Focus Article

What is Pain-Related Suffering? Conceptual Critiques, Key Attributes, and Outstanding Questions

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Abstract: Suffering holds a central place within pain research, theory, and practice. However, the construct of pain-related suffering has yet to be operationalized by the International Association for the Study of Pain and is largely underdeveloped. Eric Cassell’s seminal work on suffering serves as a conceptual anchor for the limited pain research that specifically addresses this construct. Yet, important critiques of Cassell’s work have not been integrated within the pain literature. This Focus Article aims to take a preliminary step towards an updated operationalization of pain-related suffering by 1) presenting key attributes of pain-related suffering derived from a synthesis of the literature and 2) highlighting key challenges associated with Cassell’s conceptualization of suffering. We present 4 key attributes: 1) pain and suffering are inter-related, but distinct experiences, 2) suffering is a subjective experience, 3) the experience of suffering is characterized by a negative affective valence, and 4) disruption to one’s sense of self is an integral part of suffering. A key outstanding challenge is that suffering is commonly viewed as a self-reflective and future-oriented process, which fails to validate many forms of suffering and marginalizes certain populations. Future research addressing different modes of suffering – with and without self-reflection – are discussed.

Perspective This article offers a preliminary step toward operationalizing the construct of pain-related suffering and proposes priorities for future research. A robust operationalization of this construct is essential to developing clinical strategies that aim to better recognize and alleviate suffering among people living with pain.

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Suffering is given a central place of importance within the pain literature. It is emphasized within seminal models of pain, and clinical research and practice are commonly framed in relation to the potential for mitigating pain-related suffering. Despite this emphasis, suffering is rarely defined in the pain literature and research specifically addressing this construct is largely underdeveloped within the field. For instance, of the 4 core components within Loeser’s “onion-skin” model of pain, which includes nociception, pain, suffering, and pain behavior - suffering is arguably the least developed. Loeser proposed that pain often leads to suffering, and he endorsed Eric Cassell’s conceptualization of suffering. Indeed, Cassell serves as an anchor within the leading journals in the field of pain. For example, his landmark paper on suffering published in The New England Journal of Medicine in 1982 has received more than 4700 citations. In this paper, Cassell stated that “Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner.” He added: “Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of the person.” In Cassell’s subsequent publications he defined and described suffering in a variety of ways while maintaining the general themes outlined in his landmark paper. Cassell maintained that 1) pain and suffering are distinct experiences, 2) suffering is a personal and private experience, 3) suffering can be characterized as a state or form of severe or specific distress, and 4) suffering occurs when a human recognizes that their wholeness as a person is under threat, disrupted, injured, or disintegrating. Related to 4), Cassell argued that suffering requires self-reflection and the ability to construct a personal narrative; to suffer, a person must be aware of their past, current state, and potentially impacted future. Cassell made foundational contributions to the literature. He advanced our thinking on suffering and facilitated the ongoing movement to humanize clinical care. However, researchers have provided thoughtful critiques of Cassell’s work, and these insights have yet to be integrated or addressed within the leading journals in the field of pain. A common critique is Cassell’s lack of clarity and consistency. For instance, Cassell did not settle on a consistent definition or operationalization for suffering. Cassell’s terminology is inconsistent and opaque, and his characterization of suffering has been criticized for being circular.

Authors have also questioned the requirement for self-reflection as it denies suffering to both humans and non-human animals that have a more limited capacity to self-reflect and construct narratives. These issues leave many questions and gaps in how we understand suffering.

Our field is thus left in a somewhat paradoxical state - the concept of suffering holds a central place within pain research and practice, but this concept remains poorly defined and underdeveloped. Especially concerning is research suggesting that suffering associated with pain is often overlooked, misunderstood, and inadequately addressed by healthcare providers, or even amplified when the person experiencing pain is stigmatized or not believed. The increased prevalence of suicide among people with persistent pain is likely one of the most dire indicators that more needs to be done to mitigate pain-related suffering. A clear operationalization of this construct is an essential and foundational step toward more precise research in this area and developing more systematic approaches to recognizing and alleviating suffering among patients living with pain.

The overarching aim of this article is to take a preliminary step towards an updated operationalization of pain-related suffering by 1) presenting key attributes derived from a synthesis of the literature, including Cassell’s work and related theoretical and empirical research and 2) highlighting key challenges associated with Cassell’s conceptualization of suffering that are not fully addressed in other literature. From our synthesis of the literature, we developed the following 4 key attributes of pain-related suffering: 1) pain and suffering are inter-related, but distinct experiences, 2) suffering is a subjective experience, 3) the experience of suffering is characterized by a negative affective valence, and 4) disruption to one’s sense of self is an integral part of suffering. For each attribute, we start with a synthesis statement that aims to represent general agreement in the literature, followed by the relationship to Cassell’s conceptualization and related literature. We outline outstanding questions and future research related to each attribute. The final section of the article focuses on a key challenge to Cassell’s requirement that suffering must involve self-reflection and a sense of the future. This facet of Cassell’s work has received surprisingly little attention in the pain literature despite the implication that several populations are neglected, including neonates, non-human animals, and others with limited capacity for self-reflection. This article aims to provide a foundation for future work that can create an updated and more coherent operationalization of pain-related suffering.

Synthesis of the Literature Related to Key Attributes of Pain-Related Suffering

Overview of Scope and Methods

This article is focused on suffering in the context of pain. We use the term “pain-related suffering” to refer to experiences of suffering that have some association with pain. We understand these pain-related...
experiences to represent a subset of the broader range of potential suffering experiences. Thus, we also use the term suffering when referring to these broader experiences and the related literature, or when there is no apparent added value in distinguishing these forms of suffering from those associated with pain.

Our synthesis of the relevant literature to develop key attributes of pain-related suffering started with a review of Cassell’s published works to identify the core elements within his conceptualization of suffering. Then, through a series of iterative searches, we identified and reviewed criticisms of Cassell’s work and broader literature concerning each of the identified elements in his conceptualization of suffering. The broader literature that we reviewed spanned multiple fields and disciplines, including pain, palliative care, nursing, philosophy and bioethics (including pediatric, animal welfare, and torture literature), and general literature in the medical humanities and social sciences. PubMed searches were conducted over a year and included combinations of core terms such as: Cassell, concept*, definition, model, pain, pain-related suffering, and suffering. At several points, we sought out specific literature to fill knowledge gaps and to better understand the state of the suffering literature. For example, we conducted a series of PubMed searches to identify qualitative research related to pain and suffering by integrating the following search terms: ethnograph*, grounded theory, narrative, phenomenolog*, qualitative, and review. Key authors and books on suffering were also identified through a series of Google searches and bibliography reviews. Relevant articles, book chapters, and citations were reviewed. Further, Google Scholar and researcher/lab website alerts were set up to identify new literature published by key authors/groups working in this area.

At the end of this article, we summarize all the sections in Table 1 by directly comparing our 4 theoretically and empirically supported attributes of suffering to Cassell’s work. It should be noted that the framing of these attributes is our own, based on our synthesis and critique of the literature. In certain instances, specific terms do not directly correspond to the referenced literature; in these cases, we direct readers to terminological differences. Further, the 4 attributes are intended to be considered together; each attribute is necessary but not sufficient for pain-related suffering.

Key Attribute 1: Pain and Suffering Are Inter-Related, But Distinct Experiences

Cassell and leaders in the field of pain generally agree that pain can lead to suffering (pain-related suffering) and that pain and suffering are phenomenologically distinct.37,20,35,50,89 Here, pain is defined as an “unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage.”76 p.197 Further, pain is always a personal (subjective) experience.74 The relation between pain and suffering was a recurring theme in Cassell’s work, although he avoided the term “pain-related suffering.” For example, he argued that “Suffering is most commonly associated with pain or other physical afflictions. It is now generally accepted, however, that pain and suffering are distinct and different forms of distress.”17 p.216 Consistent with Cassell, researchers Turk and Wilson89 suggested that pain can be associated with suffering (ie, pain-related suffering), yet one can experience pain without suffering or suffer in the absence of pain. Fig 1 visualizes this relationship.

Outstanding Questions and Future Research Related to Attribute 1

Authors have emphasized that it remains unclear how exactly pain and suffering are distinct, how they relate to one another, and what may set apart pain-related suffering from other forms of suffering (eg, grief-related suffering in the absence of pain).19,79,87,88 Further work is needed to explore the unique qualities of suffering that distinguish it from pain. Regarding the relationship between pain and suffering, Turk and Wilson’s19 2009 call for further research in this area is still relevant. Most research has focused on pain causing suffering. However, suffering may also contribute to pain. The potential bidirectional relationship between pain and suffering, and the influence of individual and contextual factors, needs to be better understood. Research addressing the ways that pain may directly or indirectly result in pain-related suffering and how these experiences of suffering may relate to or overlap with more established constructs (eg, pain interference, pain catastrophizing, pain-related fear) is also needed.

Key Attribute 2: Suffering is a Subjective Experience

Like pain, suffering is commonly regarded as a fundamentally subjective experience.6,32,75,90 Cassell considered suffering to be an experience that “is ultimately a personal matter—something whose presence and extent can only be known to the sufferer.”19 p.33 There is general interdisciplinary agreement that suffering is a subjective experience in the sense that the experience is personal, private, and/or lived from a first-person perspective.6,5,94,75,77,83 Although some authors outline nuanced differences in these terms, we view them as generally synonymous and relating to subjectivity. In the context of pain, Loeser clearly aligned with the view that suffering is subjective: “… to suffer will differ from one patient to another. There are no physical examination clues or laboratory tests or imaging studies that reveal its presence. We must ask the patient and listen to his or her narrative to find suffering … One cannot assess suffering in a patient whom one does not know.”50 p.6

Despite the predominant support for conceptualizing suffering as a subjective construct, some arguments have been made for the prioritization of objective measures of suffering that could be used to negate or replace self-report. For example, van Hooft44 presented an “objective” notion of suffering in which different indicators that can be judged from a third-person
of the suffering experience or provide much insight regarding the nature, meaning, or cause of pain-related suffering. Like pain, pain-related suffering may have observable expressions (words, behavior) and measures (self-report or non self-report) that may be of clinical utility, yet the experience of suffering (like the experience of pain) is understood to be fundamentally non-observable. It remains unclear how quantitative measures of suffering intensity (eg, 0-10 ratings) relate to this inherently subjective experience. Qualitative and mixed methods research on pain-related suffering are needed to more fully characterize what the experience is like and to better ground different quantification strategies.

Some emerging work has started to move in this direction. For instance, the Pictorial Representation of Illness and Self Measure (PRISM) and its various adaptations have been used to measure suffering. Generally, it involves asking a person to move a circle representing their health concern (eg, pain) in relation to another circle representing the “self”. The idea is that a shorter distance between the circles represents a greater burden of suffering, or specifically “pain-related suffering” if the health concern under investigation is pain. The PRISM task has been used in different ways, and has been promoted as a valid and reliable measure of suffering in patients with chronic non-cancer pain. Further development of this and other standardized tools may aid clinicians’ ability to recognize, assess, and address pain-related suffering. Qualitative research is also needed to develop clinical communication tools such as patient interview guides that are designed to help recognize and validate pain-related suffering. This work is particularly important as many patients object to the notion of trying to quantify their personal and idiosyncratic experiences related to pain.

**Key Attribute 3: The Experience of Suffering is Characterized by a Negative Affective Valence**

Characterizing suffering as a negative affective experience is a minor deviation from Cassell’s terminology, but adds further precision and is broadly consistent with other work in this area. Cassell often used the term distress to characterize the experience of suffering. However, the way that Cassell used this term lacked consistency and the term itself has been criticized as being inherently imprecise. For instance, without explanation, Cassell vacillated in how he characterized suffering in relation to distress, at times emphasizing its type (as a specific type of distress) while in other instances specifying degree (severe distress). Duffee rightly highlights that Cassell did not define distress and that his characterization of suffering is circular and confusing when we try to dissect it (ie, suffering is a form or state of distress, and this distress is suffering). Further, Duffee notes that the term distress is unclear and inconsistent across fields, pointing to
findings from a concept analysis of psychological distress and a review including the term existential distress. The ambiguity associated with the term distress in relation to suffering has also been discussed in the animal welfare literature, where it is argued that there is no benefit to lumping together known affective states of suffering into the class “distress.”

Characterizing the experience of suffering as having an overarching negative affective valence helps capture some of the essential attributes of Cassell’s terminology, while mitigating the shortcomings. The term negative affect is a broader yet more precise characterization and can be seen as a minimum criterion that captures related constructs and important qualities emphasized in the suffering literature. For example, suffering has been situated as a negative affect, an unpleasant or anguish-producing experience, an unpleasant emotional experience, a mood, inherently emotional, and involving intensely negative meaning. Overall, a necessary aspect of suffering appears to be its negative affective nature and pain researchers have generally assumed this.

Outstanding Questions and Future Research Related to Attribute 3

It remains unclear if there are common themes that can be reliably identified in relation to the affective experiences of people living with pain that suffer. For example, can different experiences of pain-related suffering be further characterized by feelings such as frustration, anger, or feeling overwhelmed? Although some work has been done in the context of cancer, further research is needed to characterize common themes related to negative affective elements of patients’ pain-related suffering. Further, the inter-relations between bodily and cognitive processes and these affective elements of suffering need to be explored. Better characterizing the affective experiences of pain-related suffering and understanding the inter-related processes may help clinicians better recognize and address important patterns in the clinical presentation of people that are suffering with pain.

Key Attribute 4: Disruption to One’s Sense of Self is an Integral Part of Suffering

When characterizing suffering, Cassell discussed the wholeness of the “person” or “personhood” being perceived as threatened or injured; yet, other work suggests that disruption to one’s “sense of self” better characterizes the nature and experience of suffering. Authors have criticized Cassell’s conceptualization of persons for being too complicated, unclear, not clinically accessible, and for conflicting with contemporary scholarship on personhood and selfhood. These critiques are warranted. Cassell’s “person” lacked a coherent theoretical foundation, and patients are unlikely to refer to their personhood being injured, disintegrating, or impending destruction. Further, Bueno-Gómez justly confronts the “non-existent ideal” of the “person” where one’s personhood is fully transparent to themselves and that they know when their “wholeness” as a person loses its intactness. Even Cassell’s more concise definitions of a person lack clarity, such as the definition in his work from 2011: “A person is an embodied, purposeful, thinking, feeling, emotional, reflective, relational very complex human individual of a certain personality and temperament, existing through time in a narrative sense, whose life in all spheres points both outward and inward and who does things.”

In an attempt to address these critiques of Cassell’s “person”, authors have reformulated how this concept should be addressed. For example, Tate and Pearlman argued for a focus on sense of self as it is more intuitive and consistent with patients’ narratives, citing qualitative work by Charmaz. Others have used similar strategies with varied definitions and approaches to the “self”. These ways of reframing suffering in the context of the “self” are helpful as they maintain Cassell’s general ideas, yet better align with patients’ narratives and do not contain problematic reference to injury or disintegration of a person or personhood. Further, much work has been done to define the “self”, including its narrative aspect. For example, Gallagher defined the “narrative self” as a “more or less coherent self (or self-image) that is constituted with a past and a future in the various stories that we and others tell about ourselves.” The narrative self encapsulates important features of Cassell’s person, and both constructs are tethered to reflective capacities. Even Cassell sometimes used the phrase “sense of self,” yet he preferred “person” in his definitions and has declared that “persons are not selves”. However, his distinction (see Cassell) is unwarranted. Svenaeus rightly noted that: “Cassell chooses the concept of ‘person’ instead of ‘self’ because he thinks issues of selfhood are somehow ‘self concerned’ and exclude interpersonal and worldly issues, but I do not see any reason to adopt such an impoverished notion of ‘self’.” Indeed, the selfhood literature has evolved since Cassell introduced his key ideas, and the self is now widely understood as interpersonal and social. We return to the potential benefit of using “self” over “person” below as it relates to the key challenge.

Cassell’s suffering definitions focused on the loss of “intactness”, “integrity”, “cohesiveness”, or “wholeness” in relation to personhood; yet, the term “disruption” in relation to one’s sense of self may be more inclusive and better characterize the nature and experience of suffering. Broadly synonymous with disruption, authors have focused on the interruptive, interfering, or central/consuming role of suffering in one’s life or mental experience. For instance, Edwards and McClelland both proposed that suffering has a disruptive quality in relation to one’s mental life. Likewise, in the field of pain, work has outlined that the repeated interference associated with persistent pain can be disruptive to one’s sense of self, which constitutes suffering. Even Cassell...
occurring schemes to study life stories. These established line of research has produced interview guides and cod- 
ing to his one’s sense of self seems to capture a necessary part of suffering, and this attribute distinguishes suffering from pain (ie, one can experience pain without dis- 

Outstanding Questions and Future Research Related to Attribute 4

Identity is often regarded as an important and central component of the self. Outside the field of pain, there is a well-established literature base on identity that has focused on the development and integration of one’s various life roles, values, goals, and stories. This line of research has produced interview guides and coding schemes to study life stories. These established methods might be valuable in the context of pain and suffering to study thematic aspects of identity, including ways it may be disrupted, restored, or reconstructed in relation to personal, contextual, and environmental factors. This has the potential to offer novel contributions to the field as the bulk of the psychology of pain literature has focused on states and traits, yet the construct of identity in relation to pain and suffering remains largely undeveloped. This work could also help create a common link between interventions that already focus on identity (eg, Acceptance and Commitment Therapy) and the emerging construct of pain-related suffering.

Key Challenge and Directions for Future Research

Restricting the Conceptualization of Suffering to Self-reflective Processes Marginalizes Many Populations

Cassell argued that suffering involves the person knowing their “whole” or intact personhood and perceiving that it is threatened or breached based on their ability to string together their past, present state, and sense of the future. With this perspective, he viewed suffering as an inherently self-reflective process. In other words, Cassell suggested that suffering requires the higher-order cognitive process of thinking about one’s thinking and taking a stance or perspective on one’s experience. Therefore, Cassell restricted suffering to populations with these self-reflective cognitive capacities, stating: “It is important to keep in mind that in order to suffer a person must be aware of the past and the future and be able to assign meaning.” He went on to make it explicitly clear that his view is that infants and many non-human animals cannot suffer.

Similar to Cassell, pain researchers have also endorsed the idea that suffering involves self-reflection. For example, suffering has been positioned as a “third stage” of pain processing that involves long-term cognitive or reflective processes related to meanings and impact on one’s life. When describing these self-reflective processes, authors typically indirectly link pain to the experience of suffering. For instance, pain impacts valued activities, impacting one’s identity (in a self-reflective narrative sense), which results in suffering. There is general empirical support for these self-reflective processes within the qualitative pain research literature. For example, people living with pain report worrying about their future and a loss of their sense of self, identity, roles, or control.

Although there is evidence for suffering as a self-reflective process, we must ask: is this the only mode of suffering? This is a key challenge our field of pain has not addressed despite clinicians and parents believing that infants can suffer, and a growing number of authors questioning the requirement for reflection as it denies suffering to both humans and non-human animals that have more limited capacity to self-reflect. The possibility for another mode of suffering that is more directly linked to pain remains relatively unexplored.

Making Room for Different Modes of Suffering: Can One Suffer Pre-reflectively?

“Pre-reflective” experience is an individual’s immediate experience, without higher-order self-reflective cognitive processes or existential reflection. There is now a body of evidence suggesting that we are born with the capacity for pre-reflective experience and the primitive ability to distinguish self from non-self. Pre-reflective self-experience involves a tacit level of self-hood or “mineness” of experience, often referred to as the “minimal self.” The minimal self is the foundation for the narrative (reflective) self that develops over time. Adults can experience themselves and their world both pre-reflectively and reflectively, and there are many reports of suffering without explicit self-reflection or clear connection to the self in a narrative sense. These pre-reflective experiences are anchored in the “here and now” and are often more directly related to the bodily experience of pain. Consider acute overwhelming pain that disrupts and consumes a person’s usual self-experience, such as moments of torture where individuals report nothing but their intruding bodily experience of pain. Relatedly, people living with persistent pain have described their pain as reaching “torture level” to express what appears to be suffering related to a pre-reflective dimension:

“One woman’s suffering was very deep and everyday life was a huge struggle, she explained, ‘... the fact is that the pain has reached torture level.’ Her experience was that she: ‘... works 24 hours a day enduring it and getting it together.’ In contrast to the other women, she related the cause of her suffering to the pain and physical disability in itself and not to an overwhelming life situation over a long period of time.” (our bolding and italics).
fourth: in the personal meanings and nature of subjective conditions (eg, pain and suffering) and the profound ways people experience both their bodies and their world. Existing qualitative research has focused on disruption to the narrative self and what we call “reflective suffering” involving individuals’ self-reflection and perceived life-impacts of pain. There is a need for qualitative research that explicitly explores disruption to the minimal self, especially considering recent advancements in other fields. There are opportunities to draw from the extensive selfhood literature on the relation between the minimal and narrative self, how these different aspects of the self may be disrupted, and how these disruptions may shape individuals’ pre-reflective and reflective self-experiences. Specifically, there is a need to explore the concept of “pre-reflective suffering” involving alterations in the subjective experiences of one’s body and world.

**Conclusion**

The construct of pain-related suffering is ubiquitous in the pain literature. Yet, it is largely under-developed as evidenced by the fact that there is currently no International Association for the Study of Pain definition for this construct. Cassell made foundational contributions to the literature as he advanced our thinking on suffering and facilitated the ongoing movement to humanize clinical care. However, it is clear that Cassell’s work needs to be built upon and that our conceptualization of pain-related suffering needs to evolve. This article offers a first step to advancing this construct as well as a call for future research.

**Future Research Related to Key Challenge: Exploring Two Modes of Pain-Related Suffering**

Theoretically driven qualitative research can contribute to the operationalization of pain-related suffering. Qualitative approaches offer ways to gather rich insight into the personal meanings and nature of subjective conditions (eg, pain and suffering) and the profound ways people experience both their bodies and their world. Existing qualitative research has focused on disruption to the narrative self and what we call “reflective suffering” involving individuals’ self-reflection and perceived life-impacts of pain. There is a need for qualitative research that explicitly explores disruption to the minimal self, especially considering recent advancements in other fields. There are opportunities to draw from the extensive selfhood literature on the relation between the minimal and narrative self, how these different aspects of the self may be disrupted, and how these disruptions may shape individuals’ pre-reflective and reflective self-experiences. Specifically, there is a need to explore the concept of “pre-reflective suffering” involving alterations in the subjective experiences of one’s body and world.

**Table 1. Pain-Related Suffering Attributes and Key Challenge, and Relations to Past and Future Research**

<table>
<thead>
<tr>
<th>Attribute of Pain-Related Suffering</th>
<th>Relation to Cassell</th>
<th>Future Research</th>
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<tbody>
<tr>
<td>1. Pain and suffering are inter-related, but distinct experiences.</td>
<td>Similar, however, Cassell avoided using the term pain-related suffering.</td>
<td>• How are pain and suffering distinct and what is their causal relationship?</td>
</tr>
<tr>
<td>2. Suffering is a subjective experience.</td>
<td>No substantial difference. Cassell avoided the term subjective by referring to suffering as a personal and private matter.</td>
<td>• What might distinguish pain-related suffering from other forms of suffering and established pain-related constructs?</td>
</tr>
<tr>
<td>3. The experience of suffering is characterized by a negative affective valence.</td>
<td>Cassell’s term distress is replaced with the term negative affective valence.</td>
<td>• Qualitative and mixed methods are needed to more fully characterize the experience of pain-related suffering.</td>
</tr>
<tr>
<td>4. Disruption to one’s sense of self is an integral part of suffering.</td>
<td>Cassell’s assorted terms (eg, impending destruction, injured, disintegrating), replaced with disruption. Cassell’s person replaced with sense of self.</td>
<td>• Additional tools and strategies need to be developed to support the recognition, validation, and assessment of pain-related suffering.</td>
</tr>
<tr>
<td>Key Challenge Can one suffer pre-reflectively?</td>
<td>Cassell’s suffering requires self-reflection and a sense of the future, which is at odds with examples of overwhelming acute pain and torture and neglects certain populations.</td>
<td>• Explore affective themes that may further characterize experiences of pain-related suffering and how these themes might be associated with other bodily and cognitive processes.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Use established methods from the personality literature to explore how the disruption, restoration, and reconstruction of identity relates to pain and suffering.</td>
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</table>

Authors2,10,33 have attempted to accommodate and categorize these examples of pain-related suffering by using the term “physical suffering.” They then consider other dimensions of suffering, including mental/cognitive suffering, emotional suffering, or social suffering. Clinicians and parents use a similar approach to account for children’s suffering. However, fragmenting suffering in these ways (eg, physical versus mental, or physical versus emotional) is hard to maintain conceptually and easily falls into the dualistic paradigm (ie, body and mind separate). Cassell worked hard to avoid and the field of pain is working to rehabilitate. As emphasized by Cassell,19 personal, social, and contextual factors are always inherently intertwined within the experiences of pain and suffering and should not be regarded as if they exist in isolation from one another. Using established selfhood concepts (eg, minimal self and narrative self) and the interfaced categories of pre-reflective and reflective self-experience holds potential value as it does not divide the self or experience into false dichotomies and may help produce a more inclusive and coherent conceptualization of pain-related suffering.
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We aimed to present key attributes of pain-related suffering derived from a synthesis of the literature and highlight key challenges associated with Cassell’s conceptualization of suffering. Our synthesis resulted in 4 key attributes of pain-related suffering: 1) pain and suffering are inter-related, but distinct experiences, 2) suffering is a subjective experience, 3) the experience of suffering is characterized by a negative affective valence, and 4) disruption to one’s sense of self is an integral part of suffering. We identified that existing conceptualizations of suffering require explicit self-reflection, including a sense of the past and future. This presents a key challenge as several populations are neglected, including neonates, non-human animals, and others with limited capacity for self-reflection. Addressing this challenge, we identified what appears to be a largely unexamined and overlooked mode of suffering: the ability to suffer pre-reflectively (ie, without explicit self-reflection or narrative construction). There is a need for future research on what we have called “pre-reflective suffering” as this may help validate overlooked experiences of suffering and provide insight into the potential for suffering among populations that have historically been marginalized. Moving towards a more robust operationalization of suffering will form an essential foundation for innovative research and clinical strategies that aim to better recognize and alleviate suffering among people living with pain.

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