

A New Approach to Capturing Pain Disclosure in Daily Life In-Person and Online

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Abstract

This feasibility study employed a new approach to capturing pain disclosure in face-to-face and online interactions, using a newly developed tool. In Study 1, 13 rheumatoid arthritis and 52 breast cancer patients wore the Electronically Activated Recorder to acoustically sample participants' natural conversations. Study 2 obtained data from two publicly-available online social networks: fibromyalgia (343,439 posts) and rheumatoid arthritis (12,430 posts). Pain disclosure, versus non-pain disclosure, posts had a greater number of replies, and greater engagement indexed by language style matching. These studies yielded novel, multimethod evidence of how pain disclosure unfolds in naturally-occurring social contexts in everyday life.

Keywords: Pain, pain disclosure, online social networks (OSNs), Electronically Activated Recorder (EAR), Linguistic Inquiry and Word Count (LIWC), word use

A New Approach to Capturing 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 and Lumley, and Leisen, 1997; Sullivan and Neish, 1999). In a clinical setting, pain disclosure often takes the form of quantifying pain on a single-item scale (Schiavenato and Criag, 2010), whereas in every other setting pain disclosure is, presumably, a fluid social exchange or expression. There is theoretical (Craig, 2009; Craig, 2015; Hadjistavropoulos et al., 2011) and experimental evidence (Larochette et al., 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, 2009), yet pain is experienced in the complex multilevel social contexts. For example, individuals with chronic pain (ICPs) report worse social relationships (Kelley and Clifford, 1997), more loneliness (Ressler et al., 2012), and a heightened

feeling of others not believing they are in pain (Newton et al., 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 and de Williams, 2010), how spouses respond to such disclosures (Burns et al., 2015), and subsequent ICP outcomes (Edmond and Keefe, 2015; Porter et al., 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 pain-related scenarios produced negative reactions from ICPs (Newton-John and de 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 and Karoly, 2011; Morely et al., 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 and Revenson, 2007). Understanding everyday pain disclosure provides important insight into the pain experience that can be missed in clinic or research visits (Jensen and 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 in-lab 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 et al., 2001; Mehl et al., 2012; 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 and Duggan, 2013), often yielding positive effects in offline life (Frost and Massagli, 2009; Maloney-Krichmar and 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 and Pennebaker, 2011; Pennebaker et al., 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 2011). Additionally, the automated tool expands the methodological repertoire for assessing pain disclosure, addressing a previously-identified need (Cano and 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. Study 1 used participants living with RA and BC for two reasons. First, past work has shown differences between these patient populations in their daily pain (Callahan et al., 1987; Rietman et al., 2003; Rojkovich & Gibson 1998). This provided an important potential for variability between the samples' pain disclosure.

The first aim was to show feasibility of a new tool to capture 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 et al., 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 engagement.

Study 1 Method

Study 1 was a secondary data analyses with 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 were not re-contacted for this study.

Participants

RA sample. Thirteen women with RA participated in a study called “Couples and Arthritis” (Kasle et al., 2008). They were recruited in Tucson, Arizona and the surrounding area from rheumatology clinics. There were 248 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 1. 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 et al., 2017; Robbins et al., 2011; Robbins et al., 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.

Procedure

Procedures for the RA sample can also be found in Robbins, Mehl and colleagues (Robbins et al., 2011), and for the BC sample in Robbins and colleagues (2014). 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 which is preprogrammed 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 et al., 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 (2017) 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 transcriptions 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 pain-specific 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 the Supplemental Material. The pain dictionary was broken down into three theoretical 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 (Melzack, 1975) and later theoretical work (Fernandez and Turk, 1992). Medical words consisted of pain-related words that were not pain descriptors (i.e., medications and diagnoses). A full list of words 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 indicated 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, family member, self, stranger, or unknown). Significant other was defined as a romantic partner. A family member was defined as someone that the participant is related to and was not their significant other (i.e., child, parent, sibling). A friend or acquaintance was defined as a person who the participant knew but was not their significant other or a relative. Friend and family member categories were combined for analysis purposes. Self was defined as the participant was audibly speaking with no one present and they were not on the phone. Stranger was defined as a person the participant did not know. 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 2).

Analytic Plan

The RA and BC samples were analyzed separately. Specifically, 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 2 shows the breakdown of the sensory, affective, and medical pain word use within 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 2 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.

Study 2 Method

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 potential for a more directed focus on pain.

Participants

The University of California, Riverside IRB deemed this collection of publicly-available 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.

Procedures

All public data were scraped from the sites using jsoup, a Java-based code library for HTML parsing (Hedley, 2017). 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 1 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 33,644 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, 1,122 initial posts in total.

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 and 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. In past research, LSM has been shown to indicate group cohesion (Gonzales et al., 2010) and relationship stability (Ireland et al., 2011). Additionally, LSM has been identified as a key component of emotional support in online interactions (Doré and Morris, 2018). Notably, synchrony in online replies led to feelings of heightened emotional support in that study. Therefore, we used LSM as an index of social engagement in this study.

Analytic Plan

The analyses were descriptive, not inferential, due to the non-independence of grouping by post rather than by person. In addition, the large *N* results in significant *p*-values associated with very small effect sizes and thus does not provide important information. 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 initial 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 replies were used to calculate the LSM scores.

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 shows the average number of pain words per initial post.

Social Engagement

Table 4 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 4 reveals there was greater 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.

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 (Hadjistavropoulos et al., 2011; Gatchel et al., 2007; Lumley et al., 2011). Due to methodological and feasibility constraints, the everyday social context of pain is often overlooked. This proof of concept study provided new methodologies with which the social context of pain can be explored. In the present study, a tool was used to reveal 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 all words spoken in the rheumatoid arthritis sample and 0.7% in the breast cancer 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. Past research has found pain prevalence at one-year post BC treatment to be 12% to 51% (Rietman et al., 2003), whereas daily studies of RA find 94% to 99% experience pain (Callahan et al., 1987; Rojkovich & Gibson 1998). This descriptive difference was not observed at the conversation level where people with BC (2.13%) had a slightly higher percentage of conversations which mentioned pain than people with RA (1.77%). This indicates that in this sample when a participant in the RA group did mention pain, they used more pain terms which may reflect a greater focus on the pain

when it comes up as a topic of conversation. Due to sample size limitations, however, we could not determine whether this difference between the two groups would reach statistical significance

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. Most laboratory studies focus solely on pain disclosure between patients and their significant others. One study specifically asked individuals living with chronic pain 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 important for future research to explore disclosure to those beyond one person.

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 more interpersonal engagement (LSM), compared to non-pain initial posts. LSM has been shown as one mechanism underlying successful emotional support in online interactions (Doré et al., 2018; Rains, 2016). The findings from Study 2 indicate a general positive interpersonal engagement and potentially a perception of 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 online social networks to find and provide help with their illness, which otherwise may be absent in everyday life (Greene et al., 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 et al., 2010). Further, active users feel a greater sense of perceived support than less-active users (Erfani et al., 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 (1975). Researchers have expressed the importance of investigating both types of pain classification (Fernandez et al., 1992). With the use of the new dictionary, in these specific samples we observed that sensory pain words were used more than twice as often as affective pain words in both daily life and online interactions. While there are more words in the sensory (51 words) category compared to affective (40 words), the two-to-one ratio we observed indicates a greater disparity than would be expected from the dictionary.

Conceptually, the distinction between sensory and affective pain words maps 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 et al., 2017). This may also indicate that LSM may be important for the 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 et al., 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 et al., 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. Future research should further validate the dictionary by using it in non-pain specific areas. For example, it could be used to capture pain disclosure in private OSNs or much larger public forums like Facebook and Twitter. In addition, future studies may benefit from using the pain dictionary in a more prospective design where researchers contact moderators from private online social networks to recruit participants to gain better individual-level 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 but limited datasets. Due to the intensive methodology, obtaining EAR data from clinical samples can be more challenging than with other methods (Robbins et al., 2014). Although Study 1 resulted in a large amount of audio data (approximately 355 hours), it was limited by a low enrollment rate. One concern might be that low participation may result in a non-random or biased sample. We acknowledge the small sample is not representative of all individuals living with RA and BC. Past work has found that the differences between people who do and do not choose to participate in EAR studies are very similar to the general differences between people who do and do not choose to participate in any studies (Manson and Robbins, 2017). Despite the lack of representativeness of the samples in Study 1, the preliminary findings presented here importantly provide the first, unique insight into natural pain disclosure captured in everyday life. Much more work is needed to understand the full picture of naturalistic pain disclosure, and our aim was to take a first step toward that goal.

Study 2, in contrast to Study 1, used very large datasets. We utilized 355,869 posts from two unique OSNs spanning 9 years. Of note, it is difficult to compare between fibromyalgia and rheumatoid arthritis OSNs. Beyond the different health focuses, past research has found that many factors influence the amount of interaction on any given OSN (Centola and van de Rijit, 2015). 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 with three distinctive diagnoses 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 context (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 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.

There are potential complications in combining rheumatoid arthritis, breast cancer, and fibromyalgia samples. Specifically, we were unable to distinguish between chronic and acute pain. RA and FM are defined as chronic but pain during BC can be classified as either acute or chronic (Rietman et al., 2003). In the BC EAR sample, we did not have enough information to determine whether they met the clinical definition of chronic pain. Future research should attempt to explore how pain word use may differ between acute and chronic pain. Specifically, it is important to determine whether any patterns in use of sensory, affective, and medical pain words can predict the development of chronic pain.

Conclusion

In conclusion, these studies combined novel, unique datasets and used a new tool to show proof-of-concept in identifying naturally-occurring pain disclosure in-person and online. These methods revealed a previously unstudied area within pain research and underscore the need to investigate pain disclosure as it naturally occurs (Edmond et al., 2015; Cano et al., 2017). This

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

Data Accessibility Statement

The data used for all analyses in this paper are publicly available at <https://osf.io/gxm8b/> under “Pain disclosure manuscript data.”

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Equation 1. Language Style Matching (LSM)

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

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.

Table 1. Demographics

	Study 1		Study 2
	Rheumatoid Arthritis	Breast Cancer	Online Social Networks
N	13	52	355869 ^a
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% ^b
Fibromyalgia	-	-	96.50% ^c
Years since pain symptoms began or diagnosis (M, SD)	6.9 (4.3)	0.9 (1.2)	-

Note.

^a Total number of posts in the online social network forums.

^b n=1454 unique users

^c n=7910 unique users

Table 2. Social context of naturalistically-observed pain conversations by sample in Study 1

	Rheumatoid Arthritis (<i>n</i> = 13)	Breast Cancer (<i>n</i> = 52)	Pain Disclosure Example
Percent of Total Words that were Pain Words [95% CI]	0.12% [0.11-0.13]	0.07% [0.07-0.07]	
Percent of Total Conversations about Pain	1.77% [1.29-2.25]	2.13% [1.83-2.43]	
Percent of Pain Conversations that were Sensory Pain	44.23% [30.73-57.73]	46.15% [39.15-53.15]	BC: I have a little <u>discomfort</u> , I have <u>pain</u> when I sleep.
Percent of Pain Conversations that were Affective Pain	19.23% [8.52-29.94]	19.49% [13.83-25.15]	RA: <u>Ouch</u> shoot, oh, poor little knee.
Percent of Pain Conversations that were Medical Pain	40.38% [27.04-53.72]	42.56% [35.62-49.50]	RA: I had to go in because... they can't figure out if it's <u>lower back</u> or <u>lower abdomen</u>
	Mean Proportion of Total Pain Conversations [95% CI]		
	ICC		
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] .56	0.87% [0.00 to 2.07] .68	
Other/Unknown	8.92% [1.45 to 16.39] .45	5.22% [2.35 to 8.09] .44	

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 which results in summed percentages not equal to 100. Underlined words in the pain disclosure example are those that belong to each specific type of pain dictionary.

Table 3. Mean pain word use in fibromyalgia and rheumatoid arthritis OSNs

	Mean Pain Word Use in Initial Posts (SD)			
	Total Pain	Pain Disclosure Example		
		Sensory	Affective	Medical
FM ($n = 33,644$)	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 <u>Fibro</u> .
RA ($n = 1,122$)	3.04 (4.12)	1.05 (1.55) Basically I suffer from <u>swelling, stiffness</u> and <u>pain</u> in my knee.	0.19 (0.71) As my knee has any weight on it on the floor it is <u>agony</u> !	1.80 (3.66) I had bilateral fluid removal and <u>cortisone</u> injections in my ankles yesterday afternoon.

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

Table 4. Average replies and language style matching (LSM) in OSN initial posts

	Mean Number of Replies [95% CI]				
	No Pain	Total Pain	Sensory	Affective	Medical
FM	14.13 [13.82-14.44]	15.47 [15.18-15.76]	15.73 [15.44-16.02]	15.40 [15.12-15.67]	14.91 [14.64-15.18]
RA	9.25 [8.80-9.70]	12.36 [11.77-12.95]	12.68 [12.13-13.23]	13.47 [12.74-14.20]	12.44 [11.82-13.05]
Mean LSM Values [95% CI]					
FM	.68 [.68-.68]	.78 [.78-.78]	.80 [.80-.80]	.80 [.80-.80]	.78 [.78-.78]
RA	.56 [.54-.58]	.78 [.77-.79]	.82 [.81-.83]	.80 [.79-.81]	.81 [.80-.82]

Note. Study 2, initial 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 initial 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 initial posts (Rains, 2016). There were 883 initial posts in the FM and 36 initial posts in the RA which did not have any replies.