

**Using Cognitive Capacity, Experiential Capacity, and Domains of Suffering to Inform
Assessment of Suffering in Children**

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Medical decision-making for children across the spectra of age and development may involve consideration of suffering by parents, caregivers, and medical personnel. Assessment of suffering in children is challenging, because typical child development entails a state of near constant change with respect to how children experience the world, and how they process that experience. Given this considerable variability in cognitive development across the spectrum of childhood, ethical consideration of suffering in medical decision-making for children requires that healthcare providers have robust frameworks by which to assess whether a child is capable of suffering, and if so, whether they are suffering now. This paper presents a framework in which a child's cognitive capacity and experiential capacity—the degree to which a child has access to certain aspects of physical, psychological, and existential experiences—are factors in determining their access to certain domains of suffering. Work by psychologist Phillippe Rochat is salient to the concept of experiential capacity as it relates to pediatric suffering because it provides a way to better understand a given individual's ability to engage in a certain experience at a certain time as a function of their cognitive capacity and cognitive development. Expanding on Rochat's work, and incorporating elements of accounts suggested by Eric Cassel, Erica Salter, Steven Edwards, and Noelia Bueno-Gómez, I offer a new characterization of pediatric suffering that incorporates cognitive capacity, experiential capacity, and domains of suffering. A more informed conceptualization of suffering in children provides a clear and justifiable framework for

determining whether and how patients are suffering, reduces the risk of inaccurate or unsupported secondhand claims of suffering, helps clinicians identify the needs and means to ameliorate suffering, and reduces the risk that inaccurate attributions of suffering are used to defend premature or unjustified decisions regarding treatment. I close by presenting several clinical case examples demonstrating the utility of this model.

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Preface

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1.0 Chapter One

1.1 Introduction

Despite extensive work by philosophers, ethicists, and physicians, there is no consensus on what constitutes suffering or how to identify it, yet it remains a commonly cited factor in medical decision-making for children, as demonstrated by the work of Erica Salter. This chapter begins with an examination of three philosophical approaches to suffering: Cassel's medical humanism; Edwards' phenomenology; and Bueno-Gómez's response and resistance to both of these. I then move to a critical analysis of work by Tyler Tate, Georgina Campelia, Jennifer Kett, Aaron Wightman, and Erica Salter, which specifically addresses suffering in children, and argue that although these characterizations of pediatric suffering have unique strengths and weaknesses, they all lack consideration of the spectrum of cognitive development and cognitive capacity that is part of normal child development. Turning to work by Laurel Copp, David Degrazia, Fredrik Svenaeus, and Michael Brady, I offer their work as exemplars for construction of a set of domains of suffering, including physical, psychological, and existential experiences. Returning to the need for inclusion of the broad range of cognitive development and cognitive capacity in children, I introduce the notion of experiential capacity, and explore it as a conceptual framework by which we may increase specificity in the discourse we use during conversations regarding suffering as a factor in medical decision-making.

1.2 What is Suffering?

The question, “what is suffering?” has been approached from many perspectives, of which medical humanism and phenomenology are two of the most prominent. Eric Cassell and Steven Edwards provide exemplars of these two respective viewpoints, while Noelia Bueno-Gómez’s work responds to both as insufficient, offering an account that is neither exclusively humanistic nor phenomenological. With the exception of Cassell, who mentions very young children only insofar as to justify excluding the possibility that they are capable of suffering, as detailed in the following analysis, none of these three scholars directly address suffering in children. Their work nonetheless bears exploration in this context, as the frameworks they develop and explore form the basis of many subsequent investigations into suffering in children.

Cassell, one of the most prominent figures in the modern literature of suffering, wrote that suffering is “the distress brought about by the actual or perceived impending threat to the integrity or continued existence of the whole person.”¹ However, some of the definitional intricacies suggested by Cassell have attracted significant scrutiny. He argues that suffering requires a sense of the future and past, a sense of personal identity, and concern for preservation of that identity.^{1,2} Under Cassell’s conception, the experience of suffering requires that one is able to construct a self-identity—the aforementioned “whole person,”—and that one have aims and purposes. Other elements of Cassell’s account, such as suffering as a subjective experience, a widely variable threshold for suffering between individuals, the distinction from pain, and the ability for suffering to arise from both disease and treatment, do not necessarily exclude certain categories of persons from suffering. However, making the ability to create a temporally-related self-identity with distinct aims and purposes a conditional requirement of suffering effectively renders infants, some young children, people with significant developmental delays, and nonhuman animals unable to

suffer. This may be a questionable assertion when considering the following example. Take a ten-month-old child with a bowel obstruction. The condition causes excruciating pain, nausea, and vomiting which can continue unabated for hours while the child grimaces, cries, and remains in the fetal position. Cassell's definition denies this as suffering based solely on his assertion that this patient cannot create an intact sense of the self, with no consideration for either the level or duration of duress, or any other dimension of the experience at all. Having aims, purposes, and the capacity for self-construction may certainly affect the experience of suffering, but they seem untenable candidates as necessary, conditional requirements for the capability to suffer without consideration of any other aspects of the experience of suffering.

Edwards' "intuitive concept" of suffering contains three distinct components: self; phenomenological; and temporal.^{3,4} His account takes inspiration from Wittgenstein in attempting to match the meaning of the term to the manner in which it is used in ordinary language, and emphasizes the "felt" phenomena of suffering. The self component requires that the sufferer realize that they are the individual experiencing suffering. The phenomenological component entails the feeling of suffering. The temporal component specifies that the experience be of "some significant duration."³ This account provokes two points of concern. First, the "self component" raises concerns similar to those expressed above regarding Cassell. Infants, young children, and people with significant developmental delays may not necessarily be able to comprehend and articulate what it means to suffer, *per se*, but this doesn't mean they are incapable of the experiences that can constitute suffering, as illustrated by the example of the infant with a bowel obstruction. Second, Edwards' construct is so internally oriented that it permits little by way of allowing individuals to recognize suffering in others who may not be able to communicate it themselves. This renders it less helpful in trying to identify the suffering of those who are unable to speak for themselves,

which constitute a significant number of those for whom suffering may become a relevant factor in medical decision-making, such as individuals with neurodevelopmental impairment and very young children.

Noelia Bueno-Gómez resists both the medical humanism and phenomenological approaches, proposing a “non-essential and non-naturalistic” account of suffering as “an unpleasant or even anguishing experience which can severely affect a person on a psychophysical and even existential level.”⁵ Pushing back against Cartesian mind-body dualism, she instead argues that suffering is better understood as a multidimensional entity, including cultural, social, scientific, and medical components. Unlike Cassell, she asserts that while both pain and suffering affect the whole person and are capable of attacking, destroying, or constructively expanding the “self,” none of these constitute defining features of pain or suffering. They instead serve as two of many possible life experiences that contribute to shaping the self, and may be useful in targeted management of pain and suffering. In contrast to Cassell and Edwards, Bueno-Gómez explicitly acknowledges an existential component in addition to physical and psychological manifestations of suffering. But the question of what might constitute an unpleasant or anguishing experience, or how we might identify an experience as such in an individual who cannot speak for themselves, remains unclear.

This brief discussion of the work of Cassell, Edwards, and Bueno-Gómez identifies three approaches to suffering, demonstrates some of the strengths and weaknesses associated with each, and suggests the need for further investigation regarding the nature of suffering in specific populations, such as children. It is to this task that the paper now turns.

1.3 Suffering in Children

Identifying, assessing, and palliating suffering in children presents unique challenges. In his 2020 article in *Theoretical Medicine and Bioethics*, Tyler Tate begins his account of pediatric suffering by describing what he calls the “two poles.”⁶ At one pole, which Tate calls “mirage,” is the Cassellian account by which infants and those with severe cognitive impairment are incapable of suffering because they cannot create an intact sense of self, and cannot verbalize their experience. At the opposite pole, which Tate refers to as “scandal,” sits the idea that because language is unavailable to some pediatric patients, there comes a point at which the notion that they may be suffering but unable to communicate the experience leads caretakers to believe that death may be a preferable alternative. Tate finds both positions inadequate because they fail to take into account the individual child ostensibly at the center of the discussion. They are not “sufficiently accountable to the individual child at hand, [and] the label of suffering floats freely above the...child, untethered from any objective set of criteria.”⁶ In this regard, he is consistent with Erica Salter, whose work is discussed below, noting that this ambiguity can permit clinicians’ preconceived notions regarding a quality of life that they may personally feel would be unacceptable to themselves to filter into medical decision-making for children under the guise of suffering. Using Alasdair MacIntyre’s work in human flourishing, Tate characterizes pediatric suffering as “the absence of child flourishing...in reference to an objective set of culturally embedded, species-specific conditions. It means that life is going poorly for him or her.”⁶

A notable concern with this account is the extent to which certain children would counterintuitively qualify as actively suffering under its criterion, as demonstrated by the following example. A previously healthy teenager sustains multi-system trauma, including a severe traumatic brain injury, resulting from a motor vehicle collision. He remains comatose, but with his

endotracheal tube in place, he initiates his own breaths and therefore does not qualify as dead by neurological criteria. By nearly any set of “culturally embedded, species-specific conditions,” this child is not flourishing. As a previously healthy teenager who is now severely injured, incapacitated, and unaware it seems relatively clear that life is “going poorly for him.” By Tate’s definition this child is suffering, but this is problematic, and for good reason. This child is comatose and cannot experience anything at all, including suffering. This example is extreme, but it demonstrates an important issue with this characterization of suffering—lack of flourishing unto itself is an insufficient criterion for suffering because it does not take into account the experiential aspect of suffering. Suffering is an experience, and having any experience requires at least a modicum of awareness that the experience itself is occurring. That is, an individual similar to the patient described above may be entirely unaware of anything at all, in which case they cannot have the experience of suffering.

Additionally, the absence of flourishing may be more a matter of degree than Tate’s account would allow—the effect can be more or less intense depending on the amount of flourishing denied to an individual. In the previous example, there is, ostensibly, a near-complete lack of flourishing, but what about children closer to the opposite end of such a “flourishing spectrum”? How much opportunity for flourishing is a child required to lose before they are suffering? Does any decrement in flourishing constitute suffering, or is it limited to the complete absence of flourishing? As overt criteria, the former seems too liberal, while the latter seems too restrictive. Either way, the point at which a decrease in flourishing becomes an overt “absence” and therefore equivalent to suffering remains difficult to define, making Tate’s account theoretically plausible but practically challenging.

Campelia, Kett, and Wightman argue that within the context of infants with profound neurocognitive impairment, “can this infant suffer?” is simply a suboptimal question due to acknowledged difficulties in ascertaining the lived experience of such individuals. They advocate for reframing the question as “is there suffering here?,” to include not only the subjective experience of the patient, but also the constitutive relationships of care that surround the patient.⁷ The claim is that the circumstances surrounding these infants dictate whether their relationships to caregivers, including parents and healthcare professionals, flourish or suffer, and that this should be taken into account when assessing suffering in the child. In effect, they assert that a better way to understand suffering in children with neurocognitive impairment is to include consideration of the relationships that are “partly constitutive” of the child, their suffering, and the suffering that surrounds them.

There are at least two significant objections to this approach. First, it appears to set aside an admittedly difficult problem in favor of an easier one. Discerning suffering in infants with profound neurological impairment is a thorny prospect, partially because they cannot communicate much, if anything, regarding their own experience. Discerning suffering present within relationships between neurologically impaired infants and neurologically intact adult caregivers provides a semblance of more concrete information, since the adult individuals are capable of expressing their own thoughts, feelings, desires, and emotional state. Even so, this skews the assessment of whether or not suffering is present in a given relationship towards the party more capable of expressing themselves, which in this situation will always be the caregiver. This leads to the second objection; suffering in caregivers, while a valid experience, does not necessarily constitute suffering in those for whom they care, or vice versa. Caregivers and loved ones are tasked with immense responsibility, and the emotional toll on them can be profound, but the

experience of being a caregiver brings with it specific experiences that differ from those for whom they care. While both patients and caregivers may experience intense, legitimate suffering, these are not identical and are not constitutive of reciprocal suffering in one another. This approach effectively shifts from considering the suffering of the child to considering the suffering of the parents and caregivers, and risks minimizing the experience of the child.

Erica Salter makes the case that the rhetoric surrounding suffering with respect to pediatric medical decision-making has taken on a role similar to that of “futility” in the 1990s and early 2000s. As she points out, this is not only an analytical or academic exercise. Futility and suffering are both highly subjective terms. Drawing this comparison identifies a major clinical concern regarding the use of suffering in children, namely that suffering and futility both bear a significant risk of being used, consciously or unconsciously, to “smuggle value judgments about quality of life into decision-making.”⁸ Her review of the literature found 651 occurrences of “suffering” in the pediatric ethics literature over the prior ten years, of which 52% used suffering as part of medical decision-making. Furthermore, she notes that “claims of patient suffering were three times as likely to support a life-ending decision as a life-extending decision.” This supports the notion that suffering is clearly being used as a factor in medical decision-making for children, and that it may be more likely to be deployed towards specific ends rather than assessed from an objective position. There is, therefore, significant risk that suffering can be used, without sufficient justification, to defend decisions regarding medical treatment options.

Seeking to derive a definition that may be applicable to secondhand claims of suffering in children, she suggests “a negative, subjective experience that goes beyond the experience of pain,”⁸ Her account does not depend on the individual’s ability to communicate their experience, and unlike Cassell, does not exclude those who are unable to create an intact sense of self. Salter

suggests first and foremost that we must address the experience of the patient by, to the best of our ability, ameliorating physical, psychological, and existential experiences that may contribute to suffering. Importantly, she also notes that observing perceived suffering in children may cause suffering in the observer—suffering that may be entirely legitimate, but does not necessarily indicate or constitute suffering in the child. As Salter points out, this is particularly important because the term “suffering” contains great rhetorical and persuasive force, but lacks a clear, unifying definition. It may mean vastly different things to different people, even with respect to a single child or medical decision.

Work by Tate, Campelia, Kett, Wightman, and Salter provides an informative survey of attempts to characterize pediatric suffering, and displays some of the strengths and weaknesses of work in this area. And yet, a crucial element remains missing from consideration. While all of these characterizations of pediatric suffering account for the patient’s experience in some way, they do not directly address the idea that the act of experiencing something may change and evolve with time or circumstance. The same events, including those that may predicate or manifest suffering, may not be experienced in exactly the same way by the same person at different points in their life. Moreover, children are not simply small adults—during the typical course of child development, children progress through a myriad of developmental and perceptual changes affecting how they see themselves, and how they experience the world around them. This fluctuation can lead to frequent changes in the way that a child experiences physical, psychological, and existential events, and may therefore change what it means for a child to suffer at different points in time, under different circumstances. To adequately address this challenge, we first need to examine the types of experience from which suffering may arise or manifest; this examination is the focus of the following section.

1.4 Domains of Suffering

In order to effectively examine suffering in children, we must specify some of the ways in which it is possible to suffer. That is, we must delineate “domains of suffering”—the areas of human experience from which suffering may arise. Copp, DeGrazia and Rowan, Svenaeus, and Brady have made notable contributions to this area.

In 1974, Laurel Copp called suffering “the state of anguish of one who bears pain, injury, or loss.”⁹ Her exploration focuses primarily on suffering as a response to the stimuli of pain and fear, and she notes that the experience of suffering can therefore include anticipation, consequences, experience, memory, implications, and inconvenience of pain, as well as fear of pain, isolation, and procedures.⁹ Copp’s “state of anguish” may lack a high degree of definitional specificity, but her analysis is valuable insofar as it suggests that both physical and psychological events may give rise to suffering.

David DeGrazia describes suffering as “a highly unpleasant emotional experience associated with significant pain or distress.”¹⁰ In a 1991 article coauthored by Andrew Rowan, they describe suffering and pain as both conceptually and phenomenologically different, as are suffering and anxiety. They conclude that suffering may result from, or take the form of, many states, including pain, anxiety, fear, and boredom.¹¹ Whereas Copp suggests that both physical and psychological events may give rise to suffering and describes these events in terms of their relation to pain, DeGrazia and Rowan expand on this notion to include anxiety, fear, and boredom, although they take care to note that this list is not exhaustive. While anxiety, fear, and boredom may certainly arise from pain, it is reasonable that they may also cause suffering on their own, distinct from pain.

Svenaesus takes a phenomenological approach, conceptualizing suffering as a “potentially alienating mood,” involving painful experiences regarding one’s embodiment, engagement in the world with others, or core life values.^{12,13} Svenaesus’ types of suffering include physical pain, being unable to do basic things that bestow meaning on one’s life, no longer being able to do things, no longer being the person one wants to be in the eyes of others, and loss of dignity or identity. He proposes that both the body and world of the sufferer have become “alien,” insofar as they present sensations and challenges foreign and disturbing to the individual, making one a stranger to oneself.¹³ These sensations and challenges affect the individual’s mood, which alters the way they view themselves within the world. Svenaesus thus suggests a significant existential component to suffering—it is not simply the damaging physical and psychological experiences, but the cascading effect these experiences have on the individual which make them reexamine and question what it means for them to exist in the world.

In his 2018 book *Suffering and Virtue* Michael Brady argues for suffering as a state of physical or mental experience, of which the defining characteristic is a component of “negative hedonic quality or negative affect.”¹⁴ For Brady, the necessary condition that must be present to claim or label an experience as a form of suffering is its unpleasantness, and the desire that the unpleasantness cease. That is, we suffer when we experience something unpleasant while concomitantly experiencing a desire for the unpleasant thing to stop—it is the “intrusion of negative affect upon our psyche, rather than...negative affect itself.”¹⁴ He goes on to describe suffering as a function of importance, intensity, or a combination of the two, and he qualifies this by noting that cognition may deepen the experience of suffering, but is not an ability without which a being is incapable of suffering. This cognitive qualification allows Brady to argue that his account of suffering is broad enough to include young children and animals as beings capable of

suffering, stating that “in such creatures it seems that the intensity of the negative affect that generates an occurrent desire is the primary factor.”¹⁴ He goes on to use this account of suffering to argue that suffering is essential to the development of virtue and achievement of flourishing.

This argument is defensible with respect to some suffering—what might be called “everyday suffering,”—the type commonly claimed to “build character.” For example, a toddler accompanying their parent to a grocery store may have an extremely negative reaction because they are told they may not eat the cookies in the shopping basket before they have been paid for. They may scream, wail, and throw an impressive tantrum. The child’s experience is intense, and they want it to cease. Moreover, within the limits of the child’s cognitive abilities, it is likely the intensity of desire and the sensation of being denied immediate gratification that cause the child such distress. Under Brady’s account, this child’s experience qualifies as suffering, and such experience may contribute to development of the virtue of patience. Suffering in this instance fits neatly into Brady’s paradigm. But the potential benefits to development and flourishing may appear less tenable under certain conditions, particularly when suffering exceeds a particular degree of severity, or when it occurs under certain circumstances, as illustrated by the following examples.

Imagine a young soldier, captured and tortured for information to which, by virtue of his rank, he is not privy. For some initial time, he may be subjected to physical and psychological distress that he may process as a test of his fortitude, bolstering virtue development as Brady suggests. However, if he is tortured for months or years it becomes more likely that at some point he will experience a degree of distress that provokes psychological breakdown and potential destruction of his psyche, rather than virtue development. Under these conditions, increased suffering does not continually generate concordant increased development of virtue—there is an

effective “dose” of suffering beyond which toxic effects predominate. This example identifies a situation in which the degree of suffering may become so intense as to negate the possible positive aspects suggested by Brady. In addition to the degree of suffering, situational circumstances may mitigate the potential positive effects of suffering suggested by Brady, and make them significantly less likely to come to fruition, as the following example demonstrates.

Consider a teenager with terminal osteosarcoma, a painful form of bone cancer, experiencing suffering associated with the terminal phase of her illness. For some time, she may have experienced the suffering associated with both her disease and treatment as a test of her patience, tolerance, fortitude, and grit. But as her disease progresses, her pain becomes more pervasive, and death looms closer, it is hard to imagine that her experience of suffering serves to help her flourish or build virtue. As the time of death comes nearer, the amount of time and ability to reflect on suffering shrinks concordantly, and with it the possibility of any resultant virtue development. Suffering experienced in the terminal phase of illness is, by nature, a time-limited activity, and there will be no time for subsequent reflection, flourishing, or virtue development. In this example, it is the circumstances under which suffering is experienced, rather than the degree of suffering, which negate subsequent virtue development or flourishing.

The potential positive effects of suffering which Brady proposes may therefore be less applicable when considering certain types of situations that predicate discussions of suffering within the context of medical decision-making, as suggested by the example of the teenager with osteosarcoma. But his notion that suffering requires the desire that the unpleasantness cease offers an interesting take on the psychological aspect of such an experience. The desire that an unpleasant sensation cease—our wish to be free of a certain sensation or experience—may contribute to suffering.

As Copp, Svenaeus, DeGrazia, and Brady suggest, suffering may involve experiences in several domains. For clarity, these domains of suffering will be grouped into three major categories: physical symptoms (both painful and nonpainful); psychological experiences such as fear, anxiety, boredom, isolation, the desire that the experience cease, and anticipation and memory of physical symptoms; and existential aspects such as thwarted plans or potential, anticipation of the end, fear of death, and loss of identity, dignity, bodily integrity, or familial roles and relationships. This list is representative, but certainly not exhaustive.

As previously discussed, children pose a particular challenge with respect to suffering because they typically progress through a broad spectrum of cognitive development and capacity as they grow and mature. Their relationship to the world and those around them is in near constant flux, and so is the way they experience the world around them. A valid and useful account of pediatric suffering must allow for differences in the capacity of these persons to experience the world and themselves. Not all individuals have access to all domains of suffering in equal fashion. One way to describe an individual child's position on this experiential spectrum is to introduce the term "experiential capacity," which is the focus of the following section.

1.5 Experiential Capacity

Evaluation of pediatric suffering often necessitates secondhand assessments by caregivers. As Salter has suggested, a greater degree of specificity regarding suffering may reduce the likelihood that caregivers intentionally or unintentionally smuggle in value judgments about quality of life. This is particularly salient and necessary given the frequency and manner in which suffering in children has been referenced as a factor in medical decision-making within the ethics

literature.⁸ Formalizing the concept of “experiential capacity,”—the degree to which an individual has access to certain aspects of physical, psychological, and existential experience—may help provide caregivers with an improved conceptual framework in which to discuss the ways in which a child may be suffering at a given point in time. Defined as such, experiential capacity may help increase specificity and accuracy in determining how a patient may be suffering, and potentially reduce the intentional and unintentional “smuggling,” referenced by Salter.

To illustrate, consider the example of a set of previously healthy, typically-developing two-year-old twins—twin A and twin B. Their capacity for existential experience is limited due to their age and cognitive development, but assume they have the same baseline experiential capacity with respect to physical and psychological experiences. Twin A contracts a severe viral pneumonia, is admitted to the pediatric intensive care unit, and requires placement of a breathing tube for acute respiratory failure. He has multiple peripheral intravenous access points, as well as a central venous line. He is sedated using continuous opioid infusion and intermittent benzodiazepines. He is not paralyzed. His level of sedation is assessed every thirty minutes using a validated scale, and is consistently found to be adequate. His vital signs remain appropriate for his age, and he appears to be comfortable.

With respect to his experiential capacity, we can minimize the likelihood of significant experiences within the existential domain due to his age and developmental stage, so suffering arising from an existential domain is unlikely. Provided he remains adequately sedated and comfortable, he should not have experiences within the psychological or physical domains of suffering. This could change if, for example, his IV is accidentally disconnected and his sedation infusion is interrupted. His experiential capacity would change. At first, he may regain access to the physical domain of experience. His heart rate and blood pressure may increase and he may

grimace from the discomfort of having a breathing tube in place and the residual pain from the stitches around his central venous catheter. If his sedation remains disconnected for long enough, his level of situational awareness may continue to increase, and he will gain access to psychological domains of experience such as fear, the desire that the experience cease, and anxiety. These are not guaranteed to happen, but they do represent potential ways in which he may suffer if this were to occur. However, as long as his sedation remains appropriate, the physical and psychological domains of experience remain unavailable to him.

Contrast this with his healthy brother, twin B. He has retained the full experiential capacity of a normally-developing two-year-old. He can experience pain if he stubs his toe, or nausea if he eats too much ice cream. He can be afraid of a large dog, bored if a toy is taken away, or anxious about a trip to the doctor, where he remembers receiving previous immunizations. His experiential capacity is such that he is capable of the types of lived experience that may constitute suffering. This example demonstrates that experiential capacity is a fluctuating entity—it may vary under different conditions. It is not a fixed quality, but a product of both the individual and their circumstance.

Experiential capacity thus provides a conceptual framework by which we can begin to differentiate the experiences open to twin A and twin B under their divergent circumstances. It may begin to help bring more specificity to secondhand claims of suffering, since it can serve as a guide for where to look if we are concerned a child might be suffering but unable to communicate. Experiential capacity is a function of cognitive capacity, as well as internal and external factors, a deeper exploration of which is the focus of chapter two.

2.0 Chapter Two

2.1 Introduction

The concept of experiential capacity—the degree to which an individual has access to certain aspects of physical, psychological, and existential experience—may begin to provide a useful conceptual framework for assessing secondhand claims of suffering in children by more carefully delineating the spectrum of experience open to different individuals under different conditions. These conditions include the degree to which one is aware of themselves and what is happening around them. But what factors contribute to an individual’s experiential capacity? If we are to discuss this concept and its ramifications in a rigorous and clinically-relevant manner, it is essential to address this question. In order to do so, this chapter will introduce and analyze the work of developmental psychologist Philippe Rochat, who trained under Jean Piaget. He has proposed six mental states, each of which correspond to specific cognitive capacities. These cognitive capacities can provide a useful lens through which to understand the way in which an individual is capable of understanding their own lived experience, as well as the world around them, at a given point in time. I argue that my adaptation of Rochat’s conceptual scheme provides a conceptual foundation for the notion of experiential capacity, and in doing so, can be used to produce a conceptual scheme for characterizing suffering. I propose that both internal and external factors can alter both the range and exercise of cognitive capacities, possibly to the point of dissociating the mental and physical components of typical development. To close, I offer a new characterization of pediatric suffering incorporating cognitive capacity, experiential capacity, domains of suffering, and elements of work by Salter, Edwards, Bueno-Gómez, and Cassel.

2.2 Rochat's Conceptual Scheme

Before examining the notion of cognitive capacities in detail, it is useful to understand the work of Rochat's mentor, Jean Piaget, as brief background. Piaget's cognitive developmental theory divided childhood development of thought processes and mental states into four discrete stages: sensorimotor; preoperational; concrete operational; and formal operational.¹⁵ He used the construct "schemata," in referring to the mental frameworks created as children process and react to their environment. Schemata become more refined throughout development, allowing more generalized and differentiated responses to mental stimuli.¹⁵ Piaget's approach is considered constructivist. This means that, in a stepwise progression, each of Piaget's developmental stages is sequentially fashioned by building upon and expanding capabilities acquired during the prior stage. In doing so, each stage is irreparably changed as it transforms into its successor—one can no longer return to a prior stage since it has been used as the scaffolding on which the following stage has been built. Since each of Piaget's stages represents the cumulative sum of all that has come before, developmental progression is effectively a one-way street—once a schema is processed and differentiated it becomes stored information.

Rochat proposes six mental states which emerge chronologically during development: non-conscious; unconscious; aware; co-aware; conscious; and co-conscious. In contrast to Piaget, Rochat's states are not exclusively constructive, but dynamic—each sequential state represents a relative increase in cognitive capacity compared to those prior, but "individuals can fluctuate through them depending on circumstance."¹⁶ Under Rochat's paradigm, during the typical progression of child development, each new mental state attained does not obliterate those prior, but adds successively to the array of possible states open to that individual. The notion of successive addition indicates that an individual who is capable of attaining a particular state retains

access to all states that have come before. For example, an individual who has developed to the co-conscious state will also have access to the conscious, co-aware, aware, unconscious, and non-conscious states. But an individual whose development terminated at the aware state will only have access to the aware, unconscious, and non-conscious states. Rochat suggests that after these states unfold sequentially during the normal course of human development, they continue to provide an array of possible cognitive mental states that a normally-developed human adult will oscillate between depending on circumstance. He proposes that his six states form “the variety of mental contexts of our experience of the world,” and “our experience of the self in relation to others.”¹⁷

It is the *cognitive capacity* corresponding to each of Rochat’s mental states that functions as a major factor in determining the “experience of the world,” and “experience of the self in relation to others,” to which he refers.¹⁷ As such, I will refer to them using this distinction for the purposes of my argument here, by employing the following classification:

Table 1: Mental State and Corresponding Cognitive Capacities

Mental State, proposed by Rochat	Cognitive Capacity for:
Non-conscious	No mental states (lack of cognitive capacity)
Unconscious	Unconsciousness
Aware	Awareness and unconsciousness
Co-aware	Co-awareness, awareness, and unconsciousness
Conscious	Consciousness, co-awareness, awareness, and unconsciousness
Co-conscious	Co-consciousness, consciousness, co-awareness, awareness, and unconsciousness (Not limited; “full” cognitive capacity)

To see how Rochat's paradigm can be adapted to produce a conceptual scheme for characterizing suffering, I now turn to a more detailed analysis of each cognitive capacity, the sequence in which they begin to arise during typical child development, and their interaction with both experiential capacity and domains of suffering.

As a precautionary note, it is important to acknowledge that Rochat's terminology regarding "awareness," and "consciousness" is somewhat idiosyncratic insofar as it differs from the manner in which these terms are commonly understood as synonyms. Under Rochat's classification "awareness," and "consciousness" describe two different states with distinct features. In an effort to maximize clarity and remain consistent, I will designate when I am referring to a specific cognitive capacity by using the term "cognitive capacity," in relation to these terms, as in, "the cognitive capacity for awareness," or "the cognitive capacity for consciousness." When not specified in this manner, these terms retain their commonly accepted meanings, as in the phrase "any sense of awareness," used in the following section, although I have endeavored to minimize their use as such.

2.3 Non-Conscious Individuals

Non-conscious individuals exist in "a state of mind by negation," in which one is "alive, yet not responsive and totally oblivious of what is happening around or within our own body."¹⁷ A defining characteristic of non-consciousness is that, should one's cognitive capacity change, one would have no memory of anything that occurred during the time they were in a state of non-consciousness because there was no reception of stimuli by which to trigger memory formation.

While non-conscious individuals are indeed alive, they are entirely unaware of being so. Although one can *be* in a state of non-consciousness, one cannot *experience* it, per se, since it is defined by the absence of any sensation whatsoever. Any sense of awareness means that a person is not in a state of non-consciousness. People in a deep sleep in which they are not dreaming, and those in a deep coma in which they register no stimuli, are in a state of non-consciousness. Importantly, individuals declared dead by neurological criteria are not in a state of non-consciousness, because this state is defined by the combination of being both oblivious and alive. A brain-dead patient is not alive, and therefore cannot fulfill the criterion of being “alive, yet not responsive and totally oblivious.” Furthermore, as defined by Rochat, the state of non-consciousness includes the possibility, even if exceedingly small, of transitioning to other states if individuals develop the corresponding cognitive capacities. This is not physiologically possible in a patient who fulfills death by neurological criteria, which is an irreversible state.

People in a state of non-consciousness cannot receive or process any sensory stimuli. They cannot experience anything, and therefore have no experiential capacity or cognitive capacity. They have no access to physical, psychological, or existential domains of experience, and they cannot suffer. This does not mean such an individual will never be able to suffer. If the individual’s mental state and cognitive capacity changes, the individual’s ability to experience suffering can change as well.

2.4 Individuals Limited to the Cognitive Capacity for Unconsciousness

A person whose cognitive capacity is limited to unconsciousness exists in a state without explicit evidence of awareness of environment or self, but differs from a non-conscious person in

the possibility that they may eventually become aware and conscious of sensory data processed while in a state of unconsciousness.¹⁷ Whereas those in a state of non-consciousness are incapable of receiving any external or internal sensory data, those with the cognitive capacity for unconsciousness can receive and process sensory data without concomitant awareness that this is actually happening. In Roachat's paradigm, individuals engaging with subliminal advertising are classified as exercising the cognitive capacity for unconsciousness at the moment of exposure—their brain may be actively processing the information presented to them, and they are likely to be influenced by it the next time they are presented with the product advertised, but they may not realize that a connection has been made until after the fact.¹⁸ To take a medical example, a hospitalized individual experiencing delirium resulting from a prolonged period of sleeplessness in the intensive care unit may be unconscious of the things they say or do while delirious, but they may eventually recall snippets or even more protracted segments of memories formed during the time they were limited to a cognitive capacity for unconsciousness. Having a cognitive capacity limited to unconsciousness is a capacity that agents generally only recognize in hindsight.

While a person remains limited to the cognitive capacity for unconsciousness, they have no concurrent awareness, and therefore no access to physical, psychological, or existential domains of suffering. Similar to those in a state of non-consciousness, a person with the cognitive capacity for unconsciousness cannot suffer as long as they remain in that state. What differentiates them is that events occurring while one has the cognitive capacity for unconsciousness may be recalled at a later time, and may cause suffering at that later time, whereas those occurring while an individual is non-conscious cannot cause suffering. The cognitive capacity for unconsciousness provides a dichotomous result—a person cannot suffer as long as they remain limited to this capacity with

respect to a given piece of sensory data, but events that occur during this time and are recalled later may provoke, or provide a basis for, suffering at that time.

2.5 Individuals Limited to the Cognitive Capacities for Awareness and Unconsciousness

An individual whose cognitive capacities are limited to awareness and unconsciousness, is, at most, in a “state of being alive in a sentient body in the world.”¹⁷ This differs from the cognitive capacity for consciousness in that it describes implicit, preconceptual cognitive capabilities. To paraphrase Rochat, the distinction between “seeing” and “looking,” may provide a helpful example here—“seeing” is an act of awareness via perception without a definitive object in mind, whereas “looking” implies an explicit, conscious act oriented towards a specific object. To see requires only the cognitive capacity for awareness, whereas to look is to consciously engage with the object one sees, which is a facet of the cognitive capacity for consciousness. Those with the cognitive capacity for awareness are capable of implicit, preconceptual acts like “seeing,” but not “looking.” “Hearing” and “listening” provide another example of such implicit vs. explicit actions. In Rochat’s model of typical development, awareness is the cognitive capacity with which a neurologically-typical infant is born, and which they maintain (when awake) until 6-8 weeks of age.¹⁸ When asleep and not dreaming, they are non-conscious, similar to an individual of any age who is asleep without dreaming. Awake, they have the cognitive capacity for awareness insofar as they are capable of implicit, preconceptual activities such as seeing and hearing, but not explicit, consciously directed acts like looking or listening. Typical newborns may widen their eyes or startle in response to sound, but do not voluntarily turn towards a sound until several months later.¹⁹

When limited to the cognitive capacities for awareness and unconsciousness, one cannot consciously engage with the objects of which one is aware. Psychological experiences such as fear, anxiety, and boredom, and existential experiences such as anticipation of the end, loss of identity, and fear of death all necessitate conscious manipulation of mental ideas and objects, and therefore cannot be experienced by individuals who only have capacities for awareness and unconsciousness. But the experience of pain does not necessarily require an individual to consciously manipulate a stimulus. Anyone who has ever accidentally touched a lit stove burner can testify to the fact that their hand may have reflexively withdrawn before they even realized the physical sensation of pain (although the sensation certainly follows shortly thereafter). It is reasonable then, to assert that individuals limited to the cognitive capacities for awareness and unconsciousness may indeed have access to some aspects of the physical domain of experience, particularly primal sensations such as pain.

The notion that the physical aspect of pain alone is capable of causing suffering, rather than requiring a concomitant psychological component, is not without controversy. As noted in Chapter One, Michael Brady's definition of suffering requires that the individual desire that the unpleasant sensation cease—in effect, including an essential psychological component, without which one cannot be said to suffer.¹⁴ DeGrazia and Rowan distinguish between the startle reflex of pure nociception—a visceral reaction to a noxious stimuli—as distinct from the unpleasant sensation of pain.¹¹ However, such distinctions become difficult when we consider individuals whose experiential capacity is limited only to the physical domain. Such a person, lacking the capacity for psychological or existential experience, experiences the unpleasant sensation we commonly refer to as “pain,” with no capability to reason or logically assess the origin, time frame, or potential alleviation of that sensation. I maintain that an individual for whom the sum total of experience at

a given time is one of pain, and who possesses no capability to rationally assess that pain, may indeed be suffering. Furthermore, an observer's ability to discern between pure nociception and pain in such an individual is essentially nil. As such, we are obligated to treat under the assumption that pain is present, since the harm in doing so is minimal, and to make the assumption that we are seeing pure nociception risks both protracted pain and significant harm. Acknowledging that others may come to alternate conclusions regarding this particular issue, for the purposes of this paper, I will assume that pain, with no accompanying psychological or existential component, is capable of causing suffering. Accordingly, individuals with the cognitive capacity for awareness may be capable of suffering via experiences in the physical domain.

2.6 Individuals Limited to the Cognitive Capacities for Co-Awareness, Awareness, and Unconsciousness

Individuals with the cognitive capacity for co-awareness can realize that their presence is simultaneously shared with the presence of others—that one's "presence in the world is communal rather than individual."¹⁷ They are capable of perceiving the sensation of being aware of the self as present with others, without necessarily paying specific attention to, or interacting with, anyone in particular. Rochat illustrates this capability by calling attention to the distinction between eating alone in one's apartment versus eating alone in a crowded restaurant. A typically-developed adult is exercising the cognitive capacity for co-awareness when dining alone in a crowded restaurant—they are aware of the sensation of sharing their presence with the communal presence of others and may draw comfort from that presence, even if they do not overtly interact with any particular individual—whereas this sensation is absent when eating alone in one's own apartment. From the

developmental perspective, the earliest sign of the cognitive capacity for co-awareness is typically seen around 6-8 weeks of life, when infants develop a “social smile.”¹⁷⁻¹⁹ This represents one of the first signs of shared experience with others, and is a behavior that appears in all typically-developing infants around the same time regardless of culture.¹⁹

The notion that the cognitive capacity for co-awareness can provide a source of comfort implies that a person with this capability could potentially also realize what it is like to experience the absence of that comfort—the sensation of loneliness. If this is the case, then individuals with the cognitive capacity for co-awareness must have at least some access to basic experiences within the psychological domain—loneliness, similar to fear and boredom, is a psychological experience. Individuals with the cognitive capacity for co-awareness have access to physical domains of experience by the reasoning noted above with respect to the capacity for awareness. The cognitive capacity for co-awareness does not specify any capability for self-reflection or complicated manipulation of mental objects, and therefore does not include access to existential domains. The experiential capacity of individuals with the cognitive capacity for co-awareness thus includes the potential for suffering arising from both the physical and psychological domains of experience.

2.7 Individuals Limited to the Cognitive Capacities for Consciousness, Co-Awareness, Awareness, and Unconsciousness

The cognitive capacity for consciousness is the ability to know that one knows, and know that one does not know. It “entails a self-reflective loop and an introspective process dealing with mental objects.”¹⁷ In contrast to the cognitive capacity for awareness, the cognitive capacity for consciousness is defined by the ability to engage in objectified, explicit acts such as looking and

listening. These acts involve reception of a stimulus followed by mental manipulation, resulting in “communicable hence explicit discoveries or realizations...new thoughts, decisions, proofs, sudden understandings (insights), or novel predictions.”¹⁷ Importantly, Rochat notes that the defining element of the cognitive capacity for consciousness is that it results from a “process that depends primarily on the individual’s self-reflection and thinking,”—it is exemplified within the individual, and does not depend on the existence of others.¹⁷

Developmentally, the first signs of the cognitive capacity for consciousness arise around 8-9 months of age, when infants begin to develop stranger anxiety.^{18,19} This indicates that the child has developed at least a rudimentary internal working model in which they have identified a primary caretaker with whom they have established comfort, trust, and safety.¹⁸ It also demonstrates development of the capability to differentiate between familiar and unfamiliar, and the burgeoning fear of losing contact with safe and secure individuals.¹⁸ Whereas the potential comfort from the cognitive capacity for co-awareness arises solely from the sensation of merely being present in a shared space with others, stranger anxiety begins to indicate the identification of specific individuals from whom comfort and safety arise compared to others from whom they do not. This is markedly different from comfort associated with the general presence of others. The development of stranger anxiety, which Rochat calls the “birth of consciousness,” does not imply that a 9-month-old is capable of experiencing the same degree of objective, explicit thought as a typical 25- or 30-year-old, but represents the first outward manifestation of the cognitive capacity for consciousness.

Individuals with the cognitive capacity for consciousness can experience and process physical sensations, and therefore have access to the physical domain of experience. They have the capacity for thought, mental manipulation of ideas and objects, and self-reflection, which

means they can think temporally and consequentially, and think critically regarding the effects of the self on mental objects, and vice versa. That is, they can mentally place ideas and actions within space and time, evaluate those ideas and actions from multiple internal perspectives, and imagine not only the consequences of those theoretical ideas and actions on the self, but also the ways in which the self can act and think in order to alter those theoretical outcomes. They can imagine possible outcomes, and the emotions and sensations associated with those outcomes, and therefore have access to the psychological and existential domains of experience. Their experience in the existential domain may be somewhat constricted, because the cognitive capacity for consciousness as defined in Rochat's schematic is embodied in the individual, and does not depend on the existence of others. As such, if an individual is limited to the cognitive capacities for consciousness, co-awareness, awareness, and unconsciousness, their experiences within the existential domain are limited to existential aspects referenced to the self, not those situated within the context of a specific relationship with another. For example, this would include concerns such as "what happens to me when I die?" but not "what if I can no longer be an adequate father to my children as my illness progresses?" The experiential capacity of individuals with the cognitive capacity for consciousness extends across all three available domains of suffering, but the existential domain excludes aspects situated within the context of a specific relationship to another.

2.8 Individuals with Non-Limited Cognitive Capacity: Co-Consciousness, Consciousness, Co-Awareness, Awareness, and Unconsciousness

The cognitive capacity for co-consciousness is one of objectified, explicit thought in reference to others—the ability to perceive oneself in terms of the third person; to ask “what do I think people think about me?”.¹⁷ Our self-presentation is iteratively constructed based on the representation of how others perceive and evaluate us.¹⁶ Co-consciousness is a cognitive state in which we “know of sharing knowledge with others.”¹⁷ In contrast to the cognitive capacity for consciousness, the mental objects in use during co-consciousness are outside the individual—they “exist in the social transaction...at the interface between an individual and other individuals with whom he or she is sharing the experience of being in the world.”¹⁷ The knowledge in play when using the cognitive capacity for co-consciousness differs from that when employing only the capacity for consciousness because it will survive and transcend the individual, it “is embodied in the group, including the family, the society, and the culture in which the individual evolves.”¹⁷

Rochat illustrates the cognitive capacity for co-consciousness using the following example. If I sleep through my alarm and wake up late for a scheduled meeting, I am likely to feel frustrated and irritated. I will need to call the person with whom I am scheduled to meet and explain the situation to them. If this meeting is with my boss, who generally terrorizes me, I will adopt a polite, apologetic, conciliatory tone of voice that intentionally masks my underlying frustration and irritation at having missed my alarm. The act of adopting a specific tone for this interaction is an act based on what I know with others in mind, formed within the context of the specific relationship I have with another, in this case my boss—this act marks a situational transition from my exercise of the cognitive capacity for consciousness to that of co-consciousness.¹⁷

The first evidence of the cognitive capacity for co-consciousness during typical child development occurs around 9 months of age, when children begin to demonstrate secondary intersubjectivity—the capability to share attention with others about objects in the world.¹⁸ In doing so, they form what Rochat calls an “attention triangle,” consisting of themselves, another individual, and the object in question. The infant uses this “triangle” to check in with the other to see if they are attending to the object, but also to see if they are attending to the child. The child’s interest lies not only in their own interaction with the object, but also the manner in which the other individual attends to the child interacting with the object. This is an act in which one mentally references the self from the projected viewpoint of another—positing the question, “what does the other think of me, and of what I am doing with this object?”—and represents what some developmental researchers have referred to as the “nine-month revolution.”²⁰ Co-consciousness continues to expand with language development, particularly as both receptive and expressive language skills typically undergo significant advancement from age 2–3 years.^{18,19}

Individuals with the cognitive capacity for co-consciousness have the same access to physical and psychological domains of experience as individuals limited to the cognitive capacities for consciousness, co-awareness, awareness, and unconsciousness for the reasons noted above. However, the full range of existential experiences, including those situated within the context of a specific relationship to another individual, is open to them. Whereas the cognitive capacity for consciousness is exclusively self-reflective and introspective, those with the cognitive capacity for co-consciousness utilize mental objects that “exist in the social transaction...at the interface between the individual and other individuals with whom they are sharing the experience of being in the world.”¹⁷ This includes consideration of questions that reference the self through the theoretical consideration of another, such as “what if I can no longer be an adequate father to my

children as my illness progresses?” The experiential capacity of individuals who have the cognitive capacities within all five categories includes potential for suffering across the full range of physical, psychological, and existential domains.

2.9 Cognitive Capacity is Dynamic

As previously noted, a key difference between Piaget’s cognitive developmental theory and Rochat’s developmental paradigm is that Rochat’s cognitive capacities do not arise within a strictly constructivist paradigm like those of Piaget. Whereas Piaget’s stages of development are sequentially deconstructed in order to build upon one another, effectively obliterating the previous stage during creation of the following stage, Rochat’s cognitive capacities exist on a dynamic continuum. In Rochat’s classification scheme, one does not need to permanently lose one cognitive capacity to acquire another. Rochat’s model acknowledges cognitive capacity to be at least partially dependent on factors which may be internally or externally generated, as well as cognitive development. These five cognitive capacities are in dynamic coexistence—whether individuals possess or can exercise them at a given time depends on factors (potentially both internal and external), and cognitive development.

It is important to distinguish between an individual’s developed cognitive capacities at a certain time (their baseline cognitive development), and their ability to exercise those cognitive capacities at that same moment. At a particular time, an individual’s cognitive capacities are, in part, a function of their cognitive development. During typical cognitive development, as human beings transition from infancy to childhood and adulthood, cognitive capacity increases significantly. In Rochat’s paradigm, the scope of mental states available to them expands

concordantly—a typically-developed individual would have the full range of cognitive capacities, and therefore the capacity for each of Rochat’s mental states. But cognitive development can be impeded or prevented by both internal and external factors. A genetic syndrome would be an internal factor, whereas trauma, illness, and malnutrition would represent external factors. By impeding or preventing cognitive development, these internal and external factors establish a baseline range of cognitive capacities for the individual. These are the cognitive capacities the individual *has*. This baseline may be altered, on either a temporary or persistent basis, by certain factors. For example, stroke, illness, and traumatic injury may all cause temporary or persistent changes in an individual’s baseline cognitive capacity—that is, these conditions may temporarily or persistently reduce the baseline range of cognitive capacities that the individual *has*. In contrast, an individual’s ability to *exercise* their baseline cognitive capacities may be temporarily altered by certain factors, such as sleep or administration of medications. Unlike the factors discussed above that impede or prevent cognitive development, such temporary alterations are factors which change only the cognitive capacities that an individual can *exercise* at a given moment, not the cognitive capacities they *have* at that moment. These temporary alterations include the type of oscillations that occur frequently throughout a typical day for a particular individual, as illustrated by the following example.

Assume that I am a 38-year-old man with typical cognitive development—I have developed the cognitive capacities for co-consciousness, consciousness, co-awareness, awareness, and unconsciousness. If I am in a deep, dreamless sleep, I am in a state of nonconsciousness—that is, I cannot exercise any of my developed cognitive capacities. As I awake, I briefly transition through a state in which I regain the ability to exercise my cognitive capacity for awareness—I may see and hear things in my environment, but am not yet awake enough to process and objectify

those stimuli. As I become more awake, I regain the ability to exercise my cognitive capacity for consciousness, in which I recognize that I am listening to my alarm go off, which I find irritating. I then fully wake up and regain the ability to exercise my cognitive capacity for co-consciousness as I realize that continuing to allow my alarm to ring is going to awaken and frustrate my partner who remains fast asleep (for the moment). In each of these transitions, my baseline cognitive development (the cognitive capacities I have) has not changed, only my ability to exercise them under varying conditions of wakefulness.

Medication administration provides an example of an external factor that can cause temporary alterations in the ability to exercise developed, baseline cognitive capacities. For example, if I am given a continuous infusion of fentanyl and placed in a state of deep sedation, my ability to exercise any cognitive capacity is effectively abolished. This change has not altered my baseline developed cognitive capacities. I still have the cognitive capacities for co-consciousness, consciousness, co-awareness, awareness, and unconsciousness, but I have lost my ability to exercise them. If the infusion is turned off and I return to my normal level of alertness—awake and fully oriented—I will regain the ability to exercise the full, unrestricted range of my developed cognitive capacities. Again, there has been no change to the baseline level of cognitive capacities I have developed, only my ability to exercise them.

In contrast, now assume I (the same 38-year-old man with typical cognitive development) am involved in a motor vehicle accident and sustain a significant traumatic brain injury which leaves me alive, but with severe, persistent regression in my neurocognitive status. My MRI shows significant global damage to my brain, which is highly unlikely to ever recover. My physicians determine that I now appear, at most, to have the cognitive capacities for awareness and unconsciousness (chapter three will offer a more detailed discussion of the ways in which this

determination can be made, but for now, assume this is a reasonable conclusion). The traumatic brain injury has altered my underlying cognitive developmental baseline, and reduced my potential range of cognitive capacities from five (not limited), to only two. It has not conditionally altered my exercise of baseline developed cognitive capacities—it has persistently reduced the range of cognitive capacities that I have at baseline.

Cognitive capacity is, therefore, a dynamic entity, affected by an intricate interplay of cognitive development, and both internal and external factors. The dynamic continuum suggested by Rochat is affected by internal and external factors which can impede, prevent, or regress cognitive development, as well as factors which result in only temporary changes one's ability to exercise cognitive capacities. With this in mind, I now turn to the relationship between cognitive capacity and experiential capacity.

2.10 Cognitive Capacity and Experiential Capacity

Within this proposed schema, cognitive capacities are demarcated by the capacity of an individual in each state to receive, process, objectify, and mentally manipulate internal and external stimuli. A person with a given cognitive capacity will have only a certain type or types of experiences open to them by virtue of that cognitive capacity—they set boundaries for the ways in which a person under a given set of conditions, or in a certain developmental stage, is capable of experiencing and interacting with their environment. As such, this paradigm can provide a framework in which experiential capacity is a function of cognitive capacity, and domains of suffering are, in turn, a function of experiential capacity. Cognitive capacity can be assessed by incorporating bedside observation with clinical and physiological data and can therefore provide

a logical, rational basis for evaluating experiential capacity and potential domains of suffering. To see why this is the case, let's return to the two-year-old twins discussed in chapter one.

Recall that twin A contracted a severe viral pneumonia requiring intubation and continuous sedation, whereas twin B remained a typically-developing, healthy two-year-old. We minimized the likelihood of suffering arising from the existential domain since both children are limited in this capacity by their cognitive development. If twin A's sedation, comprised of a continuous opioid infusion and intermittent benzodiazepine doses, remains adequate, he should not have access to the psychological or physical domains of suffering since these medications prohibit him from exercising any of his cognitive capacities. Using the observational and physiological data available at his bedside to describe him by means of Rochat's classification shows us *why* this is indeed the case. Suppose he is successfully deeply sedated. A continuous opioid infusion maintains his sedation and keeps him free from pain and discomfort. Intermittent doses of benzodiazepines contribute to adequate sedation and also function as an amnestic, preventing him from forming new memories. He shows no signs of physical reactivity when the lights are turned on or when there are moderately loud noises within the vicinity. He is alive, but unresponsive and oblivious of anything happening around or within him, and he will not have any memory of anything that occurs while he remains in this state. He is effectively unaware of being alive at all. He is in a state of non-consciousness during this time—he cannot exercise any cognitive capacities, and therefore has no experiential capacity, and thus cannot suffer as long as circumstances remain the same. But how might this change if circumstances are altered?

Should his IV accidentally become disconnected resulting in cessation of sedative medication delivery, his cognitive capacity will change. As his sedation lightens and he begins to wake up, he will recover the ability to exercise his cognitive capacity for awareness, and therefore

begin to gain access to certain aspects of the physical domain of experience, becoming aware of visual stimuli like bright overhead lights, auditory stimuli such as the beeping and chirping of the monitor over the head of his bed, and physical stimuli such as the presence of a foreign object (his breathing tube) in his mouth and throat. While limited to the cognitive capacity for awareness, he does not explicitly mentally process these objects but remains aware that there are a variety of stimuli present around him. As his sedation continues to wear off and he becomes progressively more aware, he can also regain the ability to exercise his cognitive capacity for consciousness. With this change, his access to the physical domain of experience deepens, and he simultaneously also gains access to the psychological domain. He can now realize that the breathing tube is uncomfortable and that he has pain at the site of the sutures holding his central venous catheter in place, so his heart rate and blood pressure increase. He also has the capacity to realize the unfamiliarity of his surroundings, and he may experience fear, anxiety, and panic. Now, he has the experiential capacity to suffer in both the physical and psychological domains. Once his IV is reconnected and his sedative medications are restarted, he will lose the ability to exercise his cognitive capacities for consciousness and awareness once more, and once he is fully sedated he will again be in a state of non-consciousness, and have no experiential capacity.

This example shows how a conceptualization of cognitive capacities based on Rochat's classification scheme can provide a more granular level of detail and rationale underpinning an individual's experiential capacity in the setting of certain factors generating particular conditions. This conceptualization reflects the dynamic nature of cognitive capacities occurring as a result of pathophysiologic processes, treatments, and interventions, which makes it particularly suited to consideration within a medical context—it readily accounts for the individual within a malleable set of circumstances. Its flexibility with respect to circumstance acknowledges the temporal

variability of cognitive capacity that may occur as a result of both disease and treatment—an individual's range of exercisable cognitive capacities may undergo fleeting, temporary, or persistent alteration as a result of both disease and medical intervention. Exploring the interplay between cognitive capacity, disease, and treatment is essential to assessing the usefulness of Rochat's classification scheme within a medical context, and it is to that interplay and its ramifications that this paper now turns.

2.11 Disease, Treatment, and Ramifications

As demonstrated by the story of twin A, sedative medications provide an example of how a medical intervention may change the ability to exercise cognitive capacities. In a similar fashion, physiological sequelae of disease may also provoke alterations in cognitive capacity. For example, a patient in acute liver failure may develop hepatic encephalopathy resulting from an acute rise in their serum ammonia level, which can cause significant alteration and depression in mental status. A typically-developed adult individual with an unrestricted cognitive capacity may instead be limited to a state of non-consciousness or the ability to exercise only the cognitive capacities for awareness and unconsciousness under such circumstances—their mental state may be altered to the point where they are simply aware of stimuli around them, but do not process or meaningfully interpret these stimuli. If treated with appropriate medication, such a patient will likely reverse course and regain the ability to exercise their baseline unrestricted cognitive capacities. Such an example constitutes a temporary alteration in an individual's range of cognitive capacity resulting from a factor (in this case, a disease process), followed by a return to the individual's baseline range of cognitive capacities as a result of proper medical intervention.

Some disease processes may have more persistent effects on cognitive capacity. Consider the example of a previously healthy, typically-developed young man who experiences a cardiac arrest. He receives cardiopulmonary resuscitation (CPR) and is transported to a hospital where staff are able to achieve return of spontaneous circulation after an additional five minutes of CPR. Unfortunately, he had a period of sustained anoxia prior to return of spontaneous circulation and has significant global brain damage, as evident on MRI. He has an intact neurological respiratory drive and he is eventually able to breathe on his own without the assistance of a ventilator, although he does require feeding via a percutaneous tube inserted directly into his stomach. Prior to suffering a cardiac arrest, he was high-functioning, and possessed a non-limited range of cognitive capacities. His experiential capacity under those prior circumstances was not meaningfully limited in any way, and he had access to the physical, psychological, and existential domains of experience. Now, following many weeks of rehabilitation, he is noted to smile occasionally, although it does not appear reliably related to any external stimuli. He will sometimes focus on faces within his field of vision, seemingly acknowledging the presence of others, but he does not appear to recognize specific individuals. He will sometimes turn his head towards a sound. He makes nonlinguistic sounds but does not form words. He flinches and grimaces when having an IV placed, and his heart rate increases temporarily, but his heart rate and blood pressure do not increase when the IV needle is placed within his field of vision prior to placement. Under the classification system described previously, he appears to be limited to the cognitive capacities for co-awareness, awareness, and unconsciousness. This represents a persistent change in his baseline range of cognitive capacities.

With respect to his experiential capacity, we know that he has access to the physical domain, since he flinches, grimaces, and becomes tachycardic with a painful stimulus (IV

placement). His access to the psychological domain of experience is unclear, but plausibly seems limited because he does not show behavioral or physiological manifestations of anxiety or fear when the IV needle is within his visual field. The extent of his injury is such that it appears he is no longer capable of the type of self-reflection or reference to others that would be consistent with the cognitive capacity for consciousness or co-consciousness, which also implies an absence of access to the existential domain of experience. Thus, the cognitive capacities for co-awareness, awareness, and unconsciousness most likely effectively represent a new baseline for him. While we cannot know his inner experience with absolute certainty, this is a reasonable assessment given the available observational data and evidence of extensive brain injury on MRI. Global hypoxic brain injury has effectively, persistently constricted the range of his baseline cognitive capacity compared to before his injury.

In children, similar injuries may result in similar constriction of cognitive capacity, but because they can receive adequate nutrition via a percutaneous gastrostomy tube (sometimes referred to as a G-tube), they may continue to grow and develop physically. In this way, these types of injuries may dissociate the child's cognitive and physical development from one another. Consider an 8-year-old girl with a severe case of bacterial meningitis resulting in extensive brain damage. She is no longer able to breathe spontaneously on her own, necessitating placement of a tracheostomy and continuous mechanical ventilatory support. She receives all nutrition via a G-tube. She is alive, with normal vital signs for age, but remains nonresponsive and oblivious to everything happening around her. Using Rochat's classification, she appears to be limited to the state of non-consciousness, and therefore has no cognitive capacities and no experiential capacity. However, since she can be provided with nutrition via a G-tube, she may continue to gain weight and grow. She may even develop secondary sexual characteristics and undergo menarche. Children

like this girl can present a complicated and sometimes confusing scenario for families and caregivers, since their physical development is so radically divorced from their cognitive development and capabilities.

These examples demonstrate the utility and flexibility of a conceptualization of cognitive capacities based on Rochat's classification system within a medical context—it reflects the manner in which both internal and external factors, such as disease processes, treatments, or interventions, can cause rapid and significant change in circumstances. Individuals may undergo significant alteration in their ability to exercise their cognitive capacities and corresponding domains of suffering depending on the presence and fluctuation of internal and external factors—a notion that this conceptual framework accounts for and embraces. Acknowledging the dynamic nature of cognitive capacity, and by association, experiential capacity and domains of suffering, calls for a recharacterization of pediatric suffering which incorporates these aspects of experience.

2.12 A New Characterization of Suffering in Children

The concept of dynamic cognitive capacity supports the notion that pediatric suffering may be best understood as a continuum of experience along which individuals may shift depending on the current circumstances. As the preceding analysis indicates, Rochat's classification can help provide a cognitive threshold at or beyond which we may be more confident that an individual is capable of experiencing suffering in a given domain under a given set of circumstances. A characterization of pediatric suffering focusing on guiding clinicians towards what is relevant in consideration of suffering should account for the intricate interplay between cognitive capacity, experiential capacity, and domains of suffering.

While firsthand information regarding the subjective experience of patients remains optimal, factors like sedation, critical illness, disease progression, developmental limitations, and delirium may make the firsthand perspective unobtainable or less trustworthy in some situations, necessitating the use of secondhand assessments of suffering. Moreover, infants and young children typically have medical decisions made for them by parents or surrogates using the best interest standard, which inherently requires a modicum of secondhand interpretation of the experience of illness and burden-to-benefit ratio. The need to balance these elements—the necessity of secondhand assessment, and the need to respect the significant rhetorical and persuasive force of suffering—would benefit from a characterization of pediatric suffering that accounts for a child’s experiential capacity given their cognitive capacity under a given set of conditions. Incorporating elements suggested by Salter, Edwards, Bueno-Gómez, and Cassel, discussed in Chapter One, I propose the following characterization.^{1,2,4,5,8}

Pediatric suffering is a distressing or anguishing experience, for which the threshold may vary widely across children. The experience of suffering is not limited to those capable of creating or possessing an intact sense of self, nor dependent on the ability to communicate about their suffering. Depending on the cognitive capacity and experiential capacity of the individual under current circumstances, suffering may involve aspects of none, some, or all of the following three domains: physical experiences (both painful and nonpainful); psychological experiences such as fear, anxiety, boredom, isolation, the desire that the experience cease, and anticipation and memory of physical symptoms; and existential experiences such as thwarted plans or potential, anticipation of the end, fear of death, and loss of identity, dignity, bodily integrity, or familial roles and relationships.

Incorporating cognitive capacity and experiential capacity increases the potential for clarity and justification in secondhand assessments of suffering and provides some common terminology by which we can discuss suffering. It also serves to refocus the assessment of suffering on the

patient, and the patient's experience. As Salter notes, observing perceived suffering in children may cause suffering in the observer.⁸ This suffering may be entirely valid, however it is incumbent upon clinicians to remain cognizant and distinguish it from suffering in patients. Projecting suffering onto others implicitly assumes that a situation we find intolerable is intolerable for that individual as well. This is what Salter has referred to as smuggling "value judgments about quality of life into decision-making."⁸ This distinction is crucial if suffering is to be considered a factor in any medical decisions, since these can be decisions of significant consequence, and should therefore be as accurately and rigorously informed as possible. The proposed characterization of suffering can potentially reduce the risk that unjustified, inaccurate attributions of suffering are used to defend premature decisions regarding medical treatment options. Accurately identifying suffering presents a valuable opportunity to address patient-specific physical, psychological, and existential factors that contribute to suffering. It provides clinicians with a remarkable opportunity to recognize and ameliorate discrete aspects of suffering, acknowledge suffering for which they do not have interventions, and identify suffering best addressed by others, such as chaplains and social workers.

2.13 The Question of Hierarchy

It is important to note that the proposed characterization of pediatric suffering is not intended to create a hierarchy of cognitive capacities or domains of suffering. No cognitive capacity is fundamentally ranked as better or worse, they are simply descriptive tools which may help clinicians recognize, understand, and communicate helpful information regarding patients. Similarly, the physical, psychological, and existential domains of suffering represent different

aspects of experience from which suffering may arise, but there is no inherent superiority or definitive gradation among them.

If an individual is suffering, and their cognitive capacity at a given time indicates that they have access to all three domains of experience, it does not necessarily follow that they must be suffering in all three domains. For any experience, the threshold of intensity that separates discomfort and suffering will vary by individual—what constitutes a tolerable situation versus an intolerable one may be vastly different for different people. For some, a certain sensation or action may never constitute suffering, while that same action or sensation, even at a relatively minimal intensity, may cause significant suffering for others. Use of cognitive capacity, experiential capacity, and domains of suffering is not intended to rank any individual's suffering above or below any others, but to begin to provide clinicians with a more specific framework and vocabulary by which to assess and describe secondhand accounts of suffering.

2.14 Impact on Life-Sustaining Treatment Decisions

Having a cognitive capacity consistent with the experiential capacity for suffering in a given domain does not, unto itself, tell us anything about the severity of suffering. This is a matter of individual tolerability with respect to both domains of suffering, and degree of intensity of suffering. Simultaneously experiencing suffering in several domains may result in a significant cumulative effect, and may increase the likelihood that suffering is felt to be intolerable, but this can vary between individuals.

Discussions regarding withdrawal of life-sustaining therapies will continue to hinge on the unique personal and intrafamilial threshold of intensity or prolongation for certain types of

suffering. In situations where no family is present this may involve surrogates, guardians, and clinicians. I do not claim that the conceptual framework I offer can generate a definitive solution to these intricately complicated clinical decisions. However, discussions including consideration of cognitive capacity, experiential capacity, and domains of suffering may provide parents, families, guardians, and clinicians with greater definition and clarity regarding secondhand assessments of suffering and may therefore contribute valuable information with which to make decisions involving life-sustaining treatment. For example, some families may give more weight to a particularly intense experience in a single domain of suffering, whereas others may feel that the cumulative burden of suffering in several ways encompassing multiple domains constitutes a greater contribution to overall suffering. The question of whether suffering is profound enough to withdraw life-sustaining therapies is one to which this framework may make a valuable contribution, but not one to which it will provide an answer on its own.

2.15 Conclusion

Chapter two offers a conceptual framework in which cognitive capacity is a strong factor in determining experiential capacity, which in turn, determines the possible domains of experience to which an individual has access under a given set of conditions. This framework provides the basis for a new characterization of pediatric suffering, incorporating the dynamic nature of cognitive capacity, experiential capacity, and domains of suffering. The direct application of this framework within a medical context necessitates a more robust demonstration of its utility within the clinical setting, including ways in which a clinician can determine what cognitive capacity an individual is most likely to possess under a given set of circumstances, how that can provide

information about potential suffering, and what clinicians may do to alleviate that suffering. Several detailed examples supporting the claim of clinical applicability are the focus of chapter three.

3.0 Chapter Three

3.1 Introduction

As discussed in chapters one and two, medical decision-making for children can involve secondhand assessment of suffering by parents, caregivers, and clinicians. To do so in an ethically-sound manner, we need better conceptual frameworks by which to meaningfully assess a child's capacity for suffering, and given that information, whether or not they are suffering now. In chapter two, I proposed a framework demonstrating the interaction of cognitive capacity, experiential capacity, and domains of suffering. I then used that framework to propose a new characterization of pediatric suffering aimed at improving clinician assessment of patients. In this chapter, I consider how clinicians can employ this framework in assessing patients. I present several scenarios that demonstrate how this framework can be used in the clinical setting, describe how its use can guide the focus of secondhand claims of suffering towards the child's experience, and help reduce the risk that clinicians inappropriately project suffering onto patients. The chapter concludes by offering three key ways in which this framework can have a significant impact within the clinical setting.

Disclaimer: All patients are fictional and are not intended to represent any particular individual.

3.2 The Case of Alex—Part One

To begin, let's examine a case that may appear somewhat obvious at the outset, but serves to demonstrate the scope and potential utility of the proposed framework.

Alex is a 15-year-old young man with relapsed, chemotherapy-refractory leukemia. Prior to his cancer diagnosis two years ago, he was an active, healthy teenager with no health problems. Following his initial diagnosis he underwent a course of intensive chemotherapy but relapsed within 6 months after his initial course of treatment. He underwent a course of second-line chemotherapy, but without significant improvement. He is not a candidate for bone marrow transplant. Prognosis has been discussed at length with Alex, his parents, and his two younger siblings, ages 13 and 10. The likelihood that he lives for more than 6-12 months is very low. He is admitted to the inpatient oncology service after developing fever, vomiting, diarrhea, and dehydration.

Alex receives appropriate fluid resuscitation and antibiotics. He remains hemodynamically stable, but he appears gaunt. He has lost a significant amount of weight and is very thin and pale, with slightly sunken eyes and hollow-appearing cheeks. At the time of admission, Alex appears tired, which is attributed to his acute dehydration. As he receives fluids and antibiotics, he regains some color in his cheeks and says that he is starting to feel better. Over the next few days, Alex becomes more withdrawn. He is generally talkative, but has been reluctant to speak with most members of his inpatient team, and is less interested than previously in talking with his mother, who has been a source of significant support throughout his illness and has been staying with him in the hospital during this admission. His vitals are normal for his age, and his physical exam, including a complete neurological assessment, remains at his baseline. One day during rounds

outside of his room, his nurse, Anna, who has taken care of him for several days as well as during previous admissions, expresses her concerns.

“It’s just really hard to see him like this,” she says, “he won’t talk to anyone, and he’s just sitting there miserable and suffering; it’s terrible.”

“Well,” replies Mark, the attending oncology physician on service this week, “Alex is recovering from a pretty bad episode of dehydration, and overall we know that his prognosis is not good, but he’s not in any pain. Maybe he’ll feel a little better when he starts to eat and drink a little more.”

“I just think,” Anna remarks, “having met him so many times before, this isn’t like him. I just think letting him suffer like this isn’t right.” She shuffles her papers, getting ready for rounds.

At this moment, Alex’s team has two options. First, they can brush off this concern because he doesn’t appear to be in any pain, and doesn’t appear to be suffering at first glance. After all, he is a chronically- and terminally-ill teenager—is it particularly surprising that he doesn’t feel very talkative? The oncology team has seventeen other patients to round on and write notes for this morning, and three scheduled admissions for chemotherapy today, not to mention the patient in the emergency department with a cancer history that they’ve already received a “heads up,” about. Besides, this conversation sounds like it might just drag on with no real path to meaningful resolution, because it could just be a difference of opinion. It is easy to repeatedly defer this conversation to tomorrow, especially on such a busy service.

Second, they can tackle what might appear to be a daunting conversation using a systematic approach with some common vocabulary that would allow all members of the treatment team to get on the same page, or at least understand one another on a more granular, detailed level with respect to the claim that Alex is suffering. Such an approach is similar to thinking through a

differential diagnosis when a patient is first admitted—doing so in a systematic fashion makes it more likely that all probable etiologies for the current presentation are discussed and evaluated, and less likely that there are major omissions that would miss certain diagnoses. Thinking through Alex’s potential suffering using a framework of cognitive capacity, experiential capacity, and domains of suffering can help justify claims that Alex is, or is not, suffering, and provide this improved level of detail—it can help guide all the clinicians involved in Alex’s treatment toward a common understanding of his situation, even if it doesn’t necessarily mean they all agree with one another. The team takes the second option, generating the following assessment.

Under the current conditions, given that Alex is a typically-developed 15-year-old boy, his baseline cognitive capacity is not limited—he has the cognitive capacity for co-consciousness, consciousness, co-awareness, awareness, and unconsciousness. We have no evidence at the current moment that his ability to exercise his cognitive capacity is diminished from baseline. He therefore has experiential capacity in all three domains: physical, psychological, and existential. Assessing Alex’s cognitive and experiential capacity at this point in time is fairly straightforward, but that certainly will not be the case for every patient. Describing Alex’s situation using this terminology gives his team a systematic approach to assess the ways that he might be suffering, which in turn, can guide them towards interventions they may otherwise not have considered at this time. This may be particularly helpful given that Alex’s cognitive capacity is, as far as we know, not limited, but he is unwilling to speak in any detail at the moment.

Given this assessment, Alex is capable of experiencing suffering in the physical domain; however, having the capability to do so does not necessarily mean he is experiencing suffering in the physical domain right now. The question then becomes, “do we have any objective evidence that he is experiencing suffering arising from the physical domain right now?” To answer this

question, we can look to physiological monitoring data, objective physical findings, and patient-reported subjective symptoms. His blood pressure and heart rate are normal for his age, whereas we would expect them to be intermittently or persistently elevated if he were in significant pain. A similar physiological response may occur if he has nausea, and he might vomit, which he is not currently doing. He does not grimace, clench his hands, or curl into a fetal position—instead, he reclines in his hospital bed and actually appears somewhat comfortable. The bone pain associated with his leukemia is well controlled with a reasonable dose of oxycodone, which he has been taking at the same dose as needed for over a year. His nausea has been well controlled with granisetron, and he does not have any ongoing vomiting. He does not complain of any pain or other physical discomfort, and in speaking with his mother, she has not noticed any signs that would indicate to her that he is experiencing physical discomfort either. This list of possible physical experiences is certainly not exhaustive, but given the available objective and subjective evidence, Alex’s treatment team feels relatively reassured that he is not currently experiencing suffering arising from the physical domain.

Alex is also capable of experiencing suffering arising from the psychological domain. The question of whether he is experiencing suffering arising from this domain right now is difficult to answer, because he is not currently in the mood to communicate his experience. But, examining the ways in which he may experience elements of this domain can suggest resources that might be of use in further exploration or intervention. Alex may certainly be afraid and anxious—he is a teenager facing a life-limiting illness who has exhausted the majority of potential treatment options. He may feel bored and isolated—he has had many hospital admissions and it is reasonable to suspect that he has previously experienced the monotony, boredom, and loneliness that can be associated with chronic illness. It also seems reasonable to suspect that he wants the experiences

of having cancer, being sick, and requiring repeated hospital admission to cease. All of these represent potential modalities of suffering arising from the psychological domain, and there is good reason to investigate them further. Some of these experiences may benefit from pharmacologic intervention—for example, benzodiazepines as needed to help with anxiety—or non-pharmacologic interventions like counseling and therapy. But before attempting intervention, it is essential to focus any available resources on gaining greater clarity regarding whether or not this is actually the case. Other resources geared towards investigating Alex’s psychological state, such as behavioral health services, psychological services, social work, and therapists, should be engaged to determine which, if any, interventions he may benefit from. Again, much like discussing a differential diagnosis, this exercise is important because it creates a specific list of potential etiologies for suffering, which in turn generates a list of possible ways to investigate and address those etiologies. It generates an increased level of specificity which the term “suffering” inherently lacks.

Alex is also capable of experiences in the existential domain. Similar to psychological experiences, the presence of active suffering arising from this domain can be difficult to ascertain under present circumstances, since Alex is not feeling particularly talkative. Again, examining potential ways in which Alex might be capable of suffering within this domain can allow clinicians to direct appropriate resources for intervention or exploration. It may also help his team put more specific terms behind the simple claim of “suffering,” so that they can communicate and understand one another more effectively regarding his experience. The treatment team should consider that Alex may be mourning the fact that he likely will not graduate high school, go to college, or have a career. Like most people, he may be afraid of his life ending, and worry what happens to him when he dies. He may mourn the loss of his identity as a big brother, and feel as

though he is incapable of being the caretaker he has always seen in himself for his younger siblings. He may see himself in the mirror and think “I am not who I used to be,” and realize he may never again be that person. He may feel as though he has let his parents, siblings, and friends down by being sick, or feel like a burden to his loved ones. All of these experiences may cause suffering arising from the existential domain. Having speculated about the ways in which Alex may be suffering, his team can attempt to determine which, if any, of these he is actually experiencing.

What potential resources does this analysis point Alex’s team toward? They should make sure they are aware of Alex’s religious beliefs, if he has any, and ensure regular access to spiritual advisors for both Alex and his family. They should enquire as to whether Alex’s siblings have received therapy or counseling—do they understand the progression of his illness and likely outcome? Ensuring family support in this manner can contribute to alleviating suffering arising in the psychological and existential domains of Alex’s experience with respect to his worries, concerns, or even guilt regarding his siblings’ well-being. Similar to experiences in the psychological domain, some in the existential domain may also benefit from behavioral health, psychological services, social work, and counseling services. Some fears and anxieties may benefit from pharmacologic intervention as well.

The analysis generated by my proposed framework and characterization of suffering indicates that, if Alex is indeed suffering right now, as his nurse suggests, that his suffering most likely arises from the psychological domain, existential domain, or both. By using this framework to identify specific elements that may be contributing to Alex’s experience of suffering at a given time, his treatment team can be more reassured that they are all talking about the same experiences when they talk about suffering. The potential experiences considered above are not an exhaustive list—the opportunity to have a dedicated discussion among the treatment team members regarding

potential domains and experiences of suffering also serves as an opportunity for team members to bring up any facet of experience they feel may be contributing to their overall sense that the patient is, or is not, suffering. This can help generate a list of potential ways in which a patient may be suffering, which in turn helps the team ensure that they are addressing these potential avenues of suffering using the most appropriate available resources. This framework and characterization of suffering make it less likely that the members of Alex's team simply assume they are all using the term "suffering," in the same way. By endeavoring to articulate and justify claims of suffering with maximum specificity, we can begin to better communicate with one another, and gain common understanding of what we mean when we say "this patient is suffering."

3.3 The Case of Alex—Part Two

What if Alex's circumstances change? Considering suffering through a framework of cognitive capacity, experiential capacity, and domains of suffering provides the flexibility to deal with changes in clinical status. This framework acknowledges that cognitive capacity is a function of both the cognitive development of the individual, as well as internal and external factors.

Alex recovers from his gastrointestinal illness and dehydration, presumed secondary to viral gastroenteritis, and is discharged home. Three months later he is brought to the emergency department with acute onset of slurred speech, confusion, and altered mental status, which has never happened to him before. He is sedated with fentanyl and midazolam, given a dose of neuromuscular blockade (paralytic), and a breathing tube is placed. A CT scan of his head shows concern for expanding leukemic infiltrate within his brain, and an adjacent, large-territory stroke. He is admitted to the pediatric ICU.

Over the next several days, Alex develops significant brain swelling. MRI of his brain performed 5 days after admission shows a large area of dead brain tissue, diffuse brain swelling, several areas of leukemic infiltrate, and mild compression of his brainstem without active brainstem herniation. Neurosurgical options to reduce the pressure in his head are discussed with his parents, and in conversation with the surgeons and ICU team, they decide against surgical intervention, as it may relieve the pressure but will not alleviate the underlying intracranial pathology. Alex does not have further episodes of elevated blood pressure and bradycardia that would indicate episodic spikes in his intracranial pressure—his brain swelling remains significant, but not worsening. He intermittently initiates breaths on the ventilator—his central respiratory drive is at least somewhat intact. He remains sedated with fentanyl and midazolam, and he is maintained on antiseizure medications as prophylaxis. Given the extensive damage to Alex’s brain and lack of treatment options for his refractory leukemia, which has now spread to his brain, his family begins to consider withdrawing life-sustaining treatments. Over the next day, they begin to discuss these considerations among themselves.

The next morning on rounds, Alex’s clinical situation remains unchanged. Speaking with the ICU team, his parents state they are still considering redirecting his goals of care, but have not made a decision yet. Later that day, a care conference is held with team members from the ICU, neurology, oncology, and palliative care services. During this meeting, John, the first-year pediatric ICU fellow who has been taking care of Alex since his admission six days prior, expresses some dismay with the fact that Alex’s parents have not yet made a decision regarding his goals of care.

“He’s just in there, suffering,” John says, frustrated, “and there isn’t anything to do. There isn’t any other way this ends. He’s just going to suffer until they make up their minds.” There is a moment of silence around the table.

“Ok, why don’t we unpack that?” replies Scott, the palliative care attending physician. “How do you think Alex is suffering?”

“It’s just miserable in there,” John responds, “he can’t do anything, he looks terrible, and allowing this to continue is just making him suffer.”

“Well, why don’t we talk about what Alex can experience right now, and what we might be able to help with?” Scott replies. The group then engages in the following evaluation.

To ascertain what Alex can experience, his team should first talk about his cognitive capacity. How can they use his current exam, physiological data, medication exposure, and imaging to inform this assessment?

Alex is currently sedated with minimal doses of fentanyl and midazolam, but he is not receiving any paralyzing agents. His neurological exam is limited due to his sedation, but his pupils are equal, round, and reactive to light. He has slightly increased deep tendon reflexes, reflective of his brain injury. He does not open his eyes spontaneously with verbal or physical stimulation. He has minor fluctuation in his heart rate and blood pressure, but no values out of the range of normal for his age. He does not meaningfully react—open his eyes, move his extremities, increase his heart rate or blood pressure—in response to any environmental stimuli like noises, talking, passers-by bumping into his bed, or changes in the light in his room. He does not show any response to the voices of his parents or siblings. This clinical state is reasonably concordant with his recent brain imaging and sedative medications, as described above. It is important to remember at the outset that Alex does initiate breaths on his own. He therefore does not warrant evaluation for death by

neurological criteria at this moment—he is alive, as is required in order to assert that he may have any cognitive capacity at all.

Given this assessment, we have no indication that Alex is capable of objectified thoughts or acts in reference to himself or others, so it is unlikely that he currently has the cognitive capacity for co-consciousness or consciousness. He shows no particular response to the presence of others, even those familiar to him, so it is unlikely that he currently has the cognitive capacity for co-awareness. He does not respond in any way to environmental noises or lights, so it is unlikely that he currently has the cognitive capacity for awareness. Delineating the difference between possessing only the cognitive capacity for unconsciousness and a state of non-consciousness may appear tricky in a patient like Alex, but his medications provide additional useful information. He is being given midazolam, a medication known to cause anterograde amnesia—it prevents the formation of new memories. While he is receiving this medication, we can reasonably posit that he will not form significant memories of anything that happens in his environment—he is pharmacologically prevented from receiving and processing sensory data in a meaningful manner. This may also be the case secondary to his underlying brain injury, but this is difficult to prove objectively. We are thus left to conclude that it is most likely Alex is in a state of non-consciousness under the current circumstances. He is alive, but unresponsive and oblivious to everything external and internal to himself. He cannot experience anything and he cannot form memories. A person in a state of non-consciousness does not have access to any domain of experience, and therefore cannot suffer.

It is important to note that this does not in any way absolve Alex's team of responsibility for ensuring his comfort. Cognitive capacity is dynamic—in this case, given Alex's history it seems unlikely to change, but not impossible. Remember that at least part of the reason Alex is

currently in a state of non-consciousness is related to his sedative medication regimen. That is to say, the medication regimen is doing exactly what it is intended to do. It is protecting Alex from the potential for suffering. The team should continue to ensure this is the case while Alex's family takes time to come to a decision, and provide them with the continued support to do so.

As Erica Salter notes, and as discussed in chapter one, observing perceived suffering may cause genuine suffering in the observer.⁸ This seems to be the most likely explanation for John's expressed concern regarding Alex. John's insistence that Alex is suffering seems more likely to represent a manifestation of John's reaction to being involved in a sad, frustrating situation, and it may be causing John genuine suffering. Recognizing suffering in the observer is important, and allows it to be addressed. John may benefit from a talk with his attending physicians, mentors, or fellowship director about ways to help mitigate the significant emotional distress one can experience working in the intensive care unit. He may benefit from therapy to address these experiences. It is also entirely possible that John is simply having a bad day—maybe he is sleep deprived, maybe his significant other is upset with him. Whatever the underlying cause, recognizing distress and potential suffering in John can help him get access to support and resources.

3.4 The Case of Sarah

Sarah is a 6-year-old girl with a complicated medical history. She had a significant anoxic event (prolonged oxygen deprivation) at the time of delivery which resulted in severe hypoxic-ischemic brain damage and long-term degeneration of her remaining cortical and cerebral brain matter. She has a tracheostomy, and lives with the support of a ventilator. She has spastic cerebral

palsy, and a seizure disorder requiring multiple anti-epileptic medications which reduce, but do not entirely stop her seizures. She also has autonomic dysregulation, sometimes referred to as “autonomic storming,” which causes intermittent discharge of catecholamines resulting in flushing, tachycardia, hypertension, sweating, and grimacing, for which she is prescribed clonidine. She requires supplementation of multiple hormones from damage to her pituitary gland. All her medications and nutrition are provided via a gastrostomy tube. Sarah is unable to walk or talk. Her facial expression is relatively static and does not vary with changes in her environment. She will occasionally turn her head towards a sound. She has damage to her visual cortex (the visual processing pathways in her brain), but prior ophthalmologic evaluation indicates she can likely perceive some colors and shapes. Her vital signs do not change at all when people speak to her. Sarah lives at a medical home for children with complex, chronic issues, and she is admitted to the local children’s hospital several times per year for intercurrent illnesses and management of her underlying conditions. Her parents moved out of state, and are only peripherally involved in her care.

Sarah is currently admitted to the pediatric intensive care unit with respiratory distress, bacterial pneumonia, and septic shock requiring escalation in her ventilatory support, placement of a central venous catheter under local anesthesia, and vasoactive medications to support her blood pressure. As she begins to improve, she has breakthrough seizures requiring titration of her antiepileptic medications, and her autonomic dysregulation flares, causing frequent swings in her heart rate and blood pressure, as well as flushing and grimacing. She has had an extensive laboratory workup for other sources of infection or organ dysfunction, which was negative. She has had long-bone films to evaluate for occult fracture, which were negative.

One day on rounds, Dan, a new pediatric resident rotating in the ICU, expresses his dismay with Sarah's situation. "I mean, I just don't understand why we keep doing these things to her," he says. "She's miserable, just lying in there by herself, having seizures and storming. And we put her through central line placement. I don't understand why we're letting her suffer like this. What is her life even like?"

When applied to such a question, the proposed framework and characterization of pediatric suffering suggests asking "to the best of our knowledge, what is Sarah capable of experiencing?" In order to do this, we need first to ascertain Sarah's current cognitive capacity. How can the information we have available regarding Sarah—her exam, physiological data, medications, imaging, and medical record—inform our assessment of her cognitive capacity?

Sarah sometimes will turn her head towards a sound, and her ophthalmologic evaluation indicates that she is likely capable of seeing colors and shapes. There is therefore evidence that Sarah has the capacity for implicit, preconceptual acts of perception like seeing and hearing. This would indicate that Sarah has the cognitive capacity for awareness and unconsciousness. But, could she also have the cognitive capacity for co-awareness, consciousness, or co-consciousness?

There is no apparent evidence that Sarah is capable of engaging in specific, objectified mental manipulation of objects and ideas, and this is consistent with the extensive damage seen on her brain imaging. It is therefore unlikely that she has the cognitive capacity for consciousness. There is no indication that Sarah responds specifically to the presence of other individuals. She may occasionally turn her head towards a noise, but her reaction is not specific to voices or speech. In the presence of others, she displays no changes in facial expression, heart rate, or blood pressure that would indicate a particular reaction to a specific person. It therefore seems unlikely that Sarah has the cognitive capacity for co-awareness.

Sarah therefore appears to most likely be limited to the cognitive capacity for awareness and unconsciousness. As such, her experiential capacity is likely limited to the physical domain—she is most likely capable of experiencing suffering arising only from physical experiences. Once we have arrived at this conclusion, the next question is “what physical experiences is Sarah having that may generate suffering, and what, if anything, can we do about them?”

Sarah’s central line was placed under local anesthesia, which provides reasonable pain control for small, minimally-invasive procedures. She may have some residual discomfort from the sutures, which can be managed with scheduled analgesics such as acetaminophen. Sarah’s autonomic dysfunction may indeed be uncomfortable, as it can entail prolonged periods of flushing, rapid temperature variability, sweating, and increased heart rate, which can create the sensation of chest palpitations. It is reasonable to believe that this constellation of symptoms can cause some people to suffer. Since Sarah is unable to communicate whether this is the case for her, it is reasonable to assume she is experiencing discomfort and provide a temporary increase in her clonidine dose, or an additional dose. Provided there are no adverse side effects from increasing her clonidine dosing, the minimal risk of this treatment supports using it rather than permitting the possibility that she remains in a state of persistent pain, discomfort, and suffering. Increased seizure frequency and recurrent post-ictal periods may also be uncomfortable enough to cause suffering—we don’t know for certain that this is the case with Sarah, but again, since she cannot communicate her experience, we should err on the side of reducing the risk of discomfort. Optimizing her anti-seizure medication regimen while she recovers from the acute phase of her illness can reduce the likelihood of repeated seizures. Finally, Sarah’s laboratory and imaging workup reveals no other significant organ dysfunction or long bone fracture, making it less likely (although not impossible) that we are missing other sources of discomfort.

Using the proposed framework and characterization of suffering allows us to assess Sarah within her individual circumstances, focusing the question of suffering on the patient and her experience. We can identify the most likely ways in which Sarah can and cannot experience suffering, and work to specifically address her situation. Sarah has several physical experiences—procedure site discomfort, autonomic dysregulation, and seizure frequency—that may potentially contribute to suffering in the physical domain, which we can identify and address with the aid of the systematic approach offered by the proposed framework.

Similar to the case of Alex, here it is important to remember that the potential for suffering in the observer should be addressed as well. It can be extraordinarily difficult to bear witness to a person experiencing critical illness, particularly for individuals who are not accustomed to the intensive care unit. Dan's response to Sarah indicates that Dan himself is likely experiencing some internal distress about Sarah's situation—Dan may even be experiencing suffering as a result of this situation. Dan's suffering, if it indeed exists, should be acknowledged, but should not guide medical decision-making for Sarah. It may indicate that Sarah has what Dan views as an unacceptable quality of life, which he has equated with suffering. It is an emotional response to perceived suffering in another human being, which unto itself, is certainly an understandable reaction, but it is incumbent on clinicians not to allow our own emotional reactions to drive potentially life-altering decisions for others. This should be an indication that Dan may need more support and guidance from his attending physicians or residency program leadership regarding the emotional stress associated with rotating through the intensive care unit.

As the example of Dan and Sarah suggests, it can be very easy for clinicians to mistakenly attribute suffering to a patient whose perceived quality of life they deem unacceptable for themselves. Dan may mistakenly attribute suffering in the psychological and existential domains

to Sarah because he evaluates her experience under a given set of conditions from the position of his own cognitive capacity. The question “how would I feel if that were me?” produces an unreliable result when the person asking it has a cognitive and experiential capacity which differs significantly from the person who is the object of the question. In particular, it can lead to unwarranted assertions of suffering in the psychological and existential domains because of the incorrect assumption that the individual in question has the cognitive capacity necessary for experience in these domains. There is a danger that such unjustified, and possibly exaggerated, secondhand claims of suffering will potentially be used to defend premature decisions regarding redirection of care or withdrawal of life-sustaining treatments. This is of particular concern with patients like Sarah, who are not capable of forming or expressing their own thoughts and opinions. This is not to say that claims of suffering represent an insufficient reason to consider withdrawal of life-sustaining treatments, but that such claims should be justified in order to be considered as factors in decisions of such magnitude. The proposed framework helps provide this justification by identifying types of suffering that patients can and cannot experience based, in part, on an assessment of their cognitive capacities. It can therefore help reduce the risk that unsupported and inaccurate secondhand claims of suffering are improperly used as factors in clinical decision-making.

3.5 Conclusion

Approaching secondhand claims of suffering through a framework of cognitive capacity, experiential capacity, and domains of suffering, and utilizing a characterization of suffering that incorporates these elements, can have positive impacts in several aspects of clinical care. As the

examples offered in this chapter illustrate, this framework offers three substantial benefits to evaluating secondhand claims of suffering in children.

First, it provides a clear and justifiable framework for determining whether and how patients are suffering, and reduces the risk that clinicians will make unspecified, inaccurate, or unsupported attributions of suffering. By asking what, to the best of our knowledge, an individual is capable of experiencing, we can include or exclude certain aspects of experience that may be contributing to their capacity or potential for suffering, thereby generating identifiable sources of potential suffering whose likelihood of occurring can be assessed. The framework suggests that we offer specific evidence to justify a claim of suffering in the same way we offer exam findings, lab results, imaging, and the history of the present illness to justify a medical diagnosis. Furthermore, by encouraging clinicians to describe their assessment beyond simple use of the term “suffering,” this framework fosters an increased degree of rigor and specificity regarding secondhand claims of suffering—it suggests that an appropriate response to claims that “the patient is suffering” is, “what makes you think that?” By urging clinicians to use clearer, more specific language with one another, this framework offers a better chance that they understand one another’s concerns.

Second, this framework can help clinicians identify means to ameliorate suffering. In generating identifiable sources of potential suffering, clinicians are empowered to address them in a targeted fashion. This could be through consulting services, medications, therapy, social work, chaplaincy, or other methods. Thus, the framework enables clinicians to identify potential avenues of suffering as well as means to alleviate them. As an ancillary benefit, it can help guide us towards clinicians and healthcare workers who may be experiencing suffering themselves, potentially resulting from witnessing perceived suffering in another. Recognizing this situation is not easy,

but the systematic analysis undertaken via this framework reminds us of the possibility. This can help identify clinicians who need more support, are struggling with the emotional demands of their work, or those potentially at risk for burnout.

Third, this framework can reduce the risk that unspecified, inaccurate, or unsupported attributions of suffering are used to defend premature or unjustified decisions to forgo treatment. Suffering is a term with significant rhetorical and emotional force, but it lacks a standardized definition or criteria and inherently includes value judgments. As such, secondhand claims of suffering are vulnerable to the assumption that an experience considered intolerable by the observer is automatically intolerable to the person experiencing it as well, as illustrated above by the case of Sarah. This may result in a tendency to use suffering as a catch-all justification for clinical decisions, for example, withdrawal or withholding of life-sustaining treatment, rather than as a factor in clinical assessments. By incorporating assessment of cognitive and experiential capacity, this framework facilitates evaluation of suffering centered on the patient's experience. In doing so, it cautions clinicians to avoid conflating a quality of life they perceive to be unacceptable with suffering on the part of the patient. By focusing on the patient's experience, and allowing for consideration of cognitive capacity, experiential capacity, and domains of suffering, this framework can help show adequate justification, or lack thereof, for secondhand claims of suffering in decisions of significant magnitude, such as redirection of care and withdrawal of life-sustaining treatments.

Despite its complicated and problematic nature, suffering remains commonly cited as a factor in medical decision-making for children. The framework and characterization of pediatric suffering presented here incorporates considerations of cognitive capacity, experiential capacity, and domains of suffering, and provides a clear and justifiable basis for secondhand claims that a

patient is, or is not, suffering. Re-framing pediatric suffering in this manner may move clinicians away from a system of thought in which “the patient is suffering” automatically begins to drift towards sanctioning a specific clinical decision or action, and towards one in which it instead begets the question “in what ways do we think this patient is suffering, and what can we do to alleviate that suffering?”

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