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Communicating about the experience of pain and fatigue in disability

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Abstract

Purpose—To examine the experiences of people with chronic disabling conditions as they communicate with health care providers about pain and fatigue.

Method—Twenty-three adults with a variety of chronic disabling conditions participated in 5 focus groups. The following issues were raised: tell me about your pain/fatigue; what things go along with pain/fatigue? how do you talk about pain/fatigue with your health care provider (HCP)? What should your HCP know that they do not ask you about?

Results—Results of qualitative analysis suggested two major themes. The first theme was labeled “Putting it in words” and suggests that both pain and fatigue are described in many ways, including the dimensions of type, intensity, level of interference and temporal aspects. Participants reported difficulty with responding to a single question that asked them to assign a number to their level of pain or fatigue. The second theme was labeled, “Let’s talk about it” and suggested that participants wanted HCPs “to listen and believe me when I describe my experience”. They wanted to be asked about how pain or fatigue interferes with life and about compensatory strategies rather than being asked to rate symptom intensity. Participants wished to be viewed as experts and to be actively involved in decisions about their health care.

Conclusions—Pain and fatigue were viewed as having many facets that are associated in complex ways with other aspects of the health/disability condition. From the participants’ perspective, assignment of a pain intensity rating does not represent the complexity of their pain experience. Suggestions are provided for HCPs when communicating about pain and fatigue with people with chronic conditions.

Keywords

Pain measurement; Fatigue; Chronic disease; Communication; Focus groups

Introduction

Pain and fatigue are among the most common patient-reported symptoms cutting across a broad range of chronic diseases and conditions [1–5]. Chronic pain has been estimated to occur in 94% of people with spinal cord injury and is considered severe and disabling in 20–40% of the population [6]. Most amputees experience phantom limb or stump pain [7]. Several surveys of

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persons with multiple sclerosis (MS) have confirmed that 53–82% of people with MS report pain related to their condition [8]. Pain was reported to be the most common secondary condition in women with cerebral palsy [9]. Fatigue commonly co-occurs with pain. It is both common and persistent in stroke [10,11], multiple sclerosis [12], cerebral palsy [13] and spinal cord injury especially with aging [14,15].

The dimensions of pain and fatigue

Although pain and fatigue are generally acknowledged to be complex, multidimensional constructs, there is little consensus on the dimensions themselves [16]. The area of chronic pain measurement was the first to acknowledge the multidimensional experience of pain. Melzack [17,18] introduce three types of pain descriptors: sensory (e.g. throbbing), affective (e.g. exhausting) and evaluative (e.g. unbearable). In a recent review of the language used to describe pain, results suggested that chronic pain experience is represented as multidimensional and individual, but that inconsistencies in domains exist across studies [19]. At least five dimensions are pertinent to the experience of pain in nearly all patient populations. These include pain intensity (how much a person hurts), pain quality (type of pain), pain location (where the pain occurs), pain interference (the impact of pain on the life situations) and the temporal aspects of pain (frequency, duration and predictability of pain). Fatigue has been characterized as multidimensional with dimensions such as physical, cognitive, and psychosocial [20].

Pain and fatigue in context

Neither pain nor fatigue occurs in isolation, and these constructs are further complicated by their association with other aspects of disability. For example, pain is associated with an increased incidence of depression, anxiety, and decreased social support in a large community dwelling MS population [21] and interferences with sleep and daily activities in SCI [22]. For many people living with MS, fatigue is chronic and compounds other symptoms of MS [23]. Fatigue is associated with depression, disability and disease pattern in MS [24]; and lower levels of social support and poorer falls efficacy scores in a post-stroke population [10]. Fatigue following stroke was also associated with more depressive symptoms, older age, and gender (women) [11]. In a group of adults with cerebral palsy, fatigue was associated with increased bodily pain, deterioration of functional skills, limitation in role function and low life satisfaction [13]. In summary, pain and fatigue exaggerate and complicate other symptoms related to chronic disabling conditions, pain causes fatigue—fatigue makes the experience of pain worse and more disabling.

Communicating with health care providers

The complexity of the constructs of pain and fatigue underscores the need to take these symptoms into account in rehabilitation practice and to develop clear channels of communication between health care providers (HCP) and people with chronic conditions. Despite the prevalence and severity of pain and fatigue, communication about these topics is difficult for the HCP and people living the disability. Even in general populations, communication with HCP is challenging. Patients have been found to voice their concerns in less than one quarter of visits and even though patients reported that they wished to receive as much information as possible, they did not typically engage in information seeking strategies [25]. For people with disabilities, communication is particularly demanding because of the complexity of the interaction between the impairment or disease process, function, and participation, and the extra knowledge, skills, sensitivity and time needed for good communication [26]. General practitioners were found to be uncomfortable communicating with patients with physical impairments [27]. Dudgeon et al. [28] interviewed participants with physical disabilities about their experiences of chronic pain. Analysis of the in-depth interviews

suggested that participants viewed pain as a personal experience and described their dilemma of communicating with HCP about pain. The participants suggested that discussing issues such as pain for which the HCP could not provide curative or palliative treatment were often not satisfying. Participants felt that the discussion of pain exaggerated the degree to which the HCP perceived them to be different or defined by their disability status.

Purpose

Communication about pain and fatigue with a HCP is an important but clearly difficult task for people with disability. The present study was conducted as part of the Patient Report Outcome Measurement Information Systems (PROMIS) NIH Roadmap Initiative that examines subjective experience associated with illness and disability including pain, fatigue, physical function, emotional distress and social function [29]. The purpose of this study was to learn more about how people with disabilities communicate with HCPs about pain and fatigue and to examine different ways in which living with pain and fatigue impacts the lives of people with chronic health conditions. The resulting information will inform HCPs in how to measure pain and fatigue in the clinical setting and how to discuss issues related to pain and fatigue with people living with long-term disability. Focus groups are used to generate qualitative data that provide insights into the attitudes, perceptions and opinions of participants solicited through the open-ended question and answer protocol [30]. Data from focus groups may help the researcher to explore the vocabulary, thinking patterns and experiences of people with chronic illnesses and disabilities [31].

Methods

Participants

Participants were recruited from the general rehabilitation population at the University of Washington Medical Center and Harborview Medical Center through posted fliers and care provider referral. Research participants were included if they were: (1) at least 18 years of age, (2) diagnosed by a physician with disabling or chronic health condition, (3) reported having experienced mild, moderate or severe pain and/or fatigue in the last 7 days, (4) able to speak and read English; and (5) willing to provide written informed consent prior to study entry. Additional inclusion criterion included ability to attend a focus group meeting at a location at the University of Washington. Parking and accommodations were covered by the project. All recruiting and focus group methods were approved by the University of Washington Human Subjects Review Committee.

A convenience sample of 23 adults with chronic disabling conditions participated in five focus groups. None of the focus groups had more than 6 participants in order to ensure that all could take part fully in the discussion. See Table 1 for demographics, clinical diagnoses, and severity ratings for pain and fatigue. Ages ranged from 26 to 60 years (mean = 45.1, SD = 11.1). Most participants were female (78%), white (96%) and reported at least a high school education (92%). Only 17% were employed either part time or full time. Many primary health conditions were reported as the primary diagnosis with spinal cord injury and multiple sclerosis being the most common. Most reported pain (87%) and fatigue (96%) in the past 7 days.

Focus groups data collection

Five focus groups ranging in length from 1½ to 2 h were conducted at the University of Washington in Seattle Washington, a facility that is both centrally located and accessible to people with disabilities. Groups were conducted by a trained facilitator (KJ) and two additional staff members who served as note takers. Focus groups were recorded using real-time transcription by a court reporter and digital audio recording. After initial clarification of the project purpose and exploring issues related to protection of confidentiality, the facilitator used

a semi-structured interview protocol including open-ended questions to elicit group participation and discussion on a specific topic area. The following are examples of open-ended prompts used: “to what extent have you been able to predict your pain/fatigue?” “in the past 30 days, how has pain/fatigue affect your ability to carry out your daily activities?” “what has been the greatest impact of your pain/fatigue on your life?” “Now let's focus on talking with doctors about pain...” and “We are interested in the best ways to ask questions about pain...” The moderator focused the discussion on the topic at hand, attempted to ensure that all participants had an opportunity to participate, and clarified participants' answers but was otherwise non-directive, non-evaluative and supportive.

Data analysis

Socio-demographic data and informed consent were collected before the beginning of the groups. Transcripts and field notes were reviewed for common themes, and summaries were validated by members of the research team. Of these themes, only those related to the communication about the experience of pain and fatigue with health care providers and relevant sub themes will be presented in this document. Transcripts were analyzed using a series of steps [32]. First, members of the research team read and re-read all transcripts to become familiar with the data and to begin the process of identifying portions of the transcripts that expressed an idea or opinions about communicating the experience of pain or fatigue. Next, a series of codes were identified that could be used to index the data, and these codes were associated with quotes in the transcript using Atlas.ti[®]. The research team then developed a framework of themes in order to interpret the data. Researchers attempted to identify the most illustrative yet parsimonious themes that reflect the multiple interpretations that participants reported about their experience of pain or fatigue.

Results

Two major themes and six sub-themes emerged from the analysis of the focus group discussions (see Table 2). Each of these is described in the following paragraphs.

Putting it into words

Participants provided detailed descriptions about how they communicated the experience of pain and fatigue.

Words to use—Participants used many different words to describe the qualities of pain—throbbing, tingling, numb, sharp, stabbing, and so on. They also used analogies such as “like sitting on razor blades,”^(F: CMT)¹ “like a bad toothache,”^(F: MS) “like an electric charge.”^(F: SCI) One participant suggested, “I really like the questionnaires that have 20 different words for pain, but even then, it doesn't really get to the heart of the matter.”^(F: RA) In addition to describing the various types, pain was characterized by location (skin pain, muscle pain, joint pain) or its temporal aspects (“sneaks up on me” (M: CVA) or “it is constant” (F: CP)). One participant preferred the word, “discomfort” to “pain”. She indicated, “There are times when I experience sensations that really don't seem to fit pain, but it's not comfortable. I'll call it ‘discomfort.’”^(F: RA) Another participant preferred to describe pain in terms of dysfunction or inability to do things. Thus, pain appears to have many dimensions—type of pain, location, impact on activities, pain experience or intensity, and temporal aspects. As one participant suggested, “When you say you're in pain, you have to qualify it.”^(F: SCI)

Participants described fatigue using phrases such as, “I feel heavy” or “I don't have enough energy to go out and do things.”^(F: RA) Other participants used analogues, “It's like a watch

¹Parentheses include the sex and diagnosis of the participant quoted.

running down and just stopping...I just have to stop thinking, stop walking, stop doing anything.”^(F: CMT) “You've got the clutch in and you're moving.”^(M: SCI) Although they used somewhat fewer different words to describe fatigue than to describe pain, a clear distinction was drawn between cognitive and physical fatigue. Cognitive fatigue was described as “mental mush,”^(F: MS) “my spirit is tired,”^(F: CP) or “my concentration just disappears.”^(F: MS) Physical fatigue was described as, “Your body wants to shut down.”^(F: MS) At times, the fatigue was explainable. For example, a man who walked with two prosthetic limbs indicated that he experienced fatigue walking when the limbs were not well-fitted. For others, fatigue often was not clearly associated with a precipitating event. The lack of ready explanation made communication about fatigue more difficult for one participant who described fatigue as follows, “It's 10 in the morning when I am feeling like I can't go on. ...What's the deal? I don't understand it. So I don't know how to relate it to anyone.”^(F: VD)

Pain and fatigue appear to share some common features. Both are multidimensional and invisible to others. However, participants viewed pain as largely negative but saw fatigue as positive and negative mix. One participant used the analogue that fatigue was like a friend and also an enemy, “like a friend because you become rejuvenated by your sleep, but it's also an enemy because you want to do something...it's so important to you and you do not have the wherewithal to be able to do it.”^(F: FA)

Assigning numbers—Participants had frequently been asked by HCPs to rate their pain on a scale from 0 to 10. Assigning a single number to their experience of pain was difficult for a variety of reasons. First, participants acknowledged that the scales were anchored with the zero point reflecting no pain and the ten point reflecting “pain as bad as you can imagine”^(M: CVA), but they did not know how to assign pain to numerical points in between. One participant commented, “I don't know what a 1 is and I don't know what a 10 is.”^(F: PPS) Another indicated, “It is pointless and frustrating to ask a person their pain on a Likert-like scale...lacking a point of reference.”^(M: SCI) Participants appeared to perceive that they were asked to use the scale to mark the number that is objective, i.e., to compare their pain with that of others but—understandably trouble doing so. For example, one participant indicated, “I think everybody experiences pain differently.”^(F: PPS) Another commented, “What's a 4 to me might be an 8 to somebody else or might be a 1 to somebody else.”^(F: PPS) Numbers were also difficult to assign because there was an interaction between level of pain, a higher than normal baseline of pain, and tolerance for pain. One participant suggested that people may use the scale differently and the numbers she assigned may not be consistent with those reported by others, “...because I believe my tolerance (for pain) is higher than the average person.”^(F: SCI) Another suggested that a score of “4” was her normal functioning level of pain. Finally, one of the participants indicated that often questions focused on a specific time frame such as the last 7 days that did not reflect his experience of pain, making it difficult to communicate the experience outside of the time frame.

Despite these difficulties, participants felt that questions about level of pain had some merit as a basis for discussions with HCPs. One participant indicated, “When they (HCPs) see a 10, wow it must really hurt and maybe that's a good starting point.”^(M: SCI) Another participant indicated that ratings of intensity were useful because the questions, “allow me to think about whether (the pain) is more than typical for me.”^(F: CP) Finally, although questions about level of pain are a starting point, participants indicated that these questions need to be accompanied by questions related to interference. One participant suggested that questions should relate to “how is it disrupting your life with specific questions that are unique to that individual.”^(M: SCI) In summary, participants had difficulty knowing how to respond to a single question that asked them to assign a number to their level of pain or fatigue. Participants felt that pain intensity or experience was a reasonable way to begin their discussion about pain but did not capture the most salient issues.

Let's talk about this

Participants provided many comments about communicating with HCPs.

Listen and validate—Participants indicated both pain and fatigue are invisible to others. As one participant indicated, “I look pretty healthy...but once I get pain and fatigue, it just stops me from doing anything.” (F: MS) Because pain and fatigue are personal experiences, participants felt these symptoms were undetectable to others and that they found themselves having to convince HCPs of their presence and seriousness. In other words, they felt that their reports were dismissed by HCPs. The following quote summarized this concern, “The biggest thing is getting the doctors and medical people to believe me, because they look at me and I'm walking.” (F: CMT)

Participants did not think their reports of pain or fatigue were credible for the HCP. Participants quoted their HCP as saying (or at least thinking) “you're exaggerating.” (F: MS) “You're just making this up.” (F: FA) “It's imaginary.” (F: MS) “You are dwelling on the problem.” (F: MS) “Here's another one of those people who likes to complain.” (F: PPS) Believability was of particular concern, if the clinical presentation was in some way atypical. For example, one participant with spinal cord injury with pain below the level of injury felt that his reports of pain were ignored because his HCP told him, “you can't feel anything below where you were hurt.” (M: SCI) Credibility was more of a problem for some symptoms than for others. For example, one participant indicated “Fatigue isn't taken seriously ...and cognitive fatigue, it's like you're making it up.” (F: MS) The perception that their reports of pain and fatigue were not credible or understood by the HCP was distressing because participants felt that “we are experts in our bodies.” (F: SCI)

Closely associated with the perception that they were not being believed is the notion that HCPs did not listen. When asked what advice they would give HCPs, one woman said, “Will you please listen to what I have to say and don't just disregard it because I'm a woman,” (F: CMT) and another said, “let me talk and listen well.” (F: VD) A common reason reported for changing HCP was that he or she “didn't listen.” (F: RA)

Questions I wish they'd ask—During each focus group, the facilitator posed the following question, “what would you like your health care provider to ask?” Participants provided many examples of questions that “no one asked”. Many of these questions related to how their lives were disrupted by pain or fatigue. For example, participants wished they were asked by their HCP: “what is pain/fatigue preventing you from doing?” (F: SCI) “Or how long does it take you to get up and get ready for the day?” (F: SCI) In addition to pain interference and intensity, questions about the duration and number of instances of pain were felt to be important. Some participants indicated that they were not routinely asked about fatigue and its affect on daily activities. They felt it was critical for HCP to ask about the impact of fatigue on cognition.

Participants also felt that people reporting pain or fatigue associated with disability should be asked about their sleep. Questions might include: “how much do you sleep at night?” (F: CMT) “Because you're exhausted, how much do you nap during the day?” (F: MS) In addition to the amount of sleep, participants wished they were asked about the quality of sleep.

Participants also indicated that they wished to be asked general questions about management of their condition. For example, “how much do you want to know about your condition and its management?” (F: SCI) “What are your goals for pain/fatigue management?” (M: SCI) “How have things changed over time?” (F: RA) “What alternative medicine approaches have you tried?” (F: MS) Participants also indicated that it is important for HCPs to know about the strategies that they used to manage their own pain or fatigue. One participant indicated that she wished HCPs would focus on strategies for coping rather than on descriptions of status,

“They speak to me less about what I can do to make myself feel better and more about what is the function, what is the angle of your leg and how can we increase your baclofen?” (F: CP) Questions about management might include: “What are you doing to take care of yourself?” (F: CP) “What do you do to make yourself feel better?” (M: SCI) “What triggers your pain?” (F: CMT) One participant preferred to lead the discussion rather than respond to questions. She indicated that she presented the HCP with a list of problems and said, “Let’s talk about this.” (F: MS)

What I need to know—Participants felt that they obtained information critical to making informed decisions through discussions with their HCP. “The more information I think you have, the better” (M: SCI) was a quote from one participant. Another person indicated, “I’ll take the information out and go home and research it myself and really build on it from there.” (F: CMT) At times, information included explanation for symptoms. When describing a valuable visit with a physical therapist, one participation reported, “she explained why I was having trouble with this particular motion and why I was fatigued... that information allows me to go back and understand better why I have to make different choices.” (F: SCI) At other times, the information that participants were seeking related to prognosis. “Is it really going to pass this time?” “What can I expect?” (F: MS) Still other times, information was needed with respect to potential side effects of treatment, “Will the intervention become another problem in itself? Will the exercise hurt me?” (F: PPS)

Negotiating a plan—Participants wanted to be included in decisions about their health. “One thing I find to be frustrating is I’m actually pretty knowledgeable about my condition and I am bothered when I see a physician speaking separately to a resident who has watched me walk.” (F: CP) Participants wished to be viewed as experts in their own condition. For example, participants noted, “We are our own experts in our bodies.” (F: SCI) “I’m competent, I’m capable, and I’m interested.” (F: MS) “Any health care people who think they know my body better than I do are wrong.” (F: SCI)

Participants with chronic pain and fatigue viewed HCPs as offering a relatively narrow range of options, typically medication and assistive devices such as canes and walkers. “Doctors have not really wanted to focus on the compensatory aspects but more on the management of pain. I would rather reduce it as much as I can then treat it.” (F: SCI) Participants preferred to focus on a broad array of strategies as exemplified by quotes such as, “I said I want to take water aerobics they said yeah, yeah, yeah that’s fine but what we really want to do is get you a cane.” (F: PPS) “There are simple lifestyle pieces that can really positively impact you. Getting more sleep is less scary than increasing my baclofen, and more effective.” (F: SCI) In summary, participants viewed themselves as experts with respect to their condition and preferred to take an active role decision-making. Further, they preferred to have many options to mitigate their pain and fatigue considered rather than a single focus on medication.

Discussion

Summary of findings

Effective communication between the patient and HCP is critical for the management of pain and fatigue in those with chronic disability. Pain and fatigue were viewed as having many facets that are associated in complicated ways to other aspects of the disabling condition. Because of this complexity, rating the intensity of pain or fatigue on a numerical rating scale does not represent accurately the experience of the individual. Participants reported that they used visual analog scales of intensity differently, with some comparing themselves to others and some using their own baseline or usual pain as the point of reference. Furthermore, Williams and colleagues [33] found that assessor status has a significant impact on ratings of

pain intensity. Communication with HCP about pain or fatigue was viewed as difficult. This is consistent with other reports that suggest patients in general complain that HCP do not listen, are hurried, and do not allow them to participate in decision making [34]. Like other reports [28,35], many participants felt that they were not believed by their HCP, perhaps because pain and fatigue are not visible to others. Participants identified many questions that they believed HCP should ask them about interference in preferred activities, sleep patterns, coping strategies, and goals for management. Participants reported that it is critical to them to have accurate information about their condition as they make decisions about treatment options. They preferred to be active in the decision-making process and to be viewed as the “expert” in their own body. Participants felt that management strategies should be holistic, targeting multiple aspects of their condition such as learning better movement patterns, reducing the level pain or fatigue thru medication, avoiding triggers of pain or fatigue, use of assistive technology, and health promotion activities.

Clinical implications

The results of the current study have implications for documenting pain and fatigue in the clinical setting. Participants identified multiple aspects or dimensions of the constructs of pain and fatigue that would be important for their HCP to know about. Some of these dimensions appear to be more easily placed on a single scale of difficulty than others. For example, it seems reasonable to expect that intensity and interference could be scaled from low to high. For other dimensions such as quality and temporal aspects of pain or fatigue, an interview or checklists may be the best way to document complaints. Participants viewed simple scales and check lists as the starting point for the discussion. Results of the current study form the basis for clinical recommendations related to communication. The following is a list of suggestion for enhancing the communication between HCPs and people with chronic disability.

Screen for pain and fatigue—Conversations between HCP and patients during most visits are narrowly focused on biomedical issues with little attention to psychosocial variables [34]. In contrast, screening for fatigue, pain and emotional distress has been found to be important for optimizing the management and reducing the risk of morbidity in patients with cancer [36]. Reasons cited for the lack of communication about fatigue in patients with cancer include HCP failure to offer intervention, the patient lack of awareness that interventions exist, patient preference to not use medication, and the patient desire not “to complain” to the HCP [37]. It appears from our study that these same issues around communication with HCP are present for people living with disabilities.

Ask about multiple dimensions of pain and fatigue—As noted earlier, participants strongly valued including psychosocial variables along with biomedical in conversations with their HCP. Barrier and colleagues [34] suggested that when presented with an initial complaint, HCPs should not interrupt with a series of questions about that symptom. Rather, they should ask the simple question, “what else?” This approach is intended to trigger a comprehensive list of problems. A similar approach may be useful as a follow up to the simple rating of the level of pain or fatigue on a 10 point scale. The question, “what else would you like to tell me about your pain or fatigue?”, may help to identify aspects of the symptoms and their consequences that are important to the person experiencing them. Most participants in the current study wished to be asked about how pain or fatigue disrupted their lives. This question style and validation of the patient experiences may also serve as an indicator that the HCP is listening and that the symptoms are credible. Such a dialogue is consistent with the strategies recommended when treating patient with medically unexplained symptoms [38,39].

Gauge level of information needed—During the acute stage of managing low back pain, patients place a high value on education and counseling [40]. The level of information desired

may change as the condition becomes chronic. People living with chronic pain and fatigue develop coping or self-help strategies often by trial and error [41,42]. Participants in the current study, all of whom experienced chronic conditions, felt that they were the experts in their bodily function and management of pain and fatigue. Thus, it is important for the HCP to find out what the patient already knows, how much the he or she wants to know, and in what format that information should be delivered. For example, some of our participants preferred information presented verbally and others preferred written information. There was a range of comfort with seeking information on the internet.

Provide accommodations for communication—Although accommodations such as wheelchair ramps to allow physical access to healthcare and other facilities are now taken for granted, accommodations to enhance communication may also be appropriate. Iezzoni and colleagues suggest that three types of accommodations in healthcare settings are needed to improve to improve communication for those with disability [26]. These include “brick and mortar” (e.g. a quiet room with furniture that allows eye to eye contact), tools (e.g. reading materials appropriate for the patient level of health literacy), and policy changes (e.g. longer appointments).

Identify the goals of management—HCPs and people experiencing chronic pain may differ in their beliefs about what treatments are important [43]. These differences can lead to poor communication. Scales for measuring patient involvement in clinical decision-making are available [44]. Participants in the current study felt that identification of goals was an important strategy for reducing disagreement and potential conflict with HCP. For example, it is important for the HCP to know that a patient's goal might be to reduce pain as much as possible through health promotion activities before medication is considered. In another example, a patient's goal may be to take part in a particular valued activity that he or she knows will result in pain. In this case, the patient may be seeking some short term strategies for pain relief. Explicitly identifying goals allows the person with a chronic condition to fully participate in the decision making process. Up-front, collaborative agenda setting for each visit has been associated with efficiency in medical encounters and plays an important role in models of clinical communication [45].

Identify what has worked in the past—As was mentioned earlier, people living with chronic pain or fatigue have often developed a set of strategies for compensation. It is important that HCP providers understand what strategies are being used and to acknowledge their potential benefit. Participants in the current study clearly used a variety of strategies to deal with pain and fatigue. It is critical that HCP know about these important patient generated techniques.

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Table 1Participant demographics and clinical diagnosis ($N = 23$)

Characteristic	<i>N</i> (%)
Sex	
Male	5 (22)
Female	18 (78)
Ethnicity	
White	22 (96)
Black/African-American	1 (4)
Education level	
Some high school	2 (9)
High school grad/GED	3 (13)
Some college/technical degree/AA	7 (30)
College degree (BA/BS)	5 (22)
Advanced degree (MA/PhD/MD)	6 (26)
Employment status	
On disability	8 (35)
Student	7 (30)
Employed	4 (17)
Other (retired, unemployed, not specified)	4 (17)
Primary diagnosis	
Spinal cord injury (SCI)	7 (30)
Multiple sclerosis (MS)	5 (22)
Cerebral palsy (CP)	2 (9)
Post-polio syndrome (PPS)	2 (9)
Amputation	1 (4)
Charcot marie tooth (CMT)	1 (4)
Rheumatoid arthritis (RA)	1 (4)
Friedreich's ataxia (FA)	1 (4)
Cerebral vascular accident (CVA)	1 (4)
Vestibular dysfunction (VD)	1 (4)
Multiple chemical sensitivities (MCS)	1 (4)
Pain in past 7 days	
No pain	3 (13)
Mild pain	4 (17)
Moderate pain	13 (54)
Severe pain	2 (9)
Don't know	1 (4)
Fatigue in past 7 days	
No fatigue	1 (4)
Mild fatigue	5 (22)
Moderate fatigue	9 (39)
Severe fatigue	7 (31)

Characteristic	<i>N</i> (%)
Don't know	1 (4)

Table 2

Theme, subthemes, and examples of issues discussed by participants

Theme	Subtheme	Example quotes
Putting it into words	Words to use	For pain; throbbing, tingling, numb, sharp, stabbing
		For fatigue: heavy, not enough energy, mental mush
	Assigning numbers	What's a 4 to me might be an 8 to somebody else
Let's talk about this	Listen and validate	The biggest thing is getting the doctors and medical people to believe me
	Questions I wished they'd ask	What is pain/fatigue preventing you from doing?
		How much do you during the day because you're exhausted?
		What are you doing to take care of yourself?
	What I want to know	The more information I think you have, the better
		Will the intervention become another problem in itself?
	Negotiating a plan	Any health care people who think they know my body better than I do are wrong