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Communicating the experience of living with chronic pain: The role of non-verbal communication and the power of lessons learned

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ABSTRACT

Background: Chronic pain is hard to communicate due to its invisible, inaudible, and imprecise nature. Outside of pain scales that try to quantify pain, individuals with chronic pain have a hard time expressing it, yet pain management relies on effective communication. This study explores how women with chronic pain enrolled in an online therapeutic writing workshop communicate the experience of living with chronic pain to fellow sufferers. **Methods**: A six-week online therapeutic writing workshop was conducted with individuals with chronic pain who responded to weekly creative writing prompts that focused on mindfulness and cognitive behavioral therapy strategies including attention, emotional regulation, and examining thoughts and attitudes. Participants were recruited by their primary care provider; seven participants enrolled. All posts were aggregated and analyzed using thematic analysis. **Results**: Data analysis from participants' posts reveal two interpretive repertoires including physical evidence of pain where participants expressed visible impacts of pain occurring in their home environments and communicated non-verbally in gestures and behaviors. Secondly, the theme of lessons learned from living with pain emerged including enhanced empathy, the need for self-care, and sharing coping skills. **Conclusion**: This study extends our understanding of the experience of living with chronic pain outside of a medical context by providing new insights gained from their creative writing responses. The online therapeutic writing workshop fostered a community of support where participants were empowered to express their pain, identify their pain behaviors, and invite cognitive restructuring to learn from their pain.

KEYWORDS

Chronic pain, cognitive behavioral therapy, illness narrative, mindfulness-based training, pain management, patient-provider communication, therapeutic writing

BIOGRAPHY

Karin L. Becker is a health communication scholar who is an advocate for using creative methods alongside technology to improve patient-provider relationships and pain management. She combines her master's in creative writing alongside her PhD in Health Communication to offer online creative writing workshops to build a community of support, provide new understanding of chronic pain's impacts, and empower individuals with empathy and advocacy.

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Introduction

Chronic pain, defined as persistent pain that lasts past three months, is a pervasive and expensive public health issue (Institute of Medicine, 2011). It is estimated 20% of people in the U.S. as well as worldwide have chronic pain and this high prevalence rate contributes to high healthcare usage and costs as well as lost productivity at work (Jiang et al., 2020; Dahlhamer et al., 2018; Foley et al., 2021). Factors associated with the likelihood of experiencing chronic pain include being female, living in poverty, having less than a high school education, and not having access to private health insurance (Dahlhamer et al., 2018). Commons sources of chronic pain include back pain, arthritis, headache, multiple sclerosis, fibromyalgia, shingles, and nerve damage, or pain from an injury (Freeman, 2020). As a subjective and multifaceted experience, chronic pain adversely impacts sufferers physically, cognitively, emotionally, socially, and professionally (Becker, 2020).

Literature review

Many chronic pain conditions cause severe pain on their sufferers, but physical examination may show no obvious underlying pathology of pain (Whitten & Cristobal, 2005). The lack of physical evidence of chronic pain places more pressure on individuals with chronic pain to effectively describe and communicate their pain (Danise & Turk, 2013). The cyclical nature of chronic pain, interspersed with relatively pain-free times, may make it difficult for individuals with chronic pain to recall its severity or its impact accurately and precisely on functionality if their medical appointment falls during a pain-free time (Linton et al., 2018).

In a social constructivist perspective, individuals are constituted and shaped by the language they use, but pain's subjective and invisible nature makes communicating it difficult (Birk, 2013; Main, 2014; Strong et al., 2009). Intake screening procedures for chronic pain often involve patients reporting pain on a numeric rating scale, 0-10, but research shows results are only moderately correlated with pain intensity and more robust measures of pain-related function and impacts to quality of life are needed (Morasco et al., 2018).

Often, patients use language and metaphoric expressions that provide rich descriptions of sensations but do little to help providers with diagnosis (Jairath, 1999). Many individuals with chronic pain complain of not being believed and that doubt and skepticism are common responses to their pain disclosures; ultimately, credibility is at the crux of the issue (Tosas, 2021; Werner & Malterud, 2003). The words and performative work needed to represent pain are frequently met with disbelief by healthcare providers and this experience of invalidation causes feelings of stigma and isolation among chronic pain sufferers (Tosas, 2021).

Since pain is an inherently private experience, the onus is on the individual to communicate it in the public domain. Pain is said to “resist language” as sufferers may recall having pain, but cannot re-experience the pain itself (Jackson, 1994, p. 214). Yet certain behaviors and expressions can be used as indicators of pain. Observational measures of pain, including non-verbal communication, can play an important clinical role in detecting pain and the pain behaviors may be less vulnerable to distortions and catastrophizing than in self-reports (Hadjistavropoulous & Craig, 2002).

In addition to non-verbal communication to get around the limitations of language to communicate pain, creative methods such as creative writing and art can foster effective means of communicating the experience of pain (Main, 2014). Creative writing is a common tool to express chronic pain as it allows sufferers to externalize pain and use metaphors to objectify pain (Jackson, 1994). Previous research suggests using creative writing can validate patients' experiences which can lead to improved patient care, health-related quality of life, and long-term capability (Helen et al., 2019). The use of therapeutic creative writing is valuable in its ability to help pain sufferers focus their attention on thoughts, feelings and rememberings, and enhance their awareness (Bolton, 2008). Given the inherent difficulty in communicating a subjective experience like chronic pain, this study combines the need for observational measures of pain alongside the value of creative methods to express pain and uses an online therapeutic writing workshop as a means to better understand the intangible experience of living with chronic pain.

Women and chronic pain

How pain is experienced, communicated, coped with, and treated differs for men and women (Hoffman & Tarzian, 2001). Research has shown women report more pain, have a higher severity of pain, and a longer duration of it (Akhani et al., 2014; Jaworska & Ryan, 2018; Silver, 2004). Musculoskeletal symptoms are more common among women than men, and women's pain is more likely to be classified as medically unexplained disorders and emotional than men's (Werner, et al. 2003).

Women are perceived to complain more about their pain than men (Silver, 2004). This "complaining" can position women in an inferior light, making them feel ashamed and shy when talking about their pain (Werner et al., 2004). Moreover, women must learn to cope with the skepticism and distrust they report receiving when disclosing their pain (Werner et al., 2004). Women often struggle for the maintenance of self-esteem and dignity at the risk of being shamed and disempowered, both as women and as patients (Werner & Malterud, 2003). Research has shown that individuals with chronic pain long to feel validated and supported and if misunderstood when communicating their pain, often feel rejected or alienated (Becker, 2013).

Using creative methods like art and writing can facilitate pain communication and aid in the articulation of a phenomenon that often resists language (Main, 2014). It is possible there is a lack of congruence between providers and patients' frames of experience when communicating pain. Pain is more than a sensory experience; it is influenced by personal moods, attitudes, and thoughts and therefore needs to be understood within the context of the affective, psychological, social, and communicative practices of chronic pain sufferers (Bourke, 2014; Jaworska & Ryan, 2018). Given the difficulty in articulating pain, alongside the distrust women experience when trying to communicate pain with their healthcare providers, this study uses creative therapeutic writing exercises to examine how chronic pain sufferers express chronic pain and its impacts on their lives with other sufferers.

Therapeutic writing

In light of the widespread use of opioids to manage chronic pain which has led to abuse and addiction, non-pharmacological approaches such as mindfulness-based interventions are recommended as adjunctive therapies to treat chronic pain (Marchand, 2012; Zeidan & Vago, 2016). Writing has long been perceived as having therapeutic value as the increased awareness, understanding, and insights are critical to coping with chronic pain and promote pain self-management and improved quality of life (Furnes & Dysvik, 2012). Previous research has demonstrated the power in and value of engaging in creative writing to gain new perspective, insights on oneself and others, and promote health and healing (Haertl & Ero-Phillips, 2017). The use of creative writing techniques can produce feelings and thoughts that extend outside the realm of pain assessments, reinforcing the value of using creative methods to empower sufferers to better express themselves (Main, 2014). Blogging about chronic pain has shown to decrease feelings of isolation and increase a sense of purpose among individuals with chronic pain (Ressler et al., 2012).

Therapeutic writing is often included as a complementary and integrative health treatment as its attention to mind-body connections can positively affect health outcomes and well-being (Eaton & Hulett, 2019). The lack of travel, appointments, and healthcare provider time makes therapeutic writing an attractive and cost-effective treatment choice, especially for a population where mobility issues are common (Guillory et al., 2015). Building off previous research that indicates storytelling and therapeutic writing are helpful to better understand the experience of living with chronic pain (Dysvik et al., 2016), this study integrates therapeutic writing alongside mindfulness-based techniques (MBT), which emphasize awareness and acceptance of pain without judgment (Marchand, 2012). By teaching individuals with chronic pain to be aware of pain and observe it calmly, mindfulness creates a detachment that can weaken pain’s effect (Lim et al., 2018). Mindfulness-based interventions have been found to lessen reports of pain (Zeidan & Vago, 2016), and have seen promising results with decreases in anxiety, depression, and increases in physical and emotional well-being among chronic cancer pain patients (Zhang et al., 2016).

Additionally, the therapeutic writing workshop integrated core principles from cognitive behavioral therapy (CBT), an approach that can help sufferers by examining their beliefs and behaviors regarding their pain, unlearning patterns of unhelpful behavior, and increasing coping skills (Furnes, et al., 2014). CBT strategies used in pain management include cognitive restructuring where individuals first identify automatic negative thoughts about pain, then reframe their thoughts, and finally, replace them with adaptive coping thoughts and behaviors (Kerns et al., 2011). CBT has been shown to be an effective psychological intervention for individuals with chronic pain by reducing their perception of pain, psychological distress, and increasing their quality of life by improving their ability to cope with their pain (Castro et al., 2012; Knoerl et al., 2016). While existing research indicates the utility of MBT or CBT for developing coping skills as a strategy for effective pain management, this study adds to the literature by using the interventions in tandem.

Given the need to better articulate chronic pain to healthcare providers to improve pain management and promote credibility, especially among women with chronic pain, this study aims to better understand how chronic pain is communicated to fellow sufferers in an unstructured, non-medical context.

Methods

Recruitment and participant selection

Healthcare providers who treated chronic pain patients at a hospital's Family Medicine Residency program in a Midwestern town in the U.S. made referrals to the therapeutic writing workshop. Selection criteria used to determine potential participants included having a diagnosed chronic pain condition with a duration of at least three months. Gender, age, race, ethnicity, education, or socio-economic standing did not limit the recruitment criteria. The recruitment procedure tapped into a sample that had already self-identified as having chronic pain and was seeking medical care for their chronic pain conditions. This referral process bolstered the workshop's credibility by having providers make the referral and endorse the workshop.

At the end of a clinical appointment, healthcare providers encouraged chronic pain patients to enroll in the free writing workshop where they could discuss their pain with others. Interested patients received a participant information sheet which explained the aims of the study, the dates of the six-week workshop, the online, anonymous nature of the workshop, and the disclaimer that no writing experience was needed. Interested participants were directed to contact the researcher for registration information via email or text.

Informed consent and ethical considerations

Interested participants were emailed a more detailed explanation of the workshop, indicating its aim was to better understand and express the experience of living with chronic pain, more than any particular chronic condition. Personal details or medical conditions did not need to be divulged, unless participants wanted to. The email noted that all participants had some form of chronic pain, and a community of support would be created among people who "get" chronic pain. It also explained the research purpose of the workshop and that the study had been approved by the university's and hospital's IRB. The research complied with the Health Insurance Portability and Accountability Act (HIPPA) and no protected health information was included.

Finally, the email provided a weblink to an informed consent survey designed in Qualtrics which explained the voluntary nature of the study and that participants could stop at any time without recourse. The first survey question asked if participants agreed to participate in the study and through skip logic, a "No" response ended the survey. Additional survey questions asked about demographic information including gender, race, and highest level of education attained.

Individuals who agreed to participate received a second email that contained a unique username and password that gave them access to the website along with tips about how to navigate the website. The writing workshop was created as a private blog and hosted through Word Press.org. To protect participants' identity, once participants gained access, they were instructed to change their username and password. They also had the choice of uploading a photo or creating an avatar to represent their online depiction.

Landing page

Once participants logged into the writing workshop, the landing page outlined the four goals of the workshop, which were informed by Jones et al. (2013) theoretical model that outlines key skills patients with chronic pain need to have to successfully manage their pain: understanding, accepting, expressing, and learning from pain. The class size was indicated so participants knew of the intimate nature of the workshop. To create a tone of inclusion, the page reiterated that no writing background was needed and there were no wrong answers or grades.

Writing workshop curriculum

The writing workshop curriculum infused mindfulness-based techniques by increasing participants' awareness, observation, and acceptance of pain (Lim et al., 2018; Marchand, 2012). Cognitive behavioral therapeutic strategies were infused in writing prompts focusing on restructuring and reframing thoughts about pain and reshaping attitudes (Furnes et al., 2014). Table 1 summarizes the workshop curriculum and the corresponding mindfulness and CBT theoretical applications.

Table 1: Writing workshop curriculum

Week	Writing Prompt	Theoretical Application
1	Taking Stock	Mindfulness: Observing and increasing awareness of pain
2	Pain Impacts	Mindfulness: Awareness and calm observation of pain
3	Credo	Cognitive restructuring: Examining current beliefs about pain
4	Pain Plan	Cognitive restructuring: Developing coping strategies
5	Pain Metaphors	Mindfulness: Accepting and detaching from pain
6	Thank You Letter to Pain	Cognitive reframing thoughts about pain

New writing prompts were posted each Monday and participants were encouraged to post their response by Thursday, then read and comment on each other's posts over the weekend. All responses were made public to the closed group and participants could post a new response as well as reply to another participant directly. With a high degree of co-morbidities to depression among individuals with chronic pain (Dahlhamer et al., 2018), it was important for me as the researcher to serve as moderator to monitor for inappropriate posts or intentions of self-harm; however, no posts were flagged or deleted for inappropriateness.

Sample size and participant characteristics

Chronic pain patients living in northeastern North Dakota and northwestern Minnesota were invited to participate in a free, online chronic pain writing workshop. Seven participants who fulfilled the criteria agreed to participate and six completed the workshop. All participants were females and identified as white. The age range varied with one participant aged between 25-34 years; three participants aged 35-44 years; two participants aged between 45-54 years and one participant aged 65 years or more. In terms of educational levels, four participants held a bachelor's degree and three held a master's, doctorate, or professional degree. This sample aligns with chronic pain demographics where women are more likely to experience chronic pain; however, the young and highly educated nature of this sample differs as prevalence rates of chronic pain are associated with advanced age and less educational attainment (Dahlhamer et al., 2018).

Data analysis

After the completion of the writing workshop, all participants' posts were aggregated, and complete transcripts were downloaded and saved to a password protected database. Then, participants' posts were uploaded into the software program NVIVO to qualitatively code the textual responses. Posts were transcribed using elements of thematic analysis to identify and report patterns (Braun & Clarke, 2006). The unit of analysis was the sentence; however, due to the nature of creative writing posts and the style of writing by each participant, punctuation and sentence structure varied. For example, the following post was divided into two sentences: "I don't feel I can share my pain with my family…I have kids it would worry and a hubs who just can't handle it." Once each participant's post was divided into sentences, then each sentence was categorized into themes.

To organize the numerous emerging themes, Weiss' (1994) method of open coding, sub-coding, and local integration was implemented. Open coding was employed by writing general themes on a separate sheet of paper, accompanied by a tally of how many times that theme occurred, with priority given to the themes that had the most tallies (Weiss, 1994). Open coding was employed to identify patterns stemming from each week's writing prompt. Then sub-coding was used to organize the themes and envision possible ways to categorize the data. The weekly patterns were then aggregated to look for overlap and emerging themes. Once each post was coded, the thematic codes were reviewed using a constant comparative method of analysis to look at emerging patterns of all responses, regardless of within which week they appeared (Strauss & Corbin, 1990). NVivo helped to conceptualize the themes into hierarchal levels and qualitatively map the data by creating "nodes" to represent each theme and "trees" to show the relationship between the nodes. Finally, the themes were organized into interpretive repertoires that provided an overarching structure. For example, the patterns of "value in living with pain; to listen with patience and kindness; be considerate of others and self'" were categorized in the empathy theme, which was subsumed in the lessons learned interpretive repertoire. The patterns of "posture, balance, walking slowly; a certain look on face'" were grouped into the category of pain behavior, which was encompassed in the physical evidence interpretive repertoire.

To be mindful of my own reflexivity, I was aware of the power dynamics that I, as researcher, posed by asking participants to share vulnerable and personal information. As much as participants were responding to the prompts and commenting to one another, they were also responding to me. Participants knew I was a woman, who lived in their local community, and who was studying chronic pain. Identifying as the same gender as participants and being a part of the local community may have positioned me more as an insider with whom they were more willing to share personal details. Additionally, my workshop aims of building language capacity to communicate pain may have positioned me as a research ally. To promote trustworthiness, I maintained a research journal for "self-supervision" where I monitored against any bias and member checked to play devil's advocate to my initial codings (Berger, 2015, p. 222).

Results

On average, participants devoted two hours a week to writing and commenting to posts. The length of posts varied from four to five sentences to eight to ten paragraphs, but typical responses were several paragraphs. Table 2 conveys the total number of responses posted for each week, followed by the number of words each post contained. Multiple entries indicate participants responding to others' posts.

Table 2: Frequency and word count by participant

	Week 1 Taking Inventory	Week 2 Pain Impact Trails	Week 3 Creedo	Week 4 Pain Plan	Week 5 Metaphors	Week 6 Thank You
No. of posts	16 posts	9 posts	6 posts	8 posts	8 posts	7 posts
Participant 1	116; 55; 18	181; 12	206	151	70	180
Participant 2	206; 83	181	214	132; 222	13;162	108
Participant 3	112; 109	203	0	0	109	148
Participant 4	109; 82; 139; 46	160; 94	29;141	161;14; 236	113; 45	54; 83
Participant 5	282	191	228	361	148	169
Participant 6	87; 20; 35	0	0	0	0	0
Participant 7	144	21; 113	87	139	36	57

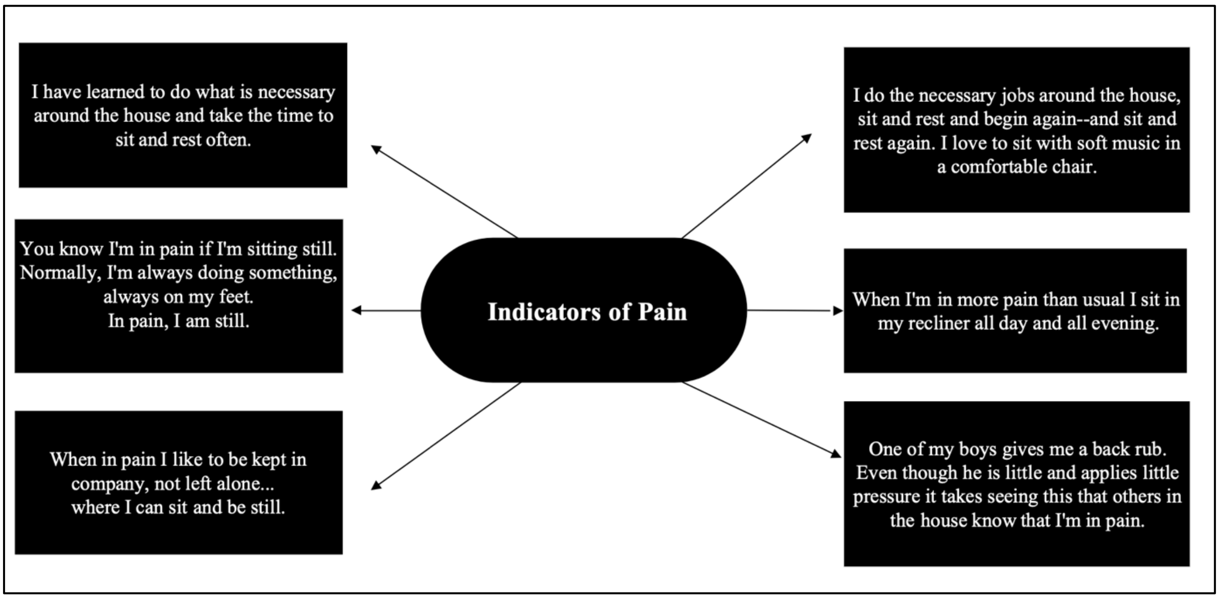
The non-medical context in which these responses were posted plays a large influence on the discourse as posts were written casually, with frequent use of sentence fragments, contractions, and shorthand abbreviations (e.g. 3x instead of writing out three times). Additionally, the anonymity and asynchronicity of the computer-mediated communication where participants' identity was portrayed through avatars may have enabled participants to be franker in their responses.

In contrast to a clinical setting with its inherent hierarchy, workshop participants were on equal footing; this parity allowed for candid conversations and enabled participants to feel safe to disclose private and personal information. Some posts were written in a stream of consciousness style, with staccato words grouped together by ellipses (e.g. "low pain days…happy as a lark, focused, ready to conquer… Sparkle, Sparkle, Sparkle…”). Capitalizing words in the middle of sentences was commonly used to note emphasis as well as other stylistic features like dashes and parenthesis to denote smiley faces :).

Interpretive repertoires

Two interpretive repertories emerged from the thematic analysis of participants’ posts: physical evidence of pain and lessons learned from living with chronic pain. The first interpretive repertoire is characterized by the physical evidence of chronic pain, both by behavior and in the home environment. Writing prompts associated with mindfulness stemming from Week 1 (observing and increasing awareness of pain), Week 2 (awareness and calm observations of pain), and Week 5 (accepting and detaching from pain) contributed to this finding. Prompts that encouraged participants to observe and accept pain caused them to note patterns and behavioral changes. The observations created a list of physical evidence that indicates the presence of pain including pain preferences (Figure 1), pain behaviors (Figure 2), and work left undone (Figure 3). Cumulatively, these non-verbal communications help to make pain visible. Exact quotes from the participants are conveyed in Figures 1-6.

Figure 1: Indicators of pain



Indicators of Pain

I have learned to do what is necessary around the house and take the time to sit and rest often.

You know I'm in pain if I'm sitting still. Normally, I'm always doing something, always on my feet. In pain, I am still.

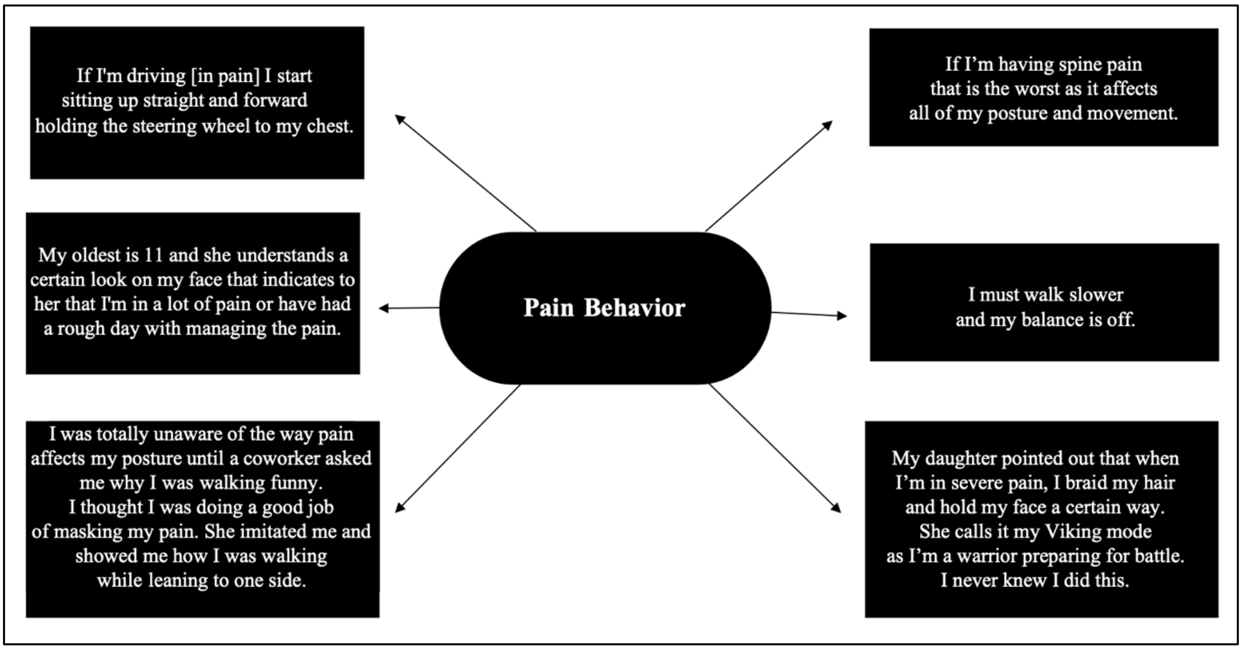
When in pain I like to be kept in company, not left alone... where I can sit and be still.

I do the necessary jobs around the house, sit and rest and begin again--and sit and rest again. I love to sit with soft music in a comfortable chair.

When I'm in more pain than usual I sit in my recliner all day and all evening.

One of my boys gives me a back rub. Even though he is little and applies little pressure it takes seeing this that others in the house know that I'm in pain.

Figure 2: Pain behavior



If I'm driving [in pain] I start sitting up straight and forward holding the steering wheel to my chest.

If I'm having spine pain that is the worst as it affects all of my posture and movement.

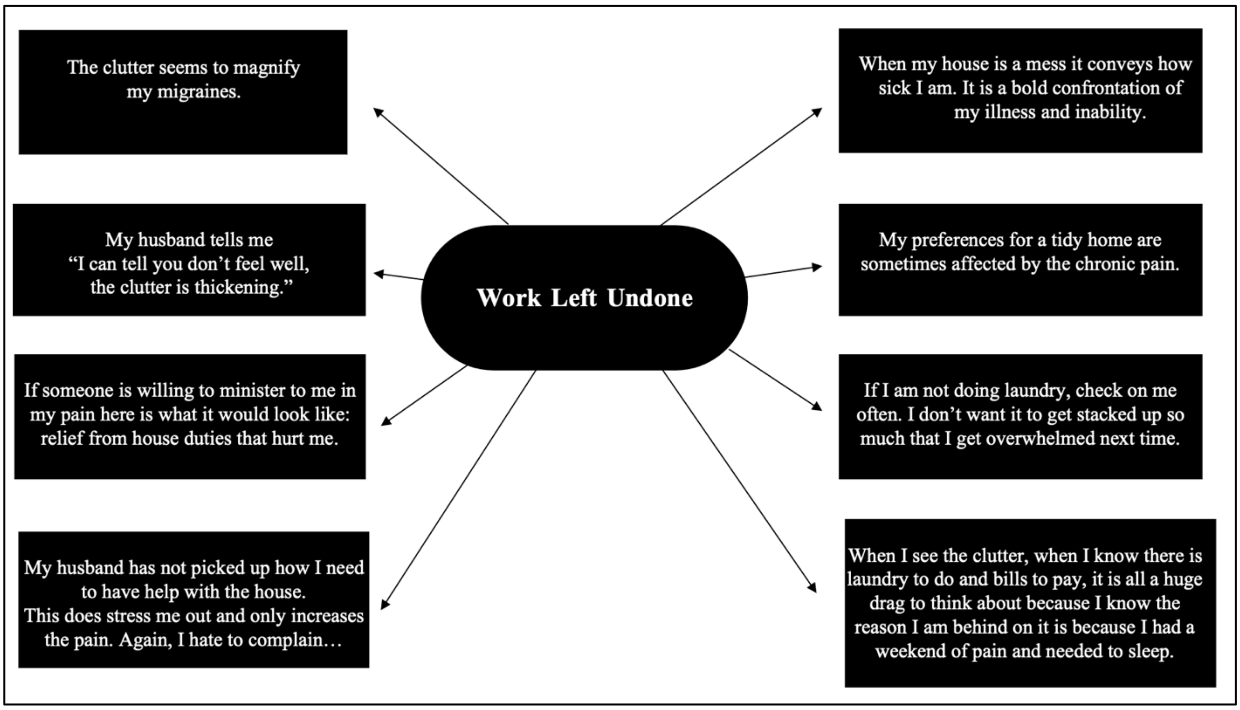
My oldest is 11 and she understands a certain look on my face that indicates to her that I'm in a lot of pain or have had a rough day with managing the pain.

I must walk slower and my balance is off.

I was totally unaware of the way pain affects my posture until a coworker asked me why I was walking funny. I thought I was doing a good job of masking my pain. She imitated me and showed me how I was walking while leaning to one side.

My daughter pointed out that when I'm in severe pain, I braid my hair and hold my face a certain way. She calls it my Viking mode as I'm a warrior preparing for battle. I never knew I did this.

Figure 3: Work left undone



The clutter seems to magnify my migraines.

When my house is a mess it conveys how sick I am. It is a bold confrontation of my illness and inability.

My husband tells me "I can tell you don't feel well, the clutter is thickening."

My preferences for a tidy home are sometimes affected by the chronic pain.

If someone is willing to minister to me in my pain here is what it would look like: relief from house duties that hurt me.

If I am not doing laundry, check on me often. I don't want it to get stacked up so much that I get overwhelmed next time.

My husband has not picked up how I need to have help with the house. This does stress me out and only increases the pain. Again, I hate to complain…

When I see the clutter, when I know there is laundry to do and bills to pay, it is all a huge drag to think about because I know the reason I am behind on it is because I had a weekend of pain and needed to sleep.

The second repertoire, lessons learned, emerged from the cognitive behavioral therapy writing prompts. Writing prompts associated with cognitive restructuring stemming from Week 3 (examining current beliefs about pain), Week 4 (developing coping strategies), and Week 6 (reframing thoughts about pain) contributed to this finding. By inviting participants to cognitively restructure and reframe the experience of living with chronic pain, pain was perceived as a teacher imparting the need for empathy (Figure 4), the importance of self-care (Figure 5), and coping skills (Figure 6).

Figure 4: Lessons learned: Empathy

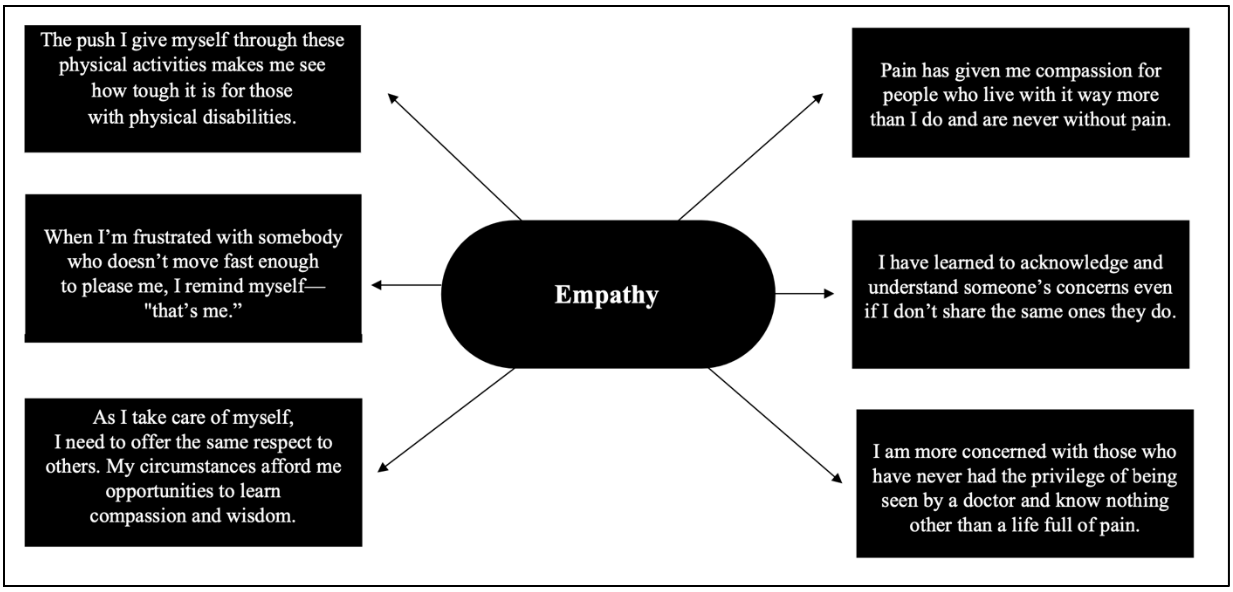


Figure 5: Lessons learned: Self care

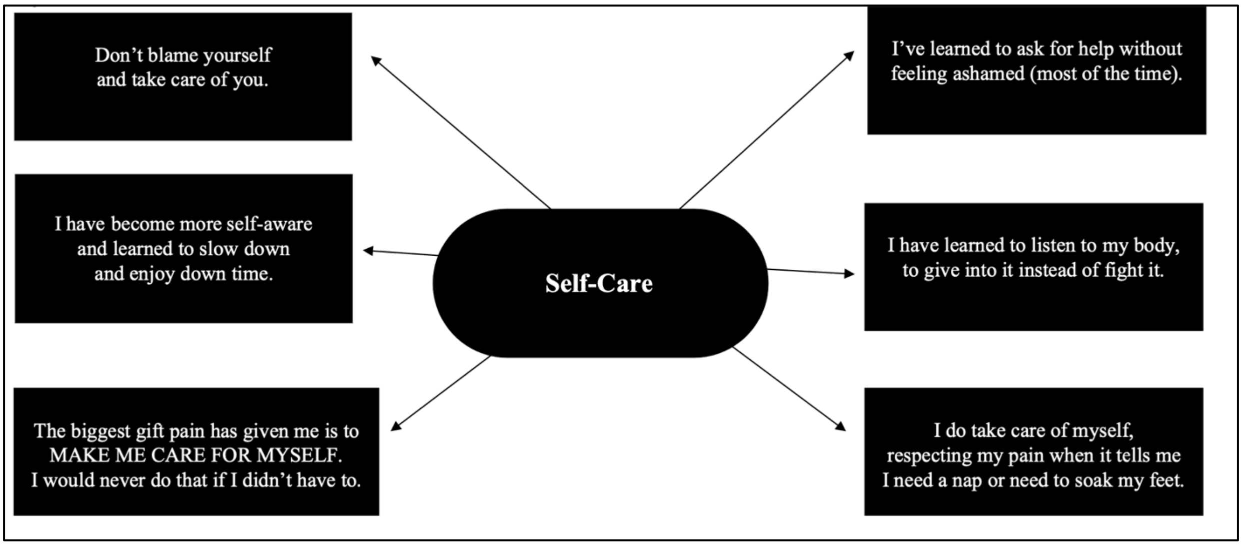
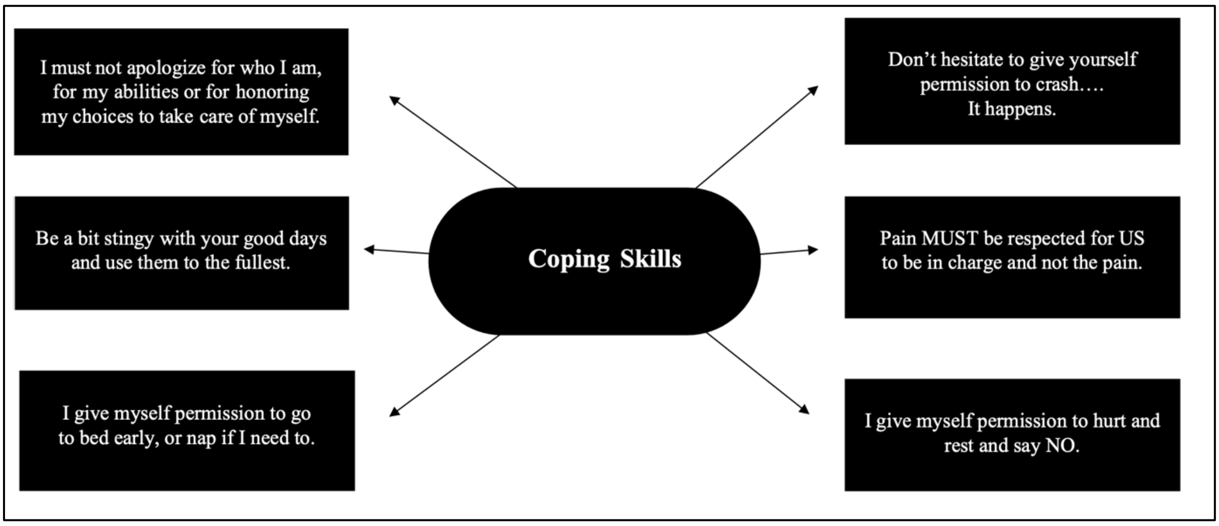


Figure 6: Lessons learned: Coping skills



Results indicate it may be easier for participants to frame their lessons learned as advice offered to others. For example, "Don't blame yourself and take care of you" and "Be stingy with your good days." In this way, experiences relating to how to live with chronic pain is passed on. Additionally, participants recognized the permission-giving that is needed to extend self-care unto themselves. "Don't hesitate to give yourself permission to crash." Offering advice to others helped participants share knowledge and validated each other's experiences. Taken together, these findings convey a shift in participants' perception about living with chronic pain, positioning pain as an opportunity to gain empathy and for learning. "My circumstances afford me opportunities to learn compassion and wisdom."

Discussion

This study used therapeutic writing as a means to understand how individuals with chronic pain communicate the experience of living with chronic pain to a community of sufferers in an informal, virtual setting. The two interpretive repertoires provide an organizational structure for how pain manifests outside of the body and the lessons participants have learned from it. Each of these repertories will be examined further.

Evidence of pain: Indicators of pain and pain behavior

The posts in the physical evidence interpretive repertoire convey how chronic pain manifests in individuals' behavior and home environments. Several participants wrote about the association between pain and sitting or stillness. In this case, the absence of movement was the visible manifestation of pain. Rather than sitting associated as a sign of relaxation, it was seen as an indicator of pain. The key to interpreting this behavior is hinged on pain disclosure as others first need to know of the pain condition to know the behavior is abnormal. While disclosing chronic pain can elicit modest benefits (Lumley et al., 2012), it was surprising that half of the workshop participants had not disclosed their chronic pain condition to their family or friends. For example, one participant who had not shared her pain condition with her friends wrote that when her friends called and asked what she was up to, she said she was having a slow day and reading. Her friends, not knowing how to interpret these cues, responded by saying, “That sounds wonderful! I’d love to have a day like that.” The participant commented, “I wanted to say, ‘Well, I would love to have a busy productive day.’ But I don’t. I haven’t figured out how to have that conversation.” This post exemplifies the challenge of disclosing pain and the need to decode pain behaviors.

The keen observations on bodily postures and behaviors highlight the importance of family in the network of care as their observations can gauge pain levels and inform pain management treatment (Lee et al., 2017). Posts show the varying degrees of awareness chronic pain sufferers have of the way their pain is manifested. For example, the perception ranges from the oblivious, “I was totally unaware of the way pain affects my posture…[and] why I was walking funny” to the attentive, “If I’m driving, I hold the steering wheel to my chest.” Who made the observations was a key finding as sometimes it was a child, “My daughter pointed out that when I’m in severe pain, I braid my hair” or “My oldest is 11 and she understands a certain look on my face that indicates to her that I’m in a lot of pain.” Other times, it was the lack of observation that intensified pain. “My husband has not picked up how I need to have help with the house…[which] stresses me out and only increases the pain.” Indicators of pain were most often observed by children or coworkers, those that have close relationships to the pain sufferer, and highlight the critical role friends and family play in a network of care.

Since pain sufferers may not be aware of their posture or facial expressions, there is need to teach their support network the importance of attending to non-verbal communication to better understand their pain language. Participants shared the need for education so that loved ones could pick up on their indicators of pain and of the role siblings can play in teaching other family members of the pain cues. “One of my boys is very sensitive but the others haven’t picked up on my pain.” Since chronic pain affects not just the individual but also the quality of life of family members, (Booker et al., 2019), developing the observational skills of family members and friends to recognize pain behavior can position them as first responders in identifying pain flare ups and offering support.

Evidence of pain: Work left undone

Participants also described the visibility of pain in terms of the impact it had on their inability to perform functions they could previously do when they were pain-free. Importantly, evidence of pain manifested outside of the body. Respondents indicated that their primary request for help came in the form of household cleaning and pet care more than self-care. The inability to keep up with household chores was an indicator of the severity and duration of their pain. “Consider all of the effort you do to help me out as investments into my health. They are not chores, tasks, or favors. They are restoring or maintaining my health, my livelihood, my independence, my esteem." In this way, supportive tasks and household chores that aid a pain sufferer's environment may be regarded as strategies for pain management.

Broadening the idea of pain management to include a person-in-environment perspective allows for a more holistic perspective of pain, taking into consideration a person's functionality and the simultaneous and multiple interactions that occur between individuals and their physical context. Including home environments in pain management assessment conversations may identify places for which support and help are needed. Previous research encourages patient intake forms for assessing pain to include more robust measures of pain-related function (Morasco et al., 2018) as well as questions that investigate the impacts of daily activities, relationships, work responsibilities, and personal goals (Becker, 2020). Building on this and inquiring about physical abilities (or inabilities) and household chores that are not getting done may help ameliorate the difficulty of communicating pain as the focus is on concrete things and visible evidence of pain (Birk, 2013; Main, 2014; Strong et al., 2009). Overall, the work left undone is often identified as women's work and reinforces the gendered discourse on the experience of living with chronic pain (Hoffman & Tarzian, 2001; Silver, 2004; Werner & Malterud, 2003).

Lessons learned from chronic pain

The second interpretive repertoire accounts for the lessons participants have learned from living with chronic pain including how pain has fostered empathy, promoted self-care, and cultivated coping skills. Posts in this interpretive repertoire align with CBT as participants' maladaptive beliefs and behaviors regarding pain are challenged (Furnes et al., 2014).

Participants shared how they have learned honesty about their limitations; trained themselves to not apologize for their pain or its impacts; expressed gratitude for what they can do; and instilled an appreciation for their family. Rather than perceiving themselves as victims, these posts illustrate the extent of stake they have in their chronic pain experience. The increased awareness bestows confidence and authority to individuals with chronic pain and reinforces previous research indicating therapeutic writing may facilitate cognitive restructuring processes (Furnes & Dysvik, 2012).

Empathy

Participants discussed how the experience of living with chronic pain has instilled in them a stronger sense of empathy and global awareness for others who are suffering all over the world. Posts like, "I am aware of the efforts that people put forth to get through their day because of their pain" shed light on a pain lens with which individuals with chronic pain view the world. As residents of a developed world, participants indicated their awareness of their privilege and access to modern medicine. While they are grateful for the accessibility, there is an underlying emotion of compassion. "I think of mothers who have nothing and have to watch their children endure pain. I think of people who have no access to medicine or doctors and I feel so grateful." In this way, pain has served as a bridge to connect with disparate others across borders and time.

The role of empathy has been found to lead to altruistic and prosocial behaviors and plays a significant role in maintaining relationships and interpersonal interactions (Xiang et al., 2018). Chronic pain may cause sufferers to withdraw from activities or isolate from others which inhibits their development of prosocial behaviors (Ma et al., 2020). The following post illustrates this struggle. “I’m learning not to apologize when the reason for backing out of my commitment is because of pain’s excessive demands and not because I’m lazy or unconcerned about others.” Therefore, the ability to relate to others is critical for individuals with chronic pain who need to overcome the disbelief of their pain.

Self-care

While numerous posts indicated the importance of taking care of oneself, these posts were overshadowed by a sense of struggle. Participants seemed to be at odds with their simultaneous roles as wives and mothers where taking care of others comes first. The idea of tending to themselves was counter-intuitive and something they have had to learn. “I have learned to listen to my body, to give into it instead of fight it.” Others acknowledged a sense of guilt they have for taking time to care for themselves or for not being at their optimal level. “I would never do that [care for myself] if I didn’t have to.” Learning to ask for and accept help seemed to be a monumental accomplishment for some participants. “We are taught to be so self-sufficient and think of others first. It’s really hard to put myself first, my own needs, especially as a woman. Motherhood and wifehood come first.”

Coping skills

Coping skills often came in the form of guidance where participants were counseling other sufferers. “Give yourself permission to grieve over the loss of normality.” These posts illustrate the extent of authority participants have gained from their chronic pain persona. For example, “Cut the crap. We don’t have time to brush the tough things under the rug.” There is a boldness and sureness in their wisdom and their counsel is said with confidence. Participants are not asking for approval or requesting permission, but rather they are the ones in charge, granting requests like “I give myself permission to be ‘off.’”

Previous research has found that the ability to adjust to chronic illness depends more on patients’ coping skills and attitudes than on the severity of the illness (Bombardier, 1990). The shift in attitudes indicated in these posts situates therapeutic writing alongside mindfulness-based strategies can play critical roles in improving coping responses and helping individuals communicate pain’s impacts in a holistic manner (Marchand, 2012).

Limitations

The study is subject to several limitations. The design of the writing workshop emphasized writing aptitude, and therefore, participants with strong writing skills may have been predisposed to enroll in the workshop. Moreover, writing ability may have caused some participants to contribute more frequently and thus gain more feedback from others. Data from the writing workshop participants are self-reported and are therefore subject to recall bias. While numerous posts detailed the association of physical pain manifesting in physical realms pertaining to domestic chores, it may be indicative of the homogenous participant sample. Since all participants in the writing workshop are women, they may have a larger role in household maintenance and prioritize household order and cleanliness more so than men. Further research is needed to determine if the focus on household clutter and mess is unique to women or if men with chronic pain experience the same aggravation.

Implications for practice

Combined, the interpretive repertoires reveal how individuals with chronic pain communicate pain, yet seldom use words. Rather, they express pain's impacts through gestures and via the work that is left undone in their home environments. This finding may compel healthcare providers to look for physical evidence of pain outside of the body and ask patients about pain's impacts on their work and daily tasks. The emphasis on indicators of pain may alleviate the need for women to perform their pain and foster credibility (Birk, 2013; Tosas, 2021). Participants' increased awareness of their pain indicators and behaviors may help them better articulate their pain and the support they need. Moreover, therapeutic writing can validate women's experience of chronic pain and overcome skepticism and disbelief (Tosas, 2021; Werner & Malterud, 2003). While this study focused on chronic pain, the value of using therapeutic writing as a tool to increase pain communication and management may be applied to other chronic conditions. The lessons learned from pain offer meaningful insight into participants' experiences of living with chronic pain and furthers our understanding of how communicating about chronic pain can foster empathy, self-care, coping skills, and support among members with a concealed disability.

Conclusions

This study conveys how individuals with chronic pain communicate the experience of living with chronic pain among a community of sufferers. The online therapeutic writing workshop was a vehicle to build a virtual community of support where participants engaged with creative writing prompts to express their experiences and were empowered to share their vulnerabilities and insights gained from living with chronic pain. The online community of writers alleviated feelings of isolation and stigma caused by insufficient language and inadequate quantitative tools to communicate pain.

Conflict of interest

I have no competing interests, financial or personal, that could have appeared to influence the work reported.

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