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# Managing Usual and Unexpected Pain With Physical Disability: A Qualitative Analysis

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**OBJECTIVE.** With physical disabilities, persons often experience secondary pain that adds to restrictions in activity and participation. We investigated pain-management strategies used by those with physical disabilities.

**METHOD.** Qualitative phenomenological inquiry was used in multiple interviews with ( $N = 28$ ) adults with physical disabilities (9 with amputation, 7 with cerebral palsy, and 12 with spinal cord injury) and subsequent thematic analysis.

**RESULTS.** Among those with physical disabilities, a distinction is made between usual and unexpected pains. Usual pain is experienced consistently or as a consequence of not getting adequate rest, exercise, or stress-free time. Managing usual pain involves uses of prevention (e.g., exercise/fitness) and/or pragmatic actions through scheduling and pacing daily activities and taking interim retreats. Unexpected pain is experienced periodically and requires an immediate response and change of activity. To manage, persons describe making efforts to create a mind and body disassociation, activating safety nets to support function and alleviate pain, and making decisions to persevere with activity and participation.

**CONCLUSION.** Advising those with physical disabilities to do proactive planning for both usual and unexpected pain may help them to use varied pain-management strategies to enhance function and minimize negative impacts on participation.

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Persons who are living and aging with physical disabilities often experience pain soon after onset of impairments, which then usually continues throughout cycles of time with the disability (Ehde et al., 2003). Such pain is a leading cause of activity limitation and reductions in participation (Fransen et al., 2002; Seers, 1996), and is of importance to occupational therapists who advise and treat these individuals. Managing pain as part of daily living becomes necessary, but tactics used by those with physical disabilities who have secondary pain have not been adequately explored. Although those who have chronic pain as a primary disabling condition has been well-studied, but with some controversy (Turk, 2005), managing pain may differ among those with physical disabilities who experience pain as a secondary disruption to function. How those with physical disabilities deal with or manage persistent pain remains unclear, and the extent to which these tactics are like those of other chronic pain populations is uncertain.

A lack of understanding about how those with physical disabilities experience and manage pain can be problematic for occupational therapists working with and advising individuals to promote function and participation. In this study we explored pain experiences and management tactics being used by those with physical disabilities. Study participants experienced persistent problematic pain and through a series of interviews described impacts from pain and lifestyle changes they made to deal with pain.

Studies have traditionally used survey assessment methods to examine the impact of chronic pain by assessing pain interference and coping responses in samples of those with chronic pain. This is usually done by asking about day-to-day

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activities (Kerns, Turk, & Rudy, 1985), the frequency or degree of disruption to activities or mood (Cleeland & Ryan, 1994), and/or the frequency of using various coping responses (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Jensen, Turner, Romano, & Strom, 1995). The associations among these domains are then examined to help identify adaptive versus maladaptive coping strategies (e.g., Boothby, Thorn, Stroud, & Jensen, 1999), active versus passive coping strategies (e.g., Brown & Nicassio, 1987), the impact of perceived control on adjustment to pain (e.g., Haythornthwaite, Menefee, Heinberg, & Clark, 1998; Tan, Jensen, Robinson-Whelen, Thornby, & Monga, 2002) and the extent to which individuals do or do not accept their chronic pain condition (McCracken & Eccleston, 2003).

Results from these types of studies have, however, been inconclusive regarding coping characteristics and impact on functional as well as psychosocial outcomes. For example, McCracken and Eccleston (2003) contend that it is difficult to conclude which coping strategies are effective in promoting health and function. In their study of 230 patients with chronic pain who sought pain clinic treatment, greater *acceptance* was associated with lessening of pain, disability, depression, and anxiety, as well as improvement in daily activity and work status. In contrast, uses of praying, hoping, and diverting attention were associated with greater disability, depression, and anxiety. Arnstein (2000) surveyed nearly 500 patients from different clinical programs and concluded that *self-efficacy* (the belief that the individual has control over pain and its impact) was the most important variable related to disability experiences from chronic pain. Interventions that would strengthen the individual's belief in his or her own abilities to manage were cited as an important component of therapy.

Pain survey strategies have also been administered to those who have physical disabilities. Widerstrom-Noga and Turk (2003) surveyed those with chronic pain associated with spinal cord injury (SCI) and found that use of prescribed medications was associated with more intense pain and interference with daily life and routine activities. Although some physical interventions were helpful, unclear patterns of relief revealed an inadequacy of available modalities to manage chronic pain related to SCI. Jensen, Engel, and Schwartz (in press) assessed pain-coping strategies used by adults with cerebral palsy and were led to recommend use of interventions that would encourage persisting with tasks regardless of pain, and limit use of resting in response to pain or catastrophizing (i.e., regarding the pain experience as considerably worse than it actually is). Although these studies provide preliminary guidance to practitioners about where they might target their interventions, the majority of these studies used strategies of coping and

adjustment to pain that were investigator-generated and not patient or client-generated. It remains possible that individuals with pain may think about their pain problem in ways that are not anticipated by researchers and may cope with these pain problems using strategies that differ from those measured in current pain-coping inventories.

This paper reports findings from in-depth interviews that were conducted with persons who have physical disabilities and secondary pain. In previous papers, we reported that physical disability-related pain often has multiple sites, sources, and associations (Dudgeon, Gerrard, Jensen, Rhodes, & Tyler, 2002). In addition to this plural nature of pain, most participants acknowledged that a relative mystery existed about the causes of pain and methods of effective pain relief. Participants described the personal nature of pain experiences, and stated that they rarely talked about or complained about pain with those they knew. Participants also expressed a hesitancy to discuss their pain experiences with health care providers. In describing pain, these individuals with various disabilities used familiar words to characterize sensory and affective components of pain, as well as analogy and metaphor to describe feelings or reactions to pain experiences (Dudgeon et al., 2005).

The following study explores and describes pain-management strategies used by those with physical disabilities regarding pain and consequences from pain in managing daily life with a disability. We used a qualitative approach to explore how individuals viewed the impact of pain on their lives, as well as how they managed decisions about planning and carrying out activities or determining his or her degree of participation. These strategies are of particular interest to occupational therapists involved in advising and counseling clients regarding uses of accommodations and goal-setting for activity performance and participation. A better understanding of how individuals with disabilities manage chronic pain, and how these coping responses impact participation, can assist therapists in addressing how individuals regard activity performance and accommodations. Daily planning and pacing of activities, uses of assistive devices and technology as well as personal assistance, may be impacted by secondary pain (Ehde et al., 2003). Prevention of secondary pain while seeking to maintain fitness and performance appear to be challenges faced by the many with physical disabilities who experience secondary pain (Dudgeon et al., 2002).

By describing the insider's perspective (Peters, 1996), this article provides a view into the inner territory of the person's mind, body, and life management; a territory that is often opaque to practitioners. Insights captured from those challenged with personal pain management are expected to be particularly helpful to other individuals with

disabilities who are developing pain-management strategies and to practitioners who advise them.

## Method

Qualitative phenomenological inquiry was used to determine how adults with physical disabilities dealt with pain and its impact. Phenomenology is one qualitative research approach designed as a means for investigating questions concerned with the lived experience (Benner, 1994; Peters, 1996). This approach involves asking individuals who experience the phenomenon of interest to participate in in-depth interviews, during which participants describe their experiences as part of day-to-day life. Questions posed are broad and open-ended without constraint of hypothesis or clinical perspective (Colaizzi, 1978). This approach allows the participant to share the information he or she feels is most crucial.

### Participants

Multiple in-depth interviews ( $N = 54$ ) were conducted with 28 individuals from a variety of disability groups. Potential participants (i.e., 9 with amputation, 7 with cerebral palsy, and 12 with spinal cord injury) were identified and contacted by liaisons (e.g., nurse clinician or therapist) working with each diagnostic group through clinical services affiliated with our pain research program. These participants with bothersome pain for 3 or more months were known to be particularly articulate and thoughtful about describing their views and experiences, and were purposively selected because their disabilities necessitated use of adaptive means of mobility as well as other medical and functional adaptations. All individuals identified and approached by liaisons agreed to participate in the study. Prior to interviews, participants signed informed consent forms and agreed to protection of identity by coding and de-identification of audiotapes and transcripts. Our institutional review board approved all study procedures.

See Table 1 for description of study participants.

### Interview Structure

In a series of in-depth and open-ended interviews, participants were asked to describe their pain and pain-management

experiences. The interview protocol consisted of up to three interviews per participant ranging from 45 minutes to 2 hours each. Interviews were conducted in person by one or more of four researchers in either a participant's home, community setting, or the researchers' offices, whichever was most convenient for the participant.

The interviews were guided by open-ended questions. The interviews were organized around broad topic areas related to pain and impact on function. A number of techniques were used to promote an open discussion, such as explicit explanation of the interview purpose and process. This explanation introduced the notion that the participant was the expert and the interviewer wished to understand what it is like to live with disability and pain. Interviews started with lead questions such as, "How would you describe your pain?" The first interview tended to focus on describing pain experiences and the impact of pain on daily activities, work, and relationships. For example, we asked, "How has pain impacted your day to day activities?" In the subsequent interviews that discussion was continued and participants were then asked about other aspects of managing pain. Because we wanted the participants to feel free to guide the interviews, the protocol was flexible and the order of discussion often shifted depending on the direction that each individual took. From the start, participants were told that they would be determining the important things to discuss. The interviewer guided the participant to fully describe pain and what they did in response to pain. Participants were encouraged to paint a vivid picture about daily management of tasks, the situations in which they occurred, and how he or she coped with pain experiences. Throughout the interviews, the researcher would attempt to echo what the participant had said and then encourage more discussion. This process enabled clarification, helped to develop a shared vocabulary, and reinforced to the participant that his or her comments were important to the interviewer.

Interviews were audio recorded and transcribed verbatim. The accuracy of the transcripts was verified by one of the researchers relistening to tapes while reading transcripts and making corrections if necessary. Following each interview, the interviewer made notes about the salient topics discussed by the participant. Other investigators listened to or read interviews and made suggestions for follow-up

**Table 1. Participant Characteristics**

	Number	Mean Age Yr (SD)	Gender M/F	HS or GED	Voc. Tech. Some College	College Grad. or Grad. School
Lower Limb Amputee <sup>a</sup>	9	47 (16)	7M/2F		6	3
Spinal Cord Injury <sup>b</sup>	12	43 (8)	11M/1F	1	7	4
Cerebral Palsy <sup>c</sup>	7	35 (10)	4M/3F	1	1	5

Note. Pseudonyms: <sup>a</sup>Bernie, Bryce, Edward, James, Jules, Kiran, Kristine, Mark, Norman.

<sup>b</sup>Ian, Kate, Kimball, Kyle, Ned, Perry, Peter, Randy, Robert, Trent, Shaw, Wesley.

<sup>c</sup>Brad, Farah, Gary, Kevin, Landon, Sarah, Susan.

questioning. Participants received transcribed interviews and the investigator's summary of the interviews and initial interpretation of shared information. Participants were invited to make corrections or amend the descriptions used. Sampling continued until the same or similar kinds of information were spontaneously introduced, as is standard practice in phenomenological and other kinds of qualitative research (Munhall, 1994).

### *Qualitative Data Analysis*

Data analysis was consistent with the principles outlined by Benner (1994). Each transcript was read multiple times in order to appreciate the essence of the entire interview. The interviews were then reexamined several times, in order to begin the process of identifying portions of the interview that expressed an idea or opinion about experiences with pain. Initial codes for this investigation were tangible and descriptive, most often using the actual words of the participants themselves. For example, "activity" was used by some participants and was combined with an overall code "details of life" for any discussion about things that he or she engaged in during the day (e.g., work, activities of daily living, instrumental activities of daily living, play/leisure). As the transcripts were reread, common themes became evident. For example, "authority" emerged as a theme that reflected the participant deciding to use his or her knowledge and expertise to carry out pain treatment and pain-prevention activities (e.g., using ice, resting, paying attention to body) as well as to negotiate with health care providers about use of pain medications or other treatments.

Over a period of months, the research team met and developed 22 codes based on the topics and themes identified. Interviews were entered into the qualitative data analysis program Atlas-ti( for textual coding separately and in joint sessions by the authors and other research staff. Transcribed interviews were coded by two or more authors with periodic analysis of agreement and confirmation in coding decisions. Differences in use of codes were then discussed until a consensus was reached and coded transcripts were amended accordingly.

Initial interpretations were presented to colleagues experienced in conducting research using a phenomenological approach and others familiar with the disability groups represented by participants. A commitment was made to honor the perspectives of participants, and credibility of the findings was validated by further discussion with the participants as part of follow-up interviews (Benner, 1994). Two previous papers have been published based on data from these interviews, focusing on the ways that the study participants described their pain experience (Dudgeon et al., 2002, 2005). The current study focuses on a specific

theme that emerged in these interviews: managing with usual versus unexpected pain.

## Results

A common distinction about pain made by all participants was acknowledging differences between pain that was usual versus unexpected. We previously reported this finding (Dudgeon et al., 2002) and will elaborate here on how these two kinds of pain problems call for different strategies to manage pain, and have different consequences in terms of decisions made by participants about activity and participation.

*Usual or expected pain* is a consistent or predictable experience as part of daily life or within weekly or monthly episodes. James said:

I know when I'm going to start to hurt, and be tired and worn out. But now I know exactly when it's going to happen. And it's lessened because my tolerance and probably my physical shape have gotten better because of more activity now.

Landon stated that with usual pains "you predict when that will happen or what you're doing. I kind of know what I can get away with, but I don't push it."

Perry characterizes usual pain in describing that:

Dealing with the pain is just dealing with the pain. It's just something that I wake up with every morning. Some mornings are worse than others. Randy notes usual pain as, "Never going away. Because I know it isn't. It's one of the things you either accept or you might as well bag it right at that point and not go any further.

Usual pain is by no means stress- or problem-free. Landon went on to describe, "You're always wondering if it's going to get worse. That's the ultimate problem." Kyle described that pain was a regular part of him, stating, "You don't even have the basis to begin to separate yourself from it. It's internalized; it's you, the pain."

In contrast, *unexpected pain* arises without warning or is unexpected for the time or situation. Brad said, "It happens when I'm stressed and when I'm bending over or step down the wrong way." Landon described that for him, "It's really hard, there's no set day, you know you really don't know what's going to happen. Some days you'll walk and get lethargic for two hours and it will clear up. Other days it's like that all day." Kristine said, "I can't predict at all when it's gonna come. It comes and there's not much I can do." Bernie also describes that unexpected pains are difficult to cope with:

It can get quite severe. There's nothing you can do. We've tried these little packages of artificial ice and tried to cool it off and it doesn't do any good. We've tried a lot of things. I

just lie there and go through with it. When it's over, it's over. If I don't feel it coming on, I can't control it. And there are the times it is just boom, it's there and it gives me a shock.

All disability groups described unexpected pain. Ian said, "I have to just bail out when I'm really in pain. I would really have to back off, because my head is spinning, or you know [the pain is] all dredged up already." Trent described, "I know the days when I'm really hurting, it's just like I get nothing done. That hurt is always nagging at you so . . . when I'm in real hurting, I don't do much."

Different techniques were described as part of attempts to manage, or cope with, usual versus unexpected pain episodes. Most participants described that they experience both and problem solved differently and creatively for each (see Table 2). Usual pain is dealt with by hoping for prevention, careful planning, and pragmatic decision making about engagement in daily activities. Unexpected pain requires an immediate response and change of activity. Participants

described trying to make a mind and body disassociation, using safety nets to help relieve pain and assist with functional needs, and prioritizing those activities for which they were willing to persevere. Specific tactics for each of these strategies are described next using participant's descriptions.

### Managing Usual Pain

To manage usual pains, choices include use of prevention, planning, and pragmatics. For anticipated pain, prevention may involve exercise/fitness, diet, sleep, and stress avoidance. Planned use of these tactics and/or pragmatism in choosing and pacing daily activities are described. Seeking and hoping for a solution or taking an interim retreat may also be used to help manage usual pain.

### Prevention

Kristine said, "Of course, the key is to prevent pain." Better "physical shape" was important to her. She described:

**Table 2. Daily Activity Planning and Participation Themes**

Usual Pains	Prevention Hopes	Careful Planning	Pragmatic Decision Making
	"I do a rigorous routine of stretching every night, every night you got to do it. So the stretching really does play a big part in everyday activity."—Kimball	"I've got things scheduled, and it makes it a little bit easier to deal with the pain, because I don't have time to think about it."—Kiran	"If I'm hurting bad I just don't go to anything but work. I'll still go to work but anything else I'll cancel."—Ronald
	"I know that losing weight has a lot to do with my general health, which is another thing I'm kind of working on."—Shaw	"I need to go out and do something. Even if I encumber some pain, it's worth it. Because if you don't have any activity, the pain . . . a minor pain will be blown up to make it even bigger."—Landon	"Pain just keeps me from tackling some of the things the need to be tackled around the house."—Norman
	"I found a lot of ways that I fight my stress. I create my own stress, by pushing myself so hard. And I've found ways that I can settle it down. I think I've found a way to use my mind."—James	"I will look at how far do I have to walk? And I will analyze whether I think I can do it, or take an alternate. I save my strength for the activities that count and try and take an easier path on the things that are not as critical."—Norman	"I tend to when I really start hurting I get real quiet and reclusive. I kind of tend to just go off and be alone. 'Cause I have a hard time communicating when something's nagging at me that bad."—Randy
Unexpected Pain	Mind and Body Disassociation	Relief Safety Nets	Prioritization and Perseverance
	"When you get involved doing other things it kind of takes your mind off of whatever your problems are. And if you've got a job to do then that kind of helps you to see it through."—Kimball	"I constantly have that support from my family and my friends. And if I didn't I don't think I would make it this far."—Kiran	"Somebody like me has got these nagging problems, but you have to kind of go out and fight it off and do something else, keep going."—Landon
	"So I want to put the TV on and try to be stupid. And try to put my mind somewhere where I won't allow the pain to come in. Or play music, something that you really have to listen to, not fluff. Something to really take the mind off."—Peter	"There is a pain that will actually make me take medication. Either Benadryl so I can fall asleep and or I'll take something like Tylenol with codeine after I haven't slept for one or two nights. I usually have some of those around."—Kristin	"I'm doing this, get on with it, get it done with, and don't sit around and think about."—Ned
	"I wish I could be a little bit more blitzed out, or detached from my body's reminder more."—Ian	"The only thing that the drugs do is they touch the mind. But they don't seem to touch the pain. The pain goes on."—Mark	"Take pain relievers, just constantly moving and stretching. Or just stay a day in bed."—Perry

I have a specific set of exercises and a specific set of manipulations. I have been doing those and I feel a ton better. I also feel psychologically a ton better because I feel there is something that can be done. . . . A bad day motivates me to exercise more the next day. If I can create a lifestyle for myself where I am more flexible, and more durable, then it's going to make my life better.

Kyle also endorsed exercise and fitness, saying "I exercise regularly, I've gotten one of these universal workout machines that was developed specifically for quadriplegics, but I don't experience [as much pain] anymore because of the exercising." Wes also had similar tactics to prevent pain. He described, "To stay limber and keep your range of motion up like that, I've got a whole set of stretching and strengthening exercises, I can basically [just] do them."

Although exercise was a common tactic, proper rest and nutrition were also endorsed as prevention strategies. Ian described that he had "learned there are just certain things I need to do to take care of myself, and one of those is to lie down. I have to nap beforehand, or be well-rested. I can't just [wait until] the end of a day to relax, because I'm so tired at that point I can't concentrate and I'm distracted by how uncomfortable my body is. So, I get rested up and I get up and I have a good meal and I take a vitamin, and I'm feeling all good." Sometimes he relied on others to help prevent excessive disruption to daily activities. He said, "I need to get myself a massage, you know a couple times a week, whether this is paid for by insurance or not. I didn't really realize it until I kind of got into this environment, [it] taught [me] that you need to do that or you won't survive." Landon related that fitness was important but challenging:

If you don't really keep fit, you're mobility is slower, you're weight goes on quicker. So now you're going to have to eat really diligently because you're afraid to put the weight on, because it doesn't help. It really doesn't. If you don't exercise the legs get lethargic, they get atrophied. When you get fatter, you're carrying much more weight. And even though it's not painful all the time, it still makes you really sweat and tire out, because now you're just dragging weight around. Now can you imagine when it hurts? Then you're dragging the weight around plus the ache in your back or ache in your leg. See it's like a double whammy.

### *Choosing and Planning Daily Activities*

Performing valued activities, and using activity to distract or mask pain was also described as a common pain-management strategy for usual pain experiences. Being active seems to serve several purposes. Landon said about his pain, "I knew it is there, you could feel it, but at least you're kind of absorbed in the movie or you're kind of displacing your pain, you're doing something else." Ian said, "I can easily

deal with pain, or at least 75% of the pain I have in a day to deal with, with just what I'm doing. You know my interest level in [what I'm doing]. So in that way it helps for sure." For James to manage regular pain he liked to have something to ". . . take apart, and put together. Something that involves hand-eye coordination . . . involves intelligence. A task that is worthwhile and personally satisfying, but also another way to ignore [the pain]." Kristine said, "Most of the time the activity I'm doing I actually enjoy so much that it's worth the pain. I'm really enjoying working and I love yard work too. And I like the fact that I can do it. I really like doing it. I'm glad that I'm physically able to do it. During the day, with activity I can kind of mask [the pain]."

Planning was important to Kristine in managing usual pain. She described that she felt the "The impact, being [disabled] . . . requires maybe more thinking and planning than what I imagine other people go through." She points out that one is ". . . thinking about the logistics, and always having part of your brain concerned with planning. I am doing fine right now because I am still doing things that I am very familiar with and I know the situation." She describes how her daily routine starts:

First thing, is it prosthesis or crutches? If I have to wear the prosthesis, I'll try and make sure I get a good fit in the morning. I'm pretty careful about cleaning it out at night, what ever I can do to minimize skin breakdown. I make sure that no clothes get caught. I'm pretty thorough with that. I'll look outside, see is it going to be . . . is there any chance it can be warm out there? I'll dress usually on the cool side to avoid getting too hot. And then hope for a good day.

Having a routine and accomplishing something were also acknowledged as a management tactic. James described, "Now I'm up at the same time every morning. And I get home roughly at the same time every night. I do about the same thing every day. I walk about the same. I'm in my leg prosthesis about the same amount of time. So it's . . . a consistent activity creates consistent reaction." For him a sense of accomplishment was also important. He describes, "The way my personality works, if I'm not productive then everything is a shambles. So being productive is probably the major key to everything else settling."

Routines were often helpful to organize, and often seemed to promote continued engagement. Kiran expressed that, "Every single day when I wake up I basically prioritize what I've got to do. What needs to be done versus what I want to do? And what I tell myself is I'm going to give myself energy to get up, get ready, and go, I have to plan something out." She went on to clarify that:

. . . it was painful but I got myself on a routine and that really helped me out because I say "No, I got to do this. I can't

miss my class, no I can't miss work, I can't do this." I said to myself, everything was scheduled. I scheduled every single thing, it worked out so great. I need that structure, and I need that to help me cope with the pain too, 'cause then I know I have the pain but I'm constantly doing something.

Mark acknowledged the importance of routine, saying, "routine to me is a blessing in disguise, for everybody."

Routines may also need modification or are acknowledged as a compromise. Susan described, "I've come up with a really good combination of things that help keep me out of pain and that allow me to sort of push the limitations of my body as far as I can without doing damage. You just make the best decisions you can at the time. And hindsight gives you a whole lot of information." Ken said that, "generally I can get through; I don't have to cancel anything. But often it's because I'm lucky and didn't have anything to rush to. I had time to fall apart. I just avoid a lot of risks." Some limits to activity routines are certainly experienced. Ian described, "It would really help my life to have that part of my health under my control, or under more control. I'll just keep going a little bit further because I want to get [my work] done, [But] then at some point you just can't deny it any more."

### *Pragmatic Decisions*

Being active and having a routine are positive ways to manage usual pain, but daily or weekly adjustments are often needed. Dealing with actual occurrences of pain and interference leads to pragmatic or sensible decisions about sticking with first choice activities, leaving some tasks alone, or abandoning participation and taking an interim or brief retreat. Kiran describes a general attitude about usual pain, "The pain is there, and it's going to be there, so I might as well just do what I want to do too. It's there, but I've got to move on and do what I want to do, because otherwise I'm going to be [stuck at home] because of this stupid pain."

Individuals often had particular priorities for activities they would stick with. Jobs were very important to those who had them. Mark described:

I'm a very hard worker. I love to work. So . . . what I did for pain is I didn't do anything. All I did was I mentally blocked it out. I just didn't think about it, or just went on. Then at the end of the day I would collapse. Then I'd get up the next day and go to work.

Ronald described:

There's been some things I really wanted to do but I just didn't feel like I could be "me" at that. I've been invited to some friends' wedding, but I just couldn't. I didn't feel like I could drive safely there because I was hurting so bad. I didn't feel I could be real sociable 'cause I was just hurting too bad, and then I've just not gone. But I'd still go to work.

For Peter, pain did not

. . . interfere with my recreational activities. Regardless, I'm going to do something for recreation. It just changes what I do. It changes what you do for your vacation, but it doesn't necessarily interfere with your vacation time. It doesn't interfere because I just do different things.

Wesley related the importance of self-care. "I'm to be cleaned up. I'm to be shaved, and I'm going to have my teeth brushed. Self-care [is very important], I take care of myself." Lower priority activities were also indicated. For example, Norman related that "dust bunnies" could be left alone. He said, "When I'm not feeling up to my normal, I certainly don't do anything around the house that needs to be done; my laundry, picking up after myself. It just sits there. I'll do some of the rudimentary things that are not so dependent on feeling in tip-top shape."

From usual pain challenges, some cumulative wear and tear throughout the week was often expressed. Some activities were left alone or participation was viewed as strained. Trent described, "I can fight through that and still be a happy camper. But if it nags on for 2 or 3 days and then slowly it just kind of eats on my nerves and everything. Then you'd say I get a little harder to get along with." Perry described, "Often there is nothing I can do to make it easier. I just deal with the uncomfortable, and those are the days where, I'm withdrawn; I don't interact, unless I have to with people. And if I do it's very minimal. Because [pain is] mood controlling."

Ultimately, participants with usual pain described routine planning of a functioning "retreat." Mark's routine retreat was to ". . . spend about an hour, generally with a cocktail and I'll just sit. I'm downloading my day and I'm loading what I want to do tomorrow, and I'm reinforcing this wall about my pain." Peter described, "I want to turn the stereo on. I want to sit and do nothing. You know, really veg. [Pain] is really there all the time; I get away from other people, get away from interactions. You might still want to listen to music or watch TV, but you don't want to think and talk to other people." James said, "I have at least 2, if not 2 1/2 days, that are fairly low-key, low-intensity days, where the activity level is very low. I call 'em my recuperating days. More often than not at least 1 day out of the week is a flat out on the floor, asleep, don't move, don't do anything day." Perry's reduction in activity was described as, "If the pain is bad I just won't do [things]. Because rolling in this chair over cracks and bumps and everything, you know it just intensifies it, so I'll just stay in my apartment and just, wait until the next day, or until it dims a little bit." Wesley said, "I just crash out." And Kate explained her need to retreat by saying:

When I'm having a big pain day? I have a tendency to sit real quietly and not do much. Not really move around

much because it's so overwhelming. I just have to sit quietly, chill out, read, watch TV, pay my bills, and stare. Basically I have to make myself very, very calm I guess is what I'm saying. And just really try to relax my body as much as possible and deal with it. And go with the waves.

Usual or expected pain lead participants to acknowledge things they did to try and prevent pain, how they ultimately need to carefully choose and plan daily activities, and how they made pragmatic adjustments by prioritizing activities and degree of participation. Sometimes a retreat is taken to get a break from routine pain experiences.

### *Managing Unexpected Pain*

Dealing with unexpected pain was characteristically different from what individuals did for the usual pains. Although not necessarily successful or satisfying, the participants described that when confronted with the unexpected pain they need to take immediate actions. Strategies for dealing with unexpected pain included creating a mind and body disassociation, utilizing safety nets, and prioritizing activities. Mind-body disassociation involved letting the body be free to do what it was doing, but keeping the mind engaged by directing a task. Safety nets included use of available medications as well as on-call friends, family, and health care providers. Ultimately, activity prioritization took place. Participants expressed unique decisions about those tasks they choose to persevere versus those they would cancel or avoid.

### *Mind-Body Disassociation*

Uses of activity were often described as one way to separate body awareness from unexpected pain. Ian described:

I can distract myself or dull it down with [my work]. I tend to work at night, get up at around 10 or 11 at night; stay up all night because it's quiet. So I'm sitting here in the living room and it's dark, and sometimes I just like to come up with something to work on my own and just go in to it fresh. But I can feel myself sitting in the wheelchair; I can feel little spots that ache. Those little things that are irritating, there's just enough they're distracting me.

Detaching from pain is often not successful. Kyle described, "My perceptions of pain are that it's something external, it's not me. But I can't, I can't manage it mentally. Or I haven't figured out how to do it. And frankly I've lost interest in trying." He described having "This [unexpected] mind-numbing pain," and that

there was no getting around that, boy there was no mental gymnastics that worked, you know that was just wiping-me-out pain. With that it hurts to do everything, I mean it hurts to breathe and the whole nine yards, just big as a mountain. It was very difficult to get any separation between you and the pain. Once you get a little separation

between you and the pain, then that's a place to stand, it's a basis to stand there where you can maybe start formulating a different way to perceive the pain. But when the pain is of you, then you don't even have the basis to begin to separate yourself from it. It's just, it's internalized.

Distracting the mind from the body took deliberate efforts, especially with unexpected pain. Ian expressed, "It takes a lot more will, I think, to put that out of my head. To put aside those expectations and the anticipation of where I think it is going to go and to just use faith I guess to let good things happen." Others tended to speak positively about how "ways of thinking" could be helpful. Kiran related that:

I get frustrated and that's when the pain . . . I can feel the pain a lot more. I learned to hide it. You don't have to hide it from [other people] I'm just . . . by hiding it what I mean by saying that was that I cope with it a little bit better.

James described that for him:

Learning is a very soothing remedy for discomfort. Whether it is emotional or physical pain. Humor also soothes the soul. It's better to laugh than cry. Crying does nothing. I've cried . . . but if you laugh at least you're not thinking about the sad. So it's better to think about the happy. That's how I think.

Mind-body disassociation was marginally successful for most participants, so they also needed to take other actions.

### *Safety Nets*

One of the ways that individuals manage unexpected pain episodes was to create what Susan called a "safety net." She described, "I created a very specific support circle of friends. I mean I had everybody meet together. I told them what kinds of things were happening to my body, what I referred to as a crisis. I actually set up a phone tree so I'd only have to call one person and then [help I needed] would sort of fall into place. And it's really cool to have friends that are willing to do it. But it was a lot of work to get that in place." Brad said, "My mom [will] come down to help me out." Norman also developed relationships at work to help him when having a particularly bad day with pain. He said:

I've got a great support group at work. A partner that I work with, he's always there. If I want a soda, he'll go downstairs and get the soda, bring it up to my desk. He's . . . anything . . . "Can I carry this? Can I carry that?" "Well, you could carry me." [Laughing] So it's nice and it's nice having people to do things with. So there's a lot of support mentally, and physically from my friends.

Another "safety net" for participants was use of medications, ranging from anti-inflammatory to opiate. Regardless of medication type, use very often came with great reluctance. Wesley indicated at times that he had sleep deprivation from pain:

I'm an expert on sleep deprivation. I take sleeping pills if I really have to. Only if I know I'm going to be hyper from pain and not want to go to sleep. But if you take a drug, that will inhibit your own awareness of your dream. Plus you wake up feeling groggy and drugged. Kind of like a hangover, I hate that. I prefer not drugging myself to sleep.

Kristine was also conflicted about taking and relying on medications. She described, "Taking medication goes back to my family, you don't take medication unless you really, really need it. It fosters chemical dependency and it was always portrayed as a bad thing. And then with my husband, he really put me right on that. He said, 'You're not taking a huge amount. We'll watch it but if you need 10 Tylenol a year, that's okay.' And so I feel more comfortable now." Periodic, or just the right time, use of medications was often described. Brad said, "Some nights, last night, I took some Excedrin PM, so I kinda slept through the night; but some nights I wake up more than once." Landon stated, "Sometimes if you take an ibuprofen it will clear it up and you feel like a new man."

A desire for an effective medication was often expressed. Norman said:

I feel pretty good today, but some days. . . . My back hurts and my leg hurts, but it's not something that's just killing me that I just sat and stooped over, not wanting to do anything. It's not that bad. But I have a lot of days that it is. And I just would like to [have a pill that would] take that edge off so that I don't get in that stupor. I've hurt myself worse by trying to get through [the pain], so then I've got 2 or 3 days I just . . . can't sleep. And that's what I'm hoping for [from a medication], just take that edge off, so I don't get bad.

Sometimes medication didn't offer a long-term solution and left participants hoping for other solutions. Mark related:

I would take one [pill] in the morning and take three of 'em a day, and it worked great. They were just super. But I had gotten away from using my mind. Medication worked for a little while, worked for about a year. I thought that would do it. That would get me over this hump. But it didn't. And in fact in a lot of ways it made things worse.

### Activity Prioritization

Mind-body disassociation and uses of safety nets worked at times, but participants also needed to prioritize and choose specific activities to engage in. Participants expressed a need to invoke extreme or novel prioritization with unexpected pain. Perseverance with activity or participation was necessary at times. Peter said:

None of this pain will make me unable to use the computer. The shoulder pain makes it very difficult to do a lot of typing. I wouldn't be able to, when my shoulder is bad, I wouldn't be able to type a letter to somebody. But I'd be

able to push the keys every so often so I could read *NewsNet*.

He also said, "Most of the time it will not stop me from doing something that I *really* wanted to do. Like we've had tickets to go see some concert for a long time, that pain is not going to stop me from going. It may lessen the enjoyment, but it won't stop me from going." A top goal for Shelly was to finish her dissertation, and nothing would interfere with that effort. Norman said that pain:

Doesn't keep me from doing my exercise, it doesn't keep me from driving, it doesn't keep me from working. It may distract me for a while, but it doesn't keep me from it. If I've got a day planned and the prosthesis is acting up then I'll just go without. Or if it's a really important thing, I'll just tough it out. And I'll be uncomfortable, but I've yet to let anything stop me.

James described his perseverance by saying: I'm tenacious, I'm very tenacious. Just because it hurts daily doesn't mean it's going to stop me. It may slow me down a little more some times than it does others but I won't quit. I'd just as soon grind my body into a pulp physically . . . all my life I've learned to live it as much as I could. And just because of this I won't stop.

Trent concludes, "I could be more active if it wasn't so painful, but otherwise I just go and do my thing; I have to."

## Discussion

The aim of this study was to understand how individuals who have physical disabilities and pain perceive their capacity to manage or respond to persistent pain experiences as part of everyday life. Strategies they used to handle pain and its consequences were differentiated by participants as a function of usual versus unexpected pain types. Managing pain is also characterized by participants as something they took authority about to manage. Faced with both usual and unexpected pain episodes, participants reported using prioritization of activities as an important coping strategy. Often they had to choose between sticking with what they were doing or abandoning daily routines. They reported active decision making about how to manage pain as part of daily living, making choices about use of prevention strategies, and working through those tasks and roles they were most committed to. Individuals assumed responsibility with creative or dynamic exercising of choices about which activities to engage in, what pain mediating strategies to use, and with whom they shared these decision-making processes.

The concept of *self-efficacy*, or belief in one's capacity to manage pain, seemed to be an important characteristic in self-managing disability and pain. In addressing pain and interference among those with arthritis, Strahl,

Kleinknecht, and Dinnel (2000) also contend that self-efficacy beliefs are associated with better function and more effective use of pain-coping strategies. For those with physical disabilities and persistent pain, narrative descriptions attest to occupational prioritization taking place. In this process, self-care, work, and socialization become the choice made by each individual. Participants in this study take on deciding, commanding, or judging what activities to engage in and how much to persist with participation.

Relating the “*strategies*” or “*tactics*” used by those with physical disabilities and pain in this sample to other pain-coping continua is somewhat difficult. For example, the conceptions of *adaptive* and *maladaptive coping* are difficult to apply to the narrative accounts in this series of individuals. The concept of maladaptive coping comes from research that seeks to link specific pain-coping responses to measures of dysfunction (e.g., depression and pain interference) (Keefe, Brown, Wallston, & Caldwell, 1989). Because we did not formally measure functioning, we can only interpret the participant’s expressed degree of satisfaction with use of a particular method to manage pain or maintain activity as an indication of effectiveness. For most of the participants, mind–body disassociation was only marginally successful and it left participants expressing either disappointment in their ability to disassociate or frustration over the lack of effective medical treatments for pain. Likewise, retreats or isolation were often described as a necessary tactic, but usually created some decrement in social participation.

The concepts of *active* and *passive* coping styles are also difficult to apply to the accounts of pain management by participants in the current study. These concepts were first applied to chronic pain-coping strategies by Brown and Nicassio (1987). Active methods are defined as those used by individuals to control pain or to continue functioning in spite of pain. Passive methods are those associated with relinquishing pain control to others, or allowing life activities to be adversely impacted by pain. Snow-Turek, Norris, and Tan (1996) classified the copy strategy assessed by the Coping Strategies Questionnaire (CSQ) (Rosenstiel & Keefe, 1983) into those that assess active and passive coping strategies. CSQ items were shown to differentiate between active and passive dimensions, although an important point was made that these coping styles were distinct constructs, and not necessarily opposite sides of a single continuum. They suggested that individuals would benefit more from decreasing passive coping strategies than by efforts to increase use of active coping methods. Ultimately, how the individual perceives the active versus passive nature of the strategy may be most important. For example, the decision to use a medication or other substances might be regarded as an active coping response by some individu-

als and a passive coping response by others. The participants in this study expressed reluctance to take a substance, and the consequences of taking a medication was often viewed as negative.

Decisions regarding medication use, in particular, appeared to be important to the study participants. Several described a strong reluctance to take analgesics. Ironically, this reluctance may contribute to a lack of efficacy of the medications that are taken. For example, current recommendations are that analgesics should be taken on a time—rather than pain—contingent basis (Max, Payne, Edwards, Sunshine, & Inturrisi, 1999), yet the current participants describe medication as part of their “safety net” to be used only as they need it. This finding suggests a disconnection between what is known about effective analgesic care and client practices, suggesting the need for greater education among individuals with physical disabilities who have chronic pain.

It is also important to recognize that increasing pain interference has been shown to be associated with greater uses of passive coping strategies (Carroll, Mercado, Cassidy, & Côte, 2002). Although retreats and use of safety nets might be viewed as passive coping methods, the appropriate use of such coping strategies in persons with disabilities may result in an overall increase in ability to participate and to feel in control over pain and its impact. Thus, whereas decreasing use of *passive* coping strategies is typically viewed as more effective than increased use of active strategies among those with chronic pain as a primary condition (Carroll et al.), it remains unclear if this general conclusion applies to all passive coping responses among those with physical disabilities and pain. Persisting with tasks, considered an active pain-coping strategy, was a tactic used by some participants, but the cumulative effects of such a strategy on the body are difficult to predict. In short, the results of this study suggest that previous assumptions about the relative effectiveness of different pain-coping strategies do not necessarily apply to persons with physical disabilities. More research is needed to help identify those coping strategies used most often among individuals with physical disabilities and persistent pain, and to determine the relative short- and long-term effects of these strategies on adjustment and function.

The qualitative approach in this study allowed for the collection of these individual’s own perception and judgments about pain. However, qualitative research tends to be focused on the experiences of a few participants and interpretations of narrative accounts by a few investigators. Selected participants in this sample may have had higher levels of education and greater likelihood of employment compared to the diversity of others with disabilities. It is

necessary, therefore, to interpret the findings from qualitative studies with caution. Although the ability to generalize research to other contexts is generally considered to philosophically inconsistent with qualitative research (Krefting, 1991), Lincoln and Guba (1985) suggested that readers can and do make their own judgments on the transferability of the data and its applicability to another context, based on their understandings of both the context of data and the participants.

Issues and themes that emerged need confirmation and testing in future investigations. In addition, it is possible that the experiences of pain reported by the participants in the current sample may be different from those of other individuals with other kinds of physical disabilities, both in the nature of pain and the strategies available to them to manage pain. More research studying these issues in additional samples of individuals with physical disabilities and chronic pain would help determine which of the findings are applicable to other populations. Other samples of individuals with physical disabilities should be recruited for use of either or both qualitative and quantitative research methods. Both kinds of inquiries can also be regarded as time-limited and shaped by prevailing attitudes and beliefs among both clients and practitioners. Thorne and Paterson (1998) noted that studies about disabilities in general have seen a shift from an initial orientation toward challenges, loss, and suffering to revealing those with chronic illness and disabilities as having expertise, with healthy and positive lifestyle implications. Although qualitative methods can be well-suited for exploring complexity, they caution that overgeneralization of qualitative findings may occur and that chronic problems have wide variations that place complex demands on practitioners (Thorne & Paterson, 2000).

### *Implications for Practice*

Occupational therapists can benefit from studying successful and unsuccessful tactics used by those with physical disabilities as they deal with the daily living consequences of pain. Strategies that are successfully used by those with physical disabilities and persistent pain may be of benefit to other clients. Such individuals often experience a variety of pain problems, regard pain as an unsolved mystery, and may keep the pain experience as a personal or private matter (Dudgeon et al., 2002). Advising and empowering clients to do proactive planning for managing or dealing with each kind of pain episode they experience may help them better manage pain and increase overall levels of participation. Findings suggest that alternatives or options for performance need to be continually explored. Secondary pain with physical disability appears to call for multiple and flexible approaches to performance. Work simplification

and energy conservation strategies can be drawn upon. These may include ways for which personal assistance can be recruited and used; how scheduling and pacing of tasks can be emphasized; ways in which adaptive devices and assistive technologies are employed; and how priorities and attitudes about performance expectations can be enhanced. Although these intervention concepts have not been explored as part of this investigation, specific suggestions for individuals should likely be best tested in a case-by-case manner.

## Summary

Findings suggest that individuals with physical disabilities and pain cope with usual pain differently than unexpected pain. Specific management strategies used for usual pain include hopes for prevention, deliberate planning, and realistic or pragmatic decision making about activities and participation. Strategies to deal with unexpected pain include attempts to disassociate the mind and body, activate safety nets for help or relief, and make decisions to persevere. Although these pain-management strategies may not provide complete pain relief or enable full function and participation, they do at least appear helpful to the individuals who were interviewed in this study. Newly disabled individuals who develop problems with persistent pain, or even individuals with many years of experience with disabilities and pain, may find this information helpful as they develop their own pain-management plans. Direct assessment of impacts from pain should occur, and performance alternatives derived from concepts of energy conservation and work simplification are recommended. ▲

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