

The words patients use to describe chronic pain: Implications for measuring pain quality



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ABSTRACT

Patients with low back pain (LBP; N = 102), fibromyalgia (FM; N = 100), and headache (HA; N = 100) were asked to describe their pain in their own words, and the words and phrases they used were then classified into 7 global domains (eg, Pain Quality, Pain Magnitude) and as many specific subdomains as needed to capture all of the ideas expressed (eg, under Pain Quality, subdomains such as sharp, achy, and throbbing). Fifteen pain quality subdomains were identified as most common. Nine of these demonstrated significant between-group differences in frequency. For example, patients with FM described their pain as achy more often than patients with LBP or HA; patients with HA described their pain as more throbbing than patients with LBP or FM; and patients with LBP described their pain as more shooting than patients with FM or HA. With the 15 pain quality subdomains representing the universe of most important pain qualities to assess, only 2 of 8 descriptive measures of pain quality were determined to have content validity. The findings are generally consistent with a study that used similar procedures in other patient samples to identify the most common words patients use to describe pain, supporting their generalizability. The findings also support the use of pain quality measures for discriminating between chronic pain conditions. Finally, the findings have important implications for evaluating and modifying pain quality measures as needed.

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1. Introduction

Chronic pain is a significant problem that has profound negative effects on individuals and society [12,24,29,30]. The need for effective pain treatments remains as critical as ever. Valid and reliable pain assessment is a necessary prerequisite to this effort. Although pain intensity is the most common pain domain assessed in research and clinical practice [20], pain intensity measures are sub-optimal for distinguishing the effects of 2 active treatments (eg, [17,25,26,28]). On the other hand, measures of pain quality (assessing domains such as burning pain) are able to identify differences in the effects of different pain treatments, especially when those treatments operate via different pathophysiologic mechanisms [10,14]. To the extent that different pain qualities reflect underlying mechanisms, pain quality measures may also be useful for predicting response to treatment, thereby allowing one to

select a therapy for an individual patient in a manner that maximizes benefit/risk [11].

To ensure that a measure of pain quality is most useful, it should assess all of the pain qualities most commonly experienced by individuals with chronic pain; that is, it should have content validity [1]. Unfortunately the majority of existing pain quality measures were developed primarily or only based on expert opinion [19]. As a result, existing measures may or may not contain the most important or common descriptors used by patients themselves. The extent to which the pain quality domains assessed by these measures are consistent with how patients actually describe their pain has been examined only on a limited basis. To address this knowledge gap, we recently examined the content validity of pain quality measures by determining how well they assess qualities spontaneously used by 2 samples of patients with pain associated with spinal cord injury and multiple sclerosis [19]. We found that only 1 measure, the Pain Quality Assessment Scale (PQAS) [13,15], assessed all 14 pain quality domains mentioned by the study participants. However, an important limitation of that study was that it studied patients who had 1 of only 2 diagnoses (spinal cord injury or multiple sclerosis, both of which contain mostly patients with neuropathic pain). It is likely that other

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chronic pain populations, in particular, patients with nonneuropathic pain, experience and describe their pain differently.

To more fully evaluate the content validity of existing pain quality measures, we sought to extend the findings from our previous study by using patients with other more common chronic pain diagnoses; specifically in this case, patients with chronic low back pain (LBP), fibromyalgia, and headache. The study objectives were (1) to identify the most common pain quality domains used by individuals with these pain conditions, and then (2) to evaluate existing pain quality measures with respect to the domains that these words represent. Because we elicited, recorded, and categorized every descriptor spontaneously mentioned by the participants when they were asked to describe their pain, we also sought to use the findings to describe the relative frequency of pain domains other than just pain quality.

2. Methods

2.1. Participants

Participants were recruited from a pool of patients who had received treatment at the University of Washington Medical Center (UWMC) and who carried a diagnosis of LBP, fibromyalgia (FM), or headache (HA) per UWMC records. A total of 3331 patients who met these initial screening criteria were sent an approach packet via U.S. mail that explained the study and provided study contact information. A total of 421 approach packets (12.6%) were returned to research staff as undeliverable. In addition, research staff were informed that 5 of the patients (0.2%) were deceased. A total of 2511 patients (75.4%) never responded to the letter. Three hundred ninety-four patients (11.9%) contacted research staff after receipt of the approach letter. Of these 394 patients, research staff were unable to reach a total of 27 patients either because the patient did not return multiple telephone calls from research staff, or the patient did not provide a telephone number in the initial message that she or he left, or the number the patient provided was wrong or disconnected. Two patients contacted research staff after the end of enrollment and therefore were not screened to determine eligibility. Research staff were able to correspond with 365 patients (11.0% of 3331 patients) to determine whether the patient was both interested in participating and eligible to participate. Inclusion criteria were: (1) reported English as their first and primary language; (2) reported to be at least 18 years of age; (3) carried a diagnosis of LBP, FM, or HA per UWMC records; (4) carried only 1 of the 3 diagnoses (except for FM, as headache and low back pain are common in individuals with FM [16]) per UWMC records; (5) reported that the pain related to the diagnosis was still bothersome; (6) reported experiencing bothersome pain associated with the diagnosis in the past 3 months; and (7) reported the worst pain intensity associated with the pain diagnosis in the past week as a 3 or more on a numeric rating scale of 0 to 10. Of the 365 patients research staff were able to correspond with, 49 patients (13.4%) were deemed ineligible to participate, and 9 patients (2.5%) declined to participate before, during, or after the screening process. A total of 307 patients (84.1% of the patients research staff were able to correspond with, or 9.2% of 3331 patients approached) were deemed eligible and maintained their interest in participating after discussing the study procedures with a research staff member.

These 307 patients provided oral consent and were enrolled in the study. One of these participants could not be reached to complete the interview after enrollment, and 4 subjects were withdrawn or terminated participation before completing the interview (1 participant was withdrawn because she or he admitted to “making up” some of the answers, 1 participant was withdrawn after she or he conceded after enrollment that his or her

worst pain intensity in the past week was in fact 0 on a scale of 0 to 10, 1 participant terminated participation because she or he reported not understanding the interview questions, and 1 participant terminated participation because she or he “did not like” the questions). Thus, 302 participants (98% of those who provided consent) completed the telephone interview and provided analyzable data. They were paid \$15 for completing the interview. All study procedures were approved by the University of Washington Institutional Review Board.

2.2. Procedures

During the telephone interview, participants were first asked to describe the pain related to their diagnosis by answering the following question: “Please describe your LBP/FM pain/HA pain in as much detail as possible. What words would you use to describe how this pain feels to you? Please describe only your LBP/FM pain/HA pain and not any other pain problems you may experience.” After responding to the first question, participants were then asked the following question: “You described your pain as [participant’s response]. Are there any other words that describe how your pain feels to you?” The first question was asked to elicit descriptors, and the second follow-up question was asked to ensure that we had a complete response from each participant; that is, to maximize the number of adjectives that the participants themselves use to describe their pain, without suggesting any to them. Interviewers wrote down the participant responses to both questions verbatim.

Participants were then asked to rate the average pain intensity of their LBP/FM pain/HA pain in the past week on a numerical rating scale of 0 to 10. Participants were also administered an interview version of the Pain Quality Assessment Scale (PQAS-R) [15], and asked to respond to the PQAS-R items over the telephone. The PQAS-R items were administered last, after the pain descriptors were elicited from the participants. However, the PQAS-R data are not needed to address the questions of this study, and are therefore not presented here. Finally, participants provided basic demographic information (sex, age, race/ethnicity) and information related to their pain diagnosis (duration in years, and for those with headache, type of headache [participants were allowed to select more than 1 type of headache if they had more than 1 headache diagnosis]).

2.3. Pain descriptor coding

Once data collection was complete, the words and phrases participants used to describe their pain were listed and then reviewed by 2 study investigators (M.P.J., L.E.J.). A classification system was created in which each word or phrase was classified into (1) a single global pain domain (eg, pain magnitude, pain quality, pain temporal domain) and (2) specific pain subdomains within each of the global domains (eg, for pain quality, burning, sharp, achy). The investigators selected the labels for the global domains (eg, magnitude, quality, temporal). However, the specific word or phrase used by the participants that occurred most frequently was used as the label for each subdomain; thus, the participants’ own descriptors defined the subdomain labels. For example, 5 words and a single phrase were expressed by the participants that related to a similar pain quality experience: burning (N = 43), hot (N = 22), searing (N = 5), on fire (N = 3), warm (N = 3), and like I have a temperature (N = 1). Because burning was the word mentioned most often by the participants within these related concepts, it was used as the subdomain label (burning in this example) for the experience that these descriptors reflect.

Each word or phrase that the first 60 participants (20 from each group) used to express a single idea or concept in response to the prompting was first classified by L.E.J. and M.P.J. as falling into a

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