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During the last half-century, pain scholars have developed and refined numerous approaches to the problem of chronic pain. Much of this work, however, focused on individuals with chronic nonmalignant pain as a primary condition. This focus group study explored the experience of disability-related pain among 32 people with multiple sclerosis (MS) living in the community. Thematic analysis of transcripts revealed 4 broad conceptualizations of the experience of living with chronic MS-related pain. The first theme, pain is pervasive, described the overwhelming and intrusive presence of pain in daily life. Participants related the physical, emotional, and social consequences of living with chronic, disability-related pain, which caused them great loss and restriction. The second theme resonated around feelings that nobody understands. The participants sought understanding and validation of their pain experiences by family, friends, and healthcare professionals and struggled with difficult issues concerning the legitimacy and invisibility of their pain. The third theme, I'm fine, referred to the propensity of participants to keep pain private from others. In part because of its contested nature, participants at times concealed their pain from others to avoid conflict and maintain some semblance of their former lives. The final theme that emerged was always a factor in the equation. The participants shared how MS had transformed their worlds into ones in which pain and discomfort had become a normal part of everyday life, requiring careful negotiation and planning to undertake activities and prevent exacerbation. It is vital that healthcare providers give people with MS opportunities to talk about pain and pain-related concerns, validate their experiences, and provide interventions that enable self-management. Clinicians are encouraged to challenge their own meanings and expectations about disability-related pain so that therapeutic interventions can be facilitated.
Available evidence on the prevalence of pain experienced in the MS population signifies the scope of the problem. Although originally thought to be a painless disease (Aring, 1973), a growing body of research conducted over the last 20 years has demonstrated a prevalence of MS-associated pain that ranged from 29% (Clifford & Trotter, 1984) to 90% (Heckman-Stone & Stone, 2001). Such variability in reported prevalence is likely the result of differences in sampling techniques, inconsistencies in the definition and measurement of pain, and assessment at different points in the disease trajectory. Yet, research published within the last decade suggests, more consistently, that approximately two-thirds of people with MS experience pain at some time during the course of the disease (Beiske, Pedersen, Czujko, & Myhr, 2004; Ehde, Osborne, Hanley, Jensen, & Kraft, 2006; Kalia & O’Connor, 2005; Rae-Grant, Eckert, Bartz, & Reed, 1999; Svendsen et al., 2003). Furthermore, the pain experienced is largely chronic in nature, although characteristic acute pain conditions also have been noted (Indaco, Iachetta, Nippi, Socci, & Carrieri, 1994; Stenager, Knudsen, & Jensen, 1991). Frequently, individuals with MS report multiple pain conditions and most describe a number of different pain sites. A substantial subset of the MS population reports that pain is the worst symptom of their disease (Ehde, Gibbons et al., 2003; Stenager et al., 1991).

Although there is a growing body of literature that documents the high prevalence and characteristics of MS-related pain, little is known about the phenomenon of pain as experienced by this group of people. This is a notable deficit because people with MS-related pain are likely to suffer associated sequelae of chronic pain, such as physical deconditioning, affective distress, and social isolation in the face of impairments already present (Benrud-Larson & Wegener, 2000). Therefore, an understanding of the ways in which those with MS make sense of pain and how this sense-making constructs relationships and actions for these individuals remains an important goal.

This article presents the findings of the qualitative component of a larger study that explored the impact of pain on the quality of life of people with MS. The qualitative inquiry seeks to understand how people with MS encounter the ambiguity that surrounds the experience of pain. In so doing, the study draws on interactionist principles and presupposes that individuals and groups construct narratives that attempt to recreate a sense of predictability and stability in a world that has been disrupted, in this case, by chronic pain (Maines, 2001). The following discussion presents the findings of the study that explored (a) the varied experiences and perceptions of pain among people with MS and (b) the ways in which people with MS make sense of and give meaning to disability-related pain.

**Method**

**Design**

A series of four focus groups was conducted to achieve an understanding of the phenomenon of MS-related pain by exploring the shared meanings, variations, and experiences of the participants. The focus group was particularly well-suited to this study because the chronic pain experience is both individually and collectively constructed. Thus, a richness of data is obtained when group members share common experiences, and the complexities of individual perspectives are enhanced by group dynamics. In this sense, the focus group is understood not simply as a convenient technique but as a social process. Given its advantages, researchers are increasingly applying a focus-group methodology to investigate the experience and impact of chronic pain in various populations (e.g., Borkan, Reis, Hermoni, & Biderman, 1995; Henwood & Ellis, 2004). However, to the knowledge of the authors, no qualitative study investigating the pain experience of people with MS has been published.

**Participants**

Focus-group participants constituted a purposive sample (N = 32) drawn from four community MS support groups located in the southeast region of Queensland, Australia. The inclusion criteria were threefold: (a) participants had a definite diagnosis of MS, (b) they had experienced MS-related pain, and (c) they were willing to discuss the impact of pain on their quality of life. In addition, to ensure heterogeneity as far as possible, participants with differing clinical and demographic characteristics were sought. These criteria aimed to provide an “expert” sample and enhance the depth of the data.

The final sample consisted of 24 women and 8 men who ranged in age from 26 to 72 years (M = 52.1 years). The level of neurologic disability varied widely within the sample; the majority were ambulatory. All study participants had lived for many years with the impact of MS-related symptoms, including pain. Thus, as a group, the participants were well qualified to discuss the experience of MS-related pain.

**Procedure**

Before commencement of the research, ethical approval was obtained from the Queensland University of Technology Human Research and Ethics Committee. The researcher contacted the support-group coordinators by telephone and initially visited each support group to discuss the aims of the research and invite members to participate.
Interested members’ names and contact details were obtained to allow a reminder call before the start of the focus groups. An appropriate time for conducting the focus groups was then negotiated at each of the support-group venues. Before the start of the focus-group discussions, participants read the study information sheets provided to them and signed forms indicating their informed consent. Anonymity was ensured by assigning pseudonyms and removing any identifying information during transcription. Each focus group consisted of 5 to 12 participants and were approximately 60 to 90 minutes in duration.

The focus-group discussions were relatively unstructured but were guided by several lead probe questions that were determined in advance. The researcher encouraged discussion and interaction among participants by interpreting questions, using minimal encouragers, and employing rephrasing and summative communication techniques. Through this process, the researcher attempted to achieve a balance between enabling participants to fully explore each topic and keeping the discussion focused. By the fourth focus group, it was apparent that a depth of data that would allow for a full analysis of the shared dimensions of the study phenomena, or what Dey (1999) referred to as “theoretical sufficiency,” had been achieved.

Data Analysis
Focus group sessions were audiotaped and transcribed verbatim by the primary investigator to ensure accuracy. Thematic data analysis began by reading each of the transcripts several times to achieve a sense of the whole (Sandelowski, 1995). Each sentence of the transcripts was then coded and data compared with data across focus groups using a constant comparative method of analysis (Strauss & Corbin, 1990). As the comparison, interpretation, and analysis progressed, substantive codes were grouped into emerging themes and subthemes.

Findings
Themes
Data analysis revealed four broad conceptualizations of the experience of chronic MS-related pain, which are presented in Figure 1. These interrelated themes provide meaningful insight into participants’ experiences and their collective understandings of living with daily disability-related pain. A broad discussion of each of these themes, along with interactive extracts from the data to illustrate each category, is presented below followed by an analysis of study findings.

Pain is Pervasive
The theme pain is pervasive encompassed the typically chronic and often severe nature of pain described by participants and reflected its perceived impact and deleterious consequences on their lives. Pain, along with other MS-related symptoms, invaded and overshadowed daily life, causing participants significant loss and restriction.

The pain never stops. Many participants encountered pain on a daily and often constant basis:

1: Well I’ve got pain in the legs that never stops… never ever, it’s there for years… and if I lay down it’s better… but it’s there all the time you know, even now.

2: But with mine, sometimes it stops, and I think, oh wonderful… but you know… it’s not long.

3: You know it’s chronic total constant pain and it affects your personality, becoming inward… down… depressive.

4: It’s just so, monotonous, so continuous and sometimes it’s hard to get off to sleep or I have to go to bed because my feet are getting restless, and you don’t know where to put them, you know, so you just go to bed, forget it…

5: Well you get so used to having a little bit of pain, I’ve got to wait until it gets really bad to know that I’m in pain!

Participants also spoke of the intense nature of their pain, often using metaphorical expressions:

1: Does anybody get that band, an imaginary corset up here around the top part from the waist up?

2: Yes, that’s common; it’s called the “MS hug.”

1: It’s hot as Hades. You think, “Oh I wish I could take it off.” So you’ve got a girdle up there, but you haven’t…

Many activities precipitated pain, including activities of daily living such as cooking, sleeping, or physical activity:

1: I’ve got my dinner and cooked it, and then go to sit down after I’ve washed up after it, and my legs are aching so much, I think what can I do… you know. Again you can walk it out a bit, but not a lot.

2: Well mine is sort of different, when I lie perfectly still, mine’s OK. The moment I stand up, the legs just ache and ache and ache, as long as I don’t move I can lie like that and get to sleep… but it is the fact that sometimes during the day when I just have to go and stop everything and lie down, it’s just the nerves seem to be in the legs, you know; it’s terrible.
3: Well I’m the opposite to that completely.

4: I’m with you Jan, it’s when I’m lying down that everything happens, the legs go into spasm like what you’re getting, and the pain is...

**Pain is controlling.** A particularly pernicious consequence of MS-related pain expressed by participants was its interference with daily life. Participants described pain as “limiting” and “controlling,” such that it generally compromised their capacity for enjoyment of activities and, at its worst, completely prevented them from engaging with others.

One participant spoke of her daily struggle with pain and fatigue:

1: I think pain takes away your motivation to do things. I think the best way I can describe to people what MS is like for me is that I wake up every morning of my life feeling like I’ve got the flu. So you really don’t want to do anything, but you have to push through that barrier and do it anyway or else you would never do anything because your first inclination is to go back to bed and lay around all day like you’ve got the flu... but tomorrow is going to be exactly the same.

2: Yeah, you’ve got to make that decision, haven’t you?

1: Yes, I’ve got to pull through that pain barrier and get on to—I’m doing it anyway so what—and take a few more Paradex which I’m more or less hooked on, that’s how it is for me anyway, what about you guys...

3: Well at least they work for you.

At times, however, participants’ pain was so overwhelming that they could focus only on the pain itself:

1: Well, once you get a migraine that’s it. Forget the day. Have a jab and go to sleep.

Researcher: So you feel it controls everything?

1: Well, I think anyone’s pain—no matter whose it is—pain takes precedence over anything else. You can’t even think with enough pain.

2: It washes over anything else that’s wrong because pain is a real pain, that’s it. You don’t care about anything else. Well that’s how I feel, and I think a lot of people with different types of pain have the same sort of thing—all they can think about is the pain.

Others recalled how pain had limited their ability to achieve goals and aspirations:

1: I found pain stopped me from doing things that I wanted years ago, so I just didn’t do it. I wanted to do more study and I couldn’t, because I couldn’t sit at night in the one place and write and do whatever. Even now if I do a bit of work on the computer I have to go and lie down, I can’t do or work an 8-hour day, so I just do my 4 hours or whatever I can... and that’s because of the pain.

2: [It] really... the biggest pain about pain is that it does control your entire life...

3: Well I think this would be the same for everybody in the room, sometimes it does stop you—you don’t make it there.

**Pain is exhausting.** Participants considered pain and fatigue to be interrelated. Enduring chronic pain depleted their energy and strength, and MS-related fatigue exacerbated pain and complicated attempts to treat it:

1: Pain is so fatiguing... pain makes fatigue worse and fatigue makes the pain worse.

2: You know, if you’ve got pain you can’t lie down, you’ve got a Catch-22, one doesn’t solve the other.

3: And you get irritable...

4: That’s like, what Lisa’s saying is sitting up may be helping stop your pain to a certain extent, but you really, really want to lay down because you’re so bugged, you just want to lie down, but you can’t lie down because that just increases the pain.

The exhaustion of living with chronic pain was also compounded by significant sleep disturbance in the forms of insomnia and frequent awakening:

1: The main effect for me is at night-time, breaking sleep up quite markedly, despite the various steps I take to reduce the painful spasms at night it still breaks up my sleep pattern quite markedly and I wake up the next morning feeling dog tired, and bits and pieces during the day which also makes life difficult, but I can usually get up and walk...
them out to a certain extent. But at night-time it’s hard because you don’t feel like getting out.

2: Night-time, yeah, probably the worst since you’ve been standing up all day, walking, you know. I get up out of bed in the morning and I think I’m 90. I get up, but it’s hard to get moving, I mean the pain in my back, I’ve got to take something.

3: I think one of the most difficult things is not being able to get to sleep at night. When you’ve got something that’s burning or cramping and you wake up and you can’t get any sleep.

“*I wish you would smile sometimes.*” The distress and losses associated with pain evoked a range of emotional responses such as anger, fear, anxiety, frustration, and depression:

1: [I]f you’ve already got depression and you’ve got pain, then it will pull you right down.

2: I think it changes your personality too, absolutely. You start to become more negative than positive—now it’s “No I can’t do that I might have bowel problems, no the pain is really bad today, I can’t ask them because I don’t want to put them out,” you know—because of constant pain.

Over time, pain eroded participants’ emotional resilience and led to feelings of helplessness and hopelessness:

1: Oh yes, you can begin to think I wish I wasn’t here. And if it gets any worse you can become suicidal.

2: Depression, because you wonder why and you’re a damn nuisance. Particularly if you’ve got a partner and that. It’s a damn nuisance. They’d be much happier if you weren’t around...

3: If you’ve got pain, for example, the wife would say, “I wish occasionally you would smile.” The trouble is the bloody pain… it does react on her (group agrees).

*“They don’t call as much as they used to…”* Having a chronic pain problem also meant greater isolation. Participants’ relationships with family, friends, and carers became more distant as ongoing pain caused them to withdraw from social activities:

1: It does control your life in the way that when you are in pain you don’t want to do anything. You don’t want to go out. And I’ve found it really hard with my friends, because they will ring up and say “Look let’s go out” or “Let’s go do something,” and mum will say “Look, Kelly’s not really well today, so we’ll give it a miss”… so you find yourself becoming really left out of the social scene...

2: Yeah, social isolation…

1: Because as much as they want to help you… but you can’t expect them to deal with your pain and you sort of find that friends become friends on a much less basis, like they don’t call as much as they used to, you don’t go out with them as much as you used to, you don’t… it really… the biggest pain about pain is that it does control your entire life, and when you are feeling well, you have to mend all those bridges that have been broken when you haven’t been… it’s like a circle that you keep going round.

3: It’s a vicious circle too.

Participants spoke of the struggle of maintaining relationships with others when dealing with the chronic and often unpredictable nature of pain and illness:

1: Well it’s when you get an invitation and you say “Well, if I’m feeling good, I’ll be there,” and friends know if I’m not there I’m not feeling good.

Researcher: And how does that affect those relationships with friends?

1: Well, for a lot of people, you’re never invited.

2: People become so accustomed to you being in pain, I think quite frankly they get sick of it.

3: And we are now a reminder of where they are going to be, eventually with age, with old age, and people don’t like to be reminded of their own fragility. So, it’s not that you’re bad company or anything (laughs)... yeah the spontaneity is going down the drain.

Others mentioned how pain interfered with sexual relationships:

1: You know pain can impact on people’s intimate relationships with their husbands, wives, that type of thing too, it does, you know, bodily pain does...

2: I don’t enjoy sex unless I’m drunk, but I think that’s very sad, but it’s because of the pain...

3: Sex, what’s that word?

4: Oh don’t ask that! (laughter)

**Nobody Understands**

The theme *nobody understands* was interwoven throughout focus-group discussions as participants expressed feelings of invalidation and struggled with others’ misconceptions and reactions to the pain that permeated their experiences. Participants’ stories and insights revealed that over time, despite their known diagnosis of MS, seeking help
or complaining of pain was invariably met with prejudice, skepticism, and, in some cases, outright confrontation. These encounters made living with pain even more difficult, because personal suffering was neither accepted nor legitimized by others.

*What you can’t see isn’t there.* Central to the notion that “nobody understands” was the perception that others failed to appreciate the subjective nature of pain. Participants discussed their not being believed or taken seriously because of the lack of physical, tangible evidence of their pain. They experienced intense frustration when others dismissed their reality with offhand comments, such as “but you look so well.”

Researcher: Do you feel like people understand…

1: No, unless it’s someone else that has MS.
2: Because you can’t see pain. When somebody hurts their leg, you know, you can see the problem.
3: Yes, most MS people look disgustingly fit.
4: Yes, that’s exactly right (group agrees).
5: When you haven’t got pain even you can’t realise the pain, so other people can’t empathise. You finish up with, nobody, even your partner can’t really understand what the pain is because it’s not describable, because they can’t accept it even when it is described…

Participants also contrasted others’ reluctance to accept their experiences of pain with the willingness to accept the pain experienced by individuals with visible injury or disease. Whereas the plaster cast for a fractured limb or a surgical scar conveys culturally sanctioned “proof” of pain and discomfort, the pain of MS remains invisible to others:

1: I feel it’s very frustrating because other people can’t see it… (group agrees) you know, “What’s wrong with you? You look all right.”
2: That’s my mother.
3: Yes, it’s not like rheumatoid arthritis, my sister has rheumatoid arthritis and her hands are all bumpy and it’s very visible, whereas people look at me and say “She’s just lazy.”
1: Because you look so well.

The lack of objective, physical evidence of pain meant having to justify or prove the existence and intensity of pain to others, or having to adopt behavior consistent with the medical and social expectations of disease-related pain to receive treatment:

But there isn’t any pain in MS, isn’t that what they all say… for years we couldn’t convince neurologists that pain was associated with MS. We had arguments for years. I tried to gather information from the Internet about it, and tried to feed it to the local neurologist. We couldn’t be too strong about it because we didn’t want to get him off side, but we managed to get the message gradually through. Now pain is very much recognised as part of MS, and an awful lot of people with MS get pain.

Another participant recounted her attempts to obtain analgesia for recurrent migraine headaches:

1: I actually did an experiment with that with my doctors. I have a walking stick which I very, very rarely use and I went in one day [without the stick] and said “Look, I’m having migraines, I need some Panadeine Forte,” and he gave me a really hard time to get a script. I went and saw him about 4 weeks later and I had my stick with me—wrote out the script no problems.
2: Sympathy stick they call it.
3: I've got one.
1: And the thing is, it is harder for people more like us for people to take us seriously because you look at us and we look fine. There is nothing you can do.

Participants became despondent as the search for treatment and relief revealed that no medical answers or solutions were forthcoming. They discussed their frustration with what they perceived as the superficial response of healthcare providers to their plight, drawing on instances where providers had trivialized their problems or responded only with generalities:

1: I think sometimes I want to chop my feet off at the ankles and they say “Oh it’s just your circulation—you just need to work on that.”
2: Yeah, well you look OK so…
3: Also if you go to your doctor and they know you have MS and you have something wrong with you they just put everything down to MS!
1: Well I went to the doctor and he said, “Well what do you expect, you’ve got MS.”
2: I hate that.
1: I don’t go to him anymore.

Clinicians’ responses left participants feeling as if seeking health care was futile:

1: Well if the doctor can’t cure you he’s not interested in you really…
2: I don’t think there are really many GPs that are interested in MS.
3: They put everything down to MS.
4: Yes, I mean you go with something else and I mean they just associate that with MS.
3: Yes, yes… (group agrees)
I’m Fine
The theme *I’m fine* emerged as participants weighed the potential costs of disclosing their pain and suffering to others against keeping their pain private. Although the focus groups facilitated a permissive and supportive environment for shared discussion and insight into their experiences, participants seldom spoke about pain with family, friends, coworkers, or healthcare providers. In addition to the risk of having their experiences invalidated, participants believed that voicing concerns about pain only heightened others’ awareness of their disability and burdened significant others with problems they could do little about:

Researcher: How about talking to your family or friends about pain?

1: Not about pain. They can see the mobility, but if I talk to friends about pain they don’t want to know… (group agrees)

2: Well there [is] no point in talking about it because there’s nothing worse than whin[ing], you know, nobody likes people whin[ing].

3: Well there is nothing they can do for you.

4: Yes, my son is my best friend but I don’t mention it to him ever.

2: Like Robin was saying, I don’t talk to my family about pain as much because there’s not much point to it anyway, I just enjoy their company, I don’t want to bother them.

Concealing pain. Given the problematic nature of communicating about pain with others, the challenge for the participants was to minimize pain behaviors and appear as normal as possible. During casual conversations, if asked how they were, participants invariably responded “I’m fine” to shift attention away from their illness:

1: And you try not to tell people because you know that you don’t want people not to ask you how you are because they’re going to get a 25-minute spiel on what’s going on, so you try and squash it as much as you can by saying to people, “oh yeah, I’m fine…”

2: A bit good, bit bad… (group agrees)

1: Well, you don’t realise what that person is going through unless you’ve actually had it yourself.

2: They actually say, “Yeah, but you look so well!” You know that’s everybody’s favourite saying. And we do…

3: You usually say, “Yeah, I’m feeling great.” (group agrees)

4: My favourite saying is “I’m fine.” Basically when people ask you how you are they really don’t want an answer.

5: Well they wouldn’t know what to do if you really did give them an answer like, “I’m in pain here, and I’m in pain there”… that’s it.

Participants made great efforts to conceal their pain to maintain normal daily activities and relationships with others. Some participants mentioned going to work despite pain flare-ups, or meeting social obligations at the cost of exacerbating pain to avoid revealing their illness to employers or friends. Most often, however, keeping pain concealed from others was achieved through selective withdrawal from activities:

Of a night-time, yes. Because the pain gets worse as the day goes on. I will get invited to go out of a night-time and I will make excuses because I can’t do that—I’ll be going somewhere else—but in actual fact I’ll be home in bed. So, I think it’s probably fatigue and pain.

*Being a burden on others.* Hiding their pain from family and friends was also driven by concerns about burdening them with additional social and emotional strain. Participants were mindful of how their pain problems altered family dynamics and restricted the activities they could share with their families:

1: You take it out on them.

2: We restrict their activity, because we don’t want to go, and they don’t want to go without us.

Researcher: So the entire family is affected?

2: Say they’ve got their heart set on something on the weekend, where it perhaps involves you going out and walking a little way and you’ve got back pain or a headache or sore feet or whatever, it’s the last thing you want to do so it’s disappointing for them.

3: I usually just sit on a chair a lot, and watch everybody else do what they want, and they think you’re a bit lazy, but you just can’t do it so…

4: You’d like to do more but you can’t.

5: Even minor things like going to the movies, I don’t know, I work so if I am in pain on the weekend, my husband says “Do you want to go to the movies,” and I say “No, I can’t deal with the pain that I’ve got, I can’t go out,” so… so it not only affects my life, it affects his as well.

Always a Factor in the Equation
The theme *always a factor in the equation* reflected participants’ global perceptions of reconciling to a life with pain. Ultimately, for individuals with chronic
MS-related pain, life becomes a process of ensuring that the distress and losses brought about by pain and illness do not predominate. Participants attempted to negotiate their daily activities and maintain their functional independence by learning to carefully consider the potential impact of activities on their symptoms.

Planning for and around pain. Although participants varied significantly in how they attempted to cope with pain, all of them believed that there was a need to actively plan their lives around pain. They learned to avoid exacerbations of pain by becoming aware of how the body responds to different situations and by constantly making decisions about whether, how often, and under what circumstances they would engage in activities:

1: You have to consider [pain] before you do something. If you know you’re going to have pain after an activity then you think, I want to do the activity and I know I’m going to have pain and put up with it.

2: Yes, you have to change your life around what you want to do.

3: I’d rather just do it and get it finished because I’m that type of person.

4: Well you learn to live with it I guess. And you learn to live around it. You learn to work around pain don’t you? (group agrees)

Part and parcel of MS. Becoming reconciled to pain was part of the broader experience of coming to accept the constellation of neurologic symptoms associated with MS. At times, participants found it awkward to discuss their experiences of pain, because for them, pain exists only within the broader context of MS-related disability. Their experiences of pain were inseparable from their everyday experiences of disability:

1: Pain is a part of MS that compounds everything else, it’s a nuisance.

2: You just learn to live with it. It’s all part and parcel of MS, that’s how I take it.

3: Yes, I have gotten used to it. It’s just part of living.

1: I guess it’s one of the many things about MS, one of the many things about MS that prevents you from being spontaneous because you’ve got to always bear in mind what can happen and whether the pain will get worse or something.

2: It’s always a factor in the equation, there’s no spontaneity, I totally agree.

3: Everything has to be planned, you’ve got to take it into consideration.

4: If it’s not bad enough with all the normal everyday problems that come along with MS, the pain to top it off, it’s just, you know, too much to bear sometimes I think...

Discussion
The findings that emerged from this study provided valuable insights into the multiple and complex ways in which people with MS make sense of and give meaning to chronic, disability-related pain. Four potentially distinct yet interrelated themes captured participants’ experiences and interpretations and reflected the multidimensional impact of MS-related pain on their lives.

Participants’ descriptions of the pervasive nature and impact of MS-related pain underscore the profound suffering and loss that accompany chronic pain in this population. Consistent with survey findings (Archibald et al., 1994; Ehde, Gibbons et al., 2003; Ehde et al., 2006), participants most often reported daily, persistent pain of moderate-to-severe intensity. Typically, participants experienced multiple yet distinct pain sites, such that chronic, bothersome pain became a background onto which other pain problems were superimposed.

As pain is endured and extends for months to years, it affects every facet of daily life and thus becomes an integral part of the identity of the person with MS. Participants repeatedly mentioned a perception that pain imposed restrictions on their activities and control over their lifestyle. Over time, a downward-spiraling process ensued, with their normal activities and interactions with others becoming significantly limited by ongoing pain, resulting in further social isolation and emotional distress.

The direct consequences of living with MS-related pain emerged as participants shared how pain had curtailed their physical activity, depleted their energy, prevented sleep, caused emotional distress and despair, and interfered with their social and intimate relationships. These findings support preliminary evidence that suggests pain is associated with significant psychosocial dysfunction in people with MS (Archibald et al., 1994; Ehde, Gibbons et al., 2003; Warnell, 1991) and echo common sequelae of chronic pain reported in the general pain literature (Hitchcock, Ferrell, & McCaffery, 1994).

For participants, however, living with the impact of pain was significantly confounded by the fact that others invalidated their experiences. Indeed, much of the suffering associated with their pain seemed to originate in the overarching perception that “nobody understands.” Although participants encountered the social stigmatization associated with having a visibly disabling condition, far worse for some was the prospect of their experiences of pain and suffering being discredited by others based
Unlike the visible manifestations of multiple sclerosis, pain is privately experienced and demonstrable to others only through the individual’s narrative or nonverbal pain behavior. It is the very nature of chronic pain—its invisibility, its subjectivity, its challenge to the biomedical paradigm—that is deeply problematic for the sufferer. Unlike the visible manifestations of MS, pain is privately experienced and demonstrable to others only through the individual's narrative or nonverbal pain behavior. Fordham and Dunn (1994) reported that “pain, as an interior landscape, is a separate world not populated by others, even when the external world is shared...knowing by others is once removed” (pp. 14–15). In the absence of any observable indicators of pain, study participants struggled to convince others that their suffering was genuine. They described a process whereby their personal experiences were systematically disconfirmed at the hands of clinicians, coworkers, friends, and family members, who, lacking an objective or external referent for pain, dismissed or refuted the legitimacy of the participants' concerns.

Participants were perhaps most acutely aware of the contested nature of their pain experience during encounters with healthcare providers. Pain had a profound impact on participants’ lives, but from their perspective, healthcare providers did not assign it an appropriate level of importance. Participants’ opinions and experiences were seemingly devalued and clinical relationships were undermined through a loss of trust and meaningful communication, an experience reflected in the study by Courts, Buchanan, and Werstlein (2004). Providers often trivialized the pain by characterizing it as a natural or expected part of the disease course, or they dismissed it altogether as an unrecognized entity in MS. These findings support those of Dudgeon, Gerrard, Jensen, Rhodes, and Tyler (2002), who found that clinicians often disconfirmed the experiences of individuals with chronic, disability-related pain, forcing them to struggle to get their pain issues addressed.

Paradoxically, although the private nature of pain was inherently problematic for participants, it also afforded them a key strategy for lessening its impact. There was a strong consensus among participants that keeping pain private or concealed from others was preferable to risking having their experiences delegitimized (Dudgeon et al., 2002). Thus, participants learned to avoid in-depth discussions about their pain or illness with others and to minimize overt expressions of pain whenever possible. These findings resonate with the work of Strauss et al. (1984), which discusses the significance of the “normalizing” tactics that individuals with chronic illness use to reduce the social stigma of illness. Similarly, Hilbert (1984) and Joachim and Acorn (2000) refer to the complex decision-making processes surrounding disclosure or concealment of pain and illness that individuals with chronic conditions must negotiate.

Distancing significant others from their pain also prevented participants from feeling that they were burdening family and friends with problems they could do little about. Participants related how family members became increasingly frustrated and even resentful as pain evolved into a chronic issue, a problem also identified by Kerns (2000). Many commented on how their pain problems created interpersonal tensions within the family and restricted their shared social activities. Henwood and Ellis (2004) found similar concerns about burdening significant others with the stress and limitations imposed by chronic pain among individuals with spinal-cord injury. Paulson, Danielson, and Soderberg (2002) likewise found that the men in their study concealed pain from their families so as not to burden them and to avoid being perceived as “whiners.”

Chronic pain, together with other MS-related symptoms, fundamentally altered the participants’ everyday experiences. Negotiating a life with pain appeared to be an ongoing and challenging process. Participants constantly struggled to maintain some sense of normalcy in their lives. The pervasive nature of pain, coupled with the uncertainty and unpredictability of illness, meant that they could take nothing for granted. Pain always had to be taken into account, and participants made choices concerning their lifestyles accordingly.

Planning for and around pain therefore emerged as a significant issue among participants. They learned to become highly attuned to their bodily experiences, so that they could prevent or minimize pain by making careful decisions about which activities to engage in. Whenever possible, they avoided known triggers such as hot or cold ambient temperatures or prolonged physical exertion. Dudgeon, Tyler, Rhodes, and Jensen (2006) identified rather characteristic patterns of coping with chronic disability-related pain.
based on individuals’ distinctions between “usual” versus “unexpected” pain episodes. Consistent with the current findings, they found that usual or expected pain was managed through prevention, by choosing and planning daily activities, and/or making pragmatic decisions by prioritizing activities and degree of participation. However, unexpected pain, which can arise without warning, necessitated strategies such as mind-body disassociation, “safety nets” (including medication or social-support networks), and activity prioritization (Dudgeon et al., 2006).

The majority of study participants conveyed a sense of acceptance of pain as one of many consequences of living with MS. There was a consensus across groups that pain was an enduring part of life that demanded continued attention and accommodation. Pain was not, however, experienced in isolation from other MS-related problems. Rather, participants’ illness experiences were the intersection of many different symptoms and challenges facing the person with MS, a fact that was reflected in their narratives (Nicolson & Anderson, 2001). Any meaningful assessment of or intervention for MS-related pain, therefore, must begin with this complexity in mind.

Implications
The themes that emerged in this study offer an insider's perspective on living with chronic, disability-related pain. The pervasive nature and impact of MS-related pain was an intrusive and often controlling factor in the lives of the study participants. They longed for understanding and validation of their pain experiences by family, friends, and healthcare professionals and struggled with difficult issues concerning the legitimacy and invisibility of their pain. Given its contested nature, participants often sought to keep pain private from others. The participants shared how MS had transformed their worlds into ones in which pain and discomfort had become a normal part of everyday life, requiring careful negotiation and planning to undertake activities and prevent exacerbation.

These findings have important implications for healthcare professionals. To adequately support clients with MS in their efforts to cope with pain, healthcare providers first need to understand and appreciate the pervasive impact of chronic pain on the life of an individual with MS. Given the myriad other MS-related symptoms that patients experience, pain may be overlooked in the clinical setting. However, clinicians should not discount the problem of pain in persons with other, more obvious impairments. It is important that clinicians allow enough time during interactions to discuss pain and pain-related concerns.

The research findings also point to a significant deficit in the literature on disability-related pain. The data gathered in the focus groups show that the delegitimization of pain familiar to those with enigmatic chronic pain conditions does not evaporate with a confirmed physical diagnosis, and yet, the invalidation that the study participants experienced does not appear in the disability-related research. This complex social phenomenon merits further exploration among people with chronic pain secondary to a physical disability.

A simple yet profound approach to alleviating the suffering associated with MS-related pain is for practitioners to acknowledge and validate individuals’ pain experiences. Much can be conveyed through the clinician’s simple actions and nonverbal communication to demonstrate the importance he or she places on the individual’s concerns and to confirm that they are believed (Clarke & Iphofen, 2005; Fordham & Dunn, 1994). Confirming to the person living with MS, as well as to the wider public and professional community, that pain is a legitimate symptom of MS is also important.

Most important, healthcare professionals need to develop techniques of engagement and active listening to better understand the processes whereby an individual gives meaning to the experience of pain. Fordham and Dunn (1994, pp. 17–20) offered useful advice concerning this process of “coming alongside” the person in pain. They identified three central tasks: (a) entering into the experience and establishing a presence by exploring the nature, meaning, and consequences of pain for the individual; (b) sustaining the connection and maintaining the presence by developing trust; and (c) helping the person to make other connections by involving relevant members of the multidisciplinary team. Most of these goals can be achieved through skilful communication, which helps to develop trust and rapport between the healthcare provider and the person with pain.

However, healthcare professionals should be cognizant that people with MS may be reluctant to disclose or discuss their pain problems. During clinical evaluations, practitioners may need to make greater efforts to explore potential pain problems with clients by asking open-ended questions, making tentative statements, and gently probing for pertinent information. Dudgeon et al. (2002) recommended that it may be helpful for some clients if the practitioner normalizes pain by stressing that it is a common problem for people with physical disabilities. Newly diagnosed clients might benefit from receiving general information about MS-related pain and direction to seek treatment promptly if pain problems occur.

Summary
The findings reported here constitute an initial step toward a greater understanding of how people with
MS view the impact of pain on their lives. These data reveal the complex perceptions and social processes at work among individuals living with chronic, MS-related pain. They also point to the need for health care providers to challenge their own assumptions and expectations about the nature and management of disability-related pain. It would seem that researchers and clinicians would do well to carefully listen to and engage with clients’ narratives about pain and illness and reflect on what they say about the human experience of disability-related pain and opportunities for therapeutic intervention.

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Note
1The numbered quotations distinguish between participants. The same number used in a different extract may refer to a different person. Any names given in quotations are pseudonyms.

References


