# UNIVERSITY OF CALIFORNIA RIVERSIDE

An In-Depth Analysis of Pain Language: How Individuals' Use of Pain Words Relate to Psychosocial Outcomes

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by

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### ABSTRACT OF THE DISSERTATION

# An In-Depth Analysis of Pain Language: How Pain Words Relate to Psychosocial Outcomes

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This dissertation investigated the language individuals use to describe their pain. First, a novel tool was developed and tested that captured and categorized pain words. There were three theoretical pain word categories: sensory pain words (e.g., pain, hurt), affective pain words (e.g., ouch, excruciating), and medical words (e.g., arthritis, ibuprofen). Next, the tool was used to examine naturally occurring pain disclosure in a group of individuals living with rheumatoid arthritis (RA) and a group of individuals living with breast cancer (BC). This study found that pain words accounted for 1% of words spoken in the RA sample and 0.7% in the BC sample. In addition, the study found that RA and BC participants disclosed pain to their significant others, as well as to many other people in their social networks such as family and friends. Next, the tool showed that in online forums designated for discussion of specific illnesses characterized by pain, pain disclosure seemed to elicit greater support. This was observed in a greater number of replies and better

engagement for initial posts that mentioned pain compared to initial posts that did not mention pain. Last, a study examined expressive writing about the most painful experience of individuals who were currently suffering from pain and those who reported no current pain. For the current pain group, a small stable relationship emerged, where greater use of affective pain words related to worse psychosocial outcomes. In addition, those in pain mentioned a greater loss of social support, described fewer instances of support, and more instances of having their pain dismissed than the non-current pain group. This dissertation found across three diverse studies that sensory pain words were used more than twice as often as affective pain words, yet affective pain words were tied to more outcomes. Pain is a continuous subjective experience and the findings in this dissertation indicate the specific words used to describe pain are associated with important psychosocial outcomes.

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# An In-Depth Analysis of Pain Language: How Individuals' Use of

#### Pain Words Relate to Psychosocial Outcomes

Pain is the leading reason people access health care in the United States ("NIH Fact Sheets - Pain Management," n.d.). Pain is a complex multifaceted problem experienced by an individual within a social context. The pain experienced is specific to an individual but it is influenced by the social environment. As researchers and clinicians continue to explore answers to the complexities of the pain experience, it is important to also address the social context in which the pain is experienced. The most common way individuals disclose pain is through language.

This dissertation explores how individuals use language to disclose their pain and how that language relates to psychological and social outcomes. I developed and established a novel tool to identify pain disclosure in several large and complex data sets. The tool was used in two studies. The first study identified pain conversations during naturally-occurring in-person and online social interactions. The second study explored indepth writing samples of individuals currently in pain to those of individuals who were, but are no longer, in pain.

The present review evaluates pain, the complexities of pain, limitations of measuring pain, and the major comorbidities associated with it. The *biopsychosocial model* provides a theoretical view of the multidimensionality of the pain experience. This model offered valuable information on how pain is connected to the comorbidities often experienced while in pain. A second theoretical model is introduced, the *social communication model of pain*, as a framework to help understand why pain disclosure

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should be investigated. Importantly, it provides a roadmap for how from the first inception of pain through the experience and expression to the receipt of the expression of pain. Lastly, I explore the role of language. Language is one main way pain is communicated yet has been largely ignored in the pain literature.

# Pain

The National Institute of Health lists pain as the leading cause of disability in the United States and estimates that it affects more people than diabetes, heart disease, and cancer combined. It is conservatively estimated that pain costs the United States between \$560-630 billion annually (Gaskin & Richard, 2012). The estimate does not account for the rapidly growing pharmaceutical, behavioral, and psychological treatment industries, nor does it account for the unintended consequence of the industries, such as the opioid epidemic (Wilkerson, Kim, Windsor, & Mareiniss, 2016). Pain has long been addressed as a major problem in the United States, which has drawn national plans to alleviate its burden (Brennan, 2015; "NIH launches HEAL Initiative, doubles funding to accelerate scientific solutions to stem national opioid epidemic," 2018).

A major hurdle in alleviating pain is addressing it on the individual level. In 2011, the National Academies Committee on Advancing Pain Research, Care, and Education stated, "Pain is a universal experience but unique to each individual" (IOM, 2011, p. 19). Further, the most common definition of pain puts the individual as the expert, noting that pain is exactly what the individual experiencing it says it is (McCaffery, 1968, p. 95). Although both definitions place the patient at the center of the pain experience, they highlight the variety of pain experiences. Fordyce (1976) underlined this complexity by introducing the distinction of pain, a biological response to tissue damage, and pain behaviors, verbal and non-verbal expressions of pain. The distinction is important in understanding how pain should be understood and investigated. Pain is experienced by the individual, but pain behaviors are expressed in a social context and are often influenced by others' responses (Keefe & Wren, 2013). Fordyce argues that pain and pain behaviors interact with each other but are distinct constructs.

## **Limitations of Pain Measurement**

The past work has provided a foundation for our current understanding of pain, but pain was historically measured using flawed methods. Early examples of ignoring the social components can be seen in the first reports of vaporized ether as a way to minimize surgical pain. In a report by Warren (1846) pain was postoperatively assessed twice. First, pain was assessed by one of his assistants as soon as the patient seemed to regain consciousness, at which point patients reported their pain level during the procedure as equivalent to a scratch. Warren reported that he subsequently asked patients directly about their pain, to which the patients replied there was absolutely no pain. A century later Beecher (1945), a doctor and a Lieutenant Colonel in the army, sought to determine if there was a relationship between extent of a battle field wound and the pain experience. Beecher targeted soldiers with severe injuries (e.g. compound fractures to large bones, penetrating wounds to the abdomen, extensive soft-tissue wounds, etc.) and asked them shortly after arriving at the field hospital if they were experiencing pain. If the soldier reported pain, Beecher then had them rate their pain on a 3-point scale. The study found that 31% did not report any pain, 44% reported slight or moderate pain, and 24% reported bad pain (the upper limit on the scale). Further, of those who reported bad pain, 73% said they did not want pain relief. Although a social psychologist would dispute the validity of these findings, the way pain was reported in the clinical setting is very close to current practices. These examples, although somewhat caricatures of a long history of investigating pain, are not far from modern investigations.

The methods used to assess pain have become more rigorous, but simple numeric rating scales have remained the gold standard (Schiavenato & Craig, 2010). In addition, a common limitation with most of the methods and studies discussed here is that they rely on one time point. Pain is a fluid experience; it is not always defined by one number at one time point and varies between and within days (Peters et al., 2000). Additional evidence has shown that individuals have diverse interpretations of the scale anchors and vacillate between actual experience and imagined experience (de Williams, Davies, & Chadury, 2000). Understanding the importance of measuring pain at a finer level than simple momentary or general retrospective reporting is not a new idea (Keele, 1948).

More recently, methodologies such as daily diaries and momentary assessments have been utilized to better understand pain. A daily diary study of rheumatology patients found significant variation in their day-to-day reports of pain (Schneider et al., 2012). Further, the researchers were able to predict associations between pain and reported depression and pain catastrophizing. Although this study looked at pain at the daily level, it highlights the fact that pain is not static, and measuring pain at one time point may not be reflective of the overall experience. An additional diary study found that over a twoweek period, there was low agreement between patients' weekly retrospective pain (e.g., in the past week how much pain did they experience) and their reports via the momentary diaries (Stone, Broderick, Shiffman, & Schwartz, 2004).

In a much larger study, patients were assessed for 28 days using a sampling rate of seven experience sampling surveys per day (Broderick et al., 2008). As with the previous research, this study found that patients' pain reports at recall differed from the average of their daily samples. Conversely, this study also showed that patients' reported 28-day pain rating was fairly accurate to the overall diary average. What is concerning with the findings is that depending on the pain survey the patient completed, there were different reported levels of pain. Although this study showed the feasibility of a large sampling rate, it may be cumbersome to ask patients in pain to respond to seven surveys a day.

There is a need to find a solution for measuring or capturing pain that is more indepth than the current gold standard single item and less burdensome than intensive diary methods. To achieve a solution, researchers and clinicians need to better understand how individuals communicate pain. It is important to incorporate both prompted and naturallyoccurring pain communication because pain is not relegated to a doctor's office or research laboratory (Jensen & Karoly, 2011).

# **Biopsychosocial Model**

Measuring pain is in part difficult because it is much more than just a direct biological response to tissue damage (Innes, 2005). In the past two decades, researchers have added to the distinction and interaction of pain and pain behaviors, most notably by applying the biopsychosocial model (Engel, 1977; Gatchel, Peng, Peters, Fuchs, & Turk,

2007). This model makes a distinction between nociception, the physical transmission of electricity along nerve pathways after actual or potential tissue damage, and pain, the individual subjective interpretation of the sensory information being received (Gatchel et al., 2007). The biopsychosocial model allows for a deconstruction of the interactions between biological, psychological, and social factors that all influence the pain experience.

The biological aspects of pain go beyond the physiological expression of actual or potential nerve damage. Neuroscientists are working to map the areas of the brain that respond to different types of nociception and how that related to perceived pain (Sawamoto et al., 2000). Research has also linked different physiological responses to the pain experience. Nociception can create a stress response in the body, causing a cascade of events, mainly the activation of the autonomic nervous system and the HPA axis. This response becomes maladaptive in chronically stressful (or painful) situations. Prolonged imbalance in the autonomic nervous system and the HPA axis has been shown to lead to prohibited growth and inability to repair tissue (McBeth et al., 2005; McEwen, 1998). These physiological responses are also incited by psychological stress associated with chronic pain (Melzack, 2005).

Depression, anxiety, and fear are commonly studied psychological co-morbidities of chronic pain. For example, research has detailed a connection between the fear of pain and heightened physiological responses (Vlaeyen, Haazen, Schuerman, Kole-Snijders, & Eek, 1995; Vlaeyen, Kole-Snijders, Boeren, & van Eek, 1995). To take the current fear example beyond biological and psychological and into the social level, fear of pain often leads to avoidant behaviors (Vlaeyen & Linton, 2000). These avoidant behaviors occur in response to threats or perceived stressors in the environment. In severe cases, this avoidant response can lead to individuals avoiding situations that may help them, such as physical therapy. There is a litany of social factors that influence both biological and psychological aspects of pain.

#### **Social Communication Model of Pain**

Craig (2009a) introduced the social communication model of pain as a theoretical roadmap to investigate and better understand how pain is not limited to the individual who is suffering. The social communication model posits that pain communication is an interplay between the biological, psychological, and social components. The model highlights the intra- and interpersonal aspects of the pain timeline. First, pain onset occurs, and the individual has a personal experience of pain (e.g., thoughts, feelings, and sensations). This experience is influenced by intrapersonal factors such as personal history and biological structures for pain (e.g., nerve connectivity). The experience is also influenced by interpersonal factors such as social and physical space. For example, a tooth pulp shock is rated as more painful in a dentist's office compared to a psychology lab (Dworkin & Chen, 1982).

Next, Craig posits that the pain experience leads to pain expression (nonverbal, verbal, or physiological). This step is influenced by the same intra- and interpersonal factors as the personal experience. In the previous WWII example, the social component played a part in the soldiers' rating of pain, such that when asked about their pain by a commanding officer, they seemed to rate objectively severe injuries as non-painful (Beecher, 1946). The expression of pain is in essence a message between two people, such

that the person in pain expresses ("encodes," in Craig's terms) their pain, and a "caregiver" decodes that message (Craig, 2009a). The decoding of the message by the caregiver is influenced by their own intrapersonal (e.g., sensitivity, biases, and knowledge) and interpersonal (e.g. relationship, duties) factors. For example, one study found that females compared to males are better at decoding nonverbal pain expressions (Prkachin, Mass, & Mercer, 2004).

Craig (2009a) lists pain management as the final step in the model, which is also influenced by intra- and interpersonal factors. The model is presented in a linear path, yet at almost every step there are bidirectional relationships. For example, personal experiences of pain lead to the expression of pain, but expression may also influence the experience. Further, the end of the model depicts pain management not pain cessation. This ongoing management can lead back to a need for reassessment and thus back to the individuals experience of the pain.

Inherent in the social communication model of pain is the communication of pain. The model explicitly details the factors influencing everything leading up to the expression and everything following the expression, but it is crucially important to understand how the pain message is communicated. An important line of research has focused on how pain is communicated through non-verbal expressions (Hadjistavropoulos, Craig, Hadjistavropoulos, & Poole, 1996; Schiavenato & Craig, 2010), and clinicians and researchers have used pictorial diagrams to allow individuals to communicate pain (e.g. Wong-Baker FACES; Wong & Baker, 2001). However, one of the most common ways people communicate pain is through language.

# Language

The specific word *pain* is a subjective label for large range of sensations (Melzack & Torgerson, 1971). Although pain researchers have occasionally focused on the language of pain, it is often seen as an afterthought. In a very broad sense, language is how most researchers investigate human beings (Pennebaker, Chung, Ireland, Gonzales, & Booth, 2007; Tausczik & Pennebaker, 2010). For example, psychologists use language to develop scales to measure constructs and explain the constructs they measured. Language is a reflection of who we are and our social relationships (Tausczik & Pennebaker, 2010).

Broadly, language can be broken down into two categories. Content words (e.g., nouns, regular verbs, and many adjectives) refer to what people are saying and make up the vast majority of all words in English. Style or function words (e.g. pronouns, prepositions, and articles) refer to how people say something. Style words make up about 0.05% of all words, yet are used in about 55% of spoken, read, or heard language (Pennebaker, Boyd, Jordan, & Blackburn, 2015). As Pennebaker writes, "the smallest, most commonly used, most forgettable words serve as windows into our thoughts, emotions, and behaviors" (Pennebaker, 2013, p. 3). If language represents thoughts, emotions, and behaviors, it would stand to reason that the words used to describe a concept such as subjective pain are potentially important.

Some research has focused on understanding the words used in pain description. For example, the McGill Pain Questionnaire (MPQ; Melzack, 1975), one of the most widely used pain scales, was one of the first standardized pain scales to account for pain descriptors. The psychometric properties of this scale have been exhaustively studied (Reading, Everitt, & Sledmere, 1982). This scale was unique in that it quantified the descriptors patients used to describe their pain. The MPQ was originally constructed by keeping a list of the words patients used to describe their pain, then further refined by having patients sort those pain descriptive words, as well as ones found in the literature, into categories (Melzack, 1975; Melzack & Torgerson, 1971). The full scale contains three categories of pain descriptors: a) sensory (e.g., pricking, sharp, dull), b) affective (e.g., fearful, tiring, sickening), and c) evaluative (e.g., tight, cold, nagging). Although this scale has made enormous strides toward putting pain into words and quantifying them, it is far from comprehensive. It also provides the words to the patients in a list as if they were choosing from a menu. Further, some of the language can be confusing and might not capture the full range of pain people experience (Chapman et al., 1985). There is also evidence that certain types of pain are not well-represented in the scale. In a study comparing the MPQ to narratives of people with physical disability, affective pain-related words in the scale did not overlap with the terms used in the narratives (Dudgeon et al., 2005). The MPQ also treats each word equally. There is evidence that certain words within the scale may identify pain intensity better than do other words (Gaston-Johansson, 1984). Identifying specific words used by individual patients allows physicians to better diagnose the source of patients' pain. Some scales attempt to address this, such as the PAINDetect scale (Freynhagen, Baron, Gockel, & Tölle, 2006), but these scales limit language even further by including fewer pain words.

The social communication model of pain notes the interaction between the pain expression and the person decoding the pain. In a very small study of chronic pain patients in an inpatient psychiatric hospital, patients were asked daily to talk about their pain (White & Sanders, 1986). The researchers found that the way they reinforced the patients' discussion of pain affected the amount of pain the patient reported.

#### **Purpose of the Dissertation and Overview of the Studies**

This dissertation developed and tested a novel tool that captured pain words, identified the importance of pain communication in three vastly different datasets, and related the pain words to psychological and psychosocial outcomes. The new methods and tools allow for a unique look into how pain is disclosed in large data and in naturalistic environments. Past researchers have attempted to capture the importance of pain words using standardized measures but have not focused on the importance of allowing the individual to provide the pain words. There is a rich literature in psychology focusing on the importance of word use. This dissertation investigated the words individuals use to describe pain and relate them to psychosocial outcomes. Chapter 2 describes the creation and validation of a tool to identify pain words in written text. Chapter 3 uses the new tool to explore pain disclosure in two unique datasets. First, in everyday conversations of individuals living with rheumatoid arthritis (RA) and breast cancer (BC) and second, in peer-to-peer interactions on an RA and a fibromyalgia (FM) specific online social network (OSN). Chapter 4 uses an expressive writing paradigm to explore differences in the writings of individuals currently in pain and individuals not currently in pain. Chapter 5 provides a general discussion of the findings from the studies presented in this dissertation.

# **CHAPTER 2: DEVELOPMENT AND VALIDATION OF A PAIN DICTIONARY**

The typical pain assessment asks individuals to rate their pain intensity on a single item, which does little to capture the complexities of the pain experience. A numerical or categorical scale cannot express the full sensory or affective nature of pain (Schiavenato & Craig, 2010). It is important to understand how individuals describe their pain (Katz & Melzack, 1999). These disclosures can play a role in diagnosis in the clinical setting but also in coping in everyday contexts. Research has shown that pain disclosure to an individual's spouse may be indicative of greater pain intensity and worse psychological well-being (Cano, Leong, Williams, May, & Lutz, 2012). These and other important aspects of pain disclosure have been studied in controlled laboratory settings (Cano, 2004; Cano & Goubert, 2017; Cano et al., 2012; T. Hadjistavropoulos & Craig, 2002). Although these studies have provided valuable insights into how individuals disclose pain, they lack the ecological validity in which social interactions typically occur. Leading researchers in the field have called for an expansion of methods used to capture pain disclosure (Cano & Goubert, 2017). To capture pain disclosure as it occurs, we developed and validated an automated tool to identify and quantify pain words in written and transcribed texts.

The Linguistic Inquiry and Word Count (LIWC) software is a simple yet powerful program used to analyze text (Pennebaker et al., 2015). LIWC uses a set of predefined dictionaries (e.g., pronouns, positive emotion words, social words) to produce a proportion of words in a specific dictionary to total words in a text. LIWC has been widely used to connect word use to meaningful psychological outcomes (Chung & Pennebaker, 2011; Tausczik & Pennebaker, 2010). The present study constructed and validated a LIWC pain-

specific dictionary. The study had two validation aims: a) to establish strong face validity through meticulous dictionary construction and repeated evaluation by experienced researchers, and b) to show known-groups validity through different patient populations. An additional exploratory aim was to determine if scores from the dictionary related to self-reported pain. The exploratory aim was only tested in Study 1 because Study 2 did not measure self-reported pain.

#### PAIN DICTIONARY CONSTRUCTION

The pain dictionary was developed using the procedure established by Pennebaker and colleagues (Pennebaker et al., 2015). First, an in-depth literature review of 22 established pain scales was compiled (Table 2.1). Additional searches were completed in Standard English dictionaries and thesauruses (e.g., burn, headache, sore). Further, pain medication generic (e.g., Acetaminophen) and brand names (e.g., Tylenol), pain-specific diagnoses (e.g., fibromyalgia), and disease-specific pain descriptors (e.g., flare) were added. The dictionary intentionally focuses on physical, not emotional, pain and contains 181 word roots (Appendix A).

Name of Measure	
Name of Measure	Citation
	Stewert B; Lancaster, G, Lawson J; Williams
	K; Daly J.(2004) Validation of the Alder Hey
	Triage Pain Score. Archive Disease in
Alder Hey Triage Pain Score	Childhood; 89:625-630
	Payen, J. F., Bru, O., Bosson, J. L., Lagrasta,
	A., Novel, E., Deschaux, I., Lavagne P, &
	Jacquot, C. (2001). Assessing pain in
	critically ill sedated patients by using a
	behavioral pain scale. Critical care
Behavioral Pain Scale (BPS)	medicine, 29(12), 2258-2263.
	Budzynski, T. H., Stoyva, J. M., Adler, C. S.,
	& Mullaney, D. J. (1973). EMG biofeedback
	and tension headache: A controlled outcome
	study. Psychosomatic Medicine, 35(6), 484-
Behavioral Rating Scale (BRS-6)	496.
	Downie, W. W., Leatham, P. A., Rhind, V.
	M., Wright, V., Branco, J. A., & Anderson, J.
	A. (1978). Studies with pain rating
	scales. Annals of the rheumatic
Box Scale (BS-11)	diseases, 37(4), 378.
	Cleeland CS. The Brief Pain Inventory User
	Guide .
	2009. https://www.mdanderson.org/educa
	opens in a new window (23 February 2016,
Brief Pain Inventory	date last accessed).
	Feldt, K. S. (2000). The checklist of
Checklist of nonverbal pain indicators	nonverbal pain indicators (CNPI). Pain
(CNPI)	Management Nursing, 1(1), 13-21.
	Ambuel, B., Hamlett, K. W., Marx, C. M., &
	Blumer, J. L. (1992). Assessing distress in
	pediatric intensive care environments: the
	COMFORT scale. Journal of pediatric
COMFORT scale	
	psychology, 17(1), 95-109.
	Gélinas, C., Fillion, L., Puntillo, K. A.,
	Viens, C., & Fortier, M. (2006). Validation of
	the critical-care pain observation tool in adult
Critical-Care Pain Observation Tool	patients. American Journal of Critical
(CPOT)	Care, 15(4), 420-427.
	Lawlis, G. F., Cuencas, R., Selby, D., &
	McCoy, C. E. (1989). The development of
Dallas Pain Questionnaire	the Dallas Pain Questionnaire. An assessment

 Table 2.1. Pain Measures Examined for Dictionary Development (Alphabetical)

	of the impact of spinal pain on
	behavior. Spine, 14(5), 511-516.
	Gracely, R. H., & Kwilosz, D. M. (1988).
	The Descriptor Differential Scale: applying
	psychophysical principles to clinical pain
Descriptor differential scale (DDS)	assessment. Pain, 35(3), 279-288.
· · · · · · · · · · · · · · · · · · ·	Bruera, E., Kuehn, N., Miller, M. J., Selmser,
	P., & Macmillan, K. (1991). The Edmonton
	Symptom Assessment System (ESAS): A
	simple method for the assessment of
Edmonton Symptom Assessment	palliative care patients. Journal of Palliative
System	Care, 7(2), 6-9.
	Merkel, S. I., Voepel-Lewis, T., Shayevitz, J.
	R., & Malviya, S. (1997). The FLACC: a
	behavioral scale for scoring postoperative
Face Legs Activity Cry Consolability	pain in young children. Pediatric
scale (FLACCS)	nursing, 23(3), 293-298.
	Lequesne, M. G., Mery, C., Samson, M., &
	Gerard, P. (1987). Indexes of severity for
	osteoarthritis of the hip and knee: validation-
	value in comparison with other assessment
Indexes of Severity for Osteoarthritis	tests. Scandinavian Journal of
of the Hip and Knee	Rheumatology, 16(sup65), 85-89.
Leeds assessment of	Bennett, M. (2001). The LANSS Pain Scale:
neuropathic symptoms and	the Leeds assessment of neuropathic
signs (LANSS) Pain Scale	symptoms and signs. Pain, 92(1-2), 147-157.
	Melzack, R. (1975). The McGill Pain
	Questionnaire: major properties and scoring
McGill Pain Questionnaire (MPQ)	methods. Pain, 1(3), 277-299.
	Kerns, R. D., Turk, D. C., & Rudy, T. E.
	(1985). The west haven-yale
Multidimensional Pain Inventory	multidimensional pain inventory
(WHYMPI)	(WHYMPI). Pain, 23(4), 345-356.
	Wheeler, A. H., Goolkasian, P., Baird, A. C.,
	& Darden, B. V. (1999). Development of the
	Neck Pain and Disability Scale: item
Neck Pain and Disability Scale	analysis, face, and criterion-related
(NPAD)	validity. Spine, 24(13), 1290.
	Fairbank, J. C., & Pynsent, P. B. (2000). The
	Oswestry disability index. Spine, 25(22),
Oswestry Disability Index	2940-2953.
	Freynhagen, R., Baron, R., Gockel, U., &
painDETECT	Tölle, T. R. (2006). Pain DETECT: a new

	screening questionnaire to identify
	neuropathic components in patients with back
	pain. Current medical research and
	opinion, 22(10), 1911-1920.
	Stratford, P. W., Binkley, J. M., Riddle, D.
	L., & Guyatt, G. H. (1998). Sensitivity to
	change of the Roland-Morris back pain
Roland-Morris Back Pain	questionnaire: part 1. Physical
Questionnaire	therapy, 78(11), 1186-1196.
	Higginson, I. J., & McCarthy, M. (1993).
	Validity of the support team assessment
	schedule: do staffs' ratings reflect those made
Support Team Assessment Schedule	by patients or their families?. Palliative
(STAS)	Medicine, 7(3), 219-228.
	Wong-Baker FACES Foundation (2016).
	Wong-Baker FACES® Pain Rating Scale.
Wong-Baker FACES Pain Rating	Retrieved January 10, 2017 with permission
Scale	from http://www.WongBakerFACES.org.

Once the full list was established, the dictionary was broken down into three theoretically-driven sub-dictionaries. Each word was assigned to either a sensory, affect, or medical sub-dictionary. The sensory and affect words were defined by the McGill Pain Questionnaire definitions (Ronald Melzack, 1975) and later theoretical work (Fernandez & Turk, 1992). Medical words consisted of pain-related words that were not pain descriptors (i.e., medications and diagnoses). A full list and downloadable LIWC dictionary file may be accessed for use at osf.io/gxm8b.

# PAIN DICTIONARY VALIDATION

Initial validity of the pain dictionary was tested in two ways. First, face validity was established by four experienced LIWC researchers, including two pain researchers. Second, using multiple datasets of individuals with different pain related diagnoses, we conducted a test of known-groups validity. A third exploratory validation was done to assess the connection between pain word use and self-reported pain.

# Electronically Activated Recorder Samples

*RA Sample*. Thirteen women with RA participated in a study called "Couples and Arthritis" (Kasle, Wilhelm, & Zautra, 2008; Robbins, 2017b; Robbins, Mehl, Holleran, & Kasle, 2011). They were recruited in Tucson, Arizona and the surrounding area from rheumatology clinics. There were 148 RA patients enrolled for the "Couples and Arthritis" study, and approximately 124 (50%) of them were given the opportunity to participate in the EAR portion of the study due to funding restrictions. Thirteen (10.5%) agreed to participate. Detailed demographic information is reported in Table 2.2. All participants had a primary diagnosis of RA, and average time since diagnosis was 6.85 years (SD = 4.26).

*BC Sample*. Fifty-two women with BC participated in a study called "Couples Coping with Breast Cancer" (Karan, Wright, & Robbins, 2017; Robbins, Focella, et al., 2011; Robbins, López, Weihs, & Mehl, 2014). Patients were recruited during their scheduled visits at the Arizona Cancer Center (University of Arizona, Tucson, AZ). Of the 647 couples approached, 210 (32.5%) were eligible, and 56 (26.7%) agreed to participate. Two couples withdrew from the study, one immediately following consent because they felt the microphone was too bothersome, and the second stopped responding to researchers prior to follow-up. One patient did not have enough sound files for analyses (fewer than 30). On average, participants were diagnosed less than one year from the study start, 10.84 months (SD = 14.34 months). All participants were on active treatment (e.g., chemotherapy or radiation) during the study.

	Study 1		Study 2
	Rheumatoid Arthritis	Breast Cancer	Online Social Networks
N	13	52	355869 <sup>a</sup>
Age (M, SD)	56 (13)	56 (14)	-
Sex			
Female	100%	100%	-
Relationship Status			
Married	100%	73%	-
Partnered	-	27%	-
Education			
≤ High School Graduate	15%	8%	-
1-4 Years of College	63%	62%	-
Graduate Education	15%	30%	-
Did not report	7%	-	-
Race			
White	92%	80%	-
Employment			
Employed	38%	44%	-
Retired	8%	44%	-
Unemployed	39%	6%	
Disability Status			
Part-time/Full-time	15%	6%	-
Illness Context			
Breast cancer	-	100%	-
Rheumatoid arthritis	100%	-	3.50% <sup>b</sup>
Fibromyalgia	-	-	96.50% <sup>c</sup>
Years since pain symptoms began or diagnosis (M, SD)	0.9 (1.2)	6.9 (4.3)	-

Table 2.2	Demographics
1 auto 2.2.	Demographics

Note. <sup>a</sup> Total number of posts in the online social network forums. <sup>b</sup> n=1454 unique users <sup>c</sup> n=7910 unique users

Detailed procedures for the RA sample can be found in Robbins, Mehl, and colleagues (2011), and for the BC sample in Robbins and colleagues (2014).

#### **OSN** Samples

The University of California, Riverside IRB deemed this collection of publiclyavailable data from three health-related OSNs as exempt from review. Data were retrieved from an FM (http://www.dailystrength.org/c/Fibromyalgia/support-group) and an RA (http://www.reddit.com/r/rheumatoid) OSN. There were no user-specific demographic data for the participants because no contact was made with the users of these sites.

Table 2.2 describes the data at the post- rather than user-level. The FM posts ranged from the beginning of the OSN on August 2, 2006 to March 9, 2015 when the OSN was terminated. These data comprise every public post for the duration of the site's existence, with 27,261 initial posts of a discussion thread. The RA sample consisted of data from March 18, 2012 to September 12, 2016. This entails all data from the first-ever post until the date the data were retrieved for this study, 885 initial posts in total.

#### *Face validity*

The dictionary went through several rounds of extensive reviews and edits. First, four general pain dictionaries were created. Each dictionary was designed to be more inclusive and larger than the previous one. This was done to compare the different dictionaries against one another to determine which dictionary captured the most accurate pain disclosures while excluding words more often found in non-pain contexts (e.g., feel, worst). The best dictionary then went through an additional review by the researchers. Next, it was tested on a subset of data from the EAR datasets. A sample of conversations

classified as pain disclosure by the dictionary was reviewed by the researchers to check if the dictionary was capturing actual pain disclosure. From this review, words were removed if they had high rates of use in non-pain contexts. Once the general dictionary was established, the researchers began the sub-dictionary classification process. The classification began with Melzack's original sorting (1975). The first two sub-dictionaries established were derived directly from Melzack's definitions: sensory (e.g., hurt, pain) and affective (e.g., excruciating, ouch) pain words. The third sub-dictionary was built to capture pain-related diagnoses and treatments, categorized as medical pain words (e.g., acetaminophen, migraine). Words that were not derived from Melzack's sorting were reviewed by the research team, guided by theoretical work by Fernandez and Turk (Fernandez & Turk, 1992). The sub-dictionaries were reviewed extensively by the researchers before final approval.

#### Known-groups validity

Known-groups validity was first tested using the EAR datasets, which compared a high-pain group (RA patients), and a relatively lower-pain group (BC patients). Known-groups validity for the pain dictionary was supported, as there were on average 1.75 times more pain words (as a proportion of total words) used by the RA sample (M = 12.37%, 95% CI [11.23-13.51]), than the BC sample (M = 7.09%, CI [6.71-7.47]). Further, known-groups validity was established within an FM and RA OSN. The pain-specific OSNs showed a high proportion of initial posts containing pain disclosure ( $M_{\rm FM} = 74\%$ , 95% CI [11.23-13.51];  $M_{\rm RA} = 77\%$ , 95% CI [11.23-13.51]).

Associations with self-reported pain

Self-reported pain was assessed in both samples in the EAR datasets. Various pain measures were included as part of diagnosis-specific scales. Exploratory analysis was done to relate each item assessing self-reported pain to scores from each pain sub-dictionary.

*RA measures.* There were five pain-related items from three different scales in the RA sample, and this sample completed each pain measure at two time points. First, each item was correlated with itself at both time points to determine if they should be averaged. Each item was related with itself across time points (rs > .45, ps < .17). Thus, each item was combined across time points to create one average measure of pain ( $\alpha s > .63$ ). The Arthritis Impact Measurement Scales 2-Short Form (AIMS2-SF; Guillemin et al., 1997) was the main measure of pain in the RA group. It consisted of a visual analogue scale used to assess pain retrospectively for the prior week and month. This scale was completed twice, one month apart. Three additional measures of pain during the past month were used. Two were items from the AIMS2-SF: a) How often did you have severe pain from your arthritis? and b) How often did your pain make it difficult for you to sleep? One was an item from the Short Form-36 (SF-36) (Ware & Sherbourne, 1992, "How much did pain interfere with your normal work?" where higher scores represented more pain).

*BC measures.* The BC sample had three measures of pain. The first item was a verbal categorical rating scale from the Functional Assessment of Cancer Therapy-Breast (FACT-B) (Brady et al., 1997). The item simply asked participants to respond to the statement "I have pain" on a five-point scale from "not at all" to "very much." Fourteen of the participants did not complete the FACT-B, and listwise deletion was applied when this variable was used. The two additional pain items were from the SF-36 health survey.

Bodily pain was assessed for the past four weeks on a six-point scale ranging from "none" to "very severe." Pain at work in the past four weeks was assessed on a five-point scale ranging from "not at all" to "extremely."

Correlations between total pain word use and self-reported pain showed small effect sizes across studies, that were somewhat likely to be due to chance ( $r_{range} = .09-.19$ , p = .14-.51). However, when looking at the sub-dictionaries within the RA and BC samples, affective pain words seemed to be more robustly related to self-reported pain. In the RA sample, affective pain word use non-significantly positively related to self-reported severe RA pain (r = .29, p = .34), pain while trying to sleep (r = .31, p = .31), and interference at work because of pain (r = .23, p = .46). In the BC sample, affective pain word use positively related to self-reported severe at work because of pain (r = .36, p = .024), interference at work because of pain (r = .23, p = .071), and pain in the past month (r = .26, p = .068).

#### DISCUSSION

A new tool to automate the identification of pain disclosure through quantitative word count was developed and validated. This tool allows for a descriptive window into how individuals verbally disclose pain. The dictionary went through a rigorous construction process based on previous empirical and theoretical research. Validation was achieved through face validity and known-groups comparisons.

Face validity was achieved in several ways. It was first achieved by following the procedures used to establish previous LIWC categories. LIWC has been an invaluable tool in exploring word use in social sciences for almost 20 years. Next, the pain dictionary benefited from a wide variety of validated self-report pain measures. The measures

provided a foundation of pain words that have been found relevant in previous investigations. Last, the multiple rounds of review by multiple experienced LIWC and pain researchers allowed for optimal refinement needed for face validity.

The unique strengths of both studies were used to help establish known-groups validity. The prediction made for unique datasets was supported, such that a known pain group (RA) used pain words more often than a group that was less defined by pain (BC). The OSN datasets further bolstered this finding, as people with FM and RA discussed pain in about 75% of initial posts. The size and diversity of both datasets provided confidence in the reliability of the new tool.

The exploratory validation process produced an interesting finding: Affective, but not sensory or medical, pain words positively related to self-reported pain. Although the RA group was underpowered, the associations were consistent with the findings in BC group. Past researchers have found that chronic pain and cancer pain patients rate their pain higher when provided affective rating scales compared to sensory pain scales (Price, Harkins, & Baker, 1987). These early findings have provided more questions than answers for researchers often due to the methodological limitation of needing to rely on self-report measures of pain words (Fernandez & Turk, 1992). The pain dictionary has the ability to investigate sensory and affective pain words without prompting the participant to choose a specific word.

The validated pain dictionary represents a novel way to investigate naturallyoccurring pain disclosure as well as pain words in large datasets. The tool has a variety of possibilities as researchers and clinicians attempt to understand the complexities of the pain experience. Advances in technology have allowed for novel methodologies to be used in pain research, and this dictionary adds an important automated tool to help navigate new types of data.

# CHAPTER 3: The Social Context of Naturally-Occurring Pain Disclosure in Daily Life In-Person and Online

Pain is a complex, subjective experience and is the leading cause for individuals to access healthcare ("NIH Fact Sheets - Pain Management," n.d.). Disclosure of pain to a healthcare provider and to close others is an important step in coping (Cano et al., 2012; Kelley, Lumley, & Leisen, 1997; Sullivan & Neish, 1999). In a clinical setting, pain disclosure often takes the form of quantifying pain on a single-item scale (Schiavenato & Craig, 2010), whereas in every other setting pain disclosure is a fluid social exchange or expression. Theoretical (Craig, 2009b, 2015; Thomas Hadjistavropoulos et al., 2011) and experimental evidence (Larochette, Chambers, & Craig, 2006) suggests that the social context, or the environment, has important implications. For example, research has found that patients may act stoic and attempt to limit the discussion of pain during an interaction with a home-care nurse (Spiers, 2006). Pain disclosure has been widely studied in clinical and controlled experimental settings but not as it naturally occurs in everyday interactions. The purpose of the present study was to examine naturally-occurring pain disclosure and its social context in-person and online.

The social communication model of pain details the interplay of biological, psychological and social factors that influence how individuals communicate pain (Craig, 2015; Hadjistavropoulos et al., 2011). According to the model, pain disclosure is a culmination of steps facing an individual in pain. Each step, from anticipating the pain event, experiencing the pain, and finally disclosing the pain is influenced by an interaction between biological, psychological, and social factors. Compared to biological and

psychological factors, social factors are often understudied in the pain experience (Craig, 2009b), yet pain is experienced in complex multilevel social contexts. For example, individuals with chronic pain (ICPs) report worse social relationships (P. Kelley & Clifford, 1997), more loneliness (Ressler, Bradshaw, Gualtieri, & Chui, 2012), and a heightened feeling of others not believing they are in pain (Newton, Southall, Raphael, Ashford, & LeMarchand, 2013). With worsening social situations, communicating pain becomes both more difficult and more important.

Accumulating evidence for the importance of social contextual factors in pain disclosure underscores the importance of understanding the context of pain disclosure to determine where it might be well-received and supported. Past research has shown that it matters how pain is disclosed (Cano & Williams, 2010), how spouses respond to such disclosures (Burns et al., 2015), and subsequent ICP outcomes (Edmond & Keefe, 2015; Porter, Keefe, Wellington, & de Williams, 2008) within laboratory studies. For example, ICPs who disclosed pain-related distress more than three times in a prompted lab discussion received more negative reactions from their spouse than those who disclosed fewer times (Cano et al., 2012). Further, one study found that spouses' most common responses to painrelated scenarios produced negative reactions from ICPs (Newton-John & Williams, 2006). Despite these findings, very little work has investigated how often, how, and with whom (other than spouses) pain disclosure naturally occurs in everyday life (Jensen & Karoly, 2011; Morely, Doyle, & Breese, 2000).

Pain disclosure may happen in therapeutic settings where patients are instructed to make such disclosures, but it can also occur in everyday conversation (Lepore, 2001;

Lepore & Revenson, 2007). Understanding everyday pain disclosure provides important insight into the pain experience that can be missed in clinic or research visits (Jensen & Karoly, 2011). The social communication model of pain posits that everyday conversation provides a different social context than a medical visit or research setting (Craig, 2015). Compared to pain disclosure in a clinical or laboratory setting, everyday pain disclosure may occur in a setting where it is not prompted or even socially appropriate. In a medical visit, pain disclosure is well-defined as part of the interaction. However, in everyday interactions with significant others, friends, or strangers, there is no clearly-defined social norm for pain disclosure.

To capture naturally-occurring pain disclosure, methods beyond self-report and inlab interactions are required. One route is a minimally-invasive method to capture momentary assessments of everyday life such as the Electronically Activated Recorder (EAR; Mehl & Holleran, 2007; Mehl, Pennebaker, Crow, Dabbs, & Price, 2001; Robbins, 2017). The EAR is a small audio-recording device worn by participants that samples ambient sound. The audio files capture participants' conversations and their social context, allowing the researcher to examine pain disclosure as it naturally happens, without prompting. However, not all pain disclosure happens in-person—technology has brought online social networks (OSNs), where people disclose in specialized forums to discuss their lives around a diagnosis. A growing number of online users are turning to peer-to-peer health networks for support (Fox & Duggan, 2013), often yielding positive effects in offline life (Frost & Massagli, 2009; Maloney-Krichmar & Preece, 2005). The EAR and OSNs offer a lens into how individuals naturally talk about pain to others, without researcher or clinician interference.

Previous practical limitations have prevented researchers from identifying pain disclosure as it happens naturally in-person and online. New tools are needed to process large amounts of social interactions. One approach is to use software that automatically identifies pain disclosure and its characteristics (Chung & Pennebaker, 2011; Pennebaker, Boyd, Jordan, & Blackburn, 2015) We developed an automated tool and used it to identify pain disclosure in large, unique datasets by recognizing proportions of words that are pain-related. Assessing natural word use is ideal because pain disclosure is often verbal, and extensive research has shown word use reveals important insights into psychological processes that go beyond standard self-report (Pennebaker, 2013). Additionally, the automated tool expands the methodological repertoire for assessing pain disclosure, addressing a previously-identified need (Cano & Goubert, 2017).

The present study explored naturally-occurring pain disclosure across different contexts. In Study 1 (in-person), rheumatoid arthritis (RA) and breast cancer (BC) patients wore the EAR, and in Study 2 (online), fibromyalgia (FM) and RA OSN posts were analyzed. The first aim was to determine naturally-occurring pain disclosure prevalence, qualities, and social engagement. The prevalence aim was exploratory, as there is a dearth of previous research on naturally-occurring pain disclosure. We hypothesized that pain disclosure will naturally occur both in-person and online, but that pain disclosure will be more common in OSNs, as they are illness-specific forums. The second aim was to determine the qualities of pain disclosure, including with whom the disclosure occurs.

Based on previous research, we hypothesized in-person disclosure would occur with the participant's spouse (Morely et al., 2000) but also others close to the participant (Robbins, Mehl, Smith, & Weihs, 2013). To further explore the quality of disclosure, we took an exploratory approach to determine the rates of different types of pain words. The third aim was to explore social engagement in response to naturally-occurring pain disclosure. We hypothesized that the context of pain disclosure would be important, specifically, online disclosure would be associated with greater support.

# Study 1

#### METHODS

Study 1 used existing data from two independent studies with similar designs, both approved by the IRB at the University of Arizona. They examined the everyday interactions of women with RA or BC.

# **Participants**

Detailed participant information can be found in Chapter 2. Detailed demographic information is reported in Table 2.2.

# Procedure

Detailed procedures can be found in Chapter 2. Upon consent, participants scheduled a visit with the researcher to complete questionnaires, including pain measures, and were provided instructions on wearing the EAR for the weekend. The EAR is an electronic device that is preprogramed to record snippets of ambient sound (rather than capturing people's conversations continuously), intended to identify naturally-occurring social interactions during waking hours (Mehl et al., 2001; Mehl, Robbins, & Deters,

2012). Participants wear the device on their waistline as much as possible during the sampling period and were unaware of when the EAR was recording. In the RA study, the EAR recorded 30 seconds of sound every 12 minutes; in the BC study, the EAR recorded 50 seconds of sound every 9 minutes. Both sampling rates provide reliable and valid assessments of daily behavior and social environments (Mehl et al., 2012). At the completion of the EAR portion of the studies, participants were given a copy of all their sound files to review. They were provided with an opportunity to delete any files prior to the researchers reviewing them. In each study, one participant deleted one sound file (out of approximately 20,000 sound files). After the weekend, participants completed another set of questionnaires. For the RA group only, this procedure was repeated one month later.

# Measures

# EAR Monitoring

The EAR software for the RA and BC studies was programmed on a Dell Axim X50 pocket PC (Mehl et al., 2012). Specific information about the EAR including privacy, confidentiality, and ethical concerns may be found in Robbins (2017b) and Manson and Robbins (2017). In the RA sample, the two EAR-monitored weekends were aggregated. *LIWC Dictionary* 

Each EAR sound file was transcribed and coded by two independent research assistants. Only the participant's portion of the conversations was transcribed. The transcripts were then analyzed using Linguistic Inquiry and Word Count (LIWC) software (Pennebaker et al., 2015). LIWC is an automated tool that provides a simple proportion of words from specific dictionaries (e.g., emotion words, pronouns, verbs) to the total words

in the writing sample. All standard dictionaries have gone through an extensive validation (Pennebaker et al., 2015).

### Pain Disclosure

In addition to the standard 2015 LIWC dictionaries, we created a novel painspecific dictionary. The dictionary was created using standard LIWC dictionary construction methods, with special attention to previously-validated pain scales. Details on construction and validation are in Chapter 2. The pain dictionary was broken down into three sub-dictionaries, such that each word was assigned to either a sensory, affective, or medical sub-dictionary. The sensory and affective words were largely defined by the McGill Pain Questionnaire definitions (Ronald Melzack, 1975) and later theoretical work (Fernandez & Turk, 1992). Medical words consisted of pain-related words that were not pain descriptors (i.e., medications and diagnoses). A full list and the downloadable pain LIWC dictionary file may be accessed at osf.io/gxm8b.

In addition to the standard proportion scores, the pain dictionary was used to classify conversations. If the participant used at least one word from the pain dictionary for a given EAR sound file, it was classified as a pain conversation. The codes were then aggregated across participants' sound files in which they spoke. This process produced a proportion score that indicates the percentage of time participants spent disclosing pain.

# Social Engagement

Each EAR sound file was coded to determine the presence or absence of a social interaction partner. Two independent research assistants coded the sound files for whether or not the participant was speaking to someone else (1 for yes, 0 for no), as well as to whom

they were speaking (i.e., significant other, friend or family member, self, or stranger or unknown). Each coding category was dichotomous, where 1 was marked if a particular type of person was present, and 0 was marked if they were not. Conversation cues were used to determine with whom the participant was speaking (e.g., familial titles, pet names). In the absence of clear cues, an "unknown" code was assigned. The independent codes were then averaged across all sound files to obtain estimates of the frequency with which participants spoke with others. Inter-coder reliability was assessed using one-way random effects intraclass correlations (Table 3.1).

## Analytic plan

The transcripts were analyzed with the standard LIWC 2015 dictionary and the pain LIWC dictionary. Social context of pain disclosure was calculated by determining the percentage of time other individuals (e.g. spouse, family/friend) were present for the pain disclosure.

#### RESULTS

#### Descriptive

The RA sample consisted of 2,940 audio files and the BC sample consisted of 9,130 valid (no technical errors) and waking (participant was not sleeping) audio files. One participant (8%) in the RA sample did not mention pain and six participants (12%) in the BC sample did not mention pain. In the RA sample, 1.77%, 95% CI [1.29-2.25], and in the BC sample 2.13%, 95% CI [1.83-2.43], of all sampled conversations were classified as pain disclosure. Table 3.1 shows the breakdown of the sensory, affective, and medical pain word use within the pain disclosure. In the RA sample, overall pain words comprised

0.12% (*SD* = .14) of total words spoken. For the sub-dictionaries, sensory words comprised 0.04% (*SD* = .05), affective words comprised 0.06% (*SD* = .13), and medical words comprised 0.02% (*SD* = .05) of total words spoken. In the BC sample, overall pain words comprised 0.07% (*SD* = .08) of total words spoken. For the sub-dictionaries, sensory words comprised 0.03% (*SD* = .05), affective words comprised 0.02% (*SD* = .04), and medical words comprised 0.02% (*SD* = .03) of total words spoken.

# Social engagement

Table 3.1 details which individuals were present for overall pain disclosure. Participants in the RA group disclosed pain to their family or friends most often, closely followed by their significant others. The BC group tended to disclose pain most often to their significant others, followed by family and friends.

	Rheumatoid Arthritis (n = 13)	Breast Cancer $(n = 52)$	Pain Disclosure Example
Percent of Total Words that were Pain	1.20%	0.70%	
Words [95% CI]	[1.12-1.35]	[0.67-0.74]	
Percent of Total Conversations about	1.77%	2.13%	
Pain	[1.29-2.25]	[1.83-2.43]	
Percent of Pain Conversations that were Sensory	44.23%	46.15%	BC: I have a little <u>discomfort</u> , I have <u>pain</u> when I sleep.
Pain	[30.73-57.73]	[39.15-53.15]	<u>↓</u> 1
Percent of Pain Conversations	19.23%	19.49%	RA: <u>Ouch</u> shoot, oh, poor little knee.
that were Affective Pain	[8.52-29.94]	[13.83-25.15]	
Percent of Pain Conversations	40.38%	42.56%	RA: I had to go in because they can't
that were Medical Pain	[27.04-53.72]	[35.62-49.50]	figure out if it's <u>lower</u> <u>back</u> or lower abdomen
		on of Total Pain	
	Conversatio IC		
Significant Other	35.76% [23.21 to 48.31] .88	70.87% [65.00 to 76.74] .78	
Friend/Family	46.42% [33.36 to 59.48] .88	50.87% [44.4 to 57.33] .95	
Self	5.35% [0.00 to 11.24]	0.87% [0.00 to 2.07]	
Other/Unknown	.56 8.92% [1.45 to 16.39] .45	.68 5.22% [2.35 to 8.09] .44	

Table 3.1 Social context of naturalistically-observed pain conversations by sample in Study 1

*Note*. Pain conversations were coded using LIWC. All conversations that contained at least one pain word from the LIWC dictionary spoken by the participant were classified as a pain-related conversation. ICCs are [1,k], from multiple pairs of independent coders. Conversation partners were not mutually exclusive, as participants could speak with multiple people in one conversation. Underlined words in the pain disclosure example are those that belong to each specific type of pain dictionary.

#### Study 2

# **METHODS**

This study examined naturally-occurring social interactions, like Study 1. However, these samples were more likely to contain pain conversations than everyday conversation, given their pain-specific purpose in these forums. Thus, Study 2 combined naturalistic, unmoderated social interactions (like Study 1) with potentially a more directed focus on pain.

## **Participants**

Detailed participant information can be found in Chapter 2.

# Procedures

All public data were scraped from the sites using jsoup, a Java-based code library for HTML parsing (Hedley, n.d.). The data were retrieved at the level of the individual posts with the user name, post time, and position in the thread retained. The structures of the OSNs were identical: all users are able to start a thread by posting a statement, and all users are able to reply to that post, or any of its replies. Table 2.2 describes the post level data.

#### Measures

## LIWC Dictionary

The standard 2015 LIWC dictionary and the pain dictionary, described in Study 1, were used to analyze the data at the post level. Each post was dichotomized as either pain or non-pain.

# Social Engagement

Language style matching (LSM) was utilized to determine social engagement in the individual threads. LSM focuses on similarity in style words (e.g., pronouns, articles) that indicate *how* a topic is discussed rather than content words, which indicate the topic of conversation. Past researchers have developed an equation using LIWC categories to determine LSM (Equation 1) (Ireland & Pennebaker, 2010). Values range from zero to one, with higher scores indicating more matching. LSM was used to quantify the level of similarity in how topics were discussed between the initial post in a thread and the subsequent replies to that thread. Past research has indicated linguistic synchrony, such as LSM, as the key component of emotional support in online interactions (Doré & Morris, 2018). Notably, synchrony in online replies led to feelings of heightened emotional support in that study.

Equation 3.1. Language Style Matching (LSM)

 $LSM_{Category1} = \frac{\left( \left| Category1_{1st \ post} - \ Category1_{\ Replies} \right| \right)}{\left( Category1_{1st \ post} + \ Category1_{\ Replies} + 0.00001 \right)}$ 

Note: Adapted from Ireland and Pennebaker (2010). An LSM score is found for each of the average of the 9 LIWC categories (personal pronouns, impersonal pronouns, articles, auxiliary verbs, common adverbs, prepositions, conjunctions, negations and quantifiers) and then they are averaged together to obtain a total LSM score.

# Analytic plan

The first set of analyses was descriptive, not inferential, due to the nonindependence of grouping by post rather than by person and the very large *N*. Word use analyses focused on the initial post of the threads rather than replies to the initial post. Posts that contained a pain word were identified using the LIWC pain dictionary and coded as pain posts. In total, there were 33,644 first posts in the FM OSN and 1,122 in the RA OSN.

Social engagement was measured two ways, both at the thread level. The first measure of social engagement was the number of replies to non-pain and pain-related initial posts. Next, social engagement was measured by linguistic synchrony using LSM. The replies within each thread were combined and then analyzed using LIWC, which provided thread-level values. Each thread then had an initial post classification and LIWC values for both the initial post and the aggregated replies. The LIWC values for the initial post and the aggregated replies. LSM scores for threads in which the initial post did not mention pain.

## Results

#### Descriptive

In both OSNs the majority of initial posts contained pain disclosure (FM = 74%, RA = 77%). Additionally, both OSNs showed very similar percentages of sensory pain, affective pain, medical pain, and total pain word use. Fifty-one percent of the FM initial posts contained sensory pain words, 20% contained affective pain words, and 55% contained medical pain words. Similarly, 55% of RA initial posts contained sensory pain

words, 20% contained affective pain words, and 60% contained medical pain words. Table 3.2 shows the average number of pain words per initial post.

# Social engagement

Table 3.3 shows that compared to initial posts that did not contain any mention of pain, initial posts that mentioned pain received more replies. This was consistent across sub-dictionaries as well.

Table 3.3 reveals there was more LSM in threads where pain was mentioned, compared to threads in which the initial post did not mention pain. This was consistent across all pain sub-dictionaries.

		Pain Disclosure Example	1	
	Total Pain	Sensory	Affect	Medical
FM ( <i>n</i> = 33,644)	2.28 (2.68)	1.00 (1.61) The <u>cramps</u> are coming in my feet and legs at the same time.	0.18 (0.54) How can I have FM and not be in <u>agony</u> every moment.	1.10 (1.81) This past Wednesday I was diagnosed with Fibro.
RA ( <i>n</i> = 1,122)	3.04 (4.12)	1.05 (1.55)	0.19 (0.71)	1.80 (3.66)
		Basically I suffer from <u>swelling</u> , <u>stiffness</u> and <u>pain</u> in my knee.	As my knee has any weight on it on the floor it is <u>agony</u> !	I had bilateral fluid removal and <u>cortisone</u> injections in my ankles yesterday afternoon.

Table 3.2. Mean pain word use in fibromyalgia and rheumatoid arthritis OSNs

*Note.* Study 2, first posts were coded using pain specific LIWC dictionaries, values represent the mean proportion of pain words to total words in first posts. Underlined words in the pain disclosure examples are those that belong to each specific type of pain dictionary.

	Mean Number of Replies [95% CI]					
	No Pain	Total Pain	Sensory	Affect	Sensory/Affect	Medical
FM	14.13	15.47	15.73	15.40	15.81	14.91
	[13.82-14.44]	[15.18-15.76]	[15.44-16.02]	[15.12-15.67]	[15.51-16.10]	[14.64-15.18]
RA	9.25	12.36	12.68	13.47	12.81	12.44
	[8.80-9.70]	[11.77-12.95]	[12.13-13.23]	[12.74-14.20]	[12.20-13.42]	[11.82-13.05]
		Mean LSM Values [95% CI]				
FM	.68	.78	.80	.80	.79	.78
	[.6868]	[.7878]	[.8080]	[.8080]	[.7979]	[.7878]
RA	.56	.78	.82	.80	.82	.81
	[.5458]	[.7779]	[.8183]	[.7981]	[.8183]	[.8082]

Table 3.3. Average re	plies and language s	tyle matching (LSM	) in OSN first posts

*Note*. Study 2, first posts were coded using pain specific LIWC dictionaries. Replies were then averaged within each category. Next, replies were combined and LSM values were calculated for the first posts and their replies. Mean values represent the amount of language style matching in each category. Higher values indicate greater matching, which could indicate more supportive replies to first posts (47). There were 883 first posts in the FM and 36 first posts in the RA which did not have any replies.

# DISCUSSION

Pain continues to be a clinical, research, and policy concern despite ample empirical attention. Theoretical evidence points to the importance of understanding biological, psychological, social contextual factors of the pain experience for developing multi-pronged approaches to alleviating pain (Gatchel et al., 2007; Hadjistavropoulos et al., 2011; Lumley et al., 2011). Due to methodological and feasibility constraints, the everyday social context of pain is often overlooked. This study explored how often and how pain disclosure naturally occurs within different social contexts: in-person (Study 1) and online (Study 2).

Using new tools, these studies provided a previously-absent understanding of how often and how naturally-occurring pain disclosure occurs. Study 1 found that pain words accounted for 1% of words spoken in the RA sample and 0.7% in the BC sample. In line with known-groups validity of our pain dictionary, people with RA, an illness partly characterized by pain, discussed pain at a higher rate than people with BC.

Beyond determining the frequency of pain disclosure, the findings from Study 1 begin to fill a void in understanding how patients talk about their pain with their social networks as a means of coping. Most laboratory studies focus solely on pain disclosure between patients and their significant others. One study specifically asked ICPs to report with whom they disclosed their pain, and most reported their significant other (Morely et al., 2000). The current study found that RA and BC participants disclosed pain to their significant others, as well as with many other people in their social networks beyond their significant others. Specifically, in the RA and BC samples, more than half of the pain conversations involved someone other than the significant other, and many conversations included more than one person. In light of this finding, it is clear that pain is disclosed to people beyond significant others, and it is important for future research to explore such disclosure.

Study 2 explored an online forum designated for discussion of specific illnesses characterized by pain, where pain disclosure seemed to have a receptive social context. Pain disclosure in an initial post was associated with receiving more peer attention (replies) compared to non-pain initial posts. In addition, pain disclosure in an initial post was associated with better engagement (LSM), and potentially more supportive responses (Ireland & Pennebaker, 2010; Rains, 2016), compared to non-pain initial posts. Research with online interactions has shown that linguistic synchrony is one mechanism underlying successful emotional support (Gatchel et al., 2007). The findings from Study 2 may indicate greater emotional support when users mention pain than when they do not mention pain in an initial post. This is consistent with previous research revealing that patients turn to OSNs to find and provide help with their illness, which otherwise may be absent in everyday life (Greene, Choudhry, Kilabuk, & Shrank, 2010). Other studies have found having more friends on health-related OSNs is related to better health outcomes, and the effect may be stronger than those in the users' real-world network (Ma, Chen, & Xiao, 2010). Further, active users feel a greater sense of perceived support than less-active users (Erfani, Abedin, & Blount, 2016). Thus, illness-related OSNs may provide a supportive forum for patients to disclose their pain where it may be more likely to be well-received than spontaneously in in-person social encounters.

These studies also provide ecologically-sound insight into the types of pain words used (sensory, affective, and medical). Melzack's distinction between sensory and affective pain words provided researchers with a framework to better investigate pain (Melzack, 1975). Researchers have expressed the importance of investigating both types of pain classification (Fernandez & Turk, 1992). With the use of the new dictionary, we observed that sensory pain words were used more than twice as often as affective pain words in both daily life and online interactions.

Conceptually, the distinction between sensory and affective pain words may map onto Cano and Goubert's (2017) differentiation between non-emotional pain talk and emotional disclosure of pain distress. This distinction is important for identifying possible adaptive strategies, as non-emotional pain talk may be a pain behavior, whereas emotional disclosure of pain may be a sign of seeking social support (Cano & Goubert, 2017). This may also indicate that language style matching may be important for ICPs, as it can be a sign of matching the type of support they are seeking.

## **Methodological considerations**

Methodological constraints in previous work have hindered the ability to determine base rates of pain disclosure and emotional disclosure of pain. This set of studies adds to this field by introducing a novel way of capturing pain communication (via the EAR and OSN posts) and identifying it (using the pain-specific LIWC dictionary developed for these studies). Study 1 utilized the EAR and found that participants disclose pain with different people in their social network. The EAR can expand on seminal laboratory research on pain communication (Cano et al., 2012; Cano & Williams, 2010) by taking it into natural, unprompted disclosure. Although beyond the scope of this study, the EAR may allow researchers to better understand the complex relationship between pain disclosure and responses from social network members over time (Edmond & Keefe, 2015).

This set of studies also validated and utilized the LIWC pain dictionary, which provided an automated approach to identifying pain disclosures through people's natural word use. This approach was the key to identifying pain disclosure in two distinctive studies, which both contained very large amounts of data. Together, the use of multiple methods provided a glimpse into the pain disclosure of participants without requiring significant effort from already-burdened patient populations, highlighting understudied areas of pain disclosure research.

## Strengths and limitations

There are several strengths and limitations of the present studies. First, these studies were designed to efficiently identify pain disclosure in a large amount of naturalistic data and thus did not measure direct consequences of disclosure. Although Study 2 did provide temporal evidence that pain disclosure preceded social engagement, longitudinal designs are needed to establish the mechanisms between pain disclosure and downstream outcomes. Further, social exchanges are interactive and cumulative, and thus not fully captured by studying discrete interactions. Some work has begun to address the complexity of pain disclosure by using daily diary methods (Burns et al., 2013), but more work using experience sampling methods in longitudinal studies is needed to fully understand this relationship.

Second, these studies combined several large datasets. Study 1 consisted of approximately 355 hours of audio data, and Study 2 utilized 355,869 OSN posts spanning 9 years. The volume of data is a strength and yielded high external and ecological validity. However, pain disclosure was dichotomized for processing feasibility, and goals of disclosure were not distinguished. For example, we did not determine whether participants disclosed as part of a catastrophizing process or as part of effective coping. Future research should investigate naturally-occurring disclosure at a finer-grained level, both in these datasets and others.

Third, this study combined two unique datasets to explore pain disclosure across different social contexts. On one hand, the diversity of contexts is a strength—but on the other hand, one could argue that it is infeasible to compare across methods and samples. Although there were some observed differences (e.g., the role of affective pain words in Study 1), the similarities in the results (e.g., the ratio of types of pain words in both studies) highlight the strength of the findings across samples and contexts. Each of study explored a different context for participants to discuss pain. One might predict that the way a participant discusses pain naturally with their social network and how a user writes posts on a health specific OSN would differ, yet we observed similarities across those contexts.

# Conclusion

In conclusion, these studies combined novel, unique datasets and used a new tool to identify naturally-occurring pain disclosure. These methods revealed a previously unstudied area within pain research and underscore the need to investigate pain disclosure as it naturally occurs (Edmond & Keefe, 2015; Kasle et al., 2008). This research takes a

step forward in providing critical insight into how patients disclose pain without researchers' interference.

# CHAPTER 4: THE ROLE OF CURRENTLY EXPERIENCING PAIN DURING EXPRESSIVELY WRITING ABOUT PAIN: PSYCHOSOCIAL OUTCOMES

Pain is a universal experience, yet researchers and clinicians continue to struggle with understanding it. A major hurdle is the simple fact that pain is subjective (McCaffery, 1968). If someone says they are in pain a clinician generally understands what they mean. Most often the clinician will use a quick quantification as a data point to help diagnose or assess the condition of the individual. This is a necessary tool, as modern medicine requires clinicians to care for many patients in a small amount of time. Yet, modern medicine seems to be failing pain patients. Research is needed to expand the knowledge of pain beyond quick quantification. New tools allow researchers the ability to capture previously hidden information in pain descriptions. The study aimed to explore unstructured pain descriptions by allowing individuals in pain to write about their pain in as much detail as possible. Further, the study aimed to compare the detailed writings of individuals in pain to those of individuals who were in comparable pain but are no longer in pain. Special attention focused on the types of pain words used and how they relate to psychosocial outcomes.

Researchers have focused on the words individuals use to describe their pain in the past. Most notably, the McGill Pain Questionnaire (MPQ; Melzack, 1975) systematically established a list of common pain words used by patients and clinicians. Work using the MPQ has shown the importance of the specific words that patients choose (Katz & Melzack, 1999). For example, researchers have found patterns in pain words chosen from the MPQ for individuals with known organic pathologies for their pain compared to those without known organic pathology (Perry, Heller, & Levine, 1988, 1991).

Although most research uses scales that have predetermined language for patients to describe their pain, there has been some work looking into the way patients describe the pain in an open-ended format. In a study looking at the words used to describe pain in the analgesic drug literature, a group of patients not experiencing pain rated the words on a visual analog scale (Sriwatanakul, Kelvie, & Lasagna, 1982). The study found large variability between the participants' ratings of the words, suggesting that there are individual differences for the use of specific pain words. Other research has attempted to categorize pain words provided by patients. In a study of guided imagery with 42 people with chronic pain, researchers asked the patients to describe their pain (Lewandowski, Good, & Draucker, 2005). In the pre-treatment baseline, the 210 responses were categorized into six main categories of pain: a) never ending, b) relative, c) explainable, d) torment, e) restrictive, and f) changeable. Although the researchers prompted the patients to discuss their pain, this study allows for a glimpse into the words patients, and not scales or medical providers, use to describe what is being experienced. Additionally, qualitative work on word use by pain patients has illuminated the use of similes (e.g., "feels like I'm being stabbed" & "fire ants are biting me"; De Souza & Frank, 2000; Duggleby, 2002), which are not captured on the scales.

Researchers have also used open-ended methods to allow participants to fully describe their pain. These methods are able to determine common themes of living with pain. For example, a study using qualitative methods found that ICPs discussed the loss of relationships as a constant theme (Kelley & Clifford, 1997). Further, ICPs provide a common theme of being dismissed or not believed when they are in pain (Newton et al.,

2013). Interestingly, researchers have tied themes in an expressive writing task to self-reported coping styles (Junghaenel, Schwartz, & Broderick, 2008). It may be important to allow for free-flowing pain descriptions because past work has shown that open responses elicit different information than forced responses. A study comparing the MPQ to narratives of people with physical disability found that the terms used in the narratives did not always overlap with the self-report measures (Dudgeon et al., 2005).

Evidence suggests that people experiencing pain may be more likely to use specific words. In a study of word completion tasks chronic pain patients tended to use more sensory pain words to complete the stems (Edwards & Pearce, 1994). Interestingly, the patient group did not differ from the control group in completing affective stems. There are also confounds in interpreting the cognitive aspects of chronic pain. In a study looking at attention to pain words, fear of pain mediated the relationship between pain and focus on pain words, so that those with high fear attenuated to the pain words more than those with low fear (Asmundson, Kuperos, & Norton, 1997). Although these studies show the importance of language, they have been conducted in pain populations with words provided to them.

To expand this line of research, this study asked individuals to use their own words to describe their pain. In addition, research has almost exclusively focused on individuals who are experiencing pain and has largely ignored individuals who were in pain but are no longer experiencing pain. The past work has operated on the assumption that the focus on specific pain language is caused by current pain but does not account for individuals who have broken free from the pain cycle. In the rare cases when healthy controls have been used, they do not account for their pain history.

The study aimed to use an established paradigm, expressive writing, to examine how individuals describe their most intense pain ever in an open-ended response. Two groups of participants were compared, individuals currently living with chronic pain and individuals who previously experienced high levels of pain but are not currently in pain. Although important information about the pain process has been established, it is not known if those insights hold true for those remembering a painful experience but not currently experiencing the pain. By investigating the experience of individuals who were but are no longer in severe pain, we may be able to find important differences in their pain descriptions. Chronic pain is a major societal issue that researchers and clinicians struggle to fully understand. Inherent in the individuals who are no longer in pain is their escape from the pain cycle. By comparing these two groups, we can take a first step into understanding individual differences in the trajectory of chronic pain.

## **Research Questions and Hypotheses**

This study explored the words and themes written in an expressive writing task about a participants' most intense pain experience ever between those in pain and those not in pain. The words and themes were related to common psychological and psychosocial outcomes.

 Are there meaningful differences in the types of pain words used in expressive writings among people with chronic pain compared to people not currently in pain?
 Past work has found a tendency for individuals in pain to use more sensory words when completing a letter-fill-in task compared to a non-pain control group (Edwards & Pearce, 1994). I predicted individuals in pain would use more sensory pain words than individuals in the non-pain group. Further, based on our past work (Study 2), I predicted a greater use of affective pain words to be related to higher self-reported pain ratings. Last, in an exploratory aim, I measured the use of similes and metaphors and relate them to self-reported pain and psychological outcomes.

- 2. Are there meaningful differences in the themes related to social support for individuals with chronic pain compared to people who do not have chronic pain? I hypothesized that social support will occur more often, with greater positivity, and be a more central theme to the writings of individuals not currently in pain. Compelling evidence has shown social support to enhance psychological well-being and help reduce pain in individuals in pain (Brown, Sheffield, Leary, & Robinson, 2003; Gil, Keefe, Crisson, & Van Dalfsen, 1987). Conversely, I hypothesized that the current pain group will discuss a greater loss of support and that it will be a more central theme than the non-current pain group. Past work has identified a complaint of chronic pain as the loss of social ties (Kelley & Clifford, 1997; Thomas & Johnson, 2000). Next, I hypothesized that the current pain group will mention dismissal of their pain more often and with more severity than the non-pain group. Past qualitative work has found pain dismissal to be a major theme for individuals with chronic pain (Newton et al., 2013).
- 3. Are there meaningful differences in the themes related to positive reframing for individuals with chronic pain compared to people who do not have chronic pain? I

hypothesized that there will be more instances of growth and reinterpretation in the non-current pain group compared to the current pain group. Past research has identified avoidant self-reported coping styles to relate to worse pain outcomes (Evers, Kraaimaat, Geenen, Jacobs, & Bijlsma, 2003; Rosenstiel & Keefe, 1983).

- 4. Do observer-rated pain descriptions relate to self-reported pain and psychological outcomes? This was an exploratory aim. There was no previous work investigating links between observer ratings of pain narratives and self-reported pain levels.
- 5. Do different linguistic and thematic factors group together to predict self-reported pain and pain comorbidities? This was an exploratory aim due to the dearth of previous research. I hypothesized that there will be meaningful clusters of word use and themes that relate to important pain-related outcomes.

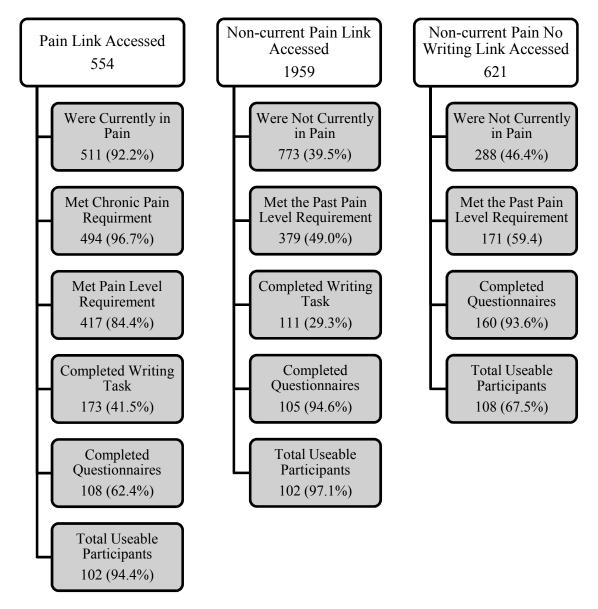
# Method

#### Participants

We used Qualtrics' Panel service (<u>https://www.qualtrics.com/online-sample/</u>) to recruit 312 total participants in two self-identified conditions: 1) individuals currently suffering chronic pain (i.e., with a chronic pain diagnosis or pain lasting over 12 weeks with the current intensity at least a 3 or higher on a 0-10 scale and 7 or higher in the past two weeks), and 2) individuals who have experienced pain anytime in the past that was at 7 or higher on a 0-10 scale but are currently no longer experiencing pain (report zero pain). A higher self-reported pain level for the past was chosen to capture more serious conditions that would be similar in severity to the chronic pain sample. The non-current pain group was assigned to one of two groups: 1) participants who completed the writing task and 2) participants who completed identical procedures except the writing task.

Qualtrics recruited from various sources, including website intercept recruitment, member referrals, targeted email lists, gaming sites, customer loyalty web portals, permission-based networks, and social media. Qualtrics did not share any identifying information with the researcher. If a participant provided such information, the data was immediately de-identified. Participants were compensated for their time through Qualtrics at a rate of \$7.50 per 45 minutes. Participants were required to be 18 years of age or older and able to read and provide consent in English. Figure 4.1 details the number of potential participants who accessed the survey.

Figure 4.1. Participant Recruitment



Note. Numbers represent number of participants.

All groups were similar in overall demographics. Table 4.1 provides a detailed

breakdown. Each group was predominately identified as Caucasian and female.

Writing Prompt		No Writing Prompt
Current Pain (n	Non-Current Pain	Non-Current Pain
= 102)	(n = 102)	(n = 108)
51.14 (15.15)	47.84 (19.00)	54.11 (15.00)
77.9	72.5	73.1
22.1	25.5	26.9
-	1.0	-
-	1.0	-
83.7	94.0	94.3
3.8	2.0	-
1.9	1.0	1.0
9.6	1.0	2.7
-	1.0	
1.0	1.0	2.0
2.9	-	-
19	49	4.6
		5.6
		1.8
		88.0
		-
110		
41 3	45.1	39.8
		4.6
		8.3
		46.3
0,111		1010
29	2 0	2.8
		18.5
		31.5
		25.9
		21.3
10.1	17.0	21.5
15.4	8.8	6.5
		11.1
		25.0
		38.0
		15.8
		3.7
	= 102) 51.14 (15.15) 77.9 22.1 - 83.7 3.8 1.9 9.6 - 1.0	= 102) $(n = 102)$ $51.14 (15.15)$ $47.84 (19.00)$ $77.9$ $72.5$ $22.1$ $25.5$ $ 1.0$ $ 1.0$ $ 1.0$ $83.7$ $94.0$ $3.8$ $2.0$ $1.9$ $1.0$ $9.6$ $1.0$ $ 1.0$ $1.0$ $1.0$ $2.9$ $ 1.9$ $4.9$ $10.6$ $5.9$ $2.9$ $5.9$ $2.9$ $5.9$ $80.8$ $82.3$ $1.0$ $1.0$ $41.3$ $45.1$ $2.9$ $1.0$ $16.3$ $10.8$ $39.4$ $43.1$ $2.9$ $2.0$ $28.8$ $17.6$ $30.8$ $28.4$ $22.1$ $33.3$ $15.4$ $17.6$ $15.4$ $8.8$ $16.3$ $13.7$ $24.0$ $25.5$ $26.9$ $32.4$ $11.5$ $16.7$

Table 4.1 Demographics and Pain Characteristics.

# Procedures

Upon completion of the consent, 204 participants first completed a 15-minute writing tasked aimed at eliciting expressive writing about pain in a narrative form. The prompt (Appendix B) asked for vivid retelling of experiences. Participants were instructed to write for the full 15 minutes. The prompt was based off of past literature using expressive writing as an intervention (King, 2002; LaCaille et al., 2013; Pennebaker, 2006). One hundred and eight participants in the non-current pain group were not given the writing task, for them to serve as a comparison group to determine any possible effects the writing task had on the self-report questionnaires that followed. After completing the expressive writing task participants completed questionnaires in the following order: pain intensity, pain catastrophizing, pain fear and avoidance, pain disclosure, subjective happiness, pain interference, satisfaction with life, stress, social support, depression symptoms, positive and negative affect, coping styles, optimism, self-medicating behaviors, personality, and demographics.

There was a programming error in the online survey. In the initial control group, the system did not record the pain intensity level for 60 participants. Qualtrics programmers fixed the error and collected an additional 60 participants to replace those with missing data. A decision was made to only use the control participants with values for their pain intensity level.

Measures

Word Use

LIWC Dictionary

The standard 2015 LIWC dictionary and the pain dictionary, described in Chapter 2, were used to analyze the data.

# Themes

Trained research assistants coded the themes blind to the condition. The full coding guide is located in Appendix C. For most codes agreement was measured using one-way random effects intraclass correlations [1;k] (Shrout, & Fleiss, 1979). For categorical variables, agreement was measured using Cohen's kappa coefficient. For low agreement the raters were asked to review the coding definition, and were given the opportunity to review their original codes and make any changes. Agreement for all coded variables is shown in Table 4.2 and example text from the writings are shown in Table 4.3.

# Social Support

Two research assistants coded the number of unique instances of social support from each writing. They then identified the provider of support as either a medical professional (e.g., doctor, nurse, chiropractor) or family or friend (e.g., spouse, parent, friend). Each instance of social support was then coded on a 0 (low positivity) to 2 (high positivity) scale. Averages were calculated across each participant's writing sample. Next, overall social support was rated for its integration into the writing. This was coded on a 1 (a little integration, social support is mentioned but it is not important to the narrative) to 3 (extreme integration, social support, they were assigned a 0.

The presence of loss of social support or social ties was coded as present or absent. In addition, loss integration was also coded to measure the role loss plays in the overall story. It was coded on a 0 (no mention of loss) to 3 (extreme integration, loss of social support plays a pivotal role in the story) scale.

Pain dismissal, the degree to which the participant feels others do not believe their pain, was coded on a 0 (no mention of dismissal) to 2 (full pain dismissal) scale.

# Positive Reframing

Positive reframing, perceiving something that was previously negative in a positive light, was independently coded by three research assistants for presence (1) or absence (0). Instances of positive reframing were further coded for growth, using the negative event to learn something, and reinterpretation, viewing the past negative event with new meaning. Each subcategory was also coded for presence (1) or absence (0). Inter-coder agreement was adequate for total positive reframing ICC[1;k] > .73, growth ICC[1;k] > .61, and reinterpretation ICC[1;k] > 73. For instances where the coders disagreed, the majority was used to decide the rating.

# **Observer-Rated** Pain

The severity of the pain descriptions used by the participants were coded on a fourpoint scale, where 0 is no mention of pain and 3 is the most severe pain description imaginable. This code was meant to reflect specifically how the participant framed the intensity of their pain when the specifically mentioned it. In addition, an overall perception of pain score was recorded on a 0 (no pain) to 10 (most severe pain possible) scale. This code was meant to view the whole writing sample and determine the participants' overall pain level. Lastly, any use of simile or metaphor to describe pain was recorded and counted.

	ICC	Mean (SD)	Range	% of Writing
				Samples
Social Support	0.75	1.56 (1.56)	0-8	62.9
Support Integration	0.45	-	-	-
Support Valence	0.95	0.27 (0.38)	-	-
Medical Support	0.69	1.01 (1.17)	-	64.7
Family/Friend	0.80	0.47 (0.80)	-	36.3
Support				
Loss of Support	0.81	0.26 (0.42)	0-1	30.0
Loss Integration	0.22	-	-	-
Pain Dismissal	0.77	0.38 (0.64)	0-2	32.4
Severity	0.18	-	-	-
Pain Rating	0.03	-	-	-
Metaphor/Simile	0.77	0.94 (1.26)	0-7	60.1

Table 4.2. Agreement and Occurrences of Thematic Codes

Note. ICC = one-way random effects intraclass correlations [1,k]. Loss was coded dichotomously and the value shown is Cohen's Kappa.

Table 4.3. Examples for Thematic Codes

Variable	Text		
Social Support			
High Positivity	By the Grace of God, I heard my Rural Mail ladie's truck, called for her, and she phoned 911 and got me a drink of water.		
Low Positivity	My uncle ended up taking me to the emergency room.		
Medical	Without treatment with my chiropractor I would be in pretty bad shape.		
Family/Friend	My grandma took me to a family friend who is also a nephrologist.		
Loss of Support	My ex would not allow home health to come up or physical therapy		
Pain Dismissal	A nurse came but didn't seem to see the extent of my pain.		
Positive Reframing			
Growth	Just as I was walking to the table, I remembered what I learned. I applied what I learned.		
Reinterpretation	Even though, I will always have a 25% disability in my foot, I am thankful I can walk again.		
Metaphor/Simile	It felt like I was being constantly stabbed and the knife was being twisted into my back the more I tried to move.		

Note. High positivity = social support high in positive valence, Low positivity = social support low in positive valence, medical = social support from a medical professional, family/friend = social support from a family member or friend.

Due to low agreement, support integration, loss integration, severity, and pain

dismissal were not used in further analyses.

## Self-Report

Pain

Participants currently in pain completed the Multidimensional Pain Inventory (Kerns, Turk, & Rudy, 1985). The MPI is a 52-item inventory consisting of 12-subscales (interference, support, pain severity, life-control, affective distress, negative responses, solicitous responses, distracting responses, household chores, outdoor work, activities away from home, social activities, and general activities). Higher scores indicated greater endorsement for the subscale category. Cronbach's alpha for this measure was 0.81. Patients not currently in pain were asked to rate their most intense pain on an 11-point scale (0-no pain at all to 10-worst pain imaginable).

All participants completed the Pain Catastrophizing Scale (PCS; Sullivan et al., 1995). The PCS is a 13-item scale to assess self-reported catastrophizing. The scale consists of three subscales (rumination, magnification, and helplessness). The PCS is an often-used and well-validated measure (Van Damme, Crombez, & Eccleston, 2004). Higher scores indicate greater catastrophizing. A typical item in the helplessness subscale states "When I'm in pain, I feel I can't go on." Cronbach's alpha for this measure was 0.94

Participants completed the Fear-Avoidance Beliefs Questionnaire (FABQ; Waddell, Newton, Henderson, Somerville, & Main, 1993). The FABQ consists of 16-items to measure fear-avoidance beliefs about pain in regard to work and physical activity. The FABQ is a well validated measure across many pain conditions (Swinkels-Meewisse, Swinkels, Verbeek, Vlaeyen, & Oostendorp, 2003). Higher scores indicate greater fearavoidant beliefs. A typical item in the physical activity subscale states "Physical activity makes my pain worse." Cronbach's alpha for this measure was 0.91.

Participants rated the degree to which they disclosed their thoughts, information, and feelings about pain in general to their significant other. Participants were instructed that a "significant other" was the person for whom they felt closest. These three items were adapted from a measure of perceived self-disclosure (Manne et al., 2004), which asked about general disclosure. The items are scored on a seven-point scale (1-not at all to 7-very much) where higher scores indicate greater perceived disclosure. A typical item asks "How much did you disclose your thoughts about your pain to your significant other?"

Participants reported the number of days of school or work missed, amount of time lost, and overall performance limitations due to pain. Due to low base rate (n = 1) these variables were not used. In addition, participants were asked about their use of illicit drugs and alcohol to self-medicate on a dichotomous scale (1 - yes; 0 - no). Only two participants reported use of drugs for self-medicating behavior, which prevented use in any group analyses. Twenty-five participants reported using alcohol to self-medicate.

Affect

Participants completed the Subjective Happiness Scale (SHS; Lyubomirsky & Lepper, 1999). The SHS is a four-item scale where higher scores indicated greater subjective happiness. A sample item asks "Some people are generally very happy. They enjoy life regardless of what is going on, getting the most out of everything. To what extent does this characterization describe you?" Cronbach's alpha for this measure was 0.87.

Participants completed the Satisfaction With Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985). The SWLS is a five-item scale, which measures self-reported life satisfaction on a seven-point scale (1-strongly disagree to 5-strongly agree). Higher scores indicate greater satisfaction with life. A sample item states "In most ways my life is close to my ideal." Cronbach's alpha for this measure was 0.89.

Participants completed the Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988), a 20-item self-report scale designed to measure positive

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and negative affect. Participants were asked to rate the extent to which they feel on ten positive terms (e.g., excited, proud) and ten negative terms (e.g., upset, scared) on a fivepoint scale (1-very slightly or not at all to 5-extremely). Higher scores indicate greater affect for each subscale. Cronbach's alpha for this measure was 0.83.

Participants completed the Life Orientation Test-Revised (LOT-R; Scheier, Carver, & Bridges, 1994). The LOT-R has ten-statements that measures optimism and pessimism on a five-point scale (1-I agree a lot to 5-I disagree a lot). Higher values represent higher optimism and pessimism in the respective subscales. A sample optimism item states "I'm always optimistic about my future." Cronbach's alpha for this measure was 0.85.

# Social Support

Participants completed the National Institutes of Health (NIH) Toolbox Adult Social Relationship (SR) Scales (Cyranowski et al., 2013). The NIH Toolbox Adult SR contains six subscales: emotional support, instrumental support, friendship, loneliness, perceived rejection, and perceived hostility. Higher scores on each subscale indicate greater endorsement of the subscale category. A sample item states "I have someone who understands my problems." Cronbach's alpha for this measure was 0.96.

# Mental Health

Participants completed the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977). The CES-D is 20-item scale which measures self-reported depression symptoms. Higher scores indicated more reported depressive symptoms. A sample item states "I felt that people dislike me." Cronbach's alpha for this measure was 0.94.

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Participants completed the four-item Perceived Stress Scale (PSS-4; Cohen, Kamarck, & Mermelstein, 1983). The PSS-4 uses a five-point Likert-scale to assess stress, with higher scores indicating greater perceived stress. A sample item asks "In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?" Cronbach's alpha for this measure was 0.80.

#### Personality.

Participants completed the Big Five Inventory-2 Extra-short Form (BFI-2 XS; Soto & John, 2017), a 15-item assessment of the five facets of personality (extraversion, agreeableness, conscientiousness, negative emotionality, and open-mindedness). Higher scores for each factor indicated higher levels of that personality facet. Negative emotionality was the only facet used in analyses. A sample item for negative emotionality is "I am someone who worries a lot." Cronbach's alpha for negative emotionality was 0.78.

#### **Data Analytic Strategy**

To address the first four research questions, I compared mean differences between the current pain group and the non-current pain group with independent samples *t*-tests. The writing was analyzed using the LIWC pain dictionary (Chapter 2). The LIWC scores provided proportions of pain words compared to total words written. All coded variables were averaged across coders to provide one value. Table 4.2 shows the mean, standard deviation, and range for all coded variables.

The remaining exploratory aims to see if pain word use could predict co-morbidities above and beyond self-reported pain were tested using correlations and multiple linear regressions. First correlations were run to test associations between pain word use, theme coding, self-reported pain, and self-reported comorbidities. Correlations between Pain LIWC variables and self-reported comorbidities which met statistical significance at p < .05 were tested in multiple linear regressions. Self-reported pain was added in each model. In addition, if medical literacy or length of pain episode was correlated with either the predictor or outcome at p < .10, it was added to the model. No additional demographic variables related to the variables in a meaningful way.

# Results

On average, the current pain group rated their most intense pain in the past two weeks at the same level as the non-pain group rated their most intense pain ever (Table 4.4). The current pain group has lived with pain for three times as long as the non-current pain group did. The cause of the pain varied in two categories between the groups. The participants responded to an opened prompt on the diagnosis or cause of their pain. The responses were categorized into five categories: accident (i.e., motor vehicle crash, workplace injury), chronic illness diagnosis (i.e., arthritis, fibromyalgia), medical or dental procedure (i.e., surgery, root canal), childbirth or labor, and unknown (i,e., replied "unknown" or left response blank). For the current pain group, because worst pain in the past two weeks was strongly related to current pain (r(100) = .50, p < .001) and analyses done with current pain did not alter the interpretation of the findings, worst pain in the past two weeks was used to compare between groups due the similar scale as the non-pain group.

	Current Pain	Non-Current Pain
Worst Pain Past Two Weeks M (SD)	9.51 (1.03)	-
Worst Pain Ever $M$ (SD)	-	9.76 (1.13)
Pain Duration Years $M$ (SD)	12.77 (11.54)	4.44 (7.36) <sup>a</sup>
Pain Cause (%)		
Accident	34.6	34.3
Medical/Chronic Diagnosis	50.0	37.3
Medical/Dental Procedure	8.7	6.9
Childbirth/Labor	1.0	15.7
Unknown	5.8	5.9

Table 4.4. Descriptive Pain Information

Note: There were 102 participants in each group.

<sup>a</sup> 36 participants did not respond to this question.

Table 4.5 shows the average number of words written per category compared to

total words for each group.

	Current Pain		Non-curi	rent Pain			
	М	SD	M	SD	t	р	d
Total Words	328.32	213.33	284.81	143.93	1.71	.088	0.24
All Pain Words	5.08	2.01	4.58	2.00	1.79	.075	0.25
Sensory Pain Words	3.21	1.41	3.36	1.62	-0.67	.506	0.10
Affective Pain Words	0.35	1.52	0.28	0.46	1.02	.308	0.06
Medical Pain Words	1.51	1.24	0.94	0.83	3.90	<.001	0.54

Table 4.5. Group Comparisons of Pain Word Use

Note. Values for pain words represent the percentage of words from the specific category to total words written. Current pain n = 102; non-current pain n = 102.

Participants in the current pain group (M = 5.08, SD = 2.10) tended to use a higher proportion of pain words overall compared to those in the non-current pain group (M = 5.08, SD = 2.10), t(204) = 1.71, p = .088. This difference was not observed in the sensory or affective pain words. The current pain group (M = 1.51, SD = 1.24) used a significantly higher proportion of medical pain words compared to those in the non-current pain group (M = 0.94, SD = 0.83), t(204) = 3.90, p < .001. On average there was no difference in use of metaphors and similes to describe pain in the current pain group (M = 0.95, SD = 1.30) compared to those in the non-current pain group (M = 0.97, SD = 1.30), t(204) = -0.10, p = .918.

Table 4.6 shows mean occurrences of themes coded in each writing sample by group. Participants in the current pain group described losing social support and encountering greater pain dismissal than those in the non-current pain group. In addition, participants in the current pain group tended to discuss family and friend social support less than participants in the non-current pain group.

Table 4.6. Mean Differences Between Thematic Coding
---

	Current Pain		Non-current Pain				
	M	SD	М	SD	t	р	d
Social Support	1.50	1.62	1.62	1.51	-0.56	.577	0.07
Support Valence	0.26	0.37	0.27	0.40	-0.23	.820	0.03
Medical Support	1.11	1.28	1.06	1.07	0.30	.766	0.04
Family/Friend Support	0.38	0.73	0.56	0.85	-1.63	.104	0.22
Loss of Support	0.33	0.45	0.20	0.38	2.15	.033	0.31
Pain Dismissal	0.50	0.73	0.27	0.53	2.56	.011	0.36
Note							

Note.

In total, positive reframing occurred in 22 of the writing samples. There was no meaningful difference between the current pain (n = 12) and non-current pain (n = 10) groups use of positive reframing, t(202) = 0.45, p = .654, d = 0.06. In the current pain group growth was used once and reinterpretation 11 times, compared to the non-current pain group where growth was used three times and reinterpretation was mentioned seven times. Table 4.7 shows the distribution of positive reframing between underlying pain type. Labor and child birth had the highest proportion of positive reframing per pain type, 29.4%.

			0 1	<b>D</b> :
	п	Positive Reframing	Growth	Reinterpretation
Accident	71	5	1	4
Chronic Diagnosis	89	8	2	6
Medical/Dental	16	3	1	2
Labor/Child Birth	17	5	0	5
Unknown	11	1	0	1

Table 4.7. Occurrences of Positive Reframing

Note. Values represent occurrences.

Table 4.8 shows the mean differences of the non-current pain expressive writing and non-current pain no expressive writing groups. When asked to recall their pain level during their worst pain experience ever, the expressive writing group (M = 9.76, SD = 1.13) had slightly higher self-reported pain levels than the no expressive writing group (M = 9.44, SD = 1.34), t(208) = 1.87, p = .062, d = 0.06. The self-reported pain measure was administered prior to the expressive writing task for the writing group.

	Writing		No Writing		_		
	М	SD	M	SD	t	р	d
Pain Intensity	9.76	1.13	9.44	1.34	1.87	.062	0.26
Depressive Symptoms	20.82	16.08	16.10	13.99	2.23	.027	0.31
Perceived Stress	9.80	3.40	8.61	3.57	2.48	.013	0.34
Negative Affect	18.31	9.39	14.81	8.50	2.83	.010	0.38
Positive Affect	33.05	9.49	33.18	9.79	-0.10	.924	0.01
Subjective Happiness	20.18	5.46	21.41	4.76	-1.73	.085	0.24
Satisfaction with Life	23.91	7.33	24.36	7.33	-0.44	.658	0.06
Note Whiting a - 102. N.	i <i>i</i> :						

 Table 4.8. Comparison of Writing and no Writing for Non-current Pain Groups

Note. Writing n = 102; No writing n = 108.

In an exploratory aim, self-reported pain and LIWC pain variables were correlated with thematic codes and self-reported comorbidities. Table 4.9 shows the bivariate relationships between self-reported pain, length of pain episode, and LIWC pain. Pain intensity and length of pain episode did not relate to any pain word use.

Table 4.7. Contentions Detween 1 and 1 and 1 of 0.5e									
Measure	1.	2.	3.	4.	5.	6.			
1. Pain Intensity	-	02	.11	.14	04	.02			
2. Pain Length	01	-	.03	.05	.06	03			
3. LIWC Pain Total	.12	.19	-	.73**	.34**	.65**			
4. LIWC Pain Sens	.07	.16	.85**	-	.05	.01			
5. LIWC Pain Aff	.06	.07	.31**	05	-	.11			
6. LIWC Pain Med	.09	.10	.58**	.12	.30**	-			

Table 4.9. Correlations Between Pain and Pain Word Use

Note. Correlations for current pain participants (n = 102) are presented above the diagonal, and correlations for non-current pain participants (n = 102) are presented below the diagonal. Pain Intensity = most intense pain in the last two weeks (current pain) and most intense pain ever (non-current pain); Pain length = length of pain episode; LIWC Pain Total = total pain words used; LIWC Pain Sens = Sensory pain words used; LIWC Pain Aff = Affective pain words used; LIWC Pain Med = Medical pain words used. \*\* $p \le .01$ 

Table 4.10 shows the bivariate relationships between self-reported pain, length of pain episode, and LIWC pain, with coded social support. For the current pain group, a higher proportion of sensory pain words was related to less description of receiving social support from medical professionals. For the non-current pain group, the length of the pain episode and the use of sensory pain words were both negatively related to the mention of social support from friends and family. Across both groups there was a positive relationship where, the greater use of metaphors and similes to describe pain was associated with a higher number of instances of social support from friends and family  $(r_{current pain}(100) = .21, n = .026)$ 

p = .036;  $r_{\text{non-current pain}}(100) = .24$ , p = .014).

Measure	SS Total	SS Valence	SS Medical	SS Family/Friend	M/S
Current Pain					
Pain Intensity	10	02	10	06	07
Pain Length	.07	02	.03	.07	05
LIWC Pain Total	26**	19	20*	<b>-</b> .18 <sup>†</sup>	02
LIWC Pain Sens	19*	23†	21*	04	01
LIWC Pain Aff	04	11	.02	11	.01
LIWC Pain Med	18 <sup>†</sup>	.01	09	21*	02
Non-Current Pain					
Pain Intensity	.16†	05	.16†	.09	.18†
Pain Length	.04	.11	06	24*	14
LIWC Pain Total	18†	.12	06	24*	14
LIWC Pain Sens	26**	.10	17†	25*	05
LIWC Pain Aff	.01	03	.07	07	01
LIWC Pain Med	.07	.10	.15	05	23*

Table 4.10. Correlations Between Social Support and Metaphors/	/Similes
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Note. Pain Intensity = most intense pain in the last two weeks (current pain) and most intense pain ever (non-current pain); LIWC Pain Total = total pain words used; LIWC Pain Sens = Sensory pain words used; LIWC Pain Aff = Affective pain words used; LIWC Pain Med = Medical pain words used; SS = Social support; M/S = Metaphors and similes.  $\dagger p \le .10$ ;  $*p \le .05$ ;  $**p \le .01$  Table 4.11 shows the bivariate relationships between self-reported pain, length of pain episode, and LIWC pain, with social support loss, and pain dismissal. In the current pain group there was a strong positive relationship where, the greater mention of pain dismissal was associated with a higher number of instances of loss of social support from friends and family (r(99) = .33, p = .001).

Measure	SS Loss	Pain Dismissal
Current Pain		
Pain Intensity	.13	08
Pain Length	11	02
LIWC Pain Total	11	20*
LIWC Pain Sens	01	23*
LIWC Pain Aff	06	01
LIWC Pain Med	<b>-</b> .18 <sup>†</sup>	06
Non-Current Pain		
Pain Intensity	.02	.03
Pain Length	.29*	.12
LIWC Pain Total	.19†	12
LIWC Pain Sens	.13	13
LIWC Pain Aff	.05	13
LIWC Pain Med	.19†	.02

Table 4.11. Correlations Between Negative Support

Note. Pain Intensity = most intense pain in the last two weeks (current pain) and most intense pain ever (non-current pain); Pain length = length of pain episode; LIWC Pain Total = total pain words used; LIWC Pain Sens = Sensory pain words used; LIWC Pain Aff = Affective pain words used; LIWC Pain Med = Medical pain words used; SS Loss= Mentions of loss of social support; Pain Dismissal = Mentions of pain being dismissed.  $\dagger p \le .05$ 

Table 4.12 shows the bivariate relationships between self-reported pain, length of pain episode, and LIWC pain, total pain catastrophizing, rumination, magnification, helplessness, fear and avoidant behavior, and alcohol self-medicating behavior. For the current pain group, highest pain intensity in the past two weeks was related to higher reported catastrophizing. Conversely, pain length was negatively related to pain

catastrophizing. For the non-current pain group, pain length was positively related to catastrophizing. For the current pain group, highest pain intensity in the past two weeks was related to greater use of alcohol to self-medicate. For the non-current pain group, length of pain episode was positively related to greater fear and avoidant behavior of pain.

Table 4.13 shows the bivariate relationships between self-reported pain, length of pain episode, and LIWC pain, with self-reported coping strategies. For the current pain group, use of affective pain words was negatively related to use of emotional support coping and acceptance coping. For the non-current pain group, use of humor coping was negatively related to worst pain and use of sensory pain words.

Table 4.14 shows the bivariate relationships between self-reported pain, length of pain episode, and LIWC pain, with self-reported social support and disclosure. For the current pain group, highest pain intensity in the past two weeks was related to greater disclosure of thoughts, information, and feelings about their pain to their significant other. There were no relationships in the non-current pain group.

Table 4.15 shows the bivariate relationships between self-reported pain, length of pain episode, and LIWC pain, with negative well-being. Table 4.15 shows the bivariate relationships between self-reported pain, length of pain episode, and LIWC pain, with positive well-being. For the current pain group, self-reported pain was positively related to negative affect. The use of affective pain words was weakly negatively related to satisfaction with life, positive affect, and optimism. Conversely, in the non-current pain group, use of affective pain words was positively related to positive affect.

Table 4.16 shows the bivariate relationships between self-reported pain, length of pain episode, and LIWC pain, with personality. There were no consistent relationships observed.

Measure	PCS Total	Rumination	Magnificat	Helpless	FABQ Pain	FABQ Work	Alcohol Use
Current Pain							
Pain Intensity	.29**	.18 <sup>†</sup>	.20*	.34**	.15	.27**	.21*
Pain Length	31**	30**	25*	29**	13	.15	.04
LIWC Pain Total	.14	.16	.08	.14	.08	12	01
LIWC Pain Sens	.07	.11	.06	.03	.02	26**	.03
LIWC Pain Aff	.03	01	08	.11	.01	.04	.07
LIWC Pain Med	.14	.14	.08	.14	.10	.10	07
Non-Current Pain							
Pain Intensity	.08	.04	.02	.13	.07	.01	.05
Pain Length	.30*	.30*	.18	.29*	.34*	.25*	28*
LIWC Pain Total	.04	.07	02	.05	.11	.05	.11
LIWC Pain Sens	.04	.08	.00	.03	.13	.14	.15
LIWC Pain Aff	.07	.10	03	.09	.12	.01	.01
LIWC Pain Med	03	06	.09	.00	05	<b>-</b> .17 <sup>†</sup>	04

Table 4.12. Correlations Between Catastrophizing and Fear Avoidance

Note. Pain Intensity = most intense pain in the last two weeks (current pain) and most intense pain ever (non-current pain); Pain length = length of pain episode; LIWC Pain Total = total pain words used; LIWC Pain Sens = Sensory pain words used; LIWC Pain Aff = Affective pain words used; LIWC Pain Med = Medical pain words used; PCS Total = Pain catastrophizing scale; Rumination = rumination subscale of the PCS; Magnificat = magnification subscale of the PCS; Helpless = helplessness subscale of the PCS; FABQ Pain = Fear and avoidant behavior questionnaire of pain; FABQ = Fear and avoidant behavior due to work place pain; Alcohol use = self-medicating use of alcohol specific to pain.  $\dagger p \le .10$ ;  $*p \le .05$ ;  $**p \le .01$ 

Measure	AC	DE	SU	ES	IS	PR	HU	AP
Current Pain								
Pain Intensity	01	.10	24*	.10	03	03	07	.01
Pain Length	.24*	13	<b>-</b> .18 <sup>†</sup>	15	20*	.22*	.07	.11
LIWC Pain Total	.01	23*	07	02	.01	.08	01	03
LIWC Pain Sens	.03	22*	20*	.09	.09	.02	.06	05
LIWC Pain Aff	05	07	.00	23*	12	09	02	20*
LIWC Pain Med	01	09	.11	04	04	.13	07	08
Non-Current Pain								
Pain Intensity	09	06	07	20†	13	02	27**	01
Pain Length	12	13	06	.06	03	.08	08	.08
LIWC Pain Total	24*	.07	04	16	12	14	16	17†
LIWC Pain Sens	20*	.14	<b>-</b> .18 <sup>†</sup>	15	09	18†	20*	20*
LIWC Pain Aff	.01	09	.09	01	02	.09	07	.06
LIWC Pain Med	17†	04	.21*	07	11	03	.05	05

Table 4.13. Correlations Between Coping Behaviors

Note. Correlations for current pain participants (n = 102) are presented above the diagonal, and correlations for non-current pain Pain Intensity = most intense pain in the last two weeks (current pain) and most intense pain ever (non-current pain); Pain length = length of pain episode; LIWC Pain Total = total pain words used; LIWC Pain Sens = Sensory pain words used; LIWC Pain Aff = Affective pain words used; LIWC Pain Med = Medical pain words used. Variables across the top row are subscales of COPE; AC = Active coping; DE = Denial; SU = Substance use; ES = Use of emotional support; IS = Use of instrumental support; PR = positive reframing; HU = Humor; AP = Acceptance.  $\dagger p \le .05$ ;  $**p \le .01$ 

Measure	Emotion	Instrumental	Friend	Thoughts	Information	Feelings
Current Pain						
Pain Intensity	.02	.07	.04	.34**	.29**	.31**
Pain Length	18†	<b>-</b> .18 <sup>†</sup>	09	11	<b>-</b> .19 <sup>†</sup>	14†
LIWC Pain Total	.06	.02	.06	.09	.05	.00
LIWC Pain Sens	.09	.06	.06	.08	.04	01
LIWC Pain Aff	16	18†	11	.04	.00	03
LIWC Pain Med	.06	.03	.06	.04	.04	.02
Non-Current Pain						
Pain Intensity	04	14	.01	.12	.06	.07
Pain Length	08	.13	.01	.05	.05	.06
LIWC Pain Total	00	12	10	12	00	03
LIWC Pain Sens	02	08	05	07	.00	.00
LIWC Pain Aff	.01	01	05	10	03	07
LIWC Pain Med	.03	12	12	09	.01	03

Table 4.14. Correlations Between Self-Reported Social Support and Disclosure

Note. Pain Intensity = most intense pain in the last two weeks (current pain) and most intense pain ever (non-current pain); Pain length = length of pain episode; LIWC Pain Total = total pain words used; LIWC Pain Sens = Sensory pain words used; LIWC Pain Aff = Affective pain words used; LIWC Pain Med = Medical pain words used. The first three variables across the top row are subscales of self-reported social support. The last three are single items referring to extent one discloses thoughts, information, and feelings about pain to a significant other.  $\dagger p \le .01$ 

Measure	Depression	Stress	Negative Affect	Pessimism	Neg Emotionality
Current Pain					
Pain Intensity	.10	.18†	.26**	.05	04
Pain Length	13	08	16	04	16
LIWC Pain Total	01	.04	11	.04	19†
LIWC Pain Sens	09	.03	10	.04	07
LIWC Pain Aff	.19†	.16	.02	.17†	.11
LIWC Pain Med	.02	03	08	05	26**
Non-Current Pain					
Pain Intensity	04	04	07	.04	.12
Pain Length	.08	.24†	01	.25*	.04
LIWC Pain Total	02	03	07	.03	<b>-</b> .18 <sup>†</sup>
LIWC Pain Sens	03	01	05	.06	<b>-</b> .17 <sup>†</sup>
LIWC Pain Aff	03	07	07	.07	10
LIWC Pain Med	.04	06	02	10	07

Table 4.15. Correlations Between Self-Reported Negative Mental Well-Being

Note. Pain Intensity = most intense pain in the last two weeks (current pain) and most intense pain ever (non-current pain); Pain length = length of pain episode; LIWC Pain Total = total pain words used; LIWC Pain Sens = Sensory pain words used; LIWC Pain Aff = Affective pain words used; LIWC Pain Med = Medical pain words used; Neg Emotionality = Negative emotionality personality facet.  $\dagger p \le .10$ ;  $\ast p \le .05$ ;  $\ast \ast p \le .01$ 

Measure	Happiness	Satisfaction With Life	Positive Affect	Optimism
Current Pain				
Pain Intensity	.07	06	.05	.05
Pain Length	.08	07	.09	.07
LIWC Pain Total	.19†	.05	.05	.04
LIWC Pain Sens	.11	.13	01	01
LIWC Pain Aff	07	18 <sup>†</sup>	<b>-</b> .18 <sup>†</sup>	<b>-</b> .18 <sup>†</sup>
LIWC Pain Med	.20*	01	.15	.13
Non-Current Pain				
Pain Intensity	.02	11	.08	.02
Pain Length	20	20	09	10
LIWC Pain Total	.07	.02	04	03
LIWC Pain Sens	.08	05	10	13
LIWC Pain Aff	.04	.16	.23*	.12
LIWC Pain Med	.01	.06	03	.12

Table 4.16. Correlations Between Self-Reported Positive Mental Well-Being

Note. Pain Intensity = most intense pain in the last two weeks (current pain) and most intense pain ever (non-current pain); Pain length = length of pain episode; LIWC Pain Total = total pain words used; LIWC Pain Sens = Sensory pain words used; LIWC Pain Aff = Affective pain words used; LIWC Pain Med = Medical pain words used.  $\dagger p \le .10$ ;  $*p \le .05$  For the current pain group, medical literacy was negatively related to self-reported pain (r(100) = -.19, p = .060), use of sensory pain words (r(100) = -.21, p = .039), pain catastrophizing (r(100) = -.20, p = .040), depressive symptoms (r(99) = -.22, p = .026), perceived stress (r(100) = -.30, p = .003), negative affect (r(100) = -.29, p = .003), and positively related to use of social support (r(100) = .32, p = .020). There was no reliable difference in the self-reported medical literacy between the current pain (M = 4.53, SD = .84) and non-current pain (M = 4.58, SD = .89) groups, t(202) = -.04, p = .687.

Next a set of regression models were computed to determine the association between linguistic pain variables and self-reported pain comorbidities. Table 4.17 shows that the use of sensory pain words has a weak negative association with medial social support while accounting for self-reported pain and literacy within both groups.

		Current F	Pain		Non-Current Pain				
Variable	В	SE B	β	р	В	SE B	β	р	
LIWC Sensory	16	.090	172	.09	-0.12	.065	180	.07	
Pain Intensity	06	.124	049	.63	0.17	.093	.180	.07	
Medical Literacy	.22	.154	.146	.15	-0.04	.117	033	.74	
$R^2$		.068				.061			
F		2.402		.07		2.328		.10	
Note.									

Table 4.17. Summary of Regression Analyses for Word Use Predicting Medical Social Support.

Table 4.18 shows that in the current pain group only, the use of medical pain words has a negative association with family and friend social support while accounting for self-reported pain, literacy, and length of pain episode.

	_	Current H	Pain		Non-Current Pain				
Variable	В	SE B	β	р	В	SE B	β	р	
LIWC Medical	12	.058	210	.04	0.01	.115	.006	.97	
Pain Intensity	02	.072	033	.75	0.11	.094	.153	.24	
Medical Literacy	.12	.089	.133	.20	0.02	.109	.027	.83	
Pain Length	.00	.006	.036	.72	0.00	.014	.020	.88	
$R^2$		.068				.025			
F		1.756		.14		0.397		.81	
Note.									

Table 4.18. Summary of Regression Analyses for Word Use Predicting Family and Friend Social Support.

There was no observed relationship within the current pain group (B = -.07, p = ..944) or the non-current pain group (B = -.19, p = ..131), for the use of sensory pain words with family and friend social support while accounting for self-reported pain, literacy, and length of pain episode.

Table 4.19 shows that in the non-current pain group only, the use of medical pain words has a negative association with use of metaphors and similes while accounting for self-reported pain and literacy.

Table 4.19. Summary of Regression Analyses for Word Use Predicting Use of Metaphors and Similes.

		Current F	Pain	Non-Current Pain				
Variable	В	SE B	β	р	В	SE B	β	р
LIWC Medical	02	.101	022	.49	-0.38	.151	242	.01
Pain Intensity	06	.124	050	.83	0.22	.151	.195	.05
Medical Literacy	.11	.152	.077	.63	0.09	.141	.060	.54
$R^2$		.011				.097		
F		0.346		.79		3.522*		.02
Noto								

Note.

Table 4.20 shows that in the current pain group only, the use of sensory pain words has a negative association with work related fear and avoidance behavior while accounting

for self-reported pain, literacy, and length of pain episode. There was no relationship observed in the non-current pain group.

	(	Current Pai	n	Non-Current Pain					
Variable	В	SE B	β	р	В	SE B	β	р	
LIWC Sensory	-2.80	.788	332	.001	-0.14	.830	021	.86	
Pain Intensity	3.50	1.084	.302	.002	-0.93	1.140	099	.42	
Medical Literacy	-1.18	1.36	084	.39	-2.22	1.337	202	.10	
Pain Length	0.19	.096	.183†	.05	0.38	.172	.265	.03	
$R^2$		.199				.115			
F		5.980		>.001		1.983		.11	

Table 4.20. Summary of Regression Analyses for Word Use Predicting Work Related Fear and Avoidant Pain Behavior.

Note.

Table 4.21 shows that in the current pain group, the use of affective pain words has a weak negative association with self-reported positive affect while accounting for selfreported pain and literacy. Conversely, the non-current pain group showed a positive association between the use of affective words and self-reported positive affect while accounting for self-reported pain and literacy.

Table 4.21. Summary of Regression Analyses for Word Use Predicting Use of Positive Affect.

	С	urrent Pa	ain		Non-Current Pain				
Variable	В	SE B	β	р	В	SE B	β	р	
LIWC Affective	-3.73	1.206	174	.08	4.76	2.037	.230	.01	
Pain Intensity	0.68	0.957	.071	.48	0.53	0.831	.063	.02	
Medical Literacy	1.52	1.169	.129	.20	0.34	1.048	.032	.53	
$R^2$		.050				.059			
F		1.728		.17		2.049		.11	
Nata									

Note.

Table 4.22 shows there was no reliable relationship within the current pain group or the non-current pain group, for the use of medical pain words with self-reported happiness while accounting for self-reported pain, literacy, and length of pain episode.

	(	Current Pa	ain		Non-Current Pain				
Variable	В	SE B	β	р	В	SE B	β	р	
LIWC Medical	0.95	.472	.200	.05	0.11	.778	.018	.89	
Pain Intensity	0.49	.584	.085	.40	0.08	.633	.015	.91	
Medical Literacy	0.52	.723	.074	.47	0.71	.732	.121	.34	
Pain Length	0.04	.052	.070	.49	-0.16	.094	214	.10	
$R^2$		.057				.057			
F		1.438		.23		0.902		.47	

Table 4.22. Summary of Regression Analyses for Word Use Predicting Happiness.

Note.

#### Discussion

This study examined expressive writing about the most painful experience an individual has experienced in those who were currently suffering from pain and those who reported no current pain. It provided an important contrast, which had previously been absent from the literature. Previous research has relied on individuals in pain and assumed their responses were unique to the pain condition they were facing. This study builds on that body of literature by showing some similarities in the way individuals currently, and those no longer, in pain describe the experience. In addition, it identified relevant differences between the two groups which were associated with important psychosocial outcomes.

That there were any similarities between the two groups is somewhat remarkable considering the intense pain the current pain group reported. The current pain group reported the same highest intensity in the past two weeks as the non-current pain group reported as their worst pain ever. In addition, the current pain group reported living with their pain almost three times longer than the non-current pain group. This study made an important contribution by exploring expressive writings and not solely relying on limited retrospective pain ratings (Stone, Broderick, Shiffman, & Schwartz, 2004; Linton & Melin,

1982). Expressive writing about pain is not a novel concept (Norman, Lumley, Dooley, & Diamond, 2004), nor is exploring the thematic narrative context of those writings (Morone, Lynch, Greco, Tindle, & Weiner, 2008). However, this study combined those approaches and added the pain dictionary developed in Chapter 2. The addition of the dictionary allowed for important distinctions in the words used to describe pain, which has previously been absent.

The expressive writings produced some noteworthy differences between the two groups. The current pain group tended to write more overall than the non-current pain group. In addition, the current pain group tended to use more pain words, using almost twice as many medical pain words. This finding may partially be explained by the underlying causes of pain. The current pain group reported more chronic medical diagnoses as the cause of their pain, whereas the non-current pain group had fewer specific descriptions for underlying pain causes. A known diagnosis, and perhaps a better understanding of the condition overall, may be responsible for the current pain group's increased frequency of medical terminology use in describing their condition. Alternatively, these findings may be an indication of attentional bias to pain (Liossi, 2012), such that those in pain were more focused on pain than those not currently in pain. Previous meta-analytic work has shown individuals in pain to have a slight bias toward pain words and pictures compared to individuals not in pain (Crombez, Van Ryckeghem, Eccleston, & Van Damme, 2013).

Thematically, the current pain group referenced a greater loss of social support than the non-current pain group. Loss of social support may play a pivotal role in chronic pain. A previous semi-structured, qualitative investigation of women living with chronic pelvic pain highlighted that the ideal support was constant while allowing for autonomy (Warwick, Joseph, Cordle, & Ashworth, 2002). Prospective research looking at individuals with rheumatoid arthritis found low social support predicted functional disability and selfreported pain at 3- and 5-year follow-ups (Evers, Kraaimaat, Geenen, Jacobs, & Bijlsma, 2003). Thus, if the current pain group did not receive the ideal support then it may have led to worse long-term outcomes.

The current pain groups' description of loss of support was further compounded by a tending to describe less support from their family and friends than the non-current pain group. Past research has shown the importance of how others provide support during pain disclosures (Snelling, 1990). Consistent findings from in lab (Cano et al., 2012) and self-report measures (Jamison & Virts, 1990) show poor familial interactions can lead to worse pain-related outcomes. This study adds to this literature by exploring the role of social support without directly asking about it. Participants raised these issues on their own during the expressive writing task.

Closely related to the loss of support, the current pain group also mentioned others dismissing their pain more than the non-current pain group. Believability is a major issue for pain patients (De Ruddere & Craig, 2016). Often the underlying cause of the pain does not have any outward physical appearances. This situation then requires the individual experiencing pain to convince their physician or even their family and friends that they are in pain. Ample evidence exists indicating ICPs do not feel their family and friends believe

their pain, which may negatively affect their relationships (Holloway, Sofaer-Bennett, & Walker, 2007; Monsivais, 2013; Toye & Barker, 2010).

This study found a strong positive relationship between pain dismissal and loss of social support from friends and family. This finding is in line with past work that identified a bidirectional relationship between the two variables (Osborn & Smith, 1998; Newton et al., 2013). Pain limits activity, which can lead to an increase in isolation (Walker, Sofaer, & Holloway, 2006). Conversely, pain dismissal by a family member or friend may lead to a weakening of the relationship and further isolation. Additional work has posited that, even if the individual in pain has the perception that others do not believe the extent of their pain, regardless of the others' actual views, the individual may remove them self from the social setting (Clarke & Iphofen, 2008). Underlying pain dismissal is the ability to adequately describe the pain experience.

Both groups averaged the use of almost one metaphor or simile to describe their pain. Specifically, 60% of the participants used at least one metaphor or simile. There is scarce specific literature that has focused on metaphoric and analogous pain language. Having issues putting pain into language is not a new problem (c.f. Scarry 1985). Linguists ascribe difficulty studying pain language to the fact that most pain descriptors are borrowed from other domains (e.g., shooting, burning; Reznikova, Rakhilina, & Bonch-Osmolovskaya, 2012). Although focus on the use of metaphors and similes in pain description, little has been done to tie it to actual outcomes. In the present study, greater use of metaphors and similes was associated with higher reports of social support from family and friends for both groups. Researchers suggest that analogous language is used to help convey an abstract concept to someone else (Loftus, 2011; Skott, 2002). In addition, researchers have posited that metaphors and similes may be a useful tool in relating pain to others in an effort to elicit empathy (Ong, Hooper, Dunn, & Croft, 2004). The findings in this study indicate that, by using metaphors and similes, the participant may have been better able to relate their pain to a family member or friend who in turn may have expressed more empathy or at least more support.

Unfortunately, as with many studies, we found that lower medical literacy was associated with worse outcomes for the current pain group. Pain has taken over the title of fifth vital sign in the past two decades (Merboth & Barnason, 2000) and recently a push has been made to make medical literacy the sixth (Heinrich 2012). Past work has shown poorer medical literacy to be connected to fewer positive health behaviors in chronic pain patients compared to non-chronic pain patients (Briggs et al., 2011). Further, in meta-analytic work, research has shown that poor literacy is tied to worse beliefs about self-care maintenance which leads to developing worse health behaviors (Mackey, Doody, Werner, & Fullen, 2016).

No observed difference emerged in the use of positive reframing between groups. This finding is interesting due to the disparity of underlying pain causes between the two groups. In the current pain group, only one participant listed childbirth as the cause of pain, whereas in the non-current pain group, 15 participants listed childbirth. Research has shown childbirth may be fundamentally different from other pains. Not in the intensity, as it is commonly used as a comparison to highlight the worst possible pain, but it is often associated with a positive outcome and it is seen as a pain experience with a relatively short duration (Ong et al., 2004). This is in line with the findings of this study, where almost 30% of individuals who described childbirth as their worst pain also provided positive reframing—by far the highest proportion of any pain cause. In addition, several individuals writing about other pains used labor and childbirth as a reference point. For example, one participant stated "The pain was worse than when I was in labor." Another stated "That is the worst pain I have ever experienced, including childbirth." One participant went as far as to use childbirth to qualify the extent of her pain "My arm was broken from the ball in my shoulder, and the pain was excruciating!!! I would rather give birth 10 times than have that kind of pain again."

There was an interesting set of results where the current pain group had a positive association between self-reported pain intensity and disclosure to their significant other. This finding fits within the theory that emotional disclosure of pain-related distress may be an indication of a need for emotional support (Cano & Goubert, 2017). Thus, increased disclosure is related to decreased pain intensity as the disclosure acts as a path to alleviate the pain. The present study also observed a stable negative relationship between disclosure and length of pain. There is evidence that too much disclosure is associated with negative responses from a significant other (Cano, Leong, Williams, May, & Lutz, 2012). The present study further found no relationship between intensity and length of pain episode. Taken together, this may indicate that disclosure wanes over time, but during instances of high pain intensity, disclosure may increase. Beyond the present study, it is important to understand the motivations of disclosure and the response provided when disclosure occurs (Cano & Goubert, 2017).

This study's exploratory regression analyses showed several noteworthy patterns. The aim was to determine if pain word use could predict comorbidities above and beyond self-reported pain and medical literacy.

Within both groups, the use of sensory pain words was negatively associated with mention of social support from medical professionals. This is somewhat counterintuitive as sensory words, such as stabbing or aching, are more often used in diagnosing than affective words (McCarberg et al., 2017). Further, there is evidence that using affective language around pain may lead to more physician bias toward the patient and belief that the pain is an emotional problem, not a biological one (McGowan, Pitts, & Carter, 1999). Yet, in this sample, a greater use of sensory pain words was associated with less mention of support from medical professionals.

Medical pain word use was negatively associated with the use of metaphors and similes in the non-current pain group. Using metaphors and similes has been theorized to provide a description to the indescribable (Schott, 2004). The non-current pain group has conquered their pain. They are no longer trying to describe the indescribable. This may allow them to define their pain with medical terms and not resort to analogous language. Those still in pain may use analogous language in lieu of medical terms as, even with a diagnosis, they are still attempting to define their pain.

There was a notable contrast between the two groups where the use of affective pain words was negatively associated with positive affect in the current pain group and positively associated with positive affect in the non-current pain group. For the current pain group, there was a small stable relationship where greater use of affective pain words related to worse outcomes. Past research has defined affective pain as a reflection of the unpleasantness of the pain experience (Price, Hawkins, & Baker, 1987). Thus, the more the participant in pain used affective or unpleasant words to describe pain, the more they reported negative outcomes. For ICPs, the relationship between pain and positive affect is more complicated than a simple relationship where pain leads to less positive affect. For example, research has shown ICPs to have a positive relationship between active coping and positive affect (Hamilton, Zautra, & Reich, 2005). In the present study, the current pain group observed a negative relationship between affective pain word use and active coping strategies. This could help further define the relationship between affective pain words and positive affect.

Conversely, participants in the non-current pain group may have benefited from higher trait positive affect. Past research has shown that higher positive affect has led to a decrease in pain over time (Zautra, Johnson, & Davis, 2005). This finding has subsequently been used in designing interventions aimed at increasing positive affect in order to help alleviate pain. For example, two studies found that providing online positive psychology interventions to patients living with chronic pain improved their pain outcomes (Müller et al., 2016; Peters et al., 2017). It is also possible that a reduction in pain leads to increased positive affect. Researchers have even proposed an upward spiral model of positive affect, resilience, and pain management (Finan & Garland, 2015). In the model, positive affect and pain reduction reciprocally enhance the other while building resilience and better pain management. This provides a path to over come pain.

Limitations and future directions

There are several limitations to address with this study. First, having participants complete the expressive writing task before completing the questionnaires may have lowered their positive emotions and raised their negative emotions (Smyth, 1998). The study was designed for the specific participant population where burnout and attrition are concerns. The expressive writing task was the most important part of the study; thus, participants were asked to complete the writing task first. In the present study, we attempted to measure the effect of the writing task on emotional state by adding an additional group which completed the same questionnaires, in the same order, without completing the writing task. After completing the writing task, the expressive writing group had higher levels of depressive symptoms, perceived stress, and negative affect than the control group. It is important to note, most of the analyses were between the two groups, both of which completed the same writing task.

A second limitation is the heterogeneity of the underlying pain causes. A diverse sample was sought as an initial attempt to answer the research questions posed. Yet, some past work has shown differences in the comorbidities of specific pain diagnoses (Gatchel, 2004). Future work should compare individuals within the same diagnosis. For example, not everyone who experiences post-operative surgical pain develops chronic pain. Designing a prospective study of individuals with post-operative surgical pain which incorporates an expressive writing task and focuses on psychosocial aspects will help researchers and clinicians better understand meaningful differences between those who develop chronic pain and those who do not. Past work has shown important individual characteristics, such as cognitive functioning and past pain to predict post-operative pain, but much of the work ignores the social aspects (Attal et al., 2014).

Third, several of the thematic coding failed to reach acceptable agreement levels in spite of multiple coding efforts. There were two groups of codes that did not work: integration and observer pain rating. Integration of social support and integration of loss of social support proved difficult to assess. Raters expressed difficulty identifying instances when the occurrence of the codes were integral for the writing. Next, ratings of how severe the pain descriptions were and overall perception of the participants' pain ratings proved to be extremely difficult to code. There is evidence that suggests it is more difficult to accurately rate an individual's pain when they are in chronic pain compared to acute pain (Teske, Daut, & Cleeland, 1983), yet agreement was equally poor in both groups. In the present study, there was an observed ceiling effect where coders had a difficult time discerning the variability in the writings. Future studies may focus on a variety of pain experiences and not the most severe.

### Conclusion

In sum, this study found stable relationships between the types of pain words used in an expressive writing task with thematic codes from the writings and common selfreported comorbidities. Additionally, an important comparison group provided new context for the standard pain study. Last, this study provided foundational exploratory evidence that certain types of pain words may predict comorbidities above and beyond selfreported pain and medical literacy. Future work should aim to replicate and expand on the findings presented here as a means to working toward a fuller understanding of pain.

### **Chapter 5: General Discussion**

Pain is a continuous subjective experience, which influences and is influenced by biological, psychological and social factors. This set of studies developed a new tool and tested it in three unique datasets in an attempt to better understand how pain is communicated to others. Communicating pain plays a vital role in the pain experience (Craig, 2009). It is paramount to receiving the support and care needed to alleviate pain. This dissertation makes an important contribution by expanding on the distinction between sensory and affective pain language. Past work has mainly attempted to capture this distinction through self-report measures which provide the list of terms (Melzack, 1975). These studies allowed the individuals to use their own words.

Chapter 2 developed and validated the pain dictionary, Chapter 3 used the dictionary in investigations of novel naturalistic datasets, and Chapter 4 used the dictionary to connect word use and psychosocial outcomes when directly asking participants about their pain. It is important to compare and contrast the findings from the three approaches as much of the current knowledge is grounded in the assumption that eliciting direct responses from participants relates to their natural pain disclosure.

### Sensory, Affective, and Medical Pain Words

Interestingly, in Chapter 3, across two diverse datasets, a two to one ratio of sensory pain words to affective pain words was observed. In Chapter 4, an almost ten to one ratio was observed. Of note, the prompt used in Chapter 4 specifically asked for participants to recount their thoughts, feelings, and emotions surrounding their pain experiences. It was surprising the prompt asking for feelings and emotions did not elicit more affective pain words. It is possible that the emotional words were surrounding the pain and not the actually affective pain words. For example, a participant from Chapter 4 who suffered from severe migraines stated, "This was a terrifying experience, and I felt completely helpless. There was nothing I could do to make the pain go away." They used a sensory pain word (pain) and affective language (terrifying and helpless) to describe the experience.

There are important clinical implications to understanding the sensory and affective aspects of pain. Past research has found that cognitive interventions which focused on the affective, but not sensory, can reduce pain unpleasantness, but not alter pain intensity (Rainville, Carrier, Hofbauer, Bushnell, & Duncan, 1999). The study also found an increase in heart-rate during the pain stimulus was connected to an increase in pain unpleasantness (affective), but not pain intensity (sensory). This connection between affective pain responses and autonomic activation added an interesting path for exploring the biological and psychological connection in pain. Research has also found changing attentional focus during pain may alter affective pain perception. In a study of women in labor, researchers instructed participants to focus on the birth of their child and not on the pain they were experiencing (Price, Harkins, & Baker, 1987). The change in focus led to a reduced rating of affective pain but no reduction in sensory pain.

There is also neuroscience research that has shown affective components of pain to be implicated in empathic pain responses (Singer et al., 2004). This provides important neurological evidence to corroborate arguments that pain expression is a pathway to receive care through engaging an empathic response (Goubert et al., 2005; Ong et al., 2004). In Chapter 4, participants used more medical pain terms than in Chapter 3. The disparity seems logical when comparing the setting between everyday pain discussion (Chapter 3 Study 1), but it may be expected that more medical pain terms would be used in the OSN posts (Chapter 3 Study 2). This may be an indication of participant bias (Norenzayan & Schwarz, 1999) or demand characteristics (Orne, 1962). In the OSN setting, participants are interacting with other participants and not responding to a research study asking them to describe their pain. If the study alters how the participants describe their pain in other settings. There is a need for further controlled studies to compare how participants may alter their descriptions of pain in different settings elicited by different demands.

### **Communicating Pain**

Pain is difficult to describe. This concept is not new and has plagued philosophers and writers for centuries (Schott, 2004). Physicians have even struggled with it for hundreds of years (Lancet, 1887). It is then logical to understand why the individuals suffering from pain have trouble fully describing it. Chapter 4 explored the use of metaphors and similes. The concept of analogous language was explored in part because of the review of OSN posts from Chapter 3. For example, one user on the FM OSN stated: "I recently started experiencing this weird feeling as if bugs or ants are crawling all over me. It makes me scratch and rub my skin all over even my scalp. Sometimes it gets so bad it feels like fire ants biting me." In the absence of a clear explanation, individuals often use other types of pain for explanatory purposes for current pain (Ong et al., 2004). The painful paresthesia described above was so foreign to the user they were forced to use colorful analogies to relate the feeling to others. It has been argued that the metaphors even serve the purpose of eliciting empathy from others by attempting to put the suffering into a relatable form (Semino, 2010).

In Chapter 4, the failure to achieve agreement on pain levels by the raters, in retrospect, was both unsurprising and fundamental to the underlying theme in this dissertation. Unsurprisingly, pain is defined by its subjective experience. As stated in one of the most commonly used definitions of pain, "Pain is whatever the experiencing person says it is and exists whenever he says it does (McCaffery 1968, p 95)." In Chapter 4, the research assistants were asked to read a stranger's thoughts, feelings, and emotions about their most painful experience, then derive a sense of the severity. It proved difficult to assess a numeric value from the subjectivity. The inability to reach agreement is also integral to the overall work presented here, if individuals are unable to convey their pain in a social or even medical context it becomes increasingly difficult to obtain the assistance they may need.

This line of research is only the first step in the pain communication process (Hadjistravropolos, et al., 2011). It is paramount to progress this work beyond the individual suffering from pain and into the recipient of the pain communication (Edmond & Keefe, 2015). There are two specific groups which pain communication is vital, within a social network to receive the assistance needed and in a medical setting to receive the care needed.

#### **Understanding Pain Communication**

Future work will need to expand on the set of studies presented here, as being able to appropriately describe pain is more complicated than simply putting the right words together. It vital for the recipient to be able to understand. Unfortunately, this is not always possible. For example, women in pain often face a more difficult time than men in interacting with their doctor (Werner, Isaksen, & Malterud, 2004). For women in pain, there can be a struggle with being believed, maintaining self-esteem, striking a balance in conveying that they are not "too strong or too weak, too healthy or too sick, or too smart or too disarranged (Werner & Malterud, 2003, p 1049)."

Pain dismissal is an especially major issue during childbirth and labor. Historically, pain during childbirth was dismissed for flawed evolutionary arguments (Reid & Cohen, 1950). Notably, a study subjected women to thermal radiation on their hand as they were in labor to try to quantify the amount of pain experienced during childbirth (Hardy & Javert, 1949). Thankfully, we have moved past cruel investigations. Yet, there are still frightening reports about the treatment of women during labor (Goer 2010). Chapter 4 observed childbirth and labor to be one of the most common experiences of an individual's worst pain ever. If the work in this dissertation is expanded, the societal and cultural norm change must accompany it. Even if the individual in pain could conjure the most accurate description of their pain experience, there is still a need for the caregiver to properly interpret the description.

Future studies should aim to identify specific cues that medical providers naturally use to determine pain. This line of inquiry would undoubtedly be complex. There are a myriad of factors interacting with one another that would need to be accounted for such as provider biases toward patient groups (Green, Ndao-Brumblay, Nagrant, Baker, & Rothman, 2004), nonverbal pain communication (Craig, 1992), individual patient differences (Craig & Best, 1977), and variability in the healthcare system (Pillay, van Zyl, & Blackbeard, 2014). In past studies medical providers complain about struggling with trying to believe patients' reports of pain (Bergman, Matthias, Coffing, & Krebs, 2013; Matthias et al., 2010). Beyond the case where individuals with addition problems are seeking medications, medical professionals must assess a complex subjective experience without much context. Yet, as the studies in this dissertation have shown, using novel approaches and new technologies may allow for new insights into how pain communication is understood. This research will require multi-methodological approaches. Research may start with using the pain dictionary from Chapter 2 to investigate patient provider interactions but add the use of automated coding of facial expressions (Littlewort, Bartlett, & Lee, 2009) and quantitative approaches to capture perceived meaning.

An additional line of research set at understanding the role of the medical provider understanding pain descriptions may follow empathy. As noted in the previous two sections, the use of affective pain words and analogous pain language may serve to elicit empathic responses (Goubert et al., 2005; Ong et al., 2004; Semino, 2010). In line with the findings from Chapter 4, empathy may provide a link between language and social support from friends and family. Conversely, there was no observed connection between affective pain word use or analogous pain language with support from medical providers. Past work has found that empathy decreases through medical school (Hojat et al., 2004). Additionally, neurological research has found medical providers down-regulate their pain empathy responses (Decety, Yang, & Cheng, 2010). There is a push to increase empathy in medical providers (Banja, 2006; Kelm, Womer, Walter, & Feudtner, 2014) as it is the foundation for patient centered care (Tait, 2008) and may lead to better care in pain patients (Goubert et al., 2005). However, some researchers have argued that decreased empathy is a sign of proper emotion regulation and allows the physician to better treat the patient (Decety et al., 2010).

## Limitations and future directions.

The weak association between pain word use and psychosocial outcomes throughout the studies presented in this dissertation poses a limitation. In Chapter 2 a tool was validated which allowed for pain words to be captured in a variety of situation. The tool was used in Chapter 3 to capture pain disclosure from 355 hours of naturally occurring social interactions and identify pain words from 355,869 OSN posts for 9 years' worth of social interactions. Chapter 4 did provide a slightly more traditional research design, but the main focus was an open-ended 15-minute expressive writing sample. In spite of the variety of methodologies, samples, and data, this dissertation observed similarities in the proportion of pain words used.

Although new approaches to capturing participant expressions of pain were presented in this dissertation, it still relied on a myriad of self-report measures. There is often a disconnect between the assessment in research and in clinical practice. Researchers often use validated measures which take time and can be tedious to complete, especially for an individual in pain. Whereas, observational research has shown providers often use different metrics or routines for assessing pain which do always relate to each other (Eriksson, Wikström, Fridlund, Årestedt, & Broström, 2016). Pain is more complex than any one measure or item. There is also a need for more ecologically valid approaches. Pain is a constant. Self-report measures are a snapshot of a never-ending experience. Chapter 2 attempts to address this by providing a way to identify pain language in large complex study designs like Study 1 in Chapter 3.

## **Closing remarks**

In sum, this dissertation has shown the that the types of words used to disclose pain are related to psychosocial outcomes. Although sensory pain words were used more than twice as often as affective pain words across the different studies, affective pain words were tied to more psychosocial outcomes. The pain dictionary adds the pain research literature by allowing a more ecologically valid approach in capturing pain expression. Future research would benefit from capturing the naturally occurring pain disclosures and responses as they happen.

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Pain Word	Sub Dictionary
abrasion*	Sensory
abstrak	Medical
acetaminophen	Medical
ache*	Sensory
aching*	Sensory
advil	Medical
affliction*	Affective
agoniz*	Affective
agony	Affective
aleve	Medical
algesia	Medical
allodynia	Medical
arthr*	Medical
asprin	Medical
atrophy	Sensory
beat*	Affective
boo-boo*	Affective
bone	Medical
bones	Medical
broke*	Medical
bruis*	Sensory
brutal*	Affective
bulding disc*	Medical
carpal	Medical
contusion*	Medical
codeine	Medical
corticosteriod*	Medical
cramp*	Sensory
crps	Medical
damag*	Medical
decay*	Medical
demerol	Medical
disabilit*	Medical
discomfort*	Sensory
drug*	Medical
dull*	Sensory

Appendix A. Pain Dictionary Root Words

epidural*	Medical
excedrin	Medical
excruciat*	Affective
exhaust*	Affective
faint*	Affective
fentanyl	Medical
fibro*	Medical
fractur*	Medical
fragil*	Affective
frozen shoulder*	Medical
gash*	Medical
gout	Medical
gnaw*	Sensory
grim*	Affective
headache*	Sensory
heartburn*	Medical
hemorrhag*	Medical
hemorrhoid*	Medical
herniated	Medical
hurt*	Sensory
hydrocodone	Medical
hyperalgesia	Medical
ibuprofen	Medical
impairment*	Sensory
inflam*	Sensory
injection*	Medical
injur*	Sensory
irritation	Sensory
joint	Medical
joints	Medical
laceration*	Medical
lesion*	Medical
lidocaine	Medical
limp*	Sensory
massag*	Medical
medicat*	Medical
medicin*	Medical
methadone	Medical
midol	Medical

migraine*	Medical
morphine	Medical
motrin	Medical
mutilat*	Sensory
naproxen	Medical
nause*	Sensory
nerve*	Medical
neuralgia	Medical
neuropath*	Medical
nonsteroidal anti-inflammatory drug*	Medical
norco	Medical
nsaid*	Medical
numb	Sensory
numbed	Sensory
numbing*	Sensory
numbness*	Sensory
numbs	Sensory
opioid*	Medical
osteoarthritis	Medical
oxyc*	Medical
ouch	Affective
ow	Affective
pain	Sensory
pained	Sensory
painf*	Sensory
paining	Sensory
pains	Sensory
pang*	Sensory
penetrat*	Sensory
percocet*	Medical
physical therap*	Medical
pierc*	Sensory
pinch*	Sensory
poison*	Medical
prick*	Sensory
pt	Medical
radiate	Affective
radiated	Affective

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Note. An "\*" indicates that any combination of letters that follow the word will also be included. For example "wrench\*", the dictionary will capture "wrench" but also "wrenches" and "wrenched".

## Appendix B. Writing Prompt

The goal of this project is to see if writing about the moment in your life where you experienced the most physical pain you can remember will relate to your health and functioning. If you are like most people, you have had painful experiences or events during your life. Such experiences may include headaches, tooth pain, joint or muscle pain. Some people are often exposed to situations that may cause pain such as illness, injury, dental procedures or surgery.

Please spend a few moments to identify your most painful experience you remember. Some pain happens only once to a person, whereas other pain happens repeatedly or continue for a long time, and may even be happening right now.

Please try to identify the experience in which you were in the most physical pain. This may be a painful experience that you have not talked about or shared much with other people, or it may be one that you don't like to be reminded of.

Now, we would like you to write about this painful experience. As you write today, your task is to do the following: a) try to make your memories of the painful experience as vivid as possible, including mental images, emotions, and sensations in your body; b) try to describe both the facts about the experience, and also write about your deepest feelings about it; c) try to write as much as you are able, even if there is some part of the experience that you are reluctant to write about.

Please take the next 15-20 minutes to write freely and honestly and not worry about language or grammar or spelling. The only rule is that once you begin writing, you continue until the time is up. If you run out of things to write about please restart telling the story.

# Appendix C. Theme Codes **Social Support**

\*\*\* All codes are Yes - 1 : No - 0 unless stated otherwise \*\*\*

The perception of support from social interactions. This can come from three main areas:

- Emotional support includes intimacy and attachment, reassurance, and being able to confide in and rely on another-all of which contribute to the feeling that one is loved or cared about, or even that one is a member of the group, not a stranger
- Tangible/Practical support involves direct aid or services and can include loans, gifts of money or goods, and provision of services such as taking care of needy persons or doing a chore for them
- Informational support includes giving information and advice which could help a person solve a problem and providing feedback about how a person is doing

## Presence

Count the number of unique instances the participant describes receiving of social support.

- Unique instances If the participant mentions multiple people in one instance of receiving support then code for each of the people
  - Example: "It was extremely helpful that my parents and husband were able to take me to the doctor when I needed to go" This would be 2 instances – 1 for parents and 1 for husband

If the participant mentions the same person but in multiple, different support instances code for each instance

> • Example: "My best friend was the first one to listen when the pain started, she was also the only one who helped me financially once I wasn't able to work" This would be 2 instances – listening and financial assistance.

If the participant mentions two instances but they are not specific, code for one instance

• Example: "My wife is always there for me when I need to vent or when I need some advice" Because it is general and not specific code 1 instance

The support can come from an individual (spouse, parent) or from a group (friends, family). Unless they mention specific members in the group with unique instances (see first bullet point) count group as one.

• Example: "parents" would be 1

"my mom and dad" would be 1

## Valence

Code valence for each social support instance.

0 – the support was low positive - ex: "My roommate happened to be there when I was first injured and was able to drive me to the hospital" 1 – the support was somewhat positive - ex: "It was nice to have my mom

to talk to about my pain"

2 – the support was very positive - ex: "I don't know what I would have done without my dad, he was always there"

## Support integration

Code integration for overall social support and not for each instance. How integrated to the overall story or narrative is the notion of social support. Take into account both amount of times mentioned AND the role it plays.

- 0 no integration
  - The participate never mentions social support
- 1 A little integration

The participant mentions social support but it seems as an aside or after thought. It is not important to the story. The story would not change if that mention of support was removed.

2 – Somewhat integration

The participant mentions social support and it has a role in the story. It draws connections to other parts of the narrative. If removed it would change some but not all of the story.

3 – Extreme integration

The participant mentions social support and it plays a pivotal role in the story. The support draws connections to many parts of the narrative. If the support was removed it would change the story completely.

## Pain Dismissal

The degree to which the participant feels others do not believe their pain. This can include significant others, family and friends, and medical professionals.

- 0 There is no mention of believability
- 1 A small amount of pain dismissal

The participant expresses a slight concern that other might not believe they are in pain. This can be direct – I sometimes feel like my wife doesn't believe how much pain I'm in. It can also be indirect – It seemed to be a little tough to get other people to understand my symptoms.

2 – Pain dismissal

The participant expresses concern that others do not believe they are in pain. "My doctor didn't believe me when I told her I was in pain"

"No one listened when I said I was in pain, they all thought I was being dramatic"

Loss

The degree to which the participant discusses the loss of social support since the start of their pain experience.

0 - no loss of support was mentioned

1 – loss of social support was mentioned

Examples "The pain was so bad I couldn't do anything, I stopped hanging out with my friends"

"It got to the point where my wife wouldn't or couldn't be there for me anymore"

Loss integration

Only code if loss is present.

How integrated to the overall story or narrative is the notion of loss of social support. Take into account both amount of times mentioned AND the role it plays.

0 - no integration

The participant never mentions any loss of social support

1 – A little integration

The participant mentions loss of social support but it seems as an aside or after thought. It is not important to the story. The story would not change if that mention of support was removed.

2 - Somewhat integration

The participant mentions loss of social support and it has a role in the story. It draws connections to other parts of the narrative. If removed it would change some but not all of the story.

3 – Extreme integration

The participant mentions loss of social support and it plays a pivotal role in the story. The loss of support draws connections to many parts of the narrative. If the loss of support was removed it would change the story completely.

#### **Positive reframing**

The process as perceiving something that was previously viewed as negative in a positive light, for example, as an opportunity, a chance to learn something new, a chance to gain a new skill, or to deepen a relationship, and so on. These are designed for the participant discussing or referencing a negative experience, such

as dealing with cancer or job-related stressors. The participant does not have to explicitly state what the negative experience is, it can be inferred.

\*The negative even can be about the self, someone else, or in general, but the participant must be the one who is reframing.\*

#### PR Presence

Does the participant express positive reframing:

Examples "The pain has made me appreciate more."

"It is bad but there are good things that have happened too."

#### Growth – Only code if PR Presence = 1

Does the participant talk about personal growth as a result of their experience? This can take the form of learning something tangible (behaviors) or abstract (emotions).

Examples "The pain has really made me stronger as a person." "Because of this, I now know I can handle anything." "It showed me that my partner can step up when needed. I have learned that I can depend on my partner"

## *Reinterpretation* – Only code if PR Presence = 1

The participant makes an attempt to change the meaning to seem more positive. The participant does not alter facts but assigns them new meaning (in a positive direction).

Examples "Being diagnosed was a blessing in disguise, I really appreciate all of life's little things now." "Although pain has it's bad side, it has brought our family closer together." "He wasn't crying because he was sad, he was crying because we made our way through it."

#### Pain

*Severity rating* 

Does the patient use any ratings of the extent of the pain? 0 - 3 scale

- 0 No mention of severity
- 1 Minimal severity "The pain wasn't that bad"
- 2 severity "The pain was bad"

3 - most severe pain "It was the worst pain ever."

## Metaphor or similes

Does the participant describe their pain with figurative language (metaphors or similes)?

Report the total count of cases. Also copy and paste the exact wording into the "M\_S\_text" cell.

Examples: "It felt like my head is in a vice."

"It was as if my leg was on fire."

"Ants are crawling all over and biting me."

## Overall perception of pain

After reading the narrative, what would you guess the participant's overall pain rating?

0 - no pain to 10 - most severe pain possible