When pain overwhelms the self

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ABSTRACT

Suffering is a foundational yet understudied construct within the field of pain. There is general agreement that pain-related suffering involves disruption to one's sense of self. The selfhood literature characterizes two inter-related modes of self-experience. One mode entails in-the-moment experiences that shape one's stream of consciousness; another involves self-reflective thoughts about the past or expected future, related to self-narratives and identity. The field's current conceptualization of pain-related suffering is exclusively anchored to the latter, self-reflective mode of experience. Our past work argues that this framing fails to account for pain's immediate, disruptive impact and denies the potential for suffering among individuals without self-reflective capacities (e.g. infants). The purpose of this theoretically-informed, phenomenological study was to explore a new potential way by which people living with pain can suffer. We conducted in-depth, qualitative interviews with 12 adults across Canada living with various pain conditions. Interviews focused on understanding the moment-to-moment experiences of their worst episodes of pain. Results revealed important accounts of pain that overwhelmed thoughts and self-reflective capacities and disrupted foundational aspects of self-experience, including senses of agency, bodily ownership and time. Participants reported that these experiences were incapacitating, dehumanizing and dissociating. The findings are remarkably similar to first-hand accounts of torture and support a new mode of pain-related suffering that does not require self-reflection and is characterized by an immediate, disruptive impact on one's sense of self. Findings will inform the development of the first theoretically-informed and evidence-based definition of pain-related suffering and help advance pain theory and practice.

Perspective: This qualitative phenomenological study characterizes how pain can radically transform one's in-the-moment sense of self. Results reveal a new mode of pain-related suffering that does not require self-reflection. This supports the expansion of traditional understandings of suffering, exclusively anchored to self-reflection, to now include two inter-related modes of pain-related suffering.

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1. Introduction

Suffering is a foundational, but understudied, construct within the field of pain. In our recent review, we detail the established attributes of pain-related suffering and outstanding questions.[1] Briefly, pain-related suffering is a subjective experience, characterized by a negative affective valence, that partially overlaps with the experience of pain. Further, disruption to one's sense of self, which characterizes suffering, is a key factor in distinguishing pain from pain-related suffering.[1,2]

To oversimplify the selfhood literature, self-experiences of adults can be categorized into two inter-related modes of experience.[3,4] One mode entails in-the-moment experiences that shape one's stream of consciousness. This includes moment-to-moment bodily experiences. Another mode involves reflection on one's experiences and life. This may consist of the different stories (or *narratives*) that shape self-identity and are anchored in the past or expected future. This mode of self-experience is commonly referred to as the *narrative-self*.[3,5,6] Importantly, the core literature that shapes how we currently understand suffering in the field of pain is exclusively anchored to this narrative mode of self-experience.[1]

Our field's current conceptualization of pain-related suffering is largely anchored to the seminal work of Eric Cassell.[7–10] Cassell understood suffering to involve threat or disruption to one's *personhood,* which can also be referred to as one's narrative-self.[6] This can involve the disruptive impact that pain can have on one's self-identity, through (for instance) the loss of valued roles, relationships and aspirations. Importantly, Cassell's conceptualization of suffering was exclusively grounded on the capacity for self-reflection, and he argued that populations without this capacity (e.g. infants and people with advanced dementia) could not suffer.[11]

Our past work[1,2] questions Cassell's exclusive focus on the narrative-self and his view that suffering requires self-reflection. Specifically, this framing neglects other important ways that pain might disrupt one's sense of self. For instance, pain can have an immediate impact on attention[12–15] that may disrupt the *in-the-moment* mode of self-experience described above. In the selfhood literature this mode of experience is referred to as *minimal-self* experience.[3,5,6] The term *minimal* is in reference to the foundational role of *here and now* experiences in contrast to the developmentally, more complex narrative-self experiences that involve reflection on the past or future. Infants are born with minimal-self experiences[16] and develop a narrative-self over time.

Disruption to the minimal-self has been studied extensively in the context of psychopathologies[5,17–26] and torture,[5,27–30] but there has not been any research that has specifically explored the role that pain can have in disrupting one's minimal-self experiences. Advancing our understanding of the intersection of pain, selfhood and suffering has important implications for helping to generate our field's first coherent definition of pain-related suffering and to better understand, recognize and address historically overlooked experiences of suffering.[1] We aimed to address these gaps by conducting a theoretically-informed qualitative study with adults living with pain, focused on understanding the moment-to-moment experiences of their worst episode of pain. Theoretically-informed qualitative methods offer unique value in studying this intersection,[1,31] including potential minimal-self disruption (see 2.2).

2. Methods

2.1. Study design

Broadly understood, phenomenology is the study of lived experience[6,32] and often focuses on alterations to one's sense of self.[4–6] Contemporary phenomenological approaches also focus on the context surrounding the experience of interest.[33,34] Precisely, we used a *front-loaded phenomenological* qualitative study design[35] whereby established phenomenological concepts and distinctions are used in the initial study planning and inform interview questions and analysis. Specifically, we targeted experiences of disruption to one's sense of self using the established framework described in Section 2.2. In accordance with guidance on conducting front-loaded phenomenological studies,[35,36] we aimed to garner new insights that may challenge or extend existing theoretical and empirical work on suffering.

It is important to recognize that phenomenology as a philosophical movement has been advanced by many, including the twentieth-century writings of Husserl, Heidegger, Sartre, Merleau-Ponty and others.[37] Further, applied phenomenology, in the form of qualitative research, has a rich history and there are many ongoing methodological debates.[35] Our study follows recent recommendations for pragmatic and clinically-relevant phenomenological research[34,35,38–42] that draws inspiration from philosophical phenomenology but does not require engagement with highly specific traditional philosophical phenomenological paradigms and methods (e.g. epoché and reduction).

Consistent with pain research recommendations,[43–45] we also used a participatory approach that integrated people living with pain (K.M. and V.M.) in all aspects of this study. We used the Consolidated Criteria for Reporting Qualitative Research (COREQ)[46] and the Guidance for Reporting Involvement of Patients and the Public (GRIPP2 Short Form).[47] Please see supplemental digital content for reporting checklists and additional study details. Ethics approval was received from the Research Ethics Office of the Faculty of Medicine and Health Sciences at McGill University (A03-B31–21B). Informed consent from all participants was obtained.

2.2. Theoretical framework

We used an established theoretical framework which understands the self as dynamic and having inter-related aspects.[3,5,19,48] Specifically, we anchored our study in the two core phenomenological concepts briefly introduced above: the *narrative-self* and *minimal-self* (Fig. 1). Our past work started to extend Cassell's conceptualization of suffering by suggesting that pain might disrupt narrative and minimal aspects of self, resulting in different and potentially interacting modes of suffering.[1,2] Below, we further delineate this theory and our study focus.

The narrative-self involves self-reflection and consists of the self-identity that we cultivate over time through the stories that we and others tell about ourselves.[3] Consistent with existing understandings of suffering, pain can disrupt the narrative-self by contributing to a loss, alteration or threat to valued aspects of one's life story.[1,2]

The minimal-self is our prereflective (or nonreflective),[4,49,50] in-the-moment experience. This involves a prereflective sense of *agency* (control) for one's actions, thoughts, sensations, emotions and feelings, and a sense of *ownership* over one's experiences, and over one's body.[3] Outside the field of pain, there is a body of evidence suggesting that these features of the minimal-self (senses of agency and ownership) may be altered or disrupted in various ways.[5] A simple example of disrupted agency can be found in involuntary movement, such as being pushed from behind.[3] In this case, one can maintain ownership (i.e. I have the sense that I am the one moving or being moved); however, sense of agency is lost (i.e. I don't have the sense of causing or controlling the movement). Ownership can also be disrupted or at least altered in some way, such as cases of depersonalization disorder involving feelings of detachment from one's body.[20]

Our study placed a particular focus on the minimal-self to characterize potential pain-related disruptions to one's sense of agency and ownership. At the same time, as clearly outlined in the literature, we understood that participants' descriptions of these potential disruptions could only be accessed through narratives, and that any minimal-self disruptions would likely inter-relate with other aspects of self, including narrative (life story) aspects (Fig. 1) and other self-related factors (e.g. social/intersubjective, affective and ecological/environmental factors).[5]

Our selfhood theoretical framework is situated within an

overarching embodied-enactive understanding of perception and action,[5,51] which aligns with our interpretivist/constructivist qualitative research paradigm.[52]

2.3. Participants

We used our pain-related networks and snowball sampling to recruit a sample of Canadian adults living with chronic pain. We used a *maximum variation*[53] approach to purposeful sampling (i.e. across age, gender, pain conditions, geographic locations) to yield a heterogeneous sample that included a wide range of suffering experiences.[1,2] Our sampling involved carefully identifying individuals who we believed would fit our eligibility criteria (see below) and be able to recount, in as much detail as possible, different times when their pain was particularly disruptive, strong or overwhelming. We also conducted screening (see below) related to participant risk and safety because in-depth phenomenological interviews on sensitive topics, like pain and suffering, have the potential to trigger intense emotions and feelings.

Potential participants were individually emailed information about the study, and those expressing interest were asked to engage in an online (Zoom) screening call with P.S. to collect demographics, assess eligibility, build rapport and determine if the quality of their audio and internet connection was adequate for an in-depth research interview. Demographics were collected (verbally through Zoom) so that we could summarize participant characteristics, contextualize the qualitative findings and help readers judge the transferability of findings. To be eligible, participants had to 1) be living in Canada (see safety plan below), 2) have daily or near-daily pain for a duration of at least one year, 3) report past experiences where their pain significantly impacted their life or daily activities and 4) be able to provide verbal consent and engage in an in-depth interview in English about the details of their pain and the ways it has impacted their life or daily living.

Consistent with guidelines[54–56] on participant safety and research with trauma-exposed populations, the screening call also involved questions to help us mitigate risks to potential participants. We only included individuals who 1) were *not currently* experiencing a high level of stress or emotional distress that was interfering with their life in a significant way, 2) were *not currently* having thoughts of self-harm and 3) had access to mental health service, either through their health care team, emergency services or helplines (e.g. they had a mobile phone with cellular service). Further, we established a safety plan in the event someone became distressed or was at risk for self-harm during the screening call or the full interview. This included knowing their physical location and contacting appropriate emergency services if needed. All individuals who were screened, regardless of their answers, were provided with a list of national and local resources and supports related to pain, distress and suicide.

Heterogeneous sample sizes for phenomenological studies are typically in the range of 3–15 participants.[57] We used the nuanced concept of *information power*[58] to guide our recruitment approach and sample size. This approach involved ongoing data collection and analysis until the data yielded little or no new information that would significantly contribute to our study aim. Factors impacting sample size according to this approach included the limited literature on this topic, our use of theory, sample specificity, the quality and depth of the interview dialogue, and our cross-case analysis.[58] Additional details regarding our information power analysis are provided in the supplemental digital content (see COREQ item 22 and corresponding image).

2.4. Data collection

We asked eligible and consenting participants to engage in an online (Zoom) recorded interview lasting approximately 90–120 min. Interviews were led by T.W. with P.S. present. Consistent with our front-loaded approach, our interview guide was based on past work on the minimal-self and its disruption[3,4,6,20,26,59] that was adapted to fit our context of pain. This front-loaded approach enabled a focused interview on specific aspects of experience to ultimately generate findings with more depth and nuance than could be achieved with more exploratory approaches.[36,60] It is important to note that this approach establishes a focus but does not predetermine the content of the interviewees' descriptions.[36] We piloted our initial interview guide with three participants (two women and one man) and subsequently refined the guide. The three pilot participants are not included in our sample size, nor are their data included in our analysis. Pilot and subsequent research participants were each compensated $50 CAD.

Please see the supplemental digital content for the final version of the semi-structured interview guide containing open-ended questions. In brief, participants were asked to identify specific times when their pain was at its worst (i.e. experiences that were particularly strong, disruptive or overwhelming). These experiences may have lasted minutes, hours or a day or two. If several experiences were identified, we asked them to focus on the most vivid, overwhelming or intense one. The interview then discussed the situational context and what the experience was like. This included a very detailed set of questions focused on what they experienced in their environment and body. Specific questions were asked about their senses of agency, ownership and time during their worst pain experiences. We focused on experiences of time because this plays a fundamental role in the coherence and continuity of self.[4–6,61] Subsequently, participants were provided the option of having a short break. During these breaks, T.W. and P.S. connected by phone to discuss areas needing further clarification and other potential questions or prompts that could be used. Participants were then asked about other pain experiences that were similar to the worst pain experience that they

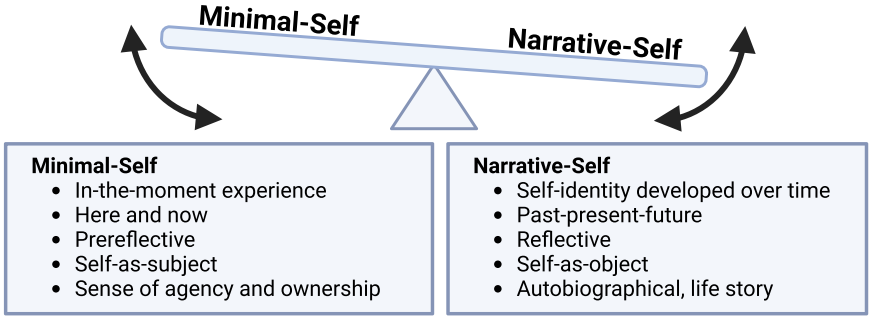

Fig. 1. Teeter-totter schematic representing dynamics between minimal and narrative aspects of self, adapted from Ataria (2022, page 69, Figure 2.2). The minimal-self is an individual's immediate experience, without higher-order self-reflective cognitive processes or existential reflection (e.g. infants are born with minimal-self and the primitive ability to distinguish self from non-self). The minimal-self is the foundation for the narrative-self that develops over time. Teeter-totter movement (shown via arrows) highlights how adults can more or less engage these aspects of self at different times: one can be immersed in-the-moment (self-as-subject) or explicitly reflect on their experience or life story (self-as-object). Minimal and narrative aspects of self dynamically interact and shape each other: movement (change) on one side of the teeter-totter can move the other side.

identified, and to describe these experiences and their contexts. Further, they were asked to describe what happened after their worst pain experience and/or similar experiences. This included discussion on any self-reflections and changes in their life story. We aimed to end conversations on a more positive note, with a tone and mood that felt ethically and morally responsible. We did this by asking (when needed) about anything positive that came out of living with pain or if they have grown in any way. Alternatively, in some cases, the interview naturally ended positively or neutrally, or the interviewer summarized positive aspects the participant disclosed during the interview.

We focused on participants' worst pain experiences because there is limited literature on this and we wanted to specifically target potential experiences involving disruptions to one's senses of agency, ownership and time. Focusing on worst pain experiences is a logical starting point because disruptions are likely to be pronounced. Arguably, a lack of these disruptions in participants' worst pain episodes would indicate that we are unlikely to find these types of disruptions in other, less extreme pain experiences.

Throughout each interview, verbal summaries of the participant's descriptions and our interpretations were presented back to the participant for confirmation or clarification - a form of *member checking*.[32] Participants were given the option to retract their data post-interview. Directly after each interview, T.W. and P.S. audio-recorded debrief sessions where they discussed their initial impressions, commonalities with previous interviews, any new insights, the functionality of the interview guide and areas for improvement or monitoring with respect to subsequent interviews.

2.5. Data analysis

Audio-recordings were transcribed verbatim and imported into NVivo (Lumivero software; Mac and Windows versions) for coding. We used a common type of thematic analysis involving a hybrid (deductive and inductive) approach to coding and theme development.[62] Our analysis strategy follows guidance on conducting theoretically-driven, yet pragmatic and clinically-relevant phenomenological qualitative research.[34,35,38–42] Specifically, this combined deductive and inductive approach to coding and theme development has been endorsed as a suitable analytical strategy in front-loaded phenomenological qualitative research.[34,42] This strategy allowed us to harness existing theory while remaining open to new insights. Specifically, our analysis involved six iterative steps: 1) developing a theoretically-based coding manual for deductive coding, 2) regularly discussing coding and integrating new interpretations and insights into an updated codebook that the independent coders applied in subsequent analyses, 3) summarizing the data and generating initial themes, 4) applying template of codes (deductive coding) and additional data-driven inductive coding, 5) connecting the codes and identifying themes and 6) corroborating and legitimizing themes.

Two team members (P.S. and M.G.) independently coded all the transcripts and regularly met to discuss coding and preliminary themes. P.S. also created brief (~2-page) summaries of key features of each participant interview. These summaries were reviewed by M.G. to check for accuracy and any missing salient features. Summaries were shared with team members (A.H., K.M., V.M., M.G.P, T.W.) and regular meetings were held with these same team members to discuss new inductively-generated codes and preliminary themes. P.S. also reviewed the post-interview debrief recordings and recorded team meetings to ensure any significant insights and reflections were incorporated into the coding scheme and generated themes. The final coding scheme can be found in the supplemental digital content. P.S. and T.W. further developed the themes which were then finalized with full team input (A.H., K.M, V.M., M.G.P., S.G.). Statements related to positionality and reflexivity can be found in the COREQ and GRIPP2 Short Form in the supplemental digital content.

2.6. Rigor

As indicated in our methods above, we used a variety of strategies to ensure rigor with consideration of established criteria for trustworthiness in qualitative research.[32,63,64] These strategies included: 1) ensuring the study aim, design, and methods aligned, 2) detailed reporting and use of established checklists (COREQ and GRIPP2 Short Form), 3) seeking a sample with a range of experiences and eliciting detailed narratives, 4) facilitating an honest and open conversation with participants through building rapport, establishing trust and familiarity, 5) real-time member checking during interviews in the form of summarizing descriptions and interpretations for confirmation or clarification, 6) triangulation of independent coding and different researchers' perspectives, 7) regular team debriefing which included our patient partners (K.M. and V.M.) sharing how the preliminary findings aligned with their personal experiences and knowledge of others' experiences that they have been made aware of through their extensive peer-support and advocacy work and 8) detailed documentation of activities and decisions (audit trail) during data collection and analysis; evidence of our audit trail is provided in the supplemental digital content which includes the final interview guide and coding scheme. To facilitate further transparency, additional team details (e.g. genders, experience, training) can be found in the supplemental digital content.

3. Results

After our three pilot interviews, we recruited and interviewed 12

Table 1
Participant characteristics.

Demographic profile of participants	
Characteristic	No. (%)* $n = 12$
Age, yr	
20–39	3 (25)
40–59	3 (25)
60–79	6 (50)
Gender	
Woman	9 (75)
Man	2 (17)
Non-binary	1 (8)
Pain duration, yr	
0-9	4 (33)
10-19	5 (42)
20-29	2 (17)
30-39	1 (8)
Geography	
British Columbia	1 (8)
Nova Scotia	6 (50)
Ontario	2 (17)
Prince Edward Island	1 (8)
Quebec	2 (17)
Primary pain condition or diagnosis†	
Arthritis / structural changes (spinal, pelvic, and/or hip)	4 (33)
Cervical dystonia	1 (8)
Chronic Migraine	2 (17)
Chronic pain or widespread pain (non-specific)	5 (42)
Chronic regional pain syndrome (CRPS)	1 (8)
Ehlers-Danlos syndrome	1 (8)
Fibromyalgia	1 (8)
Lower limb fracture	1 (8)
Low back and hip pain (non-specific)	1 (8)
Lumbar disc injury (motor vehicle accident)	1 (8)
Post-herpetic neuralgia	1 (8)
Post-surgical spinal pain	3 (25)
Sciatica	2 (17)
Severe burns	1 (8)
Spinal cord injury and neuropathic pain	1 (8)
Trigeminal neuropathy/neuralgia or facial neuropathic pain	2 (17)
Wrist pain (non-specific)	1 (8)

*The percentages are rounding to nearest whole number.
†Individual participants reported multiple primary pain conditions and diagnoses.

participants (Table 1), one of whom was recruited through snowball sampling. Although we recruited participants with chronic pain, participants' reports of their worst pain episodes included past acute pain, chronic pain flare-ups, and new acute pain experiences on top of their chronic pain. The mean duration of recorded audio for the 12 interviews was 101 min (over 20 h of recorded audio in total). Assessment of sample size using the concept of *information power*[58] revealed that we obtained adequate information to fulfill the aim of our study, so we ceased recruitment. No participants retracted their data or were excluded for any reasons.

We generated three themes which are summarized in Fig. 2. Overall, we found that pain radically transformed how participants experienced themselves and their world. Pain changed participants to different degrees, with some participants reporting extreme feelings of dehumanization and out-of-body experiences. The following sections describe our themes and subthemes related to participants' "worst" pain experiences that ranged from very recent to over 20 years ago. To help maintain participant confidentiality, we do not link all demographic details to quotations. However, we use participant numbers (e.g. Participant 1) to demonstrate the distribution of quotations, and sometimes we refer to gender and pain condition for context. The supplemental digital content provides additional supporting quotes.

3.1. Theme 1: Pain-related minimal-self disruption involves a disrupted sense of agency, disrupted sense of bodily ownership and awareness, and disrupted time

This theme describes the core characteristics of pain-related minimal-self disruption as described and exemplified by participants. We break this theme into three subthemes: *disrupted sense of agency leading to powerlessness, hopelessness and helplessness* (3.1.1.), *disrupted sense of bodily ownership and awareness - need to escape* (3.1.2.) and *disrupted time - experiencing slowed, frozen or no sense of time* (3.1.3.). Participants' experiences described in 3.1.1. and 3.1.2. fit within a spectrum (Figs. 3 and 4) ranging from less to more minimal-self disruption. Time distortions described in 3.1.3. span this spectrum.

Fig. 3. Loss of agency in the minimal-self disruption spectrum. Italicized statements are based on participants' reports to depict different categories (blue boxes) of in-the-moment experiences, ranging from less (lighter end of gradient, category C) to more (darker end of gradient, category A) minimal-self disruption during participants' worst pain experiences. Please note the features and nuanced language that delineate the categories. A) is an extreme state with more disruption, characterized by being *completely* overwhelmed (*lost my mind*) and the added feature of feeling *dehumanized* (*no longer a person*). There is more disruption moving up the spectrum, for instance, going from *losing control* (C) to *lost control* (B).

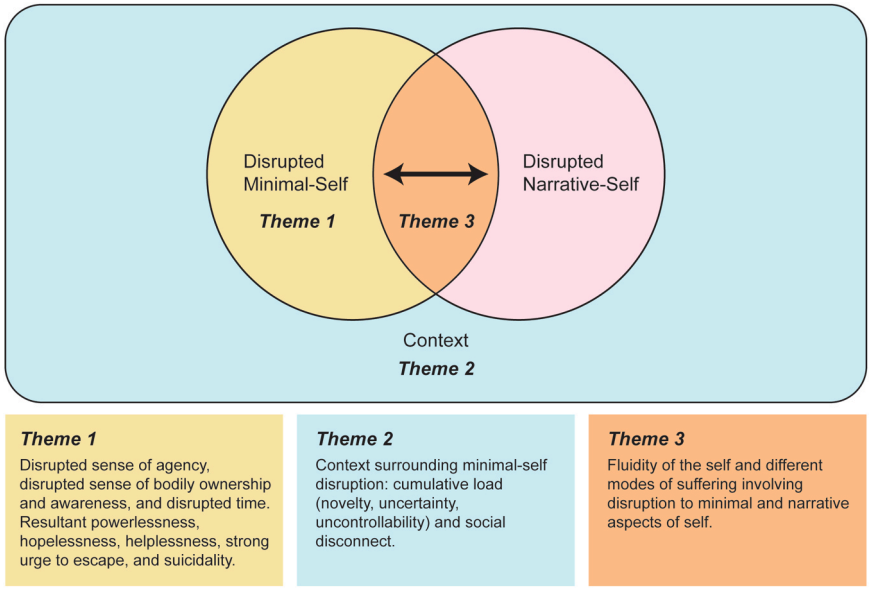

Fig. 2. Summary of themes from our qualitative study of pain-related suffering that focused on minimal-self disruption associated with participants' worst pain experiences. The simple Venn diagram depicts how pain-related minimal-self disruption can be dominant (yellow) or inter-relate (orange) with narrative-self disruption (pink). Context (blue) surrounds (and shapes) disruption to minimal and narrative aspects of self. Consistent with our study scope, please note that Theme 2 is only focused on the context surrounding experiences in which minimal-self disruption was prominent.

Fig. 4. Loss of bodily ownership in minimal-self disruption spectrum. Italicized statements are based on participants' reports to depict different categories (blue boxes) of in-the-moment experiences, ranging from less (lighter end of gradient, category B) to more (darker end of gradient, category A) minimal-self disruption during participants' worst pain experiences.

3.1.1. Disrupted sense of agency leading to powerlessness, hopelessness and helplessness

The most prominent and complex quality of minimal-self disruption across participants was a lost sense of agency (control), and this was on a spectrum where participants reported different combinations and extents to which there was a pain-related loss of control over the following: actions, thoughts, sensations, emotions and feelings (subsequently referred to as *domains*). Below, we describe this spectrum during participants' worst pain experiences, focusing on three categories (Fig. 3, categories A-C). Contextual factors appeared to influence where particular experiences were situated (i.e. A, B or C) within the spectrum; we describe these contextual factors in Theme 2.

Starting with category A (more disruption) in Fig. 3, participants described experiences in which there was a sense of total loss of control over domains and during which they felt completely overwhelmed, incapacitated and dehumanized. In these situations, participants' thoughts completely shut down, and they cognitively disconnected from their environment. For instance, they reported they couldn't interact with others or read and see as they normally did; they were in a "*fog*". Further, they felt dehumanized as they were stripped down to just a "*ball*" of pain or just a physical body or body part that lacked human qualities. In this dehumanized state, previously developed coping strategies were cognitively inaccessible. They felt they *completely* lost their mind or became "*blank*". The following quotes represent this category involving overwhelm, incapacitation and dehumanization:

> *All I was, was like this giant existence of pain … I couldn't move … it felt like I couldn't breathe … I couldn't even access like any part of my brain that was thinking based. All I could focus on was pain … I just couldn't even get to that point, like where I could cope with what was happening and like use my internal self-talk to be on my side. It's like that voice was completely missing and gone. And it was only the emotions … I just went backwards, like I went back into the embryo.* (Participant 1)

> *You feel like you've died as a person … Because pain has just overwhelmed everything … it's like the pain overrides common sense … analytical abilities were completely gone … It's almost like your brain shuts down and you're just in the pain, and the pain is consuming you … an overwhelming sense of loss of self … I'm just this ball of pain. I'm not even a person.* (Participant 5)

> *All I am experiencing in that very moment is utter pain … I'm blank except for the pain.* (Participant 9)

> *It's all-consuming … the hardest one* (pain experience) *took my mind … I wasn't there … I couldn't advocate for myself* (in the emergency department) *… the pain owned me … I found that it's the feeling of powerlessness ultimately … and I find it's terrifying … I wasn't in control of my body. My body was in control of me … It* (pain) *owns me … An articulate person becomes something different … I wasn't in control in any way, shape or form.* (Participant 10)

> *I don't think it was possible to do any type of reflection … I was just having to deal with the here and now. Rather than being able to think through it, or to think anything … It was just me and my pain.* (Participant 12)

Regarding category B (middle of spectrum) in Fig. 3, participants described feeling like they lost control over domains and were overwhelmed and incapacitated; however, they *did not* experience the extreme shutting down or dehumanized feelings described above. Participants felt like they were losing their minds because they couldn't control their actions, thoughts, sensations, emotions or feelings. For example, participants described loss of control over thoughts in the form of pain-related rumination and amplified self-consciousness. They couldn't quiet their mind or make sense of their pain or situation as it was disorienting, unpredictable and uncertain. When it became possible, some engaged in existential questioning, asking themselves: why was this happening to them? What did they do to deserve this pain and suffering? How much more could they handle? Why can't they stop it? Will this ever end? Participant 4 described their loss of control over thoughts as a "*despair cycle. It just kind of loops over and over again*" and stated they didn't have tools to get out of the loops.

Participant 6 was in a unique position that reflected a move towards the extreme end of the spectrum, coming close to the category involving feeling completely incapacitated and dehumanized (Fig. 3, category A). Overlapping with subtheme 3.1.2. described shortly, they stated: "*I couldn't relate to what my body was doing to me … my bodily functions working against me it's kind of - to me it was kind of dehumanizing*". Their thoughts didn't really stop, but they felt they were losing their ability to be in control of their own mind and body. It felt "*all-encompassing*". It was "*endless loss … I was no longer me … I had been reduced to a crumpling pile of pain … my sense of myself was going big time out the window … I was not who I thought I was anymore*". Especially highlighting the transition to a dehumanized state (moving from category B to A), they reported that they were "*turning into this glob of inhuman nothingness*".

Regarding category C (least disruptive) in Fig. 3, there was a loss of control over domains during their worst pain experiences, but they were *not completely* overwhelmed or incapacitated. They often completed daily activities and cognitive tasks, but it was challenging as their pain was "*almost overwhelming*" (Participant 11). They could not think clearly or control their actions and emotions. For instance, Participant 8 described their inability to regulate their pain-related emotion of anger when interacting with their family during suppertime. Participant 11 described how they could still communicate, but their pain was taking up most, but not all, of their attention. They noted: "*my body just didn't want to function. It didn't want to eat, it didn't want to drink. It didn't want to participate … it was just like having an angry child in me*". In turn, some participants avoided others because of difficulties engaging socially and they did not want to uncontrollably "*snap*" or "*lash*" out. Other participants worked through these challenging situations without explicitly reflecting on them in-the-moment. Participant 7 noted: "*I don't feel like I'm thinking. I'm just living through it … Suffering through the pain*". Similarly, Participant 11 shared that they were living through their pain, it was consuming them, and they noted: "*I don't really think that I reflected*".

Overall, across these three categories (Fig. 3, A-C) participants reported a collision of emotions and ultimately ended up feeling a profound sense of powerlessness, hopelessness and helplessness. This was especially pronounced on the more disruptive end of the spectrum (Fig. 3, A). Participants felt they were being controlled or owned by pain as summarized by Participant 3: "*they* (emotions) *were just kind of*

controlling me. It was very much that I was not in control. It was the pain, and the anger, and the guilt, and the shame that was all in charge." Some even felt as if they were going to die from the pain. For instance, Participant 1 stated: "*I can't even quantify where it was on that* (pain) *scale for me. Because it was almost like I was just this close to just dying from pain.*" At the time of their worst pain experience, some who could self-reflect at that moment felt suicide was the only way they might be able to exert some control. Relatedly, during moments of existential self-reflection, some felt it was the only way to alleviate their suffering: "*There was going to be no end to my suffering going forward unless I committed suicide … I could have that peace, and that peace was eating that gun.*" (Participant 6).

3.1.2. Disrupted sense of bodily ownership and awareness - need to escape

Participants also reported a disrupted sense of bodily ownership, and this was on a spectrum ranging from their body (or body part) not feeling like their own (category B in Fig. 4) to feeling disconnected from their body or having out-of-body experiences (category A in Fig. 4).

Starting with category A (more minimal-self disruption) in Fig. 4, when participants' pain or pain-related situation became unbearable, they reported an intense feeling that they needed to escape their bodies. In these situations, participants ended up feeling somewhat disconnected from their body. At the more extreme end of the spectrum within category A, three participants reported that they escaped their bodies involuntarily through what they described as dissociation and out-of-body experiences:

> *Like I'm kind of up there looking down at this happening … as if it were happening to someone else … I felt like it wasn't my body. I was just observing it, a body … I think I felt out of body when it started to get to a point where I didn't know how I would get to the next minute. So, it's like I came out of my body so that I didn't have to get to the next minute. Because it wasn't me … It was, I think, to cope with that intense bombardment that I couldn't get to the next minute in there. So, I had to get out of there.* (Participant 12)

> *I felt a little like, kind of not in my body. Like I was dissociating a little bit because of the pain and that was the first time I had ever dissociated. It was very bizarre. It felt very strange … I felt like I was kind of looking down at my body. Like I wasn't present in my body, I was looking at it from high up.* (Participant 3)

> *As long as I was dissociating, my pain was like 10 steps away from me. Like I wasn't here, and I was here, and my pain was like across the ocean.* (Participant 1)

Regarding category B (least minimal-self disruption) in Fig. 4, participants described how their bodily ownership and awareness changed during their worst pain experiences: the body came to the foreground, and they felt trapped in a body that was not theirs. The body demanded attention, and everything else was out of focus, "*foggy*" or non-existent. Further, their body felt foreign and that it betrayed them. Thus, they wanted to escape their body. Supporting quotes for this category of experiences include: "*I know that it's my own, but I don't feel it*" (Participant 8); "*I feel like I'm trapped in a body that's not mine … I wish I could just step out of this body*" (Participant 7); and "*I felt betrayed by my body you know? … I didn't own it anymore, it owned me*" (Participant 5). Additionally, sometimes the body was experienced or viewed as an object, and they described a fatiguing battle or fight with it. This category of experiences preceded category A described above.

Overall, across the spectrum (Fig. 4), participants felt an urge to escape, and some did escape through dissociation and out-of-body experiences. And, like findings in 3.1.1., suicide was discussed by some participants (who could self-reflect at that moment) as a way to escape their experience, body or situation.

3.1.3. Disrupted time - experiencing slowed, frozen or no sense of time

During their worst pain experiences, every participant reported that they experienced time slowing (i.e. short periods of objective or "clock" time seemed like hours, days or an eternity), or being stuck or frozen in time or having no sense of time (timelessness). These time distortions spanned the previously described spectrum of minimal-self disruption (Figs. 3 and 4). However, several participants commented on factors that seemed to distort or normalize their experiences of time. For example, the *presence* or *absence* of ways to track time, including a clock, phone, social interaction, TV and eating meals. Making links between the previous subthemes and disrupted time, participants also suggested that their lost sense of agency and use of "*brain energy*" (e.g. struggling to perform actions, think or interact with others), as well as feeling trapped or fighting a body that did not feel like their own, inter-related with their experiences of time distortion. Further, the elongation of time seemed to amplify feelings of wanting to escape. Distortions in time also interfaced with isolation, loneliness and social disconnect (see 3.2.2. below). Sample supporting quotes for this subtheme are provided below:

> *I had no sense of any time. Like it felt like I was frozen in space.* (Participant 1)

> *It's sort of like slow motion and time goes much slower … The pain is controlling you then everything slows down. And it seems it's never-ending. It's like a minute is an hour.* (Participant 5)

> *There was no sense of time … I couldn't have told you what day of the week it was. I couldn't tell you what time of day it was. I couldn't tell you whether it was night or day …* (I felt) *trapped and not moving forward.* (Participant 6)

> *Time … it can drift pretty significantly … If you're not able to do activities that mark time, how can you keep track of it right? Like you can't listen to the radio. You can't watch a TV show while this is happening. You can't really hold conversations with people.* (Participant 10)

> *Sometimes it seemed an eternity every minute. The nights were endless. I thought we had short nights in the summer, but they sure seemed long … time was my enemy.* (Participant 11)

Overall, participants' descriptions suggested that pain and its various life-impacts disrupted the normally prereflective passage of time. The perceived elongation of time resulted in a more explicit awareness of time, which played an important role in participants' pain-related suffering. This change in the experience of time corresponded with how the normally prereflectively experienced body came to the forefront of awareness (see 3.1.2.). Collectively, this was captured by Participant 4: "*The worst part is feeling like this is never going to end because you're so caught up in the sensations of the body.*" Taken together, the above subthemes (3.1.1., 3.1.2., 3.1.3.) characterize a distinct mode of pain-related suffering involving disruption to minimal aspects of self.

3.2. Theme 2: Context surrounding minimal-self disruption

Building on the previous theme, this theme describes the personal and social context surrounding participants' worst pain experiences involving minimal-self disruption. Participants' worst pain experiences occurred in a variety of environments, including a school, military facility, restaurant, car, private rehabilitation clinic, as well as homes and hospitals (post-surgical recovery and emergency department). Some participants moved within their environment and to different environments (when they had the capacity to do so) during and/or between their worst pain episodes. We break this theme into two subthemes: *cumulative load* (3.2.1.) and *social disconnect* (3.2.2.). Overall, these subthemes capture salient self-related factors (e.g. social/intersubjective, affective and ecological/environmental factors)[5] before, during and after minimal-self disruption.

3.2.1. Cumulative load

Participants described similar contextual factors leading up to and during their worst pain experiences and minimal-self disruptions: they reported an accumulation of new and unexpected pain-related problems

and life events resulting in them passing a "*tipping point*". Regarding pain-related problems, participants' experiences seemed to be more overwhelming when there was increased load in the form of novelty and uncertainty surrounding their pain:

> *I think the shock was like the drastic raise in pain. I think it was shocking to me it could go higher than my previous 10 that I had had … I was supposed to wake up* (from surgery) *fixed … I was just shook by it all. Like I was shook to my core and it's even more than shock.* (Participant 1)

> *I wouldn't wish it on my worst enemy … it's beyond comprehension for me … I would say again a complete dissociation with my former self. Unable to recognize really why, and what is happening to me … I felt totally out of control which was one of … the things that really I think also traumatized me … I could never tell when they* (episodes of pain) *were going to happen, or how long it would happen for.* (Participant 9)

The (potential) uncontrollability of participants' pain was central: they felt that they could not control their pain or were uncertain if they would be able to control it or handle another minute. Participants 1 and 12 believed this to be a key precursor to their out-of-body experiences (see 3.1.2.). Uncontrollability and uncertainty were also linked to strong emotions and thoughts of suicide or not wanting to exist. This is reflected in the following quotes:

> *I was getting so frustrated, and so angry with what was happening to me at the time that I was getting major headache out of it as well … I've never had a history of migraines or bad headaches in my past, but this one was almost blinding. And it was to the point that I, well I just didn't want to be anymore. It was that bad that I couldn't see living like this more than one or two more days … like my head was blowing up. Then the pain in my back and with the pain radiating. And then when I was finishing running that cycle then all of a sudden you have to go and have a bowel movement or something and then bang it would just start all over again. And it was just cycling really, really bad … even with the drugs and alcohol it wasn't making a difference anymore … It was beyond.* (Participant 6)

> *The only other emotion I could access* (during a new ~12-hour pain episode) *besides anger was shame and embarrassment that I was doing so badly coping with pain … I had worked so hard* (in the past) *… like working through suicide ideation and pain. And getting to the point where I was like "no. I can still love my life, and I can cope with pain and all these things." And then all of a sudden like here* (new, overwhelming pain episode) *I was just like wishing … I didn't even wish I would die. Like I just wished I was never conceived and like I just never existed.* (Participant 1)

Despite previously discussing their pain with others for years, participants commented that the research interview was the first time they had discussed many of these moment-to-moment aspects of their worst pain experiences and the surrounding context – these conversations were novel to them. To express their difficult-to-describe experiences and cumulative load, they were inclined to use metaphors. For instance, Participant 5 described how they felt like they were falling into a hole, well or hell. And there was a long ladder, but they couldn't climb it like they had in the past. They stated: "*it felt like the floor fell out from under me … I was falling into this hole that I would never be able to get out of … I fell into hell … And if I have to live in hell, and if I have to get out of hell by myself, I can't do it. I just cannot do it.*" When discussing cumulative load, they also used a series of other analogies but ultimately returned to the feeling of falling:

> *The overwhelming feeling is all these different emotions are colliding you know? It's like you know you're on a merry-go-round that suddenly starts spinning way, way too fast … It's almost like you've lost gravity. Like you've lost your sure-footedness on the Earth … you don't know where you are anymore. You're lost in space … it's like you lose groundedness in a way that I can't describe. And you know for me it's definitely not floating. It's definitely like a long fall down.* (Participant 5).

Our interviews were focused on the immediate pain experience; however, participants shared the role of various life events surrounding their worst pain experiences. Participants specifically discussed how new or increased life stress (e.g. work and family issues) contributed to reaching a tipping point and worsened their pain. For instance, Participant 3 noted various family and relationship challenges leading up to the day of their worst pain experience. That day started with bad weather and interpersonal conflict, and they noted: "*have you ever had one of those days that just everything goes wrong? … It was one of those days*". Similarly, Participants 5 and 6 emphasized how their pain-related problems and stressful life events contributed to reaching a tipping point:

> *It was like a piling up of all the losses … I was already at like an eight or a nine in pain with everything else going on. And I was already struggling with that for days you know? And so, I felt like I was really worn down from that already … It was just too much. It was a tipping point you know … There's tipping points with pain … it's hard for me to get back if I tip into that well.* (Participant 5)

> *Everything was culminating to one point … when you talk about a scale of 0–10, we were talking about 30 at this time … it got so bad that I started breaking my teeth - I was gritting that bad … I couldn't get any relief, either emotionally or physically … it had reached that tipping point.* (Participant 6)

Overall, participants linked their worst pain experiences to increased cumulative load which involved pain-related novelty, uncertainty, uncontrollability, and stressful life events.

3.2.2. Social disconnect

Isolation, loneliness, and overall social disconnect were described as *contributors*, *characteristics* and *consequences* of pain-related disruption to one's sense of self. Here, isolation refers to physical or social separation from others, whereas loneliness is the subjective experience related to isolation,[65] encompassing feelings of being forgotten, neglected, abandoned or alone (some participants referred to this as *feelings of isolation*). Social disconnect is a broader term encompassing isolation and loneliness.[66] Supporting this subtheme, Participant 3 described social disconnect leading up to and during their worst pain experience. They felt forgotten and believed nobody cared about them, including family members, which exacerbated their pain episode:

> *I was alone because they hadn't sent anybody to be with me which was stupid … it felt like they forgot about me … everybody forgot about me … I was so close to home, and yet I'm sitting here in a bunk by myself with nobody there … I just wanted my dad there. I didn't want to be by myself … I just wanted my dad to go "hey, you know what? It's OK. You got hurt, everybody gets hurt. It's OK … You're going to get through this." I didn't have any of that … So, that was hard … And nobody cared enough to go "hey, do you need something? Are you OK?"* (participant cries) (Participant 3)

Similarly, others described how everybody was going about their daily lives while they were left socially disconnected, suffering alone. Participant 6 stated: "*When you're suffering from pain that bad on a daily basis, I don't know why but you seem to think that you're the only one … Everybody else* (was) *going about their daily lives … I was sitting there* (alone) *and suffering in silence"*. Even when others were physically present, participants reported feeling lonely because 1) others did not understand, believe or care about what they were going through; their pain was invisible to others or 2) their pain was so overwhelming, it was as if no one was there or they were not in focus:

> *And it just felt so isolating being in that much pain … everything else is quiet in comparison. So, unless somebody is offering, or doing something*

that actually lessens the pain then it's really hard to be able to focus entirely on the other … So, in that way, you always or I'd always feel very isolated. And I don't know whether I actually am, or if it's just not feeling like other people understand what's going on. They're not able to communicate what it is that I'm dealing with. (Participant 4).

Further, there were numerous reports of intentional self-isolation. Participants felt that stigma and lack of support or understanding by others and the healthcare environment amplified their pain and threatened their core sense of self-worth. They self-isolated to avoid feelings of shame and judgement. Participants also noted that they felt exhausted and didn't want to be around others or touched. They wanted to be alone in a safe space where they could try to make sense of their situation and regain their sense of control (see 3.1.1.). However, participants often had to engage with others and the healthcare environment, which contributed to thoughts of suicide and urges to hide and further self-isolate (i.e. isolation was a *consequence* of pain-related disruption to self):

I just wanted to kill myself. Like then I wouldn't have to be there (interacting with others). *Then I wouldn't have to be in pain. I wouldn't have to explain myself … it would be the door to go out you know? Like you can't control it. You can't explain it. Nobody understands. It's so disruptive that it'd just be easier not to be here … I think that I alienated myself and I also felt alienated … It's like you want them to ask you how you are, but you don't want them to ask you. You just want to know that they would ask you.* (Participant 12).

Even when self-isolating, participants expressed they wanted the *possibility* to access others who were empathetic or to feel their caring presence somehow. Maybe not a physical presence but knowing someone understands and cares about what they are going through. However, this possible access or caring presence was *unavailable* in most situations, and participants described this as a critical factor in making their experiences so bad. Overall, participants vacillated: they wanted to be around others but also alone. Participant 12 highlights this tension and the desire for support: "*you want to be alone …* (others) *couldn't understand it anyway … I just wanted somebody who understood I guess how bad it was.*"

3.3. Theme 3: Fluidity of the self and different modes of suffering

Participants' stories suggested that their bodily experiences and self-narratives reciprocally shaped each other and fluctuated over time, which provides novel insights into the complex interactions between different aspects of the self, modes of suffering and changing contexts. Although it was not a specific aim of this study, pain-related disruptions to the narrative-self were consistently described by participants as occurring at different points in their lives. This included lost, altered or threatened aspects of one's life story or identity that were valued, such as important roles, relationships and aspirations. Participants described pain-related disruptions to core facets of their narrative-self, such as being a planner, helper, problem solver, or likewise being rational, self-sufficient or independent. When combined with a negative affective valence, these disruptions to the narrative-self constitute one mode of pain-related suffering. The other mode of pain-related suffering involves the disruptions to the minimal-self described above.

Moreover, there were many examples where disruptions to the narrative-self seemed to lead or contribute to minimal-self disruptions and vice versa. Within and across participants' descriptions of their worst pain experiences, sometimes narrative-self disruption was prominent, other times it was minimal-self disruption. Also, some participants described a back and forth between modes of suffering which related to their fluctuating pain and increasing reflective capacities as they came out of their worst pain experience. Fig. 5 illustrates the "*waves*" of severe minimal-self disruption described by participants, including Participant 1 below, whereby self-reflection and access to the narrative-self (and narrative-self disruptions) were lost and regained over time.

My pain would go down, the thoughts would come up … there was a direct relationship between the two … like my pain would go down let's say 10%. I would add in thinking about school. My pain would go down 10%, add in thinking about the fact that I'll never be the same sister. Go down 10%, oh wait, I'm going to let my parents down. You know, so it was like as I was getting control of my pain, all the thoughts (came in) - *and I think that's maybe why I keep describing it like a wave. Because it felt like literally like my pain would come in, and then like the thoughts, like it was very much between the two. Like if I had enough space in my head to be thinking about something it was there.* (Participant 1)

Additionally (not depicted in Fig. 5), in several cases, self-reflections

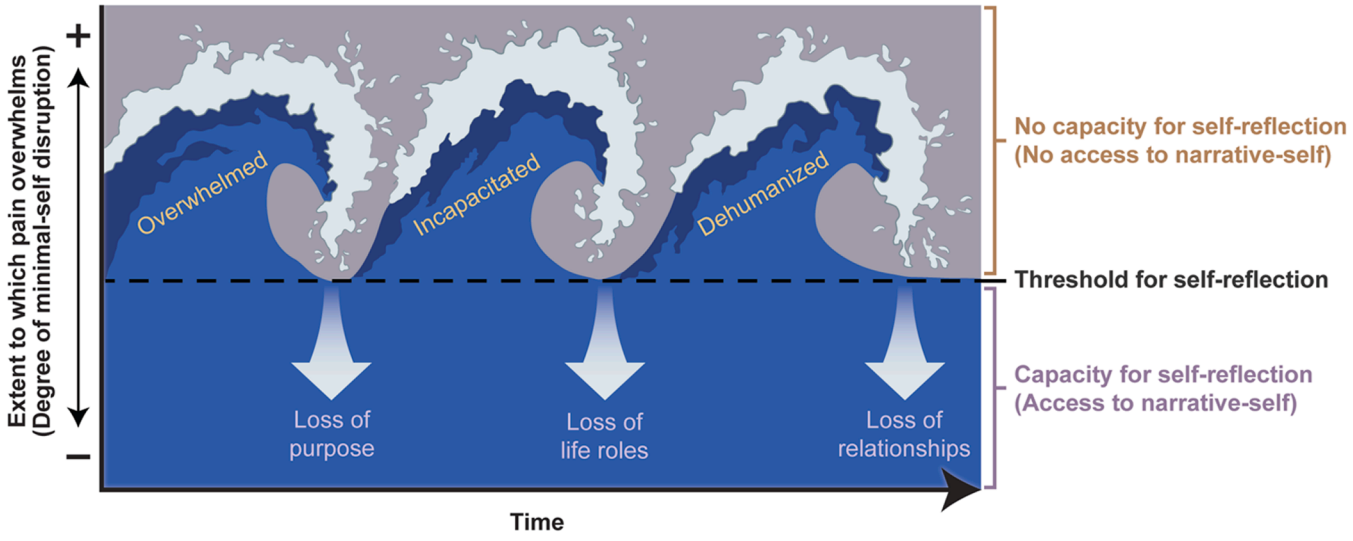

Fig. 5. Waves of minimal-self disruption. With more severe minimal-self disruption (breaking waves; e.g. overwhelmed, incapacitated, dehumanized), individuals crossed a threshold for self-reflection (dashed line), such that they were unable to engage in self-reflection and thus lost connection to their narrative selves. As the severity of minimal-self disruption subsided (water below dashed line), the capacity for self-reflection returned and was often associated (white arrows representing underwater currents) with narrative-self disruption (e.g. loss of purpose, roles, relationships). The listed words are just illustrative examples of these self-disruptive experiences.

(narrative-self) seemed to buffer (reduce) or magnify minimal-self disruption. For example, Participant 10 described newly developed spiritual narratives that buffered the disruptive nature of their pain episodes that were previously overwhelming. Similarly, other participants described slow changes to their mind-set, behaviors and how they viewed themselves (narrative-self) - all of which they felt helped prevent their pain from becoming incapacitating like it had in the past.

In contrast, there were scenarios where self-reflections and narratives negatively impacted the minimal-self. In particular, self-reflections prompted by one's pain and interactions with others (3.2.2.) interrelated with disruptions to one's sense of agency and ownership (3.1.1. and 3.1.2.). Prominently, an invalidating or unsupportive environment and unhelpful messages from others contributed to feelings of dehumanization, alienation, bodily shame, and a lost sense of control of one's emotions and bodily actions. For some, the culmination of losses and continued interpersonal challenges made the idea of suicide more plausible. Participant 12 shared: *"it wasn't so bad to commit suicide because I didn't have anything to lose anyway. I lost everything … Nobody ever understood me. Nobody would have to understand me because I wouldn't be here"*. The supplemental digital content provides additional participant examples with supporting quotes, including reports of worst pain experiences involving interactions between the two modes of suffering.

Overall, this theme reflects how pain can have cascading impacts on one's sense of self; it can permeate and disrupt minimal and narrative aspects of self. This is summarized by Participant 1: "*When they show those diagrams of identity … You have you at your core. And then you know, maybe your family. And the larger community, like where your identity* (fits) *within the community … That's what I saw crumbling; like almost from the community to my individual self … There's so much to untangle between my pain and feelings about loss of identity, and loss of self."*

4. Discussion

Pain-related suffering has historically been anchored to self-reflective experiences that involve disruption to one's personhood, or narrative-self.[7–10,67–69] However, our findings revealed important accounts of in-the-moment experiences of pain that (when most severe) overwhelmed thoughts and self-reflective capacities. Participants report that these overwhelming pain experiences were incapacitating and dehumanizing and created important disconnections with their body and sense of time. These reports align with well-established characteristics of minimal-self disruption.[5,17–26] They are also remarkably similar to accounts of torture,[5,27–30] which is defined as a form of suffering by the United Nations[70] and discussed by Scarry.[71] Therefore, we propose that these findings constitute an additional mode of pain-related suffering, that does not require self-reflection and is characterized by an immediate, disruptive impact on one's sense of self (i.e. minimal-self disruption). These findings challenge historic conceptualizations of suffering and offer support for the idea that populations with more limited capacities for self-reflection may suffer.[1]

The severity of experiences in the present work stands out as novel. Past reviews observed small-to-moderate impairments in cognitive and executive function among people with pain, based on performance in standardized evaluations of memory, attention and decision-making.[72–74] Our participants reported such strong executive function impairment, that even their ability to *consider* the completion of such tasks seemed out of reach. Similarly, past work on body perceptions has focused on distortions of the size and shape of pain-related body parts,[75–77] while our findings point to instances in which overwhelming pain experiences led to dissociated states involving the full body. Our findings, thus, help shed light on the profound depths to which moment-to-moment pain experiences have the potential to overwhelm basic function and states of consciousness.

Better understanding the severity with which pain can overwhelm likely has important theoretical implications for biopsychosocial models in the pain literature. For instance, pain-related fear in the *fear-avoidance model* has historically been understood as stemming from misguided beliefs and cognitions about pain (e.g. pain indicates bodily damage, which leads to fear-avoidance behavior; an *abnormal* response to a *normal* situation).[78–81] However, the severity of pain experiences in the present study offer another potential picture of what may drive pain-related behavior. Participants were able to vividly describe moment-to-moment pain experiences that were sometimes more than two decades old, and the content of these descriptions had important overlap with first-hand accounts of torture. Such extreme experiences of overwhelming pain may act as a type of trauma (in and of itself). Perceived risk of returning to these states may drive avoidance behavior that may persist without strong beliefs around pain-related tissue injury. Expanding historic understandings of pain-related fear, these cases may reflect a *normal* response to an *abnormal* experience. Research is needed to further explore the potential relationships between overwhelming pain and subsequent avoidance and/or trauma-related behavior, including suicidal behavior, to inform trauma-informed pain management frameworks.

Our findings also interface with *self-illness separation*.[82–85] Our findings suggest that people often employ a form of dualism as they separate their painful body (or just pain) from their self, or feel their body/pain does not fit within their *preferred self*.[86,87] As people try to maintain an intact overall sense of self, they may implicitly or explicitly place their body/pain outside of themselves. In more extreme cases, participants reported out-of-body experiences which may be an adaptive (in the short-term) dissociative defense mechanism.[5,27] Our data on such experiences help substantiate past "embodied pain" frameworks[14,15] arguing that dissociative departure from one's body is a final defense to protect self during inescapable pain. Our selfhood framework also adds precision: giving up a degree of one's bodily sense of ownership (dissociating from one's painful body) may enhance one's sense of agency.[27]

Our findings on the context surrounding minimal-self disruption align with research on pain-related uncertainty[88] and uncontrollability,[89] and research suggesting that patients with more severe pain profiles report higher cumulative life stress, co-occurring symptoms and cognitive dysfunction.[90] Notably, participants in our study emphasized that their worst pain experiences were not just related to pain intensity, and many commented that their experiences did not fit within typical unidimensional scales of intensity. Indeed, our understanding of pain-related suffering transcends pain intensity measures. This is consistent with findings that self-reported pain "flares" are not always associated with higher than average pain intensity scores, but are commonly characterized by poorer psychosocial function.[91] This all implicates evolving stress frameworks falling under the acronym STUN: Sense of low control, Threat to ego, Unpredictability and Novelty.[92,93] Our findings are also consistent with a pain model on threat to the social self,[94] which overlaps with stress frameworks.

Our findings suggest that tailored clinical management strategies may be needed to target the two modes of pain-related suffering. Regarding assessment, the severity of minimal-self disruption in this study helps shed light on patients that may be too overwhelmed to communicate. As depicted by the breaking waves in Fig. 5, such patients are unlikely to be able to complete simple tasks or converse, and are often experiencing intense, overwhelming emotions. Simply recognizing when patients are in such states is likely foundational to effective care. An increased focus on observational strategies over self-report may be needed – potentially employing assessment strategies that are used among infants or people with cognitive impairments.[95–98]

Regarding treatment, it's likely important to consider the cognitive demands of interventions in relation to the degree to which patients are overwhelmed by their pain. Best practice treatments for chronic pain often require high levels of executive function and self-reflection. These interventions may be inaccessible to patients struggling with high-levels of minimal-self disruption. Trauma-informed approaches with a focus

on immediate pain relief or simple grounding/calming techniques (when possible) may be more appropriate in such contexts to communicate safety and anchor patients to time and place. It might also be possible to tailor care for patients that experience minimal-self disruption but are not completely incapacitated. For instance, people with disrupted bodily ownership may benefit from somatic (embodied or mind-body) therapies or sensory discrimination training[99] as it might help them feel more connected to their bodies. Overall, more research is needed to develop tailored assessment and treatment strategies and to determine when, and for whom, these strategies should be employed.

The dynamics of minimal- and narrative-self disruption may also have important clinical implications. For instance, consider movement of the teeter-totter in Fig. 1 to indicate increased dominance of the narrative-self. Being stuck in this position makes it harder to be in the present. In the opposite direction, being stuck in overwhelming pain (in-the-moment) can disconnect one from valuable narrative practices that are central in one's life (e.g. self-talk coping, spiritual practices). Treatment can be seen as facilitating dynamics of the teeter-totter. Therapeutic interventions for individuals stuck in-the-moment might help them to eventually employ helpful narratives to manage potentially overwhelming states (described by Participants 6 and 10). In the other direction, redirecting attention to the present moment (e.g. mindfulness, grounding) might give temporary respite from unhelpful self-reflections, including existential thoughts of one's past or threatened future. Future research could further characterize these dynamics, gradations in alterations to one's sense of self, and transitions between pain-free states, pain (without disruption to one's sense of self) and pain-related suffering (with disruption to one's sense of self). This will require more granular research on the narrative-self to better clarify its domains, disruptions and relations to the minimal-self and its disruptions.

An inherent methodological limitation is that qualities of severe minimal-self disruptions cannot be accessed directly as they occur.[5] Obtaining real-time narratives can be logistically impossible or unethical when participants cannot communicate effectively or provide informed consent (i.e. during waves of minimal-self disruption depicted in Fig. 5, that surpass one's capacity for self-reflection). Additionally, research guidelines typically recommend excluding people who are actively distressed or suicidal.[54] These limitations require researchers to rely on safely-collected retrospective narratives to learn about these types of severe disruptions. While we cannot completely overcome these limitations, future research might reduce recall bias and obtain more nuanced details by employing longitudinal designs, ecological momentary assessment, or elicitation strategies, such as trauma-informed interview techniques using present-tense narration. Another limitation is that we did not specifically screen for comorbidities that may have contributed to participants' reports of self-disruption. For instance, our findings share features of depersonalization-derealization disorder and other psychopathologies.[5,17,19] Future research could compare qualities of pain-related suffering to non-pain conditions that involve suffering. Dedicated research is also needed on suffering related to gender, ethnicity and culture. We did not collect ethnicity data; thus, our findings may not generalize to individuals who experience systemic racism and societal oppression. We are currently assessing generalizability.[100]

In conclusion, we provide a new foundation for advancing the understanding, assessment and treatment of pain-related suffering. While the field has established that pain impacts daily activities, relations and work, our novel findings move far beyond this. We characterized how pain can radically transform how people experience themselves and their world. These findings will inform the development of a robust definition of pain-related suffering that will enable more precise communication, research and interventions.

Disclosures

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Authorship contributions

All authors contributed to funding acquisition, conceptualization, methodology, review and editing. P.S. and T.W. curated the data. P.S., M.G. and T.W. were involved in data analysis and initial theme generation. P.S. drafted the initial version of the manuscript and Figs. (1, 3, 4) with support and supervision from T.W. Graphic designer Jean YiChun Lin created Figs. 2 and 5 with guidance from P.S. and T.W. Themes, supporting quotations and figures were finalized with feedback from the whole team.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.jpain.2025.105413.

Data availability

Additional data (i.e. full interview transcripts) are unavailable to keep participants' identities confidential, consistent with standard qualitative research practices.

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