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PII: S1526-5900(22)00418-7
DOI: <https://doi.org/10.1016/j.jpain.2022.10.001>
Reference: YJPAI 4178

To appear in: *Journal of Pain*

Received date: 31 May 2022
Revised date: 3 September 2022
Accepted date: 4 October 2022

Please cite this article as: Fiona Webster , Laura Connoy , Riana Longo , Devdeep Ahuja , Dagmar Amtmann , Andrea Anderson , Claire E. Ashton-James , Hannah Boyd , Christine T. Chambers , Karon F. Cook , Penney Cowan , Geert Crombez , Amanda B. Feinstein , Anne Fuqua , Gadi Gilam , Isabel Jordan , Sean C. Mackey , Eduarda Martins , Lynn M. Martire , Peter O'Sullivan , Dawn P. Richards , Judith A. Turner , Christin Veasley , Hanne Würtzen , Su-Yin Yang , Dokyoung S. You , Maisa Ziadni , Beth D. Darnall , Patient Responses to the Term Pain Catastrophizing: Thematic Analysis of Cross-sectional International Data, *Journal of Pain* (2022), doi: <https://doi.org/10.1016/j.jpain.2022.10.001>

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Manuscript Title:

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

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Highlights:

- The term pain catastrophizing is widespread in clinical and public pain forums.
- About 3,000 patients provided their perspective on the term pain catastrophizing.
- For an open-ended item, 1/3 said the term was problematic or stigmatizing.
- There was an absence of unprompted assessment of the term for 2/3 of the sample.
- 12% reported stigmatizing experiences from the term being applied to them.

Keywords: chronic pain; patient perspective; pain catastrophizing; stigma; patient-centered; qualitative

Conflicts of Interest: The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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 four pain treatment books she has authored or coauthored. She is the principal investigator for two pain research awards from the Patient-Centered Outcomes Research Institute. Dr. Darnall is principal investigator for two 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. Dr. Mackey receives research funding from the NIH, Food and Drug Administration, and Patient-Centered Outcomes Research Institute (administered through Stanford University). He is an unpaid advisor to both ACTION (Analgesic, Anesthetic, and Addiction Clinical Trial

Translations, Innovations, Opportunities, and Networks) on their oversight committee, and the American Chronic Pain Association (ACPA) for their scientific oversight. Dr. Richards is the volunteer vice president of the Canadian Arthritis Patient Alliance, which derives some of its funding from independent arms-length grants from pharmaceutical companies.

Funding: This effort was supported in part by NIH grants from NCCIH R01AT008561 (Darnall and Mackey), NIDA K24 DA053564 (Darnall), NINDS K24 NS126781 (Mackey) and Canadian Institutes of Health Research, grant # 409316 (Webster).

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.

Perspective: Our large international patient survey results show that 45% of the sample had heard of the term pain catastrophizing, about one-third spontaneously rated the term as problematic, and 12% reported having the term applied to them with most reporting this to be a negative experience. Clinician education regarding the use of patient-centered terminology may help to improve patients' experience of care and reduce stigma.

1 1. Introduction

2 The term catastrophizing was first introduced in 1962 by Albert Ellis to describe a
3 central component in emotional dysfunction²⁴. Ellis described catastrophizing as exaggerating
4 adversities into something far worse than they actually are; seeing things at their worst when
5 they are sometimes relatively minor; and greatly exaggerating the frequency and/or danger of
6 something that you dislike²⁴. Aaron Beck later adapted the term in 1987 to describe a
7 maladaptive cognitive style in people living with anxiety and depression¹⁹. The term was first
8 introduced into the pain literature in 1987 with the advent of the Coping Skills Questionnaire
9 catastrophizing subscale (CSQ-CS)¹⁶, which includes six self-report items tapping two subscales
10 (rumination and feelings of helplessness). The CSQ-CS has been used widely in pain research
11 for 35 years. The development of the Pain Catastrophizing Scale (PCS) in 1995³⁵ spurred wider
12 measurement of pain catastrophizing in clinical and research settings. The PCS is a 13-item self-
13 report questionnaire that assesses the frequency that patients experience three elements of
14 catastrophizing within the context of pain: rumination, magnification, and helplessness³⁵. Some
15 researchers have questioned the accuracy of the measures used³⁷ and others have called for
16 revisions⁶. These early conceptualizations of catastrophizing continue to this day, in that
17 catastrophizing includes the concept of magnification of anticipated future events^{27, 36}.

18 Results from experimental and clinical research, including neuroimaging studies in
19 healthy and clinical samples, have demonstrated that pain catastrophizing is associated with
20 marked changes in the structure and function of the brain¹¹. For example, during in vivo pain
21 processing, catastrophizing was associated with increased activation of affective- and attention-
22 related brain regions³¹. Furthermore, reductions in self-reported pain catastrophizing have been
23 shown to mediate favorable changes in brain structure³². Translating these findings into clinical
24 care involves targeting such cognitive/attentional and emotional response patterns that are known
25 to impact central nervous system functioning and pain. Clinical approaches must include
26 contextual appreciation and validation of each individual's challenging medical conditions and
27 ongoing pain experience, as well as the environmental and social factors impacting their health
28 and pain. Applying a broader lens of understanding minimizes a reductive and sole focus on the
29 individual's responses to pain and promotes a comprehensive appreciation of the social,
30 psychological, and medical factors that comprise their experience²¹. For example, navigating the
31 medical system is a highly stressful experience for some individuals. Yet long absent from

32 patient reported measurement is quantification of stressors experienced from seeking healthcare.
33 Greater appreciation of the broader contextual factors may yield a more balanced understanding
34 and identify external and environmental issues requiring adjustment, keeping in mind that
35 structural issues such as poverty are unlikely to be amenable to change through treatment alone.
36 Such context could validate contributors to pain responses being measured. In turn, such
37 validation could foster increased patient receptivity to clinical recommendations around adaptive
38 pain management skills acquisition as a means to improve personal control within the context of
39 difficult circumstances²⁰.

40 While pain catastrophizing research has flourished,^{22, 33,30} with findings supporting its
41 role in chronic pain and distress^{9, 17}, some researchers have challenged current approaches. For
42 example, Crombez et al.⁶ argue for the adoption of a more person-centered approach combined
43 with a renaming of measures of pain catastrophizing to measures of pain-related worrying .
44 Chronic pain researchers have debated the suggested term pain-related worry, with critics
45 deeming it an unsuitable replacement term because pain-related worry is a consequence of pain
46 catastrophizing versus a representative of the construct per se. Advocates and people with
47 chronic pain claim the current term is stigmatizing^{15, 25}. In reflection of the stigmatization
48 experienced by patients, researchers recently validated a new scale to tap the construct of
49 catastrophizing. Based on substantial patient stakeholder feedback regarding stigma associated
50 with the term 'catastrophizing', the new scale was named the Concerns About Pain Scale¹. Such
51 efforts are geared toward making changes that reflect inclusivity of patient perspectives to assure
52 respect, reduce stigma, and increase engagement in care and response to the care received.
53 Nevertheless, some patients continue to question whether changing the name would change the
54 negative underlying assumptions of the concept itself¹.

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

62 perspectives about the term; (3) understand patient perspectives about whether an alternate term
63 is needed.

64 While future manuscripts will describe the clinician survey responses, the current
65 manuscript presents analysis of the Patient/Caregiver Proxy survey data. We note that whereas
66 some have argued against the use of the term patient²⁹, our patient collaborators and
67 stakeholders supported the use of the term patient for the current project.

68

69 **2. Methods**

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

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

83

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

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

95

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

98 The demographic and qualitative items of the patient/caregiver survey are displayed
99 below and in Appendix 1; the parenthetical red text is provided for explanatory purposes and was
100 not part of the survey. Individuals under 18 years of age and those who did not have current,
101 ongoing, or past chronic pain were excluded from enrolling as patients, though individuals over
102 18 with no history of chronic pain were eligible to enroll as a caregiver proxy (meaning they
103 were asked to complete the survey on behalf of the person with pain) if they self-identified as
104 having experience as a caregiver for an individual with chronic pain. Appendix 1 displays the
105 survey items in full. Following completion of five demographic items (presence of ongoing pain
106 (yes/no); age; gender; country of residence; duration of pain), participants were asked four items
107 specific to their exposure to the term pain catastrophizing. Note that with branching logic applied
108 as described below, this initial section assessed prior exposure to the term, and experiences and
109 perceptions therein (to minimize bias participants were asked these items prior to being provided
110 with the definition of pain catastrophizing): (1) *Have you heard of the term ‘pain*
111 *catastrophizing?’* (if yes, branching logic to the next question); (2) *Where did you first hear the*
112 *term ‘pain catastrophizing?’*; (3) *Has a healthcare provider ever described you as being a ‘pain*
113 *catastrophizer’ or said that you were ‘catastrophizing’ your pain, or used the term to discuss*
114 *your pain care?* (if yes, branching logic to the next question); (4) *If you answered yes to the*
115 *previous question, thinking back to when this term may have been applied to you, please circle*
116 *the number that best describes your level of agreement/disagreement with the following*
117 *statements.* Respondents used a Likert scale (1= strongly disagree or strongly disapprove; 7=
118 strongly agree or strongly approve) to rate seven items regarding their experiences and opinions
119 of the term.

120
121 Next, the following definition of pain catastrophizing was displayed to the survey respondents.

122 Pain catastrophizing refers to how we respond to pain we have right now, or to pain we
123 expect to have in the future. It includes thoughts we may have about pain (e.g., "I can't
124 stop thinking about how much it hurts"), feelings about pain (such as helplessness) and
125 expectations for future pain (e.g., "I worry that my pain will only get worse"). This term
126 is used in two different ways: 1) To describe a temporary state of distress about pain e.g.,
127 when anticipating pain you may experience from a scheduled procedure, when receiving
128 a new diagnosis, when experiencing new symptoms or severity of symptoms, or
129 secondary to a medical procedure or injury; 2) To describe a pattern of thinking, feeling,
130 and reacting to pain over a longer period of time. While the degree of pain
131 catastrophizing and level of pain intensity we experience are related, research shows that

132 they are different. We can control for pain intensity in research studies (by keeping it
133 constant) and see that pain catastrophizing — our level of pain-specific distress —
134 changes how pain is processed in the central nervous system.

135
136 Participants were asked three open-ended items: (1) What comes to mind when you hear
137 the term pain catastrophizing? (2) What would be a better term for pain catastrophizing? (3) Is
138 there anything else you would like to tell us about the topic? Participants also rated eight
139 candidate terms that might serve as alternate terminology to describe pain catastrophizing (see
140 Appendix 1); these candidate terms were generated by a subset of scientific and patient project
141 collaborators.

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

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

160 **Data Analysis**

161 Our analysis included both statistical and qualitative methods. Demographic items were
162 summarized as frequencies. Responses to Likert scale items were reported as means and standard
163 deviations. Responses to the three open-ended questions were analyzed using qualitative
164 thematic data analysis as described by Braun and Clarke⁵ in the context of our methodology,
165 qualitative description. Although thematic analysis requires a qualitative design from the start
166 and on its own does not constitute qualitative research, it is recognized as a useful method to
167 interpret open-ended survey data and to identify important patterns within the data⁵.
168 Additionally, thematic analysis supports the presentation of credible clinical and theoretically
169 relevant conclusions. A coding framework was developed inductively using an iterative and
170 collaborative approach by FW, BD and MZ. Codes are used to systematically categorize the data
171 based on shared characteristics and to eventually identify significant patterns. First, a subset of
172 20 responses per coder was selected and read independently by FW to create preliminary data-
173 driven codes. The preliminary codes were then compared by FW and BD to arrive at an agreed
174 upon coding framework. Collaborative coding supports the practice of reflexivity by allowing
175 each researcher to bring their own perspective to the data and examine their own assumptions¹⁰,
176 ³⁴. Once the coding framework was finalized, the codes were applied to the data by four student
177 coders (ET, HB, MW, TAL) working with BD. Themes were identified from the codes and
178 aimed to represent patterns and meaning within the data set⁵. NVivo software was used to
179 organize and manage the data²⁶.

180 **3. Results**

181 **Study Participants**

182 A total of 3,521 participants, who self-identified as patients or family members, began the
183 survey, and 2,911 (82.7%) completed it. Responses were received from individuals residing in
184 47 countries. Participants were predominantly from the United States (77.3%), followed by
185 Canada (7.6%), Australia (4.1%), the United Kingdom (3.6%), and the Netherlands (1.6%), in
186 addition to other countries listed in Table 1. Study participants (Table 2) were predominantly
187 female (82.1%), with an average age of 41.62 years. Ninety-five percent of the sample reported
188 having ongoing pain, with pain duration exceeding 10 years (68.4%).

189 Fewer than half of the respondents (44.5%; n=1,295) had heard of the term pain
190 catastrophizing. Twelve percent of the sample (n=349) reported the experience of having a
191 healthcare provider describe them as a ‘catastrophizer’; no response was received for 55% of

192 respondents for this particular item. Those who endorsed having been labeled as a pain
 193 catastrophizer' reported high levels of feeling blamed (M=5.95, SD= 1.64), judged (M=6.30,
 194 SD=1.41), and dismissed (M= 6.17, SD=1.60).

195 The coding framework we developed went beyond the three specific open-ended
 196 questions. Responses were organized into five interrelated themes: 1) What the term pain
 197 catastrophizing' means to patients; 2) consequences of the term on patient experiences; 3)
 198 association of the term with negative gender stereotypes; 4) suggestions for new term; 5) patients
 199 objecting to new term due to opposition or criticism of the *construct* itself (sub-theme suggested
 200 alternatives to finding new term). Many patients also shared their stories, some of which we have
 201 included here in our results.

202 **Emerging Themes**

203 **3.1 What does the term 'pain catastrophizing' mean to patients?**

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

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

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

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

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

226 I would use this term to describe the way a person with chronic pain can sometimes feel
 227 helpless to fight or treat their pain, and habitual fear, dread, and emotional and physical
 228 exhaustion can not only contribute to future suffering but intensify the degree of that
 229 suffering. I don't think I do this, but I understand it completely. (Participant #300)

230
 231 Other respondents accepted the term for the most part but also emphasized that, for them,
 232 the definition was not fully accurate or supportive of their experience.

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

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

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

248 **3.2 Consequences of the term on patient experiences**

249 Patients who reported that they were labelled as 'pain catastrophizers' often viewed the
 250 term pain catastrophizing through the lens of how it affected their care. 935 participants provided
 251 an open-ended response addressing this issue. For example, some patients perceived that the
 252 label was taken up in ways that positioned them as lying (referenced 16 times), minimizing their
 253 concerns (referenced 44 times), placing blame upon them (referenced 108 times), and as
 254 dismissing their concerns (referenced 138 times). Patients referred to feeling judged (referenced
 255 61 times), ignored (referenced 37 times), and belittled (referenced 27 times) as they felt the
 256 clinician believed that their pain was not real, and instead 'all in their head'. For some (n=7),
 257 this was even experienced as a 'weapon' used by clinicians against them:

258 It is insulting to patients who have no way to control their pain - especially in the
 259 context of unexplained diseases, catastrophizing is used to portray patients as
 260 'hysterical' 'attention seeking' or causing distress for themselves. It is accusatory
 261 and it is used as a weapon to blame patients for not getting better (Participant
 262 #997)

263

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

267
 268 I find it very victim blamey to use pain catastrophizing, and that it is often weaponized
 269 against disabled people, especially those who don't have a clear medical explanation for
 270 their pain. (Participant #1028)

271
 272 Below we include representative quotes that illustrate various patient perspectives. For instance,
 273 one respondent also spoke of how the term is part of medical terminology and can lead to
 274 feelings of confusion and isolation. This person recognized that the negative impacts of the term
 275 was not intentional but nevertheless it made them feel more categorized than humanized :

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

282
 283 In addition, several respondents referred to how the term minimized their pain or otherwise
 284 created a sense they could bring it under control if they tried harder. As the following response
 285 summarizes, the term implies that the patient could lessen their pain if they'd only try hard
 286 enough not to think about it .

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

295
 296 Others referred to how the use of this label led to them perceiving a lack of compassion on the
 297 part of the health care provider. The respondent below associates the term with victim
 298 blaming , negative judgment and arrogance on behalf of providers and a refusal to
 299 acknowledge the lack of pain management strategies currently available:

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

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

307
 308 Another common response pertained to stigma associated with mental illness and suggests that
 309 this characterization becomes an excuse to stigmatize patients who experience pain and refuse
 310 treatment:

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

314

315 **3.3 Association of the term with negative gender stereotypes**

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

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

326

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

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

338

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

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

350
 351 As an example of a broader perspective, one respondent explicitly applies a gender lens
 352 to describe this experience, noting how women have traditionally been viewed as more
 353 emotional and less rational . She suggests that this could then be used to blame the
 354 patient for their pain :

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

364 3.4 Suggestions for new term

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

371 Just call it PAIN (Reference #1309)

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

375
 376 If you need another word, what’s wrong with ‘pain’? Call it critical pain, constant
 377 pain, chronic pain or bad pain (Reference #738)

378
 379 One respondent suggested to flip the concept to one that *actually* reflects the realities of
 380 those living with chronic pain:

381 It needs to be emphasised that this vigilance is a NORMAL HUMAN REACTION. I like
 382 vigilance as long as it isn't hypervigilance as while that is descriptive that's another term
 383 that is becoming pejorative. (Participant #49)
 384

385 **3.5 Opposition to the *concept of pain catastrophizing* and creation of a new term**

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

389 If you are only looking for a more palatable term for the same condescending
 390 mind set, what is the point? Do you think we will be less offended when you treat
 391 us the same as before but use new nomenclature? The attitude needs to change.
 392 The patient needs to be believed. Fear of pain and actual pain are completely
 393 different things and should never be lumped together (Participant #644).
 394

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

397 How about not labeling it as a medical problem? It may be a normal reaction to
 398 an abnormal situation rather than a pathology. If a patient has untreated pain that
 399 is the primary source of disability, maybe we shouldn't see that as a pathology of
 400 the patient but as a failure in treatment. (Participant #1206)
 401

402 Chronic pain' - Worrying about future pain or consequences of your future pain
 403 when you live with a lifelong disease that causes unrelenting pain is NORMAL.
 404 There's no need to medicalize someone's pain experience or turn it into a
 405 diagnosable psychological disorder (Participant #1774)
 406

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

411 There doesn't need to be a term for this at all. It's normal for people to have
 412 worries related to pain they might experience. For patients with chronic pain, this
 413 fear' is based on real life experience. It's not an imaginary construct. Patients
 414 who have much experience with chronic pain and what it's like when it is
 415 untreated or not treated adequately 'anticipate' what may be coming, and rightly
 416 so (Participant #2106)
 417

418 There doesn't need to be a term because it is inappropriate for people to attempt
 419 to assess and control other people's experience and expressions regarding their
 420 pain . (Participant #521)
 421

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

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

435 3.5.1 Suggested alternative actions/efforts

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

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

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

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

456 Educate healthcare professionals and law enforcement to minimize the stigma
 457 associated with an already-traumatized and vulnerable patient group (Participant
 458 #37)

460 My fear is whatever is adopted the stigma is just transferred to that term.
 461 Education of medical profession on stigma and trauma is needed (Participant
 462 #274)

464
465 Lastly, calls for better treatments was emphasized:

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

469 Treat pain adequately. (Reference #604)

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

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

479

480 **4. Discussion**

481 Following public calls for the development and use of patient-centered language in pain
482 research and treatment, we aimed to investigate broad patient experience of exposure to the term
483 pain catastrophizing, patient perspectives about the term, and suggestions for potential
484 acceptable alternate terms. Findings from our anonymous, cross-sectional international survey of
485 2,911 adult patients revealed that 45% had heard of the term pain catastrophizing prior to this
486 survey. One-third provided an unprompted report of either having negative experiences or
487 perceiving the term 'pain catastrophizing' to be problematic while about 2/3 of the sample did
488 not spontaneously report negative experiences or responses to the term. Our findings document
489 negative impacts of the term pain catastrophizing in clinical care and public use. Our results also
490 point to the need for broader discussion about use of the term pain catastrophizing in the
491 scientific literature²³ and in the media.

492 Our analysis highlights several key issues with pain catastrophizing from the patient
493 standpoint. For many survey respondents, the term pain catastrophizing confers stigma and
494 suggests to them that their pain is exaggerated, that their experiences are not believed, and that
495 the problem is not their physical pain but rather their response to it. This finding builds on work
496 by Amtmann and colleagues. Their patient-centered research documented patient concerns that
497 the term pain catastrophizing and catastrophizing scales might give some clinicians a license to
498 blame the patient when the clinician is unable to help the patient manage their pain². Indeed,

499 most respondents were not as concerned with the label per se but rather the impact they felt it
500 had on their experiences with clinicians. Many patients pointed to further concern about labels of
501 pain exaggeration‘ being gendered and noted the association of the term with hysteria‘.
502 Moreover, many patients linked the meaning of pain catastrophizing with a lack of clinician
503 empathy and care. Some patients critically questioned the reason for the term and any
504 replacement term, believing that any new name will be misapplied and continue to carry
505 associated stigma and judgment. However, there was some variability among patients in their
506 views of the term. Although about one-third of respondents found it to be negative or
507 stigmatizing, a minority (6%) were accepting or supportive of the term and believed it
508 encapsulated their experience.

509 Historically, pain catastrophizing was conceptualized as a dispositional trait, thus
510 potentially and inadvertently casting blame and stigma on some patients¹⁹. Recent pain treatment
511 research has countered the dispositional conceptualization with findings suggesting the construct
512 is highly malleable, with individual longitudinal variability occurring even outside of treatment
513 contexts^{7, 38}. However, our survey results indicate that many patients find the term stigmatizing
514 despite the evolution in clinical science.

515 Our coded data for consequences of the term on patient experiences revealed that about
516 one-third of the sample perceived the term pain catastrophizing to be problematic, thus echoing
517 Amtmann et al.‘s² specific study of pain catastrophizing wherein patients described the term as
518 being stigmatizing and pejorative. We underscore that one-third of the sample provided
519 unprompted negative experiences and perceptions (i.e., responses to an open-ended question that
520 did not specifically ask about negative or positive experience), whereas for two-thirds of the
521 sample there was an absence of a response (either positive or negative). Possibly, perceptions of
522 stigma are greater for women, and as noted in the thematic analysis, the term may invoke gender
523 stereotypes about women seeking healthcare; e.g., the hysterical woman‘ who is exaggerating
524 her medical symptoms and suffering⁴³. Finally, in the broader context many patients face stigma
525 regarding having chronic pain and being difficult , a view documented by medical learners^{28, 40}
526 and physicians^{41, 42}. Stigma or mistrust of patients by clinicians^{4, 8, 12, 39} may occur when
527 diagnosis is elusive or when treatment is ineffective. An important yet overlooked context is that
528 some patients, especially those from marginalized groups, may have limited treatment options
529 and compounding stressors related to their conditions and their care. While learning more

530 adaptive coping strategies may be important for all patients, in the absence of validation of
531 contextual factors (e.g., limited medical treatment options), an isolated focus on coping may be
532 unhelpful and even harmful for some patients.

533 Taken together, our results point to the need for further study. As a scientific construct
534 with three decades of scientific findings behind it, the *construct* is unlikely to be abolished.
535 Nonetheless, application of the term and existing measures may be problematic. For example,
536 results from a small study by Crombez et al⁶ suggested that the current self-report questionnaires
537 of pain catastrophizing may not distinctively assess pain catastrophizing and instead capture
538 pain-related worrying and pain-related distress. We also highlight that researchers such as
539 Amtmann et al.² have successfully bridged a critical gap by conducting patient-centered research.
540 Based on patient recommendations, they named their new measure the Concerns About Pain
541 Scale. With this measure, important scientific research may continue with terminology that
542 patients find respectful, thus allowing for the identification of patients who could benefit from
543 being aware of how they think about their pain. While an important first step, patient-centered
544 titling of instruments alone does not address an underlying need for broad-scale change in the
545 use of potentially stigmatizing language in patient-clinician communications, public stories, and
546 the media. Indeed, the contribution of clinician communication strategies to patient experience
547 should be explored further. If indicated, clinician interventions might include education on
548 patient-centered communication strategies that are empathic, validating, non-judgmental,
549 reflective of the descriptive language patients use, and compassionate—ingredients that may be
550 crucial to minimizing patient stigma and enhancing the therapeutic alliance.

551 **4.1 Strengths and Limitations**

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

560 There are strengths and limitations to online surveys. They allow for greater efficiency,
561 reach and reduced costs with regard to data collection^{3, 14, 18}, and potentially better response
562 rates¹³. However, the degree of selective participation may result in biases¹⁴. Furthermore,
563 respondents may provide fraudulent responses¹⁸ which can impact generalizability³. We lacked
564 details about the individual context for the responses (age, socio-economic status, gender, etc.),
565 so we cannot elaborate on how such factors may influence the chronic pain experience and/or
566 understandings of pain catastrophizing.

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

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

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

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

589

590 **Author Contributions**

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

599

600 **Acknowledgements**

601 We would like to acknowledge the graduate students who assisted in a first round of coding: ET,
602 HB, MW, TAL, and Ashley Gomez for her administrative support. We thank the 3,521 survey
603 respondents who provided us with their experiences, opinions, and insights.

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729

730 Table 1. Countries represented in the study

731

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)

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

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

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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)
Sex		N(%)
	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)

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