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Defining pain-related suffering requires partnership with people living with pain and careful critical thought: a commentary on the proposed definition by Noe-Steinmüller et al.

Letter to the Editor:

Suffering is a core construct in our field—PubMed suggests more than a million publications include the terms "suffering" and "pain." Yet, it is underdeveloped, as evidenced by the lack of an International Association for the Study of Pain definition for *pain-related suffering* and the broad, indiscriminate references to suffering within these publications. The recent paper by Noe-Steinmüller et al.[5] aims to fill this gap by proposing that pain-related suffering is defined as "a severely negative, complex, and dynamic experience in response to a perceived threat to an individual's integrity as a self and identity as a person." While we appreciate their effort, the proposed definition is inadequate.

Attempts to construct definitions within our field have always required careful thought and deliberation[4] and, increasingly, need to be developed in partnership with people living with pain.[6] The process to develop the proposed definition was, in part, intentionally devoid of these qualities. A stated goal of the authors was to limit subjectivity by using simple, algorithm-like procedures and using artificial-intelligence software to "validate" findings. While this approach may seem novel and exciting,[3] we believe it is deeply flawed and sets a dangerous precedent. These methods effectively prevented any meaningful critical engagement with the literature and anchored the proposed definition of suffering to the broad and indiscriminate past use of the term. For instance, the authors emphasize that pain-related suffering is a "subjective experience," yet this directly contradicts their decision to base their definition (in part) on literature[1] that explicitly aims to objectify suffering and supersede self-report. To put these methods into context, consider what the original 1979 definition of pain might have looked like had the International Association for the Study of Pain disregarded recent seismic shifts in pain theory and simply based its definition on frequencies of key words in the literature up to that point in time.

It is also disconcerting that the authors chose to present their work as generating a "consensus definition." There are well-established methodologies for consensus-based decision-making.[2] Crucially, these integrate and empower groups of people with invested interests. Potentially harmful precedents are created by assuming that new technologies can be used as a simple surrogate for the voice and perspectives of people living with pain.

The negative impact of these methods can be clearly seen in the output definition, which we believe is fatally flawed. One of the reasons we need a definition of pain-related suffering is to inform when and how suffering is or is not associated with pain. The proposed definition, however, fails to make any link to pain. This undermines its value in differentiating pain-related suffering from other forms of suffering (eg, grief) that might be experienced among people who are not living with pain. Thus, there is no basis for characterizing this definition of suffering as *pain-related*. The focus on "threat" also restricts the temporal scope of suffering experiences to the possibility of *future* losses to integrity and identity. This fails to capture the suffering that might continue to occur after integrity and identity have already been compromised. The authors also indicate that they use the term *self* in the definition to help recognize the potential for suffering among preverbal children—a position that we argued for.[7,8] However, the word "and" in the latter part of the definition effectively undermines this goal as it means that suffering is only possible when there is a threat to *both* the *self* and *person*—as the authors point out, preverbal children have not developed an "identity as a person."

Finally, the proposed dimensions are hard to understand and poorly conceptualized. *Dimensions of pain* typically aim to either characterize necessary aspects of the pain experience (eg, sensory and emotional) or point toward broad causal factors (eg, bio-psycho-social). The proposed dimensions, however, do not fit this mold as they clearly do not apply to all experiences of pain-related suffering (eg, the authors point out that newborns cannot suffer on an existential level). Rather, the proposed dimensions appear to be a preliminary "laundry list" of terms that might potentially inform factor analysis. The lack of any meaningful anchors to underlying theory undermines this potential use, as does their apparent conceptual overlap (eg, the "personal" dimension likely overlaps with all dimensions). It thus remains unclear how these dimensions could advance clinical care.

In sum, we continue to look forward to future research in this crucial area of study that involves meaningful partnerships with people living with pain in the development of a carefully considered and theoretically informed definition of pain-related suffering.

Conflict of interest statement

The authors have no conflicts of interest to declare.

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Reply to Wideman et al.

Letter to the Editor:

We appreciate the authors' engagement with our work.[2] A primary objective of our study was to stimulate a critical discourse on the concept of pain-related suffering. In this regard, we value the opportunity for dialogue, although we were surprised by the letter's polarizing tone. We must explicitly address 4 critical points, as the arguments presented seem to foster misunderstandings that jeopardize a constructive and critical discussion.

1. Confusion of objectives: finding consensus in groups vs synthesizing the literature

Wideman et al. criticize our use of the term "consensus" and highlight methods such as the Delphi technique. We used the term to refer to "the state of the art," or else "the conceptualization that most experts have arrived at." The agreement that is achieved in Delphi and similar processes is another denotation of "consensus" and none the less important. This distinction is crucial, as we do not claim that our research encompasses both kinds of consensus.

However, the critique by the authors reveals a broader misunderstanding of our chosen approach. The Delphi technique is indeed effective for reaching consensus within groups, potentially creating new concepts and definitions reflecting the opinion of the participating groups. Our aim, explicitly stated, was not to develop a new definition but to synthesize the existing literature into an inclusive definition ("*Instead of adding yet another theory of suffering, we offer a definition that brings together insights from different disciplines and* can *serve as a consensus definition against which new theories and operationalizations can be evaluated*" [p. 11]). Consequently, this definition represents a consensus in the sense of a synthesis of existing research, rather than the personal opinion of the authors.

This synthesis can then serve as input for other consensus methods, such as those mentioned by Wideman et al. We would welcome and feel honored if professional societies used our work as a basis for further developing a suitable definition, for instance, through Delphi procedures.

2. The false dichotomy: artificial intelligence vs patient involvement

Wideman et al. reject the use of artificial intelligence (AI)-based algorithms in analyzing the concept of suffering. They argue that (1) definitions require "*careful thought and consideration*," and (2) must be developed in partnership with people living with pain. We appreciate this perspective, but we believe that this viewpoint does not contradict our approach or the use of AI in general.

First, all scientific work necessitates careful thought and consideration, and the use of AI is no exception. This is precisely why we chose *a combination of* manual qualitative analysis and natural language processing to examine the concept of pain-related suffering in the current literature, cross-validating our findings. Reducing our study to the mere use of AI would be a profound misinterpretation of our approach. Furthermore, we did not simply query ChatGPT about suffering based on its broad training data. Instead, we provided specific algorithms with concrete, comprehensible text input in a systematic procedure.

Regarding the second point, we must issue a cautionary note. The involvement of people living with pain in scientific projects is crucial for clinically meaningful progress. We draw attention to promising ongoing projects that address this issue (eg, https://painstory.science; see also https://www.youtube.com/watch?v=ZHJyL5Gmw0I). However, this does not devalue research without the direct involvement of people with lived experiences. Such polarization and the creation of a false dichotomy would be a fundamental error, akin to dismissing purely biological research as "inadequate" in the context of biopsychosocial issues.

3. Confusion over the specificity of the definition: pain-related and other kinds of suffering

Wideman et al. criticize that our definition does not "make any link to pain," which they claim, "*undermines its value in differentiating pain-related suffering from other forms of suffering (*eg, *grief)*." Wideman et al. argue that this lack of specificity in our proposed concept of pain-related suffering compared with other forms of suffering indicates the inadequacy of our approach. To repeat, our goal was to conceptualize suffering in the context of pain by analyzing the usage of this term in the pain literature. It is specific insofar as it is based on this specific literature. This approach