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#### TARGET ARTICLE



# Is Suffering a Useless Concept?

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#### **ABSTRACT**

"Suffering" is a central concept within bioethics and often a crucial consideration in medical decision making. As used in practice, however, the concept risks being uninformative, ambiguous, or even misleading. In this paper, we consider a series of cases in which "suffering" is invoked and analyze them in light of prominent theories of suffering. We then outline ethical hazards that arise as a result of imprecise usage of the concept and offer practical recommendations for avoiding them. Appeals to suffering are often getting at something ethically important. But this is where the work of ethics begins, not where it ends.

#### **KEYWORDS**

Suffering; clinical ethics; medical decision making; philosophy; values; flourishing

#### **INTRODUCTION**

A foundational question in medical ethics concerns the goals of medicine: toward which ends ought the means of medicine be directed? Answers to this question help to define medicine as a profession and set standards for the conduct of its practitioners. By most accounts, physicians are tasked with promoting health and treating illness. Additionally, consensus holds that physicians have obligations to address patients' pain and suffering. The American Medical Association's Code of Medical Ethics, for instance, reflects these twin aims: "the social commitment of the physician is to sustain life and relieve suffering" (Opinion 2.20). Whether the relief of suffering is a primary aim, secondary aim, or one aim among many remains a point of contention. Yet, there exists widespread agreement that physicians have (at a minimum) a pro tanto obligation to address (at least certain forms of) suffering.

Beyond shaping medical practice, suffering often plays an important role in circumscribing the options made available to patients and surrogate decision makers. For example, in some jurisdictions outside of the US, patients wishing to pursue medical aid in dying (MAiD) must be experiencing "unbearable" or "intolerable" suffering to be eligible (Dutch Termination of Life on Request and Assisted Suicide Act 2001; McLachlin et al. 2015). Within the US, Hawaii's MAiD law makes reference to "the right to choose to avoid an unnecessarily prolonged life of pain and suffering"

(Hawaii Our Care, Our Choice Act 2018). Suffering takes on additional ethical and legal weight when it comes to making decisions for incapacitated patients. Ethically, surrogate decision makers are guided by substituted judgment but also the best-interest standard, which requires them to consider, among other things, "the pain and suffering associated with ... intervention" (AMA). Legally, surrogates' authority may be limited if they act in ways that colorably contribute to patient suffering, such as by refusing recommended pain medication (see, for example, Massachusetts' Health Care Proxy Law Chapter 201D, Section 13 2016).

Given its significance for clinicians, patients, and surrogates, suffering is correctly regarded as a central concept for medical ethics and medical decision making. Unfortunately, the ways in which suffering tends to be invoked in practice risk raising more questions than answers. Friedrich et al. (2019) reviewed pediatric bioethics and clinical literature and found that nearly three-quarters of the appeals to suffering they evaluated "were ambiguous about the experience of suffering." Such ambiguity is not to be taken lightly in this context, since suffering "weigh[s] heavily as a burden in a benefit-burden analysis," and is commonly used to justify withholding or withdrawing life-sustaining treatment (Friedrich et al. 2019). Tate (2020) likewise warns of "growing concerns the label of suffering is used to justify end-of-life decision-making and mask quality-of-life determinations."

Responding to these concerns, Salter (2020) argues that discussions of suffering "must be accompanied by a more explicit and specific definition" and an account of "the harms that emerge from that definition (perhaps pain, agitation, fear, loneliness, anxiety, among others)." Alternatively, Kious (2022) suggests that certain conceptions of suffering take precedence over others in particular contexts. Yet another possibility is to do away with talk of suffering altogether.

In this paper, we build on the ongoing discussion by considering a series of cases in which "suffering" is invoked and analyzing them in light of prominent philosophical and bioethical theories of suffering. We outline ethical concerns that arise as a result of imprecise use of "suffering" and offer practical recommendations based upon this analysis to help clinicians, patients, and surrogates avoid the hazards associated with the concept.

#### WHAT IS IT TO SUFFER?

The ambiguity surrounding "suffering" in the context of medical decision making mirrors disagreement about the concept within the philosophical and bioethical literature. Kious (2022) helpfully sorts theories of suffering into three categories: sensation-based theories, flourishing-based theories, and value-based theories.

In sensation-based theories, we see a requirement that the sufferer be aware, in at least some basic sense, that they are experiencing something and that they ascribe a negative valence to the experience. For instance, Mayerfeld (1999) offers a sensation-based theory according to which "to suffer is to feel bad." More precisely, he states, "suffering is the antithesis of happiness; if a disagreeable feeling is worse than unconsciousness, it is suffering." Brady (2018) offers a similar account: "Suffering is a negative affective experience, and one that we desire to cease (in other words: unpleasantness that we mind, to mind some state is to have an occurrent desire that it not be occurring)."

Flourishing-based theories, by contrast, have no such awareness requirement. Van Hooft (1998), for example, holds that suffering is to be understood as "the frustration of the tendency towards fulfillment of some aspect of our being." Adopting an Aristotelian view, van Hooft distinguishes between biological, appetitive, deliberative, and contemplative aspects of being, each with associated functions. Organisms have typical characteristics that can be understood with respect to achieving these functions. For example, cardiac anatomy and physiology are necessary to pump blood in a way that allows life and other activities. In this sense, a person who has a disease, where this

usually involves some decrement in the function of an organ or a physiological process, literally suffers with that disease. Tate & Pearlman (2019) accept something like van Hooft's view, as they believe it is possible for a person to suffer simply because her life is not going well objectively, even if she believes that her life is going well or likes it the way it is. For instance, a person who is addicted to drugs and who likes being addicted would, if addiction is incompatible with flourishing, still be suffering in this sense.

One worry related to flourishing-based accounts of suffering is that they appear to be in tension with pluralistic ideas about human good. If the standards for flourishing are universal, then flourishing as a concept leaves little room for human variation, such as that embodied by people with disabilities, for example. Mindful of this concern, Tate (2020, 2022) offers a revised account, in which he argues that an individual suffers if she fails to achieve her own flourishing, where this may be relative to her own characteristics. This means that a child with a serious cognitive disorder does not necessarily suffer as a result of the cognitive disorder, but could suffer if she fails to achieve the best state possible for her given that disorder.

Kious refers to flourishing-based theories as "objective," since they hold that "suffering occurs independent of any feeling, distress, or subjective evaluation of one's circumstances, and depends only on whether one's life is going well or poorly in some objective sense-thus, on whether one is (objectively) flourishing." On any flourishing-based view, one could suffer without experiencing any unpleasant sensation, without any distress, and without being aware that one is suffering. Indeed, one could suffer in this sense without being aware of anything at all.

Value-based theories can be seen as a middle ground between views that hold that suffering lies in some brute feeling and those that hold that suffering need not involve any feeling whatsoever. The most prominent example of such a view is Cassell's account (1992, 1999, 2004), according to which suffering is a state of severe distress associated with threats to the integrity of a person. Kious has noted that Cassell's notion of personal integrity is somewhat opaque and suggests that it should be understood as dependent on whether a person feels that things she values or cares about are threatened. Cassell gives the example of a woman who loses her hair during chemotherapy for cancer; she suffers, he thinks, because she perceives the loss of her hair as a threat to her personal integrity. But her personal integrity in this case can simply be understood as a question of what she cares about: if she cares about her hair, losing it makes her

suffer; if she doesn't care about it, then she probably won't suffer due to its loss.

The range of views defended by theorists of suffering means that, for any patient described as "suffering," there is likely some account on which the description holds. So the problem is not that "suffering" is being used in senses that are incoherent or implausible. Nor is it one of pluralism per se—we find it plausible that suffering is best understood as a concept comprising a range of states and experiences. Instead, the problem is that disagreement on the conceptual level-and vagueness in colloquial, clinical, and policy usage-invites misunderstanding and equivocation into discussions that quite literally involve life and death. At the same time, diverging theoretical accounts help identify an array of considerations relevant for both clinicians and policy makers.

#### WHO SUFFERS?

With these general points in mind, let us turn to the cases, which are composites of real cases we have encountered, with some details changed to respect patient privacy:

Case 1: Elaine is a 46-year-old previously healthy female diagnosed with unresponsive wakefulness syndrome (UWS, also known as a "vegetative state") following a traumatic brain injury that resulted from a motor vehicle collision. After two weeks in the Neuro ICU, Elaine receives a gastrostomy and is discharged to a long-term acute care hospital, where she remains for the next year. During this time, she exhibits neither signs of neurological recovery nor signs of prolonged pain or distress. Elaine's physicians conclude that significant neurological recovery is extremely unlikely and decide to discuss goals of care with her sister (and legally authorized surrogate decision maker) Gail, who until now has been relatively optimistic about Elaine's prognosis. The physicians inform Gail that Elaine's UWS is likely permanent and raise the possibility of withholding further artificial nutrition and hydration "so as not to prolong her suffering."

Given that individuals with UWS have apparently lost awareness of themselves and their external environment, Elaine can be seen as suffering only according to flourishing-based theories. If we assume that her diagnosis of UWS is accurate (and she is not, for example, in a minimally conscious state), then she would not be suffering according to sensation-based theories, since we have no reason to think that Elaine is sensing much of anything. Likewise, she does not seem to be suffering according to value-based theories, since it would be implausible to suppose that Elaine presently has self-awareness or values in the relevant sense to suffer their loss. Even if we suppose that Elaine's pre-UWS values remain relevant, she is presently unaware that these values are threatened and therefore cannot be distressed by the threat.1

Interestingly, MAiD statutes with a suffering criterion diverge when it comes to the role of consciousness. In the Netherlands, for example, "unbearable suffering without prospect of improvement" (Dutch Termination of Life on Request and Assisted Suicide Act 2001) that is "palpable to the physician" (Regional Euthanasia Review Committees) is a prerequisite for MAiD. This criterion is taken to exclude those diagnosed with UWS on the grounds that the presence and nature of their suffering cannot be determined (Marijnissen et al. 2022, 3). The Belgian MAiD statute likewise requires that a patient's condition involve "constant and unbearable physical or mental suffering that can not be alleviated" (Belgian Act on Euthanasia 2002). In contrast with Dutch practice, however, patients diagnosed with irreversible coma or vegetative state are eligible for MAiD (Marijnissen et al. 2022, 3), suggesting a broader understanding of "suffering." This means that Elaine could not access MAiD under Dutch law because she does not meet the Dutch definition of "suffering," whereas she could under Belgian law because she does meet the Belgian definition. Insofar as understandings of what it means "to suffer" may be culture-bound and countries' laws reflect and protect reasonable differences in values, differential access to MAiD is not inherently concerning. But the fact that these two laws appeal to unbearable suffering yet would yield markedly different outcomes when applied to similarly situated patients underscores both ambiguity in how the term suffering is understood as well as the normative importance of definitional clarity.

Contrast Elaine's situation with George's:

Case 2: George was diagnosed prenatally with trisomy 13 (or Patau syndrome) and is born prematurely at 30 weeks gestation. After birth, he is transferred to the Neonatal ICU, where physicians inform his parents that he has a ventricular septal defect (VSD), a patent ductus arteriosus (PDA), and myelomeningocele (or open spina bifida). Treating these conditions will require a series of surgeries, including a myelomeningocele repair within the first days of life and open chest repair of the cardiac defects within the first

<sup>&</sup>lt;sup>1</sup>One could propose a counterfactual values-based theory, according to which one suffers when it is the case that one would be distressed by the threat to their values if they were aware. We will put this aside.

months. Although George is unlikely to live past his first year even with aggressive treatment, the clinical care team is willing to perform these operations. The team members worry amongst themselves, however, about the significant burdens associated with this course of treatment, particularly the pain. Before proceeding, they decide to consult palliative care. The palliative care physician sits down with George's parents to discuss the possibility of forgoing surgical intervention. During their discussion, the physician recommends comfort-focused care, noting that "aggressive treatment would cause George even more suffering."

How do the various accounts of suffering apply in this case? It seems that George would suffer according to sensation-based theories, which hold that unpleasant feelings like pain are themselves suffering, whatever else one might think or feel about having them. It also seems that George would suffer according to flourishing-based theories of suffering, though this is not as straightforward. Since George's VSD and PDA mean his heart is functioning less than effectively, surgical intervention might serve to lessen his objective suffering by improving his heart's function (as compared to no intervention). Yet, it is also conceivable that the surgical interventions would serve to increase George's total amount of flourishing-based suffering, if they cause him to live longer—and to fail to flourish for a longer period—though this depends on whether flourishing is something that can be aggregated over time.

Another issue this case raises is the possibility that interventions aimed at alleviating one kind of suffering may actually increase another, in which case there remains a question about which is to be prioritized. For instance, it might be that interventions that reduce George's flourishing-based suffering by treating his illness increase his sensation-based suffering, both acutely and over time. How these different kinds of suffering are to be balanced against each other is likely to be sensitive to context and the particularities of the kinds of suffering in question. If an intervention can greatly reduce flourishing-based suffering while only slightly increasing aggregate sensation-based suffering, that might argue in favor of the intervention; but a slight increase in flourishing at the expense of great sensation-based suffering is less likely to be justified. Moreover, some instances of suffering of a given kind may carry greater disvalue than otherspresumably, for instance, some aspects of flourishing are more important than others. All of this aside, however, it seems clear that George is not suffering according to value-based theories, since it would be

implausible to suppose that, as an infant with severe intellectual disability, he has self-awareness or values in the relevant sense, and values-based suffering refers to a person experiencing distress related to threats to things that the person cares about.<sup>2</sup>

Now consider Jerry:

Case 3: Jerry is a 59-year-old man with a past medical history of obesity and type-II diabetes who presents to the emergency department with chest pain and shortness of breath. After a cardiac workup, he is determined to have experienced a non-ST-elevated myocardial infarction (NSTEMI) and ongoing decreased left ventricular function. He is placed on an intra-aortic balloon pump (IABP) with the hope that it will serve as a short-term bridge to recovery. His physicians have determined that Jerry lacks the capacity to make complex medical decisions at this time. Even so, Jerry is often awake and alert; during these periods, he often states that he feels "trapped in this place" and expresses a desire to "get back to [his] old life." When asked whether he is experiencing physical pain, Jerry most often simply shakes his head "no." After three weeks on the IABP, Jerry's heart has shown no signs of recovery. Furthermore, he has been determined not to be a transplant candidate due to his comorbidities. Given his poor prognosis and lack of treatment options, the clinical care team holds a family meeting to discuss goals of care with Jerry's spouse and two adult children. At the meeting, the intensivist states that Jerry is "on a bridge to nowhere" and recommends removal of the IABP so that "he doesn't continue to suffer in the ICU."

Jerry is plausibly suffering according to flourishingbased theories, since his condition is frustrating the fulfillment of at least some of his aspects of being. By contrast, while life in the ICU often involves discomforts, Jerry does not indicate that he is suffering according to sensation-based theories. If the intensivist recommends removal of the IABP so that Jerry "doesn't continue to suffer in the ICU" and his family takes the physician's use of the term "suffer" to mean sensation-based suffering, then they are being asked to make a decision on the basis of a fundamental misunderstanding of the nature of his condition. They might wonder why, for example, the care team doesn't simply offer more pain medication. This illustrates how the nature of a patient's suffering will affect the alternatives that need to be presented to and discussed with the family as part of the informed consent (or informed refusal) process.

<sup>&</sup>lt;sup>2</sup>Moore (2023) notes other unique considerations in the context of end-of-life care for pediatric patients.

Although Jerry has been determined to have impaired decisional capacity, his frequent alertness and comment that he "want[s] to get back to [his] old life" suggest that values-based suffering is relevant to this case. The important question for Jerry, then, is whether continued treatment is consistent with his values and goals, and he seems to indicate it is not.

Finally, consider Kramer:

Case 4: Kramer is a 79-year-old man with moderate-stage dementia caused by Alzheimer's disease. Before retirement, he worked as a philosophy professor and had a distinguished career writing about the importance of autonomy. He now lives in a long-term care facility, where the staff helps him with tasks such as bathing, grooming, and dressing. He intermittently recognizes and is happy to see the friends and family members who visit him. Prior to the onset of his own cognitive impairment, but after watching his mother die of Alzheimer's disease, Kramer indicated that he would never want to live "that way." However, it now seems to Kramer's surrogate decision maker, Newman, that Kramer is actually quite content in his current situation. Kramer spends most of his days in the long-term care facility's lounge; he particularly enjoys when the staff play music and sometimes sings along with the radio. Recently, Kramer developed pneumonia, which has required hospitalization but could be easily and painlessly treated. Newman is conflicted about whether to consent to the provision of antibiotics, feeling stuck between knowing that "old" Kramer would have wanted to hasten death by forgoing care and realizing that "now" Kramer enjoys his life as it is. In advising Newman, the attending physician suggests that "forgoing antibiotics will help Kramer avoid greater suffering."

Kramer would not seem to be suffering according to sensation-based theories: He is well cared for, enjoys some simple pleasures, and is not exhibiting any signs of pain or distress. He may be suffering according to flourishing-based theories, since his functioning related to the deliberative and contemplative aspects of his being are substantially impaired, particularly when compared to his own baseline abilities.

Where Kramer's case gets most interesting, though, is in considering whether he is suffering according to value-based theories. On the one hand, we might think that his diminished autonomy and impaired intellectual functioning are incompatible with the values that seemed to shape the life projects he pursued prior to the onset of Alzheimer's disease. Another possibility, however, is to point out that Kramer is able to experience things he values in his current condition, such as

listening to the radio and being visited by loved ones. If we consider his current set of values to be at least as important as his previously held values, then there is good reason to suppose that he is not suffering according to a value-based theory of suffering. When thinking about value-based theories for patients whose conditions result in a significant shift in values, it is important to ask which values take precedence.

Box 1. Suffering experienced by the patients in our four cases.

	Flourishing- based	Sensation- based	Value- based
Elaine - Woman with unresponsive wakefulness syndrome	Х		
George - Infant with Patau syndrome	X	x	
Jerry - Man with heart failure	Х		x (present)
Kramer - Man with dementia	Х		x (past)

#### SUFFERING AND MEDICAL DECISION MAKING

In Box 1, we summarize the kinds of suffering experienced by Elaine, George, Jerry, and Kramer, respectively. These cases illustrate how a wide range of patients, in dramatically different circumstances, can plausibly be described as suffering, according to one account or another. But if an adult who is awake and alert in the ICU (see Jerry), an infant who is facing a series of painful interventions (see George), someone in an unconscious wakeful state (see Elaine), and a contented elderly man with dementia (see Kramer) may all be described as "suffering," then "suffering" does not appear to be very descriptively useful at all, at least not without a lot of additional explanation. As noted, use of the term "suffering" risks miscommunication, equivocation, and confusion. More importantly, ambiguity surrounding the concept can give rise to ethical concerns when there are appeals to patient suffering in the context of medical decision making.

There are several reasons for this. First, lack of clarity about what it means for a patient to suffer can threaten good decision making. If a physician informs a patient she is likely to suffer as a result of some intervention, or tells a surrogate that a patient is currently suffering, any ambiguity surrounding "suffering" could influence decisions made on the basis of that information. Such situations may arise as a result of simple misunderstanding, rather than intentional obfuscation. This, we suspect based upon our collective clinical experience, is a common problem: physicians sense that continued aggressive treatment would be non-beneficial, burdensome, or

otherwise inappropriate and attempt to communicate this to surrogates by using the term "suffering," without thinking carefully about what the term means to them or what it might mean to the patient or family. Appeals to suffering, then, may be a kind of bargaining language through which physicians attempt to exercise their expertise and authority. Where once, paternalism meant clinicians did not need to bargain with their patients—it was presumed that doctors knew best—the patient rights and autonomy movements have led to physicians playing a more ambiguous role in decision making. While it is beyond the scope of this paper, we think that the goal of understanding why the language of suffering now does so much clinical work could be advanced by comparing trends in appeals to suffering (including the context and frequency of the use of "suffering" language in conversations with patients and families) with historical shifts in approaches to decision-making, e.g. paternalism versus patient-asexpert versus shared decision-making models, and related trends in attitudes toward medical authority and expertise.

Second is that the use of "suffering" might mask value judgments that may be influenced by bias, conscious or not. Historically, bias shows up in claims that some social groups have a lesser capacity for suffering, with implications for practices involving anesthesia and pain management, for example (Pernick 1985; Hoffman et al. 2016). Biased value judgments are also well-documented to influence attitudes about the relationship between disability and quality of life (Campbell and Stramondo 2017). Whether "suffering" is more commonly invoked to justify modifying goals of care for patients with disabilities is ultimately an empirical question. But, given what we know about clinician attitudes toward patients with disabilities (Lagu et al. 2022), it seems unlikely that there is no connection between biased quality of life judgments and the way goals of care discussions are framed.

Third, and perhaps most concerningly, is the possibility that one could intentionally trade on the ambiguity of "suffering" to influence decision makers inappropriately. For example, imagine a physician invokes one sense of suffering (e.g. objective/ flourishing-based) during a goals of care discussion, knowing that the decision maker is likely to attribute an alternative meaning to the term (e.g. sensation-based) in their interpretation of the physician's message. In such a case, the physician is employing "nonargumentative influence" to nudge the patient or family (Blumenthal-Barby and Burroughs 2012). The intentional use of an ambiguous concept in order to influence decision making can be ethically problematic if it nudges a family or patient toward a decision that goes against their values and interests, or if they would feel in retrospect that they had not made autonomous choice (Blumenthal-Barby Burroughs 2012; Blumenthal-Barby 2021).

Appeals to suffering, therefore, can be unhelpful and, sometimes, harmful or misleading. How should one proceed in light of these concerns? Following Salter (2020), we suggest that clinicians ought to emphasize the particular features of a patient's condition that are most relevant for decision making, taking a pluralistic approach to suffering that draws upon the various philosophical accounts reviewed above. By making explicit the features of suffering outlined in theoretical accounts, we hope to assist clinicians and decision makers in identifying the features of a case most relevant in light of patient values and professional obligations. For example: Elaine's brain injury is such that she is very unlikely ever to appreciate the benefits of continued treatment; Jerry will need to live the rest of his life in the ICU; Surgery would improve the functioning of George's heart, but would cause him pain without addressing his other medical issues; Kramer is unlikely ever to engage in the activities that he valued most prior to his illness.

There remains a question about whether more precise language about a patient's condition should supplement or supplant appeals to suffering. Perhaps there is no problem continuing to use "suffering" in its broadest sense, so long as steps are taken to minimize the possibility of misunderstanding and miscommunication. Or perhaps "suffering" should be used to describe patients who are suffering by all or most accounts, or cases in which all parties agree that a patient is suffering. Or perhaps we should do away with talk of "suffering" altogether. Our view is that abolishing appeals to suffering in the clinical context is neither feasible nor advisable: not feasible because the language is simply too entrenched in the clinical lexicon (compare relatively recent attempts to do away with "futility"); and not advisable because "suffering" often serves as an indication of something ethically important.

With this in mind, we conclude by proposing five potential domains of suffering-drawn from the theories of considered above-along with questions a clinician might use to explore how well a patient is faring with respect to each domain (see Box 2).

Box 2. Ethically relevant considerations.

Domain	Clarifying questions
Physical Pain	<ul> <li>Does the patient currently have the capacity to experience physical pain? (requires current basic sentience</li> <li>Do we have reason to believe the patient is in pain?</li> <li>How severe is the pain?</li> <li>How long is it likely to last?</li> </ul>
Emotional Distress	<ul> <li>Is there anything (else) we can do to manage that pain?</li> <li>Does the patient currently have the capacity to experience emotional distress (e.g. experiencing anxiety, sadness, agitation, loneliness, confusion)? (requires current basic cognition)</li> <li>Do we have reason to believe the patient is experiencing such distress?</li> <li>How severe is the distress?</li> </ul>
	<ul><li>How long is it likely to last?</li><li>Is there anything (else) we can do to manage the distress?</li></ul>
Existential Distress	<ul> <li>Does the patient currently have the capacity to experience existential distress (e.g. dread, alienation, mear inglessness, uncertainty, dread, frustration)? (requires current complex cognition)</li> <li>Do we have reason to believe the patient is experiencing such distress?</li> <li>How severe is the distress?</li> <li>How long is it likely to last?</li> <li>Is there anything (else) we can do to manage the distress?</li> </ul>
Goal-Based Considerations	<ul> <li>Has the patient ever had the capacity to form goals or life plans? (requires prior complex cognition)</li> <li>What were those goals?</li> <li>How likely is the patient to continue pursuing those goals in light of her current condition?</li> <li>Is there anything (else) we can do to make it more likely?</li> </ul>
Value-Based Considerations	<ul> <li>Has the patient ever had the capacity to endorse a set of values? (requires prior complex cognition)</li> <li>What were those values?</li> <li>Does the patient currently endorse those values?</li> <li>How likely is it that the patient will be able to realize or live in accordance with those values in light of her current condition?</li> <li>Is there anything (else) we can do to make it more likely?</li> </ul>
Flourishing-Based Considerations	<ul> <li>Is there anything (else) we can do to flake it finds likely:</li> <li>How has the patient's condition influenced her functioning?</li> <li>How does the current patient's level of functioning compare to typical human functioning?</li> <li>How does the patient's current level of functioning compare to her baseline functioning?</li> <li>Is there anything (else) we can do to improve her functioning?</li> <li>What effect is the condition likely to have on the patient's life-expectancy?</li> </ul>

## **CONCLUSION**

The proceeding discussion is intended to link philosophical theorizing about suffering with various clinical contexts in which suffering may be invoked. As we have seen, the range of views defended at the theoretical level make it such that patients in vastly different clinical situations may be plausibly described as "suffering." This sort of pluralism is not a problem in and of itself; it does, however, raise ethical concerns. For one, the breadth or ambiguity of "suffering" makes general appeals to the concept largely uninformative, which may result in an impoverished decision-making process. For another, even good faith appeals to suffering can result in confusion and miscommunication if parties to the discussion understand the concept differently. More worrisome still is the possibility clinicians (or others) could trade on the vagueness of suffering to unduly influence decision making. As a way of confronting these concerns, we have distinguished among several suffering-related considerations and proposed questions meant to guide discussion and specify the most ethically relevant elements of a patient's condition. Appeals to suffering without such specification, we submit, are at best unhelpful and at worst unethical.

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### REFERENCES

American Medical Association. 2013. Code of medical ethics opinion 2.20 - withholding or withdrawing life-sustaining medical treatment. Virtual Mentor 13 (12):1038–40.



- Belgian Act on Euthanasia of May, 28 2002. Accessed in European Journal of Health Law 10: 329-335, 2003.
- Blumenthal-Barby, J. S. 2021. Good ethics and bad choices: The relevance of behavioral economics for medical ethics. Cambridge, MA: MIT Press.
- Blumenthal-Barby, J. S., and H. Burroughs. 2012. Seeking better health care outcomes: The ethics of using the "nudge. The American Journal of Bioethics: The American Journal of Bioethics 12 (2):1-10. doi:10.1080/15265161. 2011.634481.
- Boorse, C. 2016. Goals of medicine. In Naturalism in the philosophy of health: Issues and implications, ed. É. Giroux, 145–77. Switzerland: Springer International Publishing.
- Brady, M. S. 2018. Suffering and virtue. Oxford: Oxford University Press.
- Campbell, S. M., and J. A. Stramondo. 2017. The complicated relationship of disability and well-being. Kennedy Institute of Ethics Journal 27 (2):151-84. doi:10.1353/ken. 2017.0014.
- Cassell, E. J. 1992. The nature of suffering: Physical, psychological, social, and spiritual aspects. NLN Publications, (15-2461), 1-10.
- Cassell, E. J. 1999. Diagnosing suffering: A perspective. Annals of Internal Medicine 131 (7):531-4. doi:10.7326/ 0003 - 4819 - 131 - 7 - 199910050 - 00009.
- Cassell, E. J. 2004. The nature of suffering and the goals of medicine. 2nd ed. New York: Oxford.
- Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act. (2001). Senate, session 2000-2001, 26 691, no. 137.
- Friedrich, A. B., K. M. Dempsey, and E. K. Salter. 2019. The use of suffering in pediatric bioethics and clinical literature: A qualitative content analysis. Pediatric Ethicscope 32 (2). https://pediatricethicscope.org/article/the-use-of-sufferingin-pediatric-bioethics-and-clinical-literature-a-qualitativecontent-analysis/
- Hawaii Our Care, Our Choice Act 2018.
- Hoffman, K. M., S. Trawalter, J. R. Axt, and M. N. Oliver. 2016. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. Proceedings of the National Academies of Sciences 113 (16):4296-301.

- Kious, B. M. 2022. Three kinds of suffering and their relative moral significance. Bioethics 36 (6):621–7. doi:10.1111/ bioe.13021.
- Lagu, T., C. Haywood, K. Reimold, C. DeJong, R. Walker Sterling, and L. I. Iezzoni. 2022. 'I am not the doctor for you': Physicians' attitudes about caring for people with disabilities: Study examines physician attitudes about caring for people with disabilities. Health Affairs 41 (10):1387-95.
- Marijnissen, R. M., K. Chambaere, and R. C. Oude Voshaar. 2022. Euthanasia in dementia: A narrative review of legislation and practices in the Netherlands and Belgium. Frontiers in Psychiatry 13:857131. doi:10.3389/fpsyt.2022.857131.
- Massachusetts Health Care Proxy Law Chapter 201D, Section 13.
- Mayerfeld, J. 1999. Suffering and moral responsibility. Oxford: Oxford University Press.
- McLachlin, B., L. R. S. LeBel, M. Abella, et al. 2015. Carter v. Canada. 1 SCR 331. S. C. o. Canada. 35591.
- Pernick, M. S. 1985. A calculus of suffering: Pain, professionalism, and anesthesia in nineteenth-century America. New York: Columbia University Press.
- Regional Euthanasia Review Committees. Due care criteria: Unbearable suffering without prospect of improvement. Accessed at https://english.euthanasiecommissie.nl/duecare-criteria/unbearable-suffering-without-prospect-ofimprovement.
- Salter, E. K. 2020. The new futility? The rhetoric and role of "suffering" in pediatric decision-making. Nursing Ethics 27 (1):16-27. doi:10.1177/0969733019840745.
- Tate, T. 2020. Pediatric suffering and the burden of proof. Pediatrics 146 (Suppl. 1):S70-S74. doi:10.1542/peds.2020-0818N.
- Tate, T. 2022. What we talk about when we talk about pediatric suffering. In Philosophical investigations into the essence of pediatric suffering, 7–27. Cham, Switzerland: Springer Nature Switzerland.
- Tate, T., and R. Pearlman. 2019. What we mean when we talk about suffering-and why Eric Cassell should not have the last word. Perspectives in Biology and Medicine 62 (1):95–110. doi:10.1353/pbm.2019.0005.
- Van Hooft, S. 1998. The meanings of suffering. Hastings Center Report 28 (5):13-9.