Cyberhugs: Creating a Voice for Chronic Pain Sufferers Through Technology

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Abstract

Chronic pain is a pervasive and expensive public health problem affecting roughly one-third of the American population. The inability of language to accurately convey pain expressions combined with the social stigmas associated with discussing pain persuade many sufferers to remain silent about their pain. Gender politics and fear of professional repercussions further encourage silence. This article explores the need for a safe and secure place for chronic pain sufferers to talk of their pain experiences. The extent to which digital communication technology can fulfill this need is examined. This descriptive study examines the use of one online chronic pain management workshop for its ability to create an engaged community of choice. Workshop admittance was based on participants having a qualifying chronic pain condition. A thematic discourse analysis is conducted of all entries chronic pain participants posted. In addition to goal setting, participants discuss the ways in which pain affects them on a daily basis. Two themes emerge: validation and encouragement. This study suggests that chronic pain users need a discursive space to legitimate their chronic pain identity. It confirms that online websites and virtual audiences facilitate disclosure and allow for authentic communication. The benefits of computer-mediated discussion as well as its limitations are examined.

Introduction

A RECENT STUDY CONDUCTED by the Institute of Medicine claims that over 100 million American adults suffer from chronic pain, which accounts for more than the total affected by heart disease, cancer, and diabetes combined and costs up to $635 billion each year to manage it.[1] For this population, pain is an everyday occurrence. It is a constraint sufferers constantly have to navigate around, affecting their personal, social, and professional relationships, commitments, and responsibilities. Their pain also is linked to emotional unrest, depression, lack of motivation as well as being linked to other negative physical attributes, like weight gain. In examining a particular online chronic pain management website, this article seeks to analyze the discursive practices that chronic pain sufferers use given the trusted space to disclose their illness identity.

Pain Communication

Pain defies language; it is invisible, inaudible, and unmeasurable, yet the only way to legitimate pain is to express it. The only way for others to know one is experiencing pain is if the sufferer expresses pain, which is a public act. If pain is not expressed, it has no reality. Pain plays a paradoxical role of being something that cannot be denied, but also that which cannot be confirmed.[2]

Moreover, communicating about one's pain is not always beneficial. There are many complex barriers for chronic pain sufferers to voice their pain, such as negative social repercussions and many professional stigmas to disclose chronic pain conditions. Trying to express pain can be confused for calling attention to suffering. Chronic pain sufferers often fall into a pattern of communication that is more harmful than helpful.[3] Keeping pain private may protect against unwanted inquiries into subjective experiences, but it can lead to feelings of isolation and marginalization of voice.[4] Additionally, not only is it linguistically unfeasible to articulate pain as well as socially stigmatized, physical limitations and emotional complications work to further alienate this population. As a marginalized group who is discouraged from voicing their pain, chronic pain sufferers are stripped of a voice.[5]

Therefore, finding a place in society where chronic pain sufferers can discuss their experiences and their marginalization is of utmost concern. The space needs to provide a safe haven, where this oppressed population can feel safe to disclose feelings and symptoms. The creation of this safe space can help cultivate a voice, both in terms of working through the complexity of articulating phenomena that exist outside

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of language as well as discussing experiences that exist outside of mainstream society. Squires[5] argues that marginalized peoples take on particular genres of discourse and action depending on culture. Thus, the goal in creating this space is twofold: voicing concerns and experiences in a trusted place to enable the ultimate goal of finding their voice and to examine the discourse practices of a marginalized population.

The Public Sphere of the Internet

The creation of a safe place to talk of the experience of chronic pain may be achieved through technology. Specifically, the internet can provide a low-cost, high-reward environment for revealing one's illness identity. One specific online chronic pain management workshop, The Better Choices, Better Health Chronic Pain Management website, attests to the viability of digital communication technology. One of the aims of this website is to improve communication practices among chronic pain patients so that they can learn how to talk to healthcare professionals and family members about the care they need.[6]

In traditional forms of communication, importance is placed on the response; however, on the internet, where personal voices operate within the public sphere, the emphasis shifts from being heard to being able to speak.[7] When discussing cyberculture, a radical redefinition of public culture, where the public could be people sitting in the privacy of their homes, but engaged with a community of users from around the world has been called.[8] This present, but separate conception of the public applies to the online pain management workshop as it may enable chronic pain sufferers to be more interactive with their virtual audience.

Method

Discourse analysis is an interdisciplinary type of content analysis, which focuses on systems of meaning and how particular labels or concepts are developed and made powerful by the use of language.[9] In the context of communication research, this type of analysis offers a quantitative, systematic, objective technique to describe the manifest content.[10] Discourse analysis is hinged on two main premises: that language can be analyzed not just on the word or the sentence, but also on the level of the text; and the idea that language should not be analyzed as an abstract set of rules, but as a tool for social action.[11] By looking at the online entries the participants posted, discourse analysis is beneficial in focusing on what is tangible, such as the frequency of words occurring.

A discourse analysis was conducted on common themes that emerged from the weekly discussion prompts on the online pain management workshop to examine the discursive practices of chronic pain sufferers. The structure of the online workshop facilitated a thematic analysis because the website had already created categories that users could select to submit their post. The categories were Problem-Solving, Difficult Emotions, Celebrations, and Goal Setting. These posts were unstructured, informal, and all participants were encouraged to reply to each other, placing emphasis on the content over the user. To manage the numerous posts, each was first read as an individual entry under the specific category; then, the content was analyzed collectively to cross-tabulate themes.

Participants

Eighteen participants and two facilitators participated in the 6-week chronic pain management workshop that was hosted by a Midwestern health organization. The inclusion criteria consisted of participants having a definite chronic pain condition; living in North Dakota or Minnesota; having internet access; and willing to spend 2–3 hours a week in completing workshop readings and postings. Participants varied in age, gender, class, and hailed from both country and urban locales. A participant profile was created using a screen name to maintain anonymity; users' home town, health problem, and hobbies could be included in their profile if they wanted. Participants' chronic health conditions included epilepsy, high blood pressure, osteoarthritis, depression, sleep apnea, hypertension, type 2 diabetes, MS, chronic back pain, chronic sinusitis, fibromyalgia, and rheumatoid arthritis.

Data Analysis

Thematic data analysis began by reading the weekly online posts of the unstructured comments. While goal-setting was a large component of the pain management workshop, the focus of this study is on the interrelated website tabs of Difficult Emotions, Problem Solving, and Celebrations. Since posting to these tabs was not assigned or monitored by the facilitators, these posts provide meaningful insight into participants' experiences and their collective understanding of living with chronic pain.

Findings

Eight distinct concerns were posted in the Difficult Emotions tab. A total of $21(N=21)$ responses were posted to the concerns. Thematic analysis of the responses offered by users to other users' concerns show two clear themes: validation ($N=9$) and encouragement ($N=12$).

Validation

Consistent with a study that investigated the problems in trying to identify the impact chronic pain has on patients' lives,[12] one common finding from the online chronic pain management workshop was the feeling of isolation. Participants wanted to know that their chronic pain experience was not an isolated event. Validation was needed to affirm and assure users that others could relate to their experiences. Users disclosed that they were apprehensive about a diversity of health concerns, including passing their illness onto their kids; lack of physical ability and ability to get it back; getting seizures and not feeling normal; unpredictability of pain; anxiety about inability to lose weight; depression; sadness; anger; and frustration.

The airing of these personal feelings that have remained private and secret for so long needs to be met with substantiation. Responses to these posts were constructed in the form of "I statements" like "I can certainly see how that would make you feel angry and worried..." in response to one user's anxiety about the unpredictability of a seizure occurring. Another user responded by corroborating with the sufferer's emotions:

You have every right to be angry. I'm angry at my problems too.

Often, one post would elicit several responses from workshop members. The thread of responses created a

community of voices and once one person shared a difficult emotion it acted as a gate to signal it was safe for others to share their feelings too. For example, an initial post stated:

Stress from work and a new health concern. Sometimes it seems like it will never end. One thing after another, never getting a break. Tired, very tired.

Four participants responded to that parent post, which acted as validation to the voiced concern. The responses showed empathy and understanding that comes from an audience that can relate.

You wrote that you are very tired. I'm not sure if that means tired physically, emotionally or mentally but I bet it's all three.

Through the participants' shared experiences of pain, they were able to offer advice that was authentic and sincere.

Take one problem at a time. First is your health concern. If you don't take care of you, you won't be able to take care of anything else.

These posts exemplify the ability to speak freely and honestly. Absent from the posts is any editorializing from the moderators or interference from the sponsoring medical organization. This candor can build trust. As Mitra[7(p505)] notes, "the textual strategy of leaving out any editoralization also can generate trust by bringing together marginalized individuals who can speak in the company of similar others, without having their voices co-opted and transformed by institutions."

Encouragement

Once the legitimation of their condition had been realized, users wanted emotional support. Although the concerns and emotions varied, the responses were unanimously supportive and uplifting, encouraging users to stay positive and to forgive themselves. For instance, for the user who wanted to lose weight, but was frustrated by the fatigue he felt and which acted as a hindrance to him working out, all three responses received expressed comments of patience and hope. One user replied:

Believe in yourself and give yourself time.

To the user who was disappointed with the lack of physical ability she had and fearful that mobility may not return, a post encouraged her to take:

"Small steps!!! Many small steps turn into a great distance. Keep at it!!!

The need for encouragement is consistent with the Bunde et al[13] study, which examined if a website created for women who had a hysterectomy successfully provided information and support. The researchers found that women most often selected a particular support website if they felt they could relate to a similar experience or situation. "'Having gone through or currently in the same situation' was mentioned significantly more often than all other categories."[13(p84)] Honesty, encouragement, and humor also played a large part in women's selection.

While the online forum cannot allow for the physicality of touch, it can provide for a cyberhug, the virtual support that is so needed in the lives of chronic pain sufferers. Through the validation and encouragement offered via an online website, chronic pain participants gain a sense of empowerment. They transition their personal experience of pain from their private lives into a virtual public space. By disclosing of their experiences with pain, they are able to legitimize their pain identity and carve out their voice.

Discussion

Miller[14] writes of the benefits of virtual communities, including the ability of "digital communication technologies to liberate individuals from social, geographical, and biological constraints of place and proximity."[(p191)] Since the online pain management website is designed for a particular intended audience, users know they are associating with like-minded individuals. By overcoming space and distance, the website creates a community that disregards physical boundaries or immobility. A sense of shared interests or experiences can help to break down barriers and enable conversation. Nichols et al.[15(p48)] refer to these as virtual "affinity communities," which are based on common interests, even if participants lead very different real lives outside the chatroom.

As a result of these independent interests, the online interaction could be considered more meaningful, relevant, or authentic. In digital environments, the concept of authenticity holds more solvency compared with credibility. As Mitra[7(p495)] acknowledges the multitude of voices that can be heard in cyberspace allows that "some can claim to have a greater legitimacy to speak about something because of their unique history and background." Since a qualifying chronic pain condition is a stipulation for the online workshop, authenticity is granted to members by their acceptance into the workshop. As their contributions derive from their own personal experiences with chronic pain, members' posts may be deemed more authentic, as opposed to credible, than advice received from healthcare professionals.

Other benefits of the internet include the continuous presence of the web which allows users to engage with the website at their own convenience. Plus, the anonymity of an invented screen name can encourage disclosure without the risk of stigmatization. Online, chronic pain sufferers can choose to present themselves as sufferers without the threat of being viewed as complainers. Anonymity is an essential component to discursive practices as there is a strong history of bias when it comes to gender and pain.[3,16–18]

Limitations

The ability to discuss pain freely in the online chatroom may have been hampered by the two moderators who were tasked with responding to the users' health concerns and with trying to create a sense of community so that it was not just the two facilitators responding, but other users joining the dialogue. Often, to the claim on the chronic pain management website "I am so tired; can't get out of bed" the facilitators encouraged the user to get in touch with their doctor and inquire about their medication dosage.

Stemming from this type of response, it is important to consider that perhaps users on the chronic pain management website just wanted to be heard without the constant reminder of getting in touch with their doctor. For example, one user posted the following concern:

I am angry that every time I feel like I am becoming 'normal' again, a seizure or a side-effect re-enters my life. It makes me worry about what the future holds for me.

This post received three responses; two by other users and one from a facilitator. Both of the other users' comments expressed validation ("I can certainly see how that would make you feel angry and worried"). Conversely, the comment posted by one of the facilitators took on a different tenor:

> Since you are saying that the seizures are coming more often, I'd encourage you to visit with your health care provider about this.

In all 21 responses, this was the only mention of visiting with a health care professional.

It was the final comment posted to this thread and no reply was made. It is unclear if the lack of response can be interpreted as the user ignoring the comment or shutting down. However, the possibility of productive benefits stemming from retaining and embracing their sense of chronic pain is worth considering. As Miah and Rich[19(p216)] state, "cyberspace is an environment impoverished of flesh and yet, it is a space within which there is a continual engagement with body matters, including health, reproduction, body disorder, and so on." There may be redeeming qualities to just posting a statement ("I feel tired") and letting the user linger in their pain. Perhaps we need to view chronic pain in the same light as Fox et al.[20(p947)] view anorexia, as not "a wholly negative condition that must always be 'remedied through medical treatments or psychosocial intervention.' " On the other hand, as a website which employs facilitators and passwords and in which users must apply to gain participation, the facilitators could be charged with ignoring their ethical responsibility if they don't encourage participants to consult with their doctor. The pain management workshop's emphasis on problem-solving may overshadow the need for affirmation and the therapeutic value in pain expression.

Conclusion

It is clear that chronic pain sufferers face many constraints when trying to express their personal and private experience of pain. The insufficiency of language, combined with the social stigmas and gender politics all contribute to creating a hostile environment to discuss pain. Professional consequences further encourage concealment. The creation of online chatrooms devoted to chronic pain individuals is one way to establish a sense of community among disparate and isolated individuals. By examining the discursive practices of chronic pain sufferers, it is found that technology plays a significant role in creating a space to facilitate pain expression. The thematic discourse analysis reveals that validation and encouragement are issues of concern to this particular population.

This website confirms that an online website can be a feasible communication outlet because it can facilitate the transition for chronic pain sufferers to disclose their very private experience of pain to a public audience. Online chatrooms can be valid outlets for chronic pain sufferers to legitimate their pain as well as establish a sense of kinship with others. It is important that communication scholars are aware of the social stigmas chronic pain individuals contend with and work toward removing the barriers they confront. These findings also have significant implications for communication training among health care professionals. Understanding the discursive needs of chronic pain patients is critical to improve communication patterns between the patient and the provider.

Author Disclosure Statement

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