



ARTÍCULOS
DE INVESTIGACIÓN

Neonatal pediatric suffering: limits of the phenomenology of suffering?*

Róbson Ramos dos Reis

Universidade Federal de Santa Maria, Santa Maria, Brasil
robson.reis@ufsm.br

Recibido: 04/12/2023 | Aprobado: 08/03/2024

Doi: <https://doi.org/10.17533/udea.ef.355671>

Abstract: Neonatal suffering has been the focus of recent debates in pediatric bioethics and suffering theory. How can we access and conceptualize the suffering that can be attributed to newborns? How are we to discern the suffering of newborns who are non-neurotypical and may have short lives and severe neurocognitive disabilities, in addition to being entirely dependent on people or life-sustaining technologies? Phenomenology has provided valuable tools for analyzing the human experiences of suffering, but its application to neonatal suffering comes with fundamental challenges. In this paper, I consider recent contributions for elucidating the phenomenon of neonatal suffering, especially those in the field of non-experiential theories of suffering. Based on this review, a recent phenomenological approach to suffering is examined. Explicitly directed toward narrative persons, that approach appears to be inherently limited in elucidating the phenomenon of neonatal pediatric suffering. A suggestion is offered for partially elaborating the theoretical foundations of a phenomenological theory of neonatal suffering. This suggestion points towards a program for a phenomenology of the existential feelings of newborns.

Keywords: Neonatal suffering, theories of suffering, phenomenology, existential feelings

* Research for this paper was supported by CNPq (304109/2021-5) and FAPERGS (19/2551-0000691-8).

How to cite this article:

Reis, R. (2024). Neonatal pediatric suffering: limits of the phenomenology of suffering? *Estudios de Filosofía*, 70, pp. 160-179. <https://doi.org/10.17533/udea.ef.355671>





ARTÍCULOS
DE INVESTIGACIÓN

Sufrimiento pediátrico neonatal: ¿límites de la fenomenología del sufrimiento?

Resumen: El sufrimiento neonatal ha sido el foco de debates recientes en bioética pediátrica y teoría del sufrimiento. ¿Cómo debemos acceder y conceptualizar el sufrimiento que se puede atribuir a los recién nacidos? ¿Cómo podemos discernir el sufrimiento de los recién nacidos que no son neurotípicos y pueden tener vidas cortas y discapacidades neurocognitivas graves, además de ser totalmente dependientes de las personas o de las tecnologías que les sustentan la vida? La fenomenología ha proporcionado herramientas valiosas para analizar las experiencias humanas del sufrimiento, pero su aplicación al sufrimiento neonatal plantea desafíos fundamentales. En este artículo, se consideran contribuciones recientes para dilucidar el fenómeno del sufrimiento neonatal, especialmente aquellas en el campo de las teorías no experienciales del sufrimiento. A partir de esta revisión, se examina un enfoque fenomenológico reciente del sufrimiento. Dirigido explícitamente a personas narrativas, ese enfoque parece ser inherentemente limitado a la hora de dilucidar el fenómeno del sufrimiento pediátrico neonatal. Se ofrece una sugerencia para elaborar parcialmente los fundamentos teóricos de una teoría fenomenológica del sufrimiento neonatal. Esta sugerencia apunta hacia un programa para una fenomenología de los sentimientos existenciales de los recién nacidos.

Palabras clave: sufrimiento neonatal, teorías del sufrimiento, fenomenología, sentimientos existenciales

Róbson Ramos dos Reis; Full Professor in the Department of Philosophy at the Federal University of Santa Maria, Brazil. Research areas: phenomenology, hermeneutics, ontology, applied phenomenology, philosophy and health. Author of *Necessidade Existencial: Estudos sobre a Modalidade na Fenomenologia Hermenêutica* (2023), *Câncer infantil, Sofrimento e Transformação: um Ensaio Fenomenológico* (2022), *Aspectos da Modalidade* (2014).

<https://orcid.org/0000-0001-5380-1192>



1. Infant illness experiences and neonatal suffering

The phenomenological approach to child illness experiences is premised on a claim about a child's way of existing: they exist in a situated, enacted, and embodied manner (Carel, Feder & Gyorffy, 2019). As situated beings, children experience illness in a way that is partially determined by the role played by family members and caregivers. As enacted beings, they are limited in their decisions and actions by decisions made by adults. And embodiment in their case specifically means constant and rapid bodily changes. Although this condition bounds the possibilities of action for children, their actions affect adults. Furthermore, there is a significant difference between their bodily scheme and the bodily scheme of adults (Carel *et al.*, 2019). Considering that in illness experiences entail suffering (for example, in the experience of the symptoms and in diagnostic and treatment procedures), it is natural to suppose that that claim also holds for the elucidation of pediatric suffering.

To the best of my knowledge, we do not yet have a phenomenological theory of pediatric suffering. An initial challenge that must be faced in the elucidation of the conceptual grounds for such a theory lies in the ambiguity of the term "child". In the phenomenological claim mentioned above, "child" is explicitly used as an umbrella term designating a diverse group that includes newborns, infants, toddlers, preschool children, primary school age children, and adolescents (Carel *et al.*, 2019, p. 374). This is not just a semantic issue, given that the formulation of a concept of neonatal pediatric suffering appears to be a requirement issuing not only from the suffering brought about by illnesses and clinical conditions that affect newborns but also due to iatrogenic suffering issuing from advancements in medical technology. Better pre- and post-natal medical care now allows for the survival of infants with disabilities or lifelong medical conditions, though the interventions needed for their survival admittedly cause pain and discomfort (de Weerd, van Tol, Albers, Sauer & Verkerk, 2015). Although the survival of a child is possible through technological support, such as ECMO, it is also a fact that these technologies bring about new and diverse forms of suffering (Tate, 2020a). Until the 1980 newborns were considered insensitive to pain and were subjected to procedures and even surgery without analgesics (van Manen, 2019, p. 69; Anand & Hickey, 1987).

Nowadays, on the other hand, there is evidence that iatrogenic pain induced by aggressive treatments in neonatal intensive care also causes suffering in nursing teams (Green, Darbyshire, Adams & Jackson, 2014). Also, despite the subjective nature of suffering, it is acknowledged that infants may indicate non-verbally when their suffering is unbearable: through various kinds of crying, movements, and reactions to food. Scales are now available for determining the intensity of pain and discomfort in newborns. Parents and experienced caregivers may also manage to assess the intensity of suffering in newborns (Verhagen & Sauer, 2005, p. 959).

Newborn suffering is now acknowledged and suffering relief actions are performed. Palliative sedation and pediatric euthanasia (Hanson, 2016), for example, are interventions that are debated and effectively undertaken in dying children (Clément de Cléty, 2016). The concept of suffering has been operational, therefore, in medical decisions. Much like the concept of “futility”, the notion of suffering appears to have a definite and consistent meaning. Yet it is employed colloquially to refer to a wide variety of experiences, introducing surreptitiously value judgments about the quality of life of patients (Salter, 2020). In important contexts, life and death decisions are made about newborns. The Groningen Protocol, for example, explicitly states that unbearable suffering is a condition for performing euthanasia in newborns (Verhagen & Sauer, 2005, p. 961). This situation is shown to be even more pressing when one considers the outcomes of a review of the uses of “suffering” in 121 papers in pediatric bioethics. The term was used 651 times, and in 52% of the papers it was used in a context of specific medical decisions. In 32% of the excerpts, the term was used to justify decisions to terminate life, and in 10% it was used to support continuation of life (Friedrich, Dempsey & Salter, 2020).

Naturally, the critical issues brought about by the acknowledgment of neonatal suffering and the role played by that concept in the justification of medical decisions based on the notions of quality of life and the best interest of patients has been a focus of recent inquiries (Brancatisano, 2021; Isaacs, 2021; Massie, 2021; Tobin, 2021; Tate, 2020a; 2020c). This line of inquiry becomes even more complex when newborns with severe neurocognitive disabilities and low prognosis for typical development are taken into account. One such case has been brought up by Tate (2020b). Esther is a premature eight-day-old baby; she has severe lissencephaly syndrome and lives in an neonatal intensive care unit. Her medical team found out she needed surgery to remove a section of necrotic intestine. Some in the team raise questions about whether surgery is recommended in this case, given the futility of the suffering to which she will be subjected and the continued suffering she will face throughout her short life afterwards. The parents wish what’s best for Esther. A nurse questions how much can be known about the nature and extent of her suffering, if something can be known at all about it. What is and how can we know about the suffering of human beings whose mind or experiential world are especially opaque to others?

Regarding this critical context of assessment laid out by Tate there is little theorization in the recent literature and also a lack of precision regarding ontological, epistemic and ethical questions about the suffering of someone too young to adequately communicate (Tate, 2020b, p. 139). Some efforts to mitigate these problems have been made and will be looked into below, as a first step towards answering the question whether the phenomenological approach to suffering has found an insurmountable challenge in this issue.

2. Types of theories of suffering and the limits of value-based theories

A typology of theories of suffering is useful for identifying which notions of suffering are restrictive in the sense that they make requirements that are not satisfied by newborns. A recent formulation distinguished three types of theories of suffering (Kious, 2021). Theories based on feelings identify suffering with unpleasant feelings. These theories conceive suffering as feeling unwell – feeling pain, for example. Suffering is simply the opposite of happiness.

Value-based theories conceive suffering as a state of affliction associated with a loss or a threat to something one regards important or valuable. The sources of the threat may be diverse and objects of value are varied. One should note that the concept of value is to be understood in a wide sense. For example, one may value what one desires or wants, what exerts attraction, and what one is willing to obtain. Whatever is the focus of care and attention may be valuable, and relative to it one may have a favorable attitude, a feeling of love or wanting. Crucially, this notion of value does not require a propositional capacity for making assessments.

Eric Cassell's (1991) personalist theory of suffering is a paradigmatic example of this type of theory. The conative theory of suffering as a second order desire (Brady, 2018) is also an example. The notions of suffering as negative affective interpretation (Kauppinen, 2020) and as global mental disruption (McClelland, 2020) are both value-based type theories. The theory of suffering as a significant disruption of agency assumes some valuation phenomena, insofar as it purports to relativize the strict distinction between objective and subjective suffering (Corns, 2022). However, the qualification of disruption as significant or important is sufficient for situating this theory in the value-based type as well. The theory of Patient Subjective Feeling (Tate & Pearlman, 2019), which conceives suffering as a negative existential feeling associated with possible losses in the sense of self, is also an example of value-based type experiential theory. Likewise, the Comprehensive Clinical Model of Suffering is a value-based type theory, since it understands suffering as sorted along four axes (biomedical, psycho-behavioral, socio-cultural, and existential), which include domains in which suffering is experienced as a loss or threat of a loss (Phillips, Uygur & Egnew, 2023).

It is important to underscore that the complex phenomenological notion of suffering, understood as an existential feeling referred to the disruptions expressed in one's embodiment, in the full domain of intentionality, in the narrative self, and in areas of strong evaluations (Svenaesus, 2014; 2020) is also a value-based theory. Likewise, the ontological-existential view of suffering as a mismatch between identifying possibilities and the intentional context of reference, and – in the extreme case – as a fine-graining of the possibility of impossibility, assumes a

kind of valuation in the opening of intentional contexts from significant existential possibilities (Walsh, 2022).

Theories based on teleology and flourishing are situated in the field of the non-experiential views of suffering. Someone may suffer objectively regardless of having an afflictive or unpleasant experience, whenever needs that condition teleologically oriented abilities are not satisfied. Suffering is a disturbance or obstruction of the flourishing that is proper to human life. This type of theory describes suffering as a frustration of the tendency to satisfy the internal *telos* of a vegetative, conative, deliberative-volitional, and contemplative life (van Hooft, 1998).

Regarding neonatal suffering, Tate correctly pointed out that Brady's and Cassell's theories are inappropriate, because they demand experiential conditions that cannot be attributed to newborns with severe neurocognitive disabilities. Apparently the same is true of the views held by Kauppinen, McClelland, and Corns, though a more detailed examination needs to be carried out. Overall, the attribution of a valuing capacity to newborns is not ruled out *a priori*, even if it surely cannot be a valuate capacity based on an ability to judge. It appears that the theories based on feelings would be the most appropriate for accounting for newborn suffering. This seems to be the view adopted, for example, in the Groningen Protocol, in which suffering is referred to as a subjective feeling (Verhagen *et al.*, 2005, p. 959). Yet, it seems less appropriate to seek a conceptualization of newborn suffering within the framework of value-based type theories, given that they imply a kind of experiential life capable of valuations, albeit very basic ones. There are thus reasons for choosing to elucidate the notion of newborn suffering through teleological and flourishing based theories.

3. Objective suffering in newborns

A recent proposal for a theory of pediatric suffering adequate for elucidating typical newborns as well newborns with conditions such as those of Esther (severe cognitive disabilities) issues from three theoretical requirements (Tate, 2020c). First, such a theory cannot be purely experiential, that is, based on some kind of subjective experience lived in the first person by the newborn. There is intuitive support for the claim that pre-linguistic babies and babies that do not speak or have self-awareness can experience suffering and not just pain. However, their expressive abilities are robustly limited, which render opaque their feelings, emotions etc. According to Tate (2020c, pp. 148–153), not even the proposal for enhanced experiential theories, such feeling and conative theories (Mayerfeld, 1999; Brady, 2018), are adequate for newborn conditions such as those of Esther. Second, a theory adequate to that condition must be objective, that is, it must conceive suffering objectively as a lack of flourishing specific to the

species. Third, that theory must not remain at a general level, but must also account for individual babies in clinical contexts and also be adequate to the ontology of very young children. In other words, not only does it have to be individualized, as it must also cohere with the type of being that a very young child is.

Observing these requirements, the objective theory of pediatric suffering initially identifies the suffering conditions of a healthy non-disabled newborn. These are necessary and sufficient conditions for their flourishing: warmth, protection, human touch, pain relief, access to appropriate milk, etc. In the absence of these, newborns suffer. At this point, the ontology of infants brings in an important trait of pediatric suffering. Newborns are entirely dependent on others; hence, their flourishing happens only within one-way relations of care. This fact renders pediatric suffering an intrinsically social and political event. Thus, the determination of pediatric and neonatal suffering can be made objectively, by identifying the specific natural teleology of the species. By identifying the conditions for the flourishing of an individual or of a population in a particular environment, in a given stage of their development, one also discriminates the conditions for their suffering: the absence of these characteristics brings about an obstruction or disturbance in their flourishing. This demystifies or desubjectivizes pediatric suffering (Tate, 2020c, p. 156).

The theory of objective pediatric suffering is further detailed for cases of babies and children with severe neurocognitive disabilities. This specification is carried out through a critical movement that begins by noting that the human species admits a wide spectrum of individualities. Each has unique and singular trajectories and teleologies. The specific teleology of the individual relates to a set of needs that are equally unique and singular. Hence, the suffering of babies such as Esther occurs when singular needs that answer for the possibility of their singular teleology are not met. This lack is unique to each individual and evolves on a daily basis. The flourishing of these babies is likely to differ a lot from what is typical for other members of the human species (growth into a language speaking child, who is autonomous, intelligent, rational, and capable of interpersonal relations with complex intentionality emotions, etc.), but it still may happen. Tate states that there can be flourishing even in the dying of a baby such as Esther (Tate, 2020c, p. 158). In sum, individual flourishing may happen according to individual limitations and capabilities. The suffering of disabled newborns means, therefore, that the conditions that allow for the unfolding of the corresponding individual teleology are not met.

This theory was subject to a recent critical examination (Kiouss, 2023). Two overarching problems were pointed out: (1) care is said to be identical to flourishing, that is, meeting the conditions for flourishing would be identical to flourishing; and (2) there is a tension between holding that there can be species-specific flourishing and individual-specific flourishing. Both problems bring about a series of equally

troublesome consequences. The first difficulty rules out the possibility of a child suffering (not flourishing) despite being adequately cared for; it also shows a lack of a criterion for identifying *which kind* of care is needed for avoiding pediatric suffering. The second problem seems to entail the dissolution of the phenomena of suffering itself, insofar as individual-specific flourishing simply means being your own singular way. Hence, there would be no suffering properly speaking when that flourishing is prevented from happening: one then would not be able to be the unique and singular way one is. Furthermore, the relational and relative approach (social and individual-specific) threatens the very integrity of the notion of suffering. This is not the place to examine the cogency of those arguments. Yet we should underscore the philosophical orientation of the theory put forth, which is an objective suffering type theory, based on the concepts of life teleology and flourishing. Nonetheless, the need for integrating experiential elements into the theory of neonatal suffering and of the suffering of severely disabled children is acknowledged. Thus, the experiential theories of suffering – among them the phenomenological theory – could still offer a contribution to the understanding of pediatric suffering. Given this complex phenomena, a pluralistic attitude appears to be more adequate.

4. Pluralism about neonatal suffering

The pluralist concept of suffering was recently put forth aiming at integrating into a model the various ways infants and non-verbal children may suffer (Zayegh, 2022). This is a multidimensional approach to child suffering, which acknowledges that pediatric suffering can be both subjective and objective. Subjective suffering encompasses negative experiences associated with pain, discomfort, and emotional affliction. Objective suffering refers to a reduction in the capacity to attain future or present elements of well-being.

Accepting that children can suffer in a subjective sense entails an acknowledgement of some basic level of consciousness, enough to perceive negative experiences associated with pain or emotional affliction, for example. This basic level of consciousness does not require a formed sense of personality, nor the ability to communicate. This proposition is offered on the basis of studies on consciousness and the presence of emotional affliction in newborns (Zayegh, 2022, p. 205). Also, subjective suffering can be sorted into measurable components, identifiable in observable behavior and psychological changes, and potentially unmeasurable components. It is associated with the language of harm.

Child objective suffering is associated with limitations in the capabilities for attaining objective goods, present and future. Objective suffering, therefore, relates to

losses in the capacity for attaining those objective elements of well-being associated with what one conceives as human flourishing. It is important to highlight that objective suffering is not viewed as a state inherent to an individual (mere limitation in the capacity for hearing, for example, by itself does not entail suffering), but as relative to a comparison with counterfactual situations. It is associated with the language of loss (Zayegh, 2022, p. 207).

The two types of suffering, objective and subjective, can happen locally or globally. Local subjective suffering refers to a negative experience occurring at a specific moment in time. Global subjective suffering has to do with an assessment of the *quantum* of negative experiences relative to positive experiences throughout an individual's life. Local objective suffering comprises a reduced capacity for attaining an objective component of well-being – for example, ceasing to be able to walk. When a general reduction in the capacity for attaining elements of well-being occurs, one has objective global suffering.

The proposal of a pluralistic notion that accounts for the suffering of newborns and non-verbal infants has a clear practical orientation. Elaboration of this concept purports to yield a model that can be applied in the area of communication and, especially, in shared decision-making about suffering children (Zayegh, 2022, p. 208). The pluralistic approach is also theoretically promising. A positive aspect is its inclusiveness regarding the various ways a newborn can suffer. It thus counterweights the allegation that the purely experiential approaches to suffering are insufficient (Tate, 2020c, p. 154). Acknowledging, on the basis of evidence, the possibility of child subjective suffering also allows for a formulation that is not merely conceptual of the problem of the limits of the phenomenological approach to pediatric suffering. In the next section, I reconstruct in more detail this approach, aiming at defining a conceptual framework for examining the challenges posed to a phenomenology of neonatal suffering.

5. The phenomenological notion of suffering

A phenomenological approach to the suffering of persons was put forth by Fredrik Svenaeus (2014; 2018; 2020). On this approach, suffering is an affective phenomena with multiple integrated experiential levels. Although interconnected, those levels must be distinguished: proper embodiment, engagement with others in the world, core life values. As an affective phenomena, suffering is an existential feeling. Based on a thorough elucidation of this type of affective phenomena done by Ratcliffe (2008; 2020), suffering is presented as an bodily world-disclosing feeling, that is, it renders possible the modalities of intentional behavior and meaningful relations with something. Existential feelings can be positive or negative. So as to qualify the

existential feeling of suffering, a criterion of severity was introduced. Suffering is thus viewed as an alienating existential feeling experienced in one's embodiment, practical engagement with other persons or with things, and core life values. Suffering is an alienating mood (*Stimmung*) that overwhelms someone, enveloping her in an effort to maintain familiarity in the world in an absence of purpose and meaning in life (Svenaesus, 2014, p. 413).

Seen close up, suffering entails afflictive experiences in three dimensions. In embodiment, the living body is experienced as strange, which has been described as a *dys-appearance* (Leter, 1990, p. 69). The alienating mood also presents itself in the intentional dimension, that is, in one's engagement with projects and goals as well as with persons and objects. Lastly, suffering is experienced at the level of core life values. In this dimension one finds primary assessments about what is significant, that which makes up part of the basis for the structuring of the sense of self. In these values there are areas of strong evaluation: values about how other persons are to be treated, about the content of a good life, and about self-identification as someone worthy of the respect of others. This territory of core values requires interpretation, which entails a horizon of self-reflection. Naturally, that reflection is not made up primarily of theoretical or philosophical elucidation, but comprises a horizon to which one comes to belong with the support of others. Suffering presents itself, therefore, as an alienating existential feeling that impacts those areas of strong evaluation and interpreted core life values.

The phenomenological approach conceives suffering as an alienating mood, an existential feeling present in integrated experiential levels: one's embodiment, being-in-the-world, and core life values. It is, therefore, an experiential notion of suffering. Yet it also contains aspects of the theories of objective suffering based on flourishing. Suffering refers to situations in which a person is prevented from flourishing and experiences that limitation as a loss in his or her condition of being in the world. In other words, suffering is an existential feeling in which efforts to flourish are obstructed (Svenaesus, 2022, p. 379). This characteristic of the phenomenological notion of suffering must be underscored because even though situated in the category of the subjective or experiential approaches, it still incorporates a reference to objective elements of flourishing. By actually centering the elucidation of suffering in the field of the theory of affectivity and, more specifically, by focusing on existential feelings, the phenomenological theory of suffering must be placed in a very special category. Suffering is conceived as an affective pre-intentional phenomena that conditions both the experiences of harm and the fact of a loss. Thus, suffering is not presented as a threat to something one values nor as an absence of the conditions for flourishing, but as something more basic, namely, as a disruptive change in the pre-intentional affective domain that conditions the living of the threat to what one values or of that which obstructs flourishing. Naturally, the phenomenological notion

of suffering refers to the evaluative and flourishing aspects, but as derived from the alienating mood or existential feeling.

Even if the phenomenological approach to suffering has not been presented as a clinical concept ready to be used in curative treatments and in palliative care contexts, it is oriented towards situations implicated in professional health care practice. The phenomenological notion of suffering conceives health and illness as belonging to the field of philosophical anthropology, understanding human beings as capable of suffering as embodied creatures, intrinsically embedded in the world, affectively attuned and capable of flourishing. An implication of this understanding is the conception of empathy for patients as a requirement that must be developed by health care professionals. Empathy means, in this context, a basic way of acquiring knowledge about patients as suffering persons, in and through dialogue with them (Svenaesus, 2022, pp. 380–381). Given this brief reconstruction, we can now turn to the question whether the phenomenological notion of suffering is adequate for an elucidation of neonatal pediatric suffering.

6. Guidelines for a phenomenology of neonatal suffering

It is noteworthy that the elucidation of suffering experiences as transformative experiences, which is put forth based on a phenomenology of anthropological existentials, has at its origin Michael Brady's definition of suffering, which is not phenomenological (Carel & Kidd, 2020, p. 173). It is interesting that a leading figure of the phenomenological approaches to illness (Havi Carel) employs a concept formulated within the analytic philosophy of suffering. A speculative hypothesis for this fact might explain that choice based on the intent, associated to Brady's definition, of elaborating an overall theory of suffering that would include non-human animals and humans that do not yet have higher cognitive capabilities. However, that choice might be justified by the simple fact that we still do not have a phenomenological theory or notion of pediatric suffering in general and of neonatal suffering in particular.

The phenomenological notion of suffering laid out by Svenaesus is explicitly formulated to elucidate the suffering of persons. It is not sufficiently wide to include the suffering of non-human animals, nor of populations designated as pre-persons, very young persons, very old persons, and post-persons. Quite the contrary, it is a notion that purports to conceptualize the suffering of narrative persons (Svenaesus, 2018, pp. 136–144). If it is correct that a narrative person begins to emerge at around four years of age, with the beginning of the formation of stories about oneself that incorporate interpretations in the field of strong evaluations about core nuclear values, then the phenomenological concept of suffering could provide a basis for a

theory of the suffering of children and adolescents. Unless shown otherwise, this is a program yet to be developed. The phenomenological concept of neonatal suffering cannot operate under the assumption of a narrative person already established or already on its way. This is precisely an important challenge for the phenomenological theory of suffering, namely, the elaboration of a specifically phenomenological notion capable of accounting for the suffering of babies and infants with severe neurocognitive disabilities.

The elaboration of a phenomenology of neonatal suffering might benefit from two methodological suggestions. First, the formulation of a phenomenological concept of pediatric neonatal suffering needs to avoid a purely abstract procedure that would seek to identify, based on the concept of the suffering of narrative persons, those aspects that are absent in newborns. That procedure would conceive babies as small children or as small adults, formulating a concept of neonatal suffering by abstraction from aspects typical of adults or narrative persons. The second suggestion has to do with the direction of the interrogation, that is, what would the adequate question need to be to give rise to a phenomenology of neonatal suffering? This suggestion has implications, therefore, for the elaboration of the initial question. The issue raised by Tate – “what kind of a thing a child actually is” (2020c, p. 154) – can be a starting point, assuming that it is understood as a formal indication. This is an ontological issue that needs to be worked on phenomenologically.

In this case, it assumes the question about the context in which a newborn is presented as a phenomena. How do babies present themselves as babies, that is, how do newborns donate themselves as newborns? To be sure, this is a varied and changing context, but it has a formal trait. Newborns are present as such in relations of care, in the dyad baby–caregivers. This is a simplified answer, because it is formal. It comprises both the contexts of pre-natal interaction and, beyond parental care, the interventions and attention offered in neonatal intensive care units.

Having in mind this indication, the phenomenological approach cannot disregard that the systematic thematization of the constitution of human babies in relations of care and interaction has been taken up in robust empirical investigations. There is a wealth of recent investigations on the characteristics, processes, and mechanisms, at a personal and subpersonal level, that can be identified in newborns (Rochat, 2004). This seems to be a trivial indication. Yet it acquires relevance when one considers that the results of empirical investigations in Developmental Psychology have brought about a fundamental change in the understanding of the general constitution of newborns. More specifically, the hypotheses of non-dualism and syncretic sociality have been driven away as they have been shown to be deprived of an empirical basis (Reis, 2020). This means that the phenomenology of the newborn can no longer assume, as it used to, that babies are in a state of fusion, non-dissociation, natural autism or mental disorganization.

It is not possible to review here the consequential results of empirical research about the mental and experiential life of newborns (and fetuses also). It suffices to consider the following results. Newborns exhibit a sensorial awareness of painful stimuli, the ability to distinguish their own touch from that of someone else, the sense that their bodies are separate from the world, the capacity to express emotions and to exhibit signs of shared feelings (Lagerkrantz & Changeux, 2009). They have some minimum awareness of themselves as differentiated and situated alongside others in the world. They have an ecological and interpersonal sense of themselves. This self-consciousness shows itself at least in contexts of sensation, perception, action, and affection. There is empirical evidence that babies already have at birth a minimum awareness of their own bodies as unified and organized. Also, newborns have a proclivity to detect identity in the experience of things in the environment, in the experience of other persons and in subjective, embodied experience of being in the world in a felt, perceptual, and agential way (Rochat, 2011).

Since the hypothesis of non-social syncretism and baby-world fusion was dropped, the question “what kind of thing is in fact a child?” has received the following phenomenological reformulation: how must a baby be so as to have meaningful experiences of a minimum intersubjective and ecological self? Naturally, this is a research program for a phenomenological ontology of newborns, which also needs further qualification from a processual and developmental ontology. The empirical and phenomenological investigations about the experience and the experiential world of babies play an indispensable role in this program. One may also speculate that neonatal suffering, as a disruptive phenomena, might be an epistemically privileged field in this ontological program.

Even though this is a recent field of investigation, as is the project of a developmental phenomenology (Vincini & Gallagher, 2021), already an important contribution for the phenomenology of the neonatal world has been made (van Manen, 2019). Relative to the main point of neonatal suffering, one may note the incorporation into that phenomenology of the advancements made in empirical studies on pain, agitation, and other afflictive infant experiences. One should consider, for example, that the variations in the visible manifestations of suffering can vary according to illness and maturity. Also, perceived afflictive behaviors do not necessarily correspond to afflictive experiences (van Manen, 2019, p. 75).

The purpose of these indications was simply to offer suggestions for an adequate phenomenological formulation of the ontological question that should guide the elaboration of a phenomenology of neonatal pediatric suffering. On the one hand, one must consider the field of the phenomenalization of newborns: the interpersonal and care relations. Furthermore, one must take into account the best evidence coming from the empirical investigation of newborns, especially the evidence from Developmental Experimental Psychology. Regarding this point, the giving up of the

hypothesis of fusion or non-social syncretism and the acceptance of a minimal *self* already at birth is a result that renders consistent the program for a phenomenology of the newborn world. Based on it, a phenomenology of newborn suffering – which is still to be elaborated – may be outlined. To conclude this paper I will lay out a programmatic suggestion that needs to be detailed conceptually and assessed empirically.

7. The development of newborn existential feelings and suffering

The phenomenological approach conceives suffering as an affective phenomena, an alienating existential feeling that shows up in various experiential levels: in embodiment, in shared agent intentionality and in the areas of core interpreted life values. Suffering is basically an existential feeling. According to Ratcliffe, existential feelings make up an extremely diverse special class of affective phenomena (Ratcliffe, 2008; 2016; 2020). They are bodily feelings, not emotions. Also, they are bodily feelings not directed to something different from the body itself, nor to parts of one's body. Rather, existential feelings are pre-intentional, both in the sense of being conditions of all modalities of intentional experiences and in the sense of bringing about the original disclosure of the world. In formal terms, existential feelings make up a sense of reality and belonging. Reality and belonging, in turn, are conceived structurally as non-inferential experiences of possibility. More precisely, existential feelings make up a sense of being posited and of existing in a space or horizon that shelters kinds of possibilities. The possibilities are categorized, furthermore, as possibilities that matter, possibilities of intersubjective agential actualization, possibilities that foster actions pertaining to capabilities and possibilities whose actualizations are associated to affective styles of anticipation. The latter is manifestly the most complex, since human experience has a structure of anticipation of possibilities that is complicated, multifaceted, dynamic, and cohesive (Ratcliffe & Broome, 2022, p. 66). The habitual form of the affective style of anticipation of possibilities is that of basic trust (Ratcliffe, 2023, 2014). The spaces of possibilities evident in existential feelings are, finally, intrinsically dynamic and vulnerable to erosions, losses, and recoverings. In general, existential feelings act in a tacit and pre-reflexive manner, but are susceptible to changes that allow for their thematization.

The suggestion is that we elucidate phenomenologically newborn suffering by focusing investigation not only on experiential harm and teleological losses of the conditions for flourishing, but on the existential feelings of newborns. Considering the evidence provided by the Ecological Psychology of Development, which strongly indicates the presence of minimal intentional experiences already at birth and also a primary form of intersubjectivity, it is natural to infer that newborns are also affected by existential feelings. The proposed suggestion, in more general terms, consists

in elaborating a phenomenology of the development of existential feelings. This program is not limited to newborns and may be extended to babies with secondary intersubjectivity as well as children. However, for a contribution to the foundations of a phenomenological approach to neonatal suffering, the investigation would need to focus on the phenomenology of newborn existential feelings, with a special attention to chronically ill and non-neurotypical babies.

This suggestion can be further qualified by the indications coming from the operating phenomenological premise of the phenomenology of pediatric illness, namely, (1) the fact of the one-way dependency of infants regarding caring practices, and (2) the relational conception of neonatal suffering. The phenomenological premise maintains that infant patients are constitutively dependent and situated in a family and caregiver context (Carel *et al.*, 2019, p. 374). Babies exist as contingent beings, i.e. exist only if they receive the time, energy, and care of those who act in their favor (Tate, 2020c, p. 154).

The relational attitude claims that neonatal suffering should be examined not only intrinsically, but taking into account the suffering present in caring relations. In the case of non-neurotypical newborns, their suffering experiences are potentially unknowable, turning on the external perspectives of acknowledgment, relative to which there are few resources for verifying attributions of suffering. From a relational attitude one considers that the suffering identifiable in care relations can be epistemically privileged for the attribution of suffering to newborns. The assumption carried by this attitude resides in the acknowledgment of the ontologically basic nature of relations, of the constitutive interdependence and relationality of human beings, as well as of the fact that the relations in which development and flourishing happen begin very early, in a condition of extreme dependency (Campelia, Kett & Wightman, 2020, p. 168).

These three basic conceptions point to an orientation for the phenomenology of the existential feelings of newborns. One is to examine the formation of existential feelings from social relations of care, which, naturally, begin even before birth. In structural terms, the phenomenology of the development of existential feelings in newborns would examine the acquisition or freeing-up of a space or horizon of possibilities based on social and care interactions. On the other hand, dependency and relationality are not relevant only in the thematic orientation of the study of newborn existential feelings, but also have epistemic relevance. The existential feelings of caregivers are important indicators of the existential feelings of babies. To sum up, the extreme dependency of newborns does not only mean that they depend on being cared for by others to survive and have their needs met. The very constitution or freeing-up of the horizon of possibilities is constituted relationally, and must be thematically and methodologically considered in the phenomenology of infant existential feelings.

In terms of thematic topics, the ontology of existential feelings in general offers delimitation of possible fields of phenomenological inquiry. As bodily feelings, the embodiment of newborns represents a domain that is conducive to the identification of existential feelings and their dynamics. Extreme dependency, in turn, entails that intercorporeality also needs to be examined in the phenomenological analysis of infant existential feelings. As feelings of belonging to a space of possibilities, the study of the development of existential feelings in childhood ought to consider the acquisition or freeing-up of types of possibilities, considering that babies are situated in the familial horizon of possibilities. The intersubjective agential determination of possibilities, that is, that some possibilities are actualized by someone, by no-one or by more than one person can also be approached from the perspective of the primacy of caring relations.

No less relevant is the focus on the phenomenological analysis of the formation of affective styles of anticipation of possibilities. Basic trust is considered a habitual manner of anticipating actualizations of possibilities. In this sense, the studies on the development of trust and, especially, of basic trust, are crucial to the phenomenology of infant existential feelings. Given the centrality of interpersonal relations for basic trust (Ratcliffe, Ruddell & Smith, 2014, p. 5) – trusting others – the focus on relations of care assumes a privileged position in the phenomenology of the development of the affective style of anticipating possibilities. Naturally, insofar as the horizon of possibilities is a dynamic, subject to robust changes, the examination of the types of dynamics in infant existential feelings is a special field of inquiry in the phenomenological research program for a phenomenology of neonatal suffering. In this sense, studies on the regulation of existential feelings offer a starting point for that inquiry (Stephan, 2012; Ratcliffe, unpublished).

These indications for a research program of a phenomenology of the existential feelings of newborns are rather incipient and schematic. Alongside the conceptual difficulties they entail (for example, the meaning of infant space of possibilities, the criteria for sorting those possibilities, as well as the meaning of their specific dynamics), the methodological challenges are evident. The study of existential feelings in adults can make use of autobiographical material and of case reports in the psychopathological and psychiatric literature. In both cases, the resources are written documents and verbal reports. None of this is available for the study of existential feelings of newborns, except for documents occasionally produced by caregivers. In this case, empirical research is unavoidable, especially the type carried out according to the more recent phenomenological methodologies for qualitative research. Here, too, there are major challenges. To be sure, the methodologies for acquiring experiential data from interviews are pertinent to the study of experiences of relations of care. To the best of my knowledge, the phenomenological approach (Klinke & Fernandez, 2022) has not yet been applied to the analysis of observational

evidence of newborn behavior. These conceptual and methodological challenges need to be faced, so that there may be a phenomenological contribution to the theory of neonatal suffering.

8. Conclusion

In this paper I have revised two recent proposals for elucidating newborn suffering: the theory of suffering as an individual-specific non-flourishing and the pluralistic model of neonatal suffering. The pluralistic model admits that newborns may suffer in an experiential and not merely objective sense, and is relevant for a possible phenomenological approach to neonatal suffering. I considered the phenomenological notion of suffering, understood as an alienating existential feeling that is manifest in integrated levels of embodiment, shared agent intentionality, and areas of core life values. I underscored that the notion is appropriate for elucidating the suffering of persons who already have a narrative self. Evidently, it does not seem adequate for accounting for neonatal suffering, especially that of babies whose clinical condition entails severe neurocognitive disabilities. Yet it suggests a phenomenological contribution for the theory of neonatal pediatric suffering. In fact, that suggestion comprises a program for a developmental phenomenology of existential feelings, emphasizing the phenomenological elucidation of the existential feelings of newborns. This suggestion needs to face up to conceptual, methodological and empirical challenges, but it represents a promising path for approaching phenomenologically neonatal pediatric suffering. Evidently, the clinical and bioethical applications of this approach also poses urgent and theoretically robust challenges for the phenomenology of suffering.

References

- Anand, K. J.; Hickey, P. R. (1987). Pain and its effects in the human neonate and fetus. *The New England Journal of Medicine*, 317(21), 1321–1329. <https://doi.org/10.1056/NEJM198711193172105>.
- Brady, M. (2018). *Suffering and Virtue*. Oxford University Press.
- Brancatisano, S. (2021). Suffering and end-of-life decision making. *Journal of Paediatrics and Child Health*, 57(5), 766. <https://doi.org/10.1111/jpc.15461>.
- Campelia, G.; Kett, J; Wightman, A. (2020). Relational suffering and the moral authority of love and care. *Theoretical Medicine and Bioethics*, 41(4), 165–178. <https://doi.org/10.1007/s11017-020-09530-z>.

- Carel, H.; Feder, G.; Gyorffy, G. (2019). Children and health. En A. Gheaus; G. Calder; J. Wispelaere (Eds.), *The Routledge Handbook of the Philosophy of Childhood and Children* (pp. 373–383). Routledge.
- Carel, H.; Kidd, I. (2020). Suffering and transformative experience. En D. Bain; M. Brady; J. Corns, J. (eds.), *Philosophy of Suffering: Metaphysics, Value, and Normativity* (pp. 165–179). Routledge.
- Cassel E. (1991). *The Nature of Suffering and the Goals of Medicine*. Oxford University Press.
- Clément de Cléty, S.; Friedel, M.; Verhagen, A. A.; Lantos, J. D.; Carter, B. S. (2016). Please do whatever it takes to end our daughter's suffering! *Pediatrics*, 137(1). <https://doi.org/10.1542/peds.2015-3812>.
- Corns, J. (2021). Suffering as significantly disrupted agency. *Philosophy and Phenomenological Research*, 10 (3), 706–729. <https://doi.org/10.1111/phpr.12841>.
- de Weerd, W.; van Tol, D.; Albers, M.; Sauer, P.; Verkerk, M. (2015). Suffering in children: Opinions from parents and health-care professionals. *European Journal of Pediatrics*, 174(5), 589–595. <https://doi.org/10.1007/s00431-014-2440-1>
- Fitzgerald M. (2015). What do we really know about newborn infant pain? *Experimental Physiology*, 100(12), 1451–1457. <https://doi.org/10.1113/EP085134>.
- Friedrich, A. B.; Dempsey, K. M.; Salter, E. (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-suffering-in-pediatric-bioethics-and-clinical-literature-a-qualitative-content-analysis>.
- Green, J.; Darbyshire, P.; Adams, A.; Jackson, D. (2016). It's agony for us as well: Neonatal nurses reflect on iatrogenic pain. *Nursing Ethics*, 23(2), 176–190. <https://doi.org/10.1177/0969733014558968>.
- Hanson S. S. (2016). Pediatric euthanasia and palliative care can work together. *The American Journal of Hospice & Palliative Care*, 33(5), 421–424. <https://doi.org/10.1177/1049909115570999>
- Isaacs, D.; Preisz, A. (2021). Suffering and end-of-life decision-making. *Journal of Paediatrics and Child Health*, 57(9), 1356–1359. <https://doi.org/10.1111/jpc.15380>.
- Kauppinen, A. (2020). The world according to suffering. En D. Bain; M. Brady; J. Corns (eds.), *Philosophy of Suffering: Metaphysics, Value, and Normativity* (pp. 19–36). Routledge.
- Kious B. (2022). Three kinds of suffering and their relative moral significance. *Bioethics*, 36(6), 621–627. <https://doi.org/10.1111/bioe.13021>.
- Kious B. (2023). Suffering and the dilemmas of pediatric care: a response to Tyler Tate. *Theoretical Medicine and Bioethics*, 44(3), 249–258. <https://doi.org/10.1007/s11017-023-09615-5>.
- Klinke, M.; Fernandez, A. (2022). Taking phenomenology beyond the first-person perspective: conceptual grounding in the collection and analysis of observational evidence.

- Phenomenology and the Cognitive Sciences*, 22 (1), 171–191. <https://doi.org/10.1007/s11097-021-09796-1>.
- Lagercrantz, H.; Changeux, J. P. (2009). The emergence of human consciousness: from fetal to neonatal life. *Pediatric Research*, 65(3), 255–260. <https://doi.org/10.1203/PDR.0b013e3181973b0d>.
- Leder, D. (1990). *The Absent Body*. University of Chicago Press.
- Massie J. (2021). Suffering and the end of life. *Journal of Paediatrics and Child Health*, 57(7), 979–980. <https://doi.org/10.1111/jpc.15566>.
- Mayerfeld, J. (1999). *Suffering and Moral Responsibility*. Oxford University Press.
- McClelland, T. (2020). The disruption model of suffering. En D. Bain; M. Brady; J. Corns (eds.), *Philosophy of Suffering: Metaphysics, Value, and Normativity* (pp. 37–54). Routledge.
- Phillips, W. R.; Uygur, J. M.; Egnew, T. R. (2023). A comprehensive clinical model of suffering. *Journal of the American Board of Family Medicine*, 36(2), 344–355. <https://doi.org/10.3122/jabfm.2022.220308R1>.
- Ratcliffe, M. (2008). *Feelings of Being. Phenomenology, Psychiatry, and the Sense of Reality*. Oxford University Press. <https://doi.org/10.1093/med/9780199206469.001.0001>
- Ratcliffe, M. (2015). *Experiences of Depression. A Study in Phenomenology*. Oxford University Press.
- Ratcliffe, M. (2020). Existential feelings. En T. Szanto; H. Landweer, (eds.). *The Routledge Handbook of Phenomenology of Emotion* (pp. 250–261). Routledge.
- Ratcliffe, M. (2023). The underlying unity of hope and trust. *The Monist*, 106, 1–11. <https://doi.org/10.1093/monist/onac018>.
- Ratcliffe, M. (unpublished). Scaffolding regulation and the social world: A perspective on human emotional experience. Available at <https://www.academia.edu/92412177/>.
- Ratcliffe, M.; Broome, M. (2022). Beyond “salience” and “affordance”: Understanding anomalous experiences of significant possibilities (50–69). En S. Archer (ed.). *Salience*. Routledge.
- Ratcliffe, M.; Ruddell, M.; Smith, B. (2014). What is a “sense of foreshortened future?” A phenomenological study of trauma, trust, and time. *Frontiers in Psychology*, 5, 1–11. <https://doi.org/10.3389/fpsyg.2014.01026>.
- Reis, R. (2020). Fenomenologia hermenêutica e psicologia experimental do desenvolvimento. *Ekstasis. Revista de Hermenêutica e Fenomenologia*, 9(20), 149–194. <https://doi.org/10.12957/ek.2020.51551>.
- Rochat, P. (2011). What is it like to be a newborn? En S. Gallagher (ed.). *The Oxford Handbook of the Self* (pp. 57–79). Oxford University Press.
- Salter, E. K. (2020). The new futility? The rhetoric and role of “suffering” in pediatric decision-making. *Nursing Ethics*, 27(1), 16–27. <https://doi.org/10.1177/0969733019840745>.

- Svenaesus, F. (2014). The phenomenology of suffering in medicine and bioethics. *Theoretical Medicine and Bioethics*, 35(6), 407–420. <https://doi.org/10.1007/s11017-014-9315-3>.
- Svenaesus, F. (2018). *Phenomenological Bioethics: Medical Technologies, Human Suffering, and the Meaning of Being Alive*. Routledge.
- Svenaesus, F. (2020). To die well: The phenomenology of suffering and end of life ethics. *Medicine, Health Care and Philosophy*, 23(3), 335–342. <https://doi.org/10.1007/s11019-019-09914-6>.
- Svenaesus F. (2022). Health and illness as enacted phenomena. *Topoi: An International Review of Philosophy*, 41(2), 373–382. <https://doi.org/10.1007/s11245-021-09747-0>
- Tate T. (2020a). Pediatric suffering and the burden of proof. *Pediatrics*, 146(1), S70–S74. <https://doi.org/10.1542/peds.2020-0818N>
- Tate T. (2020b). Philosophical investigations into the essence of pediatric suffering. *Theoretical Medicine and Bioethics*, 41(4), 137–142. <https://doi.org/10.1007/s11017-020-09531-y>
- Tate, Tyler (2020c). What we talk about when we talk about pediatric suffering. *Theoretical Medicine and Bioethics*, 41(4), 143–163. <https://doi.org/10.1007/s11017-020-09535-8>.
- Tate, T.; Pearlman, R. (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. <https://doi.org/10.1353/pbm.2019.0005>.
- Tobin, B. (2021). Suffering and end-of-life decision-making. *Journal of Paediatrics and Child Health*, 57(9), 1360–1361. <https://doi.org/10.1111/jpc.15437>
- van Hooft, S. (1998). Suffering and the goals of medicine. *Medicine, Health Care and Philosophy*, 1(2), 25–131. <https://doi.org/10.1023/A:1009923104175>.
- van Manen, M. (2019). *Phenomenology of the Newborn: Life from Womb to World*. Routledge.
- Vincini, S.; Gallagher, S. (2021). Developmental phenomenology: Examples from social cognition. *Continental Philosophy Review*, 54, 183–199. <https://doi.org/10.1007/s11007-020-09510-z>.
- Verhagen, E.; Sauer, P. J. (2005). The Groningen Protocol—Euthanasia in severely ill newborns. *The New England Journal of Medicine*, 352(10), 959–962. <https://doi.org/10.1056/NEJMp058026>.
- Walsh, J. (2022). Into that darkness: A Heideggerian phenomenology of pain and suffering. *Journal of Phenomenological Psychology*, 53(1), 82–102. <https://doi.org/10.1163/15691624-20221399>
- Zayegh A. M. (2022). Addressing suffering in infants and young children using the concept of suffering pluralism. *Journal of Bioethical Inquiry*, 19(2), 203–212. <https://doi.org/10.1007/s11673-021-10161-9>.