SUFFERING PAINS: MEANINGS OF PAIN AND SUFFERING FOR PEOPLE WITH CHRONIC PAIN

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ABSTRACT

Chronic pain is a common problem, yet pain and pain-related suffering are vaguely defined and often conflated with one another. This can be confusing and difficult for people with chronic pain who seek treatment from health care providers. Chronic pain is often treated through the medical system which tends to favour biomedical explanations of pain and neglect or under-treat suffering. This study used hermeneutic phenomenology to explore the meaning of pain and suffering in the context of chronic pain. Eight people who experience chronic pain engaged in qualitative interviews investigating their experiences with and perspectives on pain and suffering. This study found a close relationship between the meaning of pain and suffering linguistically, conceptually, and experientially. This close understanding was interpreted through historical understandings of pain and suffering, especially mind-body dualism whereby pain is more commonly associated with the body, and suffering more commonly associated with the mind. Another finding was that the way people think about pain can lead to suffering. The types of thoughts, as well as the relationship people have to those thoughts, can have an impact on the degree of suffering experienced in response to their pain. Suffering related to pain may be eased in part by formal supports such as counselling and psychotherapy. One key implication is that professionals such as counsellors and psychologists can teach skills and provide relational support that can help a person in pain to work with their thoughts and emotions and potentially reduce or eliminate their suffering.

ETHICS STATEMENT

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TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION: THE PROBLEM OF PAIN AND SUFFERING

This study examines the chronic pain and pain-related suffering experiences of people living with chronic pain in Canada. Chronic pain is a common problem, affecting approximately eight million people in Canada (one in five Canadians) and one and a half billion people worldwide (Goldberg & McGee, 2011; Health Canada, 2021). In Western culture we primarily address pain through the medical system, a system that articulates a goal to relieve suffering but sometimes falls short of this goal (Cassell, 2004). The medical system has a long history of mind-body dualism which has led to doctors historically conceptualizing and approaching pain as a physiological problem and neglecting the treatment of suffering.

Pain and suffering are distinct but related experiences, but they are often conflated with one another and discussed as "pain and suffering" in both the literature and in wider culture (Cassell, 2004). This gets even more confusing when the International Association for the Study of Pain (IASP) defines pain as both a sensory and emotional experience, but does not have a clear definition for pain-related suffering, raising the question of whether what a person is experiencing is pain, suffering, or both (International Association for the Study of Pain, 2020).

The relatedness of pain and suffering gets further complicated by the nature of their relationship. It is easy to think that pain will lead to suffering, but it is unclear whether suffering can lead to pain (Stilwell et al., 2022). If the relationship is in fact bi-directional, it would make sense to have a clearer definition of what pain-related suffering is and how to treat it as part of the overall treatment plan for chronic pain. Currently, the definition of pain-related suffering is unclear, and where we draw the boundaries between pain and suffering is also unclear (Stilwell et al., 2022). If pain is a sensory and emotional experience, is suffering a part of pain? This is contested by the many arguments for why pain and suffering are distinct, which will be explored

further in the literature review. This ongoing debate in the literature and lack of consensus suggests that the way in which we conceptualize pain and suffering itself is currently flawed and requires reconceptualization to transform their management for the better.

Loeser (2000, p. S2) said “It is suffering, and not pain, that brings people to seek health care”. As a medical doctor Loeser likely meant medical care, but is Western medical care the appropriate treatment context for suffering? Doctors are primarily trained in the biomedical model, a model that places greater emphasis on physiology and does not always prepare doctors, nurses, and other health care personnel for how to address suffering (Cassell, 2004). When combined with the knowledge that pain and suffering are vaguely defined and often conflated with one another, it is worth questioning whether health care professionals and patients are even speaking about the same thing when they talk about pain. Is the person seeking help for their pain actually seeking the alleviation of their suffering? And if so, is ‘curing’ their pain the answer? These are questions that, according to the current literature and discourse on pain and suffering, have no clear answer.

How we define pain and suffering influences the way pain and suffering are measured, clinically assessed, and treated, which supports the need for the current study to explore the experience and meaning of pain and suffering among those navigating these experiences on a daily basis. Some have argued that the commonly used pain intensity scale is the wrong metric when trying to assess pain (Ballantyne & Sullivan, 2015). Pain intensity is often measured using a numeric scale or visual analog scale, and patients have expressed doubt that pain can be quantified or measured in this way (Robinson-Papp et al., 2015). Patients have found assigning a number to their pain intensity confusing, and they have often included things other than pain intensity in their ratings, such as sensations or pain-related experiences. Because pain does not

have an absolute value (e.g. a five on the scale could mean different things to different people), people providing these ratings have often experienced uncertainty in rating their pain.

Ballantyne and Sullivan (2015) argued that pain intensity ratings do not necessarily correlate with physical pathology or tissue damage, meaning someone can experience a high pain intensity with no underlying injury. They highlight that in neuroimaging studies, there is evidence that pain intensity can be associated with the "pain matrix" areas of the brain at first, but later that same pain sensation may be linked with brain regions involved in emotion, meaning pain may be increasingly associated with emotional and psychosocial factors over time. The authors discuss how suffering such as helplessness and hopelessness can sometimes be reflected in high ratings of pain intensity, and people who rate their pain intensity as high are often suffering – they "are often overwhelmed, are burdened by coexisting substance use or other mental health conditions, and need the type of comprehensive psychosocial support offered by multimodal treatment approaches" (Ballantyne & Sullivan, 2015, p. 2099). From my perspective, this highlights how intensity of pain is an experience, perhaps even an experience of suffering, that is more complex than sensation alone. There is complexity in the relationship between pain and suffering, and it is not a simple linear relationship between injury and sensation; in fact, it may not involve injury or tissue damage at all. Ultimately, Ballantyne and Sullivan argue that the multimodal treatment of pain is best, where the goal is to reduce pain-related distress and suffering and reduce disability – personal burdens whose meaning cannot be captured by a quantitative summary of pain. In other words, we may not be measuring the right thing when treating people with chronic pain, and the goals of the physician (to reduce pain) may not be aligned with the goals of the patient (to reduce suffering) (Loeser, 2000).

Why Suffering Matters

There are many reasons to care about suffering and the treatment or alleviation of it. A review on suicidality and chronic pain found that suicidal ideation was common in people with chronic pain, and the rate of suicide attempts was two times higher among those experiencing chonic pain when compared to the general population (Tang & Crane, 2006). The number of people with chronic pain who died by suicide was two to three times higher than the general population. This review highlighted how physical pain may progress to psychological pain, which may in turn increase the risk of suicide in people with chronic pain. Though not explicitly stated in the review, 'psychological pain' may be analogous to suffering. By reducing suffering, we may be able to lower the risk of suicide in people with chronic pain.

Chronic pain has also been implicated in the opioid crisis through over-prescribing of opioids for pain and lack of availability of non-opioid treatments for pain (Health Canada, 2021). Yet even with prescription opioids, people experiencing chronic pain continue to suffer. Pain can be disabling, and in 2022 16.7% or 4.9 million Canadians aged 15 years or older reported a pain-related disability (Statistics Canada, 2024). Chronic pain and pain-related suffering also have an economic impact, and Health Canada estimates that the health care costs and "lost production cost" (cost of disability preventing someone with pain from working) to be $38.2-40.3 billion in 2019 (Health Canada, 2021).

Stigma, or taking a stance of devaluing and discrediting experiences that deviate from social norms, is common with chronic pain (De Ruddere & Craig, 2016). In a study of women with medically unexplained chronic pain, patients reported feeling belittled, ignored, not believed, or blamed for their pain by the practitioners meant to treat them (Werner & Malterud, 2003). This led to pain patients doing 'work' to appear credible and not be labeled as 'whiners' or 'complainers'. This struggle to be taken seriously was also a task of maintaining one's own

dignity in the face of stigma around unexplained pain. The invisibility of chronic pain can also contribute to the sense that others do not believe the experiences of the person in pain since there are no obvious signs of injury (Toye et al., 2013).

Suffering is also a moral issue. Welfarism is a moral stance that people should care about making individual lives better, and this is a stance generally accepted in our society (Aguilera, 2020). Since suffering reduces or has a negative effect on a person's welfare, we should be morally opposed to suffering. This is the stance underlying Cassell's (2004) assertion that alleviating suffering is the primary goal of medicine, a view that has been widely accepted by the medical field. However, if alleviating suffering is our goal, we still have a lot of work to do, as many people with chronic pain are still suffering.

When a health care provider 'turns towards' suffering – recognizing the patient's suffering, getting curious about their experience, being present and engaged – rather than withdrawing, it can improve treatment outcomes (Epstein & Back, 2015). Epstein and Back (2015) reported that medical training on suffering is lacking, and doctors often do not address suffering due to their own feelings of inadequacy. However, it is difficult to develop assessments and training to recognize and respond to suffering when suffering, particularly pain-related suffering, is poorly defined and lacking construct clarity (Stilwell et al., 2022).

Suffering matters because suffering is implicated in pain-related suicidality, disability, and stigma (De Ruddere & Craig, 2016; Statistics Canada, 2024; Tang & Crane, 2006). Pain-related suffering causes people to seek care, and the lack of opioid alternatives for treatment of pain have played a role in the opioid crisis in Canada (Health Canada, 2021; Loeser, 2000). Alleviating suffering is also a moral concern, and we have a moral obligation to respond to

suffering (Aguilera, 2020). Lastly, responding to suffering can improve treatment outcomes (Epstein & Back, 2015).

Where Do We Go From Here?

If we are not clear on what people mean when they talk about pain and suffering, it is possible that patient and practitioner goals may not be aligned. There is also the question of who should be responsible for the treatment of suffering, and this depends on how suffering is understood in a world that compartmentalizes care into specialty areas. While Cassell (2004) claimed that responding to suffering was the responsibility of medical doctors, suffering has also been viewed as a psychological problem and even a religious or spiritual concern (Gatchel et al., 2007; Kramer, 2020). Suffering related to chronic pain is typically treated in the medical context, but medicine has historically failed to address the wider holistic suffering experienced by people with pain (Cassell, 2004). This may be in part due to the fact that doctors and other health care practitioners do not feel equipped to respond to suffering and may see it as outside of their area of practice, or do not have adequate time allotted to address suffering (Epstein & Back, 2015) .

Study Aim (Purpose)

To provide more insight into how people with pain think about, experience, and conceptualize pain and suffering, this study will explore the perspectives of pain and pain-related suffering among people who are experiencing chronic pain. These perspectives can contribute to an understanding of how people with pain make sense of the concepts of pain and suffering, and whether they see them as distinct or the same. As previously discussed, this has implications in the communication and assessment of suffering, but also in the treatment approaches taken, and ultimately how we meet the needs of those who experience pain and suffering.

CHAPTER 2: LITERATURE REVIEW

Defining Pain

Defining pain has been a challenge for humanity throughout history (Raja et al., 2020). Pain can encompass a wide variety of experiences, including the experience of suffering. Yet debates of pain and pain-related suffering in medicine and other disciplines have often found pain and suffering to be distinct but related constructs.

Various organizations often focus on pain and related constructs in isolation when overviewing pain. For example, the International Association for the Study of Pain defines pain as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (International Association for the Study of Pain, 2020). This is followed by bullet points or notes which further elaborate on the definition, such as endorsement of the ideas that pain is a personal experience, that it is influenced by biopsychosocial factors, that the concept of pain is learned, that pain can adversely affect function and well-being, and that pain can be experienced by humans and nonhuman animals that are unable to communicate it. Although the IASP definition of pain is used internationally by those working in the research and practice fields of pain, including the World Health Organization (WHO), the IASP does not have a definition for pain-related suffering (Raja et al., 2020; Stilwell et al., 2022). This raises the question of whether suffering is meant to be thought of as the emotional aspect of the "sensory and emotional" experience of pain.

Differing from acute pain, which is short-lived and usually associated with a clear cause, chronic pain is defined as "persistent or recurrent pain lasting longer than 3 months" (Treede et al., 2015, p. 1004). This definition comes from the eleventh version of the *International Classification of Diseases* of the WHO, or ICD-11, and is commonly used to define chronic pain

worldwide. It replaces a previous definition that said chronic pain was pain experienced past an injury's normal healing time, but this earlier definition did not work for some types of chronic pain where injury is not involved, such as chronic headache, cancer, or neuropathic pain (Treede et al., 2015).

The World Health Organization (WHO) has declared chronic pain a disorder in its own right, and separates chronic pain into *chronic primary pain*, which is pain that persists after an injury has healed, and *chronic secondary pain*, which is persistent pain due to underlying disease, such as arthritis (Health Canada, 2021). Pain for which there is no known underlying pathology or injury is called *idiopathic pain*, and presents a challenge for those treating it due to its inability to be understood and treated through the physiological or medical model (Bendelow, 2013). As touched on in the introduction, these cases can be frustrating to practitioners, who sometimes dismiss the pain of these patients and further marginalize them.

When reviewing the literature on chronic pain and pain-related suffering, there is a clear endorsement of the idea that pain and suffering are distinct, separate constructs, and there are clear arguments for why. This is not accounted for by the IASP, who define pain but not pain-related suffering, and whose definition of pain makes the emotional experiences of pain, including pain-related suffering, part of the experience of pain. Due to the close relationship of pain and suffering and their respective vague definitions, it becomes confusing and sometimes circular (Stilwell et al., 2022). Having clear definitions is important so that targeted treatments and assessments can be developed and is also important for communication between health care professionals and patients with pain.

Theories and Models of Pain

As our understanding of pain has changed throughout history and over time, different models and explanations of pain have evolved. This section will not explore every theory and model but instead will highlight some of the key influential models and theories that have shaped our current understanding of acute and chronic pain and the suffering that goes with it.

Cartesian Mind-Body Dualism and the Biomedical Model

In the seventeenth century, Descartes proposed a theory that mind and body were separate, and explained the workings of the body as though it were a machine (Stilwell & Harman, 2019). The idea of the separation of mind and body has remained prevalent even in modern times. Until the end of the twentieth century, the biomedical model was the dominant model used in medicine (Rocca & Anjum, 2020). This model explains health and disease as well as pain as biological dysfunction, and while this model has allowed us to make many useful medical advances, it also has its limitations (Pianese & Bordoni, 2025). Models explaining pain through purely biological means are reductionist, oversimplified, and overlook psychosocial factors and their role in illness (Bendelow, 2013; Rocca & Anjum, 2020; Stilwell & Harman, 2019). By the end of the twentieth century, models of pain and illness began to incorporate other factors such as psychosocial variables that play a role in health and illness. The context of pain – social, psychological, economic, cultural, historical, et cetera – must be taken into account to understand its complexity, which is not done in the biomedical model (Bendelow, 2013).

Gate Control Theory

Gate control theory was proposed by Melzack and Wall (1965) and although it primarily provided a physiological explanation of pain, it was novel in that it discussed the role of other stimuli, such as emotion and individual perception, in modulating the pain response. In gate control theory, pain signals are received at a “gate” in the spinal cord before travelling to the

brain where they will be processed. The gate can open or close to allow pain signals to pass through and can even modulate the pain signal's intensity. This theory was developed in part to explain what could not be explained by previous models, such as how emotion and interpretive cognition (cognitive appraisal) could sometimes amplify pain, or how the severity of an injury did not always match the severity of pain experienced by the injured person (Gatchel et al., 2007). This theory brought to light the role of emotion as a modulating factor in pain and led to a more widespread understanding that pain was not a simple sensory experience. Since suffering is often considered to be an emotional experience, this could have implications for the role suffering plays in the experience of pain.

Loeser's Onion Model

Loeser's onion model of pain describes pain as four layered aspects, such as the layers in an onion (Loeser, 2000, 2006). There layers are *nociception*, *pain*, *suffering*, and *pain behaviour*. Nociception is a physiological process of the nervous system meant to detect threat or harm to the nervous system, where specialized cells called nociceptors detect stimuli that could be potentially harmful and send these signals to the central nervous system (Armstrong & Herr, 2023). While nociception is related to pain, it is not the same as pain. Of these four layers, only the outermost later, pain behaviour, is visible to others (from the outside) and serves as a way to communicate and express pain to others. In contrast, nociception, pain, and suffering are private, subjective experiences. It is important for a clinician treating pain to recognize the layers they cannot see in order to effectively manage and treat pain (Robins et al., 2016). In Loeser's (2000) model, he discusses how suffering is not exclusive to pain and can be brought about by other 'states' such as hunger, fear, or grief. However, Loeser points out that we often use the language of pain to talk about our suffering, even when the suffering is not caused by pain. One strength of

this model is that it acknowledges suffering as a separate construct and calls for the acknowledgement and treatment of suffering as a necessary part of the treatment of pain (Loeser, 2000). He suggests that suffering can only be learned about by listening to a patient's narrative, something that modern medicine often neglects to do. It has been suggested that out of the four parts of Loeser's model, suffering is the least developed (Stilwell et al., 2022). Loeser and Black (1975, p. 83) defined suffering as "the response of the intact organism to nociceptive input". Here, suffering is seen as a response to pain, and in their article Loeser & Black discuss how suffering is influenced by factors outside of the physician's realm of practice such as gender, race, and the social environment.

By separating the experience of pain into different 'levels', Loeser conceptualizes pain as different 'parts' that interact to create the whole experience of pain. This is helpful in that it does not conflate pain and suffering with one another, but instead separates them, acknowledging that suffering itself also needs to be treated. However, Loeser's model lacks a clear definition of pain-related suffering and muddles it with other forms of suffering, further reinforcing the 'ambiguous definitions' of pain and suffering that he critiques.

Fear-Avoidance Model

The fear-avoidance model was developed by Lethem et al. (1983) to explain why pain did not always correlate in a proportional way to associated tissue damage. They believed that emotion played a role in this discrepancy, and this model was meant to explain how emotion, specifically fear, played a role in pain outcomes for patients with low back pain and sciatic pain. The fear-avoidance model tells us that when a person experiences fear of pain, there are two potential outcomes: *confrontation* or *avoidance*. Confrontation is the adaptive response, and people who confront their fear of pain are people who typically see pain as temporary and are

motivated to return to normal functioning (Lethem et al., 1983). This results in a response where the person is willing to confront their discomfort, push their limits, and do things such as exercise that help them to adapt to their pain and recover. In contrast, avoidance is considered maladaptive and leads to behavioural and cognitive avoidance of pain, which negatively affects recovery. This behaviour also reinforces the 'invalid status' of a person and does not give them an opportunity to challenge their negative pain beliefs, since they lack the necessary exposure to their pain.

The fear-avoidance model suggests that cognitive appraisal of pain and the related fear of pain influences emotional, psychological, and physiological outcomes that can help or hinder recovery, which was novel at the time it was introduced (Vlaeyen & Linton, 2000). This appraisal of pain and emotional response to the appraisal's meaning may be considered pain-related suffering by some definitions, since some definitions of pain-related suffering include the personal meaning of the pain experience, as well as a negative affective response (which we can see as aligned with suffering) (Stilwell et al., 2022). While this model has been popular since its introduction, Wideman et al. (2013) critiqued the fear-avoidance model for being too simple, claiming that it does not explain a number of factors that contribute to pain-related disability. The authors also questioned the validity of the underlying assumptions of the model which lack empirical support, such as that fear of re-injury shares characteristics with phobia disorders, or that pain and disability are always linked. In fact, there are many examples of people with chronic pain who do not experience high pain-related fear or disability.

Cognitive and Behavioural Models

With the advent of new ideas such as Melzack & Wall's gate control theory, it became more widely accepted that the experience of pain involved cognitive and affective influences

(Ehde et al., 2014). Cognitive behaviour therapy (CBT) is a psychological treatment used for a wide variety of ailments, but in the treatment of chronic pain it primarily targets pain beliefs and pain behaviours (Jensen et al., 1999; Morley, 2011).

Fordyce (1988), a clinical psychologist working with behavioural change, attempted to differentiate between pain and suffering using Loeser's definition of suffering. Fordyce felt that suffering was an "affective or emotional response in the central nervous system, triggered by nociception or other aversive events…" (p. 278). Responding to Cassell's (1982) definition of suffering, Fordyce challenged the disease model of pain, which suggests a person *has* pain, and instead shifted the conceptual focus to observable behaviours, asking instead why a person is displaying pain or suffering behaviours (Fordyce, 1988). In this learning and behaviour model, pain or suffering behaviours are not necessarily related to nociception and may have other causes, such as expectations based on past experience. Fordyce highlighted the complexity of learning in the experience of pain and gave an example of patients learning from clinicians that pain is a sign of underlying tissue damage, which is not always the case. This belief influences appraisal of their pain sensations as well as the behaviours, such as avoiding activity, that the patient may engage in.

Through the CBT lens, behaviour can be reinforced, and some pain behaviours may be reinforced in unhelpful ways depending on the context they occur within, such as the social context (Morley, 2011). This could be reactions of family members or others to a person's pain-related behaviours, for example. Another example could be the psychological context, such as a person's pain beliefs. The context is important to CBT and contemporary forms of CBT, such as acceptance and commitment therapy (Morley, 2011).

Of note to this study, the cognitive-behavioural model suggests that we can alter cognition and behaviour (Corey, 2023). Cognition could include appraisal of pain and pain beliefs, which past models, such as the fear-avoidance model or gate control theory, suggest are implicated in the overall experience of pain and pain-related suffering. An example of a cognition that could lead to emotional distress would be thinking a thought such as, "this pain will last forever." Some examples of behaviours that could be changed are avoidance of movement, favouring parts of the body, limping, or wincing.

The fear-avoidance model and Loeser's onion model also stressed the importance of pain behaviours in the total experience of pain, which according to the cognitive behavioural model, could be modified. The cognitive-behaviour model suggests that cognitions, behaviours, and emotions each influence one another, but only cognitions and behaviours are seen as being accessible for modification (Corey, 2023). As cognitive behaviour theories began to be applied to pain, evidence emerged that cognition played a role in coping, mood, pain-related disability (level of disability), and reports of pain intensity (Sharp, 2001). For example, in the fear-avoidance model fear of pain leads to avoidance of activity and a greater likelihood of disability. Looking at the same thing through a cognitive behavioural lens, this could be seen as cognitions such as beliefs that pain means injury leading to fear of movement, which in turn leads to avoidance of activity (a behaviour). If behaviours and cognitions can be modified, we can potentially disrupt this pattern and change the outcome. If we relate this to pain-related suffering, we may be able to change the emotional aspects of suffering by modifying cognitions (such as appraisal of pain) and behaviours so that suffering, and perhaps also pain, can be alleviated.

The role of psychologists in treating pain has typically been to help with adjustment to pain and supporting overall well-being, rather than to alleviate or prevent pain, which is typically

seen as a problem of the body. This mind-body dualism approach neglects to account for the role that the mental and emotional state of the person (their psychological state) plays in the overall experience of pain. If pain is truly influenced by biological, psychological and social factors, reducing a person's suffering and supporting their well-being may do more than help them to adjust to pain – it may modify the pain experience itself, or perhaps even prevent pain from becoming chronic in the first place.

The Biopsychosocial Model

Currently, the most common model used to conceptualize chronic pain is the biopsychosocial model, which is used in medicine, psychology, physiotherapy, and other disciplines (Robins et al., 2016). The biopsychosocial model was proposed by Engel (1977) as a new model of illness that challenged the biomedical model. The biopsychosocial model offered an explanation that integrated social and psychological aspects of illness that were overlooked by the biomedical model. Engel critiqued the biomedical model for its heavy reliance on biological processes to explain disease, claiming it was reductionist and embraced mind-body dualism. Furthermore, he rejected the idea that biological processes can be explained by chemistry and physics alone and suggested that the biomedical model had become dogma, forcing all disease and illness to fit within the model (without revising the model) whether it makes sense or not.

Engel criticized the historical influence of Descartes and the church, which separated the corporeal body from the mind and spirit, and conceptualized the body as an entity similar to a machine in Western medicine, which has resulted in a view of the mind as a separate entity (Engel, 1977). This emphasis on the physical body has led to a bias in the information collected from patients and the treatments offered. Engel stated "[the biomedical model] encourages bypassing the patient's verbal account by placing greater reliance on technical procedures and

laboratory measurements. In actuality the task is appreciably more complex than the biomedical model encourages one to believe" (p. 132). Thus, for Engel, to fully understand a patient's illness, including the determinants of their health and to devise an appropriate treatment, the practitioner must assess and understand contextual factors such as social context, the health care system, and the patient themselves. Psychological, social, cultural, and biological factors interact to create an outcome, and the boundaries between sickness and health lack clarity and may in fact never be clear. Engel (1977) discussed "problems of living" (a term which he did not clearly define, but which I interpreted to mean discomforts or concerns that arise in life) which may or may not be perceived as medical problems by both practitioners and patients, and the difficulty of determining what is and is not a medical concern. He makes the claim that the physician's role has always been to act in a way that has an effect on the patient's understanding of his illness (the role of educator) and that fortifies the patient in their belief that they can feel better; roles which do not fit well into the biomedical framework. While Engel did not directly address suffering in his model, viewing pain through a lens that includes biological, psychological, and social contributors to pain makes space for suffering as part of the experience of pain, since it includes subjective experiences that cannot be explained by physiology alone.

Addressing Criticisms of the Biopsychosocial Model of Pain. The biopsychosocial model has led to advances in our understanding of pain in the fields of medicine, neuroscience, genetics, psychology, and more, and is widely utilized as a way to understand pain (Gatchel et al., 2007). Despite this, it has been criticized for placing a heavier emphasis on biological and psychological factors and less on social factors, which may be more difficult to research (Pianese & Bordoni, 2025). This criticism may be more applicable to how the model has been researched and practiced than how it was conceptualized, however, in clinical practice and research, the

biopsychosocial model often misses the mark when addressing the social determinants of health. This sentiment is further echoed by (Sullivan et al., 2023) who suggest that when applied in the field of medicine, the biopsychosocial model takes on some of the flavour of the biomedical model, where biological and psychological contributors to pain are seen as modifiers of biological causes of pain (intermediaries), when in fact they may contribute to pain equally to biological factors. This has led to greater weight being given to biological factors of pain in clinical practice and even in determining legitimacy of disability due to pain. This off-balance approach does not fully account for the factors influencing and shaping the pain experience and also minimizes the role suffering may play in the total experience of pain.

Stilwell and Harman (2019) discussed extending the biopsychosocial model using enactivism to address the gaps in how the biopsychosocial model is conceptualized and utilized for people experiencing chronic pain. They argued that the current way the biopsychosocial model is understood and deployed is reductionist, suggesting linear relationships between the domains of the model and continuing to perpetuate a dualist mind-body perspective. They pointed out that this was not the way the biopsychosocial was meant to be understood in its initial conception – dualism and reductionism are the exact things that Engel (1977) sought to address in his critique of the biomedical model and proposal of a new model – but it is nonetheless how the understanding of the model has been received and utilized in medicine and clinical practice when applying it to chronic pain. The authors critique the biopsychosocial model for its lack of theoretical clarity, stating that it is inadequate and frequently applied in a fragmented manner, which results in the perpetuation of dualist and reductionist beliefs. The authors discussed the difficulty of educators, practitioners, and researchers in communicating and applying the model in a dynamic and holistic way (Stilwell & Harman, 2019). Part of this, they

argue, is due to the artificial boundaries that separate the biological from the psychological from the social, or the person from their environment.

Enactivism and the Biopsychosocial Model. Stilwell and Harman (2019) proposed extending the biopsychosocial model of pain by incorporating the work of phenomenologists and cognitive science to explain the relationships and interaction of the biological, psychological, and social aspects thereby extending our understanding of perception of pain. The philosophy of mind they propose is enactivism, a theory of embodied cognition initially put forth by researchers such as Varela, Maturana, Thompson, Rosch, Columbetti, and others (Stilwell & Harman, 2019). Enactivism may be a way to address the integration problem of the biopsychosocial model and also makes space to include the experience of the person in pain. Pain is seen not as immaterial and of-the-mind or physical and of-the-body but instead is a relational process, and to understand cognition one must look at the whole of the organism and the environment the organism exists within (de Haan, 2020). This likely would have been supported by Engel, who in his 1977 article quoted Holman (1976, p. 18): "some medical outcomes are inadequate not because appropriate technical interventions are lacking but because our conceptual thinking is inadequate."

In her paper about enactivism and psychiatric disorders, de Haan (2020) discussed how enactivism can help to address the integration problem of the bio-psycho-social model. While reductionist models are easier to understand and deploy, their simplicity is unwarranted and does not match the complexity of human illness such as psychiatric disorders or chronic pain. In agreement with Stilwell and Harman (2019), de Haan (2020) critiqued the biopsychosocial model's lack of clarity on how the biological, psychological, and social aspects of the bio-psycho-social model interact.

Pain and Emotion

Chronic pain and negative emotions (such as anger, depressed mood, anxiety, and fear) have been linked, and negative affective states can lead to increasing the perceived unpleasantness of pain (Boersma & Flink, 2025). Pain has also been defined as a sensory and emotional experience by the IASP (International Association for the Study of Pain, 2020). Yet, like suffering, there is no consensus definition of emotion (Boersma & Flink, 2025). Like suffering, most definitions of emotion involve an aspect of appraisal and subjectivity. Unlike suffering, but like pain, definitions of emotions also usually include aspects of behaviour (i.e. motivating behaviour) and physiological reactions, in other words, a sensory or bodily component.

When taken as a whole, this information further complicates the problem of separating pain from suffering. If pain and negative emotion are linked, is suffering a negative emotion? If emotion is felt in the body, how does it differ from pain? If emotion is subjective and is also a response to appraisal, how does it differ from suffering? Lastly, what is the value of separating these things, rather than allowing them to coexist without creating artificial boundaries? In the discussion of the literature on suffering, some of these questions are addressed. However, it may be confusing for the lay person experiencing pain, suffering, and/or negative affect to name what exactly feels ‘wrong’, which then makes it challenging for the practitioner to know what response or treatment might be most helpful.

Pain-Related Suffering

Suffering Overview

While the above models attempt to define and explain the elements of pain and how they can be considered together (as in the embodied cognition explanation of enactivism), without a

clear understanding of what suffering is we cannot know with any certainty how suffering is implicated in the experience of pain. Yet suffering is what motivates people to seek care, and research suggests it is distinct from pain (Loeser, 2000; Stilwell et al., 2022). As someone coming from a background in psychology, I am interested in the emotional and cognitive aspects of the experience of pain, aspects that seem to belong more to the realm of 'suffering' than pain. I also question the fact that pain has been defined as a sensory and emotional experience, which can be confusing because emotions are also often felt in the body and have a sensory component to them (Šimić et al., 2021). This further complicates the question of whether what is one is feeling in their nervous system is pain, emotion, or both, and how we might separate those aspects of experience, if that is even possible.

Suffering is something we feel, and it is phenomenologically distressing and has a negative affective valence (Edwards, 2003; Stilwell et al., 2022). It demands our attention and is a mental experience that endures longer than a brief moment. Consciousness or awareness that one is suffering also seems to be a typical part of the experience (Edwards, 2003; McClelland, 2020). Pain is not a necessary or sufficient condition for suffering, as there is evidence that people can have pain without suffering, just as people can suffer without pain (Edwards, 2003). Often, suffering is used interchangeably with the word 'pain' as well as other words such as 'distress' or 'anguish', and this can make it conceptually unclear (Best et al., 2015).

Suffering is also a central concern of Buddhism, though the word 'suffering' may not be a perfect translation of what the Buddha spoke of, which was *dukkha* (Kramer, 2020). Suffering or dukkha might be better thought of as a craving or attachment to something, such as an idea of how things 'should' be. Unlike the Western concept of suffering coming from external sources, Buddhism sees the source of suffering as coming from within the person (Chen, 2006). Some

concepts typically associated with Buddhism, such as mindfulness and acceptance, have been integrated into Western psychology practices such as Mindfulness-Based Stress Reduction (MBSR) or the idea of radical acceptance from dialectical behaviour therapy (DBT), a 'third wave' offshoot of cognitive behavioural therapy (Shapiro, 2009).

Suffering in the context of medicine is under-researched, and some have suggested that suffering is an embarrassment to modern medicine due to its inability to be resolved by science (Edwards, 2003). Suffering can also lead to doctors and health care practitioners feeling helpless and inadequate, which can lead to suffering going untreated when the practitioner does not know what to do or how to respond to patients' suffering (Epstein & Back, 2015). There is lack of training on responding to suffering in medicine, and while some practitioners may have natural presence in the face of suffering most require training to be able to do this.

Defining Pain-Related Suffering and Distinguishing Suffering from Pain

Overview of Cassell's Work. In 1986, the medical doctor Eric Cassell published his book *The Nature of Suffering and the Goals of Medicine,* a book that grappled with the idea of addressing suffering in medicine and attempted to define suffering, claiming it was phenomenologically distinct from pain and that alleviating suffering is the goal of medicine (Cassell, 2004). Cassell's work on suffering has been heavily influential on the understanding of suffering in the medical field, and therefore his key ideas will be discussed in this literature review (Tate & Pearlman, 2019). Cassell saw suffering as "the state of severe distress associated with events that threaten the intactness of person" (p. 32), and suffering would not end until this threat had passed (Cassell, 2004). While Cassell did not clearly explain what 'intactness' means in the context of this definition, he did make the claim that 'person' and 'mind' are separate, explaining how 'self' is an aspect of 'person', but there are also parts of personhood that can

only be known to others and not to the self. Mind and person are seen as different but inter-related concepts that cannot be divorced from one another. If suffering is a state of severe distress or a felt sense of threat, I question whether medicine is the appropriate field to address suffering, given that physicians are not given much training on responding to suffering (Epstein & Back, 2015). Instead, suffering may be more appropriately addressed by practitioners whose training gives distress a more central place, such as psychologists.

Suffering, according to Cassell, is also personal (Cassell, 2004). It is something experienced by an individual that can never be fully known or anticipated by another, making suffering subjective. This is an important consideration in the treatment of pain, where the doctor or practitioner relies on the patient to communicate and help them to understand the patient's pain and suffering experience so that an appropriate treatment plan can be formed. This also means that the personal meanings of pain and suffering may not be known unless directly asked about. Even then, language has limits and understanding is always incomplete (Gadamer, 2004). Another point of interest posed by Cassell (2004) is that pain and suffering do not have a clear or linear relationship – more pain does not necessarily mean more suffering. Suffering is usually greater "when they feel out of control, when the pain is overwhelming, when the source of pain is unknown, when the meaning of the pain is dire, or when the pain is apparently without end." (p. 35). This suggests that pain-related suffering includes more than just pain and involves the ways in which people think about and respond to their pain.

In *The Nature of Suffering and the Goals of Medicine,* Cassell (2004) discussed the role of perceived control in suffering. He used an example of the use of pain control medications in childbirth in the United States, and how the differences in methods could not be explained by pain relief efficacy of the method alone. The woman's desire to have some control over the

childbirth experience seemed to play a role in what methods of pain control were used. This could be of note when considering control in relation to chronic pain and pain-related suffering, an experience that often feels out of control to the person experiencing pain.

The persistence of pain poses additional opportunities for suffering. Pain that recurs or never leaves may be perceived as endless, and the anticipation of pain returning can cause suffering (Cassell, 2004). Socially, people with pain may notice that the longer they continue to discuss their pain, the less tolerance others have for hearing about their pain experience. Practitioners may also respond to patients in an invalidating way when they cannot understand the cause of a person's pain or find physical evidence to 'prove' their pain. In these situations, physicians may suggest that the pain is imagined or psychological, or even that the patient is faking their pain. The invalidation of their pain by others can contribute to greater instances of suffering in people living with pain. Not understanding the cause of pain can also amplify suffering, perhaps because the uncertainty of not knowing can increase anxiety about the potential meaning(s) of the pain.

There is also a temporal element to suffering, particularly when thinking about the future (Cassell, 2004). Even in moments when the person is 'intact', the possible future threat to their intactness can induce fear, and this fear is a form of suffering. One way this temporal fear can be addressed is by asking people to focus on the present moment, such as through Eastern mindfulness techniques (Cassell, 2004). While this may provide some relief, this can be very challenging and difficult to sustain for prolonged periods of time.

The experience of suffering is also formed by a person's past experiences (Cassell, 2004). For example, past experiences with pain and the medical system can influence the meaning a person makes of their present experience. Cassell (2004) discussed how past experiences of

suffering can lead to a more negative outlook and potentially more suffering, whereas a past filled with successes may lead to a more optimistic outlook, and this outlook may result in less suffering. This fits with the cognitive behavioural approach and the idea that past learning influences behaviour and cognitions about pain (Fordyce, 1988). A person's cultural background and experiences also shape their experience of illness and suffering (Cassell, 2004). This could include beliefs, values, diet, environment, social behaviours, gender roles, attitudes towards the sick or disabled, and other cultural factors. These cultural factors also impact a person's attitude towards themselves as well as the attitude of others towards the suffering person, and these attitudes can add to the suffering of the sufferer. Suffering comes not only from the impact of pain on the self, but also the impact of pain on social relationships and a person's place within their culture and social groups (Cassell, 2004).

Cassell (2004) also discussed the difficulty the subjectivity of suffering poses for medicine, a discipline that strives to be objective and scientific. Cassell rejected the notion of mind-body dualism and found it to be a barrier to understanding suffering, claiming "that bodily pain causes personal suffering cannot itself be understood until the dichotomy between mind and body is rejected" (p. 33). Pain and pain-related suffering cannot be separated into categories of mind (suffering) and body (pain), as the two are intertwined in Cassell's view. Still, Cassell attempted to define pain-related suffering in his book as a distinct-but-related entity when compared to pain, and this was important for moving the field forward.

Critiques of Cassell's Work. While the value of Cassell's work is clear, his work has been critiqued for setting the bar too high by stating that the intactness of a person must be threatened to qualify as suffering (Bueno-Gómez, 2017; Tate & Pearlman, 2019). There are examples of situations that do not threaten the intactness of a person but nonetheless qualify as

suffering, such as a mild, temporary illness. This highlights the subjective nature of suffering, as some may not suffer from a mild illness while others might experience suffering. However, it does challenge the idea of a threat to the intactness of a person as a criteria for suffering. Cassell has also been critiqued for employing mind-body dualism in his idea that only a 'person' can suffer and not a body, despite the fact that Cassell's work critiques this very thing. In Cassell's view, the body experiences disease and the person experiences suffering.

Cassell has also been criticized for his lack of clarity on the definition of what a 'person' is and what 'intactness' means when he speaks of suffering being the threat to the intactness of a person (Bueno-Gómez, 2017). Bueno-Gómez (2017) criticized Cassell's definition of a person for being normative, including a collection of dimensions that he considers part of the 'whole' of the person. such as their cultural background, social relationships, and perceived future, among others.

Another critique of Cassell's theory of suffering is that it requires the ability to self-reflect and it rejects the idea of objective suffering (Edwards, 2003; Tate & Pearlman, 2019). Cassell did not believe that people without this ability to self-reflect could suffer, for example people with cognitive disabilities, brain injury, severe dementia, or infants.

Lastly, Cassell has been criticized for its unnecessary use of violent language, using metaphors involving threat and attack, suggesting the source of suffering is something external (Tate & Pearlman, 2019). While this may be characteristic of some suffering experiences, it is not the experience of all.

While I agree with Cassell that suffering is subjective, involves distress, and is distinct from pain, I do not find the idea of threat to the intactness of the person to be a consistent aspect of suffering. I also do not agree with his idea that suffering requires self-reflection, though I do

find that self-reflection and thinking about or appraising a situation are often involved in the experience of suffering. Suffering without self-reflection, such as the suffering of infants or non-human animals, may be possible because of valence, or the idea that some sensations and emotions feel innately 'bad'.

Pain and Suffering are Distinct. The argument that pain and suffering are distinct is further endorsed by Massin (2020), who claims that suffering is an attitude or emotion whereas pain is a sensation. Suffering may be seen as an emotion because of its negative hedonic valence, and hedonic valence is typically a feature of emotions. While some might argue that pain also has a negative valence, there are exceptions – for example, some types of pain may be experienced as pleasurable or neutral. Suffering, however, is never neutral or 'positive'. For Massin, there are four essential differences between pain and suffering: *intentionality, location, expression*, and *compassion*. Pain and suffering differ in intentionality because pains are non-intentional, but suffering has an intention, meaning it is directed towards something other than itself. There is a difference between attitudinal and sensory experiences, and that difference is intentionality. In this case, pain is a sensory experience and suffering is attitudinal.

Pain also has a location in the body, but suffering does not have a spatial location, though it does have a temporal one. Further, pain and suffering also differ in their expression. While we can report pain, we cannot express it. Conversely, we can express our suffering. Massin (2020) believes that even expressions such as "ouch" in response to pain are expressions of suffering the pain, not direct expressions of the pain itself. Lastly, pain and suffering differ because one can have compassion for another's suffering but not their pain – one can suffer with someone but cannot experience pain with someone. Therefore, pain and suffering must be different constructs. I find Massin's arguments to be sound and I agree that pain and suffering are not the same.

For Massin (2020), the question is not what pain and suffering have in common, but how they are related. The author proposed three essential relationships between pain and suffering. The first is 'correctness', the idea that suffering is the correct emotional reaction to pain. Pain and suffering both have a negative valence, so it is 'correct' or appropriate that suffering is the reaction to pain. The second relationship between pain and suffering is that suffering is a reaction to pain, where suffering is seen as an emotion that arises in response to the felt 'badness' of the pain. The third relationship between pain and suffering is what the author calls 'naïve realism', the idea that suffering as a response to pain is correct because pain is bad. This is in contrast to the idea that "pain is bad because it is appropriate to suffer from pain" (Massin, 2020, p.89), an idea which is incompatible with the idea that we react to pain because we feel the badness of pain innately. The shift from the differences between pain and suffering to their relationship seems like an important conceptual shift to me. Much of the research on pain and suffering either conflates them without questioning it or tries to distinguish one from the other. Yet the fact that they are so often conflated with one another without question calls to our attention how closely related these constructs are. Yet they are not so closely related that we can consider them to be the same thing. Still, there is something about the relationship between pain and suffering that leads us to talk about them colloquially as though they are interchangeable, such as when we say 'the pain of loss'.

Pain and Suffering Lack a Clear Definition. Pain-related suffering and the alleviation of this suffering holds a central place in pain research, and yet as indicated above, the definition of pain-related suffering has not been operationalized by the International Association for the Study of Pain (IASP) and is an under-explored area in the literature (Stilwell et al., 2022). Despite the influence of Cassell's work and Cassell's attempts to clearly define suffering, there is

no agreed-upon definition of pain-related suffering, and the concept is thus poorly defined. Stilwell et al. (2022) reviewed the literature on pain-related suffering and came up with four attributes of this construct, as well as summarizing outstanding (unanswered) questions and areas for future research. These four attributes were: *pain and suffering are inter-related but distinct experiences; suffering is a subjective experience; the experience of suffering is characterized by negative affect valence; disruption to one's sense of self is an integral part of suffering*.

Stilwell et al. (2022) make a compelling argument for why more research is needed on pain-related suffering and highlighted the lack of a clear definition of pain-related suffering, but the article has some shortcomings. For example, when looking at definitions of pain-related suffering there is a heavy emphasis on the work of Cassell, as explored above. While this is a seminal work in the field, it neglects some other key literature on the way we understand suffering and pain as social and cultural constructs, particularly literature from other disciplines such as philosophy that have historically debated these questions. This may be in part due to the fact that the study of pain and pain-related suffering is not confined to one discipline, and has been explored in fields such as philosophy, medicine, physiotherapy, rehabilitation sciences, neuroscience, psychology, and sociology, to name a few (Gatchel et al., 2007).

Including literature from all fields may be an insurmountable task for a researcher in practical terms, however, leaving literature out means choices have to be made on what to include or exclude, and this will result in an incomplete picture of the problem. Suffering has been explored throughout history, and these contributions to our social and cultural understanding of what suffering is (and is not) are integral to the way we understand the experience of pain-related suffering and its meaning in clinical practice. Additionally, the IASP

emphasizes the importance of the interdisciplinary approach to research on pain, suggesting it's important to include research from different fields (Keefe et al., 2024).

Defining pain-related suffering and drawing up clear boundaries on what it is and is not also has its own problems. While it may be useful to define pain-related suffering so that we can better assess and measure it in clinical practice, or for tasks such as scale development, reducing a complicated construct such as pain-related suffering down to a simple definition attempts to remove some of the complexity that is an inherent part of the construct. Stilwell et al. (2022) made it clear that their goal in operationalizing the construct of pain-related suffering is meant to aid primarily in clinical practice, particularly in recognizing and alleviating pain-related suffering. Developing a brief measure of pain-related suffering that could be used in clinical practice could help clinicians to more quickly identify individuals experiencing a high level of pain-related suffering, better tailor treatment methods, facilitate better patient-clinician understanding, and encourage additional research in this area (Keefe et al., 2024). However, while having an operational definition may aid practitioners in learning to recognize pain-related suffering, true understanding of a person's suffering and tailoring treatments to their unique situation likely requires a more fulsome and nuanced understanding of the construct, something that may be lost when utilizing a simplified description or definition. The difficulty of defining pain and suffering points to the complexity of these constructs, and a simplistic definition may not be able to capture all of the nuances of the experience(s) of pain-related suffering.

Attempts to Define Pain-Related Suffering. Best et al. (2015) reviewed the pain-related suffering literature in the context of cancer nursing and attempted to create a consensus definition of pain-related suffering. This was based on themes or features of suffering that typically came up in the research. The authors explored common terminology and attributes of

suffering that commonly arose. Some common attributes that came up in the pain-related suffering literature included suffering being all-encompassing, individual (personal, subjective), objectively and subjectively alienating, difficult to articulate, multidimensional, and dynamic (Best et al., 2015). It also included aspects of hopelessness, helplessness, and meaninglessness. These all seem to be acceptable aspects of pain-related suffering; however, these features of suffering could also be applied to other forms of suffering, and seem to overlook the selfhood literature that sees suffering as a disruption to the self.

Another study that attempted to address the lack of consensus on a definition of pain-related suffering used machine learning, or artificial intelligence (AI), via a large language model and topic modelling. Noe-Steinmüller et al. (2024) systematically reviewed the literature and identified relevant articles containing definitions of pain-related suffering or suffering that was clearly related to pain. From this list, they developed a list of keywords and used the keywords to construct an integrative definition of pain-related suffering. The authors also constructed a conceptualization of the dimensions or types of suffering contained within pain-related suffering, reducing it to eight dimensions. These dimensions are *social*, *physical*, *personal*, *spiritual*, *existential*, *cultural*, *cognitive*, and *affective*.

Further to the development of the eight dimensions, the authors collected a list of antecedents and consequences of pain-related suffering which resulted in a 58-item list. While they noted that this was a high level of detail, Noe-Steinmüller et al. (2024) developed 22 "descriptors" that summarized the antecedents and consequences, and assigned two to four descriptors to each of the eight dimensions. Finally, the definition of pain-related suffering generated by the research team was cross-validated using generative AI, and the conceptual framework was cross-validated using topic modelling.

One of the strengths of this approach to defining pain-related suffering is the inclusion of a broader range of literature, and an attempt to synthesize a large volume of articles and definitions, reducing them down to a single definition. While this work is certainly helpful in collecting and organizing the large volume of literature on the topic, as well as the disparate and often conflicting definitions of pain-related suffering, this new definition is built using the materials of pre-existing definitions, and assuming those definitions are adequate and of good quality (Keefe et al., 2024).

Separating Pain from Suffering is Challenging. The idea that pain and suffering are able to be separated from one another is contested, or at least questioned (Turk & Wilson, 2009). The lack of clear definitions of both pain and suffering that delineate one from the other has been challenging, perhaps due to the constructs being inextricably linked. Suffering has been poorly defined and under-explored, especially in medicine, and this lack of clarity has made it difficult to distinguish suffering from pain. Turk and Wilson (2009) raise the point that the ISAP's definition, which includes both sensory and emotional experiences, may make suffering a feature of pain, rather than a separate construct altogether. The authors question whether suffering can truly be separated from pain or whether they have an inter-dependent relationship, such as pain being an amplifier of suffering or vice versa.

Of note to this proposed study, Turk and Wilson (2009) highlight the lack of agreement between experts on a definition of pain-related suffering, and the dearth of research exploring how the perceptions of pain-related suffering in lay people compared to that of health care professionals. This raises further questions on how pain-related suffering is perceived in each group. Another question of note raised by this article is whether pain-related suffering differs from other forms of suffering in some way and if there are unique contributions of physical pain

to suffering, a question that remains unanswered. Pain alone does not seem to be sufficient to induce suffering, but instead there appears to be some aspect of perception and interpretation at play.

Pain-Related Suffering and Disruption or Threat to the Self

Threat to the self or disruption or one's 'sense of self' is often a characteristic of suffering in the literature (Stilwell et al., 2022). As discussed previously, (Cassell, 1982, 2004) believed suffering occurred when a person experienced a threat to their wholeness, a form of disruption to one's former self. Cassell has been critiqued for conflating person and self, and his definition of self and person lack clarity (Cassell, 2004; Stilwell et al., 2022). Bueno-Gómez (2017) called attention to the fact that Cassell's definition of the self, which implies that people know themselves and have a coherent sense of self, is dated and not up to date with the current theories of self. In their paper, Bueno-Gómez (2017) suggested the use of phenomenological approaches to understanding pain and suffering, such as looking through the lens of embodiment, as an alternative to Cassell's approach.

Cassell's definition of suffering also does not account for suffering that is not self-reflective, and Cassell did not believe those without the ability to self-reflect, such as infants, could suffer (Stilwell et al., 2022). In simple terms, the selfhood literature can be divided into two types of experiences: present-focused, moment-to-moment experiences, known as the minimal self, and self-reflective experiences, which is also known as the narrative self (Stilwell et al., 2025). The literature on pain-related suffering, including the work of Cassell (2004) has exclusively focused on this self-reflective version of self and ignored the minimal self. Stilwell et al. (2025) explored the role that pain plays in disruption to the minimal self and found that pain

could disrupt the minimal self in ways such as disrupted sense of agency, bodily ownership, and awareness, which could lead to feeling powerless, helpless, and hopeless.

McClelland (2020) proposed a disruption model of suffering in which suffering is "the unpleasant disruption to your mental life that the suffered state causes" (p.37). This is similar to Cassell's definition, though the definition of mental life is vague, defined only as "the total web of mental states that constitute your mental life" (McClelland, 2020, p. 37). In the disruption model of suffering, not all disruptions lead to suffering, and some (such as love) may even be considered positive disruptions (McClelland, 2020). McClelland's disruption model of suffering proposes that suffering is at least partly agential – while some parts of suffering simply happen to us, others are something we actively do and could therefore potentially stop doing. Yet suffered states trigger urges to act in specific ways, and these urges require effort to supress or avoid acting on. Suffering also involves unpleasantness for longer than a brief moment, and this is because brief pain does not endure long enough to have an impact, but pain and discomfort that endures longer gives the mind time to respond and appraise the situation, which then allows the pain to bother the person experiencing pain (McClelland, 2020). While this model is in line with other ideas on the unpleasant or unwanted disruption of one's inner world leading to suffering, the concept of 'mental life' is poorly defined, making it unclear whether this includes the concept of self or is perhaps even a proxy for it.

Building off of the work of Ricoeur (1992/2024), Corns (2024) further developed the idea of the role of agency in suffering, characterizing an agent as distinct from their environment, able to exercise capacities that affect or change their environment, and agreeing with norms regarding its integrity as a certain type of agent. Ricoeur (1992/2024) believed that suffering was the reduction of agency, and Corns (2024) added that the reduction of agency must be significant.

Changes to one's abilities or capacities, or changes to norms and ability to fulfill these norms (such as ideas of what it means to perform a specific role) can lead to suffering. If suffering is a disruption to agency, suffering may not be considered 'bad' in all senses, as the loss of some abilities may lead to the development of others or could strengthen some social relationships, highlighting the potential value in suffering (Corns, 2024). The potential value of suffering has been explored by other authors as well: suffering may be seen as a virtuous, as something that helps us to experience and value pleasure and 'positive' emotion, and has sometimes been seen as a transformative experience (Bain et al., 2020). This challenges the views that suffering always has a negative valence.

Pain-Related Suffering, Valence, and Affect/Emotion

One of the characteristics of suffering that most seem to agree on is the negative affect valence (Stilwell et al., 2022). Aguilera (2020) argues that what differentiates suffering from pain is the net negative valence of suffering, which does not necessarily apply to pain. For example, it is possible to have pain at the same time as experiencing positive affect, resulting in an overall positive valence. This is in agreement with Massin (2020), who also believed that suffering necessarily had a negative hedonic valence, whereas pain did not. In other words, suffering feels 'bad'. In a study of pain-related suffering and cancer, some common affective themes of suffering were feelings of helplessness, hopelessness, and alienation, all of which were perceived as negative (Best et al., 2015). However, it is difficult to determine whether suffering is a collection of specific 'negative' emotions or if it is its own distinct construct (Stilwell et al., 2022).

The Meaning of Pain and its Relationship to Suffering

According to Cassell (2004), meaning is acquired through interacting socially with others and the environment. The meaning of pain then has an influence on suffering. For example, if pain interferes with one's imagined future or other aspects of personhood, a person will ascribe personal meaning to this experience. If this meaning has a negative slant to it, the person is more likely to suffer. As Cassell (2004) stated in *The Nature of Suffering and the Goals of Medicine*, "The perceived meaning of pain influences the amount of medication required to control it" (p. 34). He gives examples of how knowing the cause of pain can reduce the pain-related suffering, and how the reverse can also be true – how people may suffer immensely from relatively small amounts of physical pain when the cause of the pain is unknown. Additionally, knowing pain is due to a terminal illness such as cancer can increase a person's suffering. To Cassell, self-reflection and the ability to take a stance on the meaning of one's experience is essential to suffering. This has been contested by some who do not feel that self-reflection is required for a person to suffer (Stilwell et al., 2025; Stilwell et al., 2022).

Changing the meaning of pain in relationship to physical injury can also affect the perception of pain. Pain reprocessing therapy (PRT) is a therapy that involves reappraisal of the cause and threat value of pain, thereby changing the meaning of felt pain (Ashar et al., 2022). This is based on the idea that chronic primary pain (persistent pain with no underlying tissue damage) is a result of a "false alarm" that is actively constructed by the brain. Similar to cognitive-behavioural approaches, PRT involves education as well as changing thoughts and behaviours, with the goal of viewing pain signals as safe instead of representing threat or danger. Treatment also involves increasing self-compassionate thoughts and positive emotion. As a whole, PRT changes what pain means to the person experiencing it. Where pain was previously seen as unsafe or worrisome, it is now to be viewed as non-threatening sensation (Gordon & Ziv,

2022). According to PRT, this change in the meaning of pain can, over time, reduce or eliminate pain. The idea that the meaning of pain influences suffering is similar to the ideas put forth by cognitive behaviour theories, where appraisal of an experience can influence how a person feels or acts. Appraisal of pain is also a key part of pain theories and models such as gate control theory and the fear-avoidance model.

Other Studies on the Meaning of Pain and Suffering

To my knowledge there is no other study addressing the meaning of pain and suffering in the context of chronic pain, particularly hermeneutic studies, but other studies have explored similar topics. As discussed throughout this literature review, there have been past attempts to define pain and pain-related suffering, as well as attempts to describe them phenomenologically. This is different than my study, which explores the way we understand pain and suffering conceptually and experientially in the context of chronic pain, and how we make sense of them.

In a hermeneutic study of suffering related to trauma, Hovey and Amir (2013) asked the question of what it means to suffer. This study found that suffering affects multiple aspects of a person's life, such as their social, spiritual, and emotional lives, and these disruptions are part of the experience of suffering. One participant in the study was quoted talking about how throughout their medical experience they were never asked how it felt to have the diagnosis that they did, and their suffering was neglected. This paper discussed the complexity and personal nature of suffering, and the impact that trauma can have on a person's suffering experience. One thing that stood out to me from this article was the idea that suffering humanizes us, and that a failure to acknowledge or respond to a person's suffering can be dehumanizing. While this article explores the meaning of suffering as an experience, it primarily explores the relationship between suffering and trauma instead of suffering and pain.

Another hermeneutic study explored the experience of living with chronic pain, an experience which included suffering (Hovey, 2023). This study focused on the meaning of the lived experience of chronic pain, and explored the daily challenges participants encountered. This study included suffering as a response to the experience of pain, and depicted it as something that arises as part of the disruptive nature of the chronic pain experience. Of relevance to this present study, Hovey (2023) discussed how it was a challenge for participants to find the right words for the intense feelings that they experienced due to their chronic pain. Some participants used metaphor or poetry in their attempts to communicate their chronic pain experience, including their emotional experience. While chronic pain was a disruption to the lives of participants, re-constructing their narrative could help them to adapt and accept their new way of being, which was living with chronic pain. Hovey (2023) talked about chronic pain as a narrative experience, and approaches suffering as a response to a negative narrative and meaning that is constructed in response to the experience of persistent pain. While this study explored the meaning made of the chronic pain experience, it did not explore the experiences of pain and suffering and the language used to make sense of these experiences.

Siler et al. (2019) reviewed the literature on pain, suffering, and spirituality in the context of cancer, noting that the experiences of pain and suffering are distinct yet related for people with cancer. This study focused on cancer and not pain, but the observations about pain and suffering are applicable to this study. For example, the article described pain as a whole-person experience, rather than simply a response to injury. The authors noticed that in their review of the literature, it seemed that failure to recognize or respond to suffering could hinder pain relief. This demonstrates a relationship between pain and suffering, although the nature of that relationship was not explored in this literature review. This journal article was a literature review and not a

study, however one of the central ideas of the article is that pain and suffering are closely related to one another. The authors mention that 'pain' and 'suffering' are often used interchangeably, which is something I also noticed and which stirred my curiosity as to why that might be. Unlike my study, this literature review also explored the topics of spirituality and cancer. Since cancer can be associated with existential concerns such as death and dying, pain and suffering may mean something different in the context of cancer than it does for pain. Regardless, this article explored the close relationship between the language and experience of pain and suffering.

Another study that offered insight into the relationship between pain and suffering was a phenomenological study to investigate the effects of chronic pain on 'psychophysical unity' (Ojala et al., 2015). While this study did not explicitly examine suffering, it did look at chronic pain and its relationship to emotional distress, lost identity, and poor quality of life, which could be considered to be forms of suffering. The main theme discussed in the results of this study was 'pain affects the whole person', and the sub-themes included *psychological distress*, *sorrow and loneliness*, *extreme emotions*, *physical deterioration*, *losses in life*, *I am not enough*, *I want to be like others*, and *redfining normal life*. The relationship between these sub-themes and suffering seems clear, given that suffering has a negative emotional valence and is often associated with emotional distress, negative affect, and difficulty. The relationship between chronic pain and psychological experience is emphasized, as demonstrated when the authors wrote: "Without exception, the participants argued that pain and mind inseparably affected each other" (Ojala et al., 2015, p. 368).

Despite many studies on the meaning of pain or the meaning of suffering, the phenomenology of chronic pain, and hermeneutic explorations of suffering, a gap in the literature remains on the topic of what pain and suffering mean when we are talking about chronic pain. It

is noted that pain and suffering are distinct but related, but how they are related and how people with pain think of these concepts is a topic that has not been addressed. This study attempts to address that gap and develop a better understanding of the meaning of pain and suffering for people with chronic pain.

Conclusion

Despite the work done by numerous researchers attempting to define and understand suffering, there is still a lack of consistency in the literature on the understanding of what suffering is, and even less so for pain-related suffering. We need to understand pain-related suffering better so that we can recognize it when it's present and respond to it with appropriate treatments (Corns, 2024). Recognizing suffering and responding to it clinically is one of the reasons we need a better understanding and definition of pain-related suffering, as well as ways to assess it (Stilwell et al., 2022). Often, when people are seeking help for their pain, what they are really talking about is their suffering (Loeser, 2000). These constructs are often conflated with one another, and while chronic pain and pain-related suffering are related, they are considered to be phenomenologically distinct (Cassell, 2004). Due to a lack of research on pain-related suffering, it is unclear whether laypeople and clinicians are even talking about the same thing when they talk about pain and pain-related suffering, which has implications for practitioner-patient communication and working together towards a common goal (Turk & Wilson, 2009). This study will thus aim to explore the experiences of chronic pain and pain-related suffering in people with pain to contribute to this gap in knowledge.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

In this chapter, I will discuss the research question and the approach used, and will explain how the methodology chosen fits with the research topic. Underlying assumptions and central ideas of the methodology will be reviewed, and there will be a discussion on what rigour and integrity looks like for this method. Since reflexivity is important to the chosen method, some key ideas that emerged from my reflexive practice will be shared. Lastly, I will provide an overview of the study design, detailing the process of participant select and inclusion criteria, ethical considerations, the interview process, and how data was interpreted and analyzed for this study.

Research Question

How can we make sense of the meaning of pain and suffering for people who experience chronic pain?

Overall Approach and Rationale

Generally speaking, phenomenology is a suitable method to explore common themes associated with various human experiences, describing both the 'what' and 'how' of an experience (Creswell & Poth, 2025). As this study sought to explore experiences of pain and pain-related suffering, what they mean, and how people with pain relate to them, this approach suited my topic. In a phenomenological study, only people who have experienced the phenomenon should be selected to participate in the study, and in-depth interviews are conducted to investigate the topic in greater depth (Creswell & Poth, 2025). Following this guidance, the participants in this study were thus people who have experienced chronic pain for at least one year.

I selected hermeneutic phenomenology, also known as hermeneutics, as the methodological and theoretical lens for this study. Hermeneutics is a qualitative interpretive

approach, and I selected it to allow for a rich, complex exploration of the topic (Moules et al., 2015). Since pain is considered to be a subjective experience, it would not make sense to study pain through a lens that tries to achieve or claim objectivity. Context and subjectivity are important topics when it comes to chronic pain, as pain cannot be observed objectively and the context has an enormous impact on who experiences chronic pain and how that experience unfolds (Cassell, 2004; Engel, 1977). I also wanted a research method that could maintain the complexity of the topic. I believe the complexity of pain and suffering are part of the reason this topic can be confusing and difficult to understand, but if we attempt to reduce the complexity and 'simplify' the topic, we can no longer see it for what it is. The complexity is part of what makes pain and suffering what they are. Hermeneutics stresses the importance of the history of a topic, and pain and suffering both have long histories reaching back into antiquity (Gadamer, 2004). Throughout time, our understanding of these experiences has been shaped by religion and spiritiuality, medicine, neuroscience, psychology, philosophy, sociology, and more. Pain and suffering are nearly universal parts of human experience, and their meaning touches many aspects of human lives.

The importance of language to understanding is emphasized in hermeneutics, and language is a part of my exploration of the way we think about pain and suffering – in noticing that we use 'pain' and 'suffering' together so often, I began to wonder about the similarity of the experiences themselves (Gadamer, 2004). Finitude, or the idea that all understanding is incomplete, is also a core idea of hermeneutics (Gadamer, 2004). The topics of pain and suffering are enormous and have an extensive history that straddles many genres and fields of research, and extends outside of academic research as well. There is no way to know all there is to know about pain, and a research study can only illuminate a partial understanding. The

interpretation that results from this study presents a perspective on pain and suffering in the context of chronic pain that is situated at a specific point in history and is generated from my experiences and knowledge of the topic that I have acquired through my life and through this research, as well as the literature and participant perspectives. To return to the idea of history, pain and suffering as ideas existed before I came to this topic and will continue to be understood in new ways after this study is done.

These considerations made hermeneutics a better fit for this topic than descriptive phenomenology. Descriptive phenomenology asks the researcher to 'bracket out' or suspend their beliefs and biases on a topic so that it can be viewed objectively, but this did not work for me because I do not believe that we can be truly objective or suspend the things we know through our own experience (Laverty, 2003). Instead, hermeneutics examines the biases the researcher brings to the work and incorporates that into the analysis, making the context and perspective of the research interpretation visible. The hermeneutic approach is exploratory in nature (rather than trying to draw a definitive conclusion), which makes it a good fit for seeking to better understand how people with chronic pain differentiate pain from suffering. The differences between pain and pain-related suffering are not clearly defined in the literature, and the inclusion of the voices of people in pain was essential to exploring this process.

Hermeneutic phenomenology evolved from descriptive (also known as transcendental) phenomenology, which began with the German philosopher Husserl (Dibley et al., 2020). Husserl's phenomenology involves trying to objectively observe the essence of an experience and focuses primarily on describing the experience – how it feels and what it's like (Laverty, 2003). As above, descriptive phenomenology tries to 'bracket out' the biases and presuppositions of the researcher in an attempt to examine the phenomenon in a more unbiased manner, but

Heidegger, one of the founders of hermeneutic phenomenology, suggested that bracketing out one's experiences and perspective is not possible, and that all knowledge is seen from a specific perspective and within its context (Moules et al., 2015). This is important to the study of chronic pain, as the biopsychosocial model tells us that pain is heavily influenced by its context (Engel, 1977). Additionally, suffering is considered a subjective experience, meaning it concerns the unique perspective of the person experiencing it (Cassell, 2004).

Underlying Assumptions and Central Ideas

Hermeneutic phenomenology is primarily based on the philosophy of Heidegger and Gadamer (Moules et al., 2015). In contrast to Husserlian assumptions, hermeneutics sees understanding as value-laden and implicated in the world – what human beings experience and learn occurs within a culture and environment that makes it impossible for meaning to be objective. Even the questions we ask and the way we ask them are influenced by our values, history, culture, and situated perspective. Hermeneutic phenomenology also shifts away from simply describing the phenomenon and instead focuses on interpretation of the experience with the goal of understanding the meaning (Laverty, 2003). Therefore, one of the underlying assumptions of hermeneutics is that the world is interpretable (Moules et al., 2015). Heidegger disputed Husserl's idea of a subjective inner world and an objective outer world, instead arguing that subjectivity and objectivity are interpretations (Moules et al., 2015).

Another important concept in hermeneutics is the idea of *Dasein*, as Heidegger called it (Dibley et al., 2020). *Dasein* is a German word and has been equated to the idea of being-in the-world. It can be seen as a way of being which includes embeddedness in the world (context) and relating to the world around us, which is a part of experience and understanding (Moules et al., 2015). While Husserl suggested bracketing our experiences so that we can approach a topic with

greater objectivity, Heidegger did not believe that objectivity was possible, since all of our understanding is seen through the lens of our experiences that shape our unique perspective. We make meaning of the world based on our experiences, taking into account the cultural and historical context as well as our personal experiences with the topic or phenomenon. *Dasein* acknowledges that we are *in* the world and cannot be separated from it, and the world we are embedded within (culture, point in history/time, and other contextual factors) informs our perspective through which we understand and interpret the world and our experiences.

Hermeneutics is a process of understanding that involves back-and-forth – between question and answer, between the concealing and revealing of truth and possibility, and between the parts and whole of the phenomenon being studied (Moules et al., 2015). This is known as the hermeneutic circle and is sometimes also known as the hermeneutic spiral, since the circle can be ever widened as we connect the topic with the broader context. The hermeneutic circle begins the moment the research topic is chosen, and continues throughout the research process (Dibley et al., 2020). During my data analysis, this back-and-forth process allowed me to see if the parts of my interpretation fit with the whole – both the whole of my research (participant perspectives, personal reflections, the literature I read), and the whole of the wider topic of pain and suffering. If the parts and whole did not work together, this raised further questions for exploration. I worked through these questions by reviewing the literature and transcripts, engaging in reflection, and interpretive writing until I felt that the parts and whole worked together.

Two concepts of importance that Gadamer contributed to hermeneutics are: the idea of fusion of horizons and the concept of prejudices (Dibley et al., 2020). Gadamer proposed that each person has a horizon of understanding, which is their understanding of a topic. I as the researcher and the research participant each bring our own prejudices to the topic, which are part

of our horizons of understanding. These prejudices involve our prior experiences and learning which inform our idea of what pain and pain-related suffering are. Through the back-and-forth process of the hermeneutic circle, a fusion of horizons occurs, which is a shared understanding of a topic or a common meaning. I began to engage with and explore my prejudices at the beginning of my study and continued this process throughout the research. During the analysis phase, I continued to consider my own horizons of understanding through self-reflection, which helped me further develop a nuanced awareness of my own understanding of the phenomenon of chronic pain and pain-related suffering. I also worked to understand the horizon of understanding of the people I interviewed through the process of reading and contemplating the transcripts and what was said. I then produced a new understanding that incorporates the literature, my own perspective, and that of the participants in this study, which is the 'fusion of horizons'. This new understanding is richer, having woven together shared ideas and perspectives to create something new and illuminating.

Rigour and Integrity

Rigour is important to enhancing the credibility and trustworthiness of a study (Dibley et al., 2020). There is the potential for what objectivist qualitative research might describe as "bias" in any study, and since hermeneutics involves interpretation done by a human interpreter, bias is inevitable, but not necessarily seen as a negative. Instead, it is important for the researcher to continue to engage in a reflexive process throughout the study as a way to continually explore their own personal biases (prejudices) as they come up, and to develop self-awareness on how they view a topic, what their experiences with the topic are, and how that influences the study and interpretation. Prejudice connects us to the world and reveals our situatedness, which can help to understand a topic. However, this must be done with reflexivity and self-awareness to

ensure that the interpretation makes sense for the topic and participants, not just to the person conducting the analysis.

Hermeneutic studies are not trying to create a definitive answer to a research question, and the study is not meant to be reliable and consistent in the same sense as a quantitative study, where the study could be reproduced and achieve the same results (Dibley et al., 2020). This is because the interpreter (researcher) shapes the results of the study, and their prejudices, context, and viewpoint present a unique perspective on the topic. However, in hermeneutics there is not one final answer, but rather the researcher offers an interpretation of the topic that is tied to the researcher and context the study took place in; repeating the study with a different researcher or in a different context will likely produce different results. As previously touched on, finitude is the idea that understanding is incomplete.

Trustworthiness in hermeneutic studies can be supported through transparency – making the process visible to the reader through a clear and explicit discussion of what was done and why (Dibley et al., 2020). By explaining the method and processes undergone in my study, I hope to increase transparency and trustworthiness. Credibility is also important, and can also be enhanced by transparency, for example by explaining how the data analysis process went. Using verbatim quotes from participants and supporting conclusions with literature can also aid in demonstrating credibility by allowing the reader to see where these conclusions came from.

Address of the Topic

I have always been drawn to questions of meaning. As a person who has experienced persistent pain throughout my life, I sometimes had pain with no clear underlying cause, and this mystery led to more questions. Over the years I have absorbed information about pain from various sources such as doctors, massage therapists, physiotherapists, chiropractors, others who

experienced pain, and yoga teachers, to name a few. I read books and studied health psychology, where I learned about psychological strategies to support pain management. And still the questions remained unanswered, or at least never answered fully.

When I began my graduate research, I spent some time exploring this in the academic literature to learn more about chronic pain. The more I learned, the more complicated the topic became, and the more questions I had. It seemed that so much research – especially quantitative research – had been done on chronic pain, and yet people living with chronic pain were still suffering, still feeling lost and dismissed, still receiving mixed messages. There was no definitive answer to pain, and 'chronic pain' seemed to mean so many different things and span so many different health conditions and experiences. As a novice, it felt overwhelming and impossible to understand all of the research in its entirety. And as a person who has experienced chronic pain and sought treatment for it, it felt confusing. Why was it that I had been given different explanations and treatment plans for my pain, and why was it that none of them 'solved' it?

During this exploration of the literature I came across an article by Stilwell et al. (2022) calling for more research on pain-related suffering in an effort to operationally define it. This was interesting to me and I began to question what I thought "pain-related suffering" was, what was contained within it, and where you could draw the lines between pain-related suffering and other forms of suffering. Not surprisingly, this was an incredibly difficult task. Additionally, this article pointed out that pain had a formal IASP definition, but pain-related suffering did not. Yet when I looked at the definition of pain it seemed to contain aspects of suffering and "the pain experience" that I would not personally consider part of the pain experience itself. The problem of suffering in relation to pain was especially interesting to me as someone who studies and

works in the field of counselling psychology. In my opinion, suffering is the reason people seek counselling, and counsellors and psychologists regularly work with suffering.

In an attempt to answer my emerging questions I dug deeper, but the task felt bottomless and each answer opened up new questions. Is pain of the mind or body? Are the mind and body separate, or is that a false divide? And if the mind and body aren't separate, what is embodied cognition and how does that work? If cognition is embodied, does that change the meaning of pain-related suffering? Are pain and suffering "things" or processes? What is the nature of their relationship? How have we defined them throughout history, and why do we speak of them in ways that seem to be linked or even overlapping?

The complexity of this topic pulled me in and became increasingly prevalent in my thoughts. It became like a knot I was determined to untangle, no matter how much patience it took. I know that it cannot be fully untangled once and for all, but I hope that I have created an interpretation that helps the reader follow me on my journey as I attempt to make sense of what pain and suffering mean in the context of chronic pain, and for the people who experience them.

Prejudices and Pre-Understanding

Gadamer brings to hermeneutics the concept of pre-understanding, which he also calls prejudices (Alsaigh & Coyne, 2021; Moules et al., 2015). Pre-understanding is the experiences and knowledge on a topic that we as researchers already have before we begin the research and interview process. It is important to engage with identifying pre-understanding or prejudices before beginning the interview process, because by bringing them into awareness the researcher can have more insight on how their understanding of the topic influences the way they make meaning about it, as well as the types of questions they ask and the way they respond to

participants in interviews. Below are some ideas and understandings that emerged through my reflexivity practice that I engaged with throughout the study.

My understanding of chronic pain comes from what I have learned academically, experientially, and socially (through discussing pain with others). Pain, to me, is a bodily sensation that feels unpleasant. Yet pain, when re-appraised, can morph from pain to something else. For example, the burn in my muscles when I exercise can feel good if I see it as building the strength I desire. This reminds me of the way that sometimes cold water can feel hot before I realize it's the cold tap that's on. Our appraisal of sensation has a big impact on the way we interpret that sensation, and our appraisal is shaped by past experience. This is the basis of placebo, too, where our expectations influence our experiences and outcomes.

Like many people living in Western society, I have spent most of my life viewing pain as a medical problem. When pain feels overwhelming and out of control I have sought medical care, though less so in recent years when medical care not only did not solve my problems, but also felt invalidating and frustrating when I had what I could only characterize as unpleasant interactions with care providers who responded dismissively. Instead, I began to turn to massage therapy, mindfulness, and caring for my body through nutrition, exercise, and stress management. While this did not eliminate my pain it improved my overall well-being and experience and perhaps reduced the severity or frequency of pain flare-ups. In fact, managing stress has been one of the most impactful practices on my pain, and is part of what has led me to see pain as a nervous system problem.

My undergraduate training was in psychology, and I was taught in a program that placed a heavy emphasis on quantitative, 'empirical', 'evidence-based' research. There was a clear bias towards positivist research attempting to align the social sciences with the natural sciences. This

is common in psychology programs, but I noticed that when I began this study I had an inclination towards these scientific explanations of pain, and throughout the study I underwent a process of identifying and unpacking these biases.

So from my perspective, pain is a sensation, and it is related to emotion, but I do not consider emotion to be a part of pain. Instead, I see things through a lens informed by cognitive behaviour therapy (CBT), where thoughts, behaviours, and emotions are separate but related. In my own counselling practice I tend to align with 'third-wave' behavioural therapies such as dialectival behaviour therapy (DBT) and acceptance and commitment therapy (ACT), which draw from cognitive behavioural therapy but place a greater focus on processes and include a mindfulness element. For example, the six core processes of ACT are *acceptance, cognitive defusion, present-moment awareness* (also sometimes described as contact with the present moment)*, self-as-context, connecting with values,* and *committed action* (Hayes et al., 2012*).*

In the cognitive behavioural model thoughts can influence emotions and behaviours, just as behaviours and emotions can influence thoughts (and each other). This is often called the 'CBT triangle'. In this view, thoughts can influence the emotional response to pain. If the throughts and emotional response are negative, I would consider this to fall under the umbrella of 'suffering'. But is it pain-related suffering? Drawing a line between suffering and pain-related suffering is, in my view, absurd. Even if it was possible, it feels pointless, like labelling something 'loss-related sadness' versus 'disappointment-related sadness'. There's some nuance there, but the treatment response to the sadness is the same. Instead of trying to define the specific type of suffering, focusing on what is salient to the person experiencing pain will identify their thoughts in response to their environment and, in turn, what is relevant to caring for this person.

So what is suffering, in my opinion? Suffering is negative thoughts and emotions. There is perhaps a resistance piece here, too – that a person does not accept these thoughts or emotions and wishes things to be different. As for pain, after many years of living with pain, I have come to see pain as a whole-person experience. It cannot simply be explained by physical injury, psychological factors, or even socioeconomic factors. Instead, it appears to be the interaction of many factors that unfolds uniquely for each individual. While I am still a person living with pain, my pain has become less over the years as I learn to manage my emotions, train my mind-body connection, and support my physical body and health. I have also noticed the powerful impact of the environment or context on pain, which shapes the pain experience. In turn, it seems we also have an impact on our environment, changing and shaping it through our responsive relationship with it. I was drawn to hermeneutic phenomenology over descriptive phenomenology due to its emphasis on contextualizing knowledge and experiences, as well as its goal of understanding and making sense of, rather than simply describing, the phenomenon. It was these experiences that drew me to hermeneutics as a lens through which to understand chronic pain.

Lastly, hermeneutics appealed to me because it acknowledges that as human beings we cannot separate ourselves from our experiences and the sociocultural context we exist within (Moules et al., 2015). All human understanding comes from a situated perspective, and the idea of bracketing as associated with "pure" phenomenology and with other qualitative approaches did not appeal to me. As we enter an era of artificial intelligence, it is more important than ever to connect with that which makes us human – unique, biased, and imperfect. Research is a human endeavor, and the humanity of this pursuit must not be lost. The understanding sought in hermeneutics involves contemplation, connection, reflection, and exploring the relationship between our own experiences and the experiences of others, as well as our wider culture: the

human context. I do not seek to be objective and in fact do not even think that is possible. Our common humanity is what connects us, and I believe it is ultimately what research is in service of.

Participants and Participant Selection

The participant sample for this study included eight adults ranging in age from their twenties to their fifties, and the majority of the sample were women (one man and seven women). Gender identity was requested verbally to allow people to identify themselves however they wished. Demographic information was collected for the purpose of describing the sample in publications of this research, and only age and gender identity were requested.

In hermeneutic phenomenology, there is no clear answer on how many participants to include in a study (Dibley et al., 2020). Instead, determining how many participants is enough relies on the study design and purpose of the research, the rarity of the topic and availability of participants, the method of analysis utilized in the study, and the depth of the data being collected in each interview. Hermeneutic analysis involves exploring a topic in depth, and analysis can be lengthy and time-consuming. Eight participants was a small enough number to allow time for analysis, but a large enough number to explore commonalities in experiences and produce more richness. In this study, interviews were approximately 45 minutes to one hour in length, with five to 10 additional minutes for the collection of demographic information, and only one interview was conducted with each participant. This length was chosen to give enough time for a detailed and rich account of the person's experiences, and to avoid being too lengthy given that people with chronic pain may struggle to sit for long periods of time.

The population I chose for this study is adults (18 years of age or older) living in Alberta, Canada, who are experiencing chronic pain. The World Health Organization and International

Association for the Study of Pain (IASP) define chronic pain as "pain that persists or recurs for more than 3 months" (Treede et al., 2019). However, for the purpose of this study only people who have experienced chronic pain for one year or longer were included. I made this decision so that participants in the study had enough experience with chronic pain to be able to give a more rich and detailed account of their experience, having experienced it for longer. This is consistent with phenomenological research (Van Manen, 2014). I chose to limit my recruitment to Alberta so that participants were more likely to share some social and cultural experiences and operate within a similar health care system and health paradigm, as well as to allow for sufficient knowledge of support resources that could be offered to participants if they were to become distressed by participating in this study.

Consistent with a hermeneutic emphasis, I did not endeavour through the study to "explain" the cause of pain and instead sought to understand people's experiences of their pain and pain-related suffering. Therefore, the type of chronic pain a person may be experiencing is not as relevant to this study, and therefore there were no restrictions on the type of chronic pain or underlying condition that could be considered causal. This study excluded people without access to a computer or internet connection, since interviews were conducted over Zoom.

Participants were recruited by sending a recruitment letter and poster through my personal networks. The study poster and description was also circulated via the Canadian Psychological Association (CPA) website, which allowed for CPA members to post in their studies and recruitment information section. Additionally, posters were placed in public areas such as libraries and community centres.

Ethical Considerations

Many people living with persistent pain are unable to work or participate fully in society, leaving them marginalized, stigmatized, and socially excluded. I believe that all research should offer something to participants in return, and while the main benefit of this study was to hopefully improve future care for people in pain and contribute to a better understanding pain and suffering, that benefit may not be directly felt by participants in this study. Therefore, a token of appreciation in the form of a $20 gift card was awarded to each research participant in exchange for their time.

Talking about pain and suffering and recalling memories of distressing moments can be emotionally charged for some people. To mitigate the potential for causing distress, research questions were designed to be minimally distressing, and participants were reminded of their right to refuse to answer questions or even withdraw from the study if they felt uncomfortable or changed their minds for any reason. In addition to these measures, participants were given a list of support resources available to them if they experienced any distress from participation in this study (see Appendix E).

Another issue of concern was access. Some people living with pain may have limited mobility and could be unable to attend interviews in person, or they may live outside of the researcher's local jurisdiction. Interviews were conducted online using Zoom, which is available for free, to increase access. Although this may increase access on one hand, use of technology to conduct interviews may exclude some participants who do not have access to a computer and internet.

Insider versus outsider status of the researcher was another issue that I considered (Dibley et al., 2020). In this study, I as the researcher have insider experience with chronic pain, however, my pain is generally not disabling and thus far has allowed me to participate in society

in a way that makes my pain invisible most of the time. This may make me an outsider when compared to people who have a greater level of disability and may be unable to participate in society normally. Insider status also requires greater reflexivity and self-awareness on the part of the researcher so that the researcher's own experiences and perspectives do not cloud their ability to listen deeply to the participant's responses and stories (Dibley et al., 2020). However, insider status can also facilitate trust and understanding of the topic. To mitigate the impact of my own experiences clouding my ability to listen to others, I engaged in reflexive journaling throughout the research process to aid in developing my self-awareness and uncover my prejudices when it came to chronic pain and suffering.

Interview Process

I worked towards understanding participant experiences on chronic pain using 45- to 60-minute semi-structured interviews, which were conducted on Zoom to increase the geographical reach of the study and also minimize access barriers. The interviews were audio recorded on Zoom, and these audio files were later transcribed by me.

At the start of the interview, participants were asked for their age and gender identity, which was the demographic information collected for this study (see Appendix C). Time was taken at the beginning of each interview to ensure that participants were aware of the nature of the study, their rights (including study withdrawal deadlines and consent), and the interview process. Participants were also given an opportunity to ask questions before the interview began.

Interviews were 45 minutes to one hour long and consisted of a series of questions about the participant's experiences with chronic pain and suffering related to their pain. This length was chosen based on the advice of Moules et al. (2015) who stated that hermeneutic interviews are usually one hour to one and a half hours in length. The interview questions were meant to

gain a better understanding of the person's perspective and personal thoughts and feelings regarding their experience. In line with hermeneutics, the interviews were conversational in tone and I adopted an attitude of openness and curiosity towards the participants and topic, allowing space for silence and probing for more detail when needed (Dibley et al., 2020).

After the interview, I wrote notes in my reflexive journal on my initial impressions as well as reflecting on how I felt in the interview and what came up for me as part of my reflexive practice. These notes were not part of the data to be analyzed but instead served to help me reflect on the interview process and refine the research questions in cases where they were not achieving the level of detail required for analysis.

Interview Storage and Access

The interview transcripts were stored on an encrypted and password-protected cloud drive (Microsoft 365 OneDrive), hosted by the University of Lethbridge on Canadian servers. Raw data was accessible only to the researcher (myself) and thesis supervisor (Dr. Toupey Luft). Data will be stored for a minimum of five years after the study.

Analysis and Interpretation Process

Hermeneutic analysis does not have a clearly defined structure or process, but at the heart of hermeneutic analysis is thinking, re-thinking, engaging with the data (i.e., participant experiences as captured through interviews), reflecting, and writing (Smythe et al., 2008). Hermeneutics does not seek to give a definitive answer to the research question or find a single truth but rather invites others along on the researcher's journey to understanding and raises new questions along the way. Thinking on the research topic has no clear end but rather is a process that will continue to unfold over time (Dibley et al., 2020). The hermeneutic circle is sometimes called the hermeneutic spiral for this reason – the process could go on for as long as the

researcher engages with it, and new discoveries and insights can continue to contribute to understanding ad infinitum (Moules et al., 2015). However, in any study there needs to be an endpoint, and analysis for this study ended when there seemed to be patterns in the data that answered the research question, even if hermeneutic understanding says the answer will always be incomplete (Dibley et al., 2020).

Throughout development of the analysis, I met with my thesis supervisor (Dr. Toupey Luft) to discuss my ideas and interpretations and get feedback on their strength and credibility. These conversations helped me to identify oversights and inconsistencies, and also provided feedback on the completeness of the interpretation. Another indicator that the study was complete was that the interpretation made sense – it was coherent, and any contradictions were explained by the interpretation (Moules et al., 2026). In other words, the analysis ended when I felt I could present an understanding of the topic that brought together the literature, participant perspectives, and my own personal understanding (horizon) in a meaningful way.

The process of hermeneutic analysis is reflexive, so throughout the study I reflected on my own understanding of the topic by journalling about the topic and research process. These reflections shaped my analysis and understanding of the pain and suffering, highlighting my own prejudices and tracking the process of my understanding as I made connections between ideas and formed interpretations. Hermeneutic analysis is also recursive and non-linear, meaning there was back-and-forth between the parts of data analysis described below (Dibley et al., 2020).

Working with Interview Data

After interviews were completed, I transcribed them. I read interview transcripts through multiple times and listened to the audio files in their entirety at least once. This familiarization process was important to help me immerse myself in the data and begin to notice connections or

patterns (Dibley et al., 2020). It also provided an opportunity to view and reflect on the interviews as a whole. During this stage I made notes on my impressions and anything that stood out to me as I began to think more analytically and interpretively about the interviews. These first impressions provided preliminary direction for further theme development as the analysis progressed (Dibley et al., 2020). This was the beginning of the interpretation and data analysis stage, though according to hermeneutics, the beginnings of interpretation already began in my pre-understanding of the topic before the study was underway (Dibley et al., 2020).

I began by writing interpretive summaries to help clarify the participant's story and key points of the interview, including quotations that stand out or support the interpretation (Moules et al., 2015). This act of summarizing involved engaging with the data in a way that required thinking and reflecting and helped facilitate the early stages of interpretation. I noted initial ideas for commonalities and created a summary of potential themes (interpretive ideas that share common features or appear as patterns). These themes were preliminary and changed as the meaning of what was said was deconstructed and re-constructed into something that served to help better understand or illuminate the topic (Moules et al., 2015). For example, as I worked through the interpretation process and engaged with the process of writing, re-writing, considering, and reflecting, the interpretation changed to better tell the story of the meaning of the phenomenon and offer new insights on the topic (Dibley et al., 2020). Throughout this process, I wrote about my emerging ideas in a journal, made notes on a whiteboard to identify clusters of similar topics, and went through the transcripts to make notes on content and meaning, as well as highlighting any quotes that spoke to the emerging interpretations. Moules et al. (2015) suggests that the goal of hermeneutic analysis is not to generate themes, but to provide an interpretation – however, themes are a useful tool along the way to help build an interpretive

understanding of the topic. My analysis included a sorting process of my interpretation of participant responses into broader themes and then moved into melding those ideas into what I learned from the literature and my own horizon of understanding.

The hermeneutic circle also comes into play at this "phase", and I went back-and-forth between the themes (emerging understanding) and the interviews/conversations as a whole. By relating the themes to the whole text (transcripts), understanding of the meaning of the text can be expanded upon (Alsaigh & Coyne, 2021). Hermeneutic analysis takes the context into account, such as what a topic means in the culture it exists within (and is being analyzed within), how the meaning of the topic has developed over time, and what it means to the people that interact with the topic (Moules et al., 2015). In hermeneutics, the analysis tells a story of shared meaning through the fusion of horizons that Gadamer speaks of (Moules et al., 2015). In my analysis, I engaged in the hermeneutic circle as I attempted to weave together a new understanding of chronic pain and suffering based on the experiences of the study participants as well as my own understanding. This new, shared meaning is the fusion of horizons.

Developing Interpretations

Dibley et al. (2020) describes a process of "dwelling with the data", which is a process of contemplation and meditation on the texts or interviews gathered. This process involves wondering and asking questions of the data that may lead to new insights. In addition to reading and re-reading the data, engaging with hermeneutic philosophical texts can help to uncover meaning in the interpretation process. This was also a part of my analysis process, and I read books on hermeneutics to ensure philosophical fidelity to the topic as well as to help me understand the ways meaning is uncovered hermeneutically.

Hermeneutic analysis should not simply describe the phenomenon, but should also highlight its complexity (Moules et al., 2015). This includes paradoxes or examples that challenge the majority, raising further questions. The analysis necessarily includes the researcher and their prejudices, because everything is viewed subjectively when viewed by a human being, and the pre-understanding and prejudices a researcher brings to the work shapes how they see the topic and what they make of it (Moules et al., 2015). This improves the analysis by clarifying the researcher's relationship to the topic, situating them and creating a more complete picture of the interpretation.

While I have described the hermeneutic process here in a linear way, the reality is that data analysis is iterative (Dibley et al., 2020). Analysis involved adopting a hermeneutic stance of openness and curiosity, engaging with the hermeneutic circle, and reflecting on my own prejudices and role in the research process as I identified patterns and developed an understanding of chronic pain and pain-related suffering.

A Continuing Process

Understanding is a process that continues to unfold, and this can make it difficult to know when analysis is finished, however, the study must end at some point. A finished report or summary of themes and understanding is one in which the findings are plausible, credible, and contextualized (Dibley et al., 2020). The findings of this study do not provide a universal truth but instead are a discussion of the phenomenon and its meaning as I (the interpreter) understand it at this specific point in time, and within a specific social and cultural context. This understanding is based on conversations with study participants, engaging with the literature on the topic, and my engagement with the reflexive process.

This study presents a new understanding of the phenomenon of pain and suffering in a way that is similar to a discussion section in other hermeneutic studies (Dibley et al., 2020). A good hermeneutic study communicates what was learned from the study and what themes or ideas came up, but also illuminates the process that led to the interpretation.

CHAPTER 4: INTERPRETATION AND ANALYSIS PART 1

Pain and Suffering Are Intertwined

Pain and suffering are closely related, and in this chapter I will argue that they are intertwined and perhaps even inextricable from one another at times. The language we use to define the words 'pain' and 'suffering' is circular, and there are some definitions where we use one to define the other. While our dictionary definitions seem to reflect the historical and cultural uses of the words, academic research on pain has changed the way we understand pain and suffering, and these expanded definitions do not agree entirely with the dictionary definitions and colloquial uses of the words. Our cultural and academic understanding of pain has changed and evolved – we now think of chronic and acute pain as different, and pain is seen as more complex than mere sensation (International Association for the Study of Pain, 2020). Additionally, mind-body dualism has permeated our understanding of pain and suffering and this complicates our understanding of the experiences of pain and suffering. For participants, pain was seen as a sensation with a bodily location, but this was not so for suffering. The body and mind *feel* different, and yet there are some experiences that seem to transcend the body and mind. For example, pain and emotion are both experienced in the body and have some similarities, and yet neither is a purely physical experience. This raises the question of what the mind is, and how the mind relates to the body.

While pain and suffering can sometimes be thought of and experienced as separate, there were some moments where pain and suffering felt inseparable to participants in this study, such as pain flare-ups where pain intensity was high. In fact, some participants felt that pain could cross a threshold and become so intense that the pain was a form of suffering. This experience of intertwined pain and suffering may be reflected in research which tells us that pain and emotion

are processed in similar parts of the brain. The popular models of pain and suffering in our culture fail to reconcile the experience of having a mind and body that can feel both separate and inseparable, and this has a profound influence on the way we think about and talk about pain and suffering in the context of chronic pain.

The Language of Pain and Suffering

Making Sense of Definitions

Gadamer (2004) believed that understanding occurs through language, and therefore the language we use is central to understanding a topic. The difficulty in understanding what we mean by 'pain' and suffering' is reflected in the dictionary definitions of suffering and pain. Merriam-Webster (n.d.–a) defines 'pain' (the noun) as "a localized or generalized unpleasant bodily sensation or complex of sensations that causes mild to severe physical discomfort and emotional distress and typically results from bodily disorder (such as injury or disease)," but that leads one to wonder if the physical discomfort is the pain itself, given that the definition seems to imply that the discomfort is a result of pain. For me, this also raised the question of whether the emotional distress constitutes the experience of suffering. Merriam-Webster (n.d.–a) also defines 'pain' (the noun) as "mental or emotional distress or suffering," and this is where I begin to get confused, since my literature review revealed that pain and suffering are considered to be separate things. Is pain a body sensation, or is it an experience of distress or suffering that is either an emotion or a cognition? 'Pain' (the transitive verb) is defined as "to make suffer or cause distress to," which again supports the idea that pain and suffering are the same thing, or at least are very closely intertwined.

At this point, one might begin to wonder about the definition of suffering, and whether pain appears in the definitions of suffering. According to Merriam-Webster (n.d.–b), 'suffering'

is “the state or experience that one suffers,” or “pain.” How can the definition of pain be suffering, and the definition of suffering be pain? Merriam-Webster (n.d.–b) has multiple definitions of suffering, and as I read on, I found that as a transitive verb, ‘suffer’ is defined as “to submit to or be forced to endure,” or “to feel keenly,” or “to put up with especially as inevitable or unavoidable.” This inevitability of pain was something spoken of by many of the participants in my study. For them, part of the suffering experience was knowing that even when pain was ‘over,’ it would return.

> …but if there was an end to it, it wouldn’t be as bad as like, this is gonna hurt for a few days, and then it’ll go away, and then it’ll hurt for a few days, and then it’ll go away. Where there’s no end.

Or, as another participant described it, “Well, pain is temporary, you know, but…it coming back is not temporary, because it’ll always come back. And that’s kind of the suffering part.” As an intransitive verb, ‘suffer’ means “to endure death, pain, or distress,” or “to sustain loss or damage,” or “to be subject to disability or handicap.” Each of these definitions offers a different perspective on what it means to suffer, though the participants in my study did not agree that disability and handicap always result in suffering, and neither do I. One person I interviewed stressed that for her, suffering meant dwelling on the negative aspects of her pain and disability, and she made a purposeful decision to choose joy.

> I don’t want my pain to dominate my life. I can work around it, and I can adjust my life so that I can live my best life while managing it. But it’s not going to be the focus. I can still lead a quality life while managing it, because it’s my attitude that determines the quality, not the actions.

Evolution of Language and Understanding

Our definitions of pain and suffering are informed by the ways they have been used throughout history, and at one time the academic literature agreed with these simple definitions of pain. Over time research has changed our understanding of pain to go beyond mere sensation. We now understand that the experience of pain is complex and can exist in the absence of injury (Vader et al., 2021). The International Association for the Study of Pain's (2020) definition of pain has accompanying notes that further develop our understanding of pain, such as "Pain and nociception are different phenomenon. Pain cannot be inferred solely from activity in sensory neurons." (International Association for the Study of Pain, 2020, para. 4). Other notes from the IASP definition of pain tell us that pain is a learned concept; that it is influenced by biological, psychological, and social factors (reflecting the use of the biopsychosocial model); that it can be adaptive or it can impair functional, social, and psychological wellbeing; that it can be expressed verbally or non-verbally; and that a person's report of their experience should be respected. In other words, since pain is a subjective experience, their experience cannot be known by another person.

Additionally, chronic pain seems to be different than acute pain and has been classified as a "disease in its own right" in the International Classification of Diseases, 11th revision (ICD-11), reflecting shifts in the study of pain that tell us chronic pain and acute pain are experienced differently (Vader et al., 2021). The idea of chronic pain as a disease is a relatively new idea, and whether or not people align with this viewpoint was not explored in my study. However, the inclusion of chronic pain in the ICD-11 hints at cultural changes in the ways we think about pain, where chronic pain is distinguished from acute pain and recognized to have differing underlying mechanisms as well as impacts on the people who experience it. Labelling chronic pain as a disease may also serve the purpose of meeting requirements for third-party billing to health

insurance providers, which is another cultural factor shaping the way we conceptualize chronic pain.

Overlapping Language

In day-to-day life, we talk about pain and suffering using overlapping language such as 'emotional pain', 'suffering physically', or 'it pains me', and we seem to understand what people mean when they describe these experiences. The language reflects the experience itself, which seems to involve some level of intensity, discomfort, and unpleasantness. However, using sensory words to describe mental experiences is not unique to pain. Massin (2020) points out that we use language such as burning curiosity, itching to go – we are tickled, touched, stung by words. According to Massin (2020), we understand these to be mental experiences and the sensory language is used metaphorically. Perhaps pain has become such a common metaphor in the language of suffering that metaphorical pain (and its associated sensory language) is part of how we conceptualize suffering, and suffering is part of how we think about pain.

Gadamer (2004) believed that we use language to interpret the world. This includes metaphor and abstract language. When I look at all of the definitions of 'pain', 'suffering', and 'suffer', what I see is a close relationship that developed throughout the history of our use of the language of pain and suffering, which has perhaps become so inseparable that we must use one to define the other. But what is unique to suffering seems to be the inescapability of an unpleasant experience that must be endured. What also stands out to me is the definition 'to feel keenly'. When I spoke to people with chronic pain, many described an experience of suffering where pain and the associated thoughts and emotions took up more mental space than usual and that they were unable to ignore, often due to the intensity of the pain in those moments. For many, that was the moment that pain became suffering.

Descartes' Legacy – Pain in the Body and Suffering in the Mind

Sensation and Location

Throughout this research, I have become more aware of the ways in which we talk about the mind and the body as though their separateness is a concrete fact, despite the fact that the mind is associated with the brain, and the brain is embedded in a body. Yet there is no way to know whether the mind and body can be separated, and therefore this question does not have a clear answer. When I spoke to participants about how they thought about pain and suffering, pain was almost always talked about as bodily sensation, while suffering belonged to the mind – mental health, emotion, mood, psychological state, a state of being that, unlike pain, had no bodily location. In fact, when asked where they felt pain and suffering, there was a clear place in the body that could be associated with pain; however, when asked where they felt suffering, there was no physical place to attribute it to. Some talked about suffering having a heaviness or weight that seemed emotional in nature and drained the body of energy. For some participants, this was associated with a place in the body they typically felt similar emotions, such as the chest or throat. For others, suffering felt like it was 'everywhere'. As one participant put it,

> …if I'm in pain right now I can localize it, and I can think about where that pain is coming from. So if I have a migraine, I know exactly where it hurts in my head. I know exactly what's contributing to the pain or maybe not, but if I know my hand is hurting today I know it's in my hand, versus suffering is harder to localize. I think it's more of all around my body something just feels wrong…It also almost just feels like I'm fully just drained, like it feels like my whole body is just kind of done with everything. It's trying to go and do the best that it can, but my whole body just feels done. That's why it's hard to localize…the suffering is more all around in my body, in my mind, kind of even around me. I just feel kind of like this

heaviness. It's more of like my whole body feels weaker. It feels more difficult to kind of get through, and so it's hard to localize. It kind of just feels like the pain is dispersed everywhere, almost.

Another participant described a similar experience:

…when I think of pain it feels like I can point to this and I can say that it hurts. Suffering, I feel like you can't point to it, I would say it's something that you can't really locate. You might have a hard time trying to describe it, but it's just like…that overwhelming, overcompensating, everything kind of in a nutshell together. It's the emotional reaction to it. It's the fact that you can't let the emotions out. It's the fact that everything feels so painful right now. It's that feeling of the injustice, of like, why is this happening to me? And then having all these thoughts racing of like, well, I need to do this today, and this today, but now I have a migraine, and then it's also having to try and silence those thoughts. And it's everything that kind of comes with that. So I don't think it's something that you can really just point to. I would say it's kind of all over the body, like it's in the brain as I'm trying to silence my thoughts, but then it's also in my head because that's where the migraine is, and then it's also kind of in my throat or stomach, like where the anxiety is that comes with the migraine.

This quote is a good example of how suffering is seen as a complex experience that does not have a clear location in the body. This participant felt that pain was a bodily sensation, and pain could be part of the suffering experience, but that suffering was made up of more than just pain.

Making Sense of the Mind and Body

The idea that pain is a bodily sensation and suffering extends beyond the boundaries of the body hints at a difference in how these experiences feel to the person experiencing them. There is bodily suffering, and there is suffering that emerges from a mind attached to a physical body, but

‘mental suffering’ does not always have a bodily sensation associated with it. Additionally, the body participates in the creation of the thoughts and emotions we consider to be part of the mind. Still, we feel a distinction between mind and body, and the question of what the mind is and whether it is a product of the brain or body, or whether it is something else, remains an unanswered question (Moreira-Almeida et al., 2025). Coelho (2025, p. 86) describes the felt difficulty of this problem:

> We see and feel that part of us is physical, and another part intellectual. We cannot define life without recurring to some spiritual, invisible, intelligent force driving the physical processes that we identify with the body, but, on the other hand, it seems very plausible that this force might be a product of physical laws of nature as well. So, the state of things is in fact confusing.

The question of what constitutes the mind is a metaphysical problem, and one I make no attempt to answer. Descriptions of the mind, and disagreement about what the mind is, hints that perhaps the experience of mind and of sentience is another experience we struggle to put to language. However, understanding suffering becomes more difficult if we believe it belongs to the mind and yet cannot say with certainty what the mind is. This division of pain and suffering into the physical and mental came up many times in my interviews, such as when a participant said:

> Yeah, I mean, I think when I think about suffering itself, suffering does feel more emotional or kind of mental to me, like, I don’t know, I always attribute the physical side of things to more of the pain side. And I know you can have more of like an emotional pain as well, or a mental pain, but I think for me the suffering is more of the internal side, and how I’m conceptualizing the pain and the consequences of the pain. So it’s kind of like yes, I suffer

because I feel certain symptoms, but it's the way I'm reacting to the symptoms that relates to the suffering, if that makes sense.

The Close Relationship of Pain and Suffering

The concept of emotional pain was discussed by a few participants, and there is a similarity in our bodily responses to pain and emotional distress. As one participant pointed out, emotional pain/suffering (or distress) can have a strong physiological aspect to it.

> I would have to say, after that breakup, it is very physiological. So I have this bio data ring and I haven't gone through a breakup since I had it, this was the first time, and it measured all the physiological symptoms of the grief I was experiencing. So my heart rate variability went down, my blood pressure went up, my sleep suffered. My stress levels went up. Like, for a good couple of weeks, it was like, are you sick? Are you okay? And it was hard to tell it that there was something emotional going on, it really wanted like a physiological reason. But the same thing happens when I have a migraine or my back flares up, like my stress symptoms go up, my heart rate goes up. So there is definitely a physiological part of emotional suffering.

This participant illustrated how characteristics of a negative emotional experience such as grief can be shared with suffering and so-called 'physical pain', or pain associated with a location in the body. Another participant also discussed how emotional pain could be experienced physically:

> I would say like, physical suffering and pain can be pretty close, but it's also kind of like that heart-wrenching side of it, of just like you can feel pain physically, and you can feel that emotional pain physically, of like ugh I just did this, and I know I shouldn't have done it, and now I'm going to hurt for a long time, but it was kind of worth it, but it was also really not worth it at all [laughter].

When looking at this quote, what stands out to me is the language describing the experience of chronic pain. Words such as 'physical suffering', 'heart-wrenching', and 'emotional pain' describe aspects of the experience, and so do the cognitions or thoughts that arise. While emotions do have physiological and psychological elements to them, I tend to think of emotions as belonging to the realm of suffering, rather than pain. That said, the closeness in language and descriptions of experiences of pain and suffering (both in this study and studies I came across in my literature review) tell us that at times, pain and suffering share some of the same characteristics.

Transcending 'Mind and Body'

Perhaps, rather than framing it as mind or body, we can instead look at experience itself. Awareness is something we as humans possess, and our awareness allows us to observe the mind and body and the experiences we have as a living being. In *Mindfulness Meditation for Pain Relief*, Kabat-Zinn (2023, p. 54) says:

> …our awareness remains the ultimate mystery of science. It has the property – immediately observable by any of us in any moment we care to take a look – of being boundless, with no apparent center, nor any periphery or circumference. Whatever its nature and however it arises in us, it is obvious that it is a human capacity that allows us to know what we are experiencing. This knowing includes but far transcends mere cognitive and conceptual knowing.

This idea that knowing transcends cognitive and conceptual knowing fits with the idea of pain and suffering being experiences that affect the whole person and that cannot be divided neatly into physical and mental categories. Pain and suffering are both transient experiences we are aware of and that we feel. Even the act of reflection on pain and suffering can be seen as an

experience. While many participants said they believed that pain and suffering were different, there was also a lot of overlap in the experience, which made it hard to differentiate one from the other:

> So when it becomes part of your whole body, where you're not only dealing with the pain, you're also navigating the emotions that are with it, and how those can have a negative impact on just…on your recovery, right? Like that your mindset and your ability to manage those pieces and the traumas attached to those, how that can impact your body significantly over time.

This same participant also described the close and perhaps overlapping relationship between pain and suffering when she said:

> I think with pain, obviously there's suffering, physical suffering, right? In terms of like my leg is so sore today that I need to lay down and put my leg up. And then there's the emotional pain of…the emotional suffering related to not being the best version of yourself, not being present, not being accessible to support and help the people in your life. Yeah, I think there's two pieces to it, it's not just – it's nuanced, right? And so I think that, you know, pain in general I mean, there'd be lots of times where I would be like okay, I physically cannot do this, and I'd be frustrated. But I think there's a depression part that comes from that too, right? When you're not, I feel like there's lots of places where my depression around it would ebb and flow and the joy I found in things was minimal. Because I just, I had to really dig to find things that I could find joy in.

These quotes illustrate the difficulty of putting the experience of pain and suffering to language and show how the language we use often reflects the dualistic thinking that has permeated our cultural understanding of pain and suffering.

Beyond the Physical: What is 'Mind'?

The Kabat-Zinn (2023) idea of a knowing that transcends cognitive and conceptual knowing can be difficult to grasp if you believe the body and mind are separate entities and could also be difficult if you see the mind as synonymous with the brain. Kando (2008) cautions against equating the mind and brain with one another and talks about how the mind is an experience that may arise in part from the brain, but that is not the brain itself. This is a mistake of reductionism, which has been popularized by the positivist attitude of modern science. Siegel (2020) talks about how the mind arises partially from the physical brain, but also partially from experience such as interaction with others. In other words, instead of thinking of singular explanations of mind, both can be true. When we try to apply positivism to social sciences such as psychology it becomes more difficult, since the mind is not a part of the physical world which we can study directly. An example from Kando's (2008) paper indicates that saying mind and brain are the same is like saying that hunger and the stomach are the same thing – the stomach may be involved in the experience of hunger, but it is not hunger itself. In the same sense, pain may have a bodily location but does not arise exclusively from that part of the body and rather is an experience that is more complex.

The physiological 'pain signal' in the body is actually nociception, whereas pain is the experience that arises from nociception among other factors (such as emotions and cognition). However, in my study, it seemed that people equated pain with physical sensation alone, and did not consider the impact of their past experiences or emotional state on whether or not a sensation was perceived as pain. Participants seemed to consider the wider experience of pain – that included emotions and thoughts about pain – to be part of the mind and were generally attributed to suffering. This fits with the Miriam-Webster (n.d.) dictionary definitions of pain and suffering

and perhaps may be more in line with how the words ‘pain’ and ‘suffering’ have developed in common language throughout history.

> I would say when I like, from my perspective, when I think of pain, I guess I think of pain as a very physical thing, even if it’s coming from, you know, an emotional place, I think that when I think of pain, I think of it as kind of being able to like, point to where it hurts, type of pain, like a very physical, like, oh, it’s hurting in my head and things like that. Versus when I think of suffering, I think of pain that kind of goes beyond the physical, you know, like things that are tied into the pain, like the emotional side of things, or the stressful side of things. And kind of when it all comes together, I think that the physical pain side of things and then the feelings that come with it and things like that kind of coincide to make suffering. So I’d say suffering is maybe more complex than pain itself.

The Changing Understanding of Pain

When reading the academic literature on pain and suffering, the complexity of the experience of pain becomes obvious. There is an abundance of research on chronic pain that has resulted in a broadening of definitions of pain over time, to allow integration of new information. The IASP definition of pain referred to in my introduction chapter is an example of this, where pain is considered a sensory and emotional experience (International Association for the Study of Pain, 2020). However, this broader definition of pain means that some of our definitions of suffering (such as the dictionary definitions referenced in this chapter) may now also be definitions of pain, based on the modern conceptualization of pain (such as the IASP definition) which include emotion as a part of the pain experience. Yet, as demonstrated by the responses of the participants in this study, the average lay person or person who experiences chronic pain does not think of pain in the same way as an academic or pain researcher. For the participants, pain

and suffering were still spoken of colloquially as separate constructs, one belonging to the body and one belonging to the mind, perhaps with some overlap. The participants' understanding seems to be more in line with historical and lay definitions of pain and suffering, rather than the definitions we use in modern-day academic research and clinical practice. This is an important consideration for when a clinician or researcher is interacting with a person who experiences chronic pain, as they may have different conceptualizations of pain and suffering. Mind-body dualism has had a profound impact on our Western conceptualization of pain and suffering, and these reductionist ideas have become dogma in our culture.

Gadamer (2004) believed that the meaning of a topic and the ways the topic is understood within our culture is affected by its history, which he called *historically effected consciousness*. We interpret a topic that has a past, present, and future, and the past cannot be forgotten so that we can view something objectively – these are melded together as part of our understanding. In the case of pain and suffering, our view of them is heavily influenced by a long and rich history. In Western cultures, mind-body dualism is still a deeply entrenched idea, even as ideas shift on what a mind and body are. We grapple with trying to find a better model to explain the material and immaterial (but inextricably linked) experience of human life, which is something we feel but lack more suitable language to describe this felt difference. Instead, we use words like "mind" and "body" to describe what belongs to the physical world and what lies beyond, the parts we cannot easily explain with science and which lack a clear, knowable structure.

"An Overwhelming Storm": Pain and Suffering Combined

Pain and suffering are experienced through the body and nervous system, and even the idea of a bodily system (such as the nervous system) being separate from the rest of the body is a false divide. When I began this study I had thought of pain as a 'nervous system problem', which

helped me understand the connection between sensation, emotion, and thoughts arising in the mind, but upon further reflection this seems overly simplistic, and my understanding changed as my research progressed. Consistent with the literature, the participants in my study believed that pain and suffering were not the same thing; however, when it came to moments of greater pain and suffering, such as flare-ups, it became harder to separate them. Experientially, these flare-ups felt overwhelming and like everything felt "bad" – it became a whole, intertwined negative experience that was more difficult to say what was pain and what was suffering. "I would say when I'm in pain, it's kind of hard to differentiate between the two, because you just feel pain, and you're like oh, this is what it's always like, and it just feels really bad."

Pain Intensity and Emotion

The close relationship between pain and suffering as they are experienced in the moment may be partially explained by the medial pain system. The medial pain system refers to the parts of the brain associated with pain-related affect, such as the perceived unpleasantness of pain, whereas the lateral pain system is associated with being able to locate pain in the body and describe the sensations associated with pain (Lumley et al., 2011). Damage to the lateral pain system can make pain sensations hard to describe or locate, whereas damage to the medial pain system can eliminate the negative affective experience of pain. These connections in the medial pain system of the brain may make it difficult to have pain without negative affect and provide a partial explanation for why pain that is more intense may produce a more intense emotional response.

This also reminds me of the Ballantyne and Sullivan (2015) study (discussed in the literature review) that noted people rated their pain intensity as higher when suffering from helplessness, hopelessness, overwhelm, and mental health conditions, suggesting that pain

intensity and emotion are experienced in a closely related way. This is further supported by another study that found that while chronic pain was initially experienced in the "pain matrix" areas of the brain, over time it was increasingly associated with parts of the brain associated with emotion (Hashmi et al., 2013). However, to assume that pain and suffering are simply a result of brain structure would be a reductionist approach, as I have touched on several times in this chapter. People experiencing pain have past experiences and learning which shape things like their behaviour and thought patterns that may be associated with pain and emotion. Among the people I spoke with in this study, suffering was associated with greater pain intensity and the ongoing length of the pain episode, as well as the recurring nature of chronic pain itself, which makes chronic pain different than acute pain.

Intense pain could be a form of suffering, or as one participant called it, "the physical suffering of pain". During moments of intense pain, it is as though the pain overwhelms the capacities of the person – to act, think, or regulate their emotions. In this overwhelmed state, the person is pulled into the present, unable to shift their awareness away from the pain. As one participant described it, "when the pain is really, really, really bad I'm deeply in the moment, because surviving the moment is really difficult". Endurance of these experiences demands the full attention and presence of the person and can be very disruptive to the person's life. There also seems to be something about pain intensity that makes it more difficult to process the experience in a cognitive, reflective way. People reported being able to think about the differences between pain and suffering when reflecting on it later; however, during the active experience of suffering it felt like a singular experience, not divided into parts.

Crossing the Threshold into Suffering

Many of the participants in my study referred to a point where pain seemed to cross a threshold, either in intensity or duration, where the pain experience *became* suffering. This was described by one participant who said:

> Um, well, pain feels like a physiological symptom. So I could be at a pain level of three. I'm still experiencing pain, but given the spectrum that I experience, I'm still doing everything I want to, and it doesn't feel like I'm suffering. But when it reaches a certain point, it feels like suffering…once it's reached the point where I'm suffering it becomes like it's, it has a psychological impact, it becomes difficult.

Suffering seemed to be associated with greater intensity – not just of pain, but also of negative emotions and thoughts related to the pain. Pain could exist without suffering, and participants described these times as times when pain intensity was more manageable, either because of lower pain intensity, the presence of positive affect, or a positive distraction, such an art project or having a good time with friends. However, when suffering was present, it became difficult to put the pain in the back of their mind.

> Once it bumps over the threshold, it's usually, it's hard to…it's hard to map out what I can manage for the day. Groceries, picking up the kids from school. It's hard to picture the pain going away, even though logically, I know it always recedes at some point. I can start feeling depressed, anxious. If I sit for too long, it's not good. If I'm up for too long, it's not good.

This threshold seemed to be a point where pain was more difficult to ignore, and in this example the person was talking about intensity of pain.

Pain can also cause fatigue, and this exhaustion and low energy can contribute to suffering by further changing how the body feels as a result of pain, as well as reducing motivation and energy to participate in meaningful or desired activities. However, one participant

reported that it took time to recognize the difference between the fatigue that came from over-exertion and the fatigue that came from pain: “So, like, really bad pain days, I didn’t realize it for a long time, I used to say I’m exhausted. But I wasn’t exhausted I was in pain. Right? Until I kind of realized the difference.”

Pain and Suffering as Overlapping Experiences

To return to the idea of mind-body dualism, it seems hard to reconcile that we can feel something so wholly, and yet on reflection we make sense of it as a divided experience, categorizing it as physical or mental, or as belonging to the body or mind. For some participants, this was understood as an overlap between body and mind.

> I feel like you could Venn diagram this. I think the relationship would be, well, I think your relationship between pain and suffering is what you allow it to be, right? So I guess ultimately, where your mental health is at and how you manage to take care of not just your physical self, but like your mental self, your heart self, like you know, there’s more to care for than just your physical self, and so I think they overlap. For me personally, I think they overlap because you allow them to overlap, you know. Yeah, because you can allow yourself to be depressed and be upset and be mad over your limitations because of the pain, and that’s, I think, what creates suffering.

When questioned further, this participant said they did not mean to say that how we feel is always a choice, but that we do have *some* control, and that suffering often happens when we choose to dwell on negativity rather than try to direct our mind elsewhere and focus on what we can control. I found the idea of mental health being part of the pain and suffering overlap interesting, because poor mental health is often associated with chronic pain, and some forms of mental health struggles, such as depression, could be considered suffering (Hooten, 2016).

Shaping our Thinking: The Influence of Models

It seems to me that we use mind-body language in our culture to describe the experience of an inner world we cannot explain and a physical body which we culturally believe can mostly be explained through science. The idea that we can explain the body through science is one I personally find problematic as a researcher engaged with this topic. It seems that we try to explain the mind as a product of the brain or physiological processes, but this is a reductionist approach that cannot account for the full picture of consciousness and experience. Perhaps our continual return to the idea of the body and mind is because we do not have a better model to explain what we feel, such as that the experience of the body feels phenomenologically different from the experience of mind. There have been attempts to resolve the mind-body problem, such as Varela et al. (2016) who proposed enactivism, but these ideas are theoretical, niche, and not widely accepted and utilized by society. This may be in part because they do not *feel* right, because what is physical and has boundaries often feels more tangibly true and 'real', but there is also a seemingly endless and non-physical part to ourselves which is challenging to measure or prove within the constraints of positivist materialism (which is a dominant paradigm in Western culture).

Our experiences of pain treatment also shape the ways we think about pain and suffering, and in Canada we usually treat pain through the medical system. Despite the fact that the biopsychosocial model is widely discussed in medicine and health research, our treatment models for pain and illness do not fully reflect this model (Stilwell & Harman, 2019). Instead, there is an emphasis on the biological, the physiological, and the body – what can be seen and measured. While there have been some cultural shifts towards better psychological care, most people in my study said they sought psychological and social support on their own and did not

consider it to be a part of their formal (clinical) treatment for pain. Engel (1977) criticized the biomedical model for its reductionist approach of trying to explain illness and disease by purely physiological means, even despite clear evidence that social and psychological factors had an influence on health outcomes. The result of this critique was the development and implementation of the biopsychosocial model, but it seems that instead of building a new model from scratch, we have simply added on to the biomedical model. It is like building a house and then adding additional rooms, rather than building an entirely different house altogether. The familiar rooms are still there, and the new rooms do not quite fit with the original structure. This may be in part because the biomedical model is also supported by pharmaceutical companies which benefit financially from selling products (pharmaceuticals) to treat illness, discomfort, and disease. These large financial profits give pharmaceutical companies power that has influence on political and social structures such as the way medicine in practiced in Western society. Conversely, alternative models that do not generate such profits do not have as much sway in a capitalist society such as Canada.

We have not truly done away with mind-body dualism, even though we know, intellectually and experientially, that the mind and body are intertwined. One participant highlighted this when she said:

> And, I mean, I think we know that emotional trauma can lead to physical trauma can relate to emotional trauma and vice versa, right? We know that from the Body Keeps the Score, or, you know, intergenerational trauma and how that impacts people's physiology. And so I think there's definitely bigger pieces there, but I think when you're in it, you don't really think about it in those capacities. You think about it in a very compartmentalized way so that you can manage it, right?

This quote illustrates how the idea that the mind and body are inextricable from one another and perhaps not even separate 'things' in the first place. This perspective is becoming a part of our public consciousness, including for people with pain as they try to make sense of their chronic pain experience, and yet we lack an agreed upon model to help us conceptualize it. We are unsure of what that really looks like in a practical way, and in a way that fits with our felt experience. In the absence of the right language and model, we communicate our experience of pain and suffering using language that reflects how we experience them – language that is vague, without clear boundaries, and that is sometimes circular. The experience of pain and suffering is complex and difficult to put words to, and yet language is all we have.

Our desire to categorize or reduce our experiences in tangible easily understandable ways (both conceptually and using language) is a part of being human and we naturally categorize information to help us understand it, but it becomes more difficult when concepts are similar or have shared characteristics. The idea of the mind and the body as separate entities is a part of the history of the way pain has been described and understood within the biomedical model. However, research on pain has broadened our understanding of pain and the ways that we define it to include aspects of the experience that were historically attributed to suffering, such as emotional experiences and thoughts, cognitions, or appraisal.

Summary

Experiences of pain and suffering can feel separate at some times and inextricably intertwined at others. For example, during moments of intense pain, participants described feeling overwhelmed and struggled to differentiate pain from suffering, perhaps because intense pain was a form of suffering. The language we use to describe pain and suffering is closely related and circular at times, which can make it difficult to describe experiences such as pain and

suffering which feel distinct but intertwined. Definitions of pain and suffering in common usage differ from definitions used in the research literature, and our understanding of pain has evolved over time to include emotional experiences. However, colloquial uses of the words pain and suffering do not necessarily reflect these new discoveries, and while participants identified emotional experiences related to their pain, they did not typically consider these emotions to be a part of their pain. As our understanding of chronic pain continues to grow, consideration of the language we use to talk about pain and suffering will be important to consider, as the language we use shapes conceptual understanding.

CHAPTER 5: INTERPRETATION AND ANALYSIS PART 2

The Ways We Think About Pain Can Lead to Suffering

Thinking about pain can occur as a response to current pain, as a reflection on pain experiences, or even as thoughts about pain in the future, and some styles of thinking about pain seem to be associated with suffering. When interviewing participants, I noticed that the ways people thought about pain potentially served as an influence on whether or not they suffered, and even on how much they suffered. When participants attempted to make meaning of their experiences, some meanings were negative, and these were more likely to result in suffering. Cassell (2004) believed that part of suffering from pain involved thinking about what it meant for the person's future, and whether they felt they had control or not. In my interviews with participants, I also perceived that there was an aspect of dwelling on pain and pain-related thoughts that could serve as a form of suffering. A few participants described this using a metaphor of "sitting" in the discomfort, pain, and negativity, which seemed to keep people stuck in a state of suffering until they were able to move on and shift their focus to something else. This appeared to be associated with one's ability to direct their mental focus, and this reminded me of the potential benefits affiliated with mindfulness practices.

In my own experiences with mindfulness practice, I have learned to observe my thoughts and mindfully direct my focus to my breath, or whatever I choose as an anchor to place my awareness upon. Applying this practice brings me into the present moment rather than allowing my thoughts to carry me elsewhere. The practice of mental focus and the skill of directing it is something that can be practiced and improved upon, and these types of mindfulness exercises are commonly used in third-wave CBT therapies such as acceptance and commitment therapy (ACT) to reduce suffering that arises from negative thinking patterns (Hayes et al., 2006). I have used these therapeutic techniques in my own counselling work with clients experiencing emotional

suffering and found them to be helpful. This chapter will explore the ways we think about pain and how this is related to suffering.

Thinking About Pain: Personal Meanings of Pain

Cassell (2004) believed that the meaning a person makes of their past experiences can lead to suffering. The meaning of our experiences is shaped by their context, such as the broader historical and cultural understanding of pain and suffering (Gadamer, 2004). Some examples of cultural contextual factors might be how we behave when we experience pain (such as seeking a doctor to help us manage our pain) or the responses of friends and family when we experience pain. Meaning and interpretation are central to hermeneutics, and to understand pain it is essential to investigate the meaning of the pain experience since the personal meaning each person makes of their pain experience may result in suffering.

The contextual meaning of pain for one's life came up often in my interviews with people experiencing pain. Pain is personal and means something different for each person depending on their life context and experiences; it shapes their beliefs and the way they tell their story. For the participants in this study, meaning making seemed to be a reflective and cognitive experience, and often participants associated certain emotions with the thoughts about what pain meant for the individual and their loved ones. This makes sense from a cognitive-behavioural model, where thoughts, emotions, and behaviours can all influence one another (Corey, 2023).

While most meaning made of pain was negative, and therefore potentially contributed to suffering, there was some positive meaning that could be made of these experiences as well. For example, some participants spoke of having greater empathy for others who suffer, both from pain and from other causes such as grief or loss. Other participants noted that their children were empathic and understanding because of witnessing the participant (their parent) living with

chronic pain. However, in both the literature and my interviews with participants, suffering was precipitated when negative meanings were assigned to the experience of pain; therefore, the emphasis in this section will be on negative personal meanings of pain.

Time and Temporality

Chronic pain is different than acute pain, and as more than one participant in my study emphasized, the experience of chronic pain is very different than stubbing your toe. One way they differ involves time and temporality, and many of the participants in this study discussed how ongoing pain, and the awareness of the reoccurring and ongoing nature of pain, could be part of the suffering. For one participant, the ongoing experience of pain over time was the primary way they thought about suffering in the chronic pain experience. "Well, pain's temporary, you know, but…it coming back is not temporary, because it'll always come back. And that's the suffering part." Throughout my discussion with this participant, we returned to the idea of pain being a passing instance with an end, but how suffering to this participant meant "pain over time", and for them part of suffering was knowing that the pain would return. "Suffering is like the continuous-ness of it all", they said. Another participant said something similar:

> I think kind of, as I've mentioned, I think pain itself is like that state of what's happening at the moment for you, which can be kind of ongoing, but I think it's more of that state versus the suffering starts to become kind of a longer, kind of more persisting trait, almost, maybe trait's not the right word, but I think suffering kind of goes on for a longer period of time and is almost like trying to get you to a place versus I think the pain is more of that experience that you're having.

Yet another participant also spoke to the idea of suffering being tied to knowing that pain will return:

> I would actually say that's a big, a big part of it, I think. Yeah, like the difference between just regular pain and chronic pain is obviously, with chronic pain you know that it's gonna happen again. And I think that knowing that is, like, brings on those emotions that kind of tie the pain and the emotional part together as, like, a suffering, knowing that you're gonna have to experience it again after just having come out the other side.

Anticipating pain and anticipating its return seemed to be a universal experience for the participants in this study, and was often a source of suffering, since pain was unwanted. The length of a pain episode could also wear people down and could lead to negative thought spirals where questions began to arise about how much longer the episode would persist. In the words of a participant:

> I think when it's a flare up, the suffering aspect comes in a bit more. I think when you're not able to manage, I think pain is one thing that you feel it, but if you're not able to manage it and it keeps going on and on, then the suffering part starts to come in, where it's almost like this feeling of like, am I ever going to get out of this? Is this pain ever going to go away? Will it get better?

This wearing down could also potentially be interpreted as hopelessness or depression, and some participants did identify those emotions coming up at times.

The Need to Modify One's Life

Chronic and acute pain also differ in that chronic pain may impact a person's life day-to-day life and can change how that looks. Stubbing your toe is brief, surprising, but quickly fades and allows things to return to how it was before. When chronic pain results in changes to a

people's lives, including pain-related disability, it may mean larger changes in the way a person lives their day-to-day life compared to what we perceive as a culturally 'normal' able body. This might require paying more attention to pain triggers and knowing when to modify plans to avoid causing greater pain, as described by one participant:

> And that was a big thing too, was learning the signs to know what is going to trigger my pain a lot, right? So like I said, I'm always in pain, but if I go too hard then I'm in way more pain. So learning those signals of, oh, it's time to stop now, it's time to take a break, it's time to slow down, was a big changer in my quality of life. Like recognizing I'm going to be really tired if I continue to do this, and then realizing that oh wait, tired doesn't mean tired, it means sore, you know? So yeah, all of those processes to get me to this point, like it definitely took a long time, but it was helpful.

However, many people who experience chronic pain do not identify themselves as disabled or struggle with this label. Whether a person considered themselves to be disabled or not, chronic pain often came with limitations that could be emotional at times, especially when the limitations affected their ability to participate in their lives and relationships in the ways that they wanted.

Many participants talked about how living with pain meant having to modify expectations and plans, sometimes at the last minute. They described how they could make plans for an outing with friends, but when the day arrived, they might wake up with a migraine or back pain so bad they cannot walk, let alone hike. They may have to turn down an opportunity to do something they would love to do, but they know there would be a price to pay if they did it, and that price would be debilitating pain.

> I know I experience a lot of pain on a daily basis, and so it has restricted a lot of stuff that I can do, and it's frustrating because I want to be able to do more but I can't, and I know, like,

> there's not a cure to what's wrong with me and there's not really a lot that I can do. Like, I can take Tylenol and pain medication and that helps for a little bit, but that's not really a permanent solution. And if I just continue to do things that my friends are doing and stuff like that, it's not going to help my solution, my body long term. And so changing everything that I have to do when nobody else has to change it, like, I don't expect other people to change, it's just frustrating that I can't be on the same level as other people.

This quote illustrates the emotions and thoughts that can arise when grappling with limitations due to pain.

Injustice

There is a sense of injustice that can arise when comparing oneself to others, and frustration can arise at not being able to enjoy the same privileges that others may take for granted. When asked about what emotions they associate with suffering from pain, one participant said:

> Honestly, I think there's a lot that comes up. I think the feeling of an injustice and kind of anger, like specifically anger, frustration comes up, definitely. And I know with emotions that anger usually turns into sadness, because I'm not able to direct that anger towards, you know, myself or other people at times. If I'm directing it at the illness, the illness can't speak back to me, and I can't, kind of like, come to resolution with the illness itself. So it kind of turns more into a sadness where there's more of like that hopelessness that starts to come up, a little more kind of feelings of almost like disappointment, not in myself, but just like in the world itself, and like, kind of the cards I've been dealt. Yeah so kind of more of like those low moods that start to come in. I think it's probably what I see so like that, yeah, shift from anger to sadness.

While some people I interviewed seemed to have come to terms with the fact that having chronic pain is not 'fair' and may not allow someone to enjoy the same privileges as those who do not

experience chronic pain, others experienced it as suffering. This can perhaps be reflective of where someone is in their chronic pain journey, but I suspect that it is likely also influenced by personality traits, mental health status, and available coping skills, among other factors.

Relationships

Another area where the meaning of pain was impactful to the participants in this study was what chronic pain meant in terms of relationships with others. Cassell (2004) believed that the impact of pain on social relationships and the person's place within their cultural and social groups can lead to suffering, and this fits with some of the experiences described by the participants. The unpredictable nature of chronic pain required greater flexibility, and there were situations (such as having to go to work) that were less flexible and may have had social consequences. This limited opportunities to do desired activities, such as the social examples described above, but could also be a barrier to meeting expectations of an employer or being able keep up with responsibilities such as parenting.

When an activity is important or valued to a person there is a greater potential for suffering if they are unable to participate due to their pain. One woman shared how her suffering intensified when her pain impacted her children, "But if I'm upset because I can't take my kids outside and they really want to go outside, then I'm focused on it and I can't distract myself, and it feels worse." This tension between caring deeply for her children and feeling unable to do what she would like to do in that moment fueled negative emotions and thoughts about her situation that manifested as a sense of suffering.

Two participants raised the topic of how difficult it can be to date and begin new relationships with able-bodied people as a person with chronic pain. There is a vulnerability that comes with having to rely on others, and it takes time to build trust and care. There is also the

difficulty of communicating the experience to others, and some participants felt that they received the most empathy from others who had suffered, especially with chronic pain. However, one participant felt that her experiences were treated with empathy and understanding from the queer community as well, as most people in the queer community had a greater understanding of suffering, even if their experiences were not with pain.

> …dating in the queer community means almost everybody has been through some kind of suffering, whether it's rejection from family, friends, or a random stranger on the street. So I've actually found since I came out and started dating queer people, they understand the suffering side of it, and there's a lot of people with anxiety, depression, PTSD, all sorts of things, so it's not that difficult to explain to them.

It seems to me that the participant was saying that those who have suffered themselves may have more empathy and compassion for others who suffer, which helps the participant feel understood.

Some participants in this study spoke of the guilt that can come with feeling like a burden, or grappling with feeling like they were able to contribute in their relationships. Pain could limit a person's ability to contribute, and when they felt they were able to offer less or had to lean on a close person for assistance and support, this could stir up feelings of uncertainty or guilt. One participant described the difficulty of navigating these concerns in romantic relationships:

> …even with healthier partners, it can be hard, because you do feel like, can I cut all the vegetables? Sure. Is it going to take me 90 minutes? Or should I ask you? But then I always ask you, and you're also like, fixing the lawnmower. And then you know, it's like a constant thing where it's like, I don't want to be seen as taking advantage sometimes. And that's the

> thing, it's like, I could do it. It's gonna hurt me though, and then I can't write tonight, or my hand will be sore for like two days, but I can do it. So sometimes I find it hard. I find it hard with people that don't make it easy to ask for help, but if I'm around my friends or people who I don't even need to ask, they can just tell by looking, they're like, you look like your face is pinched or like you're walking slower. Like if someone was like can I take your backpack or something I'll be like yes, I won't hesitate, you know? But it does feel especially because I come off as so strong and because I do so many things to have access to my life, like it can be really hard to ask for help…

Another participant spoke of how she felt she was unable to be fully present in her relationships or offer support to the people she cared about in the way she liked due to her pain, and this led to feelings of guilt.

> Like the physical pain is my own, and while it can impact people around me, just putting more on their plates or not being able to be as present, or…all of those things, you're impacting people around you, right? And there's a guilt attached to that part, I think, and that's why it's hard. Regardless of how reassured I was that it was okay, you can still see the extra stressors and the extra expectations put on people that make their lives a bit harder, right? Even with work, I mean…there is this inherent guilt that I was letting them down…because I wasn't making myself available. And I would say it's probably the same in terms of my family, my immediate family, my kids and my husband. Just my inability to be there for them in a way that I wanted to be because I was so, you know…it was self-preservation for me. I was managing things to kind of preserve whatever I could preserve for myself.

For this person, the onset of her chronic pain changed the way she was able to participate in her relationships, and she felt guilt in response to her family stepping up to do tasks such as chores

that were previously hers. Grappling with the personal struggles of chronic pain reduced her capacity and physical abilities in ways that impacted relationships, and noticing these impacts was emotionally difficult. These negative emotional experiences added another layer of suffering beyond just the discomfort of the pain she experienced, and she seemed to feel that her pain was a burden to others, such as when she said, “Truly, I felt so sorry that I was inflicting this on other people too”.

Uncertainty

Uncertainty around pain can also cause suffering, especially when the uncertainty and unknowns about the pain experience made it harder to know how to manage a pain flare-up or reduce pain. One participant spoke about this when she said:

> Sometimes I do think it’s telling me something and sometimes I have no clue what it’s telling me. So there’s almost like these emotions of just like confusion, and then the frustration starts to hit, which then is the anger and then the sadness. So I think when I can localize why something is happening then it feels a lot more adaptive versus when something’s unpredictable, or I don’t know why the pain is happening when I’ve done things to manage it, or if I take medication and then it doesn’t help, then that starts to create more of, like, this negatively reinforced cycle of these more negative and un-adaptive emotions.

Chronic pain can be unpredictable, and this demands greater flexibility in day-to-day management strategies. A participant shared:

> So it is hard. I think every day is kind of unpredictable. You don’t know if today’s going to be a good day or a bad day, so you kind of have to just gauge it. So yeah, management looks a little different. I think for me I’ll try to kind of be consistent with things, but it does shift depending on the day, depending on if things are bad, if something moved a certain way, or

> the pain kind of got different, or if it's like ongoing pain that I'm just still trying to manage, it'll look different every day.

Uncertainty also showed up in not knowing what is causing the pain and, therefore, not knowing how to treat it or respond to it, especially if the person believed the pain could potentially be cured. One participant whose chronic pain experience was still fairly new, and who was seeking treatment to cure her pain, spoke to this ambiguity and uncertainty around the cause of pain:

> I just think that when there's no end in sight, it's one thing when you don't know what's wrong, but being given sort of like this, we can't figure out what's wrong with you, kind of thing. I think that weighs more heavily on you than the actual pain itself. Because every time I would go to the doctor, I would, I'm always a really optimistic person, so I would go to someone and be like okay, this time, this is going to be it, we're going to figure it out. It's going to be great. So I get in there, gung-ho, and then nothing would change. And then I'd be like, oh, dip again. And then I'd find something else. Okay, we're going to do this now, this is going to be great. So yeah, I think the ebb and flow, all of it, the ups and downs of it, and not having, not being able to see myself, like I can't do this anymore, I just can't do this anymore…

This experience of optimism followed by disappointment and a lack of answers wore this person down over time and began to lead to depression.

Reflective and Pre-Reflective Suffering

Notably, while some suffering occurs alongside pain, suffering could also occur when reflecting on the pain experience, even in the absence of pain. Similar to suffering in other areas of life, suffering can occur as a result of thinking about an experience, not just from the experience itself. Stilwell et al. (2022) offered the critique that most definitions and descriptions

of suffering in the literature involved a reflective aspect to them, a perspective which may exclude the suffering of people incapable of self-reflection, such as infants. These authors rejected this idea and point to reports of immediate, in-the-moment suffering that do not include a reflective element, such as moments of extreme pain. I agree that reflection is not always a necessary component of suffering. Intense pain and emotion are an intertwined experience of both pain and suffering, and participants described moments of overwhelming pain and suffering where the intensity of the experience felt beyond words and was experienced as "mind-numbing" as one participant called it.

One interesting aspect of these experiences is that even though they were experiences that were felt primarily somatically, the unpleasantness of pain was still present, and perhaps this negative, unpleasant appraisal of pain is part of the suffering experience. Suffering is 'bad', and therefore unwanted. But how do you make sense of the fact that something can be judged or appraised without conscious reflection? Perhaps this is partly explained by the medial pain system, a part of the brain and nervous system that tells us pain is unpleasant. This quick, faster-than-thought appraisal of pain is necessary when pain is a signal meant to keep us safe, such as when we burn ourselves on something hot, and appraisal is often an unconscious process. I also believe that there is an emotional aspect to these experiences, and that emotions tell us something about an experience, but in a way that is felt (bodily and in a way that precludes thought). Thoughts may be associated with emotions, but emotions are not thoughts. This distinction is important in cognitive behavioural therapy, since thoughts are considered accessible for modification, whereas emotions can only be modified indirectly by altering thoughts or behaviours (Corey, 2023).

Perceived Control and Helplessness

Perceived control also seemed to play an important role in how pain was related to suffering. When intense pain was unmanageable or made a person feel helpless to change it (even if only in the moment) it was often seen as suffering. This is aligned with Cassell (2004), who wrote that perceived control was an aspect of suffering. Feeling out of control and helpless could also lead to emotional experiences such as fear and anxiety which are known to be associated with chronic pain (Lumley et al., 2011). One participant described this experience of anxiety and lack of control when she said:

> There's a lot of anxiety that kind of surrounds it and I think, for me now, with the medication that I have, it's like, if I'm out and about and I've forgotten it, or I don't have it for whatever reason, and then I know that a migraine is coming, it's like that anxious feeling of like, all of a sudden I'm like, panicking, and then I know that that's probably going to make the migraine worse. I think it's just, yeah, there's a lot of anxiety surrounding it.

And yet there is an inherent lack of control in chronic pain – it is chronic because there is no way to make it go away permanently. Chronic pain can get better or worse day-to-day, yet it will always return. From my conversations with participants, it seems that over time, people with pain may notice patterns such as what triggers flare-ups, or how their pain progresses, but even then they may still be caught off guard sometimes. "It seems so nonsensical sometimes, when it flares up", one participant shared. The pain can feel meaningless, leaving the person experiencing pain wondering why now, and what caused the increase (or decrease) in pain. This perceived senselessness can decrease the sense of control a person has over their pain, and this can sometimes lead to a person feeling helpless. One participant described how helplessness was a part of their experience of suffering:

> Suffering means to me, it really, it's kind of like the being unable to do anything about it, is kind of the suffering part, because the pain happens and it's like, you know that'll pass eventually, but then you know it's just gonna hurt again tomorrow too…It's the knowing that it's always gonna be there that's kind of worse.

For this participant, knowing the pain would always come back led to a feeling of helplessness and lack of control.

When I think about a perceived lack of control leading to a feeling of helplessness, one of the first things that comes to mind is the concept of learned helplessness (Seligman & Maier, 1967). Learned helplessness is when a person or animal learns through experience that the outcome is independent of their response; therefore, what they do has no influence on the outcome. In the case of chronic pain, attempts to alleviate pain may not result in changes to a person's pain intensity or duration. As previously mentioned, the people I spoke to about their chronic pain talked about how their pain had no cure and therefore it always returned no matter what they did. Their pain felt random at times, and flare-ups occurred even when they felt that had done everything they could to prevent it. According to the theory of learned helplessness, over time this may lead to a person giving up on trying to change their situation, believing that their actions have no impact. However, when I looked up the research on learned helplessness, I discovered that Maier and Seligman (2016) have updated their theory in response to the many years of research on learned helplessness, including neuroscience research. It is now believed that passivity and increased anxiety are the default response to prolonged negative events, and that this response can be inhibited by the cerebral cortex when a person perceives that they are in control. For chronic pain, the conclusion remains the same – when nothing seems to influence the pain, perceived control is lower, and this can be associated with passive behaviour and

anxiety. Since learned helplessness can look similar to depression, lack of control over time may contribute to suffering.

Yet continuing to search for what you can control can be a way to mitigate suffering. One participant shared her attitude towards suffering that has helped her to cope despite lifelong experiences with chronic pain:

> …it's like, pain is reality and suffering is an option, or like pain is inevitable, suffering isn't or whatever—that's not true. I just like, I think that there is no way, like if you're in pain you suffer, but also you might get to have some control over how long or how much, and if you're going to spend any energy on something rather than clutching a pillow to your chest, crying, being like, why me, be like okay what can I do? Because I don't know, there's lots of things they can do. So it's not totally optional, the relationship between them. But I think we deserve a good life like everyone does…

I was struck by the determination of this participant, who faced significant challenges in her life and yet continued to rise to them, even when it was hard. To me, this took endurance but also a softness. She shared that when things got hard, she did not try to push through but instead gave herself permission to rest or feel her emotions as she needed to. However, she did not let this result in passivity. When I reflect on Seligman and Maier's (2016) new findings, I wonder if she has learned to respond by controlling what she can, which may help to protect against depression and helplessness.

I would summarize this attitude as "control what you can, let go of what you can't", which is a philosophy aligned with therapies that evolved from CBT and include a mindfulness element, such as ACT or DBT (Hayes et al., 2006; Linehan & Wilks, 2015). It takes awareness to notice what one is trying to control, and recognizing what is uncontrollable is a reflective

cognitive exercise. The gateway to exploring one's own suffering might involve examining thoughts that come up in difficult moments and evaluating what the response to those thoughts are, in terms of behaviours and emotions. Behaviours can be changed, so rather than as one participant put it, "clutching a pillow to your chest", a person might instead choose to find the small actions that make their life even a little bit better. If this change in behaviour leads to greater joy or less depression, or if it helps the person to live a life that reflects their values, then it is a step in the right direction. And, because sometimes life is hard and we will suffer, offering compassion to oneself can be an important part of recognizing and allowing the experience of suffering in, without trying to shut out the experience and push through, which can often cause further damage. In DBT there is an interplay between the dialectics of acceptance and change in response to difficulty, and while some situations may call for change, some situations may not be changeable and therefore it may be more appropriate to work towards acceptance (Lynch et al., 2006).

Attachment: Relationship to Thoughts

In the discussion of control and helplessness, I mentioned that ACT and DBT include shifts in the way one relates to thoughts, such as by applying the "control what you can, let go of what you can't" attitude. In DBT and ACT, letting go can be in the form of acceptance, such as radical acceptance in DBT, or it could take the form of techniques such as cognitive defusion in ACT (Hayes et al., 2006; Segal et al., 2023). Cognitive defusion is a part of ACT where a person does not try to change the thought but instead works to change their relationship to the thought (Hayes et al., 2006). ACT also emphasizes acceptance as an alternative to experiential avoidance, which can lead to suffering. In the case of pain, acceptance of the experience instead of avoidance can help a person to disengage and let go of their struggle with their pain, a struggle

which can cause suffering for as long as a person is engaged with it. There is some evidence that acceptance-based skills such as radical acceptance can be useful as an emotion regulation strategy (Segal et al., 2025).

Rumination: Dwelling on Pain

As previously mentioned, one person I interviewed felt that suffering was "sitting in it", and by "it" she meant the negativity and fixation on the 'bad' aspects of pain.

> For me, suffering is like you're sitting in it, right? And I try not to do that. I'm not a dweller. Like today, my hand is killing me, so sore. And I don't often say something hurts unless it really hurts, because you know when you hurt all the time you just kind of are used to it. So today my hand hurts, but there's nothing really I can do about it. So I don't sit in it. There's no point. There's no benefit to me to sit in it.

This stuck energy was reflected in other participants' definitions of suffering, where suffering could arise if they let the negativity take up too much space, or if they could not let it go. Using the lens of ACT, this attachment to negative thoughts would be called cognitive fusion (Hayes et al., 2006). The ability to re-direct the mind to something else or break free from obsessive thought cycles is something that can be developed with practice, and could be considered a skill, but excessive rumination might also be a mental health issue. For example, rumination can be related to mental health issues such as depression and anxiety disorders and can result in greater overall distress (Edwards et al., 2011).

Ruminating on worries about pain can be overwhelming and hard to put aside when a person senses that a pain episode might be approaching. For example, one participant talked about how when she experienced signs that suggested a pain episode might be coming on, she began to get anticipatory anxiety and fear which could lead to worrisome thoughts about what

was to come. During these times, she begins to think about how bad the pain episode might be, if it will be as bad as past episodes, and if her day is going to be a write-off.

> Sometimes in those moments, thinking back to super bad migraines that I've had, and then almost like the fear of, what if the one that I'm gonna have, or that's starting to come on, is just as bad as those, and what if I have to leave whatever I'm doing? And yeah, I think the thoughts just start to build up, and then they can also contribute to anxiety as well.

This suffering felt different to her than the suffering she experienced during a pain episode. During a pain episode, she described her suffering as more physical and pain-related, like she was trapped in a cycle of discomfort where something that might help alleviate one aspect of her discomfort would exacerbate another. This often led to her feeling trapped and helpless, like there was no good option. The suffering she described during a pain episode is the kind of suffering I described in the previous chapter, where the bodily experience of pain felt like a form of suffering, especially when it was more intense and triggered an emotional response. But the knowledge that pain was coming, and it was imminent, was its own form of suffering, even if the pain was not yet present.

Ruminating on these worries involved focusing on the pain experience even if the pain was not yet present, and this rumination was experienced as suffering for some, such as the participant quoted above. Another participant described how she found that focusing on thoughts about pain and suffering could amplify this experience for her, and so instead she tried not to dwell on it: "You know how, like, if you think about something, it magnifies? I don't sit and think about it, so it doesn't magnify. It's present. I recognize it's present, but that's kind of about it."

Acceptance and Experiential Avoidance

I noticed from speaking with participants that when someone was stuck in a cycle of negative thoughts about their pain experience, there was often an attitude of resistance to the experience of pain. This makes sense because pain is unpleasant and can come with suffering, both of which most people would prefer to avoid. However, when pain is inevitable or present, and there is no way to control the outcome, struggling against the experience may result in greater suffering. This is where the idea of acceptance comes in, which is not to say that we should always accept pain, but that in situations where fighting it truly will not change things, acceptance can ease some suffering.

To return to the idea of perceived injustice as a source of suffering, some participants in my study discussed how it did not feel fair that they had to experience chronic pain at times, and this perceived unfairness could lead to suffering. Other participants seemed to have a different relationship with perceived injustice that perhaps did not eliminate the suffering entirely but helped them cope. One participant put injustice into perspective by recognizing and accepting that some of her situation could not be changed, and that she was not the only person for whom things were not fair:

> And I would say, like, when I look at it, I'm like, yeah, it's way more than a full-time job for me to just function. But my alternative is what? Like, I don't want that. I don't want to be beholden or dependent on someone. I don't want to do MAiD, you know, like I don't want to, yeah, I guess I don't want to choose suffering if I don't have to, I want to just take the joy where I can get it, and I'll do a lot of things to try to make it accessible to me. It doesn't mean it doesn't exist. Like, I want to state that I'm not like David Goggins, who's like, you choose the hard or whatever. Like no...I'm often like this is so unfair. And then I remember, like, I have a lot of friends who are also disabled. It's not fair what happened to them.

This quote illustrates a shift in this participant's relationship to thoughts about injustice, which allowed this person to cope and spend less time dwelling on something unpleasant that cannot be changed. While part of this shift was putting their experience into perspective and noticing that others experience this too, another part of the shift seemed to be acceptance of things as they are.

Whether a person accepts or attempts to avoid their experience seems to have an impact on whether or not they experience suffering. At times, acceptance could take the form of surrender, and for some people this happened when they felt there was nothing they could do but let the pain episode pass. This response to helplessness and lack of control seemed to result in less suffering than the examples discussed previously, where participants tried unsuccessfully to fight for control or reflected on their lack of control and feelings of helplessness later. One participant discussed this concept of surrender when dealing with a migraine coming on:

> It just feels like I'm in so much pain. It is, like, a very helpless kind of situation. I think before the migraine it's like, what can I do to prepare for what's to come? Or like, if it's starting, I can be like okay, I need to go lay down and do this and hopefully it won't be too bad. But then when, during the peak of a migraine, I would say it's like the helplessness of, there's nothing I can do, and the things I want to do will actually make it worse. So I just need to sit with it and let it go.

This idea of letting go of control and surrendering also came up when discussing pain flare-ups or other situations where there was no hope of controlling the pain in that moment. However, not all participants I spoke to were able to give in and accept their lack of control, and when they fought it, it could result in suffering:

> When it overlaps, it's, you have pain and you're suffering at the same time. And so it's the physical part of the pain, but also the emotional part of like, this sucks. I hate this. I want this to end. I want this to go away.

This lack of acceptance of the experience could stir up a negative emotional response that was felt by this participant to be suffering. Another way to frame this would be using ACT, where the struggle against the experience of pain (experiential avoidance) could be seen as cognitive fusion that leads to suffering (Hayes et al., 2006).

Lastly, an attitude of "toughing it out", or trying to proceed to do something even when it might result in greater pain or suffering, also seemed to me to be a form of psychological resistance or experiential avoidance, where the person did not want to accept their circumstances and instead fought against them. Participants speculated that this could be due to a sense of pride, or because of internalized ableism, or even just wanting to feel 'normal'.

> I think it's more of a pride thing. I think when I was first diagnosed, it was so bad I couldn't, like, sit in a chair, so I would have to skip class. And I remember my mom reached out to the school for me and said like, hey, this is the reason why she's skipping class. Like, gave them a whole breakdown of my diagnosis. And when I came back to class my teachers would ask me if I needed accommodations or anything, and I would say no, I'm fine, it's not true. And it was this weird thing of, like, pride that I didn't want to be different, like I want to be unique in my own way, but I also don't want to be different or treated differently, I guess is the point. So I think that's a big thing, it's part of, it's kind of pride and like, everything's fine, I can manage on my own, but also this idea of like, I don't want to be looked at differently or looked at like I have a disability, even though I do technically, so it's like yeah it's kind of the strange thing of basically trying to mask all the time, yeah, it kind of gets me worn down.

This quote highlights multiple reasons a person might try to hide their struggles and endure their pain and suffering privately, but there is a cost to this behaviour, and one of these costs might be increased suffering.

Another participant shared that while she did not push herself to make herself seem as able-bodied as others, she did sometimes push past her limits to do activities she really wanted to do, even if it might result in increased pain. Knowing that a desired activity would almost certainly result in physical pain and discomfort caused her to weigh her options between physical and emotional suffering, neither of which was a desirable option. She explained:

> I've accepted it to the point where it's just like, it's okay and I don't mind it. And when I am with the people that care about me and that kind of stuff, like, we don't do the things that I can't do. But I want to be able to do those things, because they like to do them, too. It's just I don't want to cause a lot of pain to myself. And I used to be able, I used to do things that would cause pain in the long term for myself just because I wanted to do them, but then that causes suffering in the long term for me too. So it's kind of weighing the battles of what kind of suffering you want. If you want emotional suffering of like, I want to be able to do this but I can't, and you have to accept that, or you want the actual physical suffering of pain.

I wonder if there is an alternative choice, which is to truly accept the fact that something cannot be done without experiencing pain, and potentially reducing or even eradicating the emotional suffering. Another participant shared that in the past she tried to fight her limitations, but that over time she accepted her pain-related disability and this acceptance improved things for her.

> I fully accept it, right? Like I fully accept my disability. I fully accept my limitations. I'm willing to ask for help if I need it. It took me a long time to drop my internalized ableism,

because, like most people with the disease, it's progressive. So you start off typically normal bodied. And so I can understand why it's hard for people to let it go, because it took me a long time, but once I learned how and let my ego go – so much better.

Accepting things as they are in the present moment without trying to change them is commonly practiced in DBT. Radical acceptance is an exercise in DBT that draws from eastern contemplative practices such as Zen Buddhism (Linehan & Wilks, 2015). This practice helps a person to tolerate an experience that is unpleasant and can be helpful when changing the experience is not an option.

Perspective: Suffering is a Part of Life

In my interviews, I asked people what they thought about suffering – what it was, how they thought about it, and if there was any part of suffering unique to pain. Interestingly, I noticed a distinction in the way people talked about immediate versus reflective suffering. If their suffering was immediate, in-the-moment, and combined with intense pain, it could be overwhelming and difficult to deal with in that moment. Reflective suffering, such as thinking about the pain experience and the meaning of pain, was seen as more within one's control. But many participants saw suffering as a part of life, perhaps because pain had become a regular part of their experience and coping was the only option. Dwelling on the pain experience could lead to suffering, and therefore the best choice for some was to move on and try to live the best life they could despite the pain. As one participant put it, "You might be like, fuck, I drew the short straw. But it's still the only straw you have. Like, live it." Suffering at times feels inevitable, and suffering from pain shares characteristics with other forms of suffering, such as relationships ending or losing a loved one. Examples of other forms of suffering offered by participants usually involved some kind of emotional pain, returning to the close relationship between pain

and suffering. Loss and grief especially came up in examples, and these emotions were powerful and at times, overwhelming.

A Piece of the Pie: Pain and Suffering as Part of a Larger Whole

Chronic pain and suffering were one part of a bigger picture, a whole life, and life is complex. Chronic pain and suffering are like threads woven through many aspects of a person's life, including what that person's life looks like in its entirety and the meaning that they make of it. This makes sense when we think about the biopsychosocial model as it was originally intended to be understood. Pain and the suffering that can arise from it are experiences that emerge from a complex mix of ingredients that we as a society do not yet fully understand. It is not a matter of simply looking within the body to find out what went wrong, but rather understanding the whole person and their context, which might currently be beyond our ability to comprehend. With our present-day models, we are like medical students doing an autopsy, chopping the whole into parts to find out what is there, what we can see. But a human being is more than the sum of their parts, and chronic pain and suffering are a part of a greater whole, a human life. In one interview, the participant I spoke with discussed how for her, pain and its associated suffering were only a part of her life, and she tried to direct her energy to other parts of her life from which she derived meaning and joy.

> When something bad happens, I'm like that's alright, we'll go again. Like I'm mad and I'm sad and it doesn't feel fair, but once I express that, for me, then I'm able to be like, okay now what can I do about it? But I don't want to leave you with the impression that it's not hard or that I'm not emotionally impacted. I am. But I think that maybe it's not as much as other people, because the rest of my life is so wide, right? Like there's just so much going on. It's

like the pain is not smaller, but it just appears smaller because the pie is bigger, maybe. If that makes sense. And that was intentional.

Normalization of Pain

For others, pain and working through their experiences with pain felt normal, either because it had always been a part of their life or because they had experienced it for so long. “I haven’t really known any different life because I was so young when this happened” said one participant, referring to the onset of their chronic illness and pain. Another person talked about how she had experienced pain her whole life, and she noticed that those who experienced pain later seemed to have a harder time adapting or accepting their pain.

> Sometimes it seems like mental health outcomes are better if you’re in a scenario where it’s kind of like you don’t know what you’ve got ‘til it’s gone, like people that tend to become disabled later in life I’ve seen have a much harder time accepting it, whereas I’ve – not that I’ve only known pain, but I’ve known pretty significant pain my whole life. And so I didn’t really have an option to not get up anyways. You know, whereas maybe somebody who had not felt pain would be like, I can’t deal with this. Like, I don’t really know what that’s like.

Perhaps feeling like pain was a normal part of one’s life could produce a more adaptive response, such as acceptance, instead of the “I can’t deal with this” response, which demonstrates a lack of acceptance and a desire to avoid the experience.

Suffering and Mental Health

Lastly, some participants talked about how suffering from pain could be related to their mental state or mental health. Suffering could be a condition or mental state, as described by a participant: “Suffering is kind of the…the condition that you’re in and your mental state

throughout your daily life, perhaps. Whereas pain is an instance or a moment of pain. Suffering encompasses all of it. Something like that." Another participant felt it was a mental health issue:

> I think suffering is a mental health thing, and there are so many tools that we have that are easily accessible to help for mental health. And you don't need to do everything all at once, right? Small steps. You don't need to make big improvements or big change. It can be little things.

From a counselling perspective, I have seen that suffering in response to hardship is common, and who suffers, and how much, does in part have to do with their mental health status and the resources and skills a person has available to them to help them manage and cope. When Engel (1977) proposed a new model of pain that better integrated psychological and social factors, he also discussed how many people who experienced chronic illness and pain came to health care providers with "problems of living" and knowing whether or not those problems were health care problems were complex. Many factors influence the overall health of a person, but many of those factors (such as socioeconomic factors) are not addressed in our public health care system and may be beyond its scope. What we call 'mental health' goes beyond mental illness and, to me, includes the whole person and their perceived sense of wellness and belonging in the world. To re-quote a participant whom I quoted earlier in this study:

> I think your relationship between pain and suffering is what you allow it to be. So I guess ultimately, where your mental health is at and how you manage to take care of not just your physical self, but like your mental self, your heart self, you know, there's more to care than just your physical self, and so I think just, they overlap.

Improving a person's mental health may improve their resilience in the face of difficulty, and one way this could be done is through counselling or working with a psychologist. Some

participants spoke about the value of having a counsellor who helped them navigate the pain experience, providing support for the emotional difficulties they faced.

> But I also think too that having a place like counseling has been invaluable to me, like invaluable to me as just a human and a person, and in my marriage with my kids, personal growth. I just feel like, if I hadn't had that place to go, I don't know if I would have been able to navigate it as effectively as maybe I did, and there were times where I didn't navigate it effectively, and I was seeing someone for support, so I don't know. I just feel like, you know, it's, it's like you said, it's multi-dimensional, right? It's not just about the physical pain part. It's about the emotional part. So how are you taking care of that emotional part? How are you taking care of the spiritual part of yourself? How are you taking care of the physical part of yourself? You know, there's, there's so many multi-faceted pieces, and I think if you only put your hand in one pot, you know you're not necessarily addressing all the other pieces.

Another participant also found support for her suffering in a mental health professional, saying "my psychologist understands the suffering side, so I kind of see her as my ally in coping with the suffering. The doctors, like all they've got is surgery or medication". This same participant elaborated on how therapy was helpful to her:

> I had always been in therapy one way or another, and I knew, already knew, by the time I injured my back, I already knew that I was vulnerable to anxiety and depression. So I connected with her as quickly as possible and said can you please help me, like, emotionally get through this. And yeah, so she's the one that encouraged me to go back on antidepressants, she's like, I know the injury just happened. You're kind of in crisis mode right now, but if we can get ahead of this, maybe it doesn't have to go as dark as it's been before.

Counsellors, psychologists, therapists and other mental health professionals may be better equipped than doctors to support people with suffering, as their training and lens is more attuned to this type of hardship and difficulty in life. Suffering is a part of the chronic pain experience, and it is also a part of life. Having the skills and support to overcome whatever challenges life brings, including pain, is essential to well-being. Seeing suffering as a part of life can put things into perspective and may help to ease suffering by normalizing the experience somewhat, but even if suffering is normal, that does not mean we should not support people when they experience it. And if suffering is related to mental health, providing better mental health support to people experiencing pain seems like it should be a given.

Summary

It seems that the way people think about pain and the experiences associated with the chronic pain experience can influence their experience of suffering. The types of thoughts people have about pain can lead to suffering, such as reflecting or ruminating on negative experiences, or negative beliefs and meanings made of the experience. How much a person accepts their experience may also play a role, and people who attempt to avoid their experience or who do not want to accept it seem to struggle as a result of that. Some participants saw suffering as related to mental health status, and some utilized resources such as counsellors and psychologists to help alleviate their suffering. Lastly, perspective also seemed to be a way to reduce a person's suffering, and when participants were able to look at 'the big picture', normalize their experience, or focus on other parts of their life that were meaningful and valuable, they seemed to cope more effectively with their experiences of chronic pain and suffering.

Study Limitations

A chosen method for a study should fit its purpose, and hermeneutics is meant to offer one potential interpretation of a topic that is by no means the only way to interpret a topic. A good hermeneutic study should also open up new questions, offering us a new way to think of a topic and inspiring curiosity (Moules et al., 2015). Unlike many quantitative approaches that aim to narrow a topic down and control for extraneous variables, this hermeneutic study sought to expand the topic, question its complexities and contradictions, and invite mystery and uncertainty so that they could be further explored. As such, this study is not meant to provide a definitive answer on what pain and suffering mean in the context of chronic pain. The conclusions I have come to through my analysis are one way of understanding the topic, but certainly not the only way.

This interpretation is influenced by my own experiences and area of study, and I have primarily studied in the discipline of psychology, which has shaped the way I think of the topic of pain and suffering. My subject matter expertise is also limited by the disciplines I am less familiar with, and I did not include as much on topics such as neuroscience or spirituality, for example, since these are not topics I feel familiar enough with to speak on with any authority. While it is interesting to review literature from other disciplines and speculate on how that could be integrated into my understanding, I also did not read as thoroughly in disciplines where I did not have the training or expertise to interpret findings accurately.

Chronic pain takes many forms – it can lead to different levels of suffering and disability, and it is sometimes associated with underlying chronic illness, past injury, or other causes. Other times pain has no clear cause. It affects people worldwide and is incredibly complex, resulting from social and emotional experiences, past learning, perception, and more (International Association for the Study of Pain, 2020). Due to its complexity and personal nature, chronic pain

experiences can vary greatly. This study included eight participants who each experienced their pain and suffering in their own unique way, and like all hermeneutic studies, the interpretation is meant to be illuminating but not necessarily generalizable to the population at large. However, it should offer an explanation that makes sense of the topic, addressing contradictions and explaining how the author arrived at conclusions. This study did not collect information on factors that may influence the way people understand pain and suffering, such as education level, ethnicity, past experiences with counselling and therapy, or type of chronic pain. Additionally, while the participants were asked to provide their gender identity, the sample consisted of seven women and one man, and the ways in which gender influences understanding of pain and suffering was not explored. It is possible that if different factors were highlighted for future research, such as a racial or ethnocultural identities, that some different descriptions and interpretations of the pain experience may come forward.

It is my hope that this study encourages the reader to ask more questions and consider alternatives to our commonly held beliefs, and offers some insight into the meaning of pain and suffering for people with chronic pain.

Future Directions

This study included the voices of people with chronic pain, but communication about pain and suffering includes more than just people who experience pain. It could be of value in future to explore the meanings of pain and suffering for practitioners who treat chronic pain, family members of people with pain, and even lay people with no direct experience with chronic pain. If pain is in part socially constructed, it would be helpful to better understand how we collectively understand pain and suffering and how that shapes our experience.

Another area that needs further exploration is the formal (medical or helping professional) treatment of (and response to) suffering. In this study I noticed that formal treatment of suffering due to pain was not often provided to participants as part of their pain treatment. Instead, they often sought support for their suffering themselves in the form of working with a mental health professional such as a psychologist or counsellor. Others relied on support from trusted friends and family. If suffering is seen as a part of life, perhaps participants felt it was their responsibility to address it, and did not see it as a medical problem or a problem worthy of clinical care (both medical and other health professions, such as seeing a psychologist). Yet not all suffering was a result of mental processes, and the suffering associated with pain intensity discussed in my findings may not be as easy to address through psychological care. Instead, providing support with an interdisciplinary care team may be more appropriate, though it seemed from participant accounts that this was not always available. However, connection and presence seemed to be an important part of responding to suffering, and counsellors and psychologists may be better to respond to suffering than doctors due to their training and time allotted per appointment.

I noted in the analysis that some participants viewed suffering as a mental health problem, and if you see suffering as emotional distress this may be at least partially true. An American study that used national survey data found that anxiety and depression symptoms co-occurred with chronic pain more frequently than they occurred for those without chronic pain, and that those with anxiety and depression symptoms had a higher prevalence of chronic pain (De La Rosa et al., 2023). Pain catastrophizing is another psychosocial variable associated with pain, and is often associated with greater reports of pain intensity and disability (Simic et al.,

2024). While a comprehensive discussion of pain and mental health is beyond the scope of this study, there is a demonstrated and well-established link between chronic pain and mental health.

Counselling psychologists (who may go by other titles such as mental health counsellors or clinical counsellors) are well-versed in suffering, which I would argue is the main reason people seek out counselling in the first place. In my point of view, anxiety, depression, and coping with circumstances that cannot be changed (such as chronic pain) are all within the realm of what a trained counsellor is capable of addressing, and supporting people through difficulty can potentially relieve some of their suffering. With the support of a counsellor or psychologist, a person experiencing chronic pain may be better equipped to cope with suffering, such as by practicing acceptance of their experiences, putting their experiences into perspective, and improving their mental health.

CHAPTER 6: CONCLUSION

Pain and suffering are distinct but related, and the way that we understand them is shaped by the ways we have used these words throughout history. As our understanding of pain has evolved, so has the language we use to talk about pain and the suffering that can be a part of the chronic pain experience. Loeser (2000) said it is suffering and not pain that brings people to health care, but when I spoke to participants it seemed many of them sought health care for their pain, and for suffering they looked for connection with others – be that through their social connections or through more formal supports such as counselling, psychotherapy, or working with a psychologist. Welfarism tells us that suffering is a moral issue and we *should* care about suffering, and it seems to me that caring is an important part of responding to suffering in a meaningful way (Aguilera, 2020). It is my position that treating pain in a manner that is relational, caring, and present may address some of the suffering that comes with pain, which is similar to the 'turning towards' suffering suggested by Epstein and Back (2015).

In my literature review I explored the idea of defining pain-related suffering, and the value of having a definition. I can see the utility and value in a clinical setting, where the goal is to recognize and assess the suffering of a patient experiencing chronic pain in a short period of time. However, the very idea of separating pain and suffering has a dualistic flavour to it. My current standpoint is that by defining pain-related suffering we are trying to separate out part of the chronic pain experience, an experience that we have not historically been able to adequately treat due to its complexity. Instead of taking the reductionist approach of trying to define pain-related suffering, I would suggest that we try to better understand the complexity of chronic pain and its close relationship with suffering. I also question whether suffering is the right word, given that it is vague and used colloquially, which means it may have different associations for different people.

I do not seek to define pain-related suffering, but rather this study offers an attempt to better understand what pain and suffering mean in the context of chronic pain. Since all understanding is incomplete this study is only a beginning, and as others engage with this topic a new understanding will be formed – a 'fusion of horizons' between different perspectives. Language is limited, and while it attempts to convey experience there are experiences that are difficult to put to words (Gadamer, 2004). Still, words are important and reflect the ways we think about our experiences, offering hints at how something feels and attempting to bridge the gap between people who can never truly know what it is like to be the other.

Chronic pain is subjective and unique, and its subjectivity means that all treatment of another person's pain requires relationship. Relational care requires skills such as empathy, compassion, curiosity, and openness that are not easy to teach. Even so, many helping professions do not emphasize these skills or teach them minimally, and this is something I believe results in poorer quality care. Siler et al. (2019) found that pain is a whole-person experience, and if pain involves the whole person then treating the symptoms and not the person (as a complicated, emotional being) is dehumanizing. Working with a psychologist or counsellor may be one way to formally address a person's suffering, but each interaction a person in pain has with another person is an opportunity to build relationship through presence and care. This can apply to formal treatment of pain but also to informal support networks such as friends, family, and community members. It is my hope that as we work to better understand pain and suffering we do not lose sight of what it is all for. We care for one another because humanity is a collective and suffering is not something we are meant to do alone.

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APPENDIX A: PARTICIPATION INVITATION EMAIL

Subject Line: Recruiting for my research on chronic pain

Dear [Name],

As you may know, I am currently completing my master's degree in counselling psychology with the Faculty of Education at the University of Lethbridge, and I am presently conducting my own research as part of my degree. My research supervisor is Dr. Toupey Luft (toupey.luft@uleth.ca), an Associate Professor with the Faculty of Education at The University of Lethbridge. I am conducting a research study entitled, "Suffering Pains: Meanings of Pain and Suffering for People with Chronic Pain". The purpose of the study is to learn more about chronic pain and pain-related suffering, particularly in how people with chronic pain think about chronic pain and pain-related suffering, and what they feel like.

I am writing to ask if you could share this email with anyone you might know who experiences chronic pain and pain-related suffering and has experienced chronic pain for one year or longer. Participants must be adults (age 18+) residing in Alberta, Canada. I am unable to interview direct personal contacts for this study, so participants would need to be people with whom I do not have an existing relationship.

Those who have experienced chronic pain and pain-related suffering for at least one year are invited to be interviewed about their experiences. Should they agree to this interview, they will be asked to describe what their pain and suffering is like for them and how they find pain and suffering to be similar and/or different. The interview will take place on Zoom and will be approximately 1 hour in length. Interviews will be audio recorded.

If you know someone who experiences chronic pain who might be interested in participating in this study, please forward this email to them with the attached recruitment poster. They can then email me directly so I can provide an informed consent form and organize a time for an interview. I am also happy to answer any questions you may have and to provide any further information you may require. I am available at emily.lewis@uleth.ca.

The proposal for this research has been reviewed by the University of Alberta Research Ethics Board and found to be in compliance with their ethics policy. The ethics ID is Pro00159693. If you have any questions, you may contact the University of Alberta Research Ethics office at ethics@ualberta.ca or (780)492-2615 and quote ethics ID # Pro00159693.

Thank-you in advance for considering my request.

Sincerely,

Emily Lewis

Graduate Student, Counselling Psychology, Faculty of Education

University of Lethbridge

emily.lewis@uleth.ca

APPENDIX B: CONSENT FORM

PARTICIPANT CONSENT FORM

Title of Study: Suffering Pains: Meanings of Pain and Suffering for People with Chronic Pain

Contact Information

Principal Investigator:	Emily Lewis, MEd Student, Counselling Psychology
Email:	emily.lewis@uleth.ca
Supervisor:	Dr. Toupey Luft, Associate Professor
Email:	toupey.luft@uleth.ca

You are being invited to take part in a research study. Before you take part, a member of the research team is available to explain the study to you and you are free to ask questions about anything you do not understand. Please keep a copy of this form for your records.

Why am I being asked to take part in this research study?

You are being invited to take part in this study because you are a person who experiences chronic pain, and who has experienced chronic pain for one year or longer. The purpose of this research is to better understand what the concepts of pain and suffering mean to people with chronic pain.

What is the reason for doing the study?

Pain and suffering are often spoken of interchangeably, which can be confusing. Assessments and treatments for chronic pain and the suffering related to pain are based on definitions of these concepts, but the

definitions are disputed and unclear. This study will contribute to the understanding of how people with chronic pain talk about and make sense of these concepts, so that our understanding of chronic pain and pain-related suffering can become clearer.

What will I be asked to do?

We would like to interview you by having a discussion with the researcher (Emily Lewis) about what chronic pain and suffering mean to you, and how you make sense of these concepts. This will be a one-on-one conversation where you will answer questions about your experiences and perspectives related to chronic pain and suffering. The conversation will be recorded and transcribed word-for-word by the researcher.

This discussion will last between 45 minutes and 1 hour, depending on what you have to say, and will take place virtually on Zoom. You will have the option to turn off your camera at any time, and only the audio recording of your interview will be saved.

What are the risks and discomforts?

You are unlikely to experience risks and discomforts by participating in this study. However, discussing chronic pain and pain-related suffering may be uncomfortable for you. If you wish to stop at any time, you have the right to not answer a question or to end the interview. You may also withdraw from the study up until one month after your interview is complete. After one month, it will be impossible to withdraw since the information you provided will have become a part of the study. You will also be provided with a list of distress resources in case you feel any distress after participating in the study. It is impossible to know all of the risks that might happen to you in a study, but we have taken reasonable safeguards to minimize any known risks to you.

What are the benefits to me?

There may not be any direct benefit to you for participating in this research. However, you may find it helpful or interesting to talk about a subject that is often taken for granted in greater depth than you normally might. Additionally, this research may contribute to a greater understanding of how

people with chronic pain understand chronic pain and pain-related suffering, which can be useful for clinicians providing care to people with pain.

Do I have to take part in the study?

Being in this study is voluntary (it is your choice). If you decide to take part, you can change your mind and stop being in the study at any time up until two weeks after your interview has been transcribed. After that point your data will have become a part of the study and can no longer be removed. To withdraw from the study please contact Emily Lewis (emily.lewis@uleth.ca) or her supervisor Dr. Toupey Luft (toupey.luft@uleth.ca).

Even if you remain in the research study, you may wish to withdraw some or all of your responses. In the case that you wish to withdraw part of your interview, please contact the researcher and you will be sent your transcript for review. You will have one week to review the contents of the transcript and remove, change, or withdraw anything that you like. We will be unable to change or withdraw any data after the deadline (two weeks after your interview has been transcribed) has passed.

Will I be paid to be in the research study?

You will not be paid to participate in this study, however, a gift card valued at $20 will be offered as a token of gratitude for your participation. This incentive will be received or retained even if you withdraw from the study after your interview.

Will my information be kept private?

During this study we will do everything we can to make sure all information you provide is kept private. No information relating to this study that includes your name will be released outside of the researcher's office or published by the researcher. Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure your information is kept private. For interview transcriptions and publications, your name will not be used.

During analysis, electronic data will be stored on a secure drive at the University of Lethbridge. This data will be stored for 5 years after the study is complete.

The information from this study will be seen only by members of the research team. On occasion, this data will need to be checked for accuracy. For this reason, your data, including your name, may also be looked at by people from the Research Ethics Board.

Audio or video recordings, transcripts, or other study data collected or stored using online platforms may be temporarily held on servers outside of Canada. Although the research team will delete recordings or files from the platform once downloaded and transcribed, complete erasure from company backup systems cannot be guaranteed. The University of Lethbridge and the University of Alberta do not control how long backup copies are retained or who may lawfully access them under the privacy laws of those countries.

What will happen to the information that I provide?

The information that you provide will be a part of Emily Lewis's master's thesis research. It will be used to assemble a written document summarizing the findings, which will be submitted and published on a research repository. What you say may also be used as part of public or academic presentations, or in academic publications. At no point will you be identified in this work.

After the study is done, we will store your data for a minimum of 5 years. Data will be stored electronically on a secure University of Lethbridge drive. The data will be stored for a minimum of 5 years, but may be kept longer for future research. Your name will not be associated with electronic data.

What if I have questions?

If you have any questions about the research now or later, please contact Emily Lewis (emily.lewis@uleth.ca) or her supervisor Dr. Toupey Luft (toupey.luft@uleth.ca).

If you have any questions about your rights as a research participant, you may contact the University of Lethbridge research ethics office by email at

research.ethics@uleth.ca or by phone at (403) 382-7198. This office is independent of the study researchers.

Ethics review and approval is provided by the University of Alberta Research Ethics Board. If you have any questions regarding your rights as a research participant, you may contact the University of Alberta Research Ethics Office at ethics@ualberta.ca or (780)492-2615 and quote Ethics ID Pro00159693. This office is independent of the researchers.

You may also contact the University of Lethbridge Research Ethics Office at research.ethics@uleth.ca or (403)382-7198. This office is also independent of the researchers.

How do I indicate my agreement to be in this study?

By signing below, you understand:

- That you have read the above information and have had anything that you do not understand explained to you to your satisfaction.
- That you will be taking part in a research study.
- That you may freely leave the research study.
- That you do not waive your legal rights by being in the study.
- That the legal and professional obligations of the researchers and involved institutions are not changed by your taking part in the study.
- That you agree to the data being stored for 5 or more years after the study is completed.

SIGNATURE OF THE STUDY PARTICIPANT

☐ By checking this box and typing my name below, I am electronically signing this consent form.

_____

Name of Participant

_____

Date

Please save and keep a copy of this consent form for your records and reference.

APPENDIX C: DEMOGRAPHIC QUESTIONNAIRE

These questions will be asked verbally at the beginning of the interview before the recording begins.

What is your age at the time of this interview? (if participant is not comfortable with giving a specific age, age range will be acceptable – i.e. 18-29; 30-39; 40-49; 50-59; 60-69; 70-79; etc)

What is your gender identity?

APPENDIX D: INTERVIEW GUIDE

Tell me about your chronic pain.

I'd like to know more about your experiences of suffering related to your chronic pain. Can you tell me what that's like for you?

I'm interested in hearing about whether you think pain and suffering are the same or different?

Do you think pain and pain-related suffering overlap? If so, how?

When you're talking about your experiences of chronic pain and the suffering associated with that, do you find that you describe them separately or do you talk about them as if they are the same?

How do you respond to your pain and suffering? Do you respond differently to each?

APPENDIX E: DISTRESS RESOURCES

These resources are available in the case that you are feeling distress after participating in this interview. If it is an emergency, please call 9-1-1.

Suicide Crisis Helpline

- Call 988
- Toll free and available anytime

Crisis Text line

- Text CONNECT to 741741
- Available 24/7

Primary Care Alberta Addiction and Mental Health Line

- 1-877-303-2642
- 24/7, 7 days a week
- Provides support, information, and referrals to Albertans experiencing mental health concerns

Distress Line (Edmonton and Edmonton region)

- Call (780) 482-4357
- For people in distress or crisis, or supporting someone who is
- Available 24/7

Distress Centre (Calgary and Southern Alberta)

- Phone or text (403) 266-4357
- Online chat support also available: https://distresscentre.com/24-hour-crisis-support/

Distress Line of Southwestern Alberta (Operated by the Canadian Mental Health Association)

- Call (403) 327-7905 or toll free 1-888-787-2880
- Available 24/7

Rural Distress Line

- 1-800-232-7288
- Offers crisis support for rural Albertans

First Nations and Inuit Hope for Wellness Help Line

- 1-855-242-3310
- Free national telephone crisis intervention and counselling support for First Nations and Inuit
- Available 24/7

Indigenous Support Line (Operated by Alberta Health Service)

- Call 1-844-944-4744
- For First Nations, Métis and Inuit peoples, including youth and Elders, living on or off reserve,
- Indigenous listeners
- Can help you find the right service for your health care needs, including mental health

Counselling Alberta

- https://www.counsellingalberta.com/
- Counselling services available to Albertans anywhere in Alberta
- No financial barriers and no waitlist

APPENDIX F: RECRUITMENT POSTER