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CRIPPING THE PAIN SCALE: LITERARY AND BIOMEDICAL NARRATIVES OF PAIN ASSESSMENT

ABSTRACT

This article analyses the literary representation of pain scales and assessment in two chronic pain narratives: 'The Pain Scale', a lyric essay by Eula Biss, and essays from Sonya Huber's collection *Pain Woman Takes Your Keys, and Other Essays from a Nervous System*. Establishing first a brief history of methods attempting to quantify pain before my close reading, I read both Biss and Huber's accounts as performative explorations of the limitations of using linear pain scales for pain which is recursive and enduring. Considering both texts as cripistemologies of chronic pain, my literary analysis attends to their criticism of the pain scale, including its implicit reliance on imagination and memory, and how its unidimensionality and synchronic focus prove inadequate for lasting pain. For Biss, this surfaces as a quiet critique of numbers and a disturbance of their fixity, whilst Huber's criticism employs the motif of pain's legibility across multiple bodies to spell out alternative meanings of chronic pain.

Crucially, this article proposes a crip and embodied approach for reading and responding to accounts of chronic pain's measurement, including Biss and Huber's literary accounts, and the biomedical account of pains scales which this article reads alongside them. The article's analysis draws on my personal experience of chronic pain, neurodivergence, and disability to demonstrate the generativity of an embodied approach to literary analysis. Rather than bowing to the impulse to impose false coherence on my reading of Biss and Huber, my article foregrounds the impact of the re-reading, misreading, cognitive dissonance, and breaks necessitated by chronic pain and processing delays on this analysis. In bringing an ostensibly crip methodology to bear on readings of chronic pain, I hope to invigorate discussions on reading, writing, and knowing chronic pain in the critical medical humanities.

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Chronic pain, defined as pain persisting or recurring over three months, evades scientific explanation and is stubborn in the face of attempts to eliminate it (Treede et al. 2015). As this article demonstrates, this persistence is evident in biomedical writings which attempt to comprehend pain, and literary narratives which emphasise its resistance to all types of containment.[i] Literary narratives of chronic pain, which chronicle attempts at chronic pain's enumeration, are the focus of this article's analysis. Such accounts frequently depict pain assessment as an encounter in which experiences are validated or denied, treatment plans made, and personal support systems called into question. The pain scale, an assessment method in the form of a verbal rating scale or 'a line that represents the continuum of the [pain] to be rated', is ubiquitous in the clinic and in literary chronic pain narratives (McDowell and Newell 1996, 341). This article analyses the literary representation of pain scales in Eula Biss' lyric essay 'The Pain Scale' (2005) and essays from Sonya Huber's collection *Pain Woman Takes your Keys, and Other Essays from a Nervous System* (Huber 2017). I consider Biss and Huber's frustration with such scales' reductive simplification of chronic pain's complex lived reality alongside readings of biomedical texts about the origins and implementation of pain scales, demonstrating how means of conceptualising and enumerating pain might inadvertently contribute to further suffering (Levy, Sturgess, and Mills 2018, 435). I demonstrate how Huber and Biss' appropriation of the pain scales structure foregrounds chronic pain's resistance to reductive enumeration enacting a criticism of the scales which infuses the impersonal instrument with the authors' cripistemologies of chronic pain.

This article demonstrates the importance of cripistemological understandings of chronic pain, challenging an existing hierarchy which favours clinical signs and biomedical explanations over bodily epistemologies. The term 'cripistemology', coined by Merri Lisa Johnson, captures the flamboyance of claiming 'crip', a means of understanding disability beyond and in defiance of medical and social models, and epistemology, suggesting ways of knowing disability 'around and through' its lived experience, in excess of medicalised deficit models (Johnson and McRuer 2014). Cripistemology underscores the importance of disabled people's experiential and bodily knowledge, understandings which have been traditionally denied in favour of medicalised accounts; in so doing, cripistemology can help to 'situat[e] pain within discursive systems of power and privilege' to counter reductive simplifications of chronic pain's complexity (Patsavas 2014, 205). In addition, crucial to this article's crip reading process is Jasbir Puar's assertion that the word 'cripistemology' captures the cripping of knowledge production, 'a displacement […] of conventional ways of knowing and organizing knowledge' to make way for crip methodologies (McRuer and Johnson 2014, 163–64). This article raises Biss and Huber's accounts of pain assessment, for unspecified chronic pain and rheumatoid arthritis respectively, to the importance of biomedical accounts on the subject. It bears witness to their expressions of pain and frustrations with assessment, and places their literary narratives in dialogue with biomedical accounts of the pain assessment methods which they critique.

To this end, the article will briefly engage with clinical texts, including Ronald Melzack and Dennis Turk's *Handbook of Pain Assessment* (2011), Chris Pasero and Margo McCaffery's *Pain Assessment and Pharmacologic Management*

(2011), and research papers on pain scales' implementation, solidifying the grounds for Huber and Biss' critical appraisal of the pain scale and predicating my literary analysis on an account of the scales' development and clinical implementation. I demonstrate the generativity of reading literary and biomedical accounts together and of a dialogic understanding of these oft-polarised means of knowing chronic pain, nuancing understandings and approaches to pain and its assessment in the critical medical humanities.

In so doing, this article builds on existing responses to Elaine Scarry's thesis that pain is inexpressible due to its inherent resistance to language.[ii] In *The Body in Pain: The Making and Unmaking of the World*, the most well-known text on pain studies in the humanities, Scarry contends that pain enacts a monolithic attack on language, and that another's pain is always subject to doubt because it is not available for sensory confirmation (Scarry 1985, 3). I complicate Scarry's contention by responding that chronic pain has particular expressive difficulties which differ from the acute pains her text describes, recognising chronic pain as especially resistant to measurement with and communication through pain scales due to their synchronic focus and failure to address chronic pain's enduring, complex lived reality. I respond to Scarry by claiming that chronic pain's expressive difficulties do not mean it is unshareable. Instead, Biss and Huber's literary responses to the pain scale, especially in those moments where language cracks under the weight of pain, render their pain shareable and recognisable with my own experiences of chronic pain, which I treat as formative for this article's analytic work. For me, pain's attack on language and its resultant fragmentation of syntax and meaning are especially evocative of the onslaught of a pain flare and the strain of living under it.

My account of the pain scale's mechanisms and structure, drawn from biomedical texts on pain assessment, foregrounds how 'The Pain Scale' and *Pain Woman* appropriate the pain scale's form to visibly critique its reductive treatment of chronic pain. The scale, which at best yields a snapshot analysis of pain, is incompatible with pain which is enduring or recursive. Both types of narratives, literary and biomedical, underscore the difficulty associated with the task of pain's enumeration; in response, Biss disturbs the alleged fixity of points on the scale through a quiet critique of numbers and their imprecise meanings, whilst Huber constructs a new personal scale and imagines pain as a legible entity spelled out across multiple bodies. The scale's implicit reliance on memory and imagination – the inevitable result of the wording of anchors, the verbal labels which demarcate the scale's discrete range - demonstrably distorts responses and can vastly alter the nature or extent of treatment offered. Guidance for using such scales can betray a tendency towards Cartesian dualism, which is prevalent in pain discourses elsewhere and overlooks the fact that physical pain can be experienced alongside, because of, or through negative affects. Ultimately, the authors maintain that chronic pain can provide no easy answer to the questions asked by the pain scale, sustaining its questions through the cyclical and associative momentum of the lyric essay form.

Finally, this article establishes and demonstrates a methodology for engaging with narratives of chronic pain which blends reading with my disabilities and an attunement to texts' material and affective dimensions. My engagement with Biss, Huber, and the other authors on pain scales is cripistemologically inflected, and draws on my experience of chronic pain, disability, and neurodivergence. I explicitly validate and include these experiences as they come to me in reading, challenging the ableism inherent in trying to obscure them. Indeed, brain fog and neurodiverse 'sitpoints' (a term, first used by Rosemary Garland Thomson to 'cal[l] attention to the normative assumption that one perceives the world from standing rather than sitting' and which resonates powerfully with my experience of PoTS) are among perspectives contemporary disability studies has come to value for producing queer, twisted readings, bending source materials out of shape and eliciting new approaches to familiar concepts (Garland-Thomson 2005, 1570).[iii] I build on the work of crip writers such as Ann Cvetkovich, for whom impasse, which can arise from altered cognitive states, is cast in terms of its positive and productive value, considering it 'a state of both stuckness and potential' which can be freed up when 'alternative forms of writing can spring them loose as foundations for innovative thought' (Cvetkovich 2012, 21 and 81). Furthermore, my work aligns with Mel Chen's validation of brain fog as cripistemology, challenging its 'active suppression' in academia where it might 'represen[t] the near unthinkable' instead of something to channel for academic enquiry (Chen 2014, 171 and 177). My article builds on their vocabularies and enfolds stuckness, impasse, brain fog, and other cognitive states arising from my disability into this article's analytic work.

In my experience, 'stuckness', 'impasse', and 'brain fog' often coincide with fatigue, pain, nausea, dissociation, dyspraxia, Irlen syndrome, and sensory overload.[iv] Too often, these cognitive and physical states feel de-creative; far from providing access to crip analysis, they make me feel *something* which often fails to materialise as thought. Sometimes, dissociation or necessary breaks in reading result in incomplete, disjointed conclusions, or a text's meaning resonating in a body part rather than in my brain. In spite of (or perhaps because of) this challenge to my working memory and coherence, I experience an amplification of the material qualities of the texts with which I work – the weight and size of a text, the thumbprints on a page, or the creases in a book's spine speak as loudly to me as the ideas the texts contain, seeming to pursue their own trajectories and forcing me to join in. As such, my methodology entails the explicit acknowledgement of these challenges and intensities, and reproduces my work of reading and re-reading, allowing for interpretative mistakes, revisions, and circling back, and attention to the affective dimensions of a text's material qualities. My analysis considers the appropriateness of crip-materialist engagement for interpreting and reading Biss and Huber's lyric essays, which move associatively and demonstrate their own resistance to linear logic, attending to the disorienting particularities associated with the form. It also asks questions of the coherence achieved by reading such literary accounts alongside biomedical narratives of pain assessment – something which I consider generative for my analysis, even if my brain fog challenges my ability to say why. It is my hope that my methodology for engaging with chronic pain narratives, informed by my own chronic pain and associated difficulties, might invigorate discussion in the medical humanities about nonnormative routes to meaning and vouch for the embodied understanding of literary and biomedical texts.

A brief history of pain scales

Before commencing my analysis of pain scale's literary representations, I wish to briefly outline the scale's invention, structure, and clinical usage. This account, particularly of the scale's appearance and structure, is instructive for my later reading of Biss and Huber's visible adoption of the pain scale's form in order to critique it. Likewise, this section contextualises Huber and Biss' discussions of the complexity surrounding the anchor phrases in the scale, which I consider muddle attempts to quantify pain with acts of imagination, memory, and pain's perplexing subjectivity and messiness. I demonstrate how, at best, the scale yields incomplete information from which to understand the experience of the strange logic and enduring suffering associated with chronic pain, which I demonstrate with reference to my own experience of a pain assessment.

For anyone who has routinely undergone pain assessment, the phrase 'pain scale' conjures memories of healthcare professionals asking them to rate pain 'on a scale of one to ten', or a printed scale upon which to mark where pain lies. Popularised by the rheumatologist E. C. Huskisson in the 1970s, the Visual Analogue Scale (VAS) is 'a line [conventionally 10 cm long] that represents the continuum of the symptom to be rated […] marked at each end with labels that indicate the range being considered' (see Figure 1) (McDowell and Newell 1996, 341). When VAS is used to assess pain, phrases such as 'no pain' and 'pain as bad as it could be' or 'worst pain imaginable' stand at opposite ends of the line, demarcating a discrete range from which patients can rate their pain. Clinicians laud this quantification method because it is cheap, quick, and can be followed up with multiple comparative measurements (McDowell and Newell 1996, 341).

Figure 1: visual analogue scale, showing the anchors 'No pain' and 'Pain as bad as it could possibly be' (Pasero and McCaffery 2011, 55). Courtesy, Elsevier.

Figure 1 testifies to the scale's simple appearance, but its clarity is undermined by anchor wordings and how these relate to individuals' pain experiences. Clinicians have shown reticence about anchor wording, stating that 'No single-word anchor has been identified as being the best one for the number 10 [but they have tried] "worst imaginable pain", "worst possible pain", "most intense pain imaginable," "terrible pain", and "pain as bad as it can be"', presenting multiple options which belie the scale's certainty (Pasero and McCaffery 2011, 56). Upper anchors depend implicitly upon imagination, memory, and interpretation: patients asked to rate pain in relation to the 'worst imaginable pain' might compare it to their worst pain memory or treacherous imagined pains – and neither response is contraindicated. Reliance on imagination may distort ratings by intensifying the 'worst pain', resulting in inadequate treatment. For chronic pain, drawing from experience, it is easy to understate the intensity of 'new' pains, compared to the enduring pains which one abhors and must constantly endure. Anchor wording disturbs the pain scale's parameters, undermining its reliability and eliciting answers which muddle imagination, memory, and subjective measurement.

The origins of pain measurement can be traced to the First and Second World Wars, when clinical understandings of pain accelerated; physicians could directly observe pain mechanisms in war casualties with serious injuries. Scientists then developed three main strategies to measure the pain experience: psychophysics, questionnaires, and pain scales (Noble et al. 2005, 14). Despite these developments, the history of pain assessment characterises pain as solitary and 'always subjective', resistant to enumeration (IASP 2018). IASP echoes the sentiment that pain's subjectivity remains 'a central impediment' to its quantification (Melzack and Turk 2011, 4).

It is 'a complex perceptual phenomenon' which evades communication despite decades of research into enumeration methods (Melzack and Turk, 4-5). Similarly, some assert that pain is 'the most challenging and difficult area of subjective health measurement', complicated by its multidimensionality, interiority, and influence by cultural norms (McDowell and Newell 1996, 335). As a chronic pain sufferer, I know first-hand the inexactitude of quantifying enduring pain, and the difficulty of getting others to recognise its chronicity. I contend that chronic pain has more expressive difficulties than acute pain, rendering it especially resistant to enumeration.

Indeed, methods of measuring, writing, and talking about pain can have devastating and far-reaching consequences. It is in the wake of the current opioid addiction epidemic that the medical community has addressed scales' problematic nature. I wish to preface this account of pain scales' connection with the opioid epidemic by noting that I am not criticising any person whose means of managing pain includes opioids: rather, I wish to establish an account of how language to describe and measure pain, alongside outside forces including pharmaceutical representatives, reimbursement processes, and the urgency of palliating pain, has become connected with a spiralling epidemic in which thousands have developed drug dependencies or died.[v] A notable example of the profound impatct of pain's conceptualisation was its designation as the 'fifth vital sign' (5VS), a campaign adopted by US clinicians in the 1990s (Levy, Sturgess, and Mills 2018, 435). In 1990, Dr Mitchell Max decried pain medicine's lack of advancement, issuing the imperative to 'make pain visible' by giving all clinicians 'bedside tools' for rapid assessment (David W. Baker and The Joint Commission 2017). In October 2000, then-US President Bill Clinton designated the 2000s the Decade of Pain Control and Research; this period placed more onus on clinicians to rapidly assess and alleviate pain. Pain was conceptualised as an 'objective measurement of the essential physiological functions of a living organism', alongside body temperature, blood pressure, pulse, and respiration (Sapra, Malik, and Bhandari 2022). Alongside this, clinicians accepted reports that pain patients' addiction to narcotics was extremely rare (Porter, Jane and Jick, Herschel 1980). The 5VS campaign emphasised monitoring and treating pain quickly, and increased clinicians' reliance on rating scales to assess and reduce physical suffering.

In other words, the 5VS campaign and resultant over-reliance on pain scales were borne of a desire to alleviate pain. However, their unintended catastrophic consequences include the overprescription and misuse of opioid drugs, addiction, and death. The Decade of Pain Control saw clinicians overprescribing narcotic analgesics such as OxyContin to ease pain. Two decades later, 5VS was criticised as a 'contributo[r] to the opioid crisis' through its excessive emphasis on relieving pain and opioid overprescription (Chisholm-Burns et al. 2019, 424). Clinicians implicated the Numeric Rating Scale as 'directly contribut[ing] to the prescribed opioid epidemic that America is now experiencing' (Levy, Sturgess, and Mills 2018, 435). The Joint Commission, the US organisation responsible for accrediting healthcare providers, ceased promoting the campaign and instructed clinicians to abandon it. Recognising the harm caused by the scale's incomplete information, Biss' narrative, which I examine later, demonstrates doubts about pain scales' efficacy for capturing enduring pain's complex experience, articulating concerns shared by the medical community that such scales 'measure only intensity, [thus] they cannot be viewed as a comprehensive pain assessment' (Karcioglu et al. 2018, 708).

The history of pain scales' development reveals much about some clinical attitudes towards patients' attestations of pain; these can prove challenging for patients who, like me, want their pain to be witnessed in the clinic, and for a space to be held to discuss its sensation. Many sources ascribe drug evaluation as the driver for scales' invention, but I consider that this historical angle inadvertently renders patients' experiences peripheral, overwriting multidimensional pain experience with enumerative exercises. One history of pain scales emphasises using felt differences to 'establish the efficacy of analgesics and other therapies', providing 'the crucial method by which analgesic therapies can now be evaluated and compared' (Noble et al, 14 and 15). Another account, which stresses the need for clinicians to codify expressions of pain in a manner suitable for statistical analyses, indicates that the VAS and 'NPRS [are] used to measure pain change', for instance in the development of narcotics or the assessment of other treatment modalities: rather than viewing the subjective patient report as superfluous or useless, Graham emphasises clinicians' and researchers' need for an instrument which renders the pain report useable (Graham 2015, 60). However, the use of such scales primarily as 'means of quantifying patient report, with most designed specifically for RCTs [randomised controlled trials] rather than for clinical care' seems at odds with my experience of the ubiquity of pain scales in clinical settings (Graham 2015, 60–61). I consider that these accounts' emphasis on metrics subtly overwrites sensation, inadvertently shifting focus from pain towards evaluative discourses about treatment. Perhaps this reflects a limit, whereby pain can only be understood through its conditional relationship to other factors. Though I recognise the centrality of assessing treatment's efficacy, part of me feels unease that these explanations of metrics divert attention from discussions of chronic pain's experiential reality.

Historical accounts indicate that the relegation of patients' expression of pain, in favour of objective signs and symptoms, is sometimes driven by scepticism. This is somewhat surprising considering patients were encouraged to express their pain visibly and vocally in nineteenth- and early twentieth-centuries, when an expressive release was deemed physiologically beneficial and diagnostically useful (Bourke 2014, 62). Nonetheless, Turk and Melzack report that 'many clinicians suggest that the report of pain should be ignored,' considered unreliable compared to more 'objective' signs (Melzack and Turk 2011, 8). This focus on visible signs effectively effaces patients' rich personal explanation, excluding pain sufferers from analyses of their own pain.

Whilst visible clinical signs are diagnostically important, pain behaviours, and facial expressions also have significant implications for pain assessment. The Wong-Baker FACES scale is one example of the use of facial expressions, albeit in the form of illustration, in clinics. The FACES scale features linear drawings of facial expressions, ordered from least to most distressed. Users are expected to identify the facial expression which 'best illustrates the physical pain that they are experiencing', whilst avoiding reading facial expressions for emotion (Baker and Wong 2016). This scale was devised by paediatric clinicians Connie Baker and Donna Wong; working on children's wards, they observed that 'children often work through their fears or concerns through play', but severe illness or injury can prevent this (Baker and Wong 2016). The FACES website details how injured children may have their proclamations of pain disregarded in clinics, and thus receive inadequate pain relief. In response to this, with these children's help, Wong and Baker developed the FACES Scale.

Wong and Baker showed children six blank circles, asking them 'to think back to their own experiences and draw facial expressions to show how they had felt when they experienced different levels of pain'. They adapted and arranged them in a sequence of increasing pain from left to right 'because it consisted with other scales and with English reading' (Baker and Wong 2016). A copy of the FACES scale is provided below (Figure 2), underneath a conventional NRS, since they sometimes appear together for clarification.

Figure 2: A combined Wong-Baker FACES and Numeric Rating Scale.

Whilst I appreciate Wong and Baker's dedication to relieving injured and sick children's pain, and the difficulty of developing a method which is adequately informative of the nature and intensity of pain being treated, their website's usage guidelines betray a tendency towards Cartesian dualism which is prevalent in clinical pain discourses. The authors approve the scale's use 'for pain assessment only', and explicitly 'do not give permission for use in measuring emotions, mood, comfort, etc' (Wong and Baker). Whilst I understand the need for such disclaimers, and the reasons why focusing on specific elements of pain might take precedence in a clinical setting, the phrasing ignores the fact that physical pain is frequently experienced alongside, because of, or through negative affects. Further reviews indicate that FACES anchors 'confound pain measurement with nonnociceptive states' (Garra et al. 2013, 17). Despite a desire to maintain mind/body separation, chronic pain is strongly correlated with anxiety, depression, and trauma (Cosio and Meshreki 2017). In my experience, choosing an appropriate facial expression would be difficult: I am no longer able to facially express pains I have had for years, so choosing a face from the scale seems arbitrary. Pain is indissociably linked with emotion, and the distinction between them feels forced: pain and depression 'exacerbate one another', causing a vicious cycle of physical and mental anguish (Cosio and Meshreki). Indeed, certain conditions may limit facial expressiveness, masking the urgency of pain or its attendant emotions. I consider that quantifying pain using facial expressions might prove more difficult when pain has been prolonged, treatments ineffectual, and the quotidian existence of pain no longer draws a frown.

Despite the developments in pain measurement I have explored here, chronic pain, its expression, and its clinical appraisal remain difficult. Whilst revising this article, I had a hurtful, if elucidating, experience in A&E. Sent to hospital by my GP to X-ray my swollen thumb, a nurse performed my initial assessment. Assessing my hand and wrist, she dismissed my claims that the area had hurt for years. When I attempted to explain that the area was affected by osteoarthritis, she laughed with her colleague, perhaps as I appeared too young. Prising my hand for assessment, she repeatedly yelled 'you're stopping me from bending it' and to 'stop resisting,' despite my protest that I had never been able to move my hand in that direction. She asked why I had a walking aid; I explained my leg length discrepancy, PoTS, and Ehlers-Danlos to eye-rolls and sighs. I left the nurses and walked to the X-ray department in tears and whispered that I needed to speak with someone in privacy. Two radiographers did all they could to calm me and prevent me from leaving without having my X-ray, explaining, as I had felt all along, that A&E is ill-equipped to recognise and understand the baseline levels, sudden flares, and strange logic of chronic pain. Knowing what I do about pain assessment and epistemic invalidation did not make it easier to calm the physical and emotional hurt. Pain assessment in isolation, numbers without context, seem a pale imitation of life with a constant background of pain. Fortunately, many clinicians do what they can to listen to patients and make space for the stories that accompany the numbers. The experience, awful as it was, affirms my thesis that chronic pain has frustrating expressive difficulties, that assessment can be hurtful, and that enduring pain is resistant to the synchronic analysis offered by pain scales.

A crip reading of Eula Biss' 'The Pain Scale' (2005)

Figure three: a double-page section from Eula Biss' 'The Pain Scale' as it originally appeared in *The Seneca Review* (minus my orange highlights), with numbered arrow at the top.

It is exciting to think of the generative capacities of performing crip reading – until it isn't. Confronted with Eula Biss' 'The Pain Scale', what initially makes it so apparently impenetrable is its spaciousness (see Figure three above): it is around 20 pages long, constructed from short, spread-out paragraphs, each encased in a bubble of white space. At a glance, there is more white space than text. The piece appeared in *The Seneca Review* in 2005, but it is still widely circulated as a PDF, with Biss' original layout intact. As a lyric essay, a hybridised form which borrows from the creative licence of poetry and the sustained thoughtfulness of non-fiction prose, 'The Pain Scale' resists being read as one or the other. Each paragraph, immobilised in white space, suggests the succinctness of a haiku or poems by Emily Dickinson, beckoning readers to unfold their densely loaded meaning. I feel disoriented by the text on a visual level: its white spaces and serif font, combined with my dyspraxia and tinted reading glasses, resist an easy reading. Perhaps this is why I do not know where to begin: I see elements of 'The Pain Scale' which blend experimental prose and poetry, and fear I'll misunderstand it. Joe Moran considers that this structure and spacing is as important to the lyric essay as chronology and development are to more conventional narratives; this form instead 'relies […] on evocative juxtapositions, forcing the reader to make little intellectual and emotional leaps across the white space of the page' (Moran 2017, 1280). Moran's compulsion is to read across these spaces, to read paragraphs associatively, rather than to fixate upon the space itself. It occurs to me that getting stuck in the space is what I am doing wrong.

Biss' appropriation of its structure infuses the impersonal instrument with the stuff of her personal understanding of pain: half-recalled conversations, associations, questions, hesitations. Her critique of pain scales is also embedded in her text's material qualities, which mimic the layout of the scale, with numbered arrows at the start of each vignette. The essay is performative: its discussion relies on its adoption of the traditional pain scale's form. I hold the image of 'The Pain Scale' mentally alongside a numeric or visual analogue scale (see figure 1); Biss' scale overwrites the minimally labelled visual analogue scale with important personal details, reformulating the scale from a line, a series of numbers, and anchor phrases, to one which accommodates an expanse of thoughts, memories, ideas, and associations (see figure 3). One might say that, but for the arrows and numbers at the top of each page, Biss' essay transforms the appearance and mechanism of the pain scale, using its structure as a vehicle for her critique of putting numbers to pain.

Numbers appear frequently, working associatively to enable criticism of pain scales' reductiveness and imprecision. I read Biss' disturbances of numbers' meanings as key to her discussion, opening a space in which her critique of the scale can emerge. But these moments where Biss discusses numbers are scattered throughout the text, cropping up when Biss' discussion seems to have moved on, making it difficult to analyse their accretive impact. In the essay's opening paragraphs, Biss queries the use of numbers, particularly zero:

> 'The concept of Christ is considerably older than the concept of zero. Both are problematic – both have their fallacies and their immaculate conceptions. But the problem of zero troubles me significantly more than the concept of Christ.
>
> [...]
>
> Zero is not a number. Or at least, it does not behave like a number. It does not add, subtract, or multiply like other numbers. Zero is a number in the way that Christ was a man.
>
> Aristotle, for one, did not believe in Zero. (p. 5)

Biss is 'trouble[d]' by 'the concept of zero' which she aligns with the 'problematic' nature of the 'concept of Christ' (5); the seemingly calculated enumeration of pain is more an act of faith. 'Problem' is a loaded term in Biss' numerical rhetoric: a problem is an issue, an obstacle, a troubling dilemma. In the context of numbers, however, a problem becomes a puzzle or a question to be answered. Throughout this vignette, Biss is concerned with zero, which 'does not behave like a number' and 'makes some very simple numbers very difficult to solve'. The phrase 'concept of zero' almost escapes my notice, but another reading necessitates a closer look. 'Concept', a striking noun choice here, transforms the meaning of zero: it is no longer a positivist numerical value, but an abstract entity. Likewise, 'concept' reduces Christ from a person and centrepiece of religious beliefs into an idea, a fiction, a way of thinking. Quietly cynical, Biss indicates how 'zero', 'not a number', is an absolute which 'is not absolute' (6); even absolute zero is colder than zero and so 'There are zeroes beneath zeroes'. The repercussions of this juxtaposition are that when Biss is 'asked to rate [her] pain from zero to ten' (5), zero is no longer available, making the 'simple' problem of enumerating pain very difficult to solve.

Elsewhere, Biss undercuts numbers' precision. Also at zero, she asserts that 'Aristotle, for one, did not believe in Zero' (5). This sentence contains two numbers, one and zero, although seeing them both requires a perceptual shift. The 'one' of 'for one' is not a value: Biss shifts it from an exact number to a part of speech, as in the 'one' used to introduce opposing lines of argument (as in 'on the one hand'). This subtle, almost obscured 'one' (against the capitalised 'Zero') undermines the potency and stability of numbers. Zero and one are held up for discussion, and their lack of fixity gives way to Biss' lack of confidence in the pain scale.

Later, Biss performs another disturbance of numerical values. At the second point on Biss' scale, where she contemplates the value of whole numbers and affirms that 'The devil is in the fractions' (9), Biss considers that:

> Although the distance between one and two is finite, it contains infinite fractions. This could also be said of the distance between my mind and my body. My one and my two. My whole and its parts. (9)

Biss' 'one' and 'two', respectively her mind and her body, illustrate the Cartesian dualism prevalent in pain discourses, splitting body and mind on either side of 'infinite fractions'. But this is strange given Biss' hesitancy towards such dualism; she is critical of the 'researcher [who] observed that "hurting" and "feeling" seemed to be synonymous to some children, and is 'puzzled by the distinction' (13). Trying to reconcile Biss' exemplification of biomedicine's chasm between body and mind, and her explicit criticism of such distinction, is tricky; reading in a way which holds both ideas together brings with it feelings of blankness and dissociation. If, in the above quotation, 'mind' is 'one' and 'body' is 'two', by process of juxtaposition, then 'whole' and 'parts' describe a different, unexpected connection between body and mind. If Biss considers her 'mind' as the whole, of which her body is a part, then she reverses body and mind's expected metonymic relationship. Can the mind be the body's 'whole'? The association of 'mind' with 'whole' escapes my notice several times, but Biss' end-weighting of 'My whole and its parts' seems to put a quiet but important question to readers. That Biss critiques the splitting of body and mind is clear, and perhaps the metonymy of 'mind'/'whole' references the brain's centrality to pain.

The discussion of numbers in 'The Pain Scale' articulates the complexity of quantifying pain on a scale with confusing anchors. Biss foregrounds the paradox of fixed points' instability, and their reliance on memory and imagination:

> Left alone in the exam room I stare at the pain scale, a simple number line complicated by two phrases. Under zero: "no pain."
>
> Under ten: "the worst pain imaginable."
>
> The worst pain imaginable… Stabbed in the eye with a spoon? Whipped with nettles? Buried under an avalanche of sharp rocks? Impaled with hundreds of nails? Dragged over gravel behind a fast truck? Skinned alive? (11)

Biss negotiates the difficulty of quantifying pain when the scale's anchors bear no fixed meaning or relation to personal experience; for the rating experience to make sense, 'A scale of any sort needs fixed points' (5). She is caught between 'entertaining the idea that absolutely no pain is not possible' (5) and trying to understand what the 'worst pain imaginable' could mean or look like (11). Her striking imagery, the 'spoon' which stabs, 'nettles' which whip, the 'hundreds of nails' which impale, weaponises everyday objects in the causation of pain. The list's compounded absurdity emphasises scales' reliance on limitless and unhelpful acts of imagination. These phrases recall Elaine Scarry's discussion of weapon metaphors: Biss' nails, nettles, rocks and gravel, like Scarry's tools ('even the clenched fist of a human hand may be either a weapon or a tool') 'seem at moments indistinguishable, for they reside in a single physical object' (Scarry 1985, 172). As Biss claims, pain's enumeration is tied up with imagination, and with figurative and metaphorical languages.

Feeling my way along the lyric essay again, left to right, after this discussion of Biss' numerical discourse, I stop. I feel disconnected from the text, explosive brain fog and unthinking holding me at a distance from the text. The text sits in front of me, under my computer screen, inviting me to read on and say interesting things. Despite this invitation, like Mel Chen, and despite the phrase's ableist implications, I 'feel stupid' – 'what better phrase is there, sometimes, for my force of disappointment and self-repudiation in comparison to what I expected of myself […] in this type of academic employ?' (Chen 2014, 172). Despite attempting multiple immersive reading strategies (highlighting and colour-coding, excessively underlining and annotating, spatially arranging transient clouds of thought using post-it notes), I feel that the void between me and Biss' text is expanding, not closing. I listen to Biss in a radio interview to feel closer to her message (Biss, Eula 2015). Her voice sounds weighty, measured, anchored, and her pauses in speech sound like the visible spaces on 'The Pain Scale'. Phrases from secondary reading return to me, and I try to affix them to the context of Biss' text. Mintz tells us that the lyric essay resists impulses to 'superimpose narrative order on an otherwise unruly instance of pain' and 'might proceed as collage instead of plot' (Mintz 2013, 54–55). This much, I can make sense of: Biss' narrative moves by association and memory, not gradually unfolding, linear logic. Perhaps if the text itself is reluctant to seem orderly, it makes sense that my mind is reeling.

To recoup time lost through dissociation, I return to Robert McRuer's early definitions of crip theory, which affirm that the 'simultaneous articulation and disarticulation of crip identities and identifications has been part of crip theory from the start' (McRuer 2006, 41). This sentence's rhythm captures my attention: the 'articulation and disarticulation' establishes a pattern of saying and not saying, doing and undoing, making and unmaking (which is, of course, part of the subtitle of Scarry's *The Body in Pain*). The phrase resonates with my iterative attempts to engage with Biss' staging of the problematic scale: I understand the overall momentum of the essay and then, on a closer look, I realise that my reading was erroneous, and I need to revise these impressions. But this back-and-forth process, reading and searching and re-reading, lends itself well to uncovering more of Biss' questions, if not their answers.

The lyric essay resists neat conclusion, and is consistent in its 'pursuit of answers without any expectation of finding them' (Moran 2017, 1278). Biss' arrangement of material in numbered sections 'gesture[s] toward rationality of order', but this orderliness remains unfulfilled when 'the material empties out any such promise' (Shields 2013, 159). This is nowhere clearer than in the essay's final section, where:

> 'The description of hurricane force winds on the Beaufort scale is simply, "devastation occurs."
>
> Bringing us, of course, back to zero.' (25)

Biss' conclusion maintains the essay's (and chronic pain's) cyclical momentum, initiating questions which can never be answered. Brought 'back to zero', the essay sustains her attempt at 'blind calculation' (11) of pain's intensity, continuing to articulate and disarticulate, to try and re-try in a rhythm which thwarts attempts to reach coherent conclusion. This is Biss' critique of the pain scale at its most powerful: if the pain scale poses a simple question, Biss responds that there is no singular answer, that pain experiences, memories, frames of reference, and associations make up and confound our responses. The array of vignettes and memories do not make a number: like chronic pain, they are resistant to calculation or quantification. With chronic pain, when one pain has ended, another begins. Just when an end is in sight, Biss signals a new beginning and a renewed effort, no amount of repetitions of which can conclude the attempt to put words, or numbers, to pain.

Pain's legibility in Sonya Huber's *Pain Woman Takes your Keys* (2017)

Figure four: the front cover of my copy of *Pain Woman*, alongside the post-it notes I find indispensable for reading and understanding texts.

Sonya Huber's *Pain Woman Takes your Keys, and Other Essays from a Nervous System* is a collection of personal essays about Hashimoto's thyroiditis and rheumatoid arthritis (Huber 2017). Her essay, 'Alternative Pain Scale', demedicalises her pain and responds to the pain scale's awkwardness for assessing chronic pain. What strikes me first is Huber's volume's sense of orderly wholeness; it feels tangibly complete, and it is unusual to be able to hold a volume of personal pain essays in my hands. The notion of textual wholeness connects with theorisations of mastery associated with autobiographical texts; to write and publish personal material implicates a distance from and control over one's circumstances, and the neat resolution suggested by a beginning, middle, and end (Gilmore 2012).[vi] *Pain Woman,* however, offers no denouement to Huber's constant pain.

'Alternative Pain Scale' (pp. 155 - 157) most overtly exemplifies Huber's critical relationship to clinical pain assessment. Like Biss' 'The Pain Scale', Huber's essay ruminates on the confusion arising from being asked to enumerate one's pain in the clinic. Both authors start from being disoriented by the possibilities held in the phrase 'worst pain imaginable'. Huber's essay opens with a description of pain scales' difficulty:

> 'When we go to see doctors and specialists, we are often asked to rate our pain on a 1 to 10 scale. I always get confused by this instrument, partly because I don't know what each scale means. Is 1 "no pain," and would 10 be "the worst pain imaginable," such as being burned alive or torn limb from limb? Using that standard, it would seem arrogant for me to claim even an 8 if I was still able to function. So I use 1 to 7, with my 7 being "bad," though I don't tell my doctor this. That puts my normal pain at 3, but I'm not sure how it helps my doctor if I repeat the number 3 over and over.' (155)

Huber attributes the scale's imprecision to its anchors' vagueness. Like Biss, Huber signals the confusion caused by 'the worst pain imaginable', asking whether it would entail 'being burned alive or torn limb from limb?' - Huber conjures hypothetical pains to bring meaning to the rating experience, but rapidly discards them as unhelpful. She instead invents a personal ‘helpful replacement scale’, of which the essay is comprised, although her personal responses are, of course, too idiosyncratic to be ‘helpful’ to anyone administering or using the scale. Huber’s scale, running from one to twenty-one, is a series of numbered, highly personal reactions to pain, ranging from ‘bold plans to revamp diet or try new stretches’ (point 1) to the declaration that ‘Words are hard’ when pain makes her forget her own name (point 21). Her anchors’ sense of play affords Huber the fluidity to reconcile the felt, lived, tangible, mundane elements of a life with chronic pain with the cold impersonality of the numbers used to measure it: by turns, rather than only taking root somewhere between ‘no pain’ or ‘the worst pain imaginable’, her descriptions for each number are poignant, uncertain, enraged, anxious, funny, and at times contradictory to her earlier points. Huber’s description of reactions to pain, her descent through to 21, are synchronous with her own descent into progressively more unbearable pain.

Huber’s ‘Alternative Pain Scale’ crips visual analogue and verbal rating scales. Her scale is a visible departure from traditional scales in length, appearance, content, and in her incorporation of idiosyncratic pain experiences. Huber forces her scale’s numbers to participate in narrating her life, furnishing numeric values with specific, emotional reactions to pain. Pain’s emotional content cannot be accommodated in Huskisson’s VAS or the FACES scale: indeed, the FACES guidance deliberately forewarns against blurring the putative distinctions between physical and emotional pain. However, Huber is emphatic in her exploration of chronic pain’s moods and emotions: she is at turns strangely ecstatic (‘Did I invent a free and unpleasant way to get high? Everything is suddenly funny. Pain Vegas!’), overthinking and anxious (‘Do we have long-term disability? What if I can’t work anymore? […] We need to make a Plan B right now. What about eel farming? Can we put eels in the pond behind your parents’ house?’) and spiritualised by her pain (I’m learning something from the pain. It’s making me deep and spiritual, and I see shapes and colours’). Her range of emotional positions is also dialogic; she addresses interlocutors (her husband and mother) in her communication of pain, representing pain as relational, rather than a static number.

Life with chronic pain and illness, according to my experience, is more messy, paradoxical, and disorienting than it is often possible to express; in describing it to close friends and family, we cannot help but discuss it with a wholeness and composure which casts aspersions on our claims to be in constant pain – more so for those of us whose communication styles can empty articulations of discernible emotion. There is something in Huber’s articulation of pain which calls me to reread points on the scale. The language which dramatises her descent into pain is interesting, but most elucidating when language seems to crack from the weight of her pain. Such moments seem to transcend the most articulate explanations of pain or its intensity:

> ‘1. I have bold plans to revamp diet or try new stretches out of desperation borne by last night’s pain, and I am overjoyed and energized that I am right now not in pain.
>
> 2. I’m busy-busy-busy, because if I move fast, the pain won’t catch me! And I’m in motion now, but once I stop, I’ll be drawn to the couch with magnetic force.
>
> […]

> 4. Couch. All I want is my couch and Netflix.' (p. 155)

Initially, Huber's pronoun 'I' is what differentiates her scale from its traditionally impersonal counterpart. But Huber remains cognisant of her relationship to pain's presence and intensity, visibly encroaching on the borders of experience. At her first point, 'pain' is the last word in her sentence; although she lists activities and plans with vigour, they are still tinged with an awareness of pain's peripheral threat. At point two, Huber declares 'I'm busy-busy-busy, because if I move fast, the pain won't catch me!'; the short clauses' tempo suggests movement, energy, and productivity, but also that Huber can only hold her pain one clause away from herself at a time. Point four begins with the abrupt declarative 'Couch' – a one-word sentence, a piece of furniture, all she can articulate of her need for relief and comfort; point thirteen is 'I can't read. The sentences are too hard. Remember when books?' (156) – words and sentences become incomprehensible and uncommunicable. By the final point, she struggles to scramble together some fragments of language in a weak affirmation of identity: 'Words are hard. My name is… something? Whatever. "Name."' (157).

As I read down the scale, grammatical creativity and Huber's buoyant, playful voice give way to pain's life-consuming tendencies. These moments, where grammar ceases to yield to convention and language cracks, resonate with my lived reality with pain. Perhaps this linguistic disintegration is what Elaine Scarry means, claiming that 'Whatever pain achieves, it achieves in part through unsharability, and it ensures this unsharability through its resistance to language' (Scarry 1985, 4). Whilst I agree that Huber's language is transformed by pain, I consider that this effect of pain on language does, in fact, make it shareable. Pain's monolithic assault on language does not render Huber's pain unshareable: rather, it is in those moments of warped grammar that I most easily recognise the debilitating onslaught of a pain flare.

Despite this, Huber wishes for pain to have a transparency and readability beyond quantification exercises. As a corollary to scales' use of numbers, Huber imagines chronic pain to spell out messages understood in letters and words. Huber's essay 'The Alphabet of Pain' is a counter-narrative to the limitations and awkwardness of pain scales. This essay, and others in the collection including 'The Lava Lamp of Pain' and 'Amoeba Girl', metaphorically describe pain as legible, decipherable, and visible, coterminous with her yearning for chronic pain to be recognised and understood. But Huber distinguishes between the overall experience of chronic pain and the specific, physical sensations which comprise it:

> 'I'm not going to talk about the physical sensation. I'm after the meaning, the language of pain and its patterns. If chronic pain marks bodies, the bodies spell messages, books, libraries of possible solutions that are now as invisible as the pain itself' (21).

Huber challenges existing means of recognising pain, moving from marks on a scale to figurative 'marks' on the body which make pain discernible. Her invocation of 'messages, books, [and] libraries' suggests the potential for an understanding of chronic pain achieved by reading across its 'mark' on individual bodies. Whilst the description reminds readers that pain's 'solutions […] are now as invisible as the pain itself', there lingers a momentary optimism in the possibility of discussing chronic pain's complicated experiential dimensions. Huber is emphatic about the power of language, asserting that 'Chronic pain requires words to keep it at bay' (35), where the online communities of 'patient advocacy blogs and message boards', which provides a 'path towards this [desired] heteroglossia' and 'pool[s] our intelligences, research, and methods for coping into a multibeing organism' which can be channelled for physical relief and emotional reprieve. Ultimately, '[w]hat we need is a system that listens, first, to people who know how to write in pain's alphabet'.

For Huber, reimagining the pain scale in 'Alternative Pain Scale' simultaneously expresses disillusionment with scales' awkwardness and reinvigorates them with her myriad voices of annoyance, ecstasy, anxiety, and frustration: these voices are co-opted into sharing the work of numbers and accommodating the personal in the scale's impersonal mechanism. Pain's metaphoric legibility imagines an alternative to understanding another's pain, reliant on a recognition of pain's meaning spelt out across bodies. Unlike Biss, who dramatises numbers' perfunctory nature to critique scales, Huber seeks solace in words, which can foster supportive and meaningful connections with others, and hold potential to spell out a more significant meaning for chronic pain.

Conclusion: encounters with texts and chronic pain

Huber's and Biss' cripistemologies of pain assessment offer refreshing perspectives on pain scales' use in the medical community. Unlike the biomedical narratives I have consulted, Biss and Huber register chronic pain's resistance to being captured by the pain scale, and, acknowledging chronic pain's awkwardness and complexity, they illuminate the elements of imagination, speculation, and memory at play in pain assessment. But these texts' material differences fail to escape my notice.

The biomedical texts seem a little out of place in the English department where I studied prior to Covid: they are large, voluminous tomes, hundreds or thousands of pages long, commandeering a large space on my desk. The books, either hard-backed or held together by tightly curled spiral binding, are excessively thumbed and fingerprinted; their front covers curl inward at the corners, suggestive of heavy use and multiple loans. Melzack and Turk's *Handbook of Pain Assessment* (2011) announces itself with importance: gold, capitalised lettering catches the light, standing bold against a dark green, marble-effect background. By contrast, the heavily annotated printouts of literary essays or excessively post-it noted editions of chronic pain memoirs seem quiet and inconspicuous. In *Vibrant Matter*, Jane Bennett observes 'the capacity of things […] to act as quasi agents or forces with trajectories, propensities, or tendencies of their own' (Bennett 2010, viii); these texts seem to pursue their own trajectories and propensities, forcing me to join in.

Pre-covid, I had brief interactions which appeared to hinge on these texts; most happened when moving across campus, getting a DSA (Disabled Students' Allowance) funded taxi, or catching a bus. Whilst being attuned to social nuances and small talk is not my strong point, I noticed that carrying around huge biomedical textbooks drew interested questions from others, just as my purple crutch does when I am out and about. Often, my journeys are challenging aside from the inaccessibility of public transport, as I am drawn into lengthy conversation where I am frequently asked about my ‘injury’ (in response to my crutch). Whilst I generally find small talk challenging and easily misread social cues, I find these questions about my conditions frustrating because I am always addressed as an injured young person who will heal, not as a disabled young woman who uses walking aids as her normal way of traversing the world.

Taxi drivers often draw me into conversations about these books: they ask what I am studying, and generally, they elaborate on the ‘chronic pain’ part, but disregard the ‘narratives of.’ There begins an exchange wherein drivers relate anecdotes about relatives and friends who have been cured by various alternative therapies: I am recommended cupping therapists, dietary eliminations, exercises; I am told of devastating but erroneous diagnoses; I am asked whether there is a cure for my conditions and told aggressively to hold out hope for them. Such conversations happen far less often when I am reading Huber’s slim volume or a printout of Biss. Perhaps people see the big golden title on the marbled green cover of *Handbook of Pain Assessment* as a cue for the discussion of pain as a personal matter, or perhaps it is because the book is so big and unwieldy.

The literary narratives do not seem to enfold me in spontaneous commuter conversations so readily. Perhaps it is because the texts are physically small and more discreet, or perhaps reading something of specific dimensions, a printout or a small book which ‘looks’ like a novel, is less likely to elicit discussion. ‘The Pain Scale’ is stapled in the corner and unassuming amongst other papers on my desk. I have copies of it printed on white and green sheets, the latter to alleviate dyspraxia causing words to dance across my page. One of my copies is obsessively highlighted with an orange pen, indicative of an attempt to maintain concentration. Contrary to the densely formatted pages of the textbook, whose columns attempt to squeeze in as information as possible, Biss’ words have space around them; they have time to unfold to relay sophisticated messages about personal feeling and experience. They are in no hurry to impart clinical knowledge. Biss’ pauses seem to speak as loudly as her words.

These exchanges suggest that there is something powerful about the impressive materiality of a chunky biomedical textbook, and perhaps less so for the quieter, smaller texts which contain stories, ideas, theories. Perhaps this is connected to value judgements about their subject areas: the overt ‘value’ of studying the STEM subjects, and notions that studying fiction or the humanities is whimsical, less germane to society’s (medical) problems. But unless we start printing chronic pain narratives in large hardback books, pages divided into columns, when will it be possible to elevate personal accounts of pain to the importance of scientific theories or clinical protocols?

This article, which has held a space for both these accounts of pain assessment, has elaborated on the importance of cripistemological accounts of medical phenomena, the generativity of reading literary and biomedical accounts alongside one another, and of being attuned to the crip bodymind and the challenges of ensuing intensities whilst reading. Biss and Huber’s quiet criticism of the pain scale, enacted in the scale’s transmutation to incorporate personal voice, gets at something about the inefficacies of the pain scale so subtly and eloquently, questioning the scales’ efficiency without reinforcing the often-polarised relationship between medicine and literature. In Huber and Biss, I recognise my own experience of pain assessment, notably the experience of being dumbfounded by whatever the 'worst imaginable pain' might mean; indeed, both authors demonstrate the shareability of pain despite, or perhaps *because of*, its transmuting effect on language. Reading their accounts reminds us that there is '[N]o single-word anchor [which] has been identified as being the best one for the number 10', that clinical medicine has no more an exact enumeration method than 'the concept of Christ.' In my repeated ratings of my pain in the clinic, which often feel alienating and depersonalised, it helps to know that clinicians are considering the inefficacies and unidimensionality of the scale for chronic pain, that literary texts provide opportunities to think through thornier issues and imagine alternatives. This article expands on these means of knowing pain, demonstrating the possibilities achieved by reading different accounts of chronic pain together, and attending to those objects and circumstances upon which knowledge of chronic pain rests: personal essays, medical textbooks, articles printed on coloured paper, dyspraxia, dissociation, imagination, memory, misreadings, rest breaks, and conversations with fellow passengers. It nuances the understanding of pain and its assessment in the critical medical humanities, responding to pain's representation and conceptualisation, vouching for nonnormative and embodied means of doing literary analysis, and of encountering and knowing chronic pain.

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[i] The account by Treede et al demonstrates how IASP, the International Association for the Study of Pain, uses duration in the differentiation of acute and chronic pain. The sources consulted for this article agree that chronic pain is poorly understood and resistant to medical treatment or palliation.

[ii] This article contributes to many challenges to Elaine Scarry's inexpressibility theory, including discussions of pain's generativity for writing (Stoddard Holmes and Chambers 2005), the development of a more complex phenomenology of pain (McIntyre 2016), and an account of the nuanced language available for expressing pain (Bustan 2016), among many others.

[iii] PoTS, or Postural Orthostatic Tachycardia Syndrome, is a condition which I struggle with. Upon standing, my blood pressure plummets and the resultant lack of blood to the brain causes instantaneous nausea and a feeling of near collapse.

[iv] Irlen syndrome is common in dyslexia and dyspraxia, and results in visual distortions when reading. For me, letters and words dance and shimmer about disruptively on the page or screen.

[v] Statistics indicate that as many as 128 people died daily in the US from opioid misuse or addiction in 2018, with large numbers of an increasing population of opioid users transitioning to drugs such as heroin. (National Institute on Drug Abuse 2020).

[vi] As Leigh Gilmore explores, writing on chronic pain challenges the idea of neat resolution by refusing a 'wilful transcendence of pain' because the pain endures. Such accounts of chronic pain also expose the coherence of the memoir's 'I' as both 'deception and error', disrupting any expectation of mastery over the circumstances being narrated (Gilmore 2012, 84 and 88).