I have experienced pain ever since I can remember. I am one of approximately 97 million Americans, about 1/3 of the U.S. population, who report some type of chronic or persistent pain (Hardcastle, 1999; Jackson, 2000). I am also an ethnographic researcher, academic, and occupational therapist. I have read extensively the varied scholarly discourses concerning pain, and I have encountered people within my research and practice who have experienced, like myself, chronic unremitting pain. Among other more personal identities I am a spouse, mother, and woman with a chronic illness, spina bifida. As I’ll describe in the next section these professional and personal identities have all contributed to my story of pain.

I first presented this story at a scholarly symposium. The symposium focused on the potential connections between biology and occupation. In keeping with this theme I initially titled my paper *Occupation in a World of Pain*. My story seemed to resonate with the audience both from the questions asked and the stories told to me later in the day. Looking back, the message I shared with the audience was not primarily about occupation but about encounters with practitioners.

About 1 year later I became a co-investigator on two research projects funded through a disability supplement from the National Institutes of Health (National Institute of Child Health and Human Development, National Center for Medical Rehabilitation Research, #RO1 HD 3887801A1S). My research supplements an ongoing ethnographic and longitudinal study of 30 African-American families who have a child with a disability (#RO1 HD 3887801A1). For a little over a year I have followed four of the families who have children with spina bifida. As an ethnographer I have interviewed family members and practitioners and engaged with families as a participant observer in events and clinic encounters. The second project uses narrative, ethnographic, and longitudinal methods to study 15 adults with spina bifida. Through such intense involvement with children and adults who have spina bifida I have realized the importance of narrating my story both as a reflexive approach to the ethnographies described above and as a personal narra-
tive. I also discovered other scholars who were using first-person narratives in a qualitative research methodology called autoethnography (Ellis & Bochner, 2000). The term autoethnography can be used to describe a personal account of an experience and also as a reflexive text for ethnographic research. For my paper, autoethnography has become a means to frame my voice and tell this story that chronicles a 3-year period in which I experienced severe pain.

Through a review of the discourses on pain I have become aware that a “gap of representation” exists in the scholarly storyline of pain, especially in occupational therapy—the voice of the person in pain. Occupational therapists have contributed significantly to the literature on pain in disciplinary journals (e.g., Anderson, 1985; Flower, Naxon, Jones, & Mooney, 1981; Heck, 1989; McCormack, 1988; Strong, Crandom, & Maas, 1989; Walloch, 1998), in other highly regarded medical journals (e.g., Klinger, Spaulding, Polatajko, MacKinnon, & Miller, 1999; Large & Strong, 1997; Marttenson, Marklund, & Fridlund, 1999; Strong & Large, 1995; Unruh, 1996), and in a recent textbook on pain written for therapists (Strong, Unruh, Wright, & Baxter, 2002). However, I could not find not one article in the occupational therapy literature in which a researcher told his or her own story of chronic pain. What does exist are a small but ever increasing number of self-narratives and ethnographies about chronic pain in medical anthropology (Garro, 1992; Good, 1992; Greenhalgh, 2001; Jackson, 2000; Kotarba, 1983) and the popular press (Kaysen, 2001; Price, 1994). Each story portrays a unique perspective about a particular person, and particular relationships in a particular time and place. My story and others represent the voices of those neglected thus far in the storyline of pain.

I begin with a description of autoethnography as an alternative method and form of writing. My story follows without the usual interruptions of analysis. Autoethnographers use various methods to intersect story and analysis. I decided to first tell my story within an analytic frame of practitioner encounters. The remainder of my paper weaves back and forth among personal experience, other stories from the literature, and theory in order to problematize conceptions about chronic pain that can influence trust and communication in medical encounters. In the end, I will offer suggestions for practice.

Autoethnography: A Postmodern Ethnography

Traditionally, ethnographers were anthropologists who studied cultures different from their own over an extended period of time. They interviewed informants, engaged in the everyday life of the group, and recorded their encounters and observations in written fieldnotes. The researcher aimed for objectivity while participating in, observing and ultimately representing the culture studied (Denzin & Lincoln, 2000).

The advent of postmodernism in the mid-20th century challenged the idea of one grand or meta-theory as the ultimate truth for understanding or representing the world. Postmodernism posits not just one, but many possible realities. Members of the groups studied by ethnographers questioned the legitimacy of the representations of their world. This “crisis of representation” challenged the claim of objectivity in ethnography and brought with it new forms of research and writing (Denzin, 1996; Goodall, 2000; Van Maanen, 1995).

Autoethnography, a postmodern form of ethnography, expands the boundaries of ethnography and the self (Bochner & Ellis, 1996, 2002; Reed-Danahay, 1997). Since the early 1970s, literary critics, anthropologists, and sociologists have used the term to represent a variety of genres that combine ethnography and autobiography. Reed-Danahay, in her book Auto/Ethnography: Rewriting the Self and the Social (1997), describes the various definitions and textual styles that have been used in autoethnographies. She states, “The term has a double sense—referring either to the ethnography of one’s own group or to autobiographical writing that has ethnographic interest” (p. 2).

Ellis and Bochner (2000) introduced this new genre of writing to the 2nd edition of the Handbook of Qualitative Research. Deviating from the third-person essay typically written for academic textbooks, they used a first-person dialogue to show rather than tell about autoethnography. For example, a student asks Ellis to define autoethnography. She states:

I start with my personal life. I pay attention to my physical feelings, thoughts, and emotions. I use what I call systematic sociological introspection and emotional recall to try to understand an experience I’ve lived through. Then I write my experience as a story. By exploring a particular life, I hope to understand a way of life… (p. 737)

Autoethnography allows another person’s world of experience to inspire critical self-reflection. Ellis and Bochner (2000) label this type of autoethnography as “evocative narratives.” These first person narratives evoke strong emotions in the reader through a highly personal account of experience. Examples of “evocative narratives” in sociology include Ronai’s (1995) layered account of her experience as a survivor of child sexual abuse; Tillman-Healy’s (1996) stories and poems to portray her everyday life as a person with bulimia; and Ellis’s (1995) emotional narrative of her life with a partner who had emphyma and
died. In occupational therapy, Hasselkus’s (1993) reflexive narrative about her personal caregiving experience with her mother, although not explicitly stated as such, could be identified as an autoethnography. Dickie (1997), an occupational therapist, described the value of her “focused autobiography” as she studied a community of self-employed people who made crafts. By reflecting on her own experiences as a crafts person she furthered her ideas and data interpretations. The purpose of these narratives is “…to be used rather than analyzed; to be told and retold rather than theorized and settled; to offer lessons for further conversation rather than undeniable conclusions; and to substitute the companionship of intimate detail for the loneliness of abstracted facts” (Ellis & Bochner, 2000, p. 744).

Giving my personal account of pain a public voice makes me vulnerable to misunderstandings about my work. For example, the scientific and objective world of medicine and psychology dominates the pain literature. Critics may question my personal, subjective, and emotional account of pain as not scientific. Other critics may view my writing as egotistical. Bochner and Ellis (1996) label this “the self indulgent charge” and view it as “…another way [for critics] to try to reinscribe ethnographic orthodoxy” (p. 24).

Fortunately other writers have generously paved the way for my story. Arthur Frank, a sociologist, who told of his own suffering and illness experience, described several purposes for stories of illness. On a private level they give meaning to our suffering, on a public level we create communities of people who share the same experience (1995; 1997; 2000). Over the long term my autoethnography will serve two purposes. I will not only tell personal accounts of living with a chronic illness but will use my narratives as reflexive texts for my ethnographic research. What follows is my story of pain and encounters with health professionals. The type of pain I portray is unremitting and excruciating. It lasted beyond the time it should and no documented physical explanation existed.

Prelude

The story begins with my earliest memory of pain. I was 2 years old and hospitalized for pain. Ultimately there was no explanation for the pain except that it related to my diagnosis of spina bifida and could be caused by muscle spasms. I continued to have painful spasms on a daily basis and major pain attacks about every few months during my childhood. Spasms occurred on my right side, both in the front and back of my upper body. It felt like I was walking in a field of landmines. I didn’t know when a spasm would set off an explosion that would resonate down the side of my body into my leg making it difficult to walk. I tried very hard to mask pain at school or when I was with friends. I didn’t want anyone to know.

The Pain Is in Your Head

I mention the intense and severe pain of childhood as a comparison with the pain I experienced in adulthood during my first pregnancy. It felt like the painful spasms from childhood magnified 100 times. It was pounding, excruciating, and continuous. Even those words don’t portray the severity. The pain was like a demon that had taken over my body and mind. I saw it as something outside of myself that invaded my body setting off continuous explosions. I experienced a relentless throbbing in my back. Any movement set off horrible spasms. Riding in a car caused me to scream out in pain.

I worried incessantly about my baby. Did she feel the pain? How were the medications affecting her? Would the pain and medications have long range effects on her development? My obstetrician referred me to a neurologist who, without any tests or examination, said that my pain was “psychogenic.” He believed that I was worried about having a child with spina bifida. The doctors expedited the amniocentesis results with the hope that when I knew my baby was healthy the pain would subside. The pain did not go away. I miscarried at 21 weeks. During that awful night after labor and delivery, my husband, my mother, and I held our baby girl who weighed slightly less than one pound. It wasn’t until years later, while being pregnant again that I learned the amniocentesis most likely caused an infection that led to the miscarriage. At the time I believed I lost my baby due to the pain and medications. I viewed her as a casualty in the war that was waged in my body.

After I miscarried the pain continued. Now I experienced two pains: the emotional pain of losing a child, and the intense, persistent physical pain. They were intertwined. Crying intensified the physical pain and I fell into a vicious cycle of depression and pain.

During this time, while still in the hospital after the miscarriage, I was referred to a pain specialist. I had many tests but none confirmed a diagnosis or cause of the pain. The pain specialist, an anesthesiologist, suggested biofeedback as a treatment, along with medication. He said I should expect the first treatment to begin immediately while I was still in the hospital. I waited but no one came. My doctor explained that perhaps the biofeedback therapists couldn’t bring their machines to the bedside. I was surprised by his uncertainty. He discharged me several days later with a referral for outpatient biofeedback. Each day of waiting for treatment to begin was just another day of agony. It wasn’t until a week later that I was scheduled for
an appointment. I felt dazed and depressed and still in shock from losing my baby. The pain medication contributed to a sense of depersonalization. I desperately wanted relief from the constant pain so that my husband and I could realize our continuing goal to have a child.

Upon arriving at the scheduled appointment, the biofeedback therapist, a tall young woman in her late 20s, greeted us and suggested my husband go for coffee while she and I had our session. After he left I entered the room and sat in a leather reclining chair. The therapist sat across from me and began to instruct me in diaphragmatic breathing. After about 15 minutes of working on breathing exercises, she gave me “homework” to practice the exercises. My memory of the dialogue is:

Therapist: “I’ll see you next week.”
Ann: “What? That’s all. Why aren’t we doing the biofeedback today? Don’t you use a computer to do the biofeedback? I don’t see a computer. How does this work?”
Therapist: “This is how it works. [She proceeded to put a pad on my finger that would give me input. It was a less effective method of biofeedback.] This treatment will not take your pain away.”

How demoralizing to hear that a treatment I had hoped for would not take the pain away. When my husband returned, he found me sitting alone in the waiting room crying. I was furious with the therapist’s talk about my pain. What did she know? She had never had pain like this. She couldn’t see the war going on inside me. The most infuriating part of our encounter occurred when she ignored me when I experienced pain, or tried to talk to her about my pain. She was using a behavioral strategy I later read about in the literature and is in common use by pain specialists. This strategy is to avoid any discourse about pain, any “pain talk.”

Using a similar approach, on another occasion a different pain specialist talked about his new car as he massaged my neck and I experienced excruciating spasms. I couldn’t have cared less. I found this type of behavioral treatment to be patronizing and dehumanizing. I felt that my pain was being treated as if it was “in my head” and not real. The anger I felt, that my pain was not perceived as legitimate, made up the war going on inside me. The most infuriating part of our encounter occurred when she ignored me when I experienced pain, or tried to talk to her about my pain. She was using a behavioral strategy I later read about in the literature and is in common use by pain specialists. This strategy is to avoid any discourse about pain, any “pain talk.”

The most successful treatment during the first 6 months of my 3 years of continuous pain came from a radiologist whom I saw for steroid injections. I’ll refer to him as Dr. A. At my first meeting with Dr. A., I told him: “I have two goals. My first goal is to go on a trip to Russia with my husband.” (It was the Soviet Union at that time.) My husband’s Russian class was planning a 15-day tour. I wanted us both to go. I continued, “My other goal is to have a child. You are either with me or not in working toward these goals.” He agreed to help. Dr. A., my husband, and I developed an unusual partnership. There was no question that Dr. A. believed I experienced pain. Together we searched the literature about a new type of steroid injection he thought might work. After considerable discussion we agreed to give it a try.

The steroid injections succeeded in decreasing the intensity of my pain for the several weeks of my trip to Russia. Even though I limited my activities and took pain medications, I had a wonderful time and felt optimistic that my pain would be resolved. During the trip I encountered the everyday world with the world of pain lurking in the background. After a few months the steroid injections stopped working. Dr. A. worried about increasing the amount of steroids in the injections, which could cause other major problems.

A Continued Search for the Cure

One year after the miscarriage I went back to work but was in constant pain. The intensity of the pain made it difficult to hide. Sometimes I would be unable to move until the spasms subsided. My colleagues saw my furrowed brow and hesitating footsteps. Students perceived me as cold and distant.

I continued to search for something that would turn down the volume of my pain. I religiously went to physical therapy. The therapist used myofacial release, hot packs, and relaxation. There was no effect on the pain and I often felt worse. I tried hard to be positive and optimistic about each treatment. Other treatments included acupuncture and herbal remedies. I used an assortment of medications such as Vicodin, Valium, Baclofen, Dilaudid, and Methadone. None of them, even the strongest ones, had any effect on the pain.

I consulted several neurosurgeons. Most alluded to the fact that I looked too good to be in the amount of pain that I described. Everyday I showered, dressed, and put on make up. I might sit in a chair all day but felt the effort and pain I experienced during these tasks was worthwhile. When my husband took me to the doctors, many of them did not believe I had pain. My husband suggested I wear my pajamas, robe, and slippers to appointments. But I couldn’t do it.

I became less and less hopeful about solving my pain in a nonsurgical manner. After a year of trying to avoid back surgery, another neurosurgeon suggested that cutting several nerves might successfully remove the pain. This was my last resort and I had great hopes for the surgery. Five days after surgery, my pain returned exactly as before. On that
day, I couldn't stop crying. I tried to find my doctor. The nursing staff did not help. They decided my situation was not an emergency and refused to contact my physician. I paged the resident from my bedside phone and that only further angered the head nurse. I was distraught. No one knew what to do. I was desperate to get rid of the pain. I felt no one understood me. The physicians felt there was nothing more they could do. I thought if I could somehow better describe the pain they would understand and know what to do. One morning the neurosurgical resident told me that my doctors were afraid to say: “You need to go home and get on with your life.”

Get On With My Life?

What a ridiculous thing to say! How could I get on with life while I was in such severe pain? I was once again relegated to a pain management team that included an anesthesiologist and a psychiatrist. Reluctantly, I accepted a referral to see a psychiatrist. To me, a psychiatry referral meant my pain was not real. Under the psychiatrist’s care, I tried various antidepressant and antiseizure medications used for pain control. As I tried new therapies I also continued to work. On one antidepressant, my blood pressure soared; on another the room spun while I tried to lecture. An anesthesiologist tried steroid injections to no avail. He inserted a catheter into my back and each day injected an anesthetic. That didn’t work. I tried the latest TENS (transcutaneous electrical nerve stimulation) machines. They were cumbersome to wear and provided only limited relief.

The psychiatrist, who specialized in pain, did believe the pain was real. He even risked saying that it would go away. No one said that before. Through a process of trial and error we found a drug to quell the pain—Paxil. I started taking it when it was first released. After 3 days of just 20 mgs of Paxil, for the first time in about 3 years, I experienced a diminished level of pain. I still remember the moment I knew the volume of my pain was turned down. My husband and I, out to our favorite restaurant, were astonished when I got out of the car without my usual spasm. The constant throbbing had subsided. I knew the demon still lurked there but I felt I had my life back. I had won the war. My colleagues reported that they were glad to have “me” back. I found evidence in the literature for Paxil's pain relief qualities in an article on diabetic neuropathies.1 And, I learned that the pain was very much “in my head” but not in the sense that was previously conveyed by health professionals. The pain signal became “hardwired” in my brain similar to a “phantom limb pain.” This made it very difficult to treat. Despite the success of Paxil for my pain relief, I hesitate to tell health practitioners that I take it. They immediately suspect that it is really treating depression and that my pain is not real.

Back to the Everyday World

I am not pain-free but continue with a livable level of pain. I worry about “the demon” invading again because it makes itself known every now and then through lightening bolt-like pains. I still search the literature for pain treatments and try new medications. Recently I tried a new medication, Neurontin, typically used for seizures. Researchers have discovered it works for neuropathic pain. With this medication my pain level decreased such that I experienced less pain than I ever had in my entire life. I will never stop searching for a cure or trying new treatments despite being told to accept the reality of my pain and to learn to cope with it.

Problematic Conceptions of Chronic Pain

If a physical cause for pain cannot be found, then it must be psychogenic or psychosomatic.

When practitioners called my pain “psychogenic,” they believed my pain occurred due to worry about my baby and that it was not “real” (Gatchel & Turk, 1999a). A recent textbook about pain confuses the issue by perpetuating the idea of two pains: one that has an organic or physical origin (real pain) and one that is caused by psychological factors (psychogenic or psychosomatic pain). For example, Gatchel (1999) states in the opening chapter of the book, “Today, fortunately, it is now accepted that psychogenic pain is not experienced any differently than pain that arises from clearly delineated injury or tissue damage. Psychogenic and organic pain both hurt equally!” (p. 7) The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV, 1994) further confounds the issue by identifying pain as a psychiatric disorder. DSM-IV lists three subtypes of pain disorder: 1) “Pain Disorder Associated With Psychological Factors,” 2) “Pain Disorder Associated With Both Psychological Factors and a General Medical Condition,” and 3) “Pain Disorder Associated With a General Medical Condition” (p. 478). Hardcastle (1999), in her book The Myth of Pain, criticizes this view of pain as a mental disorder. She states:

Those who claim that some pains are purely subjective or psychological are being too facile. They are not appropriately valuing their patients’ ability to report their own bodily states, and they are relying too heavily on the routine diagnostic tests to ferret out any real problems. A more sophis-

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Hardcastle argues, through a philosophical analysis, that pain is best understood from a biological model, the opposite view of psychiatry and psychology. She completely dismisses the idea that psychogenic pain exists. She states, “Whatever distinction we make with respect to pain, the psychogenic/organic one should not be it. To put it starkly, no pain is a mental disorder simpliciter” (p. 34).

Psychosomatic, another problematic term, refers to an area of medicine that suggests an integration of body and mind (Gatchel, 1999). Candice Pert (1997), a physiological researcher, provides a critique of this area of medicine:

Though the fact that they are fused into one word (psychosomatic) suggests some kind of connection between the two, that connection is anathema in much of our culture. For many of us, and certainly for most of the medical establishment, bringing the mind too close to the body threatens the legitimacy of any particular illness, suggesting it may be imaginary, unreal, unscientific. (p. 18)

Words such as psychosomatic, psychogenic, and real pain imply an “in your head” cause or that pain occurs due to a subconscious mechanism. Improvement would occur if persons possessed the motivation to examine these unconscious issues and learn coping strategies to manage pain. This psychological message implies that if you are suffering it is your fault. Coping and adaptation are presented as the answers to managing pain in everyday life.

In my occupational therapy practice I have frequently heard therapists use these terms without understanding their definitions and historical meanings. I have witnessed the detrimental effect on patients’ self-esteem when these words are used in the context of their pain. For me it meant that if I would only deal with the grief of losing my baby the pain would be improved.

Defining pain as simply “what the patient says it is” (Jackson, 2000, p. 177) challenges the basic tenant of medicine that there be objective evidence apart from the subjective. So, when medical tests fail to show an exact mechanism for explaining pain, the agent of pain becomes the mind. For me, pain was diagnosed as psychogenic without any tests to support this notion. I became even more suspect when after I lost my baby and the X-rays, MRI, and CAT scan failed to describe the exact etiological mechanism. Naming my grief had the power to further diminish the focus on my pain and suffering. Rather than accept my emotional and physical pain as two separate, yet mysteriously intertwined and real experiences, health professionals wrongly linked my emotional pain with my physical pain in a linear cause–effect rationality.

Jean Jackson (2000) in her book called, Camp Pain, presents an ethnographic study of a 21-bed comprehensive pain center. After having been a former patient there herself, she became a participant observer and interviewed both patients and staff. Her research resonates strongly with my experiences. Even today, 10 years from my pain-full (I borrow this term from Jackson) time, I look for validation of my experiences. They don’t come from the medical or psychological literature but from medical anthropology and sociology.

Reynolds Price (1994), an author who vividly describes his experiences of pain in a book A Whole New Life, is a remarkable example of an effort to overcome pain using mind-training therapies such as hypnosis and biofeedback. However, if these efforts don’t work a person is perceived as not trying or not motivated to get rid of their pain. Rather than view pain as a mystery, puzzle, or anomaly in the existing paradigm of medicine and psychology the patient is viewed as wrong about their pain (Jackson, 2000). Is it psychogenic or real? The answer is it’s pain.

**If you can work, then you can’t be in too much pain.**

I tried to work and found that I could immerse myself in giving a lecture and my perception of pain would lessen. However, immediately after it would return in full force. I relished being around my colleagues who were supportive and understanding. I could engage in an intellectual or personal discussion and experience a momentary suspension of the reality of pain. I found I could read a novel and have the same experience. I read everything I could find. I immersed myself in mysteries, and biographies. I reread Norman Cousins (1981) book Anatomy of an Illness As Perceived by the Patient where he described a similar experience of using activity as an antidote to pain. Cousins told of his experience of using funny movies in his systematic program of recovery. He wrote, “I made the joyous discovery that ten minutes of genuine belly laughter had an anesthetic effect and would give me at least two hours of pain-free sleep” (p. 39). He also recounted observations of his 90-year-old friend Pablo Casals, who suffered from rheumatoid arthritis. He described his reaction as Casals approached the piano:

“I was not prepared for the miracle that was about to happen. The fingers slowly unlocked and reached toward the keys. His back straightened. He seemed to breathe more freely. Now his fingerssettled on the keys like the buds of a plant toward the sunlight. Then came the opening bars of Bach’s Wohltemperierte Klavier, played with great sensitivity and control.” (p. 72)

During the time I was working I saw a psychiatrist twice a week. Medical insurance challenged this intensive therapy stating that if I could work I didn’t need psychotherapy. The
popular conceptualization about work is that it produces stress and thus would intensify pain. It is an interesting paradox such that if I worked my pain was not viewed as legitimate; yet if I used the disability system I would be stigmatized for being paid to be in pain (Good, 1992).

Mary-Jo Del Vecchio Good (1992), a medical sociologist at Harvard, studied two professional women and their experiences of pain and work. From intensive interviews she found women experienced work as a means to escape their pain, maintain control, and feel confident about their abilities. For these women, pain threatened to destroy their self-hood. Work became a means to counter this effect and to engage in a restructuring of the self. In describing her two informants Good concludes that “it is in the realm of the world of work that both women experience control and a sense of integrated selves” (p. 68). Like the two women described in Good’s study, I found that work provided a meaning that the world of pain lacked. I was driven to succeed in my career and to find a cure for my pain so I could have a child. I lived in two worlds: the everyday meaningful world and the “pain-full” meaningless world. At times they intersected throughout the day, one overpowering the other in a constant battle.

From a broader perspective, it is not just work but any activity connected with one’s life goals that has the potential to provide moments of relief from pain. For example, in her analysis of the narratives of women in pain, Good (1992) found that “work and physical play served to fend off the intrusiveness of chronic headache and psychological pain. Focused task and goal oriented activity are the analgesics for both modes of pain” (p. 65). Mattingly (1998) defines life goals from a narrative perspective linking them with life plots that engender hope. In her study of occupational therapy practice she found that for therapy to be effective the patient and the health practitioner needed to be committed to the same vision. In my case two practitioners were committed with me in my vision of having a family—the radiologist and psychiatrist.

**You can tell by a person’s appearance if he/she is in pain.**

As described in my narrative, health professionals, particularly physicians, alluded to the fact that I looked too good to be in the amount of pain that I described. A research participant in Jackson’s (2000) ethnography aptly questioned: “Why should I look as bad as I feel” (p. 37)? Jackson found it common for her pain clinic informants to mask their pain in an effort to control it. However, these efforts caused practitioners, family, and friends to not believe they had severe pain. The difference between my inner experience and outward appearance made practitioners suspicious about my pain experience. Fitzgerald and Paterson (1995) used narratives of a group of women with pain from Temporomandibular Joint Syndrome (TMJ) to illustrate the “hidden disability dilemma” (p. 13) of chronic pain. They found that these women negotiated their public and private experiences of pain through a “continuous inner narrative” (p. 19) aimed at preserving their self-identity. Whether or not to reveal their experience of pain posed different risks depending on the situation. For me my experience of pain was hidden, but my limp and scoliosis were not. I learned from an early age to hide my pain. As an adolescent I wanted to be as much like my peers as I could. I wanted to appear “normal” despite my outward appearance. Crying out in pain would only add to my experience of feeling different. Again a paradox or dilemma exists, such that if you cry out or complain about pain then you are exhibiting “pain behaviors,” which, according to a behavioral framework, are to be ignored (Howell, 1994). Greenhalgh (2001), in her book *Under the Medical Gaze*, presents a gender model of chronic pain. She contends that some but not all women with chronic pain, in their encounters with male physicians, resort to appearing pleasant and compliant rather than angry and empowered. She argues that due to the high stakes involved in encounters with physicians many women respond in a “relationship-first” mode.

Brodwin (1992) offers an alternative interpretation of the disparity between inner and outer appearances in a discussion of the “performative aspects of chronic pain” (p. 92). This is not to say “that chronic pain itself is a performance, something voluntarily produced and under one’s control” (p. 92). Rather one chooses “…when to hide the pain and when to introduce it into social action” (p. 92). The performance, whichever is chosen, communicates about the pain. I had long ago mastered the ability to keep my pain hidden in concert with performing everyday roles as a student and friend. Only with immediate family did I show, through crying or clutching my side, how much I suffered. My performance in roles outside my family was so successful that it became an impediment for communicating how I felt to physicians. My husband, witness to both “performances,” found my presentation to physicians confusing. My outer appearance (well groomed and pleasant) created an impression to practitioners that I did not appear in distress. Quite the contrary, this appearance was a consistently performed “impression management” strategy that I had used in the past and that allowed me to fit in with peers despite the everyday experience of pain.

**Epilogue**

I have argued that the voice of the person in pain has been left out of the storyline of pain. How can we use the privi-
leged viewpoint of the person in pain to inform occupational therapy practice? The answer is not to retreat from the medical model but to supplement it. In my story I wanted both cure and care. For example, during the 3-year period of continual pain, I never stopped searching for new medical treatments. However, I also wanted a practitioner (whatever discipline) who embodied empathy and respect. While the idea of complementing the medical model with a caring relationship is hardly a new idea, it did not pervade my relationships with practitioners and was not evident from stories in the literature. I end, then, with reflections about occupational therapy practice.

Establishing an Authentic and Respectful Relationship

Engaging with a person is an active process and will not occur without trust. Trust, important in any relationship, is especially salient for a person in pain who is confronted on a daily basis by suspiciousness. Trust implies a genuine belief that a person experiences pain. Pain is what the person says it is, despite any statements to the contrary by other health professionals. Occupational therapists need to believe in a person's pain.

Yerxa (1967), described components of authentic occupational therapy in her 1966 Eleanor Clarke Slagle lecture. According to Yerxa, authentic occupational therapy implies a commitment to a patient's meaning system and a relationship that is best described as “being there” with our patients. Clark, Ennevor, and Richardson (1996) build on Yerxa's message to occupational therapists and describe techniques to develop trust and hope. They call this process “building a communal horizon of understanding” (p. 375). The techniques described such as “collaboration, building empathy, inclusion of the ordinary, listening, and reflection” (p. 376) are important for understanding patients' stories of the world of occupation and the world of pain. In my story there were two professionals who engendered trust and hope consistently whether treatments worked or not. We were partners; they listened and shared stories from their lives, their families, and their interests. They were empathetic listeners. They were not rushed or impatient as I told them about my daily struggles with pain. They didn't try to change the topic to one that was not pain related.

Behavioral strategies frequently used in pain management clinics are not consistent with an authentic relationship. Arthur Kleinman (1992), a professor of medical anthropology and psychiatry at Harvard, speaks of the behavioral discourse as “stereotyped, overly focused on pain as a problem of an individual, and dehumanizing” (p. 185). Turk and Flor (1999) provide an example of this discourse. They describe how talking about pain and suffering may enlist responses that reinforce pain communications such as walking with a limp or moaning. A cognitive-behavioral framework for pain integrates an operant conditioning emphasis on external reinforcement within the framework of information processing. Most comprehensive pain centers integrate an operant model within a rehabilitation model (Gatchel & Turk, 1999b; Turk & Gatchel, 1999). Such behavioral strategies that aim to limit discourse about pain are incompatible with attempts to elicit a narrative about the worlds the patient encounters and with establishing an authentic and respectful relationship.

Howell (1994), in her grounded theory study of 19 women with chronic nonmalignant pain, reinforces this conception. She found women's empathetic bond with health professionals as “…essential for maintaining their hope and avoiding the despair of chronic pain” (p. 119). Based on interviews with these women, she described several relational patterns through which women progressed during the course of their pain. Whether a woman moved forward in a healthy manner was highly dependent on the intersubjective and caring relationship she had with health practitioners. Validation of pain, essential for progress, meant that “…her experience of pain was viewed as originating from her body and not as psychological need, secondary gain, or sin” (p. 94). Further, she described the behavioral approaches as a way that professionals appeared to avoid engagement with the person in pain.

Attention to Future Life Goals Can Mediate Pain

Throughout my pain experience I continued to pursue my life goals. One goal was to have a child. Some practitioners felt that my goal to have a child was not realistic. For example, a woman physician prior to her physical exam said to me, “Because you have spina bifida you should not get pregnant. You'll get sick.” After that encounter I went to my car and cried. Several weeks later, after hearing my medical history, another woman physician said, “You can have a baby. What you need is a cheerleader.” The reality of my goals was dependent on my own assessment. I was the only one who could decide if my goal was realistic or not. In addition to pursuing my goal to have a child (in reality this was both my goal and my spouses’ goal), I also continued to work and pursue my career as an assistant professor on tenure track. Fortunately, I worked in an occupational therapy department where my colleagues understood my intense drive to continue working as an antidote to my pain.

Little has been written about the relationship of activity or occupation to pain. The psychological literature on
pain consistently describes distraction or diverting attention as one of several coping strategies used by people with chronic pain (Boothby, Thorn, Stroud, & Jensen, 1999). McCaul and Malott (1984) in a review of distraction research presented a theoretical argument for the value of distraction as an effective coping strategy for pain. They defined distraction as “any strategy whose purpose is to block awareness of the painful stimulus or its effects.” Examples of distraction strategies used in the research studies that they reviewed included word associations, attending to positive imagery and positive thoughts, music, and games. As this broad definition of distraction demonstrates, researchers have not distinguished distraction from meaningful activity or occupation. Researchers focus on particular strategies of distraction rather than individualizing the activity or strategy based on what is meaningful for each person. It is therefore not surprising that correlation studies demonstrated that distraction is not related to functioning and overall does not contribute to adjustment to chronic pain (Boothby et al., 1999). To the contrary, however, as discussed earlier, many descriptions in the literature describe stories where occupation mediated pain even for a short time. Good’s (1992) ethnography of two women’s experiences of pain and work provides examples of the connection of occupation and pain. She uses data from her interviews to assert that work was “the potential to be transformative as well as therapeutic” (p. 69). In addition to work being a “haven from pain” (p. 49), she found that work was an area for “self-realization and effective performance,” as well as “a vehicle for control over the intrusiveness and daily disruptiveness of pain” (p. 50). Future research in occupational science needs to investigate this powerful relationship between pain and occupation and clarify the distinction between distraction and occupation. As occupational therapists we need to enter into empathetic and respectful relationships with those in pain while sharing their visions for the future.

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References


Goodall, H. L. (2000). Writing the new ethnography. Lanham, MD: AltaMira Press.