

# Pediatric Suffering and the Burden of Proof

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## abstract

The alleviation of suffering has always been central to the care of the sick. Yet as medical technology has advanced and life-sustaining treatments multiplied, medicine's capacity to both prevent and create suffering has grown exponentially. In pediatric medicine, the ability to stave off death with life-sustaining treatments allows children to survive but also to suffer in ways that are diverse and unprecedented. However, although parents and pediatric clinicians broadly agree that all children can suffer, there is little published literature in which researchers analyze or clarify the concept of pediatric suffering. This gap is worrisome, especially in light of growing concerns that the label of suffering is used to justify end-of-life decision-making and mask quality-of-life determinations for pediatric patients with profound neurologic impairment. Moreover, the awareness that some children can experience suffering but cannot communicate whether and how they are suffering creates a problem. Does the determination of suffering in a nonverbal child lie in the judgement of clinicians or parents? In this article, I will address several important questions related to the suffering of children through an analysis of two prevalent conceptualizations of pediatric suffering and suggest a possible avenue forward for future scholarship.

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## **PEDIATRIC SUFFERING AND THE BURDEN OF PROOF**

The alleviation of suffering has always been central to the care of the sick.<sup>1</sup> Yet, although suffering is an ancient concern, Western medicine has taken a renewed interest in suffering over the past 50 years. A major reason for this renewal is the recognition that medicine can act as both a relief and a source of human suffering. As medical technology has advanced and life-sustaining treatments multiplied, medicine's capacity to create suffering has also grown exponentially. In pediatric medicine for instance, the ability to stave off death with ventilators, dialysis, left ventricular assist devices, organ transplants, and extracorporeal membrane oxygenation allows children to survive but also to suffer and in ways that are diverse and unprecedented in human history.

Western medicine's increasing recognition of human suffering raises an important question for the practice of pediatrics: what exactly does it mean to say that a child is suffering? This question is critically important. Sick children's lives literally hang in the balance, contingent on clinical evaluations of their suffering. This contingency is demonstrated by a recent analysis of the 651 occurrences of the term "suffering" in pediatric ethics articles over the past 10 years.<sup>2</sup> In the analyses, researchers found that 52% were used to support a specific medical decision. They also found that claims of patient suffering were 3 times more likely to support a life-ending decision as a life-extending decision (32% vs 10%). Reflecting on these findings, bioethicist Erica Salter<sup>3</sup> worries that claims of child suffering can both consciously and unconsciously "smuggle value judgements" into ethical deliberation that would otherwise be considered even-handed and value neutral. Salter believes that suffering has become the new "qualitative futility"<sup>4</sup> for

children, meaning that a label of suffering may mask the fact that, in reality, clinicians feel a severely ill or profoundly disabled child's life is simply not a life worth living (ie, maintaining with medical interventions).

To navigate these ethical and linguistic ambiguities, the field of pediatrics needs a thorough understanding and careful definition of child suffering. However, these do not exist. Even more concerning, medicine's dominant theory of human suffering (a theory postulated by the physician Eric Cassell) is constructed around the lives and experiences of adults and discounts that children can suffer in a meaningful way. A brief review of Cassell's theory is helpful to see why with suffering, children are once again not merely "little adults."

## **ERIC CASSELL AND THE SUFFERING OF CHILDREN**

Cassell's<sup>5</sup> definition of suffering is "the state of severe distress associated with events that threaten the intactness of the person." For Cassell, suffering is a subjective, personal, and individualized phenomenon, a view that has become nearly canonical within medicine. Unfortunately, there are a number of problems with Cassell's view.<sup>6</sup> One major problem is that it leaves no room for the suffering of infants or nonverbal children. Cassell is explicit that young children cannot suffer because they are not fully persons,<sup>7</sup> meaning that they do not possess language or a sense of identity or of the future and cannot attach meaning to their experiences. In Cassell's opinion, if a creature cannot recognize and reflect on its suffering, it is not suffering at all; it is merely experiencing pain or some other basic emotional response to its environment. This conceptualization of suffering effectively denies that a large population of pediatric patients, namely, those who are nonverbal because of either young

age or cognitive impairment, can suffer.

From the perspective of pediatric medicine, Cassell's conceptualization is incomplete. Newborns, infants, and nonverbal pediatric patients can certainly experience more than bare pain; indeed, the claim that infants and nonverbal children (and anyone with profound cognitive disability for that matter) can suffer is supported philosophically<sup>6,8,9</sup> and by the robust consensus of parents and pediatric clinicians, both anecdotally and in the published literature.<sup>10-12</sup> Whether due to social, spiritual, psychological, existential, or biological factors, there is a broad acknowledgment in pediatrics that all children can suffer, even those who cannot articulate their suffering experience. Yet this broad consensus around pediatric suffering raises its own set of thorny questions. Paradoxically, the awareness that children who cannot tell you they are suffering can suffer creates a new problem: who gets to decide when, if, and to what extent a nonverbal child is suffering? Where exactly is the location of a child's suffering? Does confirmation of suffering lie in the judgement of a child's clinicians or the child's parents? Or does confirmation require more objective data, like vital sign changes or physical examination findings such as grimacing or tachypnea? Moreover, who owns the burden of proof for pediatric suffering, especially for those patients who cannot speak for themselves?

## **ONE CHILD, MULTIPLE PERSPECTIVES**

Controversy around the reality and proof of suffering runs deep in pediatrics. For example, in a 2018 ethics rounds article in this journal, Miller et al<sup>13</sup> present the case of "J.S." a 6-month-old infant born with complex congenital heart disease. J.S., already chronically critically ill, suffers a cardiac arrest with prolonged anoxia. Now, he no longer

responds to caregivers. Instead, he cries, grimaces, and requires increasing sedation to remain calm. Medical providers frequently discuss J.S.'s suffering. The parents maintain that they want "everything done" but are seldomly present in the hospital for more nuanced goals of care discussions (they live in poverty without a car or working phone). Physicians disagree with the parents' desire to maintain life at any cost and determine that unilateral withdrawal of life-sustaining treatment is in J.S.'s best interest.

In the first commentary on the case, Miller and Eisenberg move to support the physicians' unilateral withdrawal, claiming that "to continue aggressive care is to prolong his [J.S.'s] suffering."<sup>13</sup> They then proceed to equate suffering to "harm" and conclude that prolonging J.S.'s life would therefore be unethical because it violates the harm principle, a threshold for seeking state action in cases in which a parent refuses medical intervention on behalf of a child that places their child at significant risk of serious harm.<sup>14</sup> All the while, they never attempt to define or even clarify the nature of J.S.'s suffering or how it is distinct from his pain, which can be alleviated with careful medication management.

In contrast, in the second commentary, Henriksen and Weiss assert that it is "ethically unjustified to unilaterally withdraw life-sustaining treatments for J.S."<sup>13</sup> Henriksen and Weiss contend that (echoing Salter) J.S.'s physicians have mistaken values for facts. They point out that there is nothing "futile" about the interventions being done to J.S.; on the contrary, his tracheostomy and feeding tube help him continue to breathe and grow, and a pacemaker would likely stabilize his heart disease and position him for hospital discharge, either to his home or to a skilled nursing facility. In fact, these technological interventions will all achieve their exact purposes. For

Henriksen and Weiss then, the answer to J.S.'s case boils down to a question about quality of life. If J.S.'s quality of life is sufficient (or, we could say, his suffering is insufficient), his life should be maintained. But Henriksen and Weiss believe that the burden of proof for determining an acceptable quality of life falls on clinicians because parental determinations of a life worth living must be "taken at face value."<sup>13</sup> In other words, until proven otherwise, parental determinations of quality of life and suffering are always correct. Their position is much in line with the ethos of my own specialty, pediatric palliative care.

This ethics rounds debate can also be viewed as a microcosm of a much larger, international debate surrounding pediatric quality of life, suffering, and authority. Over the past decade, a number of high-profile pediatric cases have been used to showcase the tension between physician and parental authority when there are conflicting perspectives on suffering and quality of life. For instance, in the United Kingdom, physicians sought unilateral withdrawal of life support (against parental wishes) from pediatric patients Charlie Gard, Alfie Evans, and Isaiah Haastrup. This provoked public outrage, leading some conservative pundits to decry the European "culture of death" and avow that "parents' rights are human rights"<sup>15</sup> Conversely, in the United States, the stories of patients like Jahi McMath exemplify a more liberty-oriented culture in which parental perspective and authority is near absolute. Although there was a fierce legal battle, Jahi's mother's "reality" (namely, that Jahi was not suffering and that her quality of life was acceptable) won out. After being declared brain-dead in California, Jahi's mother acquired a transfer to New Jersey where Jahi lived for four more years in an apartment with her family.

There is obviously an immense amount of detail left out of these contentious cases. Still, there is a moral to be extracted. This moral has 2 parts. First, in pediatrics, suffering, like quality of life, is generally treated de facto as a subjective phenomenon, but not in Cassell's terminology, which requires personal experience and the capacity for self-report. Rather, the presence or absence of suffering in a child who cannot speak for him or herself is determined subjectively by a second party. In pediatrics, suffering is treated as beauty is in art: 2 people may observe the same painting and one will find it beautiful, whereas the other is repulsed, but the truth simply lies in the eye of the beholder. Like this lay notion of beauty, there is no objective criterion for suffering.

Second, depending on the cultural and situational milieu, the burden of proof for justifying the existence of a child's suffering will sit with different parties. In Europe, it seems to sit with the parents, meaning that the parents have to prove that their child is not suffering. If they cannot, as was the case with Charlie Gard, Alfie Evans, and Isaiah Haastrup, their child may die. In America, the burden of proof is more often on the physicians or hospital, and parental perspectives are generally taken "at face value" (although not in the case of J.S., whose life support was unilaterally discontinued).

Contrasting this to adult medicine, Eric Cassell's definition of suffering is serviceable for one kind of suffering, namely, the first-person distressing experience that accompanies a loss of personal integrity or selfhood. However, when the person suffering is a 6-month-old infant hooked up to an extracorporeal membrane oxygenator and sedated by midazolam and fentanyl, the only accessible subjective experience is that of the child's caretakers (whether that caretaker is a parent, nurse, therapist, or physician). And when the

(1) subjective discomfort or (2) subjective hope experienced by a caretaker is projected onto the child, it becomes either the (1) presence or (2) absence of suffering.

### PEDIATRIC SUFFERING: WHO IS TO JUDGE?

So who should determine if a child is suffering? Who has the best vantage point on a child's experience? One possible way to try to answer this question is through empirical data collection. Unfortunately, empirical studies are not particularly illuminating. As multiple studies have revealed in both children and adults, physicians do not always accurately estimate their patients' quality of life.<sup>16-18</sup> There is no clear reason to think they will be better at calculating a sick or cognitively impaired child's current or future suffering. Still, perhaps surprisingly, the same can be said for parents. Multiple studies across a wide spectrum of pediatric diseases have revealed a significant gap between parental and child assessment of child quality of life.<sup>19-22</sup> Although it is true that suffering and quality of life are separate phenomena, what these findings do suggest is that neither physicians nor parents can fully understand a child's experiences independently of the child. Philosophically speaking, there is no logical reason that the lived experience (that is, the exact feelings of fear, joy, pain, suffering, peace, anxiety, or sense of well-being) of a child can be apprehended by a parent, let alone a clinician or a court of law. It appears we are caught between a rock and a hard place; try as they might, neither parent nor physician can guarantee the presence or absence of suffering in a nonverbal child. And yet as the results of J.S.'s case display, once the label of suffering is given, the ramifications can be grave.

### THE PARTICULAR CHILD

Is there a path through this morass? I believe that there is. In my opinion, the inscrutability of pediatric suffering begins to dissolve when suffering is made accountable to something other than pure perspective. This something is the body of the child. A failure to be held accountable to the body of the particular child in front of them is why both Miller and Eisenbergs' and Henriksen and Weiss's views are, as I see them, incomplete. Both fail to fully account for the reality that is J.S. In other words, Miller and Eisenberg construct a projection of suffering that is abstracted from the body and potential (albeit neurologically devastated) future of J.S. This is the same logic that underwrites the Netherland's Groningen Protocol, which authorizes the killing<sup>23</sup> of impaired infants with a "hopeless prognosis who experience what parents and medical experts deem to be unbearable suffering."<sup>24</sup> Yet on the other hand, Henriksen and Weiss advocate for an unquestioned sovereignty of parental perspective that is itself unaccountable to the body of J.S. There are some things that should not be done to a human body no matter what a parent says, for sometimes parents are, in fact, wrong. The great difficulty is of course knowing where and when to draw that line. However, before a line can be identified, a more objective theory of pediatric suffering is required. This theory will have to account for the complex social, spiritual, historical, theological, psychological, physical, biological, and linguistic realities that bind children to their parents, parents to their children, and place both in the dynamic relationship of patient, doctor, and parent. I suspect that it is only through an inquiry of this design that our analysis of and clinical response to pediatric suffering can move constructively forward.

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