Chronic Pain and Occupation: An Exploration of the Lived Experience

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KEY WORDS
- adaptive response
- chronic pain
- emotional distress
- occupation
- pain
- relationships

OBJECTIVE. There is limited research on the relationship between chronic pain and occupation. This phenomenological research study explored the lived occupational experiences of people who have chronic pain.

METHOD. Via demographic questionnaires, semistructured interviews, and field notes, data were collected on 13 participants with various types of pain.

RESULTS. Thematic analysis yielded one main theme: “Chronic Pain Is Life Changing.” The following subthemes also emerged: “Chronic Pain Triggers Emotional Distress”; “Chronic Pain Reveals the Strength of Relationships”; “Chronic Pain and Occupation Are Reciprocally Related Forces”; and “Chronic Pain Elicits Innovative Adaptive Responses.” Study participants reported experiencing myriad troubling emotions; however, they resourcefully modified their routines and tasks and found enhanced meaning in favored occupations.

CONCLUSIONS. This study illuminates the importance of therapeutic listening, the innovativeness of people who have chronic pain, and the possible therapeutic potential of occupation.

the experience of living with chronic pain. In addition, we addressed the relationship between chronic pain and occupation. In particular, the study examined the effects of chronic pain on daily routines, activities, and relationships.

Understanding Pain

The International Association for the Study of Pain defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage” (2004, paragraph 3). In the event of an illness or trauma, the purpose of pain is to alert the individual to a bodily threat. Acute pain develops suddenly as a result of injury, illness, inflammation, or surgery and ends once the underlying cause is treated (National Institute of Neurological Disorders and Stroke, 2006). The precise definition of chronic pain is debatable; however, sources agree that chronic pain typically lasts 6 or more months and can be classified according to its origin (American Chronic Pain Association, 2004; National Institute of Neurological Disorders and Stroke, 2006).

Chronic pain is a multifaceted problem consisting of both physical and psychological components. The American Academy of Family Physicians (2000) reported that 58% of patients with chronic pain “experience coexisting symptoms of depression and anxiety” (paragraph 2). These patients also identified the negative effects of chronic pain on quality of life measures, such as social and psychological well-being (American Academy of Family Physicians, 2000). Furthermore, people living with chronic pain often complain of sleep disturbances, inactivity, and decreased socialization, all of which develop as a result of chronic pain (Turk & Nash, 1993, as cited in Chesney & Brorsen, 2000). Given the complexity of this problem, several theories may be used to address both the biomedical and psychological facets of pain (Nicholson, 2000).

Forty years ago psychologists Melzack and Wall (1965) proposed that a “gate” in the central nervous system may be either opened or closed to the pathways of pain impulses. According to Melzack, “The Gate Control Theory suggested that a gate in the spinal cord, responsive to both peripheral and descending influences, modulated the transmission of pain messages to the brain” (as cited in Nicholson, 2000, p. 61). Melzack (1982) wrote that external factors—such as anxiety, emotions, and past experience with pain—can alter the interpretation and perception of pain. Melzack used this gate control theory to support the notion that a person can control his or her own pain through the introduction of distracting external forces, which explains why soothing music and associating with loved ones may be helpful to the person with chronic pain (McCaffrey, Frock, & Garguilo, 2003).

Pain also may be modulated by endogenous morphine-like substances known as endorphins. Endorphins have been called the body’s natural painkillers and may diminish or heighten feelings of pain (Bear, Connors, & Paradiso, 2001; McCaffrey et al., 2003). Pleasant experiences such as “laughing, hugging, and quiet relaxation” (McCaffrey et al., 2003, p. 283) have been shown to increase the production of endorphins, which can alter or reduce pain.

Wright (2002) offered several theories to explain the physical basis of chronic pain. The “vicious cycle” explanation is that nerve afferents from muscles excite fusimotor neurons, increase the sensitivity of muscle spindle afferents, and cause a cycle of muscle stiffness. The “pain adaptation” model holds that a painful stimulus decreases the capacity for muscle contraction. Pain causes heightened inhibition in agonist muscles and heightened facilitation in antagonist muscles, resulting in range of motion limitations, decreased movement speed, and muscle weakness.

Turk, Meichenbaum, and Genest (as cited in Turk & Rudy, 1986) developed a cognitive–behavioral model that acknowledged the role of emotions, cognition, and behavior on a person’s experience with pain. They described the pain experience as a multidimensional and complex phenomenon. To better understand and treat pain, one must recognize the influence of sensory, cognitive, affective, and behavioral factors on pain. Additionally, the patient’s attitudes and beliefs related to the pain experience must be identified, as well as his or her capabilities and response to stress.

Pain and Occupation: Implications for Therapists

The emotional and physical strain of chronic pain frequently has a negative influence on the occupational performance of people who have chronic pain. These people often are limited in their ability to engage in meaningful occupations and thus may experience diminished quality of life. Studies have explored the impact of chronic pain on quality of life; for example, Gerstle, All, and Wallace (2001) concluded that chronic pain causes stress on all components of a person’s life, including family, health, psychological status, spirituality, and socioeconomic circumstances. In a study by Hitchcock, Ferrell, and McCaffery (1994), 71% of participants indicated that chronic pain affected their personal relationships, and 87% reported that pain greatly impeded the completion of normal activities. Consistent with reports from the American Academy of Pain Management (n.d.) and the American Academy of Family Physicians (2000), participants in the Hitchcock et al. study identified depression as a major problem resulting from chronic pain.

Although studies have investigated many aspects of pain and instruments have been developed to measure and quantify the quality and intensity of pain, only a limited

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number of studies have delved into the experience of the person with chronic pain. Neville-Jan (2003), an occupational therapist, used an autoethnography (a narrative self-analysis) to reflect on her own experience of pain. Neville-Jan learned to hide her pain at an early age so she would be accepted by her peers. Although she could talk openly with her family, she did not feel comfortable sharing her experience with friends. Eventually, this facade prevented honest dialogue with her physicians. Neville-Jan also addressed the importance of work and purposeful activities; in particular, she noted, “activity connected with one’s life goals” had the potential to provide relief from pain (p. 94).

Dudgeon, Gerrard, Jensen, Rhodes, and Tyler (2002) conducted a qualitative study that focused on the subjective experience of 9 adults with physical disabilities and chronic pain. The authors conducted open-ended interviews and through thematic analysis concluded that pain was a part of daily living that affected the participants’ lifestyle choices. Similar to the Neville-Jan (2003) study, participants expressed dissatisfaction about discussing their pain with friends or health care providers. Dudgeon et al. reported that communicating their pain was a dilemma for nearly all participants. They believed that one paid a price for talking to people about issues that they could do nothing about. If they did communicate, doing so seemed to make the “being different” aspect of disability even more exaggerated. (p. 233)

Both Neville-Jan (2003) and the participants in the Dudgeon et al. (2002) study minimized their complaints of pain with friends as well as with health care providers. This finding is consistent with the Hitchcock et al. (1994) study, in which 66% of the participants reported hiding their pain from others.

The Dudgeon et al. (2002) study addressed other issues as well but highlighted the topic of pain-coping strategies. Findings from this study indicated that participants independently developed their own strategies for coping with pain. The authors emphasized that coping responses, such as relaxation techniques and exercise routines, are the same types of strategies used in pain management programs.

The importance of adaptation to chronic pain was addressed by Reitsma and Meijler (1997), who studied two groups of people who had had chronic pain for more than a year. One group—the “consumers”—had visited doctors for their pain during the past year, whereas the other group—the “nonconsumers”—did not consult physicians during that time. The nonconsumers showed less distress and were more active, and the researchers therefore deduced that the nonconsumers had learned to live well in the presence of pain. Thus, the potential appears to exist for people with chronic pain to improve the quality of their lives by learning to function in spite of their pain.

To understand the wide range of problems that can occur with chronic pain and its overall impact on occupational performance, we decided to explore the experience of chronic pain from the perspective of those who were living with it. Additionally, we addressed the relationship between chronic pain and occupation and the effects of chronic pain on daily routines, activities, and relationships.

**Method**

Institutional Review Board approval for this study was obtained at College Misericordia in Dallas, Pennsylvania. The researchers who conducted the study were four graduate occupational therapy students and two occupational therapy faculty members. The first faculty member directed the design and implementation of the study. That faculty member met with the graduate students biweekly in four-hour sessions for 7-month to design the study, analyze the data, and revise the study manuscript. Researcher communication about the study also occurred in a virtual environment for that 7-month period, as the first faculty member and the four graduate students posted manuscript revisions and changes several times per week in an electronic classroom. The four graduate occupational therapy students were the data collectors, and they conducted all of the interviews. The second faculty member validated the results of the study by reading all interview transcripts to verify the themes found by the other researchers. She also read the manuscript and met with the other researchers several times during the 7-month period, providing constructive criticism and feedback on all facets of the study. After the study was completed, the second faculty member assisted by making editorial changes in the manuscript.

**Research Design**

Our study had a qualitative phenomenological research design. Creswell (1998) described a phenomenology as a study of people who share an experience and stated that the “focus of a phenomenology is on understanding a concept or phenomenon” (p. 38). One commonly used method of data collection in a phenomenological study is an interview with people who have experienced the same phenomenon and are able to communicate and describe how it has affected their lives. We used such an interview to study our participants’ shared experience of living with chronic pain.

**Participants**

The 13 participants (4 men, 9 women) were from the eastern United States and ranged in age from 35 to 87 years. Participants were selected through purposeful sampling of accessible cases, a method described by Creswell (1998).
Participant selection was limited to people who self-reported having chronic pain for at least 2 years that had limited their function. People whose cognitive status limited their ability to convey their subjective experience were excluded from the study, as well as those who were experiencing pain as a result of recent surgery, injury, or treatment. Nine of the participants were personal acquaintances of the researchers. To reduce the likelihood of bias, these participants were interviewed by a researcher other than their acquaintance.

Most of the participants lived with a family member. Most were employed at the time of our study and included a property manager, architect, television producer, former manual laborer, teacher, custodian, homemaker, librarian, clerical worker, 2 human services workers, and 2 paraprofessionals. Ten of the 13 participants had completed at least some college, and 7 of the participants held college degrees.

The length of time the participants had experienced chronic pain ranged from 2.5 years in some younger participants to an 87-year-old who stated that she had had chronic pain most of her life. The average length of time participants had experienced pain was approximately 17 years. The participants reported diverse types of pain: 7 had some form of back or neck pain; 3 experienced cluster or migraine headaches (or both); and some had pain in other areas, including the hips, extremities, and joints.

The participants reported receiving various treatments, including medications, surgery, chiropractic treatments, acupuncture, physical therapy, and nerve blocks. None of the participants reported receiving occupational therapy.

Instrumentation

Data were collected from each participant via a demographic questionnaire, an open-ended semistructured interview, and a reflective questionnaire completed by each participant. Field notes were written by the interviewers.

Procedure

The interviews took place during summer 2004 and were conducted privately in locations chosen by the participants, including participants' homes, workplaces, and other convenient locations. Each participant was interviewed once.

At the beginning of each interview, the researcher obtained informed consent. Information about each participant's age, gender, employment status, occupation, level of education, marital status, type of housing, people lived with, length of time with chronic pain, nature and location of pain, treatments or surgeries for pain received in the past, and current treatments for chronic pain were obtained via a demographic questionnaire. Subjective information was obtained through recounts of experiences by participants as described in the interview and reflective questionnaire. The researchers conducted semistructured interviews with all participants, which consisted of asking open-ended questions and probing for more information. The researchers initiated the interview discussion by using pre-established questions regarding typical daily activities; meaningful activities and their relation to the perception of pain; the effects of the pain on various aspects of life; interactions with family, friends, and the health care community; adaptations used; and recommendations to others with chronic pain. The researchers produced field notes that described the interview setting, physical appearance, emotional expression, and demeanor of all participants. The interviews, each of which lasted approximately 1 hour, were audiotaped and transcribed verbatim.

Data Analysis

Data analysis occurred through thematic analysis, which "focuses on identifiable themes and patterns of living and/or behavior" (Aronson, 1994, paragraph 1) and includes steps such as listing patterns of experiences from transcriptions, identifying data that relates to the patterns, and combining patterns that are related into themes. The four graduate student researchers individually reviewed the 196 pages of data that were collected, identifying specific information categories. Each graduate student examined her own set of categories and analyzed them to discover common themes—that is, phenomena that were frequently or intently discussed by most of the participants. The four students then shared the common themes they individually identified and mutually decided on the one final theme and four subthemes found in all of the individual cases. The faculty chair and faculty reader of the graduate students' research committee also read all of the data and validated the themes and subthemes identified by the graduate students. Finally, direct quotes that illustrated the subthemes were selected from the interview transcripts and reflective questionnaires and are presented in this report.

Trustworthiness in this study was established through triangulation, confirmability, and transferability. Triangulation refers to "the use of multiple methods, sources, analysts, or theoretical perspectives to verify the information gained in different arenas" (Stein & Cutler, 2000, p. 175). In this study, there were multiple sources of data, including demographic questionnaires, interview transcripts, field notes, and reflective questionnaires. All of the data collection instruments were designed to study the one common experience shared by all participants: living with chronic pain. Data were collected through multiple methods, including interviews, field notes, and demographic and reflective
participant questionnaires, and multiple data collectors and analysts were used. The four researchers collected the data, using identical collection tools, and analyzed the results along with the research chair and reader. The use of diverse data sources was strengthened by the fact that all data were collected in a uniform manner.

The confirmability of a study, according to Trochim (2002), is the extent to which others can confirm its results. The results of this study are confirmable. First, the four graduate students and the two faculty researchers read through all of the data sources, including the extensive interview transcripts. The graduate students then individually identified common categories of information and noted these categories in the margins of all data documents. The thematic analysis process was completed in three data analysis meetings. During the first meeting, the graduate students compared and contrasted their respective individual findings (categories). At the second meeting, they combined their category findings, mutually agreeing on a set of common categories. At the third meeting, through careful reflection, they collapsed the numerous categories and combined them into common themes. The faculty research adviser participated in these meetings. Having read all of the data herself, the faculty adviser challenged the students on the legitimacy of their categories and themes, facilitating the process of thematic analysis. This debate lasted until the faculty adviser and graduate students agreed on the findings. The second faculty member (the reader) also carefully reviewed all data and validated the investigation’s findings. Furthermore, an extensive audit trail of the study exists; all data collection documents and interview tapes and transcripts are maintained in the office of the faculty research adviser involved in this study.

Transferability refers to the extent to which the results of a study can be applied to other people (Trochim, 2002). The diversity of our study participants is illustrated in the varying causes of their pain, their ages, and their varying situations. We contend that this diversity enhances the transferability of our findings to other people who have chronic pain.

Results

Thematic analysis yielded one broad theme and four subthemes, which are described in the following sections.

Broad Theme: “Chronic Pain Is Life Changing”

The broad theme emerging from all of the findings was “Chronic Pain Is Life Changing.” This theme explains how the participants experienced major alterations in their lives as a result of chronic pain. The life changes noted by the participants affected different aspects of their lives, including psychological state, occupational performance, relationships with others, and life satisfaction.

The participants reported missing out on satisfying life experiences because of pain. This feeling is reflected in the words of a 44-year-old human services worker with migraines and back pain who said, “When you lose a day because of chronic pain . . . [it] affects your quality of life.”

Participants spoke about limiting their involvement in favored activities and about varying their approaches to the performance of certain physically challenging tasks. When reflecting on his engagement in enjoyable activities, a 35-year-old custodian with neck and lower back pain stated succinctly, “I’ve changed my life to accept what I’m going through.” Changes in relationships with family members and friends also were reported, including relying more on family members for emotional support and relying less on friends. Participants also reported experiencing newfound meaning in favored occupations because the diversion from pain that the activity provided became important.

The major life changes experienced by our participants are further illustrated in the four subthemes uncovered by our study. The subthemes reflect the life-changing experience of having chronic pain and address the emotional, relationship, and occupational performance changes described by the participants.

Subtheme 1: “Chronic Pain Triggers Emotional Distress”

One of the life changes experienced by the participants was the presence of emotional discomfort as a result of living with chronic pain. This phenomenon is described in the first subtheme, “Chronic Pain Triggers Emotional Distress,” which illustrates how our participants’ chronic pain experiences resulted in unpleasant emotions. Sadness was repeatedly noted by the participants, and in some it was so intense that they experienced depression.

Depression, in some, appeared to be related to the participants’ inability to complete certain activities because of pain. The manual laborer explained, “It hurts all the time and you have nothing to be happy about. . . . I just don’t care, you know, I just don’t.” Depression also seemed to occur because of the effects of the chronic pain on the body. The television producer with cluster headaches discussed how pain affected his day:

You know how bad it’s going to be, so you get really depressed because you know it’s going to interfere with your day . . . and then you know that it’s just going to happen again tomorrow, and so it just perpetuates.

Many of the participants felt emotionally overwhelmed. The property manager explained, “I would say, emotionally, I do get depressed because every once in a
Feelings of frustration were expressed by the participants because the chronic pain often limited them from performing activities. A 65-year-old female retired librarian with a herniated disk said, “It’s frustrating. You want to do a lot more. I am used to running up and down [doing things] and . . . [now I] can’t.” When asked how important it was that she accomplish something, the para-professional with lower extremity pain said, “I’ll stay up until four o’clock in the morning to finish something that I want to get done. And now with this [pain] limiting me, I’m really not always able to do that, so that’s very frustrating to me.”

Some participants had feelings of frustration due to their experiences with the medical community. They believed that doctors did not understand their condition, did not listen, and at times did not treat them properly. The television producer who experienced cluster headaches said, “I’m fighting with these [medical] people to try to get my medicine, and it’s so frustrating.” He believed that a general practitioner or emergency room physician was not capable of understanding his condition, compared to a specialist such as a neurologist. However, according to the property manager, just because a health care provider is a specialist does not necessarily guarantee that he or she will act in an understanding manner. The property manager described neurologists who did not appear to be truly listening but sat jotting and doodling on their pads. She stated, “They treat you [as if] everybody who comes in with a migraine basically is the same; they don’t really listen to you.”

Participants also experienced anxiety and fear. These emotions seemed to develop out of the knowledge that the pain would be coming, but the participant was not sure when and how intense it would be. The television producer said that when a cluster headache began, “It takes over anything I’m doing no matter what it is or where I am; there’s nothing I can do when one comes on.” He described how his fear and anxiety interrupted his daily life: “Sometimes during the cycle I’m frightened that it never will end . . . that this is a dream that I’m just never going to wake up from.” Other emotional responses expressed by our participants included feelings of “why me?” guilt, anger, uselessness, being overwhelmed, bitterness, and hope.

Some described a lack of control in social situations. The homemaker with back pain and chronic obstructive pulmonary disease (COPD) said, “Socially, I’m afraid to go out without my husband, because he knows me. When I’m at a social gathering, I say I’m losing it . . . [and when I] become hyper and I can’t breathe . . . he’s right beside me saying, breathe through your nose, calm down.”

**Subtheme 2: “Chronic Pain Reveals the Strength of Relationships”**

The participants had other life changes as a result of living with chronic pain. According to the participants, their pain experiences changed the nature of their relationships with others. These changes are reflected in the second theme, “Chronic Pain Reveals the Strength of Relationships,” which shows how having chronic pain affected the intensity of participant relationships with family, friends, coworkers, and health care providers. Chronic pain often tested the strength of such relationships. Some relationships were found to be solid and sustaining, whereas other relationships dwindled because some people in the lives of the participants could not tolerate the presence of pain and its many challenges. The participants explained that family members were often the only people on whom they could rely for assistance and emotional support. Although sometimes friends were helpful and supportive, at times the participants found friendships to be lacking. The participants said that friends sometimes withdrew from relationships with the participants. The participants believed that these friends tired from hearing the complaints about pain. Additionally, participants often found that they could not discuss their pain with coworkers, who were not always receptive to hearing about the participants’ hardships. Although the participants were grateful to health care professionals who did listen to their concerns, they often believed that health care providers were not responsive to their needs.

All of the participants noted that their families were sympathetic and understanding. As an example, one of the participants, a 53-year-old human services worker with low back pain, said that her family "reacts to my pain by listening, helping when I request assistance, and treating me as normal as possible while supporting my limitations." Her words show that families were usually sensitive to a family member’s limitations. A 53-year-old para-educator with knee and hip pain stated that she was not sure whether her family believed she was experiencing pain when it first occurred; nonetheless, she noted that her family tended to be more understanding than her friends, especially as her condition related to the need for accommodation.

Friends also tended to be supportive and compassionate toward the people with chronic pain, but their responses varied. When friends were supportive, it was often not to the extent families were. Nonetheless, the custodian with back and neck pain said his friends were extremely understanding of his pain. In contrast, a 54-year-old property manager who had migraine and cluster headaches said, “My friends find my pain difficult to understand.” Others noted that, although friends were supportive, they might think
The human services worker who had migraines and lower back pain said, “It’s hard to understand others’ pain if you haven’t gone through it too.” This common thought was noted by many of the participants. A 37-year-old architect with low back pain described an incident where he was ridiculed for exercising to take care of his pain. A friend and fellow band member teased, “What do you think, you’re a rock star back there?” while the architect was stretching his back before playing drums. His humorous remark hurt the participant’s feelings. When the architect’s friend experienced similar pain, he apologized for his insensitivity. An 87-year-old retired schoolteacher with a back injury noted that some people in the public are even more insensitive, because they do not extend courtesy to wheelchair users.

Interestingly, every person in our study who experienced migraines expressed the sentiment that others could not truly understand their pain. The 39-year-old television producer with cluster headaches stated, when referring to the intensity of his pain, “I don’t think my family understands or my friends understand exactly the level of it.”

Participants often expressed the feeling of being misunderstood by the medical community. Many of the participants reported that they lacked having substantive discourse with others about their pain, including health care providers. Although the medical community was seen as helpful in the treatment of most participants’ pain to varying degrees, several people reported feeling as though their doctors or the health care community in general did not take their pain seriously. Others were frustrated with their treatment or dissatisfied with the advice given by medical practitioners. The architect said that his doctor just did not understand how his body worked. Another participant, a 43-year-old male with degenerative joint disease in the spine who was formerly a manual laborer, related a story of having chronic back pain minimally treated by emergency room doctors because he lacked health insurance coverage. The schoolteacher described having to emphatically explain her pain to doctors with the statement, “Well, then, you just have to make sure they understand how serious it is.”

Chronic pain affected the participants’ enjoyment and involvement in social activity. For example, the television producer with cluster headaches stated that “there’s a lot of times that I just won’t go anywhere because of the fear of getting one.” Some of the participants tended to avoid activity with others, whereas others modified their routines. Some believed that they were limited in the types of social activities in which they could participate; for example, a paraprofessional educator with lower extremity pain could not walk long distances owing to fatigue and pain. This participant described how her family had to go on vacation without her because of her walking limitations.

Interactions with other people included refusals to ask for help and hiding pain from others. Reasons for doing this included participants’ need to avoid feeling as though they were not being taken seriously. Some expressed a need to not focus on the pain in their dealings with others. The 62-year-old homemaker with back and neck pain and COPD said, “I’m very independent and I don’t like having people do things for me; I’m the one who does things for people.” This woman also stated that it was annoying to always discuss pain with peers and family. She commented to them, “Let’s talk about something else, other than the pain I’m always in.” The 53-year-old human services worker said that she hid her pain from family, coworkers, and friends because of her personality, because she found it difficult to ask for help.

Despite the participants’ feelings of not wanting to depend on others while exerting their independence, they noted that they had become dependent on others in various ways. For example, the human services worker with lower back pain said that she hated to ask her husband to help with chores, such as doing the laundry. Others believed that they had already lost their independence; for example, a 62-year-old homemaker could no longer drive and therefore had to ask others for transportation. She stated, “I love to go out [but] I can’t drive anymore . . . that freedom was taken away from me, because of my illness, and I resent it, I really do, I resent that I have to ask everybody [to drive].”

Subtheme 3: “Chronic Pain and Occupation Are Reciprocally Related Forces”

The participants reported another change resulting from their chronic pain experiences: They found new comfort in performing certain favored activities and steered away from performing activities that caused them discomfort. The third subtheme—“Chronic Pain and Occupation Are Reciprocally Related Forces”—shows how, as meaningful and enjoyable occupational involvement increased, pain often decreased. Pain affected both the activity levels and occupational choices of the participants. Perceptions of pain were often altered by the type of occupation engaged in. Participants noted the importance of doing things to divert attention from pain, and one participant in particular recommended doing a loved activity to help forget the pain.

Participants described times when pain stopped them from functioning. The television producer who had had
cluster headaches for 22 years said, “[The headaches will] start pretty mild and then build to the point where they’re so excruciating . . . that I cannot physically do anything at all.” Others stated that during pain episodes they simply could not do as much as they would have liked. When reflecting on what he couldn’t do because of his pain, the architect said, “[I] can’t be as active as I would like and can’t enjoy activities as much as I would otherwise.” The former manual laborer said that because of his pain, “I don’t do anything. Everyday I do absolutely nothing, and it drives me crazy. I can’tstand it. I used to be the guy who would get up and do things . . . .The hardest thing for me is sitting still.”

Some participants spoke of changing plans or avoiding certain activities when pain was expected or present. The television producer often predicted the onset of headaches, explaining,

You know when [the pain is] going to come, and what you have to do is plan your life around it. So, in other words, usually I don’t try to plan anything [at] those times so that I know that I will hopefully be safe.

Another participant, a human services worker with migraines, said, “There are days with back pain that I didn’t get out of bed. I missed work, you know, because I couldn’t move.” The property manager often worked from home because the smell of cigarette smoke in the office could trigger a headache.

Participants reported no longer engaging in preferred activities. The human services worker with lower back pain said, “I love the outdoors, I love to garden, which I can’t do anymore. I love to bike . . . and I can’t do that anymore.” The paraprofessional educator with pain in her feet stated, “I like to waitress, I used to do that part-time, and it was a lot of fun, [but] I had to give it up.”

Some said they had pain regardless of what they were doing. The former manual laborer said, “It hurts to do anything. That’s the point of this, it don’t matter what I do. It just hurts, constant, consistent, it just never goes away.” When the property manager was asked to differentiate between pain levels during liked versus disliked activities, she responded: “I get pain whether I’m doing something I like or not doing something I like, so it’s kind of hard to say, it doesn’t matter.” Others felt a difference in the level of pain depending on what they were doing and whether or not they liked the activity.

Some participants believed that enjoyable occupation decreased pain. The human services worker with lower back pain said she was “probably not as aware of [pain] when I’m doing things that I really enjoy. If I stop to think about it, I know it’s there.” However, she also stated that she couldn’t “engage in physical activities with her family, such as base-

ball, basketball, biking, and gardening” and couldn’t keep her house as clean as she would have liked.

The architect described relief from pain “when [I am] preoccupied or focused on something, whether it’s work, school, or whatever.” He said that the pain disappeared when he was playing in his band. When asked what he would recommend to others with chronic pain, the human services worker with lower back pain recommended “doing things that you enjoy doing as much as you can.” The paraprofessional educator with knee and hip pain suggested finding a passion to engulf one’s self:

What I’m going to recommend is that you find something that maybe underneath subconsciously has been your passion all your life or is your passion presently . . . and do something with that passion, if you haven’t already, because I think when you do something you enjoy, that you like, it just takes you to a different level, it takes your mind, it takes your spirit, and you really forget about yourself no matter what that is.

The enjoyed occupation acts as a diversion, as expressed by the property manager, who said one needed to be “someplace that you can be totally absorbed and not think of what’s bothering you.” When asked what she recommended to others with chronic pain, she said, “[To do] something that they truly enjoy that they can become immersed in . . . someplace where they would be comfortable and not think about the fact that they have to deal with this on a daily basis.” The paraprofessional educator with knee and hip pain said, “I think making other things more a part of your life makes the pain less part of your life.” She could no longer sit for hours to paint but instead volunteered at a horse rescue facility, finding it a wonderful diversion. She added, “[The horses’] sad life seems to be what I focus on and not myself . . . I totally give myself to them when I’m there—forgetting myself.”

Engaging in enjoyed activities helped the participants. Similarly, doing unpleasant activities increased pain levels. The clerical worker with rheumatoid arthritis said her pain was a 10 (on a scale of 1–10, with 10 being the worst) when doing something she didn’t like, whereas it was an 8 when engaging in activities she liked.

The participants’ recommendations for others with chronic pain dealt with engaging in some type of activity, either physical or mental. Recommendations given by the participants for others with chronic pain included exercise, physical therapy, and meditation. The human services worker with lower back pain treated her pain with “moderate physical activity.” She, along with several other participants, received physical therapy. The paraprofessional educator with lower-extremity pain said, “I think that exercise is the salvation of anybody that has anything wrong with
them.” Although these participants believed that staying active was important, it was difficult or impossible for some participants with chronic pain to have an active lifestyle. The former manual laborer said, “You just find yourself . . . avoiding any other activities because it’s too painful.” Other participants said that stress reduction and meditation helped them. The human services worker with lower back pain stated, “I meditate a lot while I walk. So, that helps with the overall pain reduction.” She described how quiet time cleared her mind and helped “put things into perspective.” The human services worker with migraines said that walking outdoors helped to reduce her pain: “Just getting out there and just kind of clearing my mind and all, I kind of let go of everything . . . I didn’t have as many headaches.” Although each participant seemed to have his or her own special way of dealing with pain, the most common helpful occupations were physical activities and relaxation.

A commonality among the interviewees was that they placed a great deal of importance on accomplishments; that is, they felt better when accomplishing something. The retired librarian coped with her pain by “doing as much as possible.” Although being busy may simply have kept her mind off the pain, possibly the feeling of accomplishment helped her feel better. The architect said, “I definitely feel better when I’m feeling I’m accomplishing something, doing something meaningful, fulfilling [my] potential.”

Thus, occupational involvement (in activities of daily living, work, and leisure) and pain level were closely related. The participants spoke about the positive effects of engaging in activity and explained how this helped them forget their pain.

**Subtheme 4: “Chronic Pain Elicits Innovative Adaptive Responses”**

The fourth subtheme, “Chronic Pain Elicits Innovative Adaptive Responses,” illustrates another life change—how participants adapted by making interesting temporal, lifestyle, and cognitive adaptations in their lives to cope with having pain. Frequently used temporal changes included allocating more time to undertake a task or shortening the time devoted to a task. The participants often attempted to alter schedules to lessen the chances that they would be debilitated by the pain. The television producer with a 22-year history of cluster headaches said, “What you have to do is plan your life around [the pain].” The architect with chronic back pain acknowledged similar limitations: “There are things that I can and can’t do at certain times.”

Many participants reported making lifestyle changes to accommodate their pain. Energy conservation and joint protection were used by the custodial maintenance employee, who said, “[I try] to save my body to be able to do what I have to do.” Many of the participants altered their lifestyles by eliminating certain activities, giving up a hobby or paid employment, delegating a responsibility or chore to another person, or limiting themselves to a job that was more tolerable.

Adaptations to the activity itself frequently involved changing the way a task was accomplished. The participants reported numerous unique adaptive strategies, such as using assistive devices, obtaining help from others, and taking breaks. Some of their alterations were as simple as changing positions during activities. The participant bought a small service utility vehicle so she could adjust her position while driving and get in and out of the car more easily. She also accommodated by doing tasks in shorter, more tolerable spurts and by assigning some tasks to her husband. She had an optimistic outlook and was hopeful that her pain would lessen and she would be able to resume normal activities. As a former librarian, she did voice a major frustration: She was unable to find a way to comfortably read in bed.

One participant with arthritis stated that she asked others, especially her brother, to help with larger tasks around the house. Another participant with chronic back pain said that she asked her husband to help with tasks such as carrying laundry up the steps. However, she said, she did not ask for a lot of help. She described taking rest breaks when doing housework and explained that she also had to be satisfied with what she could do, knowing that she was not able to do as much as she used to.

One participant said that she coped with migraine headaches by taking time off from work, despite feeling as though she should not. Her office was kept darker than the other offices in the building. She removed the overhead fluorescent light and used a lamp instead. She also had back pain, to which she adapted by purchasing a more comfortable chair.

A participant with chronic back pain from spinal stenosis made several adaptations in her daily routine, including
using a high stool in the kitchen during cooking and using a seat cushion and a wheelchair when needed. She also tried to make shorter car trips. When questioned, she said that these alterations were just common sense and that she did what she had to do.

The TV producer with cluster headaches stated that he planned his life around the headaches, knowing that they occurred at about the same time every day. He said, “I don’t take meetings between noon and two,” and “I [try not] to plan anything between those times . . . so that I know that I will hopefully be safe.” He also said, “Since I know . . . like right now . . . when they’re coming, I try to do everything I need to do that’s physical at least before or after that time period.” Furthermore, he said that he does not drink any alcohol at all during the cycle period.

The property manager tried to avoid certain triggers to prevent migraine headaches. She stated that her husband needed to wear unscented products and to shave in the basement because of the odors associated with these activities. Additionally, her daughter was not allowed to use hairspray around her. The property manager also gave up certain activities, such as bowling, because they were possible migraine triggers, and she ate out less frequently because she was allergic to certain food dyes, which triggered migraines. She realized that these environmental triggers also prevented her from working in an office because, until recently, smoking in public places was permitted. She said, “I had to find a job. . . [where] . . . I could be basically self-employed.”

Several of those interviewed stated that they worked at their occupations (e.g., house cleaning, gardening, self-care) in short spurts of time over the entire day, or as one interviewee stated, she “would stop, and rest, and start over again” during an activity. They also reported completing certain tasks in either the morning or the afternoon, depending on which was better for them.

One participant with lower extremity pain said that she had purchased 50 pairs of shoes, each of which would give her comfort depending on how it was designed. Elevated shoes helped her foot pain but not her hip pain. Low shoes helped remediate the pain in her hip. She explained, “I have to constantly change my shoes. . . . [Depending on] the level of pain, I change the shoe.”

On the opposite end of the spectrum, the man with degenerative joint disease and chronic back pain was unable or unwilling to alter any prior activity. He said that there was no use and that it hurt too much to bother. He seemed to have little hope of relieving pain or assuming prior activities.

Cognitive adaptations were evident in the participants. One of these strategies was assuming a positive attitude. The human services worker reflected, “A lot of [coping] is mental, changing the way I view things.” The paraprofessional educator discussed her work with abused horses, stating, “Making other things more a part of your life makes the pain less part of your life.” Two participants said a shift in priorities changed their perception of pain. Other participants said they needed to just “ignore it [the pain].” Another cognitive strategy was the attitude of gratitude. Despite the never-ending pain, participants were thankful that it was not worse. The paraprofessional educator with lower-extremity pain noted, “My pain is nothing in comparison to what other people go through, and I think I appreciate that.” The property manager echoed those sentiments, saying, “There are people who have a lot more to deal with in life and a lot more serious ailments.”

Adaptations appeared to give the participants a sense of control. The property manager explained that if the level of pain could be controlled, it was less intrusive on one’s life. She said, “If you have chronic pain . . . the pain you [can] live with is the pain you can control or keep to a minimum, where it isn’t affecting your life.” She also gained control by exploring the latest research and treatments available for her pain.

However, participants often described a lack of control. The former manual laborer could not identify any adaptations that reduced his pain. His feelings of helplessness and hopelessness echoed throughout the interview in statements such as, “There’s no help for people like me” and “I don’t want to do anything because it hurts too much, I don’t really care.”

Some of the participants indicated that they understood the need for certain adaptations but did not always implement them—for example, the attempt to avoid stress. Most participants agreed that they knew regular exercise was beneficial in decreasing stress, but few were able to maintain a consistent exercise program.

Because the focus of our inquiry was related to occupation, one of the questions we planned to ask participants was “How do you adapt or change activities in order to engage in them as comfortably as possible?” Many participants answered this question even before it was asked, by describing the changes they had made in their lives since the onset of chronic pain. Although adaptation was a persistent theme that revealed itself in many physical and cognitive forms, the adaptive capacities of each of the participants varied significantly.

Discussion

The topic of chronic pain and its life-changing influences has important implications for occupational therapy practice. Our study showed that chronic pain has negative
effects on various aspects of a person's life. Similar to findings reported by the American Academy of Family Physicians (2000) and the Hitchcock et al. study (1994), the participants in our study complained of depression, anxiety, frustration, and fear. Additionally, the participants reported limited involvement in social activities as well as a negative impact on level of independence. A few of the participants said that they were no longer able to engage in favorite activities. However, other participants reported the benefits of engaging in occupation.

In their efforts to deal with the consequences of chronic pain, participants identified various types of coping strategies and pain management techniques that were mentioned in previous pain studies. Adopting adaptive measures, using stress reduction techniques, keeping a positive attitude, and engaging in meaningful occupations may help to reduce both the physical and psychological effects of chronic pain. Furthermore, the findings from our study addressed the ability of occupation to alter the perception of pain. Neville-Jan (2003) noted that prior investigations failed to support this premise because the activities used in those studies were not meaningful. We echo Neville-Jan's call for research that focuses on how engagement in purposeful and meaningful occupation may positively affect the chronic pain experience.

With regard to relationships, findings from this study are consistent with the Neville-Jan (2003) study as well as the Dudgeon et al. (2002) and Hitchcock et al. (1994) studies. Participants in our study described family members as being supportive and understanding, but participants also noted that they needed to minimize or hide their pain from friends or coworkers. Additionally, participants expressed feelings of frustration and dissatisfaction with their experiences with health care workers. Occupational therapists may want to place more emphasis on the use of careful listening techniques when providing services to clients with chronic pain. Empathetic therapists who listen may help to enhance the occupational therapy evaluation process. In fact, all members of the chronic pain intervention team may need to become more adept at listening to client complaints, frustrations, problems, and aspirations. The participants in our study possessed in-depth knowledge of their conditions and made innovative adaptations of their own design. People with chronic pain may offer health care providers resourceful ideas for modifying the environment, adapting the activity, changing occupational performance habits, and coping emotionally with pain.

In our study, participants noted the benefits of participating in physical therapy and other forms of activity. However, none of the study participants mentioned receiving occupational therapy. We believe that occupational therapists can help people with chronic pain in definitive ways, including assisting with lifestyle modifications, recommending task adaptations, and educating clients to control pain through engagement in meaningful occupations.

Occupational therapist Jennifer Strong (1996) proposed “activity engagement, activities of daily living, preparation (through training, education and equipment provision), relaxation training, stress management, coping skills training, groupwork, and creative modalities” (p. 117) as viable occupational therapy intervention strategies for dealing with pain.

A study by Good (1992) focused on the occupation and impact of work on two people with chronic pain and described the importance of work and the pain experience, stating that work can be a place to control or escape from pain, while also serving as a forum for achieving self-awareness and control. Although Good's research was limited to the study of two professional women, the author clearly addressed the positive effects of work on the chronic pain experience. Additional studies of this nature would benefit occupational therapists who work with this population.

Helpful Resources

Occupational therapists must be aware of community resources and other types of agencies that can provide additional support to people living with chronic pain. Referrals to support groups may be valuable in learning how to cope with the multiple problems that can occur as a result of chronic pain. We encourage readers to use the numerous resources that are available to assist occupational therapists and their clients who have chronic pain, including national associations such as the American Chronic Pain Association and the National Chronic Pain Outreach Association. Community support groups sponsored by hospitals and other medical groups also are potentially very helpful.

Recommendations for Future Studies

Educational backgrounds, economic resources, and social supports varied widely among our participants. Future studies might delve into whether and how these factors affect the capacity for adaptation to pain. Studies that replicate the methods of this investigation, but that focus on participants with particular pain syndromes (e.g., migraine headaches, chronic back pain), are also recommended. Disability-specific studies may provide even deeper understanding of the occupational performance of those with chronic pain and how the pain experience may vary depending on the type of injury or problem that exists.
Limitations

Some limitations in the study design may have diminished the strength of our findings. The participants may have been inhibited by the presence of the tape recorder, and audiotaping the interviews may have made them reluctant to share private thoughts and experiences. Including participants with a variety of different pain syndromes and medical conditions may have made the scope of the study too broad. Additionally, if the researchers had held an advance information session with the participants before the study, participant comfort, and thus researcher–participant communication, might have been improved. It also would have been helpful to interview people who were not known to any of the researchers. Additionally, the absence of participant verification of the themes after data analysis was a limitation in this study.

The trustworthiness of this study may have been limited by the fact that each participant was interviewed only once. It also could have been reduced by the short time period (one 15-week semester) allocated for research proposal development and data collection. All data collection was conducted during 1 month of that semester. Additionally, the vast majority of the thematic analysis and manuscript writing occurred during another 15-week semester, during which the research team met eight times for 4 hours (32 hours total). Thus, more research team meetings and a longer time frame may have improved the depth and accuracy of our findings.

Summary

Chronic pain is a major health problem affecting a large number of people. Our findings show that chronic pain may potentially affect all areas of a person’s life, including occupational performance. In addition, emotional and psychological issues may develop. These problems may alter relationships with family, coworkers, and friends. In response to chronic pain, the participants in our study described using innovative adaptive routines and strategies to perform various types of activities, including favored occupations. Participants found engagement in meaningful occupation to be beneficial because it provided an opportunity to focus on something other than their pain.

We encourage practitioners to recognize the holistic and multifaceted approach that can be used with people who have chronic pain. Occupational therapists may address the physical and psychological needs of people who have chronic pain and thus positively affect the occupational performance of these people. Furthermore, occupational therapists can provide strategies for adaptation so that occupational performance can be improved.

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References


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