



Relational suffering and the moral authority of love and care

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Abstract

Suffering is a ubiquitous yet elusive concept in health care. In a field devoted to the pursuit of objective data, suffering is a phenomenon with deep ties to subjective experience, moral values, and cultural norms. Suffering's tie to subjective experience makes it challenging to discern and respond to the suffering of others. In particular, the question of whether a child with profound neurocognitive disabilities can suffer has generated a robust discourse, rooted in philosophical conceptualizations of personhood as well as the academic and experiential expertise of practiced health-care professionals. The issue remains unresolved because it is difficult, perhaps impossible, to ever truly know an infant's lived experience. But what if this is not the best question? What if instead of asking "can this infant suffer?" the discourse is broadened to ask "is there suffering here?" This latter question demands attention to patients' subjective experiences of suffering, but also to the web of relationships that envelop them. Without losing sight of the importance of patients' experiences, consideration of their relationships may elucidate the presence of suffering when the patients themselves are unable to provide the same clarity. In this essay, care ethics frames an examination of how suffering manifests in the loving and caring relationships that surround an infant with profound neurocognitive disabilities, changing those relationships and affecting the individuals within them. Exploring suffering through these relationships may offer clarity on the presence and content of suffering for infants with profound cognitive disabilities, in turn offering moral guidance for responding to suffering and supporting flourishing in this context.

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Introduction: the contested suffering of infants with neurocognitive disabilities

Baby Esther's cognitive disabilities and critical illness related to being born with severe lissencephaly syndrome mean that she may not be able to communicate very much about her suffering [1].¹ But the presence of suffering for caregivers in relationship with Esther may be palpable. It manifests in parents who feel helpless and agonize over whether they are doing the right thing, as well as in health-care professionals who cry in break rooms and question their own virtue and professional obligation. These caregivers reasonably have strong feelings about whether Esther suffers and, if so, how.

Standard conceptualizations of suffering entail a negative experience, such as pain, but also something more [3, pp. 12–16]. Additional criteria are typically defined as co-occurring cognitive states, such as a perception of intensity, a value, or a desire [4, p. 18]. For Michael Brady, it is a desire that the negative affect cease [3, pp. 26–27, 41]. For Eric Cassell, it is how the negative affect threatens one's "intactness" as a person [5, pp. 32, 54, 98, 287].² Suffering, by most accounts, is a subjective experience that requires some degree of self-awareness and/or a formed desire for the situation to change. However, this standard understanding of suffering presents unique challenges in the context of infants with profound neurocognitive disabilities.

All infants depend on the capability of others to interpret their experiences and act on their behalf. Historically, this dependency has rendered infants vulnerable to skepticism about their ability to have negative experiences, most notably their capacity to feel pain [8]. For instance, surgical procedures were commonly performed on newborns without anesthesia until 1987 when the practice was declared unethical by the American Academy of Pediatrics [9]. Indeed, norms of practice have been slow to change. In a 2013 survey of 237 neonatal nurses, only 44% of respondents reported that pain in the neonatal intensive care unit was well managed, and only 43% reported that pain protocols were based in research evidence [10].

Today, few would contest whether infants, including infants with profound neurocognitive disabilities, have the capacity to feel pain. And most agree that, all things considered, health-care professionals are duty bound to attempt to alleviate pediatric pain. However, infant suffering remains a contested phenomenon, especially for infants with profound neurocognitive disabilities. As stated above, suffering is thought to entail certain cognitive capacities, such as the capacity to perceive, desire, or value. But infants have not been ascribed these capacities historically, at least not in the same way as older individuals. Helga Kuhse and Peter Singer have famously argued that there are morally substantive differences between the quality of life of "normal" adults and that of infants [11, 12]. The debate similarly extends to infants with disabilities. Even as many ethicists seek to protect the well-being of

¹ The case of baby Esther is laid out in Tyler Tate's introduction to this *Theoretical Medicine and Bioethics* special issue on pediatric suffering [2].

² See also [6, 7].

all infants, skepticism about the quality of life of infants with profound neurocognitive disabilities continues to affect moral judgments and assessments of moral status [13–15]. For Esther, the extent of her neurocognitive impairment means that she may never have the cognitive ability to form and express explicit desires, values, or preferences. Thus, even while few would question that Esther has the ability to feel pain, some would argue that she lacks the cognitive capacity to experience suffering.

The unanswered question: Does baby Esther suffer?

To answer the question of whether individuals like Esther can experience suffering, theorists often turn to purportedly objective information about them. That is, because Esther cannot communicate her subjective experiences explicitly, one must rely on others to interpret her subjective experience on her behalf. But this approach is challenging. While some might see evidence of suffering in grimaces, breath holding, vomiting, alterations in vital signs, high muscle tone, or other objective physical displays, others will point out that Esther's profound neurocognitive disability means that she likely lacks the consciousness or self-awareness requisite for a person to suffer. Moreover, such physical displays cannot be mapped decisively onto suffering, as Erica Salter notes:

Most often the way suffering is “objectively” assessed is through observing behaviors that are typically associated with pain and distress, for example, air hunger, agitation, crying, certain facial expressions, and sleeplessness. However, ... these *may* be signs of suffering (and, in fact, they might even be fairly reliable signs of suffering), but they aren't *necessarily* signs of suffering. And the frequency and intensity of these behaviors is not necessarily indicative of the intensity or duration of actual suffering. [4, pp. 18–19]

To understand the subjective experience of infants like Esther, one must rely on an external perspective, with very little recourse to confirm or deny one's interpretation or judgment. One cannot ask Esther about her experience or necessarily liken her experience to one's own, and it is likewise difficult to compare her experience to that of other neurotypical children. So there is limited objective information to help resolve disputes about whether Esther suffers and how.

Attending to the individual experience of infants like Esther is critical, but we suggest that a broader question is a better guide. Rather than asking “is baby Esther suffering?” and looking solely to objective information about Esther, we advocate for an expanded view that includes those caring for her, broadening the question to “is there suffering here?” This wider outlook allows continued attention to Esther's experience while encouraging exploration into the relationships of love and care that surround her. Examining these relationships may provide additional insight that is not available when one attends only to the potentially unknowable experience of the individual infant. While suffering in relations can never act as a proxy for Esther's suffering, it can illuminate aspects of her potential suffering in two ways. First, insofar as Esther is partly constituted by the loving and caring relationships that surround

her, examining the suffering present in those relationships may shed light on the suffering experienced by Esther. Second, a relational stance can clarify suffering that is ascribed to Esther but more accurately resides in the interstices between Esther and those who have formed caring, and potentially loving, relationships with her.

Changing the question: Is there suffering here?

A more comprehensive formulation of the question at stake—“is there suffering here?”—asks caregivers to continue to attend to the individual experience of infants like Esther, while also exploring broader suffering that is intimately connected to the infant’s own experience. Here we focus on the latter to augment the discussion of Esther’s potential suffering and advance considerations for determining how best to respond. Ethical reasoning should consider the particular, dependent, and emotional relationships that are partly constitutive of Esther, her suffering, and the suffering that surrounds her. To understand suffering as constituted by relationships with Esther, we start by presenting the perspective of care ethics, exploring the various forms of caring relationships that exist and the different kinds of insight into suffering they provide in the context of infants with profound neurocognitive disabilities.

Care ethics

Care ethicists begin from a metaphysical position in which relations are ontologically basic [16, p. 4]. This means that, for care ethicists, human beings are defined not by their independence and atomistic individualism, but by their inherent interdependency and relationality. However, relational views do not discount individual choices, experiences, and identities; rather, they recognize that individuality and independence are possible only in and through interpersonal and societal relationships. Choices, values, and identities are formed in relationships with others and within intersecting social norms and cultures. While individuals exhibit uniqueness and creativity, this individuality emerges in the context of the complex relationships in which it is already enmeshed. According to this standpoint, caring relationships hold moral worth in and of themselves, and not merely because they hold benefit to the individuals within them.

The relations through which all individuals develop and flourish begin early, in a state of extreme dependency.³ Humans come into this world entirely dependent on others to survive. Though certainly individual beings, infants are not independent beings; they can subsist only in relations of care. Whether and how they suffer or flourish is utterly dependent on, and partly defined through, their relationships with others. Infants who are critically ill or have profound neurocognitive disabilities are particularly dependent on the care of families and health-care professionals alike.

³ The concept of flourishing is derived from virtue theory as an interpretation of Aristotle’s use of the Greek term *eudaimonia*. Flourishing is akin to living well, being well, or happiness in a holistic sense.

For infants like Esther, this extreme state of dependency is likely to be a permanent state.

Asking “is there suffering here?” calls for a shift in the ontology of suffering. It broadens the ethical analysis so as to accommodate a relational perspective. By looking to the caring relationships that surround infants like Esther, one can find ways of discovering moral knowledge and justifying moral action that are grounded in “receptivity, relatedness, and responsiveness” [16, p. 2]. This is a process that relies on recognition of the emotions, needs, interactions, and loving bonds of particular others. Even as one may never fully know the reality of Esther’s experience, the caring relationships that surround her can provide an additional lens for understanding the presence of suffering.

The intactness of loving and caring relationships

Cassell’s definition of suffering as something that threatens the “intactness of the person” [5, p. 56] cannot apply to individuals like Esther, who may not have the cognitive capacity for such an experience. However, the idea of an intactness that is threatened robustly captures the kind of suffering that happens in loving and caring relationships. Much like the intactness or integrity of a person, the intactness or integrity of relationships can be threatened in a variety of ways by a variety of forces.

Suffering in this relational sense is not merely something experienced by Esther, individual health-care professionals, or individual family members. Rather, suffering is fundamentally entangled in the network of relationships within which these individuals exist. To examine Esther’s relational suffering is not to probe what other individuals experience as suffering as they care for her, but to consider the suffering that occurs in the caring relationships that define and constitute Esther. On standard accounts of suffering, health-care professionals may be deeply concerned that they are causing Esther further harm and so failing in their professional obligation to protect or do no harm. In Cassell’s terms, they may experience suffering because their integrity of person is threatened when their goal is to help Esther, but their actions appear only to cause further harm. While we do not deny that such sentiments can constitute important experiences of suffering, there is another critical element to explore here. Health-care professionals may experience suffering that is grounded in a threat to their connection with their patients, as opposed to a threat to their individual identity as a person.

Caregivers strive to understand the needs of the cared-for, respond to those needs, and find affirmation that care has been “received” by or “completed” in the cared-for [16, pp. xviii, 85, 181]. The process of caring is a process of forming closer bonds. Parents and health-care professionals engage with and attune to Esther, seeking flourishing in these caring relationships, inclusive of the individuals within them. Thus, when medical circumstances thwart these relations of care, the relationships may suffer and with them the individuals who are defined in and through those ties. Suffering may be present in a way that spans the space between individual subjective experiences. Its presence depends on and is constituted by the obstruction of

shared emotions, receptivity, love, caregiving, and care-receiving that can happen in the context of profound neurocognitive disability and critical illness. Here, we categorize two broad forms of caring relationships that are relevant to infants like Esther: (a) professional caregiving relationships and (b) parental caregiving relationships. While we recognize that there are many ways of relating to Esther and many types of caring relationships within both categories, we hope to start with these broad categories in order to motivate a relational perspective on suffering.

Professional caregiving relationships in health care

Professional caregiving relationships in health care encompass the broad range of meaningful relationships between a patient and someone whose professional role is that of a caregiver, such as a physician, advanced practice provider, nurse, skilled in-home caregiver, therapist, and so forth. The roles and moral obligations of professional caregivers are typically informed by practical features of the relationship. Professional caregivers are usually compensated for their time. The relationship between carer and cared-for is often temporary because the former's shift or rotation ends or the latter is discharged or dies. The relationship may also be affected by the proximity between carer and cared-for—for instance, bedside nurses may be in more direct and frequent contact with patients than physicians. The relationship may be further influenced by the caregiver's degree of responsibility over the patient's course of care—for example, the attending physician in charge of the patient's orders may have a different relationship than the physician who is providing emergency coverage overnight.

Professional caregiving relationships in health care take a variety of forms and include an array of caring activities, but they are all similarly framed by the goals of what Joan Tronto calls “care-giving” (e.g., administering medication or providing a comforting touch) and “care-receiving” (e.g., feeling better) [17, pp. 107–108]. The role of health-care professionals in caring relationships with patients is typically characterized by actions aimed at curing or preventing illness, providing comfort, alleviating or preventing pain and suffering, as well as understanding and respecting their patients' interests and preferences when they are known. Health-care professionals and patients alike seek the fulfillment of this care, and when it is obstructed the relationship itself is undermined. Suffering, we suggest, may be found in the relationship between a health-care professional and an infant like Esther insofar as the intactness of the caring relationship between them is threatened.

For example, consider a bedside nurse caring for an infant like Esther. Due to the infant's frailty, the nurse risks causing injury when changing her diaper, in extreme cases even breaking a bone. The nurse may intuit that frequent suctioning, which is seen as uncomfortable by other patients, is uncomfortable for the infant as well—even in the absence of objective signs of discomfort. The nurse may similarly feel conflicted about his ability to respond to the infant's hunger, since she depends on tube feedings that may fill her belly regardless of whether she is hungry and may even cause pain from reflux, overfeeding, or technical problems with the feeding tube. More broadly, the nurse's past clinical experience may lead him to conclude that the standard goals of this overarching care are untenable, given that the infant

will not reach some particular threshold of functional capacity or freedom from illness. In these instances and others, the intactness of the caring relationship between patient and health-care professional may be threatened. The reality of such an infant's medical circumstances may obstruct care-giving (e.g., aspiration risk prevents the nurse from feeding the infant by mouth, causing the nurse to rely on tube feeding) as well as care-receiving (e.g., necrotizing enterocolitis prevents the infant from being fed at all). If this nurse is regularly assigned to this infant's bedside, he may face ongoing, waxing and waning threats to his caring relationship with the patient. Even as some caring activities, such as feedings, are successfully received by the infant, it may be that a multitude of others fail in some way due to the complexity of the medical circumstances. At the very least, the nurse may feel uncertain about whether many of these efforts to care for the infant are in fact received by her or benefit her in the intended manner.

As the intactness of the professional caregiving relationship is threatened, the nurse and the infant may *feel* this suffering individually, but the feeling is constituted in part by their enmeshment with each other. They are emotionally, dependently, and clinically tied to one another and, therefore, flourish or suffer relationally as a result of the ways in which the professional caregiving relationship is supported or obstructed. Thus, to come to understand the presence of suffering, one must ask whether the professional caregiving relationship is one that cures or prevents illness, relieves suffering, contributes to patient health and well-being, and allows for responsiveness, empathy, trust, and other ways of bonding between health-care professional and patient. Or, if not, perhaps profound neurocognitive disability and critical illness impede this care, threatening the intactness of the caring relationship.

Parental caregiving relationships

Parental caregiving relationships may have significant overlap with professional caregiving relationships.⁴ Just as health-care professionals feed infants, change diapers, soothe crying, and form affectionate bonds, so do parents gain clinical insight as they learn to assess signs of medical distress and maintain medical technology that their child depends upon. Still, the interconnection between parents and their children is different from that between health-care professionals and their patients in important ways.

Caregiving involves “engrossment and motivational displacement” [16, pp. 16–21, 36–46]. This is a phenomenon exemplified in many parent–child relationships. Parents can become so engrossed in their relationships with their children that their individual identities are transformed into something never fully distinguishable from their connections to their children. Motivational displacement is common in

⁴ We use the terms “parent” and “parental” broadly here. A parent need not be biologically related to the child and might be a grandparent or extended relative. Importantly, parents are those who are intimately connected with the child and take on primary and wide-ranging responsibility for the child's well-being.

this intertwined existence. For parents, this means adopting their children's goals as their own and helping to promote them.

Parental caregiving relationships also have a deep level of intimacy [18, p. 148]. This intimacy often begins early. For instance, parents can feel immense loss and sadness following an early miscarriage or an adoption that does not come through, as they had already started to form intertwined lives with the hoped-for child. So it is not surprising that many parents feel immediate affection and love for a new child—feelings that, notably, are not determined by the new infant's abilities or disabilities. As Eva Kittay articulates about her daughter Sesha:

The most important thing that happens when a woman becomes the mother of a child with disabilities is that she becomes the mother of a new child. When Sesha was born, I, along with Jeffrey, her father and my life-partner, fell madly in love with our baby. [19, p. 147]

While the love that Kittay describes here is not always immediate, sometimes taking months to develop for new parents, the connections between parents and their children expand well beyond the point at which they fall in love. These jointly physical and emotional ties are complex, ultimately encompassing so much more than particular feelings or particular moments in time.

Similarly, the intimate ties between parents and children are not traceable to the moment when the fetus becomes a "person" (whatever one might mean by this term), or even the moment when the infant first offers some form of reciprocity, such as a smile, a grasp, or a coo. Rather, the interconnections between parents and children form earlier—sometimes initially unrecognized—and develop and take on different forms over time. Health-care professionals, like parents, can form attachments of love and affection with infants, but for parents these ties typically begin long before the clinical setting and will continue outside of that environment. It is, in part, because of this that parental caregiving relationships, with some exceptions, manifest deeper emotional attachments and play a primary role in patients' narratives and identities.

The intactness of a parental caregiving relationship is constituted through intimacy, love, and support of the child's broader well-being. As one parent put it in a study of parents who chose to continue pregnancies after prenatal diagnosis of trisomy 13 or 18, "We do not love our kids because of their accomplishments. We love our kids because they are our kids" [20, p. 311]. While a parent may seek for illness to be cured or pain to be alleviated, these caring activities do not define the parent-child relationship in the same way that they define the relationship between health-care professional and patient. Parents may grieve their child's critical illness or the lack of corresponding curative therapies, but their relationships may still manifest intimacy, love, and support in important ways. For instance, they may still be able to hold their child and thereby feel the same flourishing any parent feels as this contact soothes, warms, and replenishes the strength of parent and infant alike.

Suffering may be present in parental caregiving relationships with infants like Esther insofar as the ability to form intimate and supportive relations is threatened by profound neurocognitive disability and critical illness. The child may not respond to touch, may not be soothed or grow stronger in her connections with parental

caregivers. The parental caregiving relationship may be threatened if the child's condition obstructs care-giving (e.g., the mother cannot nurse the infant) or care-receiving (e.g., efforts to soothe fail to calm the infant). When care is obstructed or obscured, parents and children alike may suffer as these relationships are constitutive of their identities. Threats to the intactness of parent–child relationships are not merely about obstacles to parents' formation of loving bonds with their children and their ability to enact familial values, but also about limitations to how children can participate in the relationship, contributing to and defining familial values and narratives. For infants like Esther, who have profound neurocognitive disabilities, parent–child caregiving relationships can be particularly central to who they are as persons and, therefore, whether they suffer or flourish [1].⁵

Whether or not a parental caregiving relationship remains intact or is threatened will ultimately depend on the particulars of the relationship in question. Do Esther's parents feel like she responds to their touch, their voice, or their presence? Does she seem calmer or more relaxed as they sing to her? How do their particular familial values cohere with Esther's interests and possible future life? What does it mean for this particular family to be connected, supportive, and loving? Understanding the narrative of the parent–child relationship, the particulars of its history and values, will be crucial for understanding whether and how the intactness of the relationship might be threatened and how it might flourish in the context of an infant with profound neurocognitive disability and critical illness. Exploring the intactness of caring relationships ultimately provides insight into the question “is there suffering here?”

Responding to suffering and the moral authority of love and care

Health-care professionals and families alike may form loving and caring bonds with infants with profound neurocognitive disabilities. While it is generally agreed that such connections are cherished and morally valued, they are rarely given the weight they deserve when it comes to understanding what constitutes suffering and how one ought to respond to suffering. These bonds are uniquely important in the context of profound neurocognitive disability. Infants with such disabilities are not able, and may never be able, to experience a threat to their identity or intactness of person. They may never be able to form desires that pain cease. For these reasons, some would argue that they cannot suffer. And yet they may exist within relationships that suffer or flourish to the extent that love and care within particular health-care professional–patient or parent–child relationships is threatened or cultivated.

It is in this way that loving and caring relationships carry moral relevance. By virtue of these relationships, health-care professionals and parents come to know an infant like Esther—beyond the data that are objectively observable. They may sense her pain or pleasure, recognize her triumph or struggle, or perceive her

⁵ See also Arthur Kleinman et al. [21] for a robust collection of essays on the topic of suffering in communal relations and across historical relations.

responsiveness or unresponsiveness to caring activities. Their proximity and attachment to the infant over time will manifest different forms of suffering and flourishing. And although no one can have full access to the experience of an infant, with or without profound neurocognitive disability, these relationships may provide some insight into the suffering that exists in relation [22]. Crucially, even when the experience of an infant is unknowable and contested, one can come to understand the suffering and flourishing of the relationships that she exists within and is partly defined through. Are loving and caring relationships threatened or intact? How and for whom? When objective information about the suffering of an infant fails to guide moral action, these questions offer a path forward.

Through these relationships one may better understand disagreements about whether Esther suffers. Health-care professionals may claim that Esther suffers because they are concerned that she will not achieve a level of cognition or function considered acceptable, that she cannot be cured, or that her pain cannot be adequately controlled. They may see a future of surgeries, ventilator dependence, and dressing and line changes that they would not wish for themselves or their own family members. Health-care professionals may experience substantial moral culpability in this setting, feeling as though they have created a life of disability and suffering, instead of saving a life that could flourish [23]. At the same time, her parents may claim that Esther flourishes because they observe her respond to their touch, see her improve day by day, or value her life and want to do everything they can to bring her home so that the relationship can continue to grow and develop. Both claims can be true when one understands them as claims of relational suffering. A professional caregiving relationship may be threatened while a parental caregiving relationship remains intact in important ways, and vice versa. Yet both types of relationships call for attention, sensitivity, responsiveness, and inclusion in medical decision-making.

The analysis, of course, necessarily changes depending on the details of the narrative at hand. Certainly the intactness of such relationships is far more complex than can be captured here. Caution must still be paid to nuance and accuracy in the process of interpretation. Professional caregivers and parents may conflate their own experiences of suffering with an infant's suffering or even suffering in the relationship. For example, an exhausted physician who carries the "moral residue" of previous ethically challenging cases may inappropriately project suffering onto patients or relationships in the present (see [24]).

Ultimately, the relational analysis of suffering that we propose asks all caregivers to consider the different types of caring relationships formed with infants like Esther and investigate the different ways in which the intactness of these caring relationships might be threatened or cultivated. This approach moves ethical analysis away from a strategic or logical process based on available objective data and toward a process rooted in receptivity and responsiveness [16, pp. 1–2; 18, pp. 225–226]. From such an approach, any ethical analysis of how to respond to infants like Esther must attend directly to the caring relationships that surround them, specifically to the experiences, emotions, and beliefs that are formed in connection with them. The task of shared decision-making becomes one of sharing perspectives on the ways that different caring relationships are threatened or supported, obstructed or cultivated, struggling or flourishing. Instead of solely working to understand what

Esther's responses—grimacing or vomiting, softening to touch or calming to loving voices—reveal about her experience of suffering, attention should be shifted to include why one caregiver feels as though the caring relationship is obstructed and unfulfilled while another sees some form of completeness and reciprocity.

Potential objection: losing sight of Esther

In the context of profound neurocognitive disability and critical illness (or any context of medical care), consideration of the presence of suffering in relationships should not stand alone as an account of suffering. Understanding the presence of suffering will also require insight into the experiences of individuals as distinct, in some sense, from their relations. A robust moral response will, of course, demand a robust appreciation for different forms and dimensions of suffering. Our aim here is to offer a framework for conceptualizing the kind of suffering that is present when the intactness of loving and caring relationships is threatened in the context of profound neurocognitive disability and critical illness. This approach serves as an additional, supplementary lens through which to evaluate suffering.

Some may worry that attending to these relationships loses sight of Esther's experience and may even treat her as a means to another's end. Exploring the perspectives of parents and health-care professionals risks drawing the focus away from Esther, privileging others' interpretations of the relationship too strongly, and misrepresenting her individual lived experience. For instance, it is possible that a parental request to continue life-sustaining treatment for an infant with profound neurocognitive disability and critical illness is seated in a parent's misattribution of flourishing to the child when it is only the parent who experiences this well-being. The request, then, could be interpreted as a self-interested use of the child as a means to support the parent's own ends.

However, this concern forces the analysis into a framework of competing individual interests when there is an alternative. As Virginia Held explains:

Those who conscientiously care for others are not seeking primarily to further their own *individual* interests; their interests are intertwined with the persons they care for. ... They seek instead to preserve or promote an actual human relation between themselves and *particular others*. Persons in caring relations are acting for self-and-other together. [25, p. 12]

It can be easy to misconstrue a parent's reasoning as self-interested or in competition with the interests of the infant when mainstream social ontologies and ethical approaches depict independent individuals in conflict. But parents do not typically think or operate in these individualistic terms. Rather, "their" values and preferences are always already enmeshed with the loving and caring relationships they hold with their children. Not only do parents adopt the interests of their children, sometimes displacing their own, but the respective interests of parents and children also become intertwined as the relationship's flourishing comes to matter in its own right.

Moreover, as we have argued elsewhere [22], a relational perspective demands consideration of the individuals within relationships even as it denies the possibility

that individuals can ever truly be separated from the dependent, caring relations in which they are constituted. To the extent that Esther depends on the caring relationships that surround her, her experience and individual identity demand the attention of those who care for her. As articulated above, caring relationships are not complete or fulfilled unless care is given in a manner that is attentive to the needs of the cared-for, such that the cared-for receives the care or responds to the care in relevant ways. Ideally, of course, parents and health-care professionals would come to understand the distinct perspective or experience of an infant like Esther in order to better appreciate and respond to her needs. By attending to her experience both within relationships and in its own right, one can ensure that Esther is treated as an end in and of herself.

Furthermore, the ability to understand and attend to relational suffering will shift with particular contexts. For instance, consider cases where an infant lacks parents or similarly loving primary caregivers. In such cases, one may need to attend to the suffering inherent in the absence of caring relations just as much as the infant's subjective experience of suffering. In fact, the absence of caring connections with primary caregivers may be constitutive of the infant's suffering insofar as the infant lacks some of the very relations of care that could otherwise constitute relational flourishing. Narratives of this sort will likely only serve to underscore the import of caring relationships to ethical analysis. An absence of caring relationships means the loss of one important avenue for understanding both suffering and flourishing, for which there is no easy replacement.

Though caregivers should continue to be receptive to infants' subjective experiences of suffering, and may come to know more as they attune to them over time, they may also find solace in the recognition that it is possible to reach a deeper, though inevitably partial, understanding of the presence of suffering in the context of these caring relationships. Ultimately, we believe that infants like Esther suffer and flourish in distinct ways that morally oblige respect and responsiveness. At the same time, the loving and caring relationships they depend on also have irreducible moral value that commands concern and attention.

Conclusion: making room for flourishing

Looking to Esther alone and seeking objective information about her suffering not only makes it difficult to arrive at certainty about whether she suffers and, if so, to what degree, but also insufficiently addresses the presence of suffering. When the discourse on suffering focuses too strongly on objective knowledge and abstracted interpretations about baby Esther's experience in the world, it may fail to consider the particular, dependent, loving, and emotional relations that are partly constitutive of Esther, her suffering, and the suffering that surrounds her. Without losing sight of the importance of Esther's subjective experience, ethical inquiry can engage in a robust exploration of the loving and caring relationships that she depends upon not just in order to gain greater insight into the suffering that is present, but also to discover potential flourishing.

Though we have not addressed flourishing in detail here, we believe that it is possible in this challenging context. Flourishing, much like suffering, depends on the particular caring relationships in the narrative at hand. It may sometimes be found in the withdrawal of life-sustaining treatment just as it may other times be found in the continuation of that same treatment. Ultimately, we hope that our account can help to illuminate suffering while also attending to the particular manifestations of flourishing—in small moments of connection, of calmness, of empathy, of care given and received, or in broader medical decisions that foster moments and relations of care.

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