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Patient Responses to the Term Pain Catastrophizing: Thematic Analysis of Cross-sectional International Data

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Abstract: Pain catastrophizing is understood as a negative cognitive and emotional response to pain. Researchers, advocates and patients have reported stigmatizing effects of the term in clinical settings and the media. We conducted an international study to investigate patient perspectives on the term pain catastrophizing. Open-ended electronic patient and caregiver proxy surveys were promoted internationally by collaborator stakeholders and through social media. 3,521 surveys were received from 47 countries (77.3% from the U.S.). The sample was mainly female (82.1%), with a mean age of 41.62 (SD 12.03) years; 95% reported ongoing pain and pain duration > 10 years (68.4%). Forty-five percent (n = 1,295) had heard of the term pain catastrophizing; 12% (n = 349) reported being described as a 'pain catastrophizer' by a clinician with associated high levels of feeling blamed, judged, and dismissed. We present qualitative thematic data analytics for responses to open-ended questions, with 32% of responses highlighting the problematic nature of the term. We present the patients' perspective on the term pain catastrophizing, its material effect on clinical experiences, and associations with negative gender stereotypes. Use of patient-centered terminology may be important for favorably shaping the social context of patients' experience of pain and pain care.

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Perspective: ***Our international patient survey found that 45% had heard of the term pain catastrophizing, about one-third spontaneously rated the term as problematic, and 12% reported the term was applied to them with most stating this was a negative experience. Clinician education on patient-centered terminology may improve care and reduce stigma.***

Key words: *Chronic pain, patient perspective, pain catastrophizing, stigma, patient-centered, qualitative.*

The term "catastrophizing" was first introduced in 1962 by Albert Ellis to describe a central component in emotional dysfunction.[24] Ellis described catastrophizing as "exaggerating adversities into something far worse than they actually are; seeing things at their worst when they are sometimes relatively minor; and greatly exaggerating the frequency and/or danger of something that you dislike".[24] Aaron Beck later adapted the term in 1987 to describe a maladaptive cognitive style in people living with anxiety and depression.[19] The term was first introduced into the pain literature in 1987 with the advent of the Coping Skills Questionnaire catastrophizing subscale (CSQ-CS),[16] which includes six self-report items tapping 2 subscales (rumination and feelings of helplessness). The CSQ-CS has been used widely in pain research for 35 years. The development of the Pain Catastrophizing Scale (PCS) in 1995[35] spurred wider measurement of pain catastrophizing in clinical and research settings. The PCS is a 13-item self-report questionnaire that assesses the frequency that patients experience 3 elements of catastrophizing within the context of pain: rumination, magnification, and helplessness.[35] Some researchers have questioned the accuracy of the measures used[37] and others have called for revisions.[6] These early conceptualizations of catastrophizing continue to this day, in that catastrophizing includes the concept of magnification of anticipated future events.[27,36]

Results from experimental and clinical research, including neuroimaging studies in healthy and clinical samples, have demonstrated that pain catastrophizing is associated with marked changes in the structure and function of the brain.[11] For example, during in vivo pain processing, catastrophizing was associated with increased activation of affective- and attention-related brain regions.[31] Furthermore, reductions in self-reported pain catastrophizing have been shown to mediate favorable changes in brain structure.[32] Translating these findings into clinical care involves targeting such cognitive/attentional and emotional response patterns that are known to impact central nervous system functioning and pain. Clinical approaches must include contextual appreciation and validation of each individual's challenging medical conditions and ongoing pain experience, as well as the environmental and social factors impacting their health and pain. Applying a broader lens of understanding minimizes a reductive and sole focus on the individual's responses to pain and promotes a comprehensive appreciation of the social, psychological, and medical factors that comprise their experience.[21] For example, navigating the medical system is a highly stressful experience for some individuals. Yet long absent from patient reported measurement is quantification of stressors experienced from seeking healthcare. Greater appreciation of the broader contextual factors may yield a more balanced understanding and identify external and environmental issues requiring adjustment, keeping in mind that structural issues such as poverty are unlikely to be amenable to change through treatment alone. Such context could validate contributors to pain responses being measured. In turn, such validation could foster increased patient receptivity to clinical recommendations around adaptive pain management skills acquisition as a means to improve personal control within the context of difficult circumstances.[20]

While pain catastrophizing research has flourished,[22,33,30] with findings supporting its role in chronic pain and distress,[9,17] some researchers have challenged current approaches. For example, Crombez et al.[6] argue for the adoption of a more person-centered approach combined with a renaming of measures of pain catastrophizing to measures of "pain-related worrying". Chronic pain researchers have debated the suggested term "pain-related worry," with critics deeming it an unsuitable replacement term because pain-related worry is a consequence of pain catastrophizing versus a representative of the construct per se. Advocates and people with chronic pain claim the current term is stigmatizing.[15,25] In reflection of the stigmatization experienced by patients, researchers recently validated a new scale to tap the construct of catastrophizing. Based on substantial patient stakeholder feedback regarding stigma associated with the term 'catastrophizing', the new scale was named the Concerns About Pain Scale.[1] Such efforts are geared toward making changes that reflect inclusivity of patient perspectives to assure respect, reduce stigma, and increase engagement in care and response to the care received. Nevertheless, some patients continue to question whether changing the name would change the negative underlying assumptions of the concept itself.[1]

It is in this context that the Rename Pain Catastrophizing study was initiated as a patient-centered project led by pain researchers, patients, their caregivers, family members, patient advocates, and clinicians from various nations and professional disciplines. The broad purpose of the study was to understand the perspectives of stakeholder groups with regard to the term 'pain catastrophizing' and whether improved and patient-centered terminology might be indicated. Accordingly, our aims were to: 1) understand prevalence of patient exposure to the term ‘pain catastrophizing’; 2) among those exposed to the term, understand patient experiences and perspectives about the term; 3) understand patient perspectives about whether an alternate term is needed.

While future manuscripts will describe the clinician survey responses, the current manuscript presents analysis of the Patient/Caregiver Proxy survey data. We note that whereas some have argued against the use of the term “patient”,[29] our patient collaborators and stakeholders supported the use of the term “patient” for the current project.

Methods

This observational cross-sectional study involved broad distribution of study invitations, as well as collection and analysis of online and anonymous survey data. The project was deemed exempt by the Stanford University Institutional Review Board. All study advertisements were electronic and included brief introductory language regarding an anonymous opinion survey on chronic pain. The study advertisements contained a link to a study website. The study website displayed the following introductory language:

> “This is a patient-centered project being led by a group of committed pain researchers, patients, patient advocates, and healthcare professionals. We aim to understand the perspective of patients, researchers and healthcare professionals with regard to the term ‘pain catastrophizing.’ We will be collecting and collating the information we receive from your responses to help us understand whether it’s time for a change in the use of this term—and to possibly create new terminology that is compassionate, patient-centered, and more considerate for use in the medical community.”

Individuals were invited to choose either the clinician/researcher survey or the patient/caregiver survey. Caregivers were asked to respond to questions about pain/identity for the person they care for (ie, as a patient proxy vs their perspective about being a caregiver). After selection of the patient/caregiver survey, respondents viewed the following text:

> “Our Goal: We aim to understand the perspective of patients with long-term pain with regard to the term ‘pain catastrophizing.’ We plan to research and develop a new term that is patient-centered and more considerate for use in the medical community. We appreciate your participation and opinions and thank you for your thoughtful contributions. All answers are anonymous and will be kept confidential. For any free-text responses, please do not include any identifying information so we can keep your responses anonymous.”

English and Spanish language versions of the patient/caregiver survey were available upon selection.

The demographic and qualitative items of the patient/caregiver survey are displayed below and in Appendix 1; the parenthetical red text is provided for explanatory purposes and was not part of the survey. Individuals under 18 years of age and those who did not have current, ongoing, or past chronic pain were excluded from enrolling as patients, though individuals over 18 with no history of chronic pain were eligible to enroll as a caregiver proxy (meaning they were asked to complete the survey on behalf of the person with pain) if they self-identified as having experience as a caregiver for an individual with chronic pain. Appendix 1 displays the survey items in full. Following completion of 5 demographic items (presence of ongoing pain [yes/no]; age; gender; country of residence; duration of pain), participants were asked 4 items specific to their exposure to the term pain catastrophizing. Note that with branching logic applied as described below, this initial section assessed prior exposure to the term, and experiences and perceptions therein (to minimize bias participants were asked these items prior to being provided with the definition of pain catastrophizing): 1) *Have you heard of the term ‘pain catastrophizing?’* (if yes, branching logic to the next question); 2) *Where did you first hear the term ‘pain catastrophizing’?*; 3) *Has a healthcare provider ever described you as being a ‘pain catastrophizer’ or said that you were ‘catastrophizing’ your pain, or used the term to discuss your pain care?* (if yes, branching logic to the next question); 4) *If you answered yes to the previous question, thinking back to when this term may have been applied to you, please circle the number that best describes your level of agreement/disagreement with the following statements.* Respondents used a Likert scale (1= strongly disagree or strongly disapprove; 7= strongly agree or strongly approve) to rate 7 items regarding their experiences and opinions of the term.

Next, the following definition of pain catastrophizing was displayed to the survey respondents.

> “Pain catastrophizing refers to how we respond to pain we have right now, or to pain we expect to have in the future. It includes thoughts we may have about pain (eg, "I can’t stop thinking about how much it hurts"), feelings about pain (such as helplessness) and expectations for future pain (eg, "I worry that my pain will only get worse"). This term is used in 2 different ways: 1) To describe a temporary state of distress about pain eg, when anticipating pain you may experience from a scheduled procedure, when receiving a new diagnosis, when experiencing new symptoms or severity of symptoms, or secondary to a medical procedure or injury; 2) To describe a pattern of thinking, feeling, and reacting to pain over a longer period of time. While the degree of pain catastrophizing and level of pain intensity we experience are related, research shows that they are different. We can control for pain intensity in research studies (by keeping it constant) and see that pain catastrophizing — our level of pain-specific distress — changes how pain is processed in the central nervous system.”

Participants were asked 3 open-ended items: 1) What comes to mind when you hear the term pain catastrophizing? 2) What would be a better term for pain catastrophizing? 3) Is there anything else you would like to tell us about the topic? Participants also rated 8 candidate terms that might serve as alternate terminology to describe pain catastrophizing (see Appendix 1); these candidate terms were generated by a subset of scientific and patient project collaborators.

Survey invitations were distributed internationally and publicly through social media postings (eg, Twitter, Facebook), website postings and via email distribution lists of pain organizations. The study advertisement and survey link were distributed through Stanford's official social media accounts (Facebook, Instagram, Twitter), and professional and research listservs. Study investigators also sent study information via email to the directors of national and international patient organizations with a request that they consider distributing the survey amongst their membership. Twelve patient stakeholder collaborators distributed the study advertisement to peers and colleagues in 4 countries. Thirty-two scientific stakeholder collaborators in 9 countries helped distribute the survey advertisement to colleagues, relevant listservs, and patients in their country. Seven national organizations (Chronic Pain Research Alliance, the American Chronic Pain Association, PainAustralia, Center for Pediatric Pain Research, Solutions for Kids in Pain Network, American Society of Anesthesiologists, Pain USA) distributed the survey. Finally, 2 international organizations (Global Alliance of Pain Patient Advocates GAPPA; a task force of the International Association for the Study of Pain), and the World Patients Alliance distributed the study advertisement and survey among members and via social media.

On May 29, 2020 the study survey went live online and it remained active for completion until August 17, 2020.

Data Analysis

Our analysis included both statistical and qualitative methods. Demographic items were summarized as frequencies. Responses to Likert scale items were reported as means and standard deviations. Responses to the 3 open-ended questions were analyzed using qualitative thematic data analysis as described by Braun and Clarke[5] in the context of our methodology, qualitative description. Although thematic analysis requires a qualitative design from the start and on its own does not constitute qualitative research, it is recognized as a useful method to interpret open-ended survey data and to identify important patterns within the data.[5] Additionally, thematic analysis supports the presentation of credible clinical and theoretically relevant conclusions. A coding framework was developed inductively using an iterative and collaborative approach by FW, BD and MZ. Codes are used to systematically categorize the data based on shared characteristics and to eventually identify significant patterns. First, a subset of 20 responses per coder was selected and read independently by FW to create preliminary data-driven codes. The preliminary codes were then compared by FW and BD to arrive at an agreed upon coding framework. Collaborative coding supports the practice of reflexivity by allowing each researcher to bring their own perspective to the data and examine their own assumptions.[10,34] Once the coding framework was finalized, the codes were applied to the data by 4 student coders (ET, HB, MW, TAL) working with BD. Themes were identified from the codes and aimed to represent patterns and meaning within the data set.[5] NVivo software was used to organize and manage the data.[26]

Results

Study Participants

A total of 3,521 participants, who self-identified as patients or family members, began the survey, and 2,911 (82.7%) completed it. Responses were received from individuals residing in 47 countries. Participants were predominantly from the United States (77.3%), followed by Canada (7.6%), Australia (4.1%), the United Kingdom (3.6%), and The Netherlands (1.6%), in addition to other countries listed in Table 1. Study participants (Table 2) were predominantly female (82.1%), with an average age of 41.62 years. Ninety-five percent of the sample reported having ongoing pain, with pain duration exceeding 10 years (68.4%).

Fewer than half of the respondents (44.5%; n=1,295) had heard of the term pain catastrophizing. Twelve percent of the sample (n=349) reported the experience of having a healthcare provider describe them as a 'catastrophizer'; no response was received for 55% of respondents for this particular item. Those who endorsed having been labeled as a 'pain catastrophizer' reported high levels of feeling blamed (M=5.95, SD=1.64), judged (M=6.30, SD=1.41), and dismissed (M=6.17, SD=1.60).

The coding framework we developed went beyond the 3 specific open-ended questions. Responses were organized into 5 interrelated themes: 1) What the term 'pain catastrophizing' means to patients; 2)

Table 1. Countries Represented in the Study

Country	*Study sample (N = 2,911) No. (%)*
United State of America	2,250 (77.3)
Canada	221 (7.6)
Australia	118 (4.1)
United Kingdom of Great Britain and Northern Ireland	105 (3.6)
Netherlands	46 (1.6)
Singapore	27 (0.9)
Ireland	21 (0.7)
New Zealand	9 (0.3)
Others*	70 (2.4)
Missing	44 (1.5)

*Other countries include Austria, Belgium, Botswana, Brazil, Croatia, Cyprus, Ecuador, Finland, France, Germany, India, Indonesia, Israel, Italy, Kuwait, Latvia, Maldives, Malta, Mexico, Nigeria, Norway, Portugal, Rwanda, Saudi Arabia, South Africa, Spain, Sweden, Switzerland, Turkey, and Venezuela.

Table 2. **Characteristics of Study Participants (N = 2,911)**

Variable	Response set	N (%)
Do you have any ongoing pain?	Yes	2788 (95.8)
	No	122 (4.2)
	Missing	1 (0.0)
Age, M (SD)		41.61 (12.03)
		N(%)
Sex	Male	459 (15.8)
	Female	2,389 (82.1)
	Non-binary	29 (1.0)
	Prefer not to say	33 (1.1)
	Other	1 (0.0)
Pain duration	< 1 years	53 (1.8)
	1-4 years	261 (9.0)
	5-10 years	599 (20.6)
	More than 10 years	1,991 (68.4)
	Missing	7 (0.2)
Have you heard about pain catastrophizing	Yes	1,296 (44.5)
	No	1,615 (55.5)
Has a healthcare provider ever described you as being a "pain catastrophizer"	Yes	363 (12.5)
	No	824 (28.3)
Missing		1,616 (55.5)
	Other	108 (3.7)
If Yes,	Responders (n)	M (SD)
I felt blamed for my pain	363	5.95 (1.64)
I felt judged.	362	6.30 (1.41)
I felt my pain was dismissed as being purely psychological or "in my head."	363	6.17 (1.60)
I felt I was taken less seriously.	361	6.16 (1.59)
I felt the information, or this term, was used against me.	362	6.00 (1.66)
I felt this information was used to prevent my access to pain treatment.	362	5.54 (1.87)

consequences of the term on patient experiences; 3) association of the term with negative gender stereotypes; 4) suggestions for new term; 5) patients objecting to new term due to opposition or criticism of the *construct* itself (sub-theme suggested alternatives to finding new term). Many patients also shared their stories, some of which we have included here in our results.

Emerging Themes

What Does the Term 'Pain Catastrophizing' Mean to Patients?

After the definition of pain catastrophizing was displayed, respondents were asked, "what first comes to your mind when you hear the term pain catastrophizing?"1,839 participants provided an open-ended response to this question. Of those, 68% of patients did not spontaneously report negative experiences or responses to the term. About 32% (n=588) spontaneously reported having a negative interpretation of the term or found it to be problematic as demonstrated by 660 references to the following: exaggeration (referenced 264 times), dismissive (referenced 95 times), overreaction (referenced 67 times), dramatization (referenced 68 times), blame (referenced 52 times), hysterical (referenced 45 times), faking (referenced 38 times) and minimizing (referenced 31 times). For example, 2 representative quotes are:

> "[They think] that you are making a big deal out of nothing - like it doesn't really hurt that bad, you are exaggerating" (Participant #91)

> "Pain catastrophizing brings to mind someone who **exaggerates** how much pain they are in in order to **gain sympathy** or more pain meds. . . . Even though that's not really the definition of it, I think a lot of people relate the word 'catastrophizing' to 'exaggeration'. . . .You need to separate these misperceptions with different terms." (Participant #388, emphasis added)

However, some indicated that the term was reasonable or useful (n=80).

> "I'm ok with the term, since it reminds me of my role in the pain process, that my attitude toward pain is critical." (Participant #128)

> "I would use this term to describe the way a person with chronic pain can sometimes feel helpless to fight or treat their pain, and habitual fear, dread, and emotional and physical exhaustion can not only contribute to future suffering but intensify the degree

> of that suffering. I don't think I do this, but I understand it completely." (Participant #300)

Other respondents accepted the term for the most part but also emphasized that, for them, the definition was not fully accurate or supportive of their experience.

> Although I absolutely understand as patients we can moderate and contribute to our pain sensations BUT terming our sensory experience as a catastrophe does not help and often my post-surgical pain and the lack of pain management is a catastrophic event in my life (Participant #2702)

> On one level, I understand that it may be an accurate psychological term - to describe catastrophic thinking patterns associated with experiences of pain. I've found it useful to recognise that some of these thought patterns aren't helpful for me in managing my pain levels, and to develop alternative ways of thinking. On an emotional level, I find it a bit demeaning and blaming. It carries the implication that my pain is imaginary, or that I'm exaggerating it (Participant #892)

> I think this term comes from the medical field or doctors perspective and not from the patients. Let me add that I fully agree our thoughts, beliefs, emotions and memories impact our pain levels. But the word "catastrophe" triggers my experiences working with doctors and them not taking it seriously. Like, "the hysterical woman" for example (Participant #565).

Consequences of the Term on Patient Experiences

Patients who reported that they were labelled as 'pain catastrophizers' often viewed the term pain catastrophizing through the lens of how it affected their care. 935 participants provided an open-ended response addressing this issue. For example, some patients perceived that the label was taken up in ways that positioned them as lying (referenced 16 times), minimizing their concerns (referenced 44 times), placing blame upon them (referenced 108 times), and as dismissing their concerns (referenced 138 times). Patients referred to feeling judged (referenced 61 times), ignored (referenced 37 times), and belittled (referenced 27 times) as they felt the clinician believed that their pain was not real, and instead "all in their head". For some (n=7), this was even experienced as a "weapon" used by clinicians against them:

> "It is insulting to patients who have no way to control their pain - especially in the context of unexplained diseases, catastrophizing is used to portray patients as 'hysterical' 'attention seeking' or causing distress for themselves. It is accusatory and it is used as a weapon to blame patients for not getting better" (Participant #997)

> "The word catastrophizing, while having a specific clinical definition, sounds to a patient (me) like I am EXAGGERATING, that I'm not being taken seriously, that the degree of my pain is all in my head" (Participant #201)

> "I find it very victim blamey to use pain catastrophizing, and that it is often weaponized against disabled people, especially those who don't have a clear medical explanation for their pain." (Participant #1028)

Below we include representative quotes that illustrate various patient perspectives. For instance, 1 respondent also spoke of how the term is part of medical terminology and can lead to feelings of confusion and isolation. This person recognized that the negative impacts of the term was not intentional but nevertheless it made them feel more "categorized than humanized":

> "But in my (and [my] friends') experience as patients, I have found medical jargon is used too much with patient/doctor interactions. This leads to patients feeling more confused and isolated from their treatment than involved. I don't believe this is intentional - medical care is a highly technical discipline. But the language can baffle a lot of the populous. This makes it better for patient/doctor terminology to be more 'humanized' than 'categorized'". (Reference #288)

In addition, several respondents referred to how the term minimized their pain or otherwise created a sense they could bring it under control if they tried harder. As the following response summarizes, the term "implies that the patient could lessen their pain if they'd only try hard enough not to think about it".

> "The term implies that the patient makes their pain worse by letting it control their thoughts or actions. It implies that the patient could lessen their pain if they'd only try hard enough not to think about it. I felt demeaned, like the pain was all inside my head, especially since at that time no 1 could figure out what was wrong with me. When you have severe chronic pain, the kind that disables you, it's all encompassing. It affects everything you do, your relationships, etc. If certain tasks or actions make it worse, of course you're going to avoid doing those things, especially if your pain isn't well controlled." (Participant #87)

Others referred to how the use of this label led to them perceiving a lack of compassion on the part of the health care provider. The respondent below associates the term with "victim blaming", "negative judgment" and "arrogance on behalf of providers" and a refusal to acknowledge the lack of pain management strategies currently available:

> "Victim blaming, lack of understanding and compassion, negative judgement, being told you simply need to develop skills to manage your pain with zero understanding or interest in what skills or strategies you currently use, lack of empathy, arrogance on behalf of providers, barriers to care being

> established, you don't exist and we don't want you exist 'go away', your pain isn't real it is all psychological go for counselling, no admission that research and knowledge hasn't caught up to genuine pain management strategies." (Participant #702)

Another common response pertained to stigma associated with mental illness and suggests that this characterization becomes an excuse to stigmatize patients who experience pain and refuse treatment:

> "This minimizes the experience of the patient and immediately makes it a mental health problem and not a real medical problem. It is an excuse to further stigmatize pain pts and refuse to treat us." (Participant #308)

Association of the Term With Negative Gender Stereotypes

Respondents made reference to "gender", "female", "women" and "woman" 169 times in their coded responses, suggesting these respondents' awareness of the association of negative stereotypes in relation to gender. One respondent suggests the term is historically rooted in the notion of "hysteria". In resistance to this term, she writes, "I don't catastrophize, I plan":

> "I despise this term, from both my bioethics & CRPS patient perspectives. It continues a long history of Healthcare apparent infantilizing or downplaying women's health issues, particularly chronic pain conditions. I associate the term pain catastrophizing with the ways in which 'hysteria' was historically used to describe women's medical conditions. As a patient with neuropathic chronic pain, joint pain, etc. – I don't catastrophize, I plan." (Participant #3222)

Similarly, another respondent perceived that women in particular are likely to have their pain minimized. She recounts how when she was labeled with this term by a pain psychologist, she felt that she was being told "I was faking it or not tough enough, weak, and attention seeking":

> "Being over dramatic about pain for attention or pain medication People with chronic pain, especially women, have likely had their pain minimized by medical professionals, friends, and family members. Being told that our mind is making it worse than it is can be very upsetting. I was very discouraged when I met with the pain psychologist at the pain clinic and was told about pain catastrophizing. It seemed like I was being told I was faking it or not tough enough, weak, and attention seeking." (Participant #476)

Another notes how the term re-directs the medical gaze away from other causes, such as trauma, and again links the term to "hysteria" and suggests the chronic pain is about the patients' "failure to properly process pain":

> "Reductionist write off of an experience. Like calling women hysterical. It fosters clinical distance by dehumanizing the patient as a 'catastrophizer', reducing their experience to a syndrome and blaming it on them. It becomes about their failure to properly process pain. They are not patients suffering from ongoing trauma, but catastrophizers railing at ghost or anticipatory pain like children afraid of a shot. It keeps people like me from admitting how much pain we are in and how often I'm experiencing it, as folks tend to write off what they cannot understand on a visceral level. It fails to center the patient or sufferer." (Participant #811)

As an example of a broader perspective, 1 respondent explicitly applies a gender lens to describe this experience, noting how women have traditionally been viewed as "more emotional and less rational". She suggests that this could then be used to "blame the patient for their pain":

> "Could be used to blame the patient for their pain. Eg, it's easy to say someone is catastrophizing and the pain isn't really that bad which could dismiss genuine physical suffering and prevent patients receiving appropriate treatment for the pain itself (rather than just their thoughts and feelings about the pain). The term catastrophizing is often inappropriately applied to women who are often seen as being more emotional and less rational which can lead to prejudice and health inequalities if women's pain is reduced to 'catastrophizing' and not treated appropriately." (Participant #819)

Suggestions for New Term

We coded 893 suggestions for a new term. Some of these were more clinically oriented, such as "negative pain-anxiety cascade", "pain-related anxiety", or "pain-related distress", with some participants noting that the latter term was useful "because chronic pain impacts so many areas of a person's life. Distress could be related to concerns about any of the areas particularly impacted by pain." Some tried to add a positive spin, suggesting "pain coping" (4 responses). However, others asked that pain just be called pain:

> "Just call it PAIN" (Reference #1309)

> "Chronic pain - intractable pain - debilitating pain. There is no point trying to pigeon hole the wording-call it what it is = debilitating & intractable pain" (Reference #679)

> "If you need another word, what's wrong with 'pain'? Call it critical pain, constant pain, chronic pain or bad pain" (Reference #738)

One respondent suggested to flip the concept to 1 that *actually* reflects the realities of those living with chronic pain:

> It needs to be emphasised that this vigilance is a NORMAL HUMAN REACTION. I like vigilance as long as it isn't hypervigilance as while that is descriptive that's another term that is becoming pejorative. (Participant #49)

Opposition to the Concept of Pain Catastrophizing and Creation of a New Term

Given the many perceived consequences of the term pain catastrophizing, 154 respondents questioned the reason for the current term in their responses, articulating their belief that it is demeaning to those living with chronic pain:

> If you are only looking for a more palatable term for the same condescending mind set, what is the point? Do you think we will be less offended when you treat us the same as before but use new nomenclature? The attitude needs to change. The patient needs to be believed. Fear of pain and actual pain are completely different things and should never be lumped together (Participant #644).

Some of the responses on the need for the existing term centered on how pain catastrophizing is a "normal" response to chronic pain:

> "How about not labeling it as a medical problem? It may be a normal reaction to an abnormal situation rather than a pathology. If a patient has untreated pain that is the primary source of disability, maybe we shouldn't see that as a pathology of the patient but as a failure in treatment." (Participant #1206)

> "'Chronic pain' - Worrying about future pain or consequences of your future pain when you live with a lifelong disease that causes unrelenting pain is NORMAL. There's no need to medicalize someone's pain experience or turn it into a diagnosable psychological disorder" (Participant #1774)

Others questioned why a new term would even be necessary, as it reinforces that what is only a theoretical concept actually corresponds to a reality or fact. As respondents below sum it up, there are no useful terms to describe experiences and expressions of chronic pain:

> "There doesn't need to be a term for this at all. It's normal for people to have worries related to pain they might experience. For patients with chronic pain, this 'fear' is based on real life experience. It's not an imaginary construct. Patients who have much experience with chronic pain and what it's like when it is untreated or not treated adequately 'anticipate' what may be coming, and rightly so" (Participant #2106)

> "There doesn't need to be a term because it is inappropriate for people to attempt to assess and control other people's experience and expressions regarding their pain". (Participant #521)

> "This term does NOT need to be replaced, but abolished in its entirety. It drips with smug ableism, and is demeaning to the patient suffering ongoing physical agony. Physical pain is NOT a 'mental disorder,' and the continued efforts to link mental health disorders and physical pain/disability MUST STOP. The physical torture that patients go through daily, cannot be overstated. And access to ethical pain relief has NEVER been so abysmal. Start treating physical pain ETHICALLY and EFFECTIVELY again, and I guarantee you will see a whole lot less 'distress' in patients". (Participant #527)

> "Pain is such an individualized response. Why do we need a new term? Why do we need any terms? Why not listen with empathy? Chronic pain patients are already demonized." (Participant #328)

Suggested Alternative Actions/Efforts

As an alternative, a small number of respondents (n = 324) suggested that there needs to be more empathic and ethical responses to patients who suffer with chronic pain—as evidenced through 10 direct references in coded responses—which shifts the focus from individual psychological states of patients to inadequate systems of care. They point out the need for "patient centered care", for patients to be believed, and for increased empathy on the part of clinicians:

> "I think it's horrible that people are being labeled at all. Pain is a very subjective experience from person to person and variable even within the life and days of the person experiencing it. Return patient centered care to the practice of medicine and the practice of medicine in regard to pain especially. We are dying while you all sit in offices trying to find more palatable labels to put on people suffering". (Participant #286)

> "Pain patients must be believed. Pain patients must be given adequate treatment. Pain patients must be the ones to define what is adequate. The patient is in charge; healthcare providers are support staff hired to facilitate and provide the access denied them by unjust regulations". (Participant #521)

Other suggestions centered on updating medical education in relation to trauma and violence informed care, specifically in relation to stigma:

> "Educate healthcare professionals and law enforcement to minimize the stigma associated with an already-traumatized and vulnerable patient group" (Participant #37)

> "My fear is whatever is adopted the stigma is just transferred to that term. Education of medical

> profession on stigma and trauma is needed" (Participant #274)

Lastly, calls for better treatments was emphasized:

> "Pain patients don't need anymore labels. They need actual evidence based treatments and medications that work which there really are not many other than opioids". (Participant #404)

> "Treat pain adequately." (Reference #604)

> "There needs to be research and development of medications that really help with physical pain and the changes that it produces in one's brain chemistry AND The role of opioids in treatment of chronic pain needs to be completely reassessed." (Reference #1635)

> "My best advice: spend real, actual time with someone with chronic pain, learn about the small things they struggle with, their fight to be normal, the things/people they've lost in their lives. Empathy is everything!" (Reference #283)

Discussion

Following public calls for the development and use of patient-centered language in pain research and treatment, we aimed to investigate broad patient experience of exposure to the term pain catastrophizing, patient perspectives about the term, and suggestions for potential acceptable alternate terms. Findings from our anonymous, cross-sectional international survey of 2,911 adult patients revealed that 45% had heard of the term pain catastrophizing prior to this survey. One-third provided an unprompted report of either having negative experiences or perceiving the term 'pain catastrophizing' to be problematic while about 2/3 of the sample did not spontaneously report negative experiences or responses to the term. Our findings document negative impacts of the term pain catastrophizing in clinical care and public use. Our results also point to the need for broader discussion about use of the term pain catastrophizing in the scientific literature[23] and in the media.

Our analysis highlights several key issues with pain catastrophizing from the patient standpoint. For many survey respondents, the term pain catastrophizing confers stigma and suggests to them that their pain is exaggerated, that their experiences are not believed, and that the problem is not their physical pain but rather their response to it. This finding builds on work by Amtmann and colleagues. Their patient-centered research documented patient concerns that the term pain catastrophizing and catastrophizing scales might give some clinicians a license to blame the patient when the clinician is unable to help the patient manage their pain.[2] Indeed, most respondents were not as concerned with the label per se but rather the impact they felt it had on their experiences with clinicians. Many patients pointed to further concern about labels of 'pain exaggeration' being gendered and noted the association of the term with 'hysteria'. Moreover, many patients linked the meaning of pain catastrophizing with a lack of clinician empathy and care. Some patients critically questioned the reason for the term and any replacement term, believing that any new name will be misapplied and continue to carry associated stigma and judgment. However, there was some variability among patients in their views of the term. Although about one-third of respondents found it to be negative or stigmatizing, a minority (6%) were accepting or supportive of the term and believed it encapsulated their experience.

Historically, pain catastrophizing was conceptualized as a dispositional trait, thus potentially and inadvertently casting blame and stigma on some patients.[19] Recent pain treatment research has countered the dispositional conceptualization with findings suggesting the construct is highly malleable, with individual longitudinal variability occurring even outside of treatment contexts.[7,38] However, our survey results indicate that many patients find the term stigmatizing despite the evolution in clinical science.

Our coded data for consequences of the term on patient experiences revealed that about one-third of the sample perceived the term pain catastrophizing to be problematic, thus echoing Amtmann et al.'s[2] specific study of pain catastrophizing wherein patients described the term as being stigmatizing and pejorative. We underscore that one-third of the sample provided unprompted negative experiences and perceptions (ie, responses to an open-ended question that did not specifically ask about negative or positive experience), whereas for two-thirds of the sample there was an absence of a response (either positive or negative). Possibly, perceptions of stigma are greater for women, and as noted in the thematic analysis, the term may invoke gender stereotypes about women seeking healthcare; eg, the 'hysterical woman' who is exaggerating her medical symptoms and suffering.[43] Finally, in the broader context many patients face stigma regarding having chronic pain and being "difficult", a view documented by medical learners[28,40] and physicians.[41,42] Stigma or mistrust of patients by clinicians[4,8,12,39] may occur when diagnosis is elusive or when treatment is ineffective. An important yet overlooked context is that some patients, especially those from marginalized groups, may have limited treatment options and compounding stressors related to their conditions and their care. While learning more adaptive coping strategies may be important for all patients, in the absence of validation of contextual factors (eg, limited medical treatment options), an isolated focus on coping may be unhelpful and even harmful for some patients.

Taken together, our results point to the need for further study. As a scientific construct with 3 decades of scientific findings behind it, the *construct* is unlikely to be abolished. Nonetheless, application of the term and existing measures may be problematic. For example, results from a small study by Crombez et al[6] suggested that the current self-report questionnaires of pain catastrophizing may not distinctively assess pain catastrophizing and instead capture pain-related worrying and pain-related distress. We also highlight that researchers such as Amtmann et al.[2] have successfully bridged a critical gap by conducting patient-centered research. Based on patient recommendations, they named their new measure the Concerns About Pain Scale. With this measure, important scientific research may continue with terminology that patients find respectful, thus allowing for the identification of patients who could benefit from being aware of how they think about their pain. While an important first step, patient-centered titling of instruments alone does not address an underlying need for broad-scale change in the use of potentially stigmatizing language in patient-clinician communications, public stories, and the media. Indeed, the contribution of clinician communication strategies to patient experience should be explored further. If indicated, clinician interventions might include education on patient-centered communication strategies that are empathic, validating, non-judgmental, reflective of the descriptive language patients use, and compassionate—ingredients that may be crucial to minimizing patient stigma and enhancing the therapeutic alliance.

Strengths and Limitations

We first discuss strengths and weaknesses of the study in terms of the sample. Our sample was predominantly women with many years of chronic pain. While we received responses from individuals residing in 47 countries, the vast majority of surveys were from female residents of Western countries and thus our results are reflective of female patient perspectives in those countries and may not generalize more broadly. The survey was constrained to adults with internet access and English or Spanish proficiency. Finally, while the study information may have been shared with patients by some clinicians, this was not a treatment-seeking sample.

There are strengths and limitations to online surveys. They allow for greater efficiency, reach and reduced costs with regard to data collection,[3,14,18] and potentially better response rates.[13] However, the degree of selective participation may result in biases.[14] Furthermore, respondents may provide fraudulent responses[18] which can impact generalizability.[3] We lacked details about the individual context for the responses (age, socio-economic status, gender, etc.), so we cannot elaborate on how such factors may influence the chronic pain experience and/or understandings of pain catastrophizing.

In terms of limitations regarding the study and survey designs, the name of the study and the survey language could have influenced participant responses with a bias toward more negative response; the study website was called "renamepc.stanford.edu" and the introductory language acknowledged we sought to understand whether a replacement term was needed. We also note that the design of the survey only allowed respondents to answer pre-determined questions.

Despite these limitations, our study results may guide important future research questions. Compelling responses of the survey suggest the need for further qualitative research on the issue of pain catastrophizing from the perspective of patients (and caregiver proxies). Specifically, future research could seek to uncover barriers to treatment and also ask about the impact of perceived gendered stereotypes on patient help-seeking. Future research approaches might also incorporate qualitative methodology to ascertain nuances and contextual issues, including patients' prior care experiences.

Major strengths of this study include multi-stakeholder collaborator engagement including 12 patient stakeholders from 4 countries, 38 scientific collaborators from 9 countries, 7 national patient organizations, and 2 international patient advocacy organizations. To our knowledge, this report represents the broadest examination of perceptions about the term pain catastrophizing among people with pain worldwide.

Having highlighted the patient perspective of the term pain catastrophizing, its material effect on clinical experiences, and associations with negative gender stereotypes, we conclude that patient-centered terminology may be the first step toward more informed understandings of the social contexts of chronic pain in pain care and research.

Author Contributions

BD was the overall project lead for the primary study. FW designed the qualitative analysis, provided training to graduate assistants, and led the coding, thematic analysis of the subset of data and drafting of the manuscript. MZ participated in the study development, implementation, and manuscript revisions. LC and RL assisted with coding, thematic analysis and writing. DY participated in data analysis and provided input into the coding framework. All co-authors participated in survey distribution and manuscript editing, and approved the final manuscript. Patient collaborators and a subset of scientific collaborators participated in the design of the surveys.

Disclosures

Dr. Darnall is Chief Science Advisor at AppliedVR, and her consulting role with this company (personal fees) is unrelated to the current research. Dr. Darnall receives royalties for 4 pain treatment books she has authored or coauthored. She is the principal investigator for 2 pain research awards from the Patient-Centered Outcomes Research Institute. Dr. Darnall is principal investigator for 2 NIH grants. Dr. Darnall serves on the Board of Directors for the American Academy of Pain Medicine, is on the Board of Directors for the Institute for Brain Potential, and is on the Medical Advisory Board for the Facial Pain Association. Dr. Darnall is a scientific member of the NIH Interagency Pain Research Coordinating Committee, a former member of the Centers for Disease Control and Prevention Opioid Workgroup (2020–2021), and a current member of the Pain Advisory Group of the American Psychological Association.

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Supplementary data

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