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"Pain is What the Patient Says it is": A Secondary Analysis of Nurses' Reflections on the Term Pain Catastrophizing

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A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Nursing

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Abstract

Background: Pain catastrophizing is a widely used concept; however, many have argued that it delegitimizes and decontextualizes patients' pain experiences. Previous studies identified that patients and clinicians think the term is stigmatizing; however, nurses' perceptions are underrepresented. Nurses offer a unique perspective that is critical to explore to foster positive change and improve patient outcomes. **Objectives:** This thesis aims to summarize the current literature on pain catastrophizing perspectives from clinicians and patients, analyze nurses' perspectives, and uncover any underlying issues with the term itself. **Methods:** This thesis consisted of a two-stage design. The first study is a scoping review that followed Arksey and O'Malley's methodology. The second study is a secondary analysis using survey data collected by Stanford University. Qualitative thematic analysis was used to analyze the open-ended survey responses from nurses. **Findings:** The scoping review included nine studies and identified six themes: (1) acceptance of pain catastrophizing, (2) inability to measure, (3) stigma, (4) cognitive processes, (5) renaming pain catastrophizing, and (6) perceptions of pain catastrophizing. The secondary analysis included open-ended survey responses from 136 nurses from which three themes were identified: (1) how nurses describe the term, (2) application of the term and patient responses, and (3) nurses' recommendations for the future. **Implications:** Nurses play a critical role in humanizing health care by challenging the status quo, advocating, and promoting social justice. Future research on pain catastrophizing should use a qualitative approach to focus on patients' and nurses' perspectives. **Conclusions:** These findings shed light on the problematic nature of the term pain catastrophizing. We argue that it is a dehumanizing concept and contradicts the definition of pain developed by the International Association for the Study of Pain. These findings support that the term is not patient-centred, neglects the multifaceted nature

of pain, and fails to acknowledge that pain is subjective. Pain is what the patient says it is, and we need to start respecting it as such.

Keywords: pain catastrophizing, chronic pain, nurses' perceptions, stigma, patient labels

Summary for Lay Audience

Doctors and nurses often use the term pain catastrophizing to refer to patients they suspect might be displaying an exaggerated response to the pain they are experiencing. However, many people disagree with the term for several reasons, not least of which is that the term is stigmatizing. Advocates of the term suggest that pain catastrophizing is not meant to shame patients but rather to understand how psychological factors might be impacting their experiences. The experience of pain is difficult to measure as there are no objective tests that can measure how much pain someone feels. Instead, care providers must rely on what patients tell them.

Given the many issues surrounding the term pain catastrophizing, this thesis includes two studies that explore how the term is operationalized, understood, and described by both patients and clinicians. The first study is a scoping review of the literature on how patients and clinicians understand the term. The second study is a secondary analysis of data from a large international survey developed by Stanford University to assess what care providers and patients think about the term. It is important to explore what nurses, in particular, think about the term because nurses care for patients with pain in many clinical settings. Nurses perform ongoing pain assessments, administer pain medication, and collaborate with the physician to ensure patients are receiving optimal pain management. They are also often the first point of contact for patients. The secondary analysis analyzes the answers given by nurses to answer the following question: how is the term pain catastrophizing interpreted and understood by nurses? This research aims to foster positive change through refinement of our understanding and use of this term. The responses from the nurses in this study have identified many problems with pain catastrophizing. This study also sheds light on important recommendations for nursing practice and future research.

Co-Authorship Statement

Riana Longo completed this work under the supervision of Dr. Fiona Webster who will be a co-author of the resulting publications and presentations produced from this thesis.

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Chapter 1: Introduction

Chronic pain affects approximately 20% of the adult population worldwide; however, chronic pain remains a complex phenomenon that is poorly understood (Alenezi et al., 2021). The International Association for the Study of Pain (IASP) describes pain as a personal experience influenced by various biological, social, and psychological factors (Raja et al., 2020). Further, the IASP states that pain is “to be defined whenever possible from the perspective of the one experiencing the pain, rather than an external observer” (Raja et al., 2020, p. 1978). The idea that pain is a subjective, personal, and multifaceted experience is central to the IASP definition of pain. As such, many clinicians have adopted a biopsychosocial approach to managing chronic pain conditions; although, the biological factors of pain have dominated the literature for years (Mescouto et al., 2020). More recently, attention has increasingly been directed to the psychological and social influences of pain (Quartana et al., 2009). In particular, one psychological factor that has become of interest to researchers in the last 20 years is pain catastrophizing. Pain catastrophizing is commonly defined as “an exaggerated negative mental set brought to bear during actual or anticipated painful experiences” and is commonly used in the clinical setting (Sullivan et al., 2001, p. 53).

Background

To fully understand pain catastrophizing, it is important to understand the origin of the concept. Albert Ellis, an American psychologist and psychotherapist, first introduced the term catastrophizing in 1962 (Ellis, 1962; Turner & Aaron, 2001). Ellis founded Rational Emotive Psychotherapy, an approach to help identify and challenge irrational and negative thought patterns that may result in psychological distress (Leung, 2012). Catastrophizing was believed to be an important component of these irrational thoughts and was described by Ellis to be

exaggerating hardships as something much worse than they were (Leung, 2012). Aaron Beck, a psychiatrist, later revised the term to describe a maladaptive cognitive style in those who experience anxiety and depression (Leung, 2012; Quartana et al., 2009). Beck also believed catastrophizing to be an irrational negative prediction of future events (Quartana et al., 2009). Central to these conceptualizations, developed in the context of psychology, is the idea of an irrational or exaggerated response to a perceived threat.

It is unknown when pain-related catastrophizing was formally introduced; however, research in this area started to develop in the late 1970s. Spanos and colleagues (1979) concluded that participants who engaged in catastrophic thinking during a cold pressor procedure reported higher pain levels (Spanos et al., 1979). Spanos et al. (1979) categorized participants as catastrophizers if they reported thoughts resembling worry or fear and could not redirect their focus away from the pain (Sullivan et al., 1995). Chaves and Brown (1987) reported similar findings in their research. They found that those who engaged in what they labelled as catastrophic thoughts during a dental procedure were more likely to experience higher levels of distress during the procedure (Chaves & Brown, 1987). The researchers defined catastrophizers as individuals who were more likely to exaggerate the threat of the pain stimuli (Chaves & Brown, 1987; Sullivan et al., 1995). In 1983, Rosenstiel and Keefe developed the *Coping Strategies Questionnaire* to evaluate pain-related thoughts experienced by those with chronic pain (Rosenstiel & Keefe, 1983; Sullivan et al., 1995). A catastrophizing subscale is included in this questionnaire and reflects elements of helplessness and pessimism (Rosenstiel & Keefe, 1983). Finally, in 1995, Sullivan and colleagues developed the *Pain Catastrophizing Scale* (PCS), a 13-item self-report instrument to measure pain catastrophizing (Sullivan et al., 1995). The PCS was designed to encompass the previous perspectives on catastrophizing and has

become the most widely used pain catastrophizing instrument (Sullivan et al., 1995). The three dimensions that the PCS measure are rumination, magnification, and helplessness (Sullivan et al., 1995). Research on pain catastrophizing began to proliferate after the PCS was developed (Neblett, 2017).

Since introducing these measures, pain catastrophizing has become inserted as an important determinant of poor pain-related outcomes, such as higher pain intensity, disability, anxiety, and depression (Neblett, 2017; Quartana et al., 2009). Patients who score high on pain catastrophizing measures are labelled as catastrophizers. The term pain catastrophizing implies that patients are exaggerating their pain, which may unintentionally foster patient blame. The early conceptualizations of pain catastrophizing are rooted in a psychological model. Though psychological factors may influence the pain experience and are to be addressed when assessing pain, pain catastrophizing measures limit the pain experience to a psychological influence alone and overlook the physiological experience. As a result, the severity of pain that patients report may be inadvertently dismissed because of the presence of psychological elements, such as rumination or magnification. Further, measuring pain catastrophizing fails to address social factors that influence pain, such as lack of social support or low income, limiting the ability to understand the individual pain experience fully. Connoy and Webster (2021) noted that oppressive structures inform the experiences of people living with chronic pain and are related to marginalization and exclusion. However, chronic pain research continues to be led by biomedical approaches that are not prepared to address these social inequities (Connoy & Webster, 2021). For example, evidence shows that women experience more chronic pain than men (Flentje et al., 2015; Pieretti et al., 2016), including those in lower socioeconomic status populations (May et al., 2018), and tend to be over-represented among those with chronic pain conditions that are not

straightforward in their diagnosis and treatment, such as fibromyalgia. Women with fibromyalgia are more likely to be labelled as pain catastrophizers (Werner & Malterud, 2003). From the outset then, conceptualizations of pain catastrophizing delegitimize some patient experiences and do not consider the unique context of the pain experience. As set out by the IASP, pain is a subjective and personal experience (Raja et al., 2020). Thus, it is critical to challenge the term pain catastrophizing as it contradicts the belief that pain is an individual experience with various biological, psychological, and social influences and fails to recognize patients' reports of pain as credible (Raja et al., 2020).

The research surrounding the impacts of pain catastrophizing on the pain experience is comprehensive; however, understandings of how clinicians and patients perceive the construct are underrepresented. In the existing literature, researchers found that clinicians and patients think the term pain catastrophizing is stigmatizing and believe that pain catastrophizing measures are pejorative (Amtmann et al., 2018; Pelekanou & Thomson, 2021). Sleijser-Koehorst and colleagues (2019) found that clinicians view the PCS as a feasible and valid measure of pain catastrophizing; however, they also recognize that it is negative sounding and suggestive. In a study conducted by Amtmann et al. (2020), the researchers developed a new pain catastrophizing measure named the *Concerns About Pain* scale, opting not to use the term catastrophizing due to its stigma. The researchers recommend that clinicians follow the administration of the *Concerns About Pain* scale with the administration of a scale that measures a more positive construct, such as pain-related self-efficacy, due to participants' concerns regarding the negativity of the instrument (Amtmann et al., 2020). Researchers also found that several patients and clinicians acknowledge that pain catastrophizing scores may be misinterpreted or used to deny treatment (Amtmann et al., 2018, 2020; Sleijser-Koehorst et al., 2019). Further, some patients fear that

pain catastrophizing measures will promote clinicians' beliefs that their pain is not real (Amtmann et al., 2018). Osteopaths in one study support this fear by revealing that in the early stages of their career, they judged patients presenting with behaviours they deemed as catastrophizing and would blame the patient (Pelekanou & Thomson, 2021). Although there is limited research on clinicians' and patients' perspectives of the term pain catastrophizing, what the current literature points to is the stigmatizing and problematic nature of the term.

As early as 1968, Margo McCaffery, a pioneer in the field of pain management for nursing, famously defined pain as “whatever the experiencing person says it is, existing whenever and wherever the person says it does” (McCaffery, 1968, p. 95); however, people with chronic pain continue to feel disbelieved and stigmatized by their clinicians (Allvin et al., 2019; De Ruddere & Craig, 2016; Newton et al., 2013; Slade et al., 2009). A study completed by De Ruddere et al. (2014) found that pain in the absence of a clear medical cause and in the presence of psychosocial influences, such as job stress and depression, is taken less seriously by clinicians. In a phenomenological study conducted by Hansson and colleagues (2011), people with chronic pain described feeling discredited and as though clinicians were calling their pain experience into question. It is well documented that people with chronic pain often feel that their clinicians think their pain is exaggerated, which may result in patients feeling blamed and invalidated (De Ruddere & Craig, 2016). Furthermore, using psychological labels to describe patients, such as pain catastrophizer, promotes stigma and stereotypes, leads to isolation, and creates barriers to quality patient care (Garand et al., 2009; Knaak et al., 2017; Newton et al., 2013). In the context of pain catastrophizing, it is critical to consider the impacts language has on patient blame, stigma, and access to effective pain management.

Significance to Nursing Practice

Nurses' perspectives of the term pain catastrophizing in the literature are largely understudied. However, the nursing profession is rooted in core values such as social justice, patient advocacy, and empathy, making their perspectives on patient labels, such as pain catastrophizing, extremely valuable (Canadian Nurses Association, 2017). Nurses are thought to be the cornerstone of pain management given their role in continuous pain assessments, administering pain medication, evaluating the effectiveness of pain treatment, and advocating for optimal pain management (Lewthwaite et al., 2011; Ware et al., 2011). Further, they often have the most frequent contact with patients and liaise between patients and physicians; thus, their attitudes toward the term pain catastrophizing would provide relevant and useful insights into how the term is used and how it impacts patients.

Pain assessment and management are critical roles nurses perform as they encounter patients with pain in almost all clinical settings (Lewandowski, 2004). Furthermore, nurses are essential to translating research into practice to foster cultural and behavioural practice changes (Curtis et al., 2017; Powers, 2020). Nurses also have a role in challenging the status quo and addressing social inequities. It is within the moral norms and principles of nursing to comprehensively address the pain experience of patients as unique and worthy of attention (Carroll, 2018). Therefore, nurses are equipped to utilize the findings from this thesis to accelerate health care reform in the context of pain catastrophizing. Nurses are uniquely positioned to challenge the term pain catastrophizing in the clinical setting and develop strategies to minimize the stigma those living with chronic pain face. Finally, nurses have a responsibility and are well-situated to lead the humanization of health care by advocating for patients, reducing stigma, and eliminating barriers to care (Morse, 2012).

Research Questions and Objectives

The current literature on pain catastrophizing highlights several problematic issues with the concept and uncovers significant research gaps concerning how clinicians and patients perceive the term. It is well documented that those with chronic pain often feel stigmatized and disbelieved by their clinicians (Allvin et al., 2019; De Ruddere & Craig, 2016; Newton et al., 2013; Slade et al., 2009). Furthermore, the use of patient labels may exacerbate these feelings. In its discursive construction, the term pain catastrophizing is a negative-sounding psychological label that delegitimizes and decontextualizes patients' experiences, contributes to feelings of stigma, and is not patient-centred. Therefore, it is critical to better understand pain catastrophizing by exploring how patients and clinicians describe, understand, and experience the concept; however, these perspectives are currently understudied. Moreover, to our knowledge, nurses' perspectives of pain catastrophizing are absent in the literature. Nurses' unique set of values and ability to establish therapeutic nurse-client relationships makes their perceptions of the term pain catastrophizing particularly useful to explore. Investigating nurses' understandings and interpretations of the term will be helpful to identify if the term pain catastrophizing creates any barriers to care and may enable the development of strategies to minimize the stigma associated with the term. Finally, nurses are innovative clinicians who can lead positive and transformative change that is patient-centred.

This thesis includes two inquiries that aim to summarize the current literature on pain catastrophizing perspectives from clinicians and patients, analyze nurses' perspectives, and uncover any underlying issues with the term itself. The first study was a scoping review that mapped the literature on how clinicians and patients understand, experience, and describe pain catastrophizing. The scoping review was conducted according to Arksey and O'Malley's (2005) methodological framework and refinements of the framework proposed by Levac et al. (2010).

The scoping review identified that perceptions of the term pain catastrophizing by both patients and clinicians are largely understudied. Furthermore, the scoping review revealed that nurses' perspectives are not included in the literature, highlighting a significant research gap. The second study builds on the gaps identified and the knowledge developed from the scoping review. It aims to explore nurses' perspectives of the term pain catastrophizing by undertaking a secondary analysis of a subset of survey data collected by Stanford University from their study *Rename Pain Catastrophizing* (Stanford University, n.d.). Qualitative thematic analysis described by Braun and Clarke (2006) was used to analyze the open-ended survey responses from nurses. This study aimed to answer the following research question: how is the term pain catastrophizing interpreted and understood by nurses? The objectives of this thesis are as follows: (1) summarize the current literature on pain catastrophizing perspectives from clinicians and patients, (2) investigate how nurses understand, describe, and use the term pain catastrophizing in practice, and (3) identify and uncover any underlying issues with the term pain catastrophizing.

Statement of Reflexivity

This statement of reflexivity serves to recognize my role as a researcher in constructing knowledge and the impact my position may have on the analysis and interpretation of data (Finlay, 2002; Tracy, 2010). My interest and motivation in pursuing this thesis stem from my clinical practice with the chronic pain population and resultant engagement with the pain literature. As a Registered Nurse working closely with this population, I am aware of the stigma, blame, and invalidation patients feel when seeking treatment. In my practice, I often witness clinicians describe patients as catastrophizers and subsequently assume that management strategies will likely not be successful with these patients. As a Registered Nurse, my report to physicians about patients is instrumental in laying the foundation for how the physician will view

the patient and how much credibility they will assign to the patient account. As such, I have made a conscious effort to acknowledge patients' reports of pain as real and valid, especially when communicating with other clinicians. However, at the start of my career, I would catch myself conforming to the paternalistic idea that clinicians are the experts of the patient's pain rather than the patient. Pursuing a Master of Science in Nursing and gaining clinical experience has allowed me to adopt a more critical lens in all areas of my practice. Analyzing how we currently deliver care to patients with a critical position has highlighted the importance of language and labels, which has motivated me to explore perspectives of the term pain catastrophizing.

Patients have shared that they feel as if friends, family members, and clinicians do not believe the severity of their pain or think they are exaggerating. Patients have also shared concerns about people thinking they are lazy, unmotivated, attention-seeking, drug-seeking, or dramatic. The literature supports that people with chronic pain experience stigma and often feel that their legitimacy is questioned (Waugh et al., 2014). When reflecting on my practice experiences and my interpretations of the term pain catastrophizing, I struggle to understand the benefit of the concept. From my perspective, as someone who has not experienced chronic pain, I feel that measuring pain catastrophizing and labelling patients as catastrophizers provides no benefit to pain management. I also recognize the stigma attached to the term and have witnessed clinicians perceive patients labelled as catastrophizers to be difficult and, thus, take their pain concerns less seriously. Being reflexive about my assumptions towards the term pain catastrophizing is useful to mitigate against any bias in my thinking or writing and help me remain open-minded to differing perspectives (Finlay, 2002). Furthermore, understanding how

my role may influence analysis enhances this study's transparency, trustworthiness, and accountability (Finlay, 2002).

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Chapter 2: The Muddled Concept of Pain Catastrophizing: A Scoping Review

Pain catastrophizing, defined as "an exaggerated negative mental set brought to bear during actual or anticipated painful experiences," is a widely used and accepted term both clinically and within the scholarly literature (Sullivan et al., 2001, p. 53). The term catastrophizing was initially introduced in 1962 by Albert Ellis as a core element in emotional dysfunction (Neblett, 2017). Aaron Beck later refined the term in 1976 to explain a *maladaptive cognitive style* that exacerbates symptoms in individuals with anxiety and depression (Quartana et al., 2009; Sullivan et al., 1995). From the outset, the foundational conceptualizations of catastrophizing are rooted in the realm of psychology. While the concept may be useful in addressing psychological conditions, in the context of pain, it delegitimizes patient experiences and decontextualizes their experiences and health outcomes from social factors, such as income, housing, and food security (Booher, 2019; Fitzpatrick et al., 2015).

The acceptance of the term was reinforced clinically with the development of the *Pain Catastrophizing Scale* (PCS) in 1995 (Neblett, 2017; Sullivan et al., 1995). The PCS is a 13-item self-report questionnaire that conceptualizes pain catastrophizing as a multifaceted construct encompassing rumination, magnification, and helplessness (Sullivan et al., 1995). Sullivan and colleagues (1995) developed the PCS to facilitate research on how pain catastrophizing influences the pain experience. Attention to the PCS has led to a body of research dedicated to measuring the relationship between pain catastrophizing and adverse pain outcomes, such as higher pain intensity, anxiety and depressive symptoms, and higher levels of disability (Neblett, 2017; Quartana et al., 2009). A systematic review conducted by Wertli et al. (2014) found that higher pain catastrophizing scores predicted pain and disability in patients with nonspecific low back pain. The use of pain catastrophizing scores as a predictor of pain-related outcomes within

the scholarly literature and clinical practice suggests that several researchers and clinicians accept pain catastrophizing as a measurable construct (Crombez et al., 2020). Consequently, the term pain catastrophizing has been incorporated into many theoretical models to guide future research and clinical practice, including the Fear-Avoidance Model of Pain, the Misdirected Problem-Solving Model, the Communal Coping Model of Catastrophizing, and the Transactional Model of Stress and Coping (Neblett, 2017; Quartana et al., 2009).

The conceptualization of pain catastrophizing implies that patients are exaggerating their pain experience. It also offers an essentialized and individualized notion of experience that fails to consider how differing social contexts, such as health inequities, might influence people's experiences. The concept does not consider the broader social factors that influence the pain experience, such as marginalization or structural violence, or allow the possibility that so-called catastrophizing behaviours may be a normal response to constant pain and suffering (Martorella et al., 2008). Such conceptualizations do not align with the definition of pain as a personal experience that is influenced by biological, psychological, and social factors (Raja et al., 2020). Further, pain catastrophizing does not support the notion that a person's subjective report of their pain experience should always be accepted, as outlined by the International Association for the Study of Pain (Raja et al., 2020). In contrast, the biopsychosocial model of pain potentially offers a counter perspective (Fillingim, 2017). Exploring pain catastrophizing from this model may offer new understandings of this construct (Martorella et al., 2008). However, the biopsychosocial model itself has been critiqued for emphasizing the biological and psychological aspects while neglecting the social. Finally, some researchers have challenged the validity of the construct pain catastrophizing and have argued instead that it is not conceptually distinct from other related constructs, such as negative affect, fear of pain, worry, and pain-related anxiety

(Crombez et al., 2020; Flaskerud, 2015; Flink et al., 2013; Leung, 2012; Quartana et al., 2009). The construct pain catastrophizing, its true benefit, and what it is measuring is not clearly understood. This scoping review aims to map the literature on how clinicians, researchers, and patients understand, experience, and describe pain catastrophizing and identify research gaps on perceptions of the term. These findings will inform our current understanding of pain catastrophizing and may encourage clinicians to consider this construct's legitimacy and benefit.

Methods

A scoping review approach was selected for this study. Scoping reviews are intended to map the key concepts of a research area, summarize key findings, and identify research gaps (Levac et al., 2010). Scoping reviews are particularly beneficial in areas that have not been reviewed comprehensively before (Arksey & O'Malley, 2005). This scoping review was conducted according to the Arksey and O'Malley (2005) methodological framework. Refinements of this framework proposed by Levac et al. (2010) were also considered, such as mutually considering the study's purpose with the research question, ensuring a balance between feasibility and comprehensiveness by excluding grey literature, and following their recommendations for collating, summarizing, and reporting results. The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) were also referenced when further guidance was required (Tricco et al., 2018). This scoping review follows five steps: (1) identifying the research questions, (2) identifying relevant studies, (3) study selection, (4) charting the data, and (5) collating, summarizing, and reporting results.

Identifying the Research Question

This scoping review seeks to answer the following question: how is the concept of pain catastrophizing understood, experienced, and described by patients and clinicians in the

literature? As recommended by Levac et al. (2010), the purpose of the study will be mutually considered with the research question. The purpose of this scoping review is to enhance our current understanding of pain catastrophizing and understand how the construct is utilized, experienced, and interpreted in clinical practice.

Identifying Relevant Studies

To be included in this scoping review, studies needed to be primary studies or reviews published in the English language. Studies were selected if they were published from 2010 to 2021. This time frame was chosen to prioritize recent and relevant evidence. Studies were included if they focused on pain catastrophizing and how the construct is perceived or experienced by patients, researchers, or clinicians. If the study only focused on pain catastrophizing, it was excluded. Levac et al. (2010) suggest considering the balance between feasibility and comprehensiveness by not compromising the ability to accomplish the study's purpose and answer the research question. Thus, grey literature was not included to ensure this review's feasibility. Intervention studies were also excluded to filter out the many studies that took the term at face value and therefore measured pain catastrophizing as a predictor of poor pain-related outcomes. Conference abstracts, unpublished studies, commentaries, and editorials were not included. Studies were excluded if full texts were not freely accessible.

Potentially relevant studies were identified by searching electronic databases. Reference lists of studies included in this review were also scanned to supplement the search. The search was applied to MEDLINE, CINAHL, and PsychInfo and was conducted on October 7th, 2020. An updated search was performed on November 29th, 2021, for studies published in 2020 – 2021. The search was split into two topics, pain catastrophizing and perceptions. Free-text keywords were searched, in addition to Medical Subject Headings (MeSH) when available. One

reviewer (RL) drafted the search strategy and refined it through consultation with an experienced librarian. For pain catastrophizing, the following terms were searched: “pain catastrophizing” and catastrophizing. For perceptions, the following terms were searched: definition*, conceptualization, concept*, perception*, perspective*, experience*, “lived experience,” discourse, linguistics, language, belief*, qualitative, terminology, connotation*, understanding, word*, stigma, stigmatize*, stigmatizing, description*, concern*, bias, attitude*, renaming, rename, relabel, change, label, reappraisal, interview*, term, and review. The Boolean operator “OR” was used to combine searches within topic areas, and “AND” was used to combine the two topic areas. Search filters applied for the first search were publication year 2010 to current and English language. The updated search was limited to publication year 2020 to 2021 and studies published in English. The final search strategy was performed using MEDLINE; searches were then adapted for CINAHL and PsychInfo. Refer to Appendix A for the first search strategy used in MEDLINE. The final search results were exported into Covidence, and duplicates were automatically removed.

Study Selection

Titles and abstracts from the search results were screened for relevance by the primary researcher (RL). Studies that were relevant and met the inclusion criteria progressed to full-text screening for further assessment. When uncertainty was met, another reviewer was consulted (FW). Studies selected were not assessed for methodological quality because scoping reviews aim to summarize the literature regardless of methodological quality (Arksey & O’Malley, 2005; Levac et al., 2010).

Charting the Data

RL developed a data-charting framework to determine which variables to extract from the studies included in this review to answer the research question. The data-charting form included the following headings: authors, year of publication, research aims, phenomena of interest, country of study, study population, methodology, methods, relevant findings, and conclusions. RL independently applied the data-charting framework to the included studies. FW was consulted to resolve any uncertainty met during data charting.

Collating, Summarizing, and Reporting Results

The final step was broken down into three parts in alignment with the recommendations proposed by Levac et al. (2010): (1) analyze the data, (2) report results, and (3) apply meaning to the results. Arksey and O'Malley's (2005) framework involves a descriptive numerical summary and a thematic analysis to analyze the data. A descriptive numerical summary was completed to describe the characteristics of the included studies. A qualitative thematic analysis approach was utilized by categorizing findings that are thematically alike to complete the analytical stage. Reporting results are articulated through themes to support the study's purpose: identifying how pain catastrophizing is understood, experienced, and described by clinicians, researchers, and patients. Finally, the significance of the results and the practical implications for future research and clinical practice are discussed.

Results

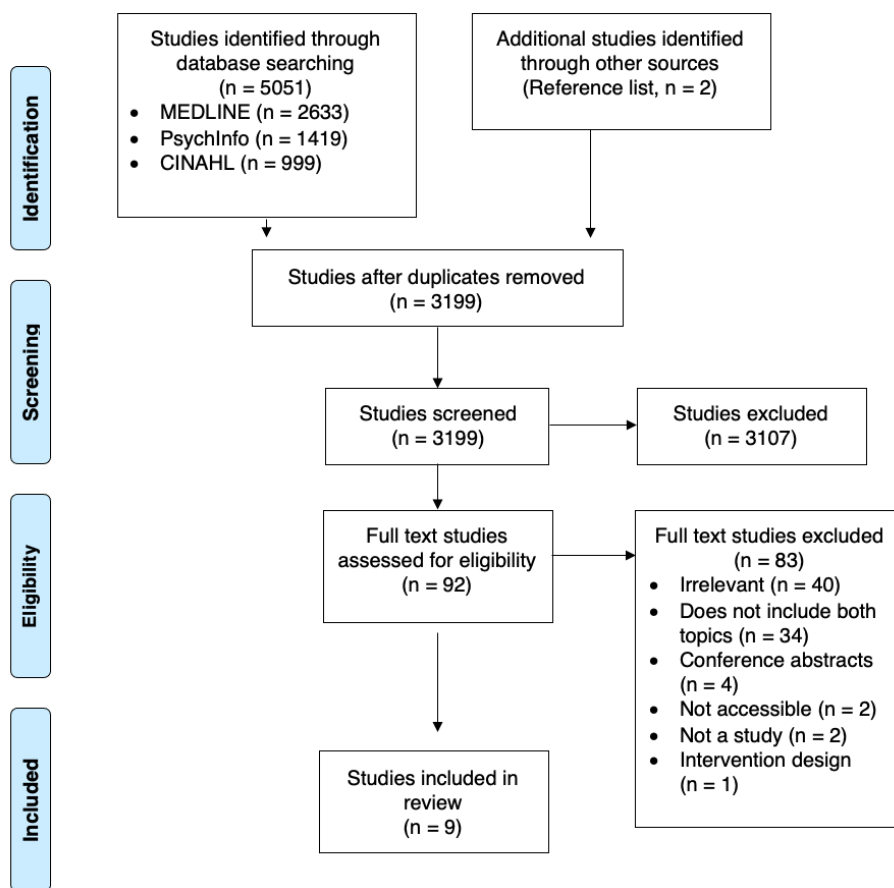
Study Selection

A total of 5051 studies were identified from electronic database searches, 4424 were identified in October 2020, and an additional 627 were identified in November 2021, representing a large number of new articles in one year. Two studies were identified through an ancestry search of references. After duplicates were removed, 3199 studies were screened for

relevance. After screening titles and abstracts, 92 full-text studies were assessed for eligibility. Of the full-text studies, 83 were excluded for the following reasons: 40 were not relevant to the research question, 34 did not include both pain catastrophizing and how the construct is perceived or experienced by patients, clinicians, or researchers, four were conference abstracts, two were not freely accessible, two were not a study, and one was an intervention study. One full-text study assessed for eligibility was met with uncertainty because it did not follow a formal review process (Flink et al., 2013). A second reviewer (FW) was consulted to resolve this uncertainty. The final consensus was to include the study in this review as scoping reviews do not assess the methodological quality of studies; instead, they seek to identify the relevant literature (Arksey & O'Malley, 2005; Levac et al., 2010). After assessing the full-text studies, seven were considered eligible for the review after the first search, and an additional two were considered eligible after the updated search. A total of nine studies proceeded to data charting and analysis. Figure 2-1 displays the study selection process.

Figure 2-1

PRISMA Flow Diagram of Study Selection



Study Characteristics

The nine studies included in this review were conducted from 2013 to 2021. Studies originated from six different countries. Two studies were conducted in the United States of America, one in Luxembourg, one in Australia, one in the Netherlands, one in Ireland, one in the United Kingdom, and two were not applicable. The majority of the study participants were from North America, followed by Australia and Europe, and lastly, Ireland and the United Kingdom.

Study Designs

A variety of study designs were used in the studies included in this review. Four studies used a qualitative design, two studies were quantitative, one used quantitative and qualitative

methods, one was a review, and one was a development of the conceptualization of catastrophizing. The methodology recommended by the Patient-Reported Outcome Measurement Information System (PROMIS) was followed in two connected studies included in this review (Amtmann et al., 2018, 2020). The first study utilized a qualitative approach to review candidate items of a new pain catastrophizing measure (Amtmann et al., 2018). This study involved patient advisors, an expert panel, focus groups, and cognitive interviews (Amtmann et al., 2018). The second phase study adopted a quantitative approach, applying psychometric methodology and item response theory (Amtmann et al., 2020). Interpretative phenomenology was used in one of the qualitative studies in this review, and constructivist grounded theory was used in another (Pelekanou & Thomson, 2021; Schütze et al., 2017). A critical realist paradigm was used in one qualitative study that used semi-structured interviews and qualitative thematic analysis (Heffernan et al., 2021). Discriminant content validity was used in the second quantitative study in this review (Crombez et al., 2020). The mixed-methods study was a modified Delphi study, which included quantitative and qualitative analyses in the final round of their study (Sleijser-Koehorst et al., 2019). One study used a formal systematic review and a qualitative meta-synthesis design (Synnott et al., 2015). The final study involved developing a conceptualization of catastrophizing and informally reviewed conceptual models (Flink et al., 2013).

Research Areas and Participants

The studies included in this review represent viewpoints from clinicians and patients. Seven out of nine studies focused on clinicians' and researchers' perceptions, and only three focused on patients' perspectives and experiences. Four studies discussed renaming the construct (Amtmann et al., 2018, 2020; Crombez et al., 2020; Flink et al., 2013). Adults with chronic pain participated in three studies, and adolescents with chronic pain participated in one study

(Amtmann et al., 2018, 2020; Heffernan et al., 2021; Schütze et al., 2017). Physiotherapists participated in one study, and osteopaths participated in another (Pelekanou & Thomson, 2021; Synnott et al., 2015). Expert clinicians and researchers with various backgrounds participated in two studies (Amtmann et al., 2018; Sleijser-Koehorst et al., 2019). The study population was not specified in one study and was not applicable in another (Crombez et al., 2020; Flink et al., 2013). Table 2-1 provides a descriptive summary of the included studies.

Table 2-1

Descriptive Summary of the Included Studies

Authors (Year) <i>Country</i>	Research aims	Study design/methods	Study population	Relevant findings
Amtmann et al. (2018) <i>United States</i>	To develop an item bank to measure PC. Part one of a two-part study.	Qualitative. An expert panel, patient advisors, focus groups, CIs. Followed PROMIS framework.	Pain clinicians and researchers, individuals with CP.	Participants in focus groups found it difficult to discuss PC as they felt catastrophizing was unhelpful and made it harder to live with CP. Participants felt that the term PC has a negative connotation and worried PC scores would support clinicians' belief that their pain is not real or be used to deny treatment. Of the 40 PC items, 38 were deemed problematic by participants and underwent revisions. The new scale was named <i>Pain Appraisal Scale</i> .
Amtmann et al. (2020) <i>United States</i>	To develop an item bank to measure PC. Part two of a two-part study.	Quantitative. Psychometric methodology and IRT. Followed PROMIS framework.	People with LBP, knee OA, DM neuropathy, MS, SCI, pain-associated amputation.	Researchers developed a 24-item bank with reliability and validity to measure PC. The authors named the item bank <i>Concerns About Pain</i> (CAP) scale due to the stigma attached to catastrophizing. The authors recommended following the CAP scale with a positive construct because participants found items pejorative.

Table 2-1 (continued).

Authors (Year) <i>Country</i>	Research aims	Study design/methods	Study population	Relevant findings
Crombez et al. (2020) <i>Luxembourg</i>	To determine to what extent items from PC measures are relevant for the construct PC.	Quantitative. Discriminate content validity.	Not specified.	PC instruments had content that was equally well or even better captured by the constructs worrying about pain or pain-related distress. The authors recommended renaming PC to pain-related worrying. The authors argued that PC cannot be assessed by a self-report questionnaire, as PC requires contextual information and expert judgement.
Flink et al. (2013) <i>Not applicable</i>	To add to the existing theoretical models of PC by proposing a development of the conceptualization, catastrophizing, that stresses its function as an emotional regulator.	Informal review of conceptual models and a development of the conceptualization of catastrophizing.	Not applicable.	The authors conceptualized PC as repetitive negative thinking, with an intrinsic function to reduce negative affect. The authors suggested renaming PC to catastrophic worry.
Heffernan et al. (2021) <i>Ireland</i>	To explore beliefs about pain and experiences of catastrophizing and worry among adolescents with CP.	Qualitative. Critical realist and contextualism paradigm. Semi-structured interviews.	Adolescents with CP.	Participants described pain-related worries and thought of worry as fluid and impacting the mind, body, and behaviour. Participants also described disappointment, fear, and worry due to pain uncertainty and ineffective treatment. The authors concluded that there is a need for psychological interventions targeting acceptance of uncertainty and informing education on mind/body connections in adolescents with CP.

Table 2-1 (continued).

Authors (Year) <i>Country</i>	Research aims	Study design/methods	Study population	Relevant findings
Pelekanou & Thomson (2021) <i>United Kingdom</i>	To explore osteopaths' experiences, understandings, and attitudes towards PC in patients and their strategies to manage it.	Qualitative. Constructivist grounded theory. Semi-structured interviews.	Osteopaths	Participants found the construct PC useful and felt comfortable managing it in patients. Participants recognized that the term is problematic and results in stigmatizing patients. The authors concluded that osteopaths should avoid labelling patients as catastrophizers and instead should identify catastrophizing aspects of the patient's presentation, contextualized within their unique experience.
Schütze et al. (2017) <i>Australia</i>	To explore metacognitions by documenting attitudes towards rumination in patients with LBP.	Qualitative. Interpretative phenomenology. Semi-structured interviews.	Adults with LBP with high PCS scores (>30).	Participants had positive and negative attitudes towards rumination. Rumination was seen as a problem-solving and coping strategy. It was seen to cause psychological and social harm, exacerbate pain, and be uncontrollable.
Sleijser- Koehorst et al. (2019) <i>Netherlands</i>	To reach a consensus on the most relevant and feasible self- administered questionnaires to assess PC.	Mixed methods. Modified Delphi study with 3 rounds. Qualitative analysis of experts' experiences with questionnaires in round 3.	Experts with medicine, allied health, and psychology backgrounds.	A consensus was reached for the PCS and the revised version of the CSQ. The PCS was considered feasible and valid. The PCS was also described as suggestive and negative sounding. Experts reported that patients worry about how clinicians will perceive their responses.
Synnott et al. (2015) <i>Not applicable</i>	To identify PTs' perceptions about managing the cognitive, psychological, and social factors in people with LBP.	Systematic review and qualitative meta- synthesis of qualitative studies.	PTs with experience in treating patients with LBP.	Some PTs labelled patients with LBP as demanding, attention- seeking, and poorly motivated. PTs only partially recognized the roles that cognitive, psychological, and social factors play in LBP. PTs feel underprepared to address these issues.

Note. Chronic pain (CP), cognitive interviews (CIs), Concerns About Pain scale (CAP), Coping Strategies Questionnaire (CSQ), diabetes mellitus (DM), item response theory (IRT), low back pain (LBP), multiple sclerosis (MS), osteoarthritis (OA), pain catastrophizing (PC), Pain Catastrophizing Scale (PCS) Patient-Reported Outcome Measures Information System (PROMIS), physiotherapists (PTs), spinal cord injury (SCI).

Themes

The literature was mapped thematically into six different domains: (1) acceptance of the construct, (2) inability to measure pain catastrophizing, (3) stigma, (4) cognitive processes, (5) renaming the construct, and (6) perceptions of pain catastrophizing. An overview of the themes can be viewed in Table 2-2.

Table 2-2

<i>Themes</i>	<i>Authors (year)</i>
Acceptance	Amtmann et al. (2020) Amtmann et al. (2018) Flink et al. (2013) Pelekanou & Thomson (2021) Sleijser-Koehorst et al. (2019)
Inability to measure	Crombez et al. (2020)
Stigma	Amtmann et al. (2020) Amtmann et al. (2018) Crombez et al. (2020) Pelekanou & Thomson (2021) Sleijser-Koehorst et al. (2019) Synnott et al. (2015)
Cognitive processes	Amtmann et al. (2018) Heffernan et al. (2021) Schütze et al. (2017)
Renaming	Amtmann et al. (2020) Amtmann et al. (2018) Crombez et al. (2020) Flink et al. (2013)
Perceptions of pain catastrophizing	Pelekanou & Thomson (2021)

Acceptance

Our review identified that the construct pain catastrophizing is well-accepted by many researchers and clinicians (Amtmann et al., 2018, 2020; Flink et al., 2013; Pelekanou & Thomson, 2021; Sleijser-Koehorst et al., 2019). More specifically, some researchers and clinicians viewed pain catastrophizing as a clinically useful and measurable construct (Amtmann et al., 2018, 2020; Pelekanou & Thomson, 2021; Sleijser-Koehorst et al., 2019). Two studies in

this review aimed to develop a new measure of pain catastrophizing, suggesting that pain catastrophizing is a clinically relevant variable to measure in individuals with pain (Amtmann et al., 2018, 2020). Clinical experts also reported that the PCS is a valid and useful instrument to measure pain catastrophizing in people with chronic pain (Sleijser-Koehorst et al., 2019). Experts supported the utility of the PCS because standardized scores are available, fostering the belief that pain catastrophizing can be objectively measured (Sleijser-Koehorst et al., 2019). In addition to the perception that pain catastrophizing is measurable, several researchers and clinicians shared a similar conceptualization of the construct. Pain catastrophizing was often described as an exaggerated and negative cognitive response to pain, leading to sustained negative affect (Amtmann et al., 2018, 2020; Flink et al., 2013; Pelekanou & Thomson, 2021). Pain catastrophizing was also widely recognized as contributing to poor pain-related outcomes (Amtmann et al., 2018, 2020; Flink et al., 2013). Osteopaths in one study described pain catastrophizing as a useful clinical construct because it highlights psychological barriers to pain management, is helpful to communicate with other clinicians, and identifies predictors of chronicity (Pelekanou & Thomson, 2021). These participants also felt that using pain catastrophizing in clinical practice can help understand the context of the patient's response to pain (Pelekanou & Thomson, 2021). However, pain catastrophizing measures only capture the psychological elements of the pain experience at the individual level and leaves out the social context of patients' lives. A new conceptualization, discussed by Flink et al. (2013), conceptualizes pain catastrophizing as a form of negative repetitive thinking and problem-solving behaviour. This conceptualization builds on the many models and theories used to describe pain catastrophizing (Flink et al., 2013). Attempts to explain and interpret pain catastrophizing through models and theories suggest acceptance of the construct. Overall, several

clinicians and researchers viewed pain catastrophizing as an acceptable and clinically useful construct to measure in individuals who experience pain.

Inability to Measure

Although most researchers and clinicians accepted pain catastrophizing as a measurable construct, one research group did not support this view. Crombez et al. (2020) argued that self-report instruments cannot measure pain catastrophizing. In this discriminant content validity, items of six common pain catastrophizing measures were complemented with items from questionnaires measuring other related constructs, including pain-related worrying, vigilance, pain severity, distress, and disability (Crombez et al., 2020). English speaking, adult participants, recruited via a recruitment application rated to what extent each item was appropriate for measuring pain catastrophizing and the other related constructs using an online survey (Crombez et al., 2020). Findings revealed that the items of the pain catastrophizing measures were equally well, or even better, captured by pain-related worrying or pain-related distress; thus, the researchers raised doubts about the ability of self-report instruments to truly measure pain catastrophizing (Crombez et al., 2020). The standardization of pain catastrophizing measures agreed upon in the other studies was also disputed by Crombez et al. (2020). The researchers argued that the reference standard required to measure pain catastrophizing would involve determining that someone's beliefs about their pain experience are exaggerated or incorrect (Crombez et al., 2020). Making inferences about the reality of an individual's pain experience requires an objective measure of actuality, the population standard for worrying about pain, and an expert judgment that the individual's perception is extreme (Crombez et al., 2020). These elements and the contextual information required to make expert judgements are not provided by self-reported measures (Crombez et al., 2020). Though the researchers did not elaborate on the

contextual information required to assess pain, social inequities would be important to address and are not included in measures of pain catastrophizing. The authors concluded that pain catastrophizing cannot be measured, and instead, pain catastrophizing measures should be renamed to pain-related worrying (Crombez et al., 2020). These findings provide a stark contrast to the commonly held view that pain catastrophizing is a valid and measurable construct.

Stigma

Several researchers, clinicians, and patients recognized the stigma attached to the term pain catastrophizing (Amtmann et al., 2018, 2020; Crombez et al., 2020; Pelekanou & Thomson, 2021; Sleijser-Koehorst et al., 2019). Many clinicians and researchers viewed the term as suggestive, negative sounding, and stigmatizing (Amtmann et al., 2020; Sleijser-Koehorst et al., 2019). Osteopaths in one study described the term as a “pejorative” (p. 4), “judgemental” (p. 4), and “psychosocial” (p. 7) patient label that may hinder the ability to treat patients and understand their pain experience effectively; however, these same participants also reported that pain catastrophizing is a clinically useful construct (Pelekanou & Thomson, 2021). This contradiction highlights the muddled nature of how clinicians perceive the term as harmful, yet it continues to be widely used and even thought of as useful. In another study, researchers removed the word catastrophizing from the title of their pain catastrophizing measure to reduce the stigma experienced by patients (Amtmann et al., 2020). The possibility of patients’ pain experience being dismissed by clinicians based on pain catastrophizing scores was also acknowledged by researchers and expert clinicians (Amtmann et al., 2020; Sleijser-Koehorst et al., 2019). Amtmann et al. (2020) developed a guidance document for clinicians on how to interpret their pain catastrophizing instrument in a way that validates patients’ pain and reduces stigma. Researchers reported that the stigma associated with the term pain catastrophizing and the

negativity of the items used to measure the construct might leave patients feeling misunderstood or depressed (Amtmann et al., 2020; Crombez et al., 2020). One group of researchers recommended administering a measure of a more positive construct after their pain catastrophizing instrument to balance the negativity (Amtmann et al., 2020). Osteopaths also cautioned that, in conversations with patients, the term pain catastrophizing should be framed in a way that does not imply their experience is psychosomatic or fabricated (Pelekanou & Thomson, 2021). The findings from these studies highlight how frequently researchers believe the term can be used in a negative way that confers stigma and patient blame.

Only one study in this review, completed by Amtmann et al. (2018), explored how patients experience the term pain catastrophizing. Almost all patients in this study reported that the term pain catastrophizing has a negative connotation and is stigmatizing (Amtmann et al., 2018). Patients felt that the term makes it seem like they are making up their pain or making it seem worse than it is (Amtmann et al., 2018). Patients worried that their pain catastrophizing scores would reinforce clinicians' beliefs that their pain was exaggerated or be used to deny interventions, a fear also acknowledged by clinicians and researchers (Amtmann et al., 2018, 2020; Sleijser-Koehorst et al., 2019). In developing a new pain catastrophizing measure, Amtmann et al. (2018) reported that 95% of items required revisions because they were deemed problematic by participants in cognitive interviews. Even after revisions, participants still felt that the items were pejorative (Amtmann et al., 2018). These findings demonstrate that patients' perceptions of pain catastrophizing are underrepresented in the literature. It is essential to gain a deeper understanding of patients' experiences to facilitate patient-centred care and minimize stigma.

Most clinicians and researchers recognized and attempted to minimize the stigma associated with pain catastrophizing; however, some clinicians might inadvertently add to the stigma (Pelekanou & Thomson, 2021; Synnott et al., 2015). Synnott et al. (2015) found that some physiotherapists labelled patients presenting with behaviours suggestive of cognitive, social, and psychological factors as being difficult, complex, and challenging. Additionally, Synnott et al. (2015) suggested that to some clinicians, catastrophizing is understood to contribute to extravagant behaviours, with one physiotherapist referring to patients as “those extravagant pain people” (Synnott et al., 2015, p. 73). Further, a qualitative study found that osteopaths believed pain catastrophizing helps identify risks for chronicity and differentiate “whether someone is a very simple patient or a really complicated patient” (Pelekanou & Thomson, 2021, p. 4). Associating behaviours deemed as catastrophizing with being a so-called complicated patient automatically puts the patient at a disadvantage and may foster preconceived stigmatizing attitudes. Osteopaths also reported that they were judgemental towards patients they believed were catastrophizing at the beginning of their career and would blame the patient for their emotional response to pain (Pelekanou & Thomson, 2021). There is a clear need to develop effective strategies to minimize the stigma associated with the term pain catastrophizing.

Cognitive Processes

Three studies in this review focused on the cognitive processes of behaviours believed to be associated with pain catastrophizing, such as rumination and worry, from patients’ perspectives (Amtmann et al., 2018; Heffernan et al., 2021; Schütze et al., 2017). Rumination, a core dimension of alleged pain catastrophizing, was the topic of interest in the study conducted by Schütze et al. (2017), focusing on adults with chronic low back pain. The experience of worry in adolescents with chronic pain was explored in another study (Heffernan et al., 2021). The final

study exploring patients' cognitive processes focused on pain catastrophizing as a whole (Amtmann et al., 2018).

Adolescents with chronic pain described worry as being fluid and impacting the mind, body, and behaviour (Heffernan et al., 2021). Participants often conceptualized worry as a cognitive process that impacts thinking patterns, such as ruminating or “thinking about it all the time” (Heffernan et al., 2021, p. 462). Worry was also felt physically within the body, with one participant describing it as feeling just “like butterflies” (Heffernan et al., 2021, p. 462).

Adolescents in this study described worry as a “ripple effect”, in that one worry often ripples to cause many other worries (Heffernan et al., 2021, p. 462). Pain-related worries, such as the functional impacts of pain and fear about the future impacts of pain on participants' lives, were also discussed (Heffernan et al., 2021). Adolescents believed that pain-related worry and distress were mostly due to living with uncertainty about the trajectory of their pain (Heffernan et al., 2021). Further, participants described a cycle of hope followed by disappointment due to limited success in attempts to treat their pain (Heffernan et al., 2021).

Several participants described thinking about what the researchers termed the worst-case scenario when ruminating or worrying about their pain (Amtmann et al., 2018; Heffernan et al., 2021; Schütze et al., 2017). Adolescents with chronic pain sometimes worried that they would experience serious harm, such as seizures or amputations, due to their pain (Heffernan et al., 2021). These adolescents attributed this thinking to their pain's uncertain and unpredictable nature (Heffernan et al., 2021). However, given that pain is a response to actual or potential tissue damage, these thoughts described as worst-case scenario thinking are not unreasonable (Raja et al., 2020). Adults with chronic pain also experienced worst-case scenario thinking and viewed this type of thinking as a coping strategy, providing them with a sense of preparedness

(Schütze et al., 2017). Ruminating was also seen as a coping mechanism, as participants believed it helps them solve problems by encouraging them to engage in helpful behaviours (Schütze et al., 2017). However, some participants recognized that their attempts to solve problems with repetitive thinking patterns are often unsuccessful (Schütze et al., 2017). Likewise, adolescents with chronic pain viewed worrying as both helpful and unhelpful in influencing behaviour (Heffernan et al., 2021). Participants explained that worrying promotes caution and productivity, yet it also leads to avoiding activities, such as going out with friends (Heffernan et al., 2021). Social harms, such as damaged relationships resulting from pain, was a common fear expressed by many participants (Amtmann et al., 2018; Schütze et al., 2017). Participants described the negative spiral they often fall into while in pain and their fear of “losing everybody around [you] that cares a little bit” as a result (Amtmann et al., 2018, p. 112). Participants also reported that repetitive negative thinking and worrying about pain have psychological consequences, such as depression, stress, anxiety, anger, sadness, and helplessness (Amtmann et al., 2018; Heffernan et al., 2021; Schütze et al., 2017).

Without agreeing with the term, participants perceived that the behaviours associated with pain catastrophizing, such as worry and rumination, were difficult to control due to the constant nature of their pain (Amtmann et al., 2018; Heffernan et al., 2021). One participant shared, “I am constantly in pain and constantly thinking about the pain level that I’m in and how I can get out of it... So, you’re pretty much constantly thinking about it” (Schütze et al., 2017, p. 472). Overall, participants felt that ruminating and worrying are unhelpful and make their pain worse; however, due to the constant nature of chronic pain, these behaviours may be unavoidable and difficult to control (Amtmann et al., 2018; Schütze et al., 2017). These findings provide

valuable insights into patients' pain experiences and the subsequent unavoidable negative thinking and worrying, often labelled as pain catastrophizing.

Renaming

Renaming the construct was suggested in four studies (Amtmann et al., 2018, 2020; Crombez et al., 2020; Flink et al., 2013). Crombez et al. (2020) proposed changing the term pain catastrophizing to pain-related worrying to facilitate a more person-centred approach. Pain-related worrying was proposed as the new term because it was found that standard measures of pain catastrophizing had content that was better captured by the construct worry about pain (Crombez et al., 2020). Additionally, researchers felt this new term would minimize stigma and encourage clinicians to explore what patients are specifically worried about (Crombez et al., 2020). In another study, Amtmann et al. (2018) changed the name of their pain catastrophizing measure to the *Pain Appraisal Scale* and later to the *Concerns About Pain* scale (Amtmann et al., 2020). Researchers renamed their instrument because participants with chronic pain reported that the term pain catastrophizing is stigmatizing (Amtmann et al., 2018; 2020). Researchers believed that excluding catastrophizing from the instrument name would minimize stigma and facilitate more appropriate clinical interpretations of their instrument (Amtmann et al., 2018; 2020). However, participants still felt that the items of the instrument were negative. Lastly, Flink et al. (2013) suggested renaming pain catastrophizing to catastrophic worry due to the many similarities between the different forms of negative thinking. Flink et al. (2013) argued that catastrophic worry provides a more precise description of what they believe pain catastrophizing entails: negative repetitive thinking. However, all of these studies believe that the term is capturing something clinically useful, and rather than retiring the concept entirely, they instead want to simply rename it.

Perceptions of Pain Catastrophizing

Only one study in this review explicitly focused on how clinicians, specifically osteopaths, perceive the construct pain catastrophizing using a qualitative approach (Pelekanou & Thomson, 2021). For the most part, osteopaths associated pain catastrophizing with ruminating, helplessness, and exaggeration (Pelekanou & Thomson, 2021). Participants in this study described pain catastrophizing as an exaggerated response to pain that “is disproportionate to what is actually going on physically” (Pelekanou & Thomson, 2021, p. 3). Further, osteopaths believed that pain catastrophizing is related to how the brain modulates the degree of pain experienced depending on the context, including elements like mood, anxiety, and fear (Pelekanou & Thomson, 2021). Participants believed pain catastrophizing to be distinct from anxiety, which they viewed as an appropriate response to a stressful situation; however, the researchers perceived pain catastrophizing as lacking what they called a “logical degree of awareness or reflection” (Pelekanou & Thomson, 2021, p. 3). Finally, participants in this study understood pain catastrophizing as an extremely negative reaction by patients, often resulting in worst-case scenario thinking or viewing pain as “apocalyptic” (Pelekanou & Thomson, 2021, p. 4). Osteopaths in this study also discussed their attitudes towards patients they labelled as pain catastrophizers. Participants reported that earlier in their careers, they were more likely to be judgemental of patients demonstrating signs of catastrophizing and even blame patients for their pain response (Pelekanou & Thomson, 2021). However, over time and with clinical experience, they acknowledged the negative impact of labelling patients (Pelekanou & Thomson, 2021).

Discussion

This scoping review synthesized the literature on how pain catastrophizing is understood, experienced, and described by clinicians, researchers, and patients over the last eleven years.

Findings from this review demonstrate that many clinicians accept pain catastrophizing and believe it to be a measurable construct, yet there are many tensions around the term, including stigma and the belief by some clinicians that pain catastrophizing cannot be assessed objectively. Some researchers have raised doubts about the ability to measure pain catastrophizing because it requires judging that the experience of a person's pain is worse than the situation demands, which is currently impossible given that pain is a subjective experience. Instead, these researchers suggested renaming pain catastrophizing measures to pain-related worrying (Crombez et al., 2020). These findings underscore the current issues with the concept of pain catastrophizing and resulting problems with its measurement. Pain catastrophizing instruments are rooted in a psychological model, which leaves out context, individual experiences, social factors, and any understanding of health inequity (Crombez et al., 2020; Martorella et al., 2008). The term and instruments measuring the concept support a paternalistic approach to medicine in which the physician is the expert, and the patient is problematized. Osteopaths in one study supported the idea of a paternalistic approach by admitting that they blamed patients they believed were pain catastrophizing in the early stages of their careers (Pelekanou & Thomson, 2021). Research supports that patients include experiences and sensations other than pain intensity in their ratings in commonly used pain intensity measures, suggesting that pain intensity cannot be accurately captured by self-report instruments (Robinson-Papp et al., 2015). Pain is a subjective experience influenced by various biological, psychological, and social factors (Raja et al., 2020). For example, research supports that people with lower socioeconomic status experience poorer chronic pain outcomes than those with higher socioeconomic status (Booher, 2019). However, social factors that may impact the pain experience are not reflected in pain catastrophizing measures.

Therefore, clinicians must consider the multiple influences contributing to the individual experience of pain rather than relying on self-report questionnaires that decontextualize the pain experience from other important influences. Moreover, clinicians should consider the possibility that catastrophizing behaviour is a normal response to debilitating pain and suffering, or lack of access to effective treatment, rather than a cause of increased pain and poor outcomes (Martorella et al., 2008). Patients' responses to pain should no longer be labelled as pain catastrophizing, and clinicians should instead consider catastrophizing behaviours to be a normal response to pain and its subsequent impacts on patients' lives. However, the current literature mapped in this review suggests that we are still far away from such a position in relation to how people with chronic pain are understood and treated.

Findings from this scoping review shed light on the issues surrounding the ambiguity of pain catastrophizing as a unique construct, the lack of clarity regarding what is being measured, and if such a construct is even measurable. Many researchers have challenged whether pain catastrophizing is a redundant construct or a distinct entity, making it unclear what the construct is actually measuring (Leung, 2012; Quartana et al., 2009). Researchers argue that pain catastrophizing is not conceptually distinct from other related psychological constructs, such as depression, anxiety, and worry (Quartana et al., 2009). Furthermore, pain catastrophizing is thought to be an additional variable that taps into the idea of a negative pain schema, which is believed to include pain anxiety, fear of pain, and helplessness (Quartana et al., 2009). However, this idea of a negative pain schema does not acknowledge that worry, fear, anxiety and helplessness may be normal responses to chronic pain and the ensuing losses it causes in the lives of sufferers, such as loss of employment, social isolation, and loss of independence. Shifting our focus to the material consequences of chronic pain, its inadequate treatment, and

lack of access to appropriate care, and away from psychological responses, such as anxiety, would result in an increased focus in studying how to provide timely and effective care.

Individuals with chronic pain commonly report experiencing stigmatization by others, including their clinicians (Allvin et al., 2019; De Ruddere & Craig, 2016; Slade et al., 2009). A study completed by De Ruddere et al. (2014) found that clinicians take patients' pain without a known medical cause and in the presence of psychosocial influences, such as job stress, relational problems, and depression, less seriously. Furthermore, some have argued that diagnostic labels used to classify patients activate stigma and stereotypes, creating barriers to quality patient care (Garand et al., 2009; Knaak et al., 2017). Attaching a psychological label, such as pain catastrophizing, to a patient can lead to clinicians focusing on the label rather than on the individual experience (Pelekanou & Thomson, 2021). Further, psychological labels devalue the pain experience, encourage stigma, and dismiss patients' concerns (Amtmann et al., 2018; Pelekanou & Thomson, 2021). These findings support the notion that labelling patients' experiences of pain as catastrophizing creates stigma and ultimately hinders pain outcomes. In this review, patients and clinicians acknowledge the stigma associated with pain catastrophizing and the possibility that pain catastrophizing scores will be used to invalidate pain experiences or withhold treatment (Amtmann et al., 2020; Pelekanou & Thomson, 2021; Sleijser-Koehorst et al., 2019). Nevertheless, they continue to support the construct and conduct research to improve its measurement. Finally, assessing pain catastrophizing means establishing that someone's pain experience is wrong or exaggerated, which problematizes the patient and further perpetuates stigma (Crombez et al., 2020; Martorella et al., 2008). Using language that fosters patient blame, stigma, and invalidates patients' experiences may create barriers to effective pain management

(Carr, 2016). Therefore, clinicians should carefully consider using pain catastrophizing measures and terminology in their practice.

Several of the researchers in this review have acknowledged the stigma associated with the term pain catastrophizing and support an increased effort to minimize these stigmatizing attitudes (Amtmann et al., 2018, 2020; Crombez et al., 2020; Pelekanou & Thomson, 2021; Sleijser-Koehorst et al., 2019). One solution for minimizing the term's stigmatizing effects is to rename the construct, and various suggestions were proposed to rename pain catastrophizing instruments. However, renaming does not mean the concept has shifted, and patients in one study reported that the items measuring pain catastrophizing were still pejorative even after renaming the instrument. The use of stigmatizing labels has been widely recognized with the term schizophrenia. Research in this area shows that changing the name of schizophrenia does not resolve the stigma associated with the condition, and efforts need to address the way mental illness is perceived by the public and clinicians (Gaebel & Kerst, 2019). Researchers suggest that education, positive advocacy, and reconceptualization are required to adequately address the stigma of schizophrenia (Gaebel & Kerst, 2019). Likewise, it is possible that minimizing the stigma associated with pain catastrophizing will require similar measures, specifically addressing the way clinicians perceive chronic pain. Renaming pain catastrophizing only partly addresses the stigma; thus, research instead should focus on developing more effective approaches to reduce the stigma associated with chronic pain and developing more effective treatments for those who suffer.

The small number of studies relevant to the research purpose indicates the need for further research on this topic. Although interest in the term pain catastrophizing has proliferated since introducing the PCS, patients' perceptions of pain catastrophizing are largely

underrepresented in the literature. A concept analysis conducted by Martorella et al. (2008) found that patients' perspectives and experiences of pain catastrophizing were mainly ignored. Our scoping review echoes this finding, with only three studies representing patients (Amtmann et al., 2018; Heffernan et al., 2021; Schütze et al., 2017). The lack of diverse perspectives leaves out an important piece of the phenomenon, such as the possibility of behaviour labelled as catastrophizing to be a normal response to pain and suffering (Martorella et al., 2008). Patients are in an ideal position to help enhance our understanding of the term pain catastrophizing and surface the dehumanizing aspects of the term; therefore, patients' perspectives need more representation in the literature utilizing a qualitative approach. It is also important to note that the involvement of nurses was not identified in any of the studies included in this review, despite their key role in pain assessment and management (Lewthwaite et al., 2011). Exploring nurses' attitudes and perceptions of the term pain catastrophizing may provide useful insights into the clinical use of the term and its impact on patients given their close relationship with patients and their professional commitment to patient advocacy (Lewthwaite et al., 2011).

Of the studies included in this review, six incorporated a qualitative component (Amtmann et al., 2018; Heffernan et al., 2021; Pelekanou & Thomson, 2021; Schütze et al., 2017; Sleijser-Koehorst et al., 2019; Synnott et al., 2015). The studies that utilized qualitative approaches have provided valuable insights into how patients experience the term pain catastrophizing and have uncovered the problematic nature of the term. Qualitative research provides descriptions of experiences that are personalized and subjective while also considering the unique context of people's lives (Morse, 2012). Critical qualitative research also provides theories and concepts that position individual experiences within the broader context of participants' lives, taking into account issues such as marginalization and structural inequities. In

the context of chronic pain, this can expose important elements of the pain experience, such as racism or structural violence, that are not accessible with quantitative approaches (Osborn & Rodham, 2010). Finally, a qualitative approach can identify how the term influences care from patients' perspectives and reveal consequences resulting from the term that cannot be easily seen (Martorella et al., 2008; Morse, 2012). It is imperative that future research on the term pain catastrophizing adopts qualitative methodologies to further uncover attitudes towards the term and the problems associated with its clinical use.

Strengths and Limitations

This scoping review was the first review to explore how pain catastrophizing is understood, experienced, and described by clinicians, researchers, and patients. An important strength of this scoping review is adhering to the rigorous methodological approach developed by Arskey and O'Malley (2005) while also considering recommendations proposed by Levac et al. (2010). Only one reviewer (RL) was involved in study selection and data charting, which may impose reviewer bias; although, a second reviewer (FW) was consulted whenever uncertainty was met. Excluding grey literature for feasibility reasons and having only one reviewer select studies may increase the risk of lost information. However, the search strategy was developed with an experienced librarian, and the search was exhaustive and comprehensive. Lastly, only studies in the English language were selected, which may increase the risk of publication and language bias.

Conclusion

This scoping review mapped the literature on how clinicians, researchers, and patients understand, experience, and describe pain catastrophizing. Findings from this scoping review have identified important contradictions between problematizations of the concept's validity, its

role in producing stigma, and its continued use in clinical settings. Our findings also reveal a paucity of research on patients' perceptions and experiences with pain catastrophizing. Future research should employ critical qualitative methodologies to represent patients' perspectives by capturing the subjective experience of chronic pain in ways that are sensitive to issues such as marginalization and health inequities. Qualitative research approaches could identify which patients are most likely to be labelled as catastrophizers, such as members of racialized communities and women, given the bias and systemic discrimination in the health care system that may disadvantage these groups when seeking pain treatment. More effective strategies are required to minimize the stigma associated with the term pain catastrophizing and chronic pain as a whole. Although research on pain catastrophizing measures is useful to inform theory, these measures may have little clinical use, undermine treatment, and amplify patient blame. Instead, future research should explore this construct's use in clinical practice and ways in which stigma can be reduced. Clinicians are catalysts for change and are well suited to challenge the acceptance of pain catastrophizing as a legitimate and measurable construct and question who benefits from this construct. Additionally, the potential for pain catastrophizing behaviours to be a normal reaction to pain and suffering rather than being viewed as a cause for worse pain and poor outcomes needs to be considered. Labelling behaviour as catastrophizing and utilizing pain catastrophizing measures should be carefully considered to minimize feelings of stigma and blame. Perhaps, clinicians should consider eliminating pain catastrophizing measures from their practice and lexicon.

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Chapter 3: “Pain is What the Patient Says it is”: A Secondary Analysis of Nurses’ Reflections on the Term Pain Catastrophizing

The pain experience is personal, subjective, and influenced by various biological, psychological, and social factors (Raja et al., 2020). The biological causes of pain have dominated the literature for years; however, psychological and social elements have become progressively identified as having significant influences on pain (Quartana et al., 2009). In particular, one psychological element that has become of interest to researchers is pain catastrophizing (Quartana et al., 2009). Pain catastrophizing is described as “an exaggerated negative mental set brought to bear during actual or anticipated painful experiences” (Sullivan et al., 2001, p. 53) and has become a widely used concept clinically and within the scholarly literature despite mounting concerns about both its conceptualization and its role in stigmatizing people who experience pain.

Background and Significance

As noted in Chapter 2, the term catastrophizing first emerged in relation to emotional dysfunction rather than in relation to chronic pain (Neblett, 2017; Quartana et al., 2009). It was later adapted to describe a maladaptive cognitive technique used by individuals with depression and anxiety (Quartana et al., 2009). It is unclear when pain-related catastrophizing was introduced; however, research on pain catastrophizing escalated after the development of the *Pain Catastrophizing Scale* (PCS) in 1995 (Neblett, 2017; Sullivan et al., 1995). The scale brought legitimization to the concept and helped promote its entry into medical use. The catastrophizing subscale of the *Coping Strategies Questionnaire* is another standard pain catastrophizing measure that includes six self-report items focusing on helplessness and pessimism in the context of pain (Quartana et al., 2009; Rosenstiel & Keefe, 1983). Since

introducing these measures, pain catastrophizing has become inserted as an important determinant of pain-related outcomes, such as higher pain intensity, disability, anxiety, and depression (Neblett, 2017; Quartana et al., 2009). Clinicians have come to consider pain catastrophizing a risk factor for predicting poor outcomes and chronicity of pain (Leung, 2012).

A review of the literature discovered that patients' and clinicians' perceptions of the term pain catastrophizing are largely understudied. Further, to our knowledge, there is no existing research that explores how nurses perceive the term. Overall, patients and clinicians think the term is stigmatizing and suggestive (Amtmann et al., 2018, 2020; Pelekanou & Thomson, 2021; Sleijser-Koehorst et al., 2019). Clinicians also acknowledge that pain catastrophizing scores may be misinterpreted and used to deny treatment (Amtmann et al., 2018, 2020; Sleijser-Koehorst et al., 2019). Moreover, Crombez and colleagues (2020) argue that pain catastrophizing cannot be measured with self-report questionnaires because these measures do not assess contextual information. These researchers emphasize the personal and subjective nature of pain and claim that clinicians need to consider the context of the pain experience to make an expert judgment that an individual's perception of their pain is extreme (Crombez et al., 2020). This still retains the idea that the clinician, rather than the patient, can determine what the pain experience is. Analyzing the existing research has uncovered the problematic nature of the term pain catastrophizing and highlights the need to explore perceptions of the term further, specifically, the need to explore nurses' perceptions.

The nursing perspective is valuable given that nurses frequently have the closest contact with patients and are often the first point of contact (Kress et al., 2015). Nurses are at the centre of pain management through their role in assessing pain, administering pain medication, advocating for adequate pain management, and assessing the effectiveness of pain treatments

(Lewthwaite et al., 2011; Ware et al., 2011). Therefore, insights into the term pain catastrophizing from nurses may enable the development of effective strategies to minimize the stigma attached to the term and help identify if the term creates any barriers to care, such as withholding treatment. The primary goal of the nursing profession is advocating for patients while providing high-quality patient-centred evidence-based care. More specifically, in a study completed by Pellico et al. (2014), nurses who care for people with chronic pain described patient advocacy as an important part of their position that allows them to provide patient-centred approaches to pain; thus, it is critical to understand pain catastrophizing from a nursing viewpoint to foster positive change and refinement of the construct (Tingen et al., 2009). Further, nursing-led research is recognized as a vital mechanism to improve patient outcomes, making nurses well situated to lead and participate in this research. Nurses are essential to translate research into practice, which facilitates cultural and behavioural practice changes (Curtis et al., 2017; Powers, 2020). As pain catastrophizing continues to be a widely used clinical construct, it is crucial to explore how nurses understand, describe, and interpret the construct to facilitate higher quality patient-centred care and improve patient outcomes. Therefore, this study aims to answer the following question: how is the term pain catastrophizing interpreted and understood by nurses?

Methods

This study is a secondary analysis of open-ended survey data utilizing a subset of data collected by Stanford University from their study *Rename Pain Catastrophizing* (Stanford University, n.d.-c). The primary study aims to understand patients', researchers', and health care professionals' perspectives of the term pain catastrophizing and to create new terminology that is more patient-centred (Stanford University, n.d.-c). The motivation behind the primary study was

based on anecdotal evidence that both patients and clinicians find the term unhelpful and believe it contributes to distress and patient alienation (Pearce, 2020; Stanford University, n.d.-b). The original study's researchers collected data via two anonymous online surveys available internationally: (1) health care professional or researcher survey, and (2) patient or caregiver survey (Stanford University, n.d.-c). Survey data was collected anonymously from May 2020 to August 2020 and included demographic, close-ended, and open-ended questions (Stanford University, n.d.-a). The health care professional and researcher survey targeted pain researchers and clinicians. Detailed information about respondents' professions was asked in the survey questions (Stanford University, n.d.-b). The patient or caregiver survey sought patients with ongoing pain or who have experienced pain in the past and caregivers who care for people with ongoing pain (Stanford University, n.d.-d).

A focused secondary analysis of the open-ended responses from nurses within the health care professional and researcher survey was conducted to answer the research question for this study. According to Heaton (2008) and Braun and Clarke (2021), open-ended survey responses can be considered qualitative data. Heaton (2008) states that "secondary analysis involves the re-use of pre-existing qualitative data derived from previous research studies. These data include material such as semi-structured interviews, responses to open-ended questions in questionnaires, field notes and research diaries" (p. 34). Secondary analysis aims to investigate new or additional research questions (Heaton, 2008). This study used secondary analysis to investigate new research questions surrounding nurses' perspectives of pain catastrophizing using data from the primary study. Supplementary analysis, a subtype of secondary analysis, was used for this study (Heaton, 2004). Heaton describes supplementary analysis as providing a more in-depth investigation of an aspect of the data that is only partially addressed in the primary study

(Heaton, 2008). Although nurses' perspectives are considered in the primary study, the focus is on the perspectives of researchers, health care professionals, and patients as a whole, with an overall goal of determining whether it is time to change the term pain catastrophizing (Stanford University, n.d.-c). Focusing on the responses from nurses within the health care professional survey allows a more detailed investigation of how nurses understand the construct; therefore, supplementary analysis was used as an adjunct to the primary work (Heaton, 2004).

The open-ended questions that were asked in the primary survey were as follows: (1) Please briefly describe what the term catastrophizing means to you. If you are unsure, please just jot down a few words that come to mind that you associate with the term, (2) Have you ever used the term pain catastrophizing in the context of your communications with patients? If yes, can you describe how patients respond to the term? (3) Please tell us what first comes to your mind when you hear the term pain catastrophizing, and (4) Is there anything else you would like to tell us on this topic? Please feel free to attach a separate page if you'd like to provide further comments or insights (Stanford University, n.d.-b). Nurses' responses to the demographic questions were also collected to provide a demographic summary and included: primary role (health care professional/researcher), pain specialist (yes/no), professional discipline, years in practice, age, gender, and country (Stanford University, n.d.-b).

Data Analysis

The paradigm informing this research was restricted by the original study design, which was situated in the post-positivist paradigm. Therefore, a critical lens could not be correctly applied as that would have required congruence in study design throughout and, importantly, a research design that elicited questions on social and structural issues. Instead, the data was based on four open-ended questions, two of which were overlapping. Therefore, a constructivist-

interpretivist paradigm was adopted to underpin thematic analysis. The constructivist-interpretivist paradigm views truth as socially produced, subjective, and dependent on individual experiences (Braun & Clarke, 2006; Miller & Crabtree, 1999; Ponterotto, 2005). This paradigm aims to theorize and understand the social, cultural, and structural contexts that facilitate individual data accounts (Appleton & King, 2002; Braun & Clarke, 2006). Analyzing the data within this paradigm is particularly useful to understand nurses' perspectives of the term pain catastrophizing. However, our ability to identify nurses' perspectives was limited to the four survey questions without any follow-up or prompts. A critical social lens was then drawn on to make sense of the significance of the findings in relation to the literature and uncover problems associated with the term pain catastrophizing (Weaver & Olsen, 2006). Drawing on the critical social paradigm allows researchers to raise awareness of social problems, examine the context of inequities that creates suffering, and challenge the status quo (Ponterotto, 2005; Weaver & Olsen, 2006). This approach is confirmed by Weaver and Olsen (2006), who suggest that a pluralist approach to research can be used to confront problems that cannot be addressed by adhering to a single paradigm.

Responses to the open-ended survey questions were analyzed using qualitative thematic analysis described by Braun and Clarke (2006). It is important to note that this does not in and of itself constitute qualitative research, which requires a qualitative design from the outset. However, thematic analysis can be conducted across many different data types, including survey data (Braun & Clarke, 2021, p. 22) and, therefore, can be used to identify, analyze, and report patterns and themes within a survey data set (Braun & Clarke, 2006). Furthermore, thematic analysis supports the presentation of credible, clinically, and theoretically relevant conclusions

(Braun & Clarke, 2006). Data analysis using a thematic analysis approach is predicated within a constructivist-interpretivist paradigm.

Data was organized into themes and meant to capture patterns in the data related to the research question (Braun & Clarke, 2006). Themes were organized around how respondents describe, view, conceptualize, understand, and measure pain catastrophizing, and how respondents describe and perceive patients they deem as catastrophizers. Qualitative survey data offers a “wide-angle lens” on a topic, providing the ability to capture diverse perspectives (Braun et al., 2020, p. 643). Therefore, this analysis sought to provide a detailed description of the entire data set, rather than focus on one particular aspect, given that the survey data set is broad rather than deep (Braun & Clarke, 2006). This analysis approach is useful for understudied areas and when studying groups whose views are not well understood (Braun & Clarke, 2006; Braun et al., 2020). The raw survey responses were reviewed to begin the process of preliminary data coding (Rouder et al., 2021). Codes were developed deductively from the four open-ended questions that respondents were asked; however, the subcodes were inductive and data-driven in that they were developed based on the responses to each question. From here, a coding framework was finalized and applied to the rest of the data (Rouder et al., 2021). Themes were identified from the codes and represent patterns and meaning in the data set (Braun & Clarke, 2006). The following six steps set out by Braun and Clarke (2006) were followed to complete the analysis: (1) familiarize yourself with the data, (2) generate initial codes, (3) search for themes, (4) review themes, (5) define and name themes, and (6) produce the report. NVivo 12 software was used to organize and manage the data.

Ethical Considerations

The primary study from which this data comes received a formal exemption from the Stanford Institutional Review Board (Stanford University, n.d.-a). This study received ethics approval from the Western University Health Science Research Ethics Board (see Appendix B for ethics certificate).

Findings

Demographic Summary

One hundred thirty-six survey respondents identified as nurses, although not all respondents responded to each question. All respondents identified primarily as health care professionals (100%). The majority of respondents identified as nurses (89.71%), followed by nurse practitioners (7.35%), nurse anesthetists (2.21%), and nurse-midwives (0.74%). Many nurses considered themselves pain specialists (46.32%); however, most nurses reported not being pain specialists (51.47%). Most nurses had more than ten years of practice experience (63.97%), followed by 5-10 years (19.85%), 1-4 years (13.97%), and less than one year (2.21%). The mean age of survey respondents was 49 years, with most nurses falling into the 51-60 age group (28.68%) and the fewest number of nurses in the 20-30 age group (8.09%) and 71-80 age group (2.21%). The survey respondents predominately identified as female (89.71%). The survey was available internationally; however, most respondents reside in the United States (58.82%), followed by the United Kingdom (16.18%) and Canada (12.5%). Additional respondent demographics are summarized in Table 3-1.

Table 3-1*Demographic Summary*

Variable	Respondents (N= 136) N (%)
Primary role	
Health care professional	136 (100%)
Researcher	0 (0%)
Pain specialist	
Yes	63 (46.32%)
No	70 (51.47%)
Did not answer	3 (2.21%)
Professional discipline	
Nurse	122 (89.71%)
Nurse practitioner	10 (7.35%)
Nurse anesthetist	3 (2.21%)
Nurse-midwife	1 (0.74%)
Years in practice	
Less than 1 year	3 (2.21%)
1 – 4 years	19 (13.97%)
5 – 10 years	27 (19.85%)
More than 10 years	87 (63.97%)
Age (years)	
Mean age (years)	49 years
20-30	11 (8.09%)
31-40	26 (19.12%)
41-50	32 (23.53%)
51-60	39 (28.68%)
61-70	22 (16.18%)
71-80	3 (2.21%)
Did not answer	3 (2.21%)
Gender	
Male	7 (5.15%)
Female	122 (89.71%)
Non-binary	1 (0.74%)
Prefer not to say	4 (2.94%)
Did not answer	2 (1.47%)
Country	
Australia	6 (4.41%)
Belgium	1 (0.74%)
Canada	17 (12.5%)
Iran	1 (0.74%)
Ireland	2 (1.47%)
Saudi Arabia	1 (0.74%)
Singapore	3 (2.21%)
United Kingdom	22 (16.18%)
United States	80 (58.82%)
Did not answer	3 (2.21%)

Themes

Nurses were asked four open-ended questions, as outlined above. The findings are organized around three themes that were identified based on the responses to the open-ended questions: (1) How nurses describe the term pain catastrophizing, (2) Application of the term and patient responses, and (3) Nurses' recommendations for the future. An overview of the themes and associated subthemes can be viewed in Table 3-2.

Table 3-2

Themes

Themes	Subthemes
How nurses describe the term pain catastrophizing	Exaggerated response Stigmatizing psychological behaviours Damaging consequences Dismisses patient concerns
Application of the term and patient responses	Patients' responses to the term Nurses' application of the term
Nurses' recommendations for the future	

Theme One: How Nurses Describe the Term Pain Catastrophizing

When asked how they understand the term, nurses, for the most part, included negative ideas in their descriptions of pain catastrophizing. The four most common descriptions of the term were captured as subthemes, including an exaggerated response, stigmatizing psychological behaviours, damaging consequences, and dismissing patient concerns. Nurses were asked two very similar questions: (1) Describe what the term pain catastrophizing means to you, and (2) What comes to mind when you hear the term pain catastrophizing? Therefore, the responses of these two questions were combined into theme one. Responses from the question, "Is there anything else you would like to tell us on the topic?" were also included if responses were related to how nurses understand or describe pain catastrophizing. However, the wording of these

questions did not allow the ability to clearly capture the difference between what nurses thought the term was meant to describe and whether or not they agreed with that description.

Subtheme One: The Term Describes an Exaggerated Response. Many nurses (79 responses) described pain catastrophizing as suggesting that patients exaggerate their pain; however, as noted, there is no way of knowing if the respondents supported this idea as being accurate or not. In other responses, it is clear that the respondents believed pain catastrophizing is an accurate label. Pain catastrophizing was associated with exaggeration in 79 responses.

Many respondents believed the term pain catastrophizing describes a response to pain that is disproportionate to the nature of pain in that the response is "dramatic" (Respondent 28) or an over-reaction. This thought is demonstrated in the following response: "A response to pain that is incongruent with injury or lack thereof so more pain than there should be" (Respondent 10). Although pain cannot be objectively measured, some nurses believed they know the level of pain the patient should be in and associated pain catastrophizing with "dramatizing" (Respondent 96), for example: "Patient exaggeration of pain. Patient is dramatizing pain and pain isn't as severe as reported by [the] patient" (Respondent 96). Some nurses described pain catastrophizing as a magnification of pain and pain-related impacts: "Intense, worry like thoughts about pain. Specifically, the magnification of the pain's present and future impacts, the likelihood that things will not improve, that the pain experience is intractable" (Respondent 123).

A small handful of nurses (4 responses) shared their belief that pain catastrophizing is a form of exaggerating in order to have attentional needs met, such as for treatment, emotional responses, or a need to be listened to or believed. One nurse believed pain catastrophizing is a way patients express a need for opioids: "Pain out of proportion, anxiously overstating pain symptoms and need for opiates" (Respondent 133). The following nurse highlighted that pain is

subjective and conceptualized pain catastrophizing as a *judgment* of someone else's pain level, for example, believing that the pain is being exaggerated to have needs met. This conceptualization contradicts some of the previous statements, in that some nurses felt they knew what an appropriate pain response was:

The judgement made when someone perceives and labels another person's subjective pain experience as an exaggeration to have some need met. The need may be variable, including: attempts to acquire controlled medication for reasons other than treating legitimate pain (substance abuse, financial gain/dealing, scoring for someone else's use); a pseudo addictive adaptation to have [their] subjective pain believed as real, serious, and needing adequate treatment; someone who is seeking an emotional response - pity, empathy, codependency, anger, etc.; a fear response of anticipated future pain; or a combination thereof. (Respondent 11)

In this next response, the nurse believed pain catastrophizing to be a strategy to get the listener to understand the severity of pain, "Pain terms exaggerated to inform the listener of how intense the patient interprets the pain experience to be" (Respondent 101).

In only two examples, the nurses were particularly stark in how they conceptualized pain catastrophizing. These nurses described patients exhibiting pain catastrophizing behaviours as "attention seeking" (Respondent 88). One nurse went on to describe pain catastrophizing as: "Exaggerated, unhealthy obsession with the negative. Drama. Attention seeking" (Respondent 28). In these responses, the nurses have attached stigmatizing judgements in their descriptions of pain catastrophizing.

Subtheme Two: The Term Describes Stigmatizing Psychological Behaviours. Many nurses described pain catastrophizing as being related to stigmatizing psychological behaviours, such as anxiety, worry, fear, and ruminating (66 responses). In this first example, the nurse described pain catastrophizing as ruminating over pain and not being able to control it: "Worry and rumination about pain. Lack of self-efficacy to control pain. Helpless around pain control"

(Respondent 9). Likewise, the following nurse described pain catastrophizing as an emotional response to pain, citing rumination and hopelessness: “Pain catastrophizing is a negative cascade of cognitive and emotional responses to actual or anticipated pain—magnification, rumination, and feelings of hopelessness” (Respondent 63). This description of pain catastrophizing supports the commonly held belief that pain catastrophizing encompasses psychological behaviours, such as magnification, rumination, and helplessness, as defined by Sullivan et al. (1995). Fear was commonly discussed within the responses. Nurses described pain catastrophizing to be associated with fear of pain and its subsequent impacts. The next nurse conceptualized pain catastrophizing as fear and the inability to control pain, which the previous respondents also discussed. This nurse also pointed to some things patients may be fearful of:

Fear. Fear of the pain returning and not being able to cope with it. Fear of running out of the medications that allow patients to function. Stress, anxiety, lack of control - over the pain itself, over whether or not I'll be able to get a refill in time, over being labeled a drug seeker because my pain is no longer controlled with my current medications/dose.
(Respondent 35)

Some nurses described pain catastrophizing as not having the mental capabilities to cope with the pain, in ways that seemingly place the responsibility on the patient:

It describes someone who, at that point in time, does not have the physical or mental skills or tools available to them in that moment to be able to cope with the pain they are experiencing or may experience in the future. (Respondent 1)

Many respondents related pain catastrophizing to negative thinking patterns. The following nurse understood pain catastrophizing to be focusing on the negative and, more specifically, thinking of the worst-case scenario, which was commonly discussed in the responses: “Pattern of thinking where thoughts go to the worst possible outcome. “Never get rid of the pain” or “My life is ruined because of this pain”” (Respondent 38).

Some respondents described pain catastrophizing as an emotional response with consequences on pain outcomes. This nurse believed that pain catastrophizing is an emotional response that makes the pain worse: “Emotional response to pain, either by person experiencing pain or by caregiver, that amplifies level of pain and impact on function” (Respondent 68). The following respondent described a similar thought identified in previous responses, which is the idea of pain being psychological and all in people’s heads, specifically that emotions can cause people to “will” (Respondent 120) themselves into pain. However, this nurse suggested that this idea is believed by those who have not experienced chronic pain: “The idea (by someone who has never experienced chronic pain) that pain and emotions are linked to such an extent that people in chronic pain *will* themselves into having unbearable pain” (Respondent 120). Lastly, the following nurse elaborated on this damaging sequel and described pain catastrophizing as a negative cognitive focus on pain that leads to worse outcomes, such as depression and anxiety:

An omnipresent cognitive focus on pain intensity by the patient with chronic pain that is predominantly negative resulting in undesirable outcomes such as the degree of disability a patient thinks they have, and an exacerbation/development of other comorbid conditions such as depression and anxiety. (Respondent 33)

Subtheme Three: The Term Has Damaging Consequences. Fewer respondents (38 responses) explicitly disagreed with the term and described it as stigmatizing and as having damaging consequences for patients, such as negatively affecting treatment. Although fewer nurses overtly disagreed with the term, these respondents were very vocal. One nurse firmly believed that the term pain catastrophizing “needs to be struck from clinical practice” because by using it, clinicians are “running the risk of significant patient harm” (Respondent 96). Further, many nurses described the judgemental nature of the term and how it is a barrier to understanding the pain experience, “...Pain is multifaceted, and [the] term feels judgemental and

limits understanding of the persons pain experience, as someone who has been living with chronic pain for many years” (Respondent 23). Some nurses went on to say that pain catastrophizing may negatively affect treatment. The following nurse suggested that the term is used as a negative and stigmatizing label for patients that clinicians do not want to treat:

“Doctors use it to label chronic pain patients that they don’t want to treat, similar to drug seeker, frequent flyer, junkie, faker” (Respondent 46). The following respondent described the subjective nature of pain, emphasizing that some clinicians believe they know what an appropriate level of pain is. This nurse also mentioned how the term could negatively affect treatment for these patients:

I've heard MDs and RNs say people are faking or unable to rate pain appropriately when their nonverbal cues don't match what they (MD/RN) feel the person's pain level "should" be. The word "catastrophizing" only reinforces that misconception and affects how people with pain are treated. It's high time for a change. (Respondent 88)

This next nurse further emphasized the effects the term can have on treatment or *lack* of treatment: “It is used in a negative manner to rationalize lack of treatment and dismiss pain patients who are in need of help” (Respondent 67). Some respondents felt that using the term pain catastrophizing is “blaming the patient” (Respondent 122) and exacerbating the stigma already faced by people living with chronic pain. This next nurse believed that the stigma associated with pain catastrophizing could lead to patients losing trust in their clinician: “That it’s unhelpful and stigmatizing and likely to compound problems and create mistrust between patient and health care worker” (Respondent 87). In this example, the nurse believed that pain catastrophizing exacerbates the bias against those who live with pain. This respondent also pointed to the subjective nature of pain, highlighting the fact that nobody can feel another person’s pain:

Catastrophizing increases the bias against pain patients that is already negatively skewed. It is demeaning. Pain and chronic pain is a subject that is hard enough for others to comprehend the severity of a person's pain especially when no one else can feel or necessarily see another person's pain. (Respondent 16)

Some nurses strongly felt that "pain is what the patient says it is" (Respondent 120) and emphasized the importance of believing patients. In the following example, the nurse forcefully felt that the term is a way to "humiliate" (Respondent 120) patients, and it should be eliminated. This nurse drew attention to the idea that pain is "all in their minds" (Respondent 120) and that instead, the attention should be placed on believing patients:

The term 'it is all in their minds' - we have lost the phrase - pain is what the patient says it is... If someone told me they were a doctor dealing with pain catastrophizing I'd see it as yet another way to humiliate patients who live in pain - PLEASE BAN THIS HORRIBLE WORD and make sure that the person who thought of it is subjected to a day of constant pain, then we will see how pain is perceived. (Respondent 120)

To contrast with the above responses, only four respondents explicitly stated that they agree with and support the term. One nurse believed that pain catastrophizing is an accurate term to describe how people feel when experiencing pain or in this "mental space", sharing, "[Pain catastrophizing is] an accurate description of the panic and distress that people feel when they are in this mental space" (Respondent 66). However, some of these nurses also recognized how the term could be suggestive or negatively perceived by patients. This next nurse explained how the term makes sense from a clinician standpoint; however, they recognized that the term suggests the patient is overreacting. This respondent also noted the personal nature of the pain experience:

As a healthcare provider the term makes perfect sense to me. If I were to use it with a patient, I feel I would have to preface with a definition, example, and get feedback from the patient. Pain is so personal and so many patients I see for pain are really protective

about their pain experience. If I were to say, “you seem to be pain catastrophizing”, it may seem like I am suggesting they are overreacting... (Respondent 129)

Subtheme Four: The Term May Be Used to Dismiss Patient Concerns. Some respondents (28 responses) felt that the term was misused by clinicians in that clinicians use the term to dismiss patients’ concerns and discount their pain experience. In this first example, the nurse believed the term is used by providers to dismiss patients’ experiences of pain. This nurse also described an ideal understanding of pain catastrophizing as a negative feedback loop:

Ideally, it [pain catastrophizing] refers to the negative feedback loop of "I'm in a lot of pain - I can't focus on anything else but my pain - I don't know how to get rid of the pain or get out of this overwhelming situation - pain has taken over my life and I don't know if it's ever going to be better". However, it's frequently used by health care professionals to dismiss, downplay, or "find an easy fix" for patients who are in pain and need help coping. (Respondent 22)

Some nurses believed that the term is used to diminish the pain experience. This next nurse described this and reiterated the association between pain catastrophizing and exaggerating, “This is an extreme diminishment of the patient’s pain experience. “Catastrophizing” immediately brings to mind someone saying that a person’s pain is not as bad as they experience it” (Respondent 93). A few nurses believed that clinicians use pain catastrophizing as a label to dismiss patients: “Sounds like the patient is in a real or future crisis and the healthcare community and professional is not interested in treating the pain but on labeling the patient” (Respondent 14). In the following example, the nurse believed that clinicians use the term as a “shortcut” to addressing and *understanding* the problem. This nurse also believed the term to be out of scope for most clinicians:

The definition is out of the scope of practice for the majority of medical professionals. The adoption of the term by medical professionals, is a shortcut to avoid true understanding of the complex experience of a patient with pain. (Respondent 47)

This next nurse strongly believed that the conceptualization of pain catastrophizing as an over-reaction is not valid because pain is a subjective and individual experience: “An UNWARRANTED, OVER REACTION by the person experiencing pain, which is not or cannot be felt or understood by the healthcare professional...” (Respondent 23). The following respondent believed that pain catastrophizing “discredits” (Respondent 96) patients' pain experiences. This nurse also made it clear that they disagreed with the term as it relates to exaggeration. Finally, this respondent stressed the importance of listening to patients:

Pain catastrophizing is a concept that discredits the patient. As health care providers it is our job to listen to our patients. That is how a proper patient assessment is obtained. Pain catastrophizing means the patient is exaggerating their pain. I do not agree with that concept, and I believe it needs to be struck from clinical practice. If we do not strike this concept from practice, we are running the risk of significant patient harm. Pain is a real stimuli. Evidence based practice relies on patient being treated as an individual. It's not up to staff to dismiss someone's complaint of pain as over exaggerated. That is exactly what the concept of catastrophizing does. The concept has no place in clinical practice. (Respondent 96)

Finally, this last nurse viewed the concept as “a put-down by professionals, who feel better by making pain a mental-health problem” (Respondent 97). In this example, the problem that the nurse puts forward is not that mental illness itself is problematic, which would contribute to the tendency to discredit or stigmatize mental illness, but rather that a mental health diagnosis is being made that is not predicated on diagnostic criteria, and instead is based on the clinician’s belief that the patient is exaggerating their pain.

Theme Two: Application of the Term and Patient Responses

Theme two encompasses how nurses perceived their patients’ reactions to the term and the context of how nurses use the term in practice and communications with their patients. Among the sample, only 19 nurses explicitly discussed whether or not they use the term in practice. Sixteen nurses answered yes to using the term in their practice, and for the most part,

they perceived patients' reactions to be negative or confused. Three nurses explicitly stated that they do not use the term in practice. Nurses were asked: "Have you ever used the term pain catastrophizing in the context of your communications with patients? If yes, can you describe how the patients responded to the term?". It is important to note that only 19 nurses out of 136 responded to this question; however, it cannot be assumed that the nurses who did not respond do not use the term in practice. Interestingly, most nurses who answered that they do use the term also recognized that patients disliked it (9 nurses); however, many reported still using the term in practice (16 nurses).

Subtheme One: Patients' Responses to the Term. For the nurses who reported using the term in practice (16 nurses), most nurses (9 responses) perceived that their patients resisted the term in that patients became defensive or offended. In this first example, the nurse believed their patients hate it: "Patients hate it. I only use it because they see it elsewhere" (Respondent 3). Another nurse identified three stages of the response: "1-defending the statement 2- denial 3-quiet" (Respondent 105). Two nurses perceived that their patients think clinicians are using the term to minimize their pain experience, which supports some of the nurses' views about how the term dismisses patients' concerns. This first nurse believed that patients find the term offensive: "Some patients find it 'offensive' and believe that we are making light of their pain" (Respondent 79). In this second example, the nurse perceived that their patients felt that their clinicians did not believe their reports of pain. This nurse also believed that some patients do not understand the term, which was shared by other respondents: "Do not understand the term or thinks healthcare workers do not believe their severity of pain" (Respondent 25).

Some nurses (6 responses) perceived that their patients did not understand the term and required an explanation. One nurse stated that pain catastrophizing is frequently a new term to

patients. This nurse also believed the use of the term provides an opportunity for reflection: “The term is often new to patients; it gives them a moment of pause sometimes when they hear the phrase and reflect on their relationship with their pain” (Respondent 33). Two nurses thought that patients “don’t understand” (Respondent 94) the term and an “additional explanation [is] required” (Respondent 94).

In contrast, only two nurses reported that patients responded well and were accepting of the term. This first nurse stated that patients have “no problems, they fully understand the term and can engage with it” (Respondent 66). The second nurse reported that patients are “usually accepting and have acknowledged that it can be the case...” (Respondent 48).

Subtheme Two: Nurses' Application of the Term. Some nurses (6 responses) described resistance to using the term in practice. Three nurses *explicitly* reported that they do not use the term. These nurses understood how patients might react poorly to the term *if* used and choose not to use it because it is negative sounding: “It means to worry or anticipate future pain and how it will affect you. In my mind it is a negative phrase. I don’t use it” (Respondent 130). “No sorry, I’ve never said it to the patient as it’s too negative & would probably be taken badly” (Respondent 106). Similarly, this next nurse reported that they use the term in the context of mental health and pain but can understand how it may be misperceived in the context of *treating* pain:

...I use catastrophizing when discussing mental health. As a mental health provider, I have been treating a lot more patients around the psychology of pain and pain experience. I can see how catastrophizing may be perceived wrong in the context of treating pain though. (Respondent 129)

Some nurses described using the term only in specific contexts. For example, one nurse talked about using the term with other clinicians but not with patients: “I haven't used the term with

patients, but I have used the term with physicians in report and have often seen it in clinical notes” (Respondent 122). Another nurse described using the term only when discussing cognitive behaviour therapy (CBT) with the patient, a common form of psychotherapy, in the context of chronic pain.

I tend to use it as part of a discussion around CBT and unhelpful thinking styles and give examples in differing scenarios including pain, so not aimed at the individual as a being but a thinking style they may fall into when in a highly distressed state and without the means to cope or adapt. (Respondent 1)

Although most nurses resisted the term, one nurse was more accepting of the term. This nurse described the concept's usefulness in research and clinical practice, however, they can see how it “implies a patient problem”: “I think the concept is very useful clinically and in research, but the term implies a patient problem rather than a shared circuit in the brain. I think it is also about pain habits” (Respondent 9).

Theme Three: Nurses’ Recommendations for the Future

Nurses had the opportunity to provide further insights and comments in the survey’s last question, “Is there anything else you would like to tell us on this topic?”. For the most part, nurses responded to this question with suggestions on how to improve future care and pain management. Some nurses suggested eliminating or renaming the term pain catastrophizing. Theme three will summarize the recommendations nurses made for the future.

Only one nurse suggested a new term to replace pain catastrophizing when given the opportunity to provide further insights at the end of the survey: “pain related mental/emotional distress” (Respondent 129). Moreover, one nurse suggested that there should be a better term but did not provide an alternative. This respondent also echoed previous responses in that the current term is negative sounding and suggests patient blame. This nurse also provided insight into why

patients may respond the way they do, highlighting how previous experiences influence current experiences:

Thank you for addressing this. I do think there should be a better, simpler term, that does not sound so negative or "medical speak". These patients already feel threatened and need something that explains their response in a more positive manner and does not sound blaming, or that they are a bad person. Many times, their response is based on a bad experience in the past that was due to ineffective (or no treatment) for their pain. (Respondent 48)

Most nurses who discussed ways forward suggested a more thorough assessment of pain and stressed the importance of listening to patients rather than categorizing them. In the following example, the nurse provided a series of questions that should be asked of patients instead of labelling them:

Instead of labeling a chronic pain person [health care] providers should ask how do you think you are coping with your pain? Do you have negative thoughts and/or emotions more often than positive ones? What are your positive thoughts/emotions? What are your negative thoughts/emotions? Lists of thoughts and emotions can be given to help the patient decide on the true answers. Thoughts, emotions, and words can be difficult to form for chronic pain patients. From these answers a more individualized plan of care can be formed. (Respondent 16)

Nurses stressed that it is “important to carefully listen to what patients tell us about their pain and how it affects their life” (Respondent 103). Further, many nurses emphasized the subjective nature of pain, in that “pain is what the patient says it is, not how we see them acting” (Respondent 43).

Similarly, a few nurses strongly felt that the focus urgently needs to be on *treating pain*, especially in the context of the opioid epidemic. This next nurse discussed the issue of undertreated pain in response to the opioid crisis and stressed the importance of adequately treating pain:

We have moved in a dangerous direction of undertreating pain due to the opioid crisis of abuse of illicit drugs. People in pain are dying as a result of untreated pain. Treating pain is very important. We do not need to be losing lives due to untreated pain. (Respondent 96)

In this next response, the nurse felt strongly about “pulling the pendulum of opinion towards center” (Respondent 11) concerning pain treatment. This nurse mentioned countering the negative belief system concerning people with pain as a strategy to move forward. In this response, the nurse strongly felt that pain is currently treated as “barbaric” (Respondent 11).

Finally, this nurse commented on the importance of offering accessible treatment for those who struggle with pain and addiction:

I think everything that can be done to counter the extreme negative, suspicious, and moralized belief system currently entrenched in healthcare concerning people with pain needing pain treatment should be considered. Pulling the pendulum of opinion towards center, avoiding the extremes of overtreatment and undertreatment desperately needs to happen. The way we treat pain and the people having pain currently is barbaric... If we are so concerned about addiction and overdose, we need to offer treatment, endorse, and refer patients to community-based programs and free support groups. If we don't want to prescribe opioids for chronic pain, we need to teach patients non-pharmacological methods of pain management and offer alternative treatments. And heavens forbid a person who has a substance abuse history also has a real need for pain management. We need to not criminalize cancer patients for wanting to have their pain managed so they can have some measure of quality of life, and certainly not abandon them at end of life because we don't "believe" in palliative care and hospice. (Respondent 11)

Some nurses strongly felt that “we need to get rid of this term” (Respondent 3). Additionally, some nurses restated the issue of “not adequately managing people’s pain” (Respondent 41) due to the opioid crisis. The following nurse urged that going forward, clinicians need to treat patients’ pain at the level they report, emphasizing the subjective nature of pain. This nurse pointed to the lack of trust in the medical community:

I think we need to eliminate this term. We live in a society that is overly sensitized to the opiate crisis and now we are not adequately managing people’s pain. People with

greenstick fractures in the ER [are] receiving Tylenol. There has to be a proactive stance to manage pain at the level the patient reports. Otherwise, we destroyed all rapport with patients, and we generalize that all patients are drug seeking. This reinforces a lack of trust in the medical community and makes all of our jobs more difficult. (Respondent 41)

Some respondents did not suggest a new term but believed pain catastrophizing to be a “normal human response” (Respondent 67) to pain. In the following example, the nurse shared a personal experience of chronic pain and disagreed with the belief that catastrophizing is an exaggerated pain response, an association that many other respondents made. This nurse also suggested that the response to pain should not be overlooked, a shared idea by other nurses in the sample:

Personally, have experienced chronic pain, I think it's entirely understandable but to call it catastrophizing, to me, associates it with exaggerating when the anxiety associated, I believe is a totally normal response and should be dealt with by medical professionals as well, not overlooked. (Respondent 10)

Finally, a few nurses felt that a new term would not be helpful. In this first example, the nurse instead emphasized the importance of improving trust within the doctor-patient relationship:

I'm still unhappy with the terms I suggested. Real pain is real pain. Some need riskier meds for a few, or several days. You can change the name, but my experience is you can't change the doctor-patient relationship and the trust it MUST be based upon. (Respondent 128)

In this last example, the nurse seemed to feel that changing the term would change the concept's meaning and create ambiguity. This nurse also discussed the therapeutic relationship, highlighting the importance of honesty, empathy, and compassion:

Changing the word for something changes the meaning of the concept. To refer to pain “catastrophizing” as anxiety/distress/vigilance is a perfect example of conflation (merging two separate concepts together). This merely creates misunderstanding and ambiguity. Honesty is incredibly important in pain management. When emotionally charged concepts are explained with empathy and compassion to patients, the therapeutic relationship is strengthened. It does a disservice to the therapeutic relationship (both patient and practitioner) to circumvent this process linguistically. (Respondent 66)

Discussion

The purpose of this study was to explore nurses' perceptions and interpretations of pain catastrophizing to inform our understanding of this term from their perspective, drawing on a large international survey. In interpreting this data, attention is drawn to the specific role of nurses in *Humanizing Health Care* as put forward by Janice Morse, a leader in qualitative research, and consider how a nursing perspective enables a strong critique of the term and its use in practice (Morse, 2012). This paradigm, humanizing health care, will act as a theoretical framework to guide nursing practice and research implications as theory may enter a study at any point in the research process (Sandelowski, 1993). Morse (2012) defines humanizing health care as:

A perspective on attitudes, beliefs, expectations, practices, and behaviors that influence the quality of care, administration of that care, conditions judged to warrant (or not warrant) empathetic care, responses to care and therapeutics, and anticipated and actual outcomes of patient or community care. (p. 54)

Morse argues that the current health care system dehumanizes and demoralizes patients (Morse, 2012). The findings from this study and the literature identify that pain catastrophizing adheres to this notion of dehumanization and demoralization. Humanizing health care is a social agenda for qualitative health research; it improves patient outcomes and induces less suffering (Morse, 2012). Morse's conceptualization of humanizing health care is consistent with the nursing perspective, in that care and research must be person-centred and individualized (Morse, 2012). Humanizing health care adds a critical dimension to health care and research. It provides a moral perspective, identifies significant issues, advocates for vulnerable populations, and creates humanizing change (Morse, 2012).

The findings from this study identified how the term pain catastrophizing is understood and taken up by nurses, resulting in a strong critique of the concept. For the most part, nurses associated pain catastrophizing with negative ideas about what the term means. Pain catastrophizing was commonly described as an exaggerated response to pain, encompassing stigmatizing psychological behaviours, having damaging consequences for patients, and dismissing patient concerns. Most nurses associated the term with the suggestion that patients are exaggerating their pain. Some described pain catastrophizing as stigmatizing psychological behaviours, such as fear, worry, and rumination. Some of these respondents felt that patients categorized as pain catastrophizers lack the skills to cope with and control pain. The questions posed in the survey did not allow a clear answer to whether or not nurses agreed with these characterizations. However, their responses to additional questions suggest that they did not. While few nurses were explicit in disagreeing with the term, those that did were quite vocal in their beliefs. Many of these nurses described what they perceived as damaging consequences of the term, such as poor treatment and stigma. These nurses perceived the term as stigmatizing and pejorative. Some of these nurses emphasized that pain is subjective and stressed the importance of believing patients' reports of pain. Finally, some nurses believed that clinicians often misuse the term to discount patients' experiences and perhaps use it to label patients they do not want to treat.

When asked if nurses use the term in practice, few nurses explicitly reported using it. For the most part, these nurses perceived that their patients became offended and defensive when this term was applied to them. Other nurses felt that patients did not understand the term. A small number of nurses reported that their patients understood and supported the use of the term.

Furthermore, some nurses reported that they did not use the term in practice because of its negative connotation and subsequent impacts on patients, such as stigma.

Finally, nurses provided recommendations for clinical practice in ways that suggested reimagining how we care for people with chronic pain. In the clinical setting, where the term is widely used, it is nurses who are calling attention away from the term and towards the problem of the way we deliver care, reflecting the critical role nurses play in humanizing health care. Many of the nurses proposed that pain assessments needed to be more comprehensive. These nurses also recommended that clinicians listen to patients and believe the pain level that patients report, emphasizing the subjective nature of pain. Some nurses underscored the importance of treating pain in the context of the opioid crisis. These nurses highlighted the urgent epidemic of undertreated pain and argued that more accessible services need to be provided to those living with pain. Some of the nurses who suggested ways forward thought that the term should be eliminated and believed that a new term would not be helpful. Instead, these nurses suggested that the therapeutic relationship needs to be strengthened, focusing on empathy, honesty, and compassion.

Our findings shed light on the problematic nature of the term pain catastrophizing and also highlighted how widely accepted it is within the clinical setting. While the nurses in our study commonly felt the term could be stigmatizing, many associated it with exaggeration and psychological behaviours, and some seemed to accept these associations as an accurate description of pain responses deemed as pain catastrophizing. Catastrophizing was developed and refined in the context of psychology by Albert Ellis and Aaron Beck (Leung, 2012; Quartana et al., 2009). The resultant tendency has been for clinicians, including nurses, to understand patient responses to pain that they believe are inaccurate or exaggerated to be psychological in

nature. Pain-related catastrophizing, defined as “an exaggerated negative mental set brought to bear during actual or anticipated painful experiences,” situates pain catastrophizing in the psychological model (Sullivan et al., 2001, p. 53). From inception, pain catastrophizing is centred around the idea of an irrational or *exaggerated psychological* response to current or future events (Leung, 2012; Quartana et al., 2009). Our findings suggest that nurses’ understandings of the term reflect an awareness of the social history of the concept and how it has been used against patients. For example, nurses associated the term with suggesting the patient is exaggerating, reflecting the early definitions of the term. At the same time, they are trained within a biomedical model that accepts and promotes medical labels and diagnoses.

Many nurses in our study strongly felt that pain is subjective and the term pain catastrophizing attempts to define patients’ pain experiences objectively; however, the existing research on pain catastrophizing demonstrates a stark contrast to these beliefs. The wide range of literature that focuses on measuring pain catastrophizing as a predictor of pain-related outcomes promotes the belief that pain catastrophizing can be objectively measured (Quartana et al., 2009). Further, several clinicians have described pain catastrophizing as a clinically useful construct (Pelekanou & Thomson, 2021; Sleijser-Koehorst et al., 2019). Nurses in our study provide a potentially critical perspective that shifts the focus away from objectively defining patients’ responses and instead towards understanding their subjective experience. Importantly, our findings support nurses’ awareness that the term pain catastrophizing does not align with the International Association for the Study of Pain (IASP) definition of pain, which is described as a personal and *subjective* experience modified by life events and shaped by biological, psychological, and social factors (Raja et al., 2020). The IASP emphasizes that pain is to be defined “from the perspective of the one experiencing the pain, rather than an external observer”

(Raja et al., 2020, p. 1978). At the core of the IASP definition of pain is subjectivity; however, nurses in our findings believed that the term pain catastrophizing neglects the subjective nature of the pain experience.

Furthermore, some nurses were quite vocal in indicating that clinicians need to listen to and believe patients' reports of their pain and that "pain is what the patient says it is" (Respondent, 120). However, it is well documented that people who live with chronic pain frequently feel disbelieved by their clinicians, which can have detrimental effects (Allvin et al., 2019; De Ruddere & Craig, 2016; Newton et al., 2013; Slade et al., 2009). A study conducted by Tveiten and Knutsen (2011) revealed that patients often feel that their level of pain is not believed by their clinician, leading to feelings of demoralization and lack of credibility. The literature also supports that it is not uncommon for clinicians to make patients feel that their pain is made up or exaggerated, especially if there is no known physical explanation for their pain (Clarke & Iphofen, 2005; De Ruddere et al., 2014; Tveiten & Knutsen, 2011). It is evident that not taking patients' reports of pain at face value hinders the ability to provide patient-centred care. For example, if the pain assessment is inaccurate and not true to the patient's self-report of pain, mismanagement and undertreatment are likely to occur (Clarke & Iphofen, 2005; Waterhouse, 1996). Our findings support these possibilities; some nurses felt that pain catastrophizing "is used in a negative manner to rationalize lack of treatment and dismiss pain patients who are in need of help" (Respondent, 67). The IASP reiterates that "a person's report of an experience as pain should be accepted as such and respected" (Raja et al., 2020, p. 1979); however, our findings and the literature suggest that this is not always the case. Self-report is recognized as the gold standard for pain assessment; however, labelling an individual's pain experience as pain catastrophizing contradicts this standard (Suzuki, 2017).

Nurses in our study believed that the term pain catastrophizing dismisses patients' concerns and described the term as an "extreme diminishment of the patient's pain experience" (Respondent 93). This is in keeping with other research that has found that pain catastrophizing delegitimizes patient experiences. For example, people with chronic pain in a study conducted by Amtmann et al. (2018) reported feeling worried that scores from pain catastrophizing measures will reinforce clinicians' beliefs that their pain is not real, be used to withhold treatment, or exacerbate feelings of stigma. Delegitimation is described as "the experience of having one's perceptions and definitions of an illness systematically disconfirmed" (Ware, 1992, p. 347) and is related to depicting an individual's experience as unimportant or psychologic (Newton et al., 2013; Ware, 1992). Our findings echo the idea of delegitimation in that many nurses believed that the term pain catastrophizing minimizes patients' experiences of pain and is "a put-down by professionals, who feel better by making pain a *mental-health problem*" (Respondent 97). Although psychological factors may impact pain in various ways, pain catastrophizing attributes the pain response to be solely psychological, which leaves out the social context, does not consider structural inequities, such as racism and sexism, and fails to acknowledge that pain is subjective. We know, for example, that women experience more chronic pain than men and that those with lower socioeconomic status have worse pain outcomes compared to those who have higher socioeconomic status (Booher, 2019; Flentje et al., 2015; Pieretti et al., 2016). Finally, psychologizing pain can prematurely end efforts to diagnose pain conditions accurately and severely limits the treatments offered to manage pain (Bilkey, 1996; Birk, 2013).

Nurses in our findings identified the stigmatizing role of pain catastrophizing and shared concerns that "catastrophizing increases the bias against pain patients that is already negatively skewed" (Respondent 16). The act of disbelieving patients and potentially withholding treatment

facilitates enacted stigma, described as unfair treatment or discrimination against others with a stigmatizing condition (Newton et al., 2013). The experience of stigma is common in the chronic pain population and can have harmful consequences for patients (Allvin et al., 2019; De Ruddere & Craig, 2016; Slade et al., 2009). In the clinical setting, stigma is associated with under-assessing and underestimating pain by clinicians, discounting patients' self-report of pain, disbelief of the extent of suffering, and undertreating pain (De Ruddere et al., 2012; Kappesser & Williams, 2013; Tait et al., 2009). Moreover, stigma contributes to poor self-esteem, feelings of inferiority, social withdrawal, and suboptimal physical and psychological well-being (De Ruddere & Craig, 2016). Our findings also highlight the problematic nature of labelling patients as pain catastrophizers: "Sounds like the patient is in a real or future crisis and the healthcare community and professional is not interested in treating the pain but on labelling the patient" (Respondent 14). Using labels to describe patients promotes stigma and stereotypes, creating barriers to quality patient care (Garand et al., 2009; Knaak et al., 2017). Failing to believe patients' subjective reports of pain and using language that fosters patient blame, stigma, and invalidates patients' experiences presents significant challenges in providing effective pain management, overcoming stigma, and promoting optimal patient outcomes.

Nursing Practice Implications

Central to the paradigm of humanizing health care is fostering social justice (Morse, 2012). Nurses play a pivotal role in promoting social justice as it is a core nursing responsibility, making them well suited to lead the humanization of health care (Canadian Nurses Association [CNA], 2017). Nursing ethics "is concerned with how broad societal issues affect health and well-being" (CNA, 2017, p. 3) and advocating for improvements to the social determinants of health. Nurses often spend the most time with patients, work closely with physicians, and

facilitate communication between patients and physicians (Kress et al., 2015). Further, nurses in the clinical setting have an important role in performing ongoing pain assessments and working with the interdisciplinary team to develop pain management strategies (Al-Shaer et al., 2011). Therefore, nurses are uniquely positioned to be leaders in performing holistic pain assessments that consider the social context of the pain experience. Additionally, nurses can promote eliminating dehumanizing patient labels, such as pain catastrophizing, from clinical practice. Nurses have an important role in identifying social inequities and advocating for equitable social conditions. Eliminating barriers to care is a crucial responsibility of the nursing profession and is imperative for the chronic pain population as they often feel stigmatized and may delay seeking treatment (Carr, 2016).

Implementing the humanizing health care agenda requires challenging the status quo (Morse, 2012). The term pain catastrophizing has been around for decades, yet its use in clinical practice is seldomly questioned. However, nurses operate in a climate that “encourages the act of questioning the status quo” (CNA, 2017, p. 16). Nurses in our findings challenged the status quo in the context of pain catastrophizing and are well equipped to bring these concerns to the policy level. Our findings underscore that pain is what the patient says it is; however, the literature suggests that patients often feel that clinicians do not believe their reports of pain. Morse (2012) argues that “keeping the person and his or her daily life on the policy-negotiating table enables the humanization of health care” (p. 68), highlighting the importance of patient advocacy. Nurses’ professional commitment to advocacy allows them to advocate for patients’ narratives to be seen as credible at the policy level to overcome stigma and improve patient outcomes. Nurses can utilize the findings from this study to promote humanizing health care by performing more comprehensive pain assessments, listening to patients, encouraging other clinicians to listen to

patients, valuing patients as credible experts of their pain, and viewing pain as a subjective, multifaceted phenomenon. Translating research into practice is an important role of nurses and enables cultural and behavioural practice changes; therefore, nurses should utilize these findings to ignite necessary change in the clinical setting (Curtis et al., 2017; Powers, 2020). At its core, pain catastrophizing is a dehumanizing term. Nurses are catalysts for change in advancing health care reform and should challenge the use of pain catastrophizing. Lastly, nurses have a voice in public policy and a responsibility to advocate for patients at the macro level to foster change; therefore, they can be leaders in humanizing health care in the context of pain management.

Nursing Research Implications

The current research on perceptions of pain catastrophizing is limited. To our knowledge, this is the first study that explores how nurses understand pain catastrophizing. Nurses offer a unique perspective to this topic based on their close relationships with patients and their core values and responsibilities, such as empathy, advocacy, and promoting justice (CNA, 2017). However, to humanize health care, future inquiry needs to focus on the patient perspective, which is largely understudied. Qualitative research in the humanizing health care paradigm focuses on the subjective domains of patients' experiences and is sensitive to gender, age, and culture (Morse, 2012). Therefore, using a humanizing health care approach to study pain catastrophizing from the patient perspective may shed light on the decontextualizing nature of the term and capture the subjectivity of the pain experience within a biopsychosocial context. Furthermore, qualitative inquiry allows researchers to challenge hidden phenomena, providing the means to go beyond surface-level (Morse, 2012). Challenging pain catastrophizing and gaining a deeper understanding from patients may drive necessary change in using pain catastrophizing clinically. Nurses have an important role in research involvement and are well-

positioned to lead qualitative research using a humanizing health care approach on pain catastrophizing from the patient perspective. Nursing research is patient-centred and focuses on making patients' voices heard; thus, nurses' involvement in developing studies focused on patients' experiences with pain catastrophizing is critical (Mallick-Searle & Marie, 2019). The pain experience must be studied with a social justice lens to humanize health care.

Strengths and Limitations

Secondary analysis allows for the investigation of new research questions and provides opportunities to expand research on a topic (Heaton 2004; Johnston, 2017). In our study, a subset of survey data was analyzed from a large international study conducted by Stanford University. A strength of our study is that the original study collected vast amounts of data, which resulted in a large subset of data, including responses from 136 nurses, for this analysis. Having a large sample size was beneficial in this study as it allowed us to investigate a wide breadth of diverse perspectives, despite individual responses being brief, which is particularly useful for understudied populations (Braun et al., 2020). However, secondary analysis of survey data also comes with limitations. First, the data used for this analysis was not collected to address our particular research question. As a result, survey questions were not worded to develop a deep understanding of how nurses perceive the term pain catastrophizing. Nurses' responses to the open-ended questions varied in depth. Some nurses provided rich and complex responses; however, for the most part, responses were brief. Additionally, survey questions were repetitive. The questions were: (1) Please briefly describe what the term catastrophizing means to you. If you are unsure, please just jot down a few words that come to mind that you associate with the term, (2) Have you ever used the term pain catastrophizing in the context of your communications with patients? If yes, can you describe how patients respond to the term? (3)

Please tell us what first comes to your mind when you hear the term pain catastrophizing, and (4) Is there anything else you would like to tell us on this topic? Please feel free to attach a separate page if you'd like to provide further comments or insights (Stanford University, n.d.-b). This wording framed how respondents could respond and did not allow for thoughtful and meaningful dialogue. This, in turn, limited the ability to investigate our research question further. Second, given that this was a secondary analysis and data was not collected from in-depth interviews, there was no opportunity for follow-up or to collect additional data from respondents (Johnston, 2017). The inability to ask follow-up questions poses a significant limitation in our research, as it was impossible to know if nurses supported the associations they described.

Conclusion

This study provides an initial exploration of nurses' perspectives on the term pain catastrophizing, which are largely underrepresented in the literature. Nurses in our study commonly associated pain catastrophizing with exaggeration, psychological behaviours, damaging consequences, and dismissing patient concerns. Few nurses reported using the term in practice; however, they felt that most patients resisted it or were confused by it. Some nurses chose not to use the term when communicating with their patients due to concerns raised around stigma. Respondents made insightful recommendations for future practice, focusing on more comprehensive pain assessments, believing patients' reports of pain, and strengthening the therapeutic relationship. These findings shed light on the problematic nature of pain catastrophizing. At its core, pain catastrophizing is a dehumanizing concept that delegitimizes and decontextualizes the individual pain experience. Furthermore, pain catastrophizing contradicts the IASP revised 2020 definition of pain and is not patient-centred. The concept neglects the multiple domains that influence the pain experience, fails to acknowledge pain as a

subjective phenomenon, and does not consider the possibility for catastrophizing behaviours to be a logical response to constant pain. Many nurses in our study believed that pain catastrophizing is dismissive and discounts patients' pain experiences. Similarly, the literature supports that many people with chronic pain feel disbelieved by their clinicians, which exacerbates stigma and leads to mismanagement of pain. It is evident that pain catastrophizing is dehumanizing, and there is an urgent need to humanize health care. Nurses play a critical role in leading the humanization of health care by challenging the status quo, advocating for patients at the policy level, and promoting social justice. Future research on pain catastrophizing should be nurse-led and needs to take place in the humanizing health care paradigm using a qualitative approach. Most importantly, future research needs to focus on the patient perspective and provide a voice to those affected by the term. "Pain is what the patient says it is" (Respondent 120), and we need to start respecting it as such.

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Chapter 4: Discussion of Implications

This thesis mapped the literature on how clinicians and patients currently understand and describe the term pain catastrophizing and analyzed nurses' perceptions of the term. Although pain catastrophizing is a widely used clinical concept, these findings have identified several issues with the term and significant research gaps on the topic. Our scoping review revealed limited research on how clinicians, specifically nurses, and patients understand, describe, or interpret pain catastrophizing. The nurses in our secondary analysis described pain catastrophizing as an exaggerated response to pain, encompassing stigmatizing psychological behaviours, having damaging consequences for patients, and dismissing patient concerns. Furthermore, few nurses reported using the term in practice. Those who have used the term in practice perceived patients to respond with resistance or confusion. Nurses also discussed ways to move forward, emphasizing comprehensive pain assessments and believing patients' self-reports of pain. Overall, the interpretation of these findings suggests that pain catastrophizing is a problematic and dehumanizing term that can provoke stigma and create barriers to pain management. This section will provide a focused discussion of the implications for nursing practice, education, and research.

Implications for Nursing Practice

Situated in a profession centred around caring, empathy, and connecting with people, nurses provide a unique perspective that offers the potential to humanize health care (Fahrenwald et al., 2005). In keeping with this idea, nurses in this study associated the term pain catastrophizing with dismissing patients' concerns, discounting patients' pain experiences, and having damaging consequences for patients, such as exacerbating stigma and negatively affecting treatment. Many nurses felt that the term pain catastrophizing needed to be eliminated

from clinical practice. Rather than find a better term, nurses focused their suggestions for the future on improving systems of care. They reiterated the importance of thorough pain assessments and accepting patients' reports of pain at face value. These findings highlight the importance of nurses assuming leadership in improving future practice and subsequently improving patient-centred care.

Pain assessment and management are core nursing responsibilities that require nurses to recognize pain as multifaceted and influenced by various factors (Lewandowski, 2004). Therefore, nurses' involvement in treatment planning can be optimized to improve patient outcomes by performing comprehensive and accurate pain assessments that accept patients' pain as real. The literature supports that failure to adequately assess pain and accept patients' self-reports of pain as valid contributes to undertreatment and mismanagement of pain (Clarke & Iphofen, 2005; Lewandowski, 2004; Waterhouse, 1996). Further, nurses in our study suggested that labels, such as pain catastrophizing, may be used to dismiss patients and lead to unfair treatment. As famously defined by Margo McCaffery, pain is "whatever the experiencing person says it is, existing whenever and wherever the person says it does" (McCaffery, 1968, p. 95). Many nurses in our findings supported this conceptualization of pain and believed that "pain is what the patient says it is" (Respondent 120). However, it is well documented that many patients who live with pain feel disbelieved and discredited by their clinicians (Allvin et al., 2019; De Ruddere & Craig, 2016; Newton et al., 2013; Slade et al., 2009). Inaccurate assessment of pain is common across various disciplines, and there is frequently a disconnect between clinicians' objective pain assessment and patients' subjective self-report (Idvall et al., 2005; Johannessen, 2019; Lewandowski, 2004; Ruben et al., 2018). It is critical that clinicians accept the pain experience as subjective and allow the person experiencing pain to be a credible expert of their

own experience (Lewandowski, 2004). Nurses' roles in interprofessional collaboration and leadership makes them well-positioned to lead this approach to pain assessment, influence practice changes across disciplines, and improve patient outcomes (College of Nurses of Ontario, 2018).

Many of the nurses in our findings argued that the term pain catastrophizing exacerbates the stigma those living with chronic pain face. Stigma is associated with many consequences, such as undertreatment of pain, lack of access to care, social withdrawal, and poor physical and mental health (De Ruddere et al., 2012; Kappesser & Williams, 2013; Tait et al., 2009). Stigma within the chronic pain population is entrenched in cultural and social norms that clinicians have inadvertently enforced (Monsivais, 2013). Our findings provide an opportunity for nurses to reflect on their attitudes towards chronic pain in an effort to engage in strategies to minimize stigma. Clinicians in a qualitative study reported that self-reflection helped mitigate judgemental attitudes towards people with chronic pain that they believed were exhibiting catastrophizing behaviour (Pelekanou & Thomson, 2021). Self-reflection can be a useful method for nurses to address stigmatizing attitudes at an individual level. However, addressing systemic stigma is essential to delivering high-quality care, achieving optimal patient outcomes, and promoting social justice (Nyblade et al., 2019). Within their ethical responsibilities, nurses have an obligation to eliminate social inequities and overcome barriers to health, which nurses can begin to address through stigma reduction (Canadian Nurses Association [CNA], 2017). To address stigma at an organizational level, nurses can exercise their role in leadership to facilitate dialogue among the interprofessional team and patients to promote a unified effort in stigma reduction (Pinto-Foltz & Logsdon, 2009). Research suggests that including people who experience stigmatization in stigma response, for example, by sharing their personal stories, is best practice;

thus, it is critical that patients are active partners in stigma reduction initiatives (Nyblade et al., 2019). Given that nurses have the closest contact with patients, they are well-positioned to facilitate patient involvement and empowerment (Kress et al., 2015). However, it must be cautioned that we need to develop better ways of including diverse patient voices without overburdening individuals or specific communities.

Some of the nurses in our study challenged the use of pain catastrophizing clinically, explicitly disagreed with the term, and believed the term to be a damaging and dismissive label. These findings highlight important concerns regarding pain catastrophizing, which presents an opportunity for nurses to leverage their ethical obligation to advocate for patients, promote social justice, and challenge the status quo (CNA, 2017). At an individual level, nurses can promote social justice by observing and challenging the health care system for stigmatizing attitudes (Pinto-Foltz & Logsdon, 2009). Further, nurses can exercise their role in patient advocacy by promoting the elimination of stigmatizing language and dehumanizing patient labels within their practice environment (CNA, 2017; Pinto-Foltz & Logsdon, 2009). Lewandowski (2004) suggests that people with chronic pain are often labelled and stereotyped as "malingerers who exaggerate the intensity of pain" or as "problem patients", and therefore argues that nurses have an obligation to act as an advocator and educator for these patients (p. 103). Further, Lewandowski (2004) urges nurses to accept patients' response to pain as real by recognizing that those who catastrophize are *not* exaggerating their pain intensity; they are simply experiencing *more* severe pain. Our findings indicate that the use of the term pain catastrophizing needs to be questioned, and nurses are uniquely positioned to challenge the status quo.

Implications for Nursing Education

The findings from this thesis have significant implications for nursing education and curricula. Nurses in our findings often associated the term pain catastrophizing with psychological behaviours or cognitive processes. These findings shed critical light on what others have termed the psychologization of the knowledge and treatment of pain throughout medical training. According to this theory, because chronic pain is often met with diagnostic uncertainty, clinicians frequently offer a psychological diagnosis, which may prematurely cease additional diagnostic and treatment efforts (Bilkey, 1996; Birk, 2013). Others have argued that attributing pain to the realm of psychology transfers the responsibility from the medical community to the individual, perpetuating patient blame and making the individual responsible for their suffering because there is no readily identifiable cause (Birk, 2013). Once psychologized, those with chronic pain are further subjected to delegitimation and stigmatization (Birk, 2013). Our findings suggest that nurses strongly associate the term pain catastrophizing with psychological issues, with many associating it with mental illness, coping, and exaggeration; therefore, adhering to the theory of psychologizing pain. Although the biopsychosocial approach to pain management is considered the gold standard, others have argued that the emphasis continues to be placed on biological and psychological influences, while social elements, such as social supports and socioeconomic status, are often overlooked (Mankelow et al., 2021; Purcell et al., 2019). The biomedical model is arguably deeply entrenched in nursing education, culture, and practice environments (Johannessen, 2019). As a result, nurses may hold beliefs and values that closely resemble biomedicine and inadvertently psychologize pain (Johannessen, 2019).

The contradictions between nurses' insights that the term pain catastrophizing causes harm to patients and the seeming lack of rejection of its clinical use highlight the need to adapt

nursing curricula and continuing education to focus on the *biopsychosocial* approach to pain and move away from the bio-psycho model of pain. A systematic review completed by Mankelow et al. (2021) concluded that biopsychosocial education strategies improved undergraduate students', including nursing students, pain-related attitudes and knowledge. Furthermore, the researchers found that implementing biopsychosocial education increases the likelihood of students following evidence-based practice in their future careers (Mankelow et al., 2021). Nevertheless, pain education at the undergraduate level for clinicians across disciplines is often inadequate, fragmented, and inconsistent (Briggs et al., 2011; Ung et al., 2016). One strategy to improve the consistency and fragmentation of pain education in nursing programs is to follow the International Association for the Study of Pain (IASP) curriculum on pain for nursing (IASP, 2018). This curriculum adopts a biopsychosocial approach to pain and has successfully improved clinicians' attitudes, beliefs, and knowledge of pain (Briggs et al., 2011; Watt-Watson et al., 2004). Furthermore, Morse (2012) suggests that humanizing health care, a paradigm for health care and research that provides a moral perspective and focuses on identifying significant issues, advocating for vulnerable populations, and creating humanizing change, be present in nursing curricula. Morse (2012) argues that humanizing health care is associated with less suffering and improved outcomes; thus, it is critical to implement this paradigmatic position in nursing education to shape the future generation of nurses. The positive impacts of biopsychosocial education coupled with nurses' pivotal role in pain management highlight the importance of refining nursing education to be more comprehensive, taught through a humanizing health care lens, and reflect the biopsychosocial model (Ung et al., 2016).

Recommendations for Future Research

This thesis has contributed to the limited research that explores nurses' perceptions of the term pain catastrophizing. The findings from this thesis have identified several recommendations for future research on pain catastrophizing to improve our understanding of the term with implications for nurses' roles in chronic pain management. First, future research of all methodologies, including quantitative designs, should be conducted within a critical paradigm that considers systemic and structural inequities to explore patients' perspectives of the term pain catastrophizing. Our scoping review found that only six studies included a qualitative component. Although qualitative thematic analysis was used for the secondary analysis, the primary study from which we got our data did not utilize a qualitative methodology from the start. Therefore, we could not use a proper qualitative approach or achieve congruency among paradigmatic position, methodology, data collection methods, and data analysis. Morse (2012) describes a social agenda for qualitative health research, known as *Humanizing Health Care*:

A perspective on attitudes, beliefs, expectations, practices, and behaviours that influence the quality of care, administration of that care, conditions judged to warrant (or not warrant) empathetic care, responses to care and therapeutics, and anticipated and actual outcomes of patient or community care. (Morse, 2012, p. 54)

The humanizing health care perspective focuses on the person and the subjective domains of their life (Morse, 2012). It is sensitive to the context of their experiences, which facilitates a *biopsychosocial* approach to research, and subsequently, a more thorough understanding of the pain experience from patients' perspectives (Morse, 2012). Conducting qualitative health research with a humanizing health care perspective gives credit and a voice to patients' thoughts, lived experiences, feelings, and wishes (Morse, 2012). Our findings provide a small preview of the damaging consequences pain catastrophizing might have for patients from a nursing perspective; however, providing a voice to patients will amplify these insights and reveal hidden,

deep-rooted issues with the term. Further, qualitative inquiry describes the status quo from patients' perspectives, which can "serve as a sensitizer" for those reading the work (Morse, 2012, p. 58). In this way, exploring patients' perspectives can bring the problematic nature of the term pain catastrophizing to the attention of the public, clinicians, and policymakers (Morse, 2012). Investigating patients' experiences with the term pain catastrophizing will uncover nuances of the term, examine patients' needs, and provide opportunities for change (Morse, 2012). Keeping patients at the policy-negotiating table is critical to humanizing health care (Morse, 2012); therefore, future research on the term pain catastrophizing must represent patients' voices and experiences.

Second, nurses' perceptions of the term pain catastrophizing are understudied, though they offer a unique and valuable perspective. Although this study analyzed survey data, which makes it challenging to capture thoughtful and meaningful dialogue, the nurses in our findings have provided critical insights on the term pain catastrophizing. Therefore, these perceptions should continue to be explored using a qualitative lens to enable researchers to go below the surface of these brief responses (Morse, 2012). The nursing profession is grounded in patient-centred values, such as empathy, advocacy, promoting social justice, and providing compassionate care (CNA, 2017). Nurses are at the forefront of caring for patients with pain; they have the closest and most consistent contact with patients throughout their pain management journey (Kress et al., 2015; Lewandowski, 2004). Our findings demonstrate that through their unique position, nurses are valuable resources to identify patients' needs, which can be helpful to improve patient care (Galehdar et al., 2020). Further, qualitative inquiry of nurses' perspectives may uncover underlying social, cultural, or structural factors that influence their accounts and may provide insights into their role in perpetuating or breaking stigma (Braun

& Clarke, 2006). Morse (2012) claims that it is important for qualitative health research to facilitate change through new approaches to care. In our findings, nurses provided recommendations for the future that reimagined care and re-focused attention away from patient labels and instead to systems issues in providing care; thus, their perspectives need to be explored further to facilitate practice changes and produce transformative knowledge (Sandelowski, 2004).

Lastly, future research on the term pain catastrophizing could be led by nurses. An important reason to conduct qualitative health research is to identify social inequities in the health care system and work to resolve these inequities (Morse, 2012). Humanizing health care is consistent with the nursing discipline as it is centred around conducting research with a social justice perspective and challenging the status quo (Morse, 2012). Further, qualitative researchers provide insider evaluations, which allows them to serve as advocates for patients and communities (Morse, 2012). Given that nurses have the most frequent contact with patients and have an ongoing role in assessing and managing pain, their role as insiders in the research process can be extremely valuable. Nurses have an ethical responsibility to promote social justice, challenge the status quo, and advocate for patients, making them well-positioned to lead qualitative research on pain catastrophizing using a humanizing health care approach (CNA, 2017). Finally, nurses are equipped to translate humanistic care into practice and influence remedial action through their role as research investigators (Morse, 2012); therefore, nurses need to lead qualitative research on pain catastrophizing to create humanizing change.

Conclusion

This thesis consists of two inquiries that aim to summarize the current literature on the term pain catastrophizing perspectives and analyze nurses' perspectives. Though chronic pain is

a common and debilitating condition, it remains a complex and poorly understood phenomenon. As a result, chronic pain is often psychologized, and those who live with chronic pain are subjected to stigma and patient labels, such as pain catastrophizing. Our findings shed light on the problematic and dehumanizing nature of the term pain catastrophizing; however, it continues to be a widely used concept clinically and within the scholarly literature. Our scoping review identified that perceptions of pain catastrophizing are largely understudied, specifically those of nurses and patients. Nurses in our secondary analysis provided valuable perspectives on pain catastrophizing and often associated it with an exaggerated response to pain, stigmatizing psychological behaviours, having damaging consequences for patients, and being used to dismiss patient concerns. Further, nurses perceived patients' responses to the term as negative or confused; for this reason, perhaps, many nurses did not use the term in practice. Nurses also provided important recommendations for future practice, including comprehensive pain assessments, listening to, and believing patients, and eliminating the term pain catastrophizing from practice.

The findings from this thesis have important implications for nursing practice, nursing education, and future research. Nurses can exercise their roles in interprofessional collaboration and leadership by setting the standard for accurate and thorough pain assessments that view patients as credible experts of their pain. Further, nurses are responsible for eliminating social inequities and improving barriers to health care by engaging in stigma reduction strategies. Nursing curricula and education can be refined to focus on the biopsychosocial approach to pain by following the IASPs pain curriculum for nursing at the undergraduate level. Finally, nurses need to lead qualitative research with a humanizing health care approach to further our understanding of pain catastrophizing. Future research on pain catastrophizing needs to represent

patients' voices and experiences to enable the humanization of health care. Though pain catastrophizing has been around for decades, it is time for nurses to challenge the status quo to promote humanized and patient-centred health care.

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Appendix A

Scoping Review Search Strategy

Search Strategy: MEDLINE Database

Search number	Searches
1.	Catastrophization/
2.	“pain catastrophizing”.mp.
3.	Catastrophizing.mp.
4.	1 or 2 or 3
5.	Perception/
6.	Perception*.mp.
7.	Patient Satisfaction/
8.	Health knowledge, attitudes, practice/ or Attitude to health/ or belief*.mp.
9.	Qualitative research/ or qualitative.mp.
10.	Definition*.mp.
11.	Concept*.mp.
12.	Conceptualization.mp.
13.	Experience.mp.
14.	“lived experience”.mp.
15.	Discourse.mp.
16.	Linguistics.mp. or linguistics/
17.	Language/ or lanauge.mp.
18.	Terminology.mp. or Terminology as Topic/ or Standardized Nursing Terminology/
19.	Connotation*.mp.
20.	Understanding.mp.
21.	Word*.mp.
22.	Stereotyping/ or Social stigma/ or stigma.mp.
23.	Stigmatize*.mp.
24.	Stigmatizing.mp.
25.	Description*.mp.

Search number	Searches
26.	Concern*.mp.
27.	Bias/ or bias.mp.
28.	Attitude*.mp. or “Attitude of Health Personnel/ or Attitude/
29.	Renaming.mp.
30.	Interview*.mp. or Interview/
31.	Rename.mp.
32.	Relabel.mp.
33.	Change.mp.
34.	Label.mp.
35.	Term.mp.
36.	Review/ or review.mp.
37.	Reappraisal.mp.
38.	Perspective*.mp.
39.	5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38
40.	4 and 39
41.	Limit 40 to (English language and yr = 2010-current)

Note. ‘.mp.’ indicates a keyword search, and ‘/’ indicates a MEDLINE subject heading.

Appendix B

Ethics Approval Letter



Date: 25 March 2021

To: M. Fiona Webster

Project ID: 116752

Study Title: How Clinicians Understand and Use Pain Catastrophizing: A Secondary Analysis of an International Survey

Application Type: HSREB Initial Application

Review Type: Delegated

Full Board Reporting Date: 06/April/2021

Date Approval Issued: 25/Mar/2021

REB Approval Expiry Date: 25/Mar/2022

Dear M. Fiona Webster

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. **All other required institutional approvals and mandated training must also be obtained prior to the conduct of the study.**

Documents Approved:

Document Name	Document Type	Document Date	Document Version
Pain catastrophizing survey questions	Online Survey	12/Jan/2021	1
Thesis Proposal	Protocol	04/Feb/2021	1

No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the trial.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Please do not hesitate to contact us if you have any questions.

Sincerely,

Ms. Jhananee Subendran, Ethics Coordinator on behalf of Dr. Philip Jones, HSREB Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).

Curriculum Vitae

Post-secondary Education and Degrees:	MScN – Western University, London ON <i>2019 – present</i>
	BScN – Western University, London ON <i>2014 – 2018</i>
Honours and Awards:	Ontario Graduate Scholarship <i>2020 – 2021</i>
	Dean’s Honor List – Western University <i>2014 – 2015, 2015 – 2016, 2016 – 2017, 2017 – 2018</i>
Related Work Experience	Graduate Research Assistant for Dr. Fiona Webster – Western University <i>May 2021 – present</i>
	Integrative Practicum Preceptor – Western University <i>Sept 2019 – present</i>
	Registered Nurse – St. Joseph’s Health Care, Pain Management Program <i>2018 – present</i>
	Graduate Teaching Assistant – Western University <i>2020 – 2021</i>
	Registered Nurse – London Health Sciences Centre, Subacute Medicine/Palliative Care <i>May 2018 – Nov 2018</i>

Academic Accomplishments and Research Contributions:

Longo, R., Oudshoorn, A., & Befus, D. (2021). Cannabis for Chronic Pain: A Rapid Systematic Review of Randomized Control Trials. *Pain management nursing: official journal of the American Society of Pain Management Nurses*, 22(2), 141–149.
<https://doi.org/10.1016/j.pmn.2020.11.006>

International conference presentation: *Cannabis for Chronic Pain: A Rapid Systematic Review of Randomized Control Trials*. Western University, Nursing Legacy Research Conference, May 25th, 2021.

Poster presenter: *Cannabis for Chronic Pain: A Rapid Systematic Review of Randomized Control Trials*. Canadian Pain Society, Annual Scientific Meeting, April 28th, 2021.