemic-based appeal.

What sort of special knowledge would come from witnessing a person's suffering? The short answer is knowledge about the burdens of care relative to the benefits. A non-present family member who sees only the benefits (the patient is still alive), does not appreciate the suffering-related burdens or dignitary harms that go along with treatments and interventions. With this missing knowledge, they cannot make decisions that protect and promote the patient's interests because the patient's overall interests are determined by the net balance of burdens and benefits.

There are two objections to this line of thinking. The first is that family member surrogate decision-makers could simply be informed about the suffering-related burdens without having to bear witness to them—and in this way, they could have all the knowledge and information that they need to make good decisions for the patient. The second objection is that regularly witnessing patient suffering (as the clinical team does) might cause distortions in judgment and decision-making about patient interests rather than improve them. Let us examine each argument in turn.

While it is true that a family member who does not directly witness patient suffering (perceived/actual, experiential/non-experiential) could have knowledge of it in a sense (the clinicians can inform them of it), there is a sense in which they do not really know it unless they see it. Those present to directly witness a patient's suffering have more contact points to appreciate its frequency and intensity, all of which are difficult to convey verbally to someone who has not witnessed it. Witnessing suffering can generate a profound and immediate understanding of it.

To see how important knowledge and insight can come from *seeing* or *experiencing* something, consider a thought experiment from philosopher of mind Frank Jackson. Jackson asks us to imagine a scientist, Mary, who knows everything there is to know about the science of color and vision. However, Mary has lived her life in a black-and-white room and has never seen color, until one day, she leaves the room and sees red for the first time (in an apple). Before seeing red, Mary could tell you a lot about red—she had a lot of knowledge about it. For example, she knew the physical and scientific properties of the relevant wavelengths and the various processes and functions that occur in the brain when those wavelengths are processed in the brain. However, when Mary sees the color red, she comes to know the "qualia" or the qualitative, emotional, subjective experience of seeing red—a kind of knowledge and appreciation that she did not have before when simply having certain dry, descriptive facts about red. I think there is something to be gleaned from the example in terms of the kind of deeper knowledge and appreciation that comes along with seeing or witnessing the suffering of another. When family members bear witness to the suffering of (or harm done to) a patient in UWS/MCS, they gain more of an understanding about what the patient might be experiencing (in the case of MCS) or of the overall situation that the patient is in, including all of the harms and misfortunes relative to its benefits (in UWS or MCS).

A similar example comes from the philosopher Sophie Grace Chappell's work on epiphanies. An epiphany, she writes, is a "sudden manifestation or perception of the essential nature or meaning of something" (p. 3), "a revealing scene or moment" (p. 4), that comes "not by argument or deduction, but by our directly and immediately seeing or otherwise experiencing it" (p. 4), it can often be a "moral illumination" (p. 6), and "demands a response" (p. 11). Chappell recounts how the philosopher Peter Singer came to see the wrongness of animal suffering inflicted by humans, not by philosophical argument, but by something like an epiphany in the face of witnessing it (p. 51). Chappell also quotes the journalist Owen Jones, who refers to a video clip of "a van taking pigs on their last journey to be slaughtered and one of them sticks their snout out the side to enjoy the sensation of wind on their face" and concludes "I'm never eating pork again." (p. 52).

While the above examples suggest the direct, immediate epistemic *benefits* of witnessing a patient's suffering, what about the objection that witnessing suffering can also create distortions in judgment—distortions present in the clinicians at the patient's bedside, but not in the family members who rarely (if ever) visit? The idea here is that witnessing the perceived suffering of a patient in UWS/MCS stirs emotions in the witness that might result in inaccurate projections about the experience or state of the patient. This experience and the emotions that accompany it can create epistemic liabilities such as one-sided judgments, focusing effects, bias, or vested interests.[33] There is some evidence of some of these effects in our empirical findings given that the patients are not conscious or are only minimally conscious, yet clinicians expressed significant concerns about patient spasticity, posturing, pain, and the meaninglessness of lying in bed for the rest of one's life.[34] Relatedly, a recent study on nurse's experiences bearing witness to patient suffering found that nurses reported a focused awareness of their *own* vulnerabilities and feelings of anger, helplessness, and guilt.[35] Finally, as mentioned earlier, several authors such as Tate, Salter, and Nelson et al. remind us of the dangers that judgments of suffering can be subjective, ill-defined, and smuggle in value judgments.[36,37,38] Thus, witnessing the experiential or non-experiential "suffering" of patients in an unconscious or minimally conscious state might be a "double-edged sword," producing both epistemic benefits and liabilities (smuggling in problematic value judgments)—like other instances of experiential knowledge.[39]

A consequentialist analysis

There is a second explanation and argument for the view that those who witness the suffering of a patient in UWS/MCS (e.g., the clinical team) ought to have more of a say or moral authority in terms of decision-making for the patient than those who do not witness it (e.g., a non-visiting family member/surrogate decision maker). This explanation has nothing to do with knowing more or better about what is not in the patient's best interests. Rather, the justification is focused on the clinical team's interests. The argument goes something like this: seeing and believing that a patient is suffering (even potentially, intermittently, or non-experientially) without any likely improvement in their condition is distressing for clinicians and the situation (assuming the diagnosis and prognosis are correct) is non-beneficial to the patient. If the family is not present to have a real stake in the matter, then from a consequentialist view, their interests and preferences matter little, and the interests of the clinical team ought to have considerable (even most) moral weight. Thus, the clinical team ought to have significant moral authority in determining the decisions that are made in the case at hand.

There is certainly something to be said for this argument, but there are several assumptions built into the argument that need to be true for it to succeed. One is that the patient herself/himself does not stand to benefit from further intervention or treatment—in other words, that she will certainly not improve. Only then, is it clear that her suffering does not come along with any benefit to her. This is hard to say with certainty in the case of UWS/MCS, especially given documented errors in the diagnosis of a patient as having irreversible UWS when the patient was really in, or came to be in, an MCS. Second, it must also be true that the family's non-presence means that they do not really have a stake in the matter and cannot have their interests significantly thwarted or advanced by decisions made about their loved one's interests and care. This is questionable since we can imagine that family members have an interest in having their loved one be alive and this interest remains regardless of how present they are for the life of that loved one. For example, many people move far away from their family and friends and may even lose touch with them, but the fact that their loved ones remain alive matters to them and how their life goes. Family members of patients in a UWS/MCS can have an ongoing interest in their loved one's existence, which they can learn about through calls and updates from the medical team without necessarily being present at the bedside regularly. Third, for the consequentialist argument to succeed, it must be the case that there are no alternative ways for the clinical team to deal with or mitigate the negative consequences of the "secondary suffering" (from watching the suffering of the patient). This is also doubtful. In rare cases, however, it might be the case that all assumptions are granted (the patient truly does not stand to benefit, neither does the family, and there is no way for the clinical team to mitigate their secondary suffering due to watching the patient suffering as they perceive it). In these rare cases, the interests of the clinical team ought to have considerable (even most) moral weight. Thus, the clinical team ought to have significant moral authority in determining the decisions that are made in the case at hand.

Obligations to bear witness

There is a final way to make sense of the moral importance of witnessing suffering and the frustration with family members who are not present with patients who are in a UWS and MCS and perceived to be suffering in some way. Perhaps family members simply have an obligation to see this suffering. That is, part of what it *is* to be a family member, a surrogate decision maker, and to *care* for and about someone is to be present in their suffering. There is a sort of *moral standing* that comes from watching someone you care for or about suffer. In the case of non-visiting family members but daily present clinicians, clinicians *have* this moral standing, more so than the family members (so the clinicians might have thought). This moral standing or moral authority might translate into an entitlement to have more of a say about what happens—i.e., into a sort of decisional authority, so the team may think.

This normative picture of obligations to stand by a suffering patient (or loved one) regardless of their level of awareness (and beyond implications for decision-making), is interesting. The source of such an obligation would be relational (e.g., as a family member, friend, physician) and it would arise from caring relationships and the roles, duties, and obligations that are part of them. As a result of carrying out this obligation, the carer gains a sort of moral standing, authority, or entitlement that is not granted to those who do not live up to this obligation.

As a psychological explanation for *why* some people (e.g., the clinicians we interviewed) feel that it is important to bear witness to the suffering of a patient who is unaware, this explanation is persuasive. However, as a normative justification for the importance of making (or wanting) a family member to see the suffering of their loved one (the patient), it is less convincing. Standing with and by a [conscious] person who is suffering because your presence helps them psychologically or physically does indeed seem like something we would expect (we can call it an obligation) from a caring relationship. However, in cases of unawareness (UWS or MCS-), the witnessing does not do any good for the patient. That is not to say that family members cannot still care for and about the patient in various ways—it is just not clear that watching them suffer for the sake of it is one of those ways. Why would we want family members to watch their loved one experience what we perceive as suffering if it does not improve or change decision-making and nothing can be done by family members to relieve or alleviate the suffering? It is not clear what the obligation, virtue, or good in witnessing this is.

Some might respond that the family has an obligation to the clinical team to join them in the tough project of witnessing the suffering of the patient. The clinicians that we interviewed may have thought that so long as they must do the moral work of witnessing suffering and caring for a suffering patient day in and day out then their family members ought to be alongside them to also do this moral work. In response to this view, while it would be nice for the family members to express solidarity, support, and appreciation for the clinical team in this way, it is hardly a moral obligation that they have.

Conclusion

In closing, I offer a summary of the main claims that I have argued for in this paper. First, concerns about the non-experiential suffering of patients in UWS and MCS are expressed by clinicians who care for these patients, but claims of non-experiential suffering are conceptually dubious. Concerns about the non-experiential suffering of patients with brain death, UWS, and MCS are perhaps better described as concerns about harms or wrongs (e.g., dignity-based harms), but even then, face significant philosophical critique. Moreover, attributions of non-experiential suffering carry a significant risk of problematic use including the import of unsupported hidden value judgments. Second, the moral obligation or goodness of family members bearing witness to patient suffering (beyond epistemic-based gains for decision-making) in cases where non-conscious patients are unaware is unclear. Bearing witness to these patients' non-experiential (and experiential) suffering seems over-valued or mis-valued in many cases. These two major claims may be tied together in the sense that the conceptually dubious nature of non-experiential suffering in cases of UWS/MCS may undermine traditional moral arguments for the importance of family members being regularly present to bear witness to the experience of actual suffering of conscious loved ones.

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Notes

1. Peterson A, Kostick K, O'Brien K, Blumenthal-Barby JS. Seeing minds in disorders of consciousness patients. *Brain Injury* 2020;**34**(3):390–8.
2. Kostick K, Kothari S, O'Brien K, Halm A, Blumenthal-Barby JS. Conceptualizations of consciousness and continuation of care among family members and health professionals caring for patients in a minimally conscious state. *Disability and Rehabilitation* 2021;**43**(16):2285–94.
3. See note 1, Peterson, Kostick, O'Brien, Blumenthal-Barby 2020:390–8.
4. See note 2, Kostick, Kothari, O'Brien, Halm, Blumenthal-Barby 2021:2285–94.
5. Here I mean to set aside cases where a person is incorrectly diagnosed as UWS but is aware—there is a vast literature on the frequency of diagnostic mistakes, whereby clinicians diagnose a patient as having no consciousness, but the patient has some (as in the case of MCS), or cases where clinicians underestimate the level or frequency of consciousness. There is no *conceptual* mistake in these cases, simply a diagnostic mistake. Here, I mean to focus on cases where the diagnosis is *correct*.
6. Some would go even further and say that the ability to experience negative and positive affective states ("sentience") is necessary to even be deserving of moral consideration—to be a "welfare subject" with moral status. For example, David DeGrazia holds this view. According to him, when a being has "moral status," its interests matter for its own sake, and in ways that create moral obligations about how we (moral agents) ought to treat that being (DeGrazia 2021, 40). "Sentience" is necessary for a being to have interests or to be a welfare subject and sentience involves something beyond mere consciousness—it involves the ability to have affectively valanced experiences like pleasure, pain, or frustration. Rocks are not welfare subjects because they are not sentient; "most" humans are. See DeGrazia D. An interest-based model of moral status. In: Clarke S, Zohny H, Savulescu J, eds. *Rethinking Moral Status*. Oxford: Oxford University Press; 2021.
7. DeGrazia D. An interest-based model of moral status. In Clarke S, Zohny H, Savulescu J, eds. *Rethinking Moral Status*. Oxford: Oxford University Press;2021.
8. Tate T. What we talk about when we talk about pediatric suffering. *Theoretical Medicine Bioethics* 2020;**41**(4):143–63. p. 147.
9. My colleagues and I have built on this typology to further specify various domains relevant for assessing "suffering"-related states in patient care, including physical pain, emotional distress, existential distress, goal-based considerations, value-based considerations, and flourishing-based considerations. See Nelson RH., Kious BM, Largent E, Moore B, Blumenthal-Barby J. Is suffering a useless concept? *The American Journal of Bioethics*, Published Online First 6 June 2024, 1–8.
10. Kious BM. Three kinds of suffering and their relative moral significance. *Bioethics* 2022;**36**(6):621–7.
11. See note 6, Tate 2020:153
12. Tate T. From sickness unto life: How community and belonging can bolster wellbeing during serious illness and end-of-life care. In: Phillips T, Araújo N, Jones TW, Taylor J, eds. *Narratives of Wellbeing*. Cham: Palgrave Macmillan; 2024: 127–141.
13. See note 9, Tate 2024:129.
14. See note 6, Tate T. 2020:158.
15. See note 6, Tate 2020:160.
16. Feinberg J. *Harm to Others*. Oxford: Oxford University Press; 1984.
17. Nagel T. Death. Noûs 1970;**4**(1):73–80.
18. Fischer JM. Death, badness, and the impossibility of experience. *The Journal of Ethics* 1997;**1**(4):341–53.
19. Corns J. Suffering as significantly disrupted agency. *Philosophy and Phenomenological Research* 2022;**105**(3):706–29.
20. This is different from saying that a person's *behavior* was wrong. For example, if I hit a mannequin, thinking it is a person, we might say that no "wrong" or harm to the mannequin took place, but I still *did* something wrong—e.g., I intended to harm another person.

21. Rosenbaum SE. How to be dead and not care: a defense of Epicurus. *American Philosophical Quarterly* 1986;**23**(2):217–25.

22. Brady MS. *Suffering and Virtue*. New York: Oxford University Press; 2018.

23. Brady MS. Suffering as experiential–a response to Jennifer Corns. *Philosophy and Phenomenological Research* 2023;**107**(1):24–30.

24. Silverstein HS. The evil of death revisited. *Midwest Studies in Philosophy* 2000;**24**(1):116–34.

25. Nelson RH, Kious B, Largent E, Moore B, Blumenthal-Barby J. Is suffering a useless concept? *The American Journal of Bioethics*, Published Online First 6 June 2024, 1–8.

26. Salter EK. The new futility? The rhetoric and role of "suffering" in pediatric decision-making. *Nursing Ethics* 2020;**27**(1):16–27.

27. Tate T. Pediatric Suffering and the Burden of Proof. *Pediatrics* 2020;**146**(Suppl 1):S70–S74.

28. See note 23, Tate 2020:S70–S74.

29. Friedrich AB, Dempsey KM, Salter EK. The use of suffering in pediatric bioethics and clinical literature: a qualitative content analysis. *Pediatric Ethicscope* 2020;**27**(1):16–27.

30. See note 6, Tate 2020:151.

31. See note 21, Nelson, Kious, Largent, Moore, Blumenthal-Barby 2024:1–8.

32. There is a distinction to be drawn between willfully avoidant and circumstantially avoidant family members (e.g., those who live far away or who have other accessibility issues that make visiting impossible or difficult). Most of the frustration was directed towards family members who were willfully avoidant, although cases certainly exist on a spectrum (e.g., how difficult is visiting).

33. Nelson RH, Moore B, Lynch HF, Waggoner MR, Blumenthal-Barby J. Bioethics and the moral authority of experience. *The American Journal of Bioethics* 2022:**23**(1):12–24.

34. See note 28, Nelson, Moore, Lynch, Waggoner, Blumenthal-Barby 2022:12–24.

35. Eifried S. Bearing witness to suffering: the lived experience of nursing students. *Journal of Nursing Education* 2003;**42**(2):59–67.

36. See note 23, Tate 2020:S70–S74.

37. See note 22, Salter 2020:16–27.

38. See note 21, Nelson, Kious, Largent, Moore, Blumenthal-Barby 2024:1–8.

39. See note 28, Nelson, Moore, Lynch, Waggoner, Blumenthal-Barby 2022:12–24.

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