

## CHAPTER 1

# WORLDS OF PAIN

*Somewhere within us, say the pundits, there is a sensorium commune, an undetermined site wherein the nature of pain is revealed. More elusive than the Holy Grail for which medieval man sought widely and in vain, the quest for the sensorium commune has preoccupied and frustrated [hu]man's thinking since time immemorial. To find it, and define it, may resolve the problem of dealing with it; but, so far, biopsychosocial research has only given new insights into the complexity of the quest.*

—Todd, *Pain: Historical Perspectives*

### CHRONIC PAIN PATIENTS

"Pain patients," as chronic pain sufferers are generally referred to in the medical and particularly in the psychological literature, often have been defined as a relatively homogeneous group (Aronoff 1985:472; Kotarba 1983; Sternbach 1974, 1984; Lindsay and Wyckoff 1981; Fordyce 1976). Aronoff's description of the stereotypical "chronic pain patient" provides an excellent example. Director of the Boston Pain Center and one of the leading American specialists in chronic pain, Aronoff states:

These [pain] patients share many of the following characteristics: preoccupation with pain, strong and ambivalent dependency needs, feelings of isolation and loneliness, characterologic masochism (meeting other people's needs at their own expense), inability to take care of self-needs, passivity, lack of insight into patterns of self-defeating behavior, inability to deal appropriately with anger and hostility, and the use of pain as a symbolic means of communication. . . . Chronic pain can often represent conditioned psychosocioeconomic disorders in which personal gains may play an important role. (1985:472)

The widespread belief in a single, homogeneous "type" of chronic pain patient has led to homogeneous care and treatment programs which are ineffective for many patients. In many instances the failure of these programs is attributed to characteristics of the patients, who are assumed to be somewhat neurotic and in some way gaining from the pain (Aronoff, 1985). This is often a case of "blaming the victim." It is just as likely that the practitioners' inability to help these patients reflects a current lack of biomedical knowledge or the inflexibility of their programs, which cannot meet the needs of diverse populations that suffer from chronic pain.

Patients in the New England pain center and Puerto Rican populations to be presented in this book vary significantly in many ways: in cultural and psychological characteristics, in reported pain intensity, and in behavioral, cognitive, and psychological/emotional responses to pain. The diversity in these populations in coping strategies and day-to-day responses to the chronic pain experience is particularly clear in two case studies gathered from the Puerto Rican study. These case studies introduce us to the lived worlds of the chronic pain sufferer. (Fictitious names are used in the case studies to protect patient confidentiality.)

#### MEETING THE CHALLENGE OF PAIN: CASE STUDY NUMBER ONE

Manuel, a professional Puerto Rican with an advanced degree, is in his mid-fifties and was interviewed during 1992 and 1993 in Puerto Rico. He has had chronic pain associated with severe rheumatoid arthritis for more than fifteen years. The joints of his fingers are noticeably deformed, he walks with a limp, and he has severe arthritis in his fingers, hands, knees, hips, feet, toes, ankles, and spine. One of his hips has been replaced surgically. His physician believes Manuel should not be working at all, and that he urgently needs to have joint replacement surgery in several additional joints.

Manuel, however, refuses both of these prescriptions. He said his work keeps him going, and that he has no intention of stopping the work he loves or of having further surgery. Typical of other Puerto Rican men interviewed, Manuel believes his self-image, happiness, and "manhood" depend on his ability to work. When his arthritis became severe, one of his methods for adapting to his increasing pain and disability was to relocate his office to his home. Clients now travel to him, which reduces his travel and allows him to rest as needed. He said he considers himself fortunate, and he recognizes that if his employment involved manual labor he would have had to stop working long ago. However, with great determi-

nation and contrary to his physician's advice, he continues to work. During his busiest season, Manuel works many fifteen-or sixteen-hour days. He said he believes his work is the most important factor in coping and adapting to the pain.

On a visit to his office, it was clear Manuel had designed it to accommodate his arthritis. He had a sofa on which he could lie down as needed, special cushions on his desk chair, and a specially designed computer table and chair. Manuel's numerous topical remedies as well as his oral arthritis medications were handy and easily accessible.

He also is determined to continue his social activities. Married with three grown children, he loves to go to parties with his wife, and especially loves to dance. Despite one artificial hip and severe arthritis in his other hip, his knees, and his feet, Manuel continues to dance regularly. He said he recently had one of the worst days of his life in terms of pain intensity, although, he proudly said, he still went to an anniversary party and danced throughout the day. The pride and pleasure Manuel finds in dancing is understandable, as dancing is an integral part of the Puerto Rican social fabric (unless restricted by religion). In addition, being a good dancer is a highly regarded ability, especially for males.

Manuel told me, "You have to learn to live with the pain and forget about it. I always remember that there are others who are worse off than I am. I must keep my mind clear and continue to work and do the things I enjoy." In order to ensure the "clear mind" he values, Manuel deliberately takes only anti-inflammatory medications, and refuses opiates or other medications prescribed solely for pain.

Manuel said he has found ways to live with his pain and still work and enjoy his life. He clearly does not like to dwell on his condition, but was willing to discuss it as long as the focus was on how to cope with the pain effectively. He defines his status as "mainly healthy." Manuel exhibited a strong sense of having control over his life, and he clearly takes pride and satisfaction in his ability to adapt to the arthritis and to cope effectively. "I have a good life," he said.

In light of his determination to ignore his pain, it is not surprising that Manuel's score on the McGill Pain Questionnaire (MPQ), which is a standardized and widely used instrument for assessing pain quality and intensity levels, was very low and extremely low on its *affective* section of the questionnaire. Unlike the majority of Puerto Ricans of both genders who view expressiveness as appropriate, Manuel appears determined not to become emotional about his pain or to focus on it. He does admit, somewhat reluctantly, that the pain is occasionally tiring and troublesome, but for the most part he feels he can live with it as long as he can work and engage in pleasurable activities. When asked whether he was determined

to overcome his pain, he responded, "I am not just determined to, I *do* overcome it."

#### DISABILITY, DESPAIR, AND CHRONIC PAIN: CASE STUDY NUMBER TWO

Our second Puerto Rican case study is Jesus, of middle-class background. He was in his forties when interviewed during 1990 and 1993. Although Manuel and Jesus share a similar cultural perspective on the importance of work to self-control, self-fulfillment, and sense of "maleness," Jesus has been unable to continue to work. As a result of Jesus's inability to continue working and the resulting loss of his self-esteem, his chronic pain experience differs significantly from Manuel's.

Like Manuel, Jesus also has an advanced degree, and prior to his pain problem he had a successful professional career. His position required both office work and frequent travel. Jesus reported that he felt in control of his life before developing severe postsurgical back problems following disk surgery approximately four years ago. (He also now has degenerative joint disease of the spine and arthritis in his knees.) However, since developing the chronic pain, he reported having lost all sense of control over his life.

Jesus wants desperately to return to some type of work; however, he is caught in the trap of the current disability system of the United States. He and his doctor believe he could work in an office for about four hours per day. Extensive travel is impossible. When Jesus and his doctor suggested to his disability benefits provider (which is the private insurance carrier for his old employer) that he work twenty hours per week for his old employer at the office (with the stipulation that he could not engage in travel), his old employer said he could only return to his position if he worked forty hours per week and did the same traveling he engaged in before the disability occurred. His disability compensation is tied to his old employer—thus his choice was to work forty hours per week and engage in extensive travel, or, if he wanted to work a twenty-hour week, give up his disability benefits through his old employer and try to find a new half-time position. Obviously, even if he could find such a position, it would not pay as well as the benefits which are based on his former forty-hours-per-week salary and he would permanently lose the current benefits, including his health insurance.

Jesus is the sole support of his wife and four children. He has significant financial responsibilities, with two children already in college and a third child only a year away from entering college. With disability compensation as the major source for financing his children's higher educa-

tion, he sees no choice but to remain on disability—yet he feels worthless because he is not working.

As a result of his grave professional and financial concerns, Jesus reported to his center physician and at interviews that he is severely depressed and sees a psychologist regularly. He is a deeply unhappy man who sees little purpose in life and defines himself as unhealthy and disabled. He believes the pain has ruined his life. He said the pain and disability have taken away all control he once had over his life and that the accompanying inability to work has resulted in the loss of his manhood.

Resulting from his depression and despair, Jesus has attempted suicide more than once, as confirmed by his physician at the medical center, who was deeply worried about him. During several interviews, including two home visits, Jesus was greatly disturbed about his inability to work, to engage in sports with his teenage son, or to attend the boy's sports competitions. Despite having a very supportive wife, children he clearly adores, and a loving extended family, Jesus is unable to find any meaning and purpose in his life as long as he continues to have pain. He reported thinking constantly of his pain and disability.

Consistent with his view that only an outside person or force could influence his current circumstances, Jesus continues to seek the care and advice of a host of medical and psychological specialists. He has read about chronic pain treatment centers and wants to seek such services; however, no live-in treatment centers exist on the island. (Apparently the Medical Sciences Campus of the University of Puerto Rico had been developing an outpatient chronic pain clinic, which was not fully operational when we met with Jesus.) Upon the recommendation of his physician at the center, Jesus would seek care at an inpatient chronic pain treatment facility on the mainland, but his disability insurance company has refused to finance such treatment.<sup>1</sup> Very upset by the insurance company's decision, he said that unless he could attend a pain clinic or find a

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1. The decision of the insurance company is obviously based on short-term economic considerations, as live-in chronic pain treatment centers are very expensive, and there is a perception, among "third-party payers, that pain program treatment for back pain is ineffective in attaining specific socioeconomic goals, such as cost effectiveness and return to work" (Tollison et al. 1989:1116). However, Tollison et al. found this perception to be inaccurate in their study of treatment outcome, which found that back-injured pain center patients participating in programs based on an industrial medicine model used fewer analgesics; required fewer hospitalizations for additional diagnoses, treatments, and surgery; and were more likely to return to work than a comparison group of patients denied comparable treatment (1115).

physician who could cure his pain and disability very soon, he would commit suicide.

Given his severe depression, Jesus's desire to return to some type of work should not be ignored, as Dworkin et al. (1986) found that activity is especially important in the treatment of depressed chronic pain patients. However, the disability system, as well as an inflexible former employer, contribute to the problems Jesus faces. Even for professionals such as Jesus, with private disability insurance rather than workers' compensation, the current system offers little help to those who want to return to work but need a restructured work environment or flexible work schedule to accommodate their pain and disability.

The cases of Manuel and Jesus demonstrate the complexity of the quest to understand and effectively treat chronic pain and the need to assess the environmental context in which each pain sufferer attempts to cope with the pain and any associated disability. In the next chapter, an overview of theories of human pain perception and of chronic pain studies and treatment programs is offered to provide a picture of the current state of understanding of this complex and troublesome area of human experience.