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# PAIN AND DISABILITY



Clinical, Behavioral, and Public Policy Perspectives

INSTITUTE OF MEDICING 000



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## Clinical, Behavioral, and Public Policy Perspectives PROPERTY OF NAS-NAE

**INSTITUTE OF MEDICINE** 

Committee on Pain, Disability, and Chronic Illness Behavior

Marian Osterweis, Arthur Kleinman, and David Mechanic, Editors

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This report has been reviewed by a group other than the authors according to procedures approved by a Report Review Committee consisting of members of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

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This volume is the final report of a study conducted under Contract No. 600-85-0263 with the Social Security Administration, Department of Health and Human Services.

#### Library of Congress Cataloging-in-Publication Data

Pain and disability.

RB 127

1987

CI

Includes index. 1. Intractable pain-Social aspects. 2. Intractable pain—Public policy. 3. Intractable pain—Economic aspects. 4. Disability evaluation. I. Osterweis, Marian. II. Kleinman, Arthur. III. Mechanic, David. 1936-IV. Institute of Medicine (U.S.). Committee on Pain, Disability, and Chronic Illness Behavior. [DNLM: 1. Chronic Disease. 2. Disability Evaluation. 3. Pain. 4. Public Policy. 5. Sick Role. WL 704 P14435] RB127.R33213 1987 362.1 87-11232 ISBN 0-309-03737-9

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## Preface and Acknowledgments

The 1984 amendments to the Social Security Act (P.L. 98-460) included the first statutory standard defining how pain should be evaluated for purposes of determining eligibility for disability benefits. By that time considerable concern had developed about symptom complaints, especially pain, that were not adequately accounted for by objective medical evidence of disease or injury. During 1980 and 1981 there had been a "purging" of the disability rolls that caused a strong public reaction and the eventual reinstatement of many beneficiaries. Furthermore, the administrative law judges were overturning about 50 percent of the cases they heard, thus granting benefits to people who had been denied at the lower levels; and in about half their cases, the federal courts were remanding cases back to administrative review or were awarding benefits.

Observers believe that claimants with mental impairments and those with symptom complaints, such as pain, were disproportionately represented among those who appealed initial denials and subsequently were allowed benefits, as well as among those disqualified during the 1980–1981 Continuing Disability Reviews who were later reinstated. The federal courts, moreover, were handing down opinions that included directives to the Social Security Administration (SSA) about how to evaluate pain for purposes of determining eligibility for disability benefits that ran counter to the existing regulations. Clearly the issues were controversial.

As part of the 1984 legislation, Congress mandated the Secretary of the Department of Health and Human Services (HHS) to appoint a commission for the evaluation of pain whose task it was to study the current pain evaluation policy and recommend changes as appropriate. It was further mandated that the commission "shall work in consultation with the National Academy of Sciences." That consultative activity fell to the Institute of Medicine (IOM), a component of the Academy complex. Given its short life and limited resources, the HHS Commission on the Evaluation of Pain was not able to explore fully the variety of issues surrounding chronic pain, illness behavior, and disability. Thus, at the suggestion of the commission, the SSA requested that the IOM convene a committee to conduct a more detailed study to expand on the work of the commission.

Specifically, the Institute of Medicine was asked to explore:

 $\bullet$  the relationship between medical illness and pain as a symptom complaint

• the distinction between acute and chronic pain

• the pathway from acute pain to chronic pain to chronic pain syndrome and to the inability to function

• the concept of illness behavior, especially as it relates to people with chronic pain

• how various disability benefit programs deal with complaints of chronic pain that are not fully accounted for by objective medical findings

 $\bullet$  promising approaches to the assessment and measurement of chronic pain and dysfunction

• promising approaches to the rehabilitation of chronic pain patients

• how the SSA benefit structure and administrative processes may affect pain complaints.

Further, the IOM committee was asked to consider making recommendations regarding:

• possible changes in the way the SSA deals with pain in the context of disability determinations

• the role that rehabilitation might play in the current disability program in relation to patients with chronic pain

• promising areas of research that would further our understanding of the nature of chronic pain and its measurement.

A diverse group of experts from the IOM membership and beyond was appointed to the study committee. The eighteen members included representatives from various medical specialties (primary care, orthopedics, neurology, physical medicine and rehabilitation, psychiatry), the social and behavioral sciences (psychology, sociology, anthropology), political science, economics, law, ethics, and public policy. One member, Eric Cassell, served as liaison from the HHS Commission on the Evaluation of Pain as well as being an active member of the IOM committee. The committee held five two-day meetings during which it debated the issues, heard presentations from SSA officials and pain measurement experts, and reviewed early drafts of the report. The published literature from the many disciplines with an interest in pain and disability and the informed judgment of the committee form the basis for the report.

The entire committee has worked hard on the overall report, but some chapters benefit particularly from the work of one or more members. Deborah Stone took major responsibility for Chapter 2, the sociopolitical background of the problem. Monroe Berkowitz took the lead on Chapter 5, the economic perspective. Chapter 6, the epidemiology of pain, was based on work by Walter Spitzer and his colleague at McGill University, Mary Ellen Thomson. Howard Fields drafted Chapter 7, the physiology of pain. Much of Chapter 9 on psychiatric perspectives was written by Boris Astrachan with the assistance of Yale colleagues Lawrence H. Price, Richard S. Schottenfeld, and Steven Southwick. Drafting of Chapter 10, chronic pain in clinical practice, was led by John Stoeckle and Robert Boyd. Richard Chapman took responsibility for Chapter 11, the measurement and assessment of pain. June Rothberg, David Simons, and William Spencer did much of the drafting of Chapter 12, rehabilitation approaches to pain.

Comprehensive projects of this kind depend on the capabilities and efforts of staff. The committee was fortunate, indeed, to have the staff support of Marian Osterweis, study director. Her understanding of the various dimensions of the pain problem, and outstanding organizational skills and talents in bringing together diverse materials in meaningful ways, contributed in an essential way to every aspect of this committee's report including conceptualization, research, and drafting. Cynthia Howe, research associate, made major contributions to this endeavor. Her tireless research efforts, clear thinking, and fine prose are reflected throughout the report, the last particularly in Chapter 3. Fredric Solomon, director of the Division of Mental Health and Behavioral Medicine of the IOM, participated in the committee's deliberations and ably assisted in its conceptualizations and in various aspects of the report. And, finally, Sabrina Dave, project secretary, competently handled all the meeting logistics and the preparation of the manuscript for this report.

The committee's work was aided by two commissioned background

papers, one on cross-national comparisons of disability policies by Eldon Wegner, Department of Sociology, University of Hawaii, and the other on the history of the Social Security disability programs by Edward Berkowitz of George Washington University and Daniel M. Fox of the State University of New York at Stony Brook. In addition, Harold Merskey, London Psychiatric Hospital, London, Ontario, provided a valuable background paper on psychiatric approaches to chronic pain. Thomas Csordas, a medical anthropologist at Harvard Medical School, assisted in the drafting of Chapter 8. Deborah Swansburg, of the Institute of Medicine staff, drafted important sections of Chapters 3 and 4. Jerry Mashaw, Yale Law School, and Robert Gerwin, a practicing neurologist in the Washington, D.C., area, were helpful in reading and commenting on drafts of some chapters. Thomas Drury and Kathleen Danchik of the National Center for Health Statistics were invaluable in providing statistics and references from the Center.

Of great value to the committee in its deliberations were the presentations of the Panel on Assessment of Pain and Dysfunction, brought together at our meeting of April 14, 1986. Presenters were committee member Howard Fields; David Florence, People's Community Hospital Authority, Wayne, Michigan, and former member of the HHS Commission on the Evaluation of Pain; Francis Keefe, Pain Management Program, Duke University; Frances Marcus-Lewis, University of Washington School of Nursing, Seattle; Harold Merskey, London Psychiatric Hospital, London, Ontario; and Richard Sternbach, Pain Treatment Center, Scripps Clinical Medical Group, La Jolla, California. A grant from the Upjohn Company that helped to defray expenses for this session was much appreciated.

Finally, we would like to acknowledge the contribution of the staff of the Social Security Administration. Patricia Owens, Associate Commissioner for Disability during most of this project, attended many of the committee's meetings and made herself and her staff available for assistance. Nancy Dapper, Executive Director of the Commission on the Evaluation of Pain, was an unfailing source of information and data. Gary Thorne ably carried out his responsibilities as project officer and coordinated all requests for information. Victoria Dorf was always willing to track down the facts and numbers needed by the committee.

ARTHUR KLEINMAN, M.D. Chairman

DAVID MECHANIC, Ph.D. Vice-Chairman

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## PAIN AND DISABILITY





### Summary

Making decisions about people who suffer from chronic pain is one of the most troublesome of the problems faced by public and private insurers who determine eligibility for disability, including the Social Security Administration (SSA). The problem was brought sharply into focus in 1980–1981 when SSA's intensified "continuing reviews" of disability cases resulted in the termination of benefits for nearly half of those reviewed. People suffering from chronic pain were believed to be among those removed from the rolls in disproportionate numbers. The 1980–1981 "purging of the rolls" has been followed by years of appeal and litigation from many of those whose allowances were discontinued; more than half who appealed have had their benefits restored. Further, in recent years there has been considerable tension between the SSA system and the federal courts over the subject of chronic pain; claimants who had been denied benefits by the SSA often were later awarded them by the courts to which they appealed.

In response to these problems, the 1984 amendments to the Social Security Act included the first statutory standard defining the way in which pain should be evaluated by the SSA in determining eligibility for disability benefits. It further required the Secretary of the Department of Health and Human Services to appoint the Commission on the Evaluation of Pain. This commission was to work in consultation with the National Academy of Sciences; the Institute of Medicine (IOM) fulfilled this role for the Academy. The commission's life was short and it recommended further study by the IOM. This report is the result of that more detailed study.

#### **2** PAIN AND DISABILITY

Specifically, the IOM was asked to explore the relation between medical illness and pain as a symptom; the pathways from acute pain to chronic pain and the inability to function; the concept of illness behavior, especially as it relates to people with chronic pain; the ways in which various disability benefit programs deal with symptoms of chronic pain that are not fully accounted for by clinical findings; promising approaches to the assessment and measurement of chronic pain and dysfunction; promising approaches to the rehabilitation of chronic pain patients; and how the SSA benefit structure and administrative processes may affect pain complaints. The IOM was further asked to consider making recommendations for possible improvements in the way the SSA deals with pain in making disability determinations, the role that rehabilitation might play in the current disability program in relation to patients with chronic pain, and promising areas of research to develop a better understanding of the nature of chronic pain and its measurement.

#### CHRONIC PAIN

Everyone suffers severe pain from time to time; for most of us, each episode ends with the resolution of the symptom or the disorder producing it. A small but significant proportion of individuals treated may get less than optimal relief, have recurrences, and develop chronic pain. What differentiates people who develop chronic pain from those who do not, and those who can function with the pain from those who become disabled by it, is not well understood. At the time of a person's first episode of pain it is usually difficult to predict the course of the condition for a given patient, the likelihood of recovery, the response to specific therapies, or the potential for rehabilitation and a return to a more active role.

Despite progress in our understanding of the physiology of pain pathways in the body, very little is known about the mechanisms underlying such common clinical problems as low back pain. Even when there is demonstrable degeneration of the spine and compression of a nerve root—a condition generally acknowledged to be extremely painful—it is not known what it is about the condition that actually causes pain.

Much research and clinical experience with pain have demonstrated that there is no clear relation between the amount of tissue damage and the degree of discomfort or functional disability. The nature of the pain and underlying physiological factors do have an impact on the course from acute pain to chronic pain to functional disability. Yet for many, and perhaps most, of those who follow this course, psychosocial factors are inextricably intertwined with physiological change and may even be primary.

The concept of illness behavior provides a useful framework for understanding and describing the multiple psychosocial influences that affect the ways in which people monitor their bodies, define and interpret their symptoms, come to view themselves as sick and disabled, take remedial action, and seek lay and professional sources of help. A crucial premise in the concept is that illness and the illness experience are shaped by psychological, social, and cultural factors along with the genetic, physiological, or other biological bases of disease; all of these factors interact to influence the development, course, and outcome of illness. Complaints of chronic disabling pain that seem disproportionate to clinical findings may be clarified by the concept of illness behavior. It also helps to explain why some people who have well-substantiated diagnoses of painful diseases and obvious physical limitations continue their usual routines and push themselves beyond what one might expect.

Psychological and physical factors are not completely separate in their effects on the maintenance of pain. For example, stress and anxiety increase muscle contraction and would thus be expected to exacerbate any pain problem to which this factor contributes. Conversely, any treatment that induces relaxation will reduce muscle contraction and perhaps lessen pain. This phenomenon may represent a linkage of the psychosocial and the somatic factors that influence pain tolerance.

There is evidence that chronic pain is sometimes associated with mental disorders and substance abuse. The nature of the relation, especially in terms of cause and effect, is often unclear. Just as there is diversity among chronic pain patients in general, so, too, are individuals with chronic pain and psychiatric disorders a heterogeneous group. Many patients have affective disorders, particularly depression; others suffer from substance abuse, personality disorders, and various somatoform disorders, such as hypochondriasis and somatization disorder. In some patients these disorders may be secondary to chronic pain, but in others they predate the pain or reflect alternative expressions of the same underlying psychobiological disorder. Whatever their etiological significance, each of these psychiatric disorders, if untreated, may exacerbate the pain condition, render other treatment less effective, and impede recovery.

There is no direct, objective way to measure pain. Although it is possible to identify neural activity that ordinarily causes pain, there can also be pain without any neural activity; conversely, there can be activity in the primary afferent nociceptors without pain. The awareness of pain is a perception and, therefore, subjective. Well-defined instruments for assessing pain and related variables are all based ultimately on self-report, observation, or both. No method can yield unequivocal evidence of the presence of pain apart from the patient's report and behavior. In recent years considerable attention has focused on the assessment of the *effects* of pain, such as functional limitations. Such measures are not always good proxies for pain severity because the correlation between pain severity and functional impairment is imperfect. On the other hand, functional measures may be more relevant than pain severity if the reason for the assessment is to determine whether a person can work or engage in other activities. Most experienced clinicians tend toward the eclectic: data of various types are used to build a broad picture of the individual patient. Decisions for diagnosis and treatment are based on interpretations of the results of a combination of formal and informal assessment techniques.

In their search for relief, chronic pain patients often seek care not only from several different physicians but also from nontraditional healers, and they may undergo numerous treatments over a period of months or years. At some point in their quest for relief, they may be referred to specialized pain management programs, or pain clinics, for rehabilitation. Such programs vary substantially in terms of their staffing, treatment orientation, and criteria for accepting patients. There is evidence that some of the effects of chronic pain and attendant disability can be reversed with comprehensive treatment through rehabilitative medical, behavioral, and social management. There is also evidence that some disabled pain patients can be rehabilitated (i.e., returned to normal activity) even when pain relief is not achieved.

#### SOCIAL SECURITY ADMINISTRATION DISABILITY PROGRAMS

The SSA administers two disability compensation programs. The Social Security Disability Insurance (SSDI) program is designed to protect those with a recent work history in SSA-covered employment. The disability portion of the Supplemental Security Income (SSI) program is aimed at those without a recent work history; claimants must meet a financial needs test to receive benefits under this program. The programs use the same definition of disability and the same procedures for determining whether or not a person is disabled, as set forth in law and in SSA regulations. The definition of disability in the Social Security Act is very restrictive in comparison with definitions in other disability compensation programs in the United States and abroad. Some programs compensate those who are disabled partially and temporarily, as well as those who are totally and permanently disabled. The SSA definition, however, requires the inability to work at any "substantial gainful activity" because of a medically determinable physical or mental impairment expected to result in death or to last for at least 12 months. Further, such impairments must be demonstrable by medically acceptable clinical and laboratory diagnostic techniques. A complex set of regulations has evolved to implement the statute. The SSA has established a set of medical evaluation criteria referred to as the "listing of impairments." This listing defines the disorders and level of severity that, in the absence of substantial gainful activity, are presumed to prevent a person from working.

The procedures by which SSA decides who is disabled for work are complicated. An individual seeking compensation files a claim for benefits at one of the SSA offices located throughout the country. Information gathered by this office (which usually includes medical records from the claimant's personal physician) is forwarded to the disability determination service (DDS) located in each state. A team of examiners decides on the claimant's eligibility based on a review of the records. The claimant must not be working for substantial gain, defined as earning more than \$300 a month. The claimed impairment must be considered severe, that is, it must seriously interfere with basic work activities. If the impairment meets the criteria for one of the entries in the listing of impairments, disability is presumed and benefits are awarded; or, if the impairment is found to "equal" one of the listings (i.e., to be equivalent in severity and effect on the ability to work), benefits are awarded. If, however, the impairment does not "meet or equal" the listing of impairments, the claimant is further evaluated for "residual functional capacity," defined as what the claimant is capable of doing despite the impairment. In such a case, to be awarded benefits the claimant must be found incapable of engaging not only in his or her usual work but also in any work that exists in the national economy, taking into account the claimant's age, education or training, and previous work experience.

Claimants who are denied benefits initially may appeal the decision. A "reconsideration" is carried out by a different team of examiners at the state DDS. Claimants still denied benefits may appeal to an administrative law judge (ALJ) employed by the SSA; this is the only time that a claimant is seen in person by a decisionmaker. The next recourse is to the Appeals Council of the SSA. Claimants denied benefits at all levels within the SSA system may then appeal to the federal courts.

Added to the complexity of the determination process is the sheer volume of activity. It is estimated that more than 1.5 million people file claims each year at the 1,300 local SSA offices. The Social Security Act requires that decisions be made on an individual, case-by-case basis; at the same time, decisions are to be made as consistently and equitably as possible. As a result, resolving a particular claim may take months or years, especially if it is based on a symptom complaint or on an impairment that does not "meet or equal" the listing of impairments; chronic pain falls into both of these categories.

Many diagnoses that are adequate to presume disability in the SSA system do include pain as a symptom: for example, various kinds of arthritis, disorders of the spine, and other musculoskeletal disorders. However, pain in the absence of these diagnoses, or pain with few clinical findings of disease progression or anatomical abnormalities, generally leads to the conclusion at the initial level of determination that the individual is ineligible for benefits, although if appealed to higher levels of review and ajudication this decision may be reversed. The SSA estimates that about 150,000 applicants per year (10 percent of the total) have pain as their primary complaint without clinical findings to fully substantiate it.

#### **Problems in the System**

Historically, many forces came together to produce the Social Security disability programs. These forces continue to operate, some functioning to keep the program within the established boundaries and others pushing against these boundaries, such that there is continual tension among the various elements within the program as well as from various external forces interacting with the program. These include tensions between the Congress and the SSA; among physicians, claimants, and SSA administrators; between ALJs and administrators; and between the federal courts and the SSA. Further difficulties come from the use of medical definitions of disability to determine what is actually a functional issue—the ability to work and from the dual goals of the disability programs—income support for the disabled and rehabilitation.

These tensions and inconsistencies are evidence that an appropriate system of checks and balances is operating. The goal should not be to eliminate the tensions but to assure a decision-making process that is as accurate and fair as possible. Human judgment and subjectivity are inherent in that process and appropriate to determinations that require a combination of so many different kinds of informationmedical, psychosocial, functional, and vocational. The very different perspectives of Congress, SSA employees, medical professionals, and judges will necessarily result in differences of opinion. In addition, the political climate and national economy exert a powerful influence on the context within which decisions are made. In the face of political conservatism and a tight economy, for example, Congress and the SSA have a greater stake in keeping people off of the disability rolls. At the same time, when unemployment rates are high, more people apply for disability benefits. Some groups of claimants (including those with mental impairments, chronic pain, and other symptom complaints) are probably more likely to be denied benefits than others in such circumstances. Balancing the competing goals of the nation with individual needs, while maintaining the program's integrity, is an inherently difficult task.

#### **CRITICAL GAPS IN KNOWLEDGE**

In reviewing data, hearing testimony, and analyzing the published literature, the study committee was struck by some crucial gaps in our knowledge and understanding of chronic pain and its relation to disability:

1. Inconsistencies in definitions and measurement make it difficult to generate reliable estimates about the numbers of people in the population with chronic pain and their associated dysfunction and social disabilities. These are the people at risk for becoming unable to work and applying for SSA benefits.

2. There is a severe lack of data available about the numbers and characteristics of SSA claimants and beneficiaries in the disability program whose primary complaint is pain and how they fare over time.

3. There are no reliable methods for predicting which patients with acute and subacute pain will develop chronic disabling pain. Although many factors are known to correlate with chronic disabling pain, predictive models have not been developed and tested. Epidemiological studies suggest that fewer than 10 percent of people with acute back pain develop chronic pain.

4. Assumptions about the ability of early treatment and rehabilitation to interrupt the course of chronic pain are largely untested. Although there is general agreement that the longer one has had a chronic condition, the more difficult it is to achieve rehabilitation, there are few data that attest to the effectiveness of early intervention.

5. There is an imperfect correspondence between severity of pain and dysfunction. People can have severe pain with minimal functional limitations or minimal pain with severe limitations.

#### RECOMMENDATIONS

The committee makes six major recommendations:

1. The SSA should develop a better system for routine data collection and information retrieval for its disability programs. This would help the SSA to know more about the numbers, characteristics, and outcomes of claimants and beneficiaries generally, and to know more about pain claimants and other troublesome categories of claimants specifically. In doing so, the SSA should collaborate with other agencies, particularly the National Center for Health Statistics and the Bureau of the Census, on routine and special data collection activities.

2. Neither "chronic pain syndrome" nor "illness behavior" should be added to the regulatory listing of impairments. Although the committee acknowledges the value of these terms in certain contexts, they should not be used for SSA disability purposes. There has been no demonstration of a common etiology, a predictable natural history, a clearly defined constellation of symptoms, or a specific treatment for the various pain conditions that would suggest a basis for positing a single chronic pain syndrome.

Similarly, illness behavior is neither a disease nor a diagnosis. The concept is intended to represent the varied behavior of individuals responding to illness or to the belief that they are ill. All individuals exhibit such behaviors in varying ways. The concept and perspectives associated with illness behavior facilitate appropriate inquiry and further understanding but are not intended to describe clinical status.

This recommendation does not mean that chronic pain, and chronically painful conditions, should be ignored in the administrative process. On the contrary, the committee believes that pain should be attended to in a more thorough and systematic fashion in the determination of eligibility for disability benefits, as discussed in the next recommendation.

3. Significant pain, even in the absence of clinical findings to account for it, should trigger a functional assessment of the capacity to work. Under current SSA procedures, a pain claimant without objective clinical findings to account for the pain is denied benefits

early in the evaluation process. The committee's recommendation is that a primary complaint of pain allow an early assessment of the claimant's functional capacity for work. Disability benefits have never been awarded on the basis of self-reported pain entirely uncorroborated by objective findings, nor should they be. However, the kinds of acceptable evaluation and corroboration should not be limited to medical evidence of an underlying disease process. With or without such findings, consideration should also be given to serious functional limitations and to the effect of pain on the claimant's life. This means not only assessing physical abilities such as sitting, standing, lifting, and walking, but also examining the ways in which pain affects sleeping, eating, relationships with others, the ability to concentrate, and work activities. The SSA's recently revised mental illness listings provide a precedent for this approach. They are based on integrated functional criteria, not simply a diagnosis, by which claimants are evaluated primarily on their ability to function in daily life, including work.

An increased emphasis on functional evaluation of claimants early in the evaluation process holds promise for preventing some errors of commission and omission in eligibility determinations, and for averting at least some of the later appeals for higher review and adjudication.

4. SSA should support the design and execution of two major demonstration/evaluation projects.

A. Several methods for assessing pain claimants early in the evaluation process should be developed and compared.

The committee suggests that three methods be compared. (1) One or more easily administered questionnaires or pain assessment techniques should be incorporated into the initial determination in a rigorous experiment to test the reliability, the effects on the ratio of allowances to denials, and the practical constraints of including such instruments in this stage of the review. (2) A sample of claimants should be offered an early face-to-face hearing at the state level. The SSA should evaluate the consequences of such a hearing and determine the extent to which the approach can be standardized and yield consistent decisions. (3) The value of an integrated functional assessment for pain claimants early in the determination process should be investigated. Under the current system, such assessments are conducted late in the evaluation process, if at all. The committee believes there is potential for using careful descriptions and measures of functional disturbances in performance and activities of living as surrogate variables for the severity of chronic pain conditions.

#### **10** PAIN AND DISABILITY

B. The efficacy of early rehabilitation interventions with chronic pain patients should be assessed.

Under the current system, the need to "prove and re-prove" one's disability is so great that it can undermine the claimant's subsequent motivation for rehabilitation. The requirements for proving work disability and the requirements for acceptance into rehabilitation must be disentangled if rehabilitation is to become a realistic goal within SSA. Although SSA disability programs do include features intended to provide incentives for rehabilitation (e.g., a trial work period with continuation of disability and medical benefits), such opportunities are seldom used. Further, by the time claimants apply for SSA disability benefits, chronicity is well established and functional impairments are severe. Early identification and rehabilitation hold promise for preventing long-term disability, and ultimately reducing the number of claimants and beneficiaries.

The possible value of early and active rehabilitation for pain patients should be thoroughly explored. The committee recommends that the SSA support a demonstration/evaluation project to identify pain patients before they apply for disability benefits and to offer them a package of multidisciplinary rehabilitation, time-limited cash benefits, and medical benefits. For both ethical and practical reasons, however, the committee does not recommend mandatory rehabilitation requirements for SSA pain claimants or beneficiaries.

5. The Secretary of the Department of Health and Human Services (HHS) should take the lead in ensuring that a broad research initiative on pain and disability is undertaken within HHS and in cooperation with other federal agencies as appropriate. This should include at least one major longitudinal epidemiological study to identify the determinants of chronic disabling pain; clinical studies of the efficacy of commonly used treatment methods (i.e., medication, physical therapy, and surgical interventions) and the optimal timing of interventions to prevent chronic disabling pain; methodological studies to develop and validate measures of clinical phenomena, psychosocial variables, and pertinent outcomes relevant to chronic pain and disability; and health services research to elucidate the contributions of important sociocultural variables to the course of illness and illness behavior, and to study the interactions of the health care delivery system and disability programs with patient/claimant behavior.

6. The training of health care professionals should foster a comprehensive and multidisciplinary approach to patients with pain. This should include attention to important psychological, social,

and cultural contributions to the development of chronicity and associated illness behavior. Such an orientation is likely to improve the diagnosis, treatment, and rehabilitation of chronic pain patients and prevent or lessen long-term negative outcomes.

On the basis of the available evidence, the committee believes that health care providers are not adequately trained to manage patients with pain. The committee makes two recommendations in this area. The first is that a cadre of physicians be trained in aspects of each of the medical specialties most relevant to pain. The resulting group of experts would be capable of performing multidisciplinary assessment and treatment and of training primary care providers who deal with chronic pain patients. The second recommendation is that organizations and boards who review postgraduate training programs for primary care providers (family physicians, internists, pediatricians, gynecologists, nurse practitioners, etc.) should examine their accreditation processes to assure that these programs attend to a number of educational goals. Primary care providers should, for example: (1) appreciate the complexity of chronic pain, associated illness behavior, and psychosocial and cultural influences on pain; (2) be aware of commonly overlooked physical and psychiatric disorders that may account for the pain or contribute to it; (3) be able to make appropriate referrals of chronic pain patients to practitioners in other disciplines: and (4) understand the potential for an inadvertent negative impact of health care providers on the course of chronic pain problems and disability.

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Chronic pain, especially musculoskeletal pain, is a common health problem afflicting a substantial proportion of the adult population and interfering with every aspect of their lives. The course of chronic pain and disability is inextricably intertwined with social, psychological, economic, and cultural factors. As a clinical problem, chronic pain is often elusive and intractable. As a public policy problem, determining whether claimants whose pain and dysfunction are not accounted for by objective clinical findings are disabled for work is difficult to do in an efficient, fair, and reliable manner. Pain is inherently subjective; there are no thoroughly reliable ways to measure it; and the correlation between the severity of pain and the level of dysfunction is imperfect.

## 1 Introduction

Pain is the most common presenting complaint seen by physicians (Lawrence and McLemore, 1983). Sometimes the pain is the result of obvious injury or is associated with readily identifiable disease; at other times, it has no obvious cause or seems disproportionate to the disease or injury. Some pain disappears with healing or is self-limited, but some persists. Some disease processes, of course, cause long-lasting, severe, and even debilitating pain; but for most people, an episode of acute pain does not become chronic. Musculoskeletal conditions such as low back pain, joint pain, arthritis, and rheumatism are the leading causes of disability in people during their working years (Kelsey et al., 1979; U.S. Department of Health and Human Services, 1980). Back complaints are second only to upper respiratory conditions in accounting for work absenteeism (Rowe, 1969).

Many different kinds of chronic pain can be identified. Each has its own characteristics and different effects on patients. For patients the experience of pain is also highly variable. Some people with moderate pain are severely impaired, whereas others with severe pain are able to continue functioning normally. How an individual experiences and manifests pain depends on a complex interaction among numerous physiological, psychological, social, and cultural variables, as well as on past pain experiences and how the pain has been handled by the practitioners the patient consults.

Because of the considerable differences in types of pain and patients, it is inappropriate to speak of "the" chronic pain patient as if there were only one type. Similarly, we do not use the term "chronic pain syndrome," as it implies a homogeneity among conditions that are actually quite dissimilar.

The experience of pain is more than a simple sensory process. It is a complex perception involving higher levels of the central nervous system, emotional states, and higher order mental processes. As is true for other symptoms, people who experience pain, especially pain of long duration, tend to develop behavioral and psychological responses to their symptoms. It is not always possible to identify the causes of pain, how it is expressed, and its behavioral and psychological reactions and consequences. In common parlance, one may hear about "shirkers" (or malingerers) and other people in "real" pain. In fact, experienced clinicians believe that true malingerers are relatively rare. Further, "real" pain is an extraordinarily complicated phenomenon. The physical and neurological disorder cannot provide a complete explanation for chronic pain or the patient's experience of pain. Moreover, neurological mechanisms for pain are not yet fully understood. For example, even in the case of the impingement of a lumbar disc into a nerve root, a condition that is associated with intense back pain for many people, neurologists cannot really explain why pain is experienced.

What, then, accounts for the development of chronic pain? The concept of illness behavior, a social psychological term used to describe the responses of persons to being ill or to believing that they are ill, elucidates and provides a framework for understanding the observed differences among pain patients. Illness behavior is a process that includes a perception of one's own symptoms, an attribution of meaning to them (from something trivial to an ominous indicator of serious illness), and the way in which one seeks help in dealing with the symptoms. Such behavior is influenced by the person's personality and coping style and by the surrounding culture and society. The fact that such factors can be strong influences on the pain or other symptoms that people experience does not, however, make the pain any less real.

Not only is pain a symptom that can cause substantial discomfort, suffering, and alterations in way of life, but as a clinical problem it is often resistant to diagnosis and treatment. For physicians, who are trained to diagnose and cure disease, pain reports that are not fully accounted for by a diagnosable disease can be frustrating. For the patient in chronic pain who visits a doctor expecting to find relief and an explanation for the pain, going away with neither can be equally frustrating. In a search for the pain's cause and for a way of relieving it, long rounds of tests, treatments, and referrals to specialists may ensue, often to no avail and sometimes compounding the problem. A breakdown in basic trust strains the doctor-patient relationship, making medical encounters increasingly difficult for both parties.

In addition to its significance as a personal and clinical problem, chronic pain has become a sociopolitical and economic problem for public and private disability insurers. The Social Security Administration (SSA) is particularly concerned about how pain should be considered in the process of determining eligibility for disability benefits, especially when such pain seems disproportionate to objective medical findings (e.g., histories, physical examinations, x rays, and laboratory tests) relating to a past injury or ongoing disease process. Although recognizing that pain is ultimately a subjective experience, insurers must have criteria for determining eligibility for benefits that not only are fair but also can be replicated by multiple assessors. A serious problem is posed by having to decide how much dysfunction can be attributed to pain when the severity cannot be measured. Although medical professionals are relied on for data about disease and dysfunction, the ultimate judgment about who qualifies for benefits is made by program administrators, and sometimes judges, who must assess such data in light of the applicable laws and regulations.

From a sociopolitical and economic perspective, the question is how to assure benefits for all who need them, while avoiding a policy so generous that it imposes an unacceptable fiscal burden. Every society defines some categories of people who are exempt from work because of their age or infirmity. The distinction between those who are expected to work and those who need to be supported by public funds varies from program to program and from country to country. Criteria for eligibility are often arbitrary, such as the age at which one becomes eligible for "old age" benefits or the point at which defective vision constitutes "legal blindness."

Whereas many programs here and abroad recognize disability as partial and temporary as well as total and permanent, the SSA's definition is more stringent: "inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months" (42 USC, 423 (d) (1)). Although disability programs may set different boundaries to divide those judged disabled from those able to work, the criteria for those boundaries, even if arbitrary, must readily distinguish the two groups and be feasible to apply fairly and equitably. A society may accept conventional definitions of, for example, "elderly" as a basis for exemption from work, but may find it considerably more difficult to judge that a medical disorder is so incapacitating that it keeps one entirely from working. In the case of a symptom complaint such as pain without identifiable disease processes that fully account for it, the task can be extremely complex. Because the experience of pain is different for each person, how is it possible to assess pain and determine a severity beyond which one should not be expected to work? This is the crux of the problem for the SSA and for others who insure against disability.

#### **OVERVIEW OF THE REPORT**

Part I of the report describes the SSA's disability system, exploring its history, rationale, and sociopolitical context; describing program characteristics and procedures; and identifying problem areas and tensions in the way the system works. Many forces and pressures operate at every level of the system, from an individual's initial decision to apply for disability benefits, through the eligibility determination process by which a claimant must show proof of disability to an agency charged with helping those in need while safeguarding public money, to the often differing viewpoints of the agency and the courts as to how disability decisions should be made.

Part II provides a broad view of chronic pain and disability from the perspectives of economics and epidemiology. Chapter 5 summarizes what is known about the costs of disability and examines the relation between disability rates and features of the economy. During times of economic downturn and high unemployment, more people apply for, and receive, disability compensation. Estimates of the prevalence of chronic pain in the general population and its relation to work disability are examined in Chapter 6.

Part III focuses on the patient who suffers from chronic pain. Chapter 7 reviews the anatomy and neurophysiology of pain drawing primarily on studies of experimentally induced acute pain. Possible physiological mechanisms to explain chronic pain and promising directions in the area of pain measurement are explored. The experience of pain, how the patient behaves in response to it, and the social and psychological pressures contributing to its development and maintenance are discussed in Chapters 8 and 9.

Issues in the clinical management, assessment, and rehabilitation of chronic pain and associated dysfunction are examined in Part IV. Chapter 10 includes a discussion of the many aspects of diagnosing and treating chronic pain and elements of the doctor-patient relationship that may be adversely affected by the often difficult search for a diagnosis and relief. Because pain cannot be measured directly, various indirect methods for assessing its effects on patients have been devised. Chapter 11 reviews a variety of assessment techniques and suggests ways to use them more appropriately in clinical practice and in disability determination. Although it is generally believed that early rehabilitation of pain patients would be an effective means of managing pain and limiting dysfunction, few data exist to support the idea. Various approaches to pain rehabilitation are discussed in Chapter 12. Studies of treatment outcomes, including those that explore the hypothesized effect of receipt of disability benefits on outcomes, are analyzed.

Finally, Part V contains the committee's conclusions and recommendations. It should be noted that the committee worked from the assumption that the existing legal definition of disability for the SSA (requiring the total inability to work and implying permanent impairment) was so rooted in the philosophical and political issues that led to the creation of the program and that have accompanied it throughout its history (discussed in Chapter 2) that it would not be fruitful to entertain seriously recommendations for changing the definition. Further, such an endeavor would be beyond this study's scope and mandate. Within the constraints of this definition, however, many programmatic and procedural issues were considered. The committee's conclusions and recommendations (1) address ways to improve the assessment of chronic pain patients within the Social Security disability programs; (2) suggest demonstration projects to provide further information for such improvement; (3) offer views on the clinical management of patients with chronic pain; and (4) identify promising research and data collection activities that would add significantly to the existing knowledge about chronic pain, illness behavior, disability, and their interrelations.

Because of its breadth, this report should interest many different audiences, including those policymakers, insurers, program administrators, health care professionals, clinical researchers, and members of the public who are concerned about the nature of chronic pain and how it relates (and might better relate) to disability benefits. The detailed discussions of the nature of pain, the origins and treatment of pain, and the pathway from acute to chronic pain and then to chronic disabling pain should provide useful information to clinicians, researchers, and the public. This discussion is also the context for the analysis of disability policy and procedures, thereby contributing to the ongoing process of informing public policy.

#### A NOTE ABOUT DEFINITIONS

Terms relating to chronic pain and resulting disability are defined and used in a number of different ways both in the literature and by disability program administrators. For example, the SSA uses the word "impairment" with two quite different meanings: an impairment is a disease, such as rheumatoid arthritis, and also the inability to do something that results from a disease. The HHS Commission on the Evaluation of Pain (U.S. Department of Health and Human Services, 1987) defined impairment as the psychophysiological manifestation of an injury or disease. This lack of uniformity arises both from the varied disciplines concerned with these issues and from the complexity and incomplete understanding of the concepts themselves.

Recognizing that there is room for disagreement, the committee chose to adopt a modified version of the World Health Organization (WHO) definitions of several key terms. These definitions are used consistently throughout this report in order to avoid misunderstanding.

• *Impairment*: Any loss or abnormality of psychological, physiological, or anatomical structure or function. (This is the same as the WHO definition.)

The functions that are lost or become abnormal because of chronic pain may include walking, sitting, bending over, anticipation, memory, cognition, and mood.

• Functional limitation: Any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being that results from an impairment. (This is the WHO definition of "disability.")

This is a loss of capabilities as a result of the inability to effectively integrate purposeful functions (physical and/or psychosocial) because of pain, disease, or impairment. This loss may include functions such as visiting family or friends, typing for hours, gardening, housecleaning, shelving merchandise, or operating a chain saw.

• Disability: A disadvantage for a given individual (resulting from an impairment or a functional limitation) that limits or prevents the fulfillment of a role that is normal (depending on age, sex, social, and cultural factors) for that individual. (This corresponds to the WHO definition of "handicap.")

Disability limits or prevents fulfilling a role in life. Because of pain, a person may no longer be able to perform satisfactorily at home, school, and work and in social settings (i.e., as a father, mother, employee, student, etc.). The committee emphasizes that patients with chronic pain are heterogeneous. Any time period used to define chronic pain is arbitrary. The committee chose to use the terms acute pain and chronic pain as they were defined by the HHS Commission.

• Acute pain: Pain of recent onset and probable limited duration.

• Chronic pain: Pain lasting for long periods of time. More than 6 months is a commonly used duration. Such pain may be associated with a residual structural defect that persists long after the acute episode or pain associated with the persistence of the disease process, as in arthritis. Chronic pain may also be pain persisting past healing time without objective physical findings of residual structural defect or pain persisting past the active state of a disease process. Pain that recurs regularly and frequently over long periods of time is also considered chronic pain.

As we have noted, all of these terms can and have been used differently. We try in this report to be as clear as possible. Often, we use terms such as work disability, social disability, and legal disability, as appropriate.

Low back pain is used as an example throughout this report for several reasons: more clinical, epidemiological, and administrative information is available for back pain than for other types of pain; chronic musculoskeletal pain, and particularly chronic low back pain, is the most common of the "problem" cases for the SSA disability system; and the issues surrounding the assessment and management of back pain and patients with such pain are illustrative of those of chronic pain conditions in general. This does not mean that back pain is necessarily representative of all other types of pain.

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## PART I THE PROBLEM OF PAIN FOR THE SOCIAL SECURITY ADMINISTRATION





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## 2 The Sociopolitical Background of the Pain Issue

In the Disability Benefits Reform Act of 1984, pain is singled out as a special problem for the Social Security disability system. For the first time in the history of the program, the legislation provides a statutory standard for the evaluation of pain. To understand why Congress should feel called on to legislate in detail about the medical evaluation of pain, and what concerns are behind the charge to the Institute of Medicine (IOM) study committee, it is necessary to understand something of the history of the Social Security disability programs and their place in American social policy.

## THE LEGISLATIVE BACKGROUND OF THE PAIN PROBLEM IN DISABILITY INSURANCE

Disability insurance for the general population came relatively late in the United States. Disability pensions for veterans began soon after the Civil War. State workers' compensation schemes for on-the-job injuries came into being in the first two decades of the twentieth century. Railroad workers and federal, state, and municipal employees typically had early and generous coverage. Professionals and whitecollar workers could and did obtain commercial policies as early as the 1920s. In short, groups that were either politically well organized or economically well off achieved some wage protection against disability by the early part of this century. Yet the average person, who was either not a member of one of these groups or was disabled by some reason other than a work accident, was subject to a devastating loss of income.
#### Early History of Social Security Disability

Redistributive social programs and collective arrangements for income security have always met with strong opposition in American political culture, and disability insurance was no exception. It took the Great Depression to provoke passage of the Social Security Act in 1935, providing old age pensions for workers and their dependents. Disability insurance was not included, although by that time it was an established part of the Social Security programs of other major industrial countries.

Nevertheless, the Social Security program was supported by a staunchly committed bureaucracy and a network of academic social welfare specialists and labor union advocates. From the beginning, they were determined to expand the program (Derthick, 1979). For them, the worthiness of a broad Social Security program was never in question; only the timing and nature of expansion was a matter of debate. As early as 1935 President Roosevelt appointed a committee to study the feasibility of including medical care and disability benefits. In the following two decades, several citizen advisory councils, with representatives from labor, business, and the public, were asked to consider various aspects of federal disability insurance.

The early consensus of these experts and advocates was that, although disability insurance was a socially desirable program in principle, in practice its administrative difficulties and potential costs would be so enormous that delay was the better part of wisdom. Policymakers and planners understood that the crux of the problem lay in the *definition* of disability. In its 1938 report, the Social Security Board said

The extent to which costs would increase depends on the definition of disability which could be made effective. If a fairly strict definition were adopted and maintained, the board believes that additional costs would be kept within reasonable limits. (Social Security Board, 1939)

An informal committee of the 1937 advisory council tried to come up with a workable definition of disability. In an effort to constrain administrative burdens, the council reluctantly concluded that mental disability should be excluded from any program because it was too difficult to determine (Berkowitz, 1976).

By 1948, when an advisory council recommended disability insurance for the first time, program planners understood the likely problems of the program, because there had been considerable experience with both private disability insurance and the federal government's own War Risk Insurance program for World War I veterans. They knew that disability insurance was difficult to administer, that a program's scope and costs were dependent on the definition of disability, that any program was likely to expand, that people tend to rely on disability insurance in times of high unemployment, that the courts would be a strong force for liberalizing the definition of disability, and that any program would be sensitive to economic conditions, even if the formal definition of disability were very strict (see Chapter 5).

The 1948 advisory council, whose report set the basic framework for the future disability program, made clear that the definition of disability would be the crucial mechanism for containing costs:

The definition of 'disability' used in a disability program will in large part determine the feasibility of administration and the costs of the program. The proposed definition is designed to establish a test of disability which will operate as a safeguard against unjustified claims. (Advisory Council on Social Security, 1948; emphasis added)

The underlying concern of the report was to prevent abuse of the program. The report repeatedly discussed the need for "strict" tests to eliminate the possibility of awards based on purely subjective perceptions of need. It is full of phrases conveying this concern: "strict test," "safeguard," "strict eligibility requirements," and "carefully circumscribed and restricted program."

The solution proposed by the 1948 advisory council, and the idea that gave planners confidence in their ability to contain a disability insurance program through definition, was to rely on a *medical determination* of disability:

The Council recommends that compensable disabilities be restricted to those which can be objectively determined by medical examination or tests. In this way, the problems involved in the adjudication of claims based on purely subjective symptoms can be avoided.... The danger of malingering which might be involved in connection with such claims would thereby be avoided. (Advisory Council, 1948; emphasis added)

The report went on to say that claimants would have to submit to medical examinations and periodic reexaminations, and that benefits should be terminated if a beneficiary refused to submit to medical reexaminations.

In 1954, Congress passed a "disability freeze," which provided that workers over age 55 who became totally and permanently disabled before the age of 65 would not have to make Social Security contributions during the period of disability in order to remain eligible for an old-age pension at age 65 (Berkowitz and Fox, 1986). The freeze was the equivalent of a waiver-of-premium provision in commercial insurance. Although the 1954 amendments represented a major change in principle—a legal recognition of disability as an administrative category in Social Security—the serious discussion of how to define and determine disability did not occur until the next year, when the Senate Finance Committee held hearings on a cash benefit program for the disabled.

#### Physicians' Concerns About Medically Determined Disability

In the 1955 hearings, the possibility of objectively determining disability by medical examination was a major issue. Physicians from virtually every state and national medical society, as well as from many specialty societies, testified. They were overwhelmingly against government involvement in medicine. More important, a substantial bulk of physician testimony, and a significant reason for their opposition to disability insurance, had to do with the profession's belief that physicians *cannot* determine disability on a purely "medical" basis.

On this technical objection to disability insurance, physicians marshalled numerous arguments. They insisted that disability determination is inherently subjective and value-laden, and that honest physicians could legitimately disagree about the existence of a person's disability. They testified that "medicine is not an exact science," that disability is a social and psychological problem, and that judgments about who should work are political, not medical, questions. As a representative of the American Academy of General Practice put it:

Unfortunately, medical science has not reached the point of being able to unerringly state whether or not a man is totally and permanently disabled.  $\ldots$  Is the delivery boy who loses both legs totally and permanently disabled? Or is the certifying doctor supposed to point out that he can still run a drill press and probably make more money? (Senate Finance Committee, 1956)

Physicians spoke from their experiences in certifying people for other disability programs—commercial insurance, Workers' Compensation, veterans benefits, civil service programs—and concluded that clinical definitions of disability are not workable. Skeptical congressmen, those in favor of disability insurance, questioned why physicians could not determine disability for the Social Security program if they were already doing it for other programs. Physicians tried to illustrate the problem by using specific examples, such as severe chronic headaches, backaches, heart disease, rheumatic disease and arthritis, alcoholism and drug addiction, and neuroses. They explained that these conditions are frequently but not always disabling, are the most common bases of disability claims, and yet are also the hardest to determine and verify clinically. To drive home the point, one doctor cited a poll of heart specialists on the seemingly simple question of whether President Eisenhower was "physically able" to serve as President after his heart attack—114 said "yes," 93 said "no." Even specialists on a particular disease had no answer to the problem of determining work ability.

Beyond the technical impossibility of clinically defining and determining disability, physician testimony indicated other problems with medical certification, problems that have a direct bearing on the pain issue. They pointed out the destructive contradiction of a medical system that simultaneously certifies people as totally disabled and seeks to rehabilitate them. They voiced concern that the very process of labeling a person as disabled could weaken the motivation for recovery and rehabilitation. They insisted that income awards on the basis of disability would provide a financial disincentive to rehabilitation, encourage malingering, and educate people to see injuries as opportunities for financial gain.

In addition, most physicians testified that the process of certifying a patient's disability for a government program would be in conflict with the physician's therapeutic relationship with that patient. Disability certification for purposes of cash benefits required the physician to mediate between the patients' and the government's interests. In such gatekeeping roles, physicians would be "caught in a squeeze," and forced to "serve two masters." Patients could and would simply shop around for a doctor willing to provide evidence of their impairments, and friends and family, as well as patients, would put unbearable pressure on physicians, reducing their ability to make good clinical judgments. Introducing such tensions into the doctor-patient relationship would undermine its therapeutic effectiveness (Stone, 1984).

Despite such testimony, Senator Alben Barkley of the Senate Finance Committee expressed a stubborn faith in medicine that was shared by most of his colleagues:

I am not willing to concede that after all the years of experience and growth and investigation and practice in the medical profession that they cannot with some reasonable degree of certainty arrive at a *medically determinable point where a man is totally and permanently disabled*. (Senate Finance Committee, 1956; emphasis added)

Thus, the Social Security Disability Insurance Program was built on the dubious foundation of an old medical model of disease that was not even fully accepted by the American Medical Association (AMA) at the time. According to this model, disease always has an underlying organic or anatomical basis, and "real" disease can be reliably identified by physicians through clinical techniques. This is a popular conception of disease and medical knowledge that the medical profession by and large finds naive (see Chapter 10), but that drives public policy. The medical model of disability became the core of the Social Security program at its inception, and the model is reinvoked at every attempt at program reform.

#### The Concept of Impairment

Central to the definition of disability, as well as to the current legal controversy over the use of subjective evidence of pain in eligibility determination, is the concept of impairment. Impairments are anatomical, physiological, or psychological conditions that decrease a person's ability to function, but are not necessarily related to work ability. For example, a person may have reduced lung capacity as compared with people of the same size, but may not be affected in work, social roles, or activities of daily life. Only those impairments that preclude meeting the physical or mental requirements of a job and thus cause an inability to work are deemed disabilities. Both the medical profession and Social Security administrators consider impairment a medical phenomenon and disability an administrative/legal one. In theory, physicians provide the program only with evidence about impairments, and the program's own specialists in disability determination provide the administrative/legal determination of disability.

In 1958, the AMA, through its Committee on the Medical Rating of Physical Impairment, began producing "Guides to the Evaluation of Permanent Impairment." For its purposes, the Social Security Administration's (SSA) Division of Disability Operations developed a "Listing of Medical Impairments," which would automatically qualify people for the program. The expectation was that most awards would be made on the basis of these listings, but there was also a provision for people who did not "meet" the listings (i.e., did not have exactly the conditions described) but who "equaled" the listings (i.e., had conditions with equally incapacitating results). An advisory committee of outside medical consultants also suggested that certain nonmedical factors would have to be considered in some cases: age, education, training, experience, and other individual factors (see Chapter 3).

Both the AMA's guides and the SSA's listings envisioned an entity called "impairment" that was located in the individual and demonstra-

ble by medical tests. The notion of purely functional impairment, totally independent of context, is described in the AMA Guides:

permanent impairment cannot vary because of the circumstances of its occurrence or the geographic location of the patient at the time. Furthermore, unlike disability, permanent impairment can be measured with a reasonable degree of accuracy and uniformity on the basis of impaired function as evidenced by loss of structural integrity, pathological findings, or pain substantiated by clinical evidence. (American Medical Association, 1960; emphasis added)

Henry Kessler, a prominent member of the AMA committee and developer of a widely used disability evaluation system, later wrote

Clearly, so long as the objective is strictly limited to accurate description of the damage, the medical "factor" remains distinct from all else and can be reduced to a scientific procedure of unquestionable validity. (Kessler, 1970; emphasis added)

This concept of a distinct, medically identifiable impairment within individual anatomical, physiological, or psychological makeup and totally independent of social, economic, or geographic context is at the root of the current problem with cases that turn principally on the applicant's pain. As discussed in Chapter 10, a broad biopsychosocial model is needed to understand chronic pain. A narrow biomedical model is inadequate because, notwithstanding enormous increases in our understanding of the physiological mechanisms of pain and our ability to map the pathways of transmission of neural impulses, many types of pain simply cannot be explained biologically or documented with physiological techniques (see Chapter 7). Furthermore, physiology cannot tell us how neural impulses are *interpreted* by the individual or how the complex interplay of social, cultural, economic, psychological, and physiological factors shape the pain experience.

The SSA uses its concept of impairment as a proxy test for motivation to distinguish those who *cannot* work from those who *will* not work. An impairment is supposed to be a condition beyond a person's control that prevents the person from working. As such, an impairment is considered prima facie evidence of a genuine inability to work.

Thus, the distinction between objective and subjective evidence of impairments is crucial. The Social Security program has always been guided by the principle that every impairment in the listings, and every award of benefits, must be verified by objective evidence.

Clinical medicine has traditionally distinguished between "symptoms" and "signs," symptoms being sensations or observations perceptible to and reported by the patient, and signs being the manifestations of disease or abnormalities observable by the physician. It is commonly believed that whereas the presentation of symptoms can be manipulated by the patient, signs and laboratory findings are not amenable to manipulation. Thus, in developing the medical listings, the SSA sought to build them on signs and laboratory findings rather than on symptoms. Early program regulations stated

There should be evidence that medically ascertainable anatomical, physiological, biochemical or psychological aberrations exist. Allegations of inability to work as a result of impairment such as dyspnea, *pain*, lack of musculoskeletal function, decreased vision or hearing, decreased memory, etc. should be shown to result from structural physiological or psychological changes which can be identified by the use of clinical and laboratory diagnostic techniques. An alleged impairment is medically determinable only if it can be verified by the use of clinical and laboratory techniques. (Code of Federal Regulations 404.1510 (a), 1961; emphasis added)

The notion that all impairments should be verifiable by objective evidence is administratively necessary for an entitlement program. Yet this notion is fundamentally at odds with a realistic understanding of how disease and injury operate to incapacitate people. Except for a very few conditions, such as the loss of a limb, blindness, deafness, paralysis, or coma, most diseases and injuries do not prevent people from working by mechanical failure. Rather, people are incapacitated by a variety of unbearable sensations when they try to work.

This fundamental problem with the concept of impairment was first articulated by William Roemmich, M.D., the Chief Medical Officer of the Social Security Disability Insurance (SSDI) program for 15 years, who stated

Most diseases which we encounter in our program prevent work because they produce in man an uncomfortable sensation when he works. These sensations are dyspnea, pain, fatigue, or a combination of all three.... There are no biological techniques at present which can measure dyspnea, pain or fatigue. There are biological sequelae of physical exercise in health and disease, but so far these have defied predictable patterns. (Roemmich, 1961; emphasis added)

Thus, pain is a major problem for the disability program because it does not fit the medical model of impairment on which the program rests.

#### **Disability and the Labor Market**

In addition to problems with the medical model of impairment, the program has been subject to periodic swings in its congressional mandate from demanding a strict, tightly controlled program based on medical identification of the permanently and totally disabled, to de-

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manding a program more sensitive to the social and economic realities of the labor market, including job opportunities for people with partial disabilities.

By 1958 it was clear to program officials that medical conditions and other reasons for unemployment interacted in a complex way. Employer hiring practices, technological changes in an industry, and local or cyclical business conditions all might conspire to keep the person with a medical problem from being hired or retained. Congressmen, too, were aware of the complicated relationship between disability and unemployment, and a major oversight report of the House Ways and Means Committee in 1960 (the "Harrison Subcommittee Report") pushed the SSA away from its purely medical concept of impairment:

It is essential that there be a clear distinction between this program and one concerned with unemployment.... The Department [of HEW] should make a thorough study of this situation to see if criteria can be developed which retain the basic emphasis of the program on major medical impairment but at the same time allow for a more realistic assessment where there are multiple bars to employment, e.g. age, employer bias in hiring, and other factors that limit job opportunity. (House Ways and Means Committee, 1960; emphasis added)

In the same year, a major appeals court ruling did what the Harrison subcommittee had asked for. *Kerner* v. *Flemming* was brought by a man who had held a variety of jobs as a carpenter, mechanic, furniture repairman, and salesman and who now suffered from a cardiac condition, diabetes, and anxiety. He acknowledged that he was able and willing to do light, sedentary work, but he was unable to obtain a job because of his medical history. The SSA denied his claim, on the grounds that he was in fact able to engage in substantial gainful employment. The appeals court, however, held that the "mere theoretical ability to engage in substantial gainful employment is not enough if no reasonable opportunity for this is available" (*Kerner* v. *Flemming*, 1960). In the next few years, the courts tended to liberalize eligibility criteria by showing an increased willingness to allow consideration of the job market, the applicant's occupation and experience, and the likelihood of he or she getting a job in his or her home state.

In 1967, Congress responded to *Kerner* v. *Flemming* and what it perceived as a judicial attack on the program's boundaries with a new set of tightening amendments. A person would be considered disabled only if, because of physical or mental impairments,

he is not only unable to do his previous work but cannot, considering his age, education and work experience, engage in any kind of substantial gainful work which exists in the national economy, regardless of whether such work exists in the immediate area where he lives, or whether a specific job vacancy exists for him, or whether he would be hired if he applied for work. (Social Security Act Amendments of 1976, sec. 223(d)(2)(a); emphasis added)

Yet the courts continued to construe the law liberally, and the program began to grow rapidly.

The number of applications per year increased by approximately 80 percent from 1969 to 1974 (from 725,000 to more than 1,300,000); the number of new awards per year increased by about 50 percent during the same period (Senate Finance Committee, 1982). Observers have speculated about many reasons for this growth, in addition to judicial liberalization. Analysts within the SSA's Office of Research and Statistics cite increased public awareness of the program, especially after the passage of SSI in 1972 (Lando and Krute, 1976); increases in SSI benefit levels relative to predisability earnings (Lando et al., 1979); and a decline in the rate of terminations due to recovery, rehabilitation, or return to work (Treitel, 1979). The General Accounting Office blamed the growth on the SSA's lax oversight of the state disability determination agencies, inadequate case-processing standards, insufficient quality review procedures, and a lack of standards for obtaining consultative examinations (General Accounting Office, 1976, 1978, 1979).

Whatever the reasons for growth, the program just as inexplicably began to contract in 1975. The number of new applications dropped, annual new awards declined, and the rate of allowances, which had never been below 40 percent between 1969 and 1974, fell to 33 percent by 1979 (Senate Finance Committee, 1982).

Although the growth had already slowed, Congress passed amendments in 1980 mandating more intensive periodic review of beneficiaries already on the rolls: "continuing disability investigations" (CDIs). The SSA followed its mandate and terminated benefits for about 500,000 people between 1981 and 1983. The terminations stimulated thousands of legal appeals, mobilized an advocacy network of lawyers and claimants' representatives, provoked constituency pleas to congressmen and congressional pleas to the SSA, and generated a great deal of adverse publicity. Eventually 290,000 of the terminated claimants (almost 60 percent) were reinstated. Congress was pressured—by advocacy groups, constituents, and state governments (29 of which had directed their disability determination services to stop conducting CDI reviews in accordance with SSA policy)—to swing the other way (Mashaw, 1985).

#### The 1984 Amendments

In the 1984 Disability Benefits Reform Act, Congress sought once more to protect the program with the traditional safeguard: medical criteria. The amendments called for the development of better medical criteria in three areas that had been the source of controversy in many of the appeals. The first area was mental disability, in which the CDI reviews had been concentrated. The amendments called for the SSA to create a new listing of mental impairments. The second area was a new "medical improvement standard," which would protect beneficiaries from being terminated unless the SSA could demonstrate that they had shown medical improvement. The third area was pain, a symptom that had led to a multiplicity of conflicting and confusing court decisions (see Chapter 3).

The nature and scope of the current problem with pain cases in the Social Security program remains unclear. As is discussed in more detail in Chapter 4, controversy over pain cases is manifested in the courts, in the SSA's nonacquiescence policy, in Congress' attempt to legislate a pain standard in the 1984 amendments, and in the calls for a pain commission and for this study by the IOM.

Two possible problems posed by the pain cases should be distinguished. One problem could be that too many people who are really able to work are getting onto the rolls and/or that too many people who are genuinely incapacitated by pain are denied eligibility. The other problem might be that regardless of correctness, decisions on disproportionate pain cases are so inconsistent across judicial circuits, and across the various levels of administrative and judicial review, that the system is perceived as violating norms of fairness. It is possible to remedy the second problem without affecting the first (e.g., by legislating a national standard, as Congress did in the 1984 amendments). It is too soon to judge the effects of the 1984 legislation, but it may represent progress. A successful resolution of the consistency problem could substantially reduce the political controversy over pain, without restructuring the current SSDI program.

#### DISABILITY, PAIN, AND DISTRIBUTIVE JUSTICE

All societies have two distributive systems, one based on work and the other on need. Both systems are necessary: distribution according to work in order to ensure economic production and stimulate productivity, and distribution according to need in order to preserve community, express compassion, and help ensure human survival. Yet these systems coexist in an uneasy tension. The two principles tend to undermine each other. The policy problem for any society is to decide when the normal work-based rules of distribution should be suspended and some form of social aid should take over.

To solve this problem, a society needs rules to determine who belongs in each system. The rules must express culturally legitimate rationales for not working. They must use criteria susceptible to external validation, because their purpose is to distinguish those who cannot work from those who will not work. In addition, the rules must be sufficiently restrictive to preserve the dominance of the work-based system.

The modern welfare state has adopted a categorical resolution of this problem. A person fitting into one of the categories is automatically entitled to aid, without a further showing of inability to work. Typically, the categories are childhood, old age, survivorship, illness, and disability. Three of the categories are relatively straightforward childhood, old age, and survivorship. To determine whether someone fits these categories is a very simple matter, because age (for childhood and old age) and death (for survivorship) are easily determined. Illness is more problematic. Not only is it more difficult to define and count, but the issues of what services a person really needs, and what the public ought to pay for, are increasingly contentious.

Most problematic is disability, because it concerns the relation between an individual's physical or mental condition and his or her ability not only to work, but also to be hired despite limitations. Moreover, although injury and disease have always evoked sympathy and charity, they have also long been suspect, precisely because they excuse people from traditional obligations such as working. Injury and illness are perceived as more easily feigned than age or other conditions that qualify for social aid.

Thus, although eligibility for disability insurance appears to be a matter of medical determination, it really concerns the fundamental question of who deserves social aid. Societies construct definitions to implement their own concepts of fairness, and even within a society the definitions change over time. In short, definitions of disability have strong cultural connotations and reflect the politics and history of their national context.

In the major program of the United States, the SSDI program, disability is defined as the inability to earn a fixed amount of money (about \$300 a month) in any job that exists in substantial numbers in the entire national economy, regardless of whether there is a job the person can do in his or her community and regardless of whether that person would be hired. (It was not until 1967 that age, education, and training began to be factored into determinations.) The inability to work must be due to a physical or mental impairment.

This very stringent definition expresses the dominant American ethos of the primacy of work. It reflects the long-standing American political tradition of minimizing the redistributive role of government. It expresses our "frontier spirit" to think it appropriate to ask people to uproot themselves and move around in search of work. Finally, the insistence on medical "proof" as a prerequisite for insurance benefits expresses our faith in the ability of science to resolve what are fundamentally issues of justice and politics.

One aspect of the disability definition in the Federal Republic of Germany highlights the different ways in which countries impart meaning to the concept. Like its American counterpart, the West German Social Security disability program relies on physical and medical impairments as the basis for awarding benefits. Yet it defines disability as an inability to earn a fixed amount of money (much higher than the American amount) by doing one's previous job or any other job that corresponds to one's education and capabilities and that does not entail a significant decline in social status (Wegner, 1986). This definition recognizes that jobs provide both income and a social identity—they locate people in a hierarchy of prestige. Class has always been a legitimate criterion in German social policy and political discourse.

The definitions used for public and private employees in the Netherlands illustrate two more aspects of the cultural components of disability. There, a person is disabled if he or she is *unable to earn what similarly trained healthy people earn in the same community* by working at the place where the person last worked or in a similar place. This definition expresses the idea that what matters about the standard of living is one's means relative to others. In addition, it deems legitimate individuals' rootedness in communities.

This national variety in the definition of disability for public programs illustrates that societies have a great deal of choice about how they define disability and that the definitions express very different cultural notions of justice. In contemplating refinements of disability definitions, consideration must be given to the broader implications for justice that such definitions hold.

The 1984 Disability Benefits Reform Act, like most legislative reforms of SSDI, relied on more refined medical criteria to determine eligibility in controversial cases. Yet as efforts to improve the fairness

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of the Social Security disability programs by refining the medical standards were undertaken, there was a major change in how disability was understood outside the Social Security program. Beginning in the late 1960s, many people (including some disabled people) began to see disability as a civil rights issue. Physical and mental handicaps are viewed as conditions likely to lead to discrimination, especially in the labor market, but also in housing, transportation, education, and other services and opportunities.

This understanding of disability has been given a great deal of recognition in other areas of public policy. Most notably, Section 504 of the Rehabilitation Act of 1973 seeks to protect people with handicaps against discrimination in the workplace. This legislation offers a striking contrast to the SSA's definition of disability. Section 504 defines a person as handicapped who:

- has a condition that substantially limits his or her employment;
- has a record of such a condition; or
- is perceived as having such a condition.

The definition acknowledges that in addition to actual bodily condition, work disability is as much a function of how a person is regarded and treated by others (especially by employers). By contrast, the SSA's definition fails to recognize the real barriers to employment of disabled people. Elaboration of more precise medical criteria, for pain or any other condition, will not deal with this problem.

The issue of eligibility criteria for claimants who experience disabling pain that is not medically verifiable or that is disproportionate to clinical findings of disease or injury raises some other questions of distributive justice as well. Indeed, the difficult questions about pain cases are simply specific instances of the larger questions of justice surrounding the program:

• Does a person have a legitimate reason to receive social aid? Is he or she "deserving?"

- How badly off does someone have to be before society should help?
- Do we give equal recognition to equivalent kinds of suffering?

In SSA disability claims in which pain is the chief disabling condition, these questions become more specific: Does the claimant "really have" pain? How much pain is necessary to prevent a person from working, or how much pain should a person be expected to tolerate? In addition, should we expect all people to tolerate the same degree of pain? Even if we could measure pain precisely and be confident that interpersonal comparisons about degrees of pain were valid (neither of which we can do-see Chapters 7 and 11), the issues of distributive justice would remain.

Every distributive program will make errors, because distributive justice is not a matter of technically correct criteria. There will always be disputes over political and moral judgment. Even if all the errors of technical misclassification could be eliminated, disputes over moral judgments (i.e., Does this person deserve aid?) would remain. All distributive programs go through cycles of political controversy in which they are accused of making too many errors (of either stringency or leniency), resulting in reforms introduced to target aid more "efficiently" to the truly needy. Furthermore, because the Social Security program makes hundreds of thousands of decisions involving a combination of medical, social, economic, and psychological factors, misclassification errors are inevitable. The pursuit of technical accuracy should not blind us to the program's other goals: rendering justice, making speedy decisions, being understandable to claimants, and maintaining an entitlement rather than an adversarial climate.

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# **3** Disability Determination and the Role of Pain

The Social Security Administration (SSA) administers two national disability programs: Social Security Disability Insurance (SSDI), established under Title II of the Social Security Act, and Supplemental Security Income (SSI), established under Title XVI of that Act. SSDI is a social insurance program designed to provide benefits to those who have been employed but are no longer able to work because of a medically determined impairment. The SSI program, on the other hand, is intended to protect those who do not have a recent work history.

#### **OVERVIEW OF THE SOCIAL SECURITY DISABILITY SYSTEM**

#### **The Programs**

Applicants to SSDI must demonstrate a "current connection with the work force" in order to be eligible for benefits under this program. That is, an applicant must have worked in Social Security-covered employment for a minimum number of quarters within a prescribed period of time in the recent past; specific requirements are based on the worker's age. For those who have contributed to the Old Age, Survivors, and Disability Trust Fund while working, benefits under this program are considered an entitlement and are awarded without a financial means test. As of December 1985, SSDI benefits paid to the 2.7 million disabled workers (receiving an average monthly allowance of \$470) and more than 1.2 million of their dependents totaled \$1.5 billion per month (U.S. Department of Health and Human Services, 1987).

There are no work requirements to receive benefits under SSI, but applicants must demonstrate financial need. Income and resources from all sources are considered in determining need. In addition to those judged disabled, needy blind and aged persons are eligible for SSI benefits; however, the disabled account for more than 60 percent of the total number of SSI beneficiaries (U.S. Congress, 1982). In November 1985, benefits totaling \$0.7 billion per month were paid from general tax revenues to 2.6 million disabled people under SSI (U.S. Department of Health and Human Services, 1987).

A significant proportion of claimants can apply for benefits under SSDI and SSI simultaneously. These are people who have worked long enough and recently enough to meet the criteria for SSDI but whose earnings were at a very low level. Because the monthly benefit under SSDI is based on past earnings, these same people may be able to qualify for an additional amount from SSI on the basis of need. Nearly 300,000 people currently receive benefits under both programs (Social Security Administration, 1985b).

The SSDI program has grown considerably in the past 25 years. Between 1960 and 1985, the number of beneficiaries increased by 480 percent and the total annual benefits paid under the program increased by 778 percent. This growth far outstripped the increase in the U.S. adult population, which grew by only 51 percent during that period, and that of the working population insured for disability under SSA, which increased by 135 percent. The SSI program has shown a more modest growth pattern during its shorter history. From 1975 to 1984, the number of disabled and blind beneficiaries grew by 25 percent, whereas the total annual benefits for the blind and disabled under SSI increased by 24 percent; the adult population increased by 15 percent over that same period. (See Figure 3-1 and Tables 3-1 and 3-2.)

#### **Program Definitions**

In administering both of its disability compensation programs, the SSA is bound by statutory definitions of disability. As set forth in the Social Security Act, disability is

[An] inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months. (42 USC, 423 (d)(1))



FIGURE 3-1 Trends over time for Social Security Disability Insurance (SSDI). (SSA: Social Security Administration.)

Further, "physical or mental impairment" is defined in the statute as:

an impairment which results from anatomical, physiological, or psychological abnormalities which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques. (42 USC, 423 (d)(3))

In order for a physical or mental impairment to be considered a disability within the meaning of the statute, it must prevent the claimant from engaging not only in his or her previous work but in any kind of work that exists in the national economy, taking into account the claimant's age, education, and work experience.

A complex set of regulations has evolved to implement the statute. The SSA has established a set of medical evaluation criteria referred to as the "Listing of Impairments" (20 CFR, 404, Subpart P, Appendix 1; see also U.S. Department of Health, Education, and Welfare, 1979). This listing defines a level of severity of impairment that, in the absence of substantial gainful activity, allows a presumption of disability by those charged with evaluating disability claims. The listing contains more than 100 examples of medical conditions. They are arranged according to 13 body systems and describe impairments in terms of symptoms, signs, and laboratory findings.

Symptoms are defined in the regulations as the claimant's own

	Year						Summary
Measure	1960	1965	1970	1975	1980	1985	1960-1985
No. of beneficiaries	455,371	988,000	1,492,948	2,488,774	2,861,253	2,647,127	
(disabled workers)							
Percentage change		117	51	67	15	L	481
Benefit payments (millions) <sup>a</sup>	\$ 568	\$1,573	\$3,067	\$ 8,414	\$15,437	\$18,000	
Percentage change		177	95	174	83	17	
Benefit payments (millions) <sup>b</sup>	\$1,838	\$4,654	\$7,302	\$14,189	\$18,013	\$16,143	
Percentage change		153	57	94	27	-10	778
U.S. population, noninstitutional adults (thousands)	119,106	128,459	139,203	154,831	169,349	179,798	
Percentage change		80	80	11	6	9	51
Workers SSA-insured for disability (thousands)	46,400	53,300	72,400	83,300	98,000	108,900	
Percentage change		15	36	15	18	11	135
Percentage of U.S. adult population	39	41	52	54	58	61	
NOTE: Compiled using data from: Star 1985; Social Security Programs in the L	tistical Abstr United State	ract of the U s, Social Sec	nited States, 1 urity Bulletin	. Vol. 49, No.	), Bureau of th 1, January 19	ne Census, Wa 186; and the S	shi

 TABLE 3-1
 Trends over Time for Social Security Disability Insurance

<sup>a</sup> Current dollars. <sup>b</sup> Constant dollars, 1982. Constant dollars were calculated using the Gross National Product Implicit Price Deflator provided by the Bureau of Economic Analysis, U.S. Department of Commerce.

SSI (Blind and Disabled)	Year			Summary
	1975	1980	1984	1975–1984
No. of beneficiaries (disabled workers)	2,007	2,334	2,500	
Percentage change		16	7	25
Benefit payments (millions) <sup>a</sup>	\$3,273	\$5,204	\$7,392	
Percentage change		59	42	
Benefit payments (millions) <sup>b</sup>	\$5,519	<b>\$6</b> ,072	\$6,851	
Percentage change		10	13	24

### TABLE 3-2Trends over Time for SupplementalSecurity Income (SSI)

NOTE: Compiled using data from: Statistical Abstract of the United States, 1986 (106th ed.), Bureau of the Census, Washington, DC, 1985; Social Security Programs in the United States, Social Security Bulletin, Vol. 49, No. 1, January 1986; and the Social Security Bulletin, Annual Statistical Supplement, 1984–1985.

<sup>a</sup> Current dollars.

<sup>b</sup> Constant dollars, 1982. Constant dollars were calculated using the Gross National Product Implicit Price Deflator provided by the Bureau of Economic Analysis, U.S. Department of Commerce.

perception of his or her physical or mental impairments. Signs are anatomical, physiological, or psychological abnormalities that can be observed with medically acceptable clinical techniques. Laboratory findings are manifestations of anatomical, physiological, or psychological phenomena demonstrable by replacing or extending the perceptiveness of the observer's senses; they include chemical, electrophysiological, roentgenological, and psychological tests (20 CFR 404.1528).

The 10 musculoskeletal impairments in the listing include active rheumatoid arthritis, arthritis of a major weight-bearing joint, arthritis of one major joint in each of the upper extremities, disorders of the spine, osteomyelitis, soft tissue injuries, and various amputations, anatomical deformities, and fractures. The full text for two impairments in the SSA listing follows.

#### Disorders of the spine:

- A. Arthritis manifested by ankylosis or fixation of the cervical or dorsolumbar spine at 30° or more of flexion measured from the neutral position, with X-ray evidence of:
  - 1. Calcification of the anterior and lateral ligaments; OR
  - 2. Bilateral ankylosis of the sacroiliac joints with abnormal apophyseal articulations; OR

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- B. Osteoporosis, generalized (established by X-ray) manifested by pain and limitation of back motion and paravertebral muscle spasm, with X-ray evidence of either:
  - 1. Compression fracture of a vertebral body with loss of at least 50 percent of the estimated height of the vertebral body prior to the compression fracture, with no intervening direct traumatic episode; OR
  - 2. Multiple fractures of vertebrae with no intervening direct traumatic episode; OR
- C. Other vertebrogenic disorders (e.g., herniated nucleus pulposus, spinal stenosis) with the following persisting for at least 3 months despite prescribed therapy and expected to last 12 months. With both 1 and 2:
  - 1. Pain, muscle spasm, and significant limitation of motion in the spine; AND
  - 2. Appropriate radicular distribution of significant motor loss with muscle weakness and sensory and reflex loss.

Active rheumatoid arthritis and other inflammatory arthritis. With both A and B.

- A. Persistent joint pain, swelling, and tenderness involving multiple joints with signs of joint inflammation (heat, swelling, tenderness) despite therapy for at least 3 months, and activity expected to last over 12 months; AND
- B. Corroboration of diagnosis at some point in time by either:
  - 1. Positive serologic test for rheumatoid factor; OR
  - 2. Antinuclear antibodies; OR
  - 3. Elevated sedimentation rate.

As these examples illustrate, particular signs, symptoms, and laboratory findings (often at precise levels) are specified for each condition in the listing of impairments. Pain is often mentioned. In addition, the listings often specify that these indicators of impairment must be present despite therapy of a particular type or duration, and that the condition must be expected to last 12 months.

#### **The Application and Evaluation Process**

An individual seeking disability compensation first files a claim with one of the more than 1,300 district and branch offices of the SSA. About 1.5 million initial claims are filed each year. Employees of the district office interview the claimant, help complete the disability application, obtain information about the claimant's work background, and obtain the names of the claimant's physicians and other sources of treatment. The district office staff also must advise the claimant of his or her rights and responsibilities in the application process.

The claim is then referred to a state agency known as a disability determination service (DDS). The DDS is responsible by law and regulation for making decisions about whether or not the claimant is disabled. the date the disability began, and, if appropriate, the date the disability stops or is expected to stop. Each claim is evaluated by a two-member state team. One of the team members is a nonphysician referred to as a disability examiner, who is knowledgeable about the legal and administrative requirements for entitlement under the disability programs; the other is a physician who makes the medical determination of impairment. The state disability determination services have their own policies regarding the qualifications of the personnel they employ. For physicians, generally the only requirement is that they are licensed to practice in that state, not that they be board certified. They may be employed part time or full time. Physicians tend to be internists and general or family practitioners so that they can process a broad range of cases, and also because the states typically do not pay high enough salaries to be able to hire specialists. By federal law, specialists are only required in adverse mental impairment cases, but usually psychiatrists are brought in on all mental cases. With this exception, the physicians who conduct the paper reviews at the state level are likely not to have the specialized expertise that may be needed to judge particular cases.

The evaluation team is presented with a file on each claimant containing the forms filled out by the individual with the help of the SSA district office and the information forwarded to the DDS by physicians and others who have treated the individual. These forms differ from state to state, but generally include what is believed to be the pertinent information about the medical conditions that prevent the individual from working, as well as other information about past work history and current level of income. The completeness of such files may vary from state to state and from applicant to applicant. The evaluators can ask for more information from the claimant or from the treating or examining physician in order to complete the assessment. They may also ask for an examination of the claimant by a consulting physician paid by the SSA.

The evaluation team is required to evaluate the claim in a particular fashion set forth in regulation and provided to employees in training sessions and manuals. This procedure is known as the sequential evaluation process and consists of up to five steps. (See Figure 3-2 for a schematic depiction of the sequential evaluation process.)



FIGURE 3-2 Sequential evaluation process. (RFC: residual functional capacity. SGA: substantial gainful activity.)

The first step in the sequential evaluation process is a nonmedical determination as to whether or not the claimant is "engaging in substantial gainful activity" (SGA). SGA is defined by regulation as "work that involves doing significant and productive physical or mental duties and is done for pay or profit." It is evaluated using earnings guidelines also set forth by regulation; since 1980, earnings of more than \$300 per month have usually been found to be evidence of SGA. Earned income alone is considered in the determination of SGA, but certain impairment-related work expenses may be deducted from earnings. An individual found to be working for substantial gain is denied benefits, and the evaluation process stops for that claimant.

For those claimants not currently working for substantial gain, the process continues to a second step. Here the determination is made as to whether or not the claimant has a severe impairment. An individual's impairment (or combination of impairments) is judged to be severe when it has a significant negative effect on the individual's ability to perform basic work activities. Basic work activities include the capacity for sitting, standing, walking, lifting, pushing, pulling, handling, seeing, hearing, communicating, and understanding and following simple instructions. When symptoms are alleged, it must be shown that the impairment(s) could reasonably produce the symptom. When an impairment and related symptoms are judged not to be severe, the claim is denied.

When the claimant's impairment is found to be severe, the evaluator proceeds to the third step. Now it must be determined whether or not the condition falls under the regulatory Listing of Impairments mentioned earlier. A claimant is said to "meet" the Listing of Impairments when the medical evidence in his or her file substantiates all of the signs, symptoms, and findings called for in the listing. A claimant who is judged to meet the listing is found disabled on the basis of medical evidence alone and is awarded benefits.

An individual may also be found disabled at this third step if the impairment or impairments are found to be equivalent to the level of severity and duration of a listed impairment. A program physician or psychologist decides whether a claimant's impairment is of equivalent severity by comparing the set of signs, symptoms, and findings that describe the individual's impairment with those specified for the most closely corresponding listed impairment. A claimant whose impairment "equals" the listing is judged disabled on the basis of medical evidence and receives benefits.

When the claimant's impairment is found not to "meet or equal" the Listing of Impairments, the evaluator proceeds to a fourth step and then, if necessary, to a fifth step. At these steps, vocational factors are considered. First. an assessment of residual functional capacity is made by the program physician to determine the claimant's ability to perform physical or mental functions required for work despite the limitations caused by the impairment and related symptoms. An evaluation is made of the individual's exertional (basic strength) capacities (e.g., walking, sitting, standing, lifting, carrying, pushing, or pulling), including an assessment of his or her maximum ability for sustained activity on a regular basis. The assessment also includes an evaluation of such other significant physical functions as reaching, handling, seeing, hearing, and speaking. Again, this assessment is done by reviewing information in the file only: the evaluator does not see the claimant face to face. In the case of claimants applying on the basis of mental conditions and other nonexertional impairments, the assessment of residual functional capacity must include an evaluation of the claimants' capacity for the mental demands of work. Such claimants are assessed on the basis of their level of functioning. including such things as relationships with family members and others, and the ability to carry out necessary daily tasks, such as shopping for and preparing meals and caring for personal hygiene.

Based on the assessment of residual functional capacity, the disability evaluator determines whether the claimant can perform work as before (Step 4). If the individual can perform that past work, he or she is found not disabled and benefits are denied. If the claimant cannot do the past work, a determination is made as to whether he or she can do *any* work that exists in the national economy (Step 5). For exertional impairments, such determinations are made by consulting a matrix known as the "grids." Exertional requirements of jobs are classified from "sedentary" to "very heavy," using the definitions in the *Dictionary of Occupational Titles* published by the U.S. Department of Labor; skill levels are classified as skilled, semiskilled, and unskilled. For nonexertional impairments (e.g., mental impairments), the grids are used as a framework for deciding disability.

Considerations of age, education and training, and past work experience must be taken into account at Step 5. SSA regulations classify age 55 and over as "advanced age," the time at which age adversely affects the individual's vocational adaptability such that he or she cannot be expected to take on work different from that performed in the past.

#### **The Appeals Process**

A claimant who is denied benefits at the initial determination may request a reconsideration. About 60 percent of the 1.5 million claimants who receive initial determinations each year are denied; 50 percent of these, or about 450,000, ask for a reconsideration (see Figure 3-3).\* The reconsideration is carried out by a different examiner/medical consultant team at the state disability determination services. This team goes through the same five-step sequential evaluation process used by the initial evaluation team. The applicant may provide additional evidence or claim a worsening of the condition.

If benefits continue to be denied on reconsideration (as they are in 80 percent of the cases reconsidered), the claimant may request a hearing before an administrative law judge (ALJ). About 70 percent of denied claimants, or 252,000 each year, request such a hearing. The SSA employs about 700 ALJs in its Office of Hearings and Appeals. The ALJ can request and receive evidence from any source and has the authority to issue subpoenas. The applicant may appear in person at a hearing, with or without a representative, and may present witnesses and additional evidence or may request that the ALJ make a determination by reviewing the existing file, including any new evidence submitted. The ALJ also follows the sequential evaluation process in making a decision. In about 50 percent of the cases, the ALJ overturns the decision of the previous adjudicators.

A claimant who is dissatisfied with the decision of an ALJ can request a review by the Appeals Council of the Office of Hearings and Appeals. The Appeals Council can decline to review a case; if it chooses to consider a case, it may affirm, modify, or reverse the ALJ's decision. In addition, the Appeals Council can initiate a review of any ALJ's decision even if the applicant does not make such a request. Usually the Appeals Council sees only the record from the ALJ hearing and the SSA file. It may, however, request additional evidence or information from the claimant and, rarely, may invite a claimant to appear before the council. The Appeals Council reviews the procedural aspects of the earlier steps, but it does not review the merits of the case itself.

<sup>\*</sup>Numbers and percentages in this section and the accompanying figure are estimates provided by the SSA. The SSA has figures on the number of cases adjudicated at each level each year that are quite reliable. Figures on the number of cases that arrive at each level are less accurate. The SSA does not have a system for tracking individual claimants over time through the various levels of appeal. Moreover, until recently the SSA has not tried to categorize pain claimants or to count them because pain essentially fell outside its disease-oriented and anatomical systems approach to disability. Despite the well-known problems involved in adjudicating claims that turned principally on pain, pain was not a priority for the disability program until it attracted political attention.





60,000 cases/year are disposed of by Appeals Council\*\*

FIGURE 3-3 Disposition of claimants for SSDI benefits.

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Applicants who wish to pursue claims after benefits have been denied by the council are permitted by statute to appeal their cases through the federal court system (see Weinstein, 1984). An estimated 95 percent of the more than 52,000 Social Security cases pending in the 94 federal district courts at the end of 1985 were disability claims (Pear, 1986). Applicants may continue to appeal their cases up to the U.S. Supreme Court. The standard of review throughout the federal court system is whether the lower levels of adjudication followed appropriate procedures in making their decisions, and most important, whether the decision was supported by substantial evidence. Chapter 4 discusses some of the problems that arise when the appeals process is carried out in practice.

#### **Program Benefits**

Although a person may apply for SSA compensation at any time after becoming disabled, cash benefits under SSDI cannot begin until 5 months from the date of onset of the disability, as established by the disability determination services. The monthly payment awarded to SSDI beneficiaries is dependent on the amount of money they earned during SSA-covered employment. A complex formula is applied to arrive at the specific amount in each case. The benefit amount does not relate to the nature of the impairment or to the underlying medical condition. The recipients of SSI all receive the same basic federal payment; however, some states supplement this federal payment. Medicare (for SSDI) and Medicaid (for SSI) coverage is also available to disability beneficiaries; eligibility requirements vary between the two programs. As long as the disabling condition continues and other program requirements continue to be met, SSDI benefits can continue until the recipient is eligible for benefits under the old age provisions of the Social Security Act. Disability beneficiaries are subject to periodic review by the SSA to assure their continued eligibility. The kind of impairment generally determines the interval for the periodic reviews. The statutory requirement is for a review at least every three years. However, in cases of permanent impairment the Secretary has the discretion to conduct reviews less frequently; in cases where the beneficiary is expected to recover fairly quickly, the periodic reviews may be conducted more frequently.

#### **Incentives for Rehabilitation and Return to Work**

Despite the requirement that a person be totally disabled and unable to work for an extended period of time, some rehabilitation provisions are a part of the SSA disability programs. Any disability claimant may be referred to a state vocational rehabilitation agency, and the SSA reimburses the state agencies for those beneficiaries who eventually return to work for at least 9 consecutive months and who meet other specified requirements.

Beneficiaries may also take advantage of a trial work period during which they may work and earn money without forfeiting disability payments. (Under SSI, however, any such earnings affect the amount of the monthly payment.) This provision is available to beneficiaries whether or not they participate in a rehabilitation program. The trial work period is little used. The SSA estimates that fewer than 10,000 of the more than 6 million beneficiaries annually engage in trial work. Whether this is because they are too impaired to work, fear losing benefits, or have no incentive to return to work given the structure of the program is not clear (see Chapters 4 and 5). Other incentives intended to encourage rehabilitation include the extension of Medicare coverage for a period of time after a beneficiary has returned to work and a provision for special SSI cash benefits and extended Medicaid coverage for individuals who would normally lose eligibility because of SGA. In addition, under a program for achieving self-support, SSI recipients are permitted to set aside income or resources for a work goal, such as education and training. Little is known about the characteristics of the small number of people who take advantage of these provisions and what distinguishes them from the vast majority who do not. Such information would be very useful to have.

As discussed in Chapters 4 and 12, there is some contradiction between the two program elements—the stringent standard of proof required to be found "totally" disabled on the one hand, followed by a push to be rehabilitated.

#### PAIN'S ROLE IN THE DETERMINATION OF DISABILITY

#### Pain in Social Security Law and Regulation

The SSA revised several sections of its regulations pertaining to disability in August of 1980. The sections concerning the evaluation of symptoms were changed to include specific mention of pain as a symptom to be considered and evaluated in the determination of disability (see Goldhammer and Bloom, 1983). These regulations stated that pain and other symptoms could be the basis for a finding of disability only when medical signs and findings show a medical condition that could be expected to produce the pain. Social Security

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Ruling 82-58 further discussed the role of symptoms such as pain in the evaluation process, stating

The effects of symptoms must be considered in terms of any additional physical or mental restrictions they may impose beyond those clearly demonstrated by the objective physical manifestations of disorders. Symptoms can sometimes suggest a greater severity of impairment than is demonstrated by objective and medical findings alone.

The SSA's policy as put forth in regulation was written into law in 1984 as Section 3(a) of P.L. 98-460, the Social Security Disability Benefits Reform Act of 1984 (see Social Security Administration, 1984a). This was the first time a standard for evaluating pain was codified in law. Part of the text reads

An individual's statement as to pain or other symptoms shall not alone be conclusive evidence of disability as defined in this section; there must be medical signs and findings, established by medically acceptable clinical or laboratory diagnostic techniques, which show the existence of a medical impairment that results from anatomical, physiological, or psychological abnormalities which could reasonably be expected to produce the pain or other symptoms alleged and which, when considered with all evidence required to be furnished under this paragraph (including statements of the individual or his physician as to intensity and persistence of such pain or other symptoms which may reasonably be accepted as consistent with the medical signs and findings), would lead to a conclusion that the individual is under a disability. Objective medical evidence of pain or other symptoms established by medically acceptable clinical or laboratory techniques (for example, deteriorating nerve or muscle tissue) must be considered in reaching a conclusion as to whether the individual is under a disability.

#### Pain and the Application Process

The first indication that pain is involved in a disability case may come during the interview at an SSA district office. The claimant may describe pain as part of the reason for the disability, or the interviewer may ask questions that elicit the allegation of pain from the claimant. When pain does enter the picture at this early point, the interviewer asks about the effect of the pain on the claimant's capacity for basic functions such as sitting, standing, and walking. Information obtained by a district office interviewer is part of the file sent to the DDS for adjudication.

In the course of its information gathering, the DDS may obtain material from the claimant's treating or consulting physicians, from hospital records, and from interviews with members of the claimant's family or with friends who have knowledge of the individual. These sources may mention the presence of pain and may give information that corroborates the claimant's descriptions of pain.

When medical evidence is available that supports the claimant's allegation of pain, the claim can be resolved relatively easily. The difficulty arises when the medical evidence does not support the claimant's description of pain as to its severity, duration, and frequency, and when the determination cannot be made on the basis of other factors routinely considered, such as whether the condition meets or equals a listing.

In such cases, the adjudicator must consider all of the available information relative to the pain. This includes not only the medical evidence but also information from family, friends, neighbors, coworkers, or others who are familiar with the claimant and can provide additional information about the claimant and the effects of the impairment(s) and any related symptoms. Usually the claimant is asked to provide the names of such individuals, who may then be interviewed by a DDS employee. Such information may include descriptions of the claimant's daily activities, behavior patterns, and differences between the claimant's activities before and after the onset of the pain.

Much of the material in the file is obtained through the use of standardized forms on which are recorded information about the claimant's impairment(s), the onset of the condition, the date the claimant last worked, and the nature of this work. Many of the state agencies have developed special forms or revised versions of a basic form that are used to request information from specialists who have treated or examined a claimant. Although there is no system-wide standardized form for eliciting information about pain, a number of states have developed special questionnaires for cases in which pain is a particular issue. Some of these pain questionnaires are addressed to the treating physicians and ask for the history, nature, extent, duration, and severity of the claimant's pain as observed or treated by the doctor. Other pain forms elicit more information from the claimant, in terms of the pain's effect on daily activities, relationships with others, and the ability to work and carry out work-related activities.

#### Pain and the Sequential Evaluation Process

SSA has detailed operating guidelines for its adjudicators that include review of the law and regulations relative to the evaluation of pain. Adjudicators often must make a determination with information that, particularly in the past, was not adequate for eliciting or interpreting information about chronic pain. The increased use by some states of specialized forms for obtaining information about pain and the release of a Program Circular on the Evaluation of Pain (No. 05-85-OD) in August of 1985 serve to remind adjudicators of current SSA policies for the evaluation of pain.

The first step of the process, the judgment as to whether the claimant is working for substantial gain, is the same whether or not pain is alleged by a claimant. A person working at the level of substantial gain or above is not eligible for benefits, regardless of the severity of the impairment or the severity or frequency of pain or any other symptom.

At the second step, the decision as to whether or not an impairment is severe enough to significantly limit basic work activities must be based on a weighing of all the evidence, including reports of pain. When the pain described is out of proportion to the medical findings, the claim of pain must be further investigated to look for any limitations imposed by the pain in addition to those indicated by the medical evidence. Consideration may also be given to the possibility of a mental impairment as the basis for the pain.

The determination as to whether or not an impairment "meets or equals" a listing in the regulatory Listing of Impairments is the third step of the process. Pain appears among the required criteria for some listings. In such cases, the pain must simply be present, along with the other criteria; it need not be quantified: "Unless specifically indicated ... quantification or evaluation of the intensity or the functionally limiting effects of that symptom is not required to determine whether the documented findings meet the requisite criteria" (Social Security Administration, 1985a). However, in determining whether an impairment is equivalent to a listing, pain cannot be substituted for a missing sign or finding. For example, a history of severe joint pain cannot make up for a lack of x-ray evidence when such evidence is required under a particular listing.

When no listing is met or equaled, so that residual functional capacity must be assessed, the limitations imposed by pain must be considered. Medical findings such as evidence of muscle atrophy, reduced joint motion, muscle spasm, and sensory and motor disruption are among the "usually reliable indicators of pain and the effect such pain may have on the individual's work capacity" (Social Security Administration, 1985a). When greater limitation due to pain is reported than can be demonstrated by such objective findings alone, adjudicators are instructed to consider other evidence, including detailed descriptions from the claimant, from physicians, and from other persons who know the claimant, about such matters as:

• the nature, location, onset, duration, frequency, radiation, and intensity of any pain;

• precipitating and aggravating factors (e.g., movement, activity, environmental conditions);

• the type, dosage, effectiveness, and adverse side effects of any current or previous pain medication;

- past or current treatment, other than medication, for relief of pain;
- functional restrictions; and
- the claimant's daily activities.

SSA guidelines emphasize that adjudicators must consider all evidence, medical and nonmedical, that relates to subjective complaints such as pain. The guidelines further indicate that "in instances in which the adjudicator has observed the individual, the adjudicator is not free to accept or reject that individual's subjective complaints solely on the basis of such personal observations" (Social Security Administration, 1985a).

#### Pain and the Courts

Over the past 20 years, a significant number of federal cases were decided in which the alleged disability was wholly or substantially related to pain (see Zaiser, 1984). Each of the federal circuits has been faced with such cases and each has developed its own line of precedent-setting decisions. When a circuit court opinion is particularly broad based or well founded in legal principle, the tendency among the circuits has been to adopt that case law as precedent, although there are exceptions. One of the earliest cases in which the Secretary's decision to deny benefits was overturned, and which has been overwhelmingly adopted by the circuits, was *Page* v. *Celebrezze*, 311 F. 2d 757 (5th Cir. 1963). In that case the court enunciated the following standard:

If pain is real to the patient and as such results in that person being physically unable to engage in any gainful occupations suited to his training and experience, and this results from 'any medically determinable physical or mental impairment,' the disability entitles the person to the statutory benefits even though the cause of such pain cannot be demonstrated by "objective clinical and laboratory findings."

Not long after this case, the determination was made in Ber v. Celebrezze, 332 F. 2d 293 (2d Cir. 1964) that the subjective complaints of the severity of pain must be taken into full consideration by the administrative adjudicator and that it is improper to determine that the claimant's particular condition cannot produce the stated degree of disabling pain. "What one human being may be able to tolerate as an uncomfortable but bearable burden may constitute for another human being a degree of pain so unbearable as to subject him to unrelenting misery of the worst sort," the judge wrote.

During the 1970s the evolution of policy and standards for assessing pain continued. Many of the circuit courts continued to reinforce the policy stated in Page v. Celebrezze, that objective clinical and laboratory findings were not necessary for a finding of disability. It was enunciated consistently that the only threshold requirement was the presence of a medically diagnosed impairment that could plausibly cause the claimant's pain (Miranda v. Secretary, 514 F. 2d 996 (1st Cir. 1975); Baerga v. Richardson, 500 F. 2d 309 (3d Cir. 1974)). Until guite recently the two landmark cases on pain as a legitimate disability most often cited as authority by various courts were Marcus v. Califano, 615 F. 2d 23 (2d Cir. 1979), and Aubeuf v. Schweiker, 649 F. 2d 107 (2d Cir. 1981). The net effect of these two cases was that "subjective pain may serve as the basis for establishing disability even if such pain is unaccompanied by positive clinical findings or other medical evidence" (Marcus v. Califano); that a claimant's subjective complaints of pain cannot be rejected because of the absence of substantiating objective evidence unless there is contradictory evidence contained within the record; and that the opinion of the treating physician as to a claimant's disability is binding on the adjudicator.

These two cases, following in a long line of related cases, created significant precedent for disability claimants who experienced substantial disabling pain. Over the next several years there were numerous cases in which pain was determined to be the primary cause of disability, resulting in the awarding of benefits to claimants who had been denied them by the administrative process. This outcome, however, came about only for claimants who appealed unfavorable administrative decisions. Administrative evaluators are not bound by the evolving judicial standards on pain. It is likely that, during that time period, claimants who might have been awarded benefits based on the judicial standards were denied awards in the administrative evaluation process and did not pursue appeals.

Of particular influence in recent years has been the case of *Polaski* v. *Heckler*, 751 F. 2d 943 (8th Cir. 1984); we discuss this case in some detail because of its importance. Polaski was a beneficiary whose benefits had been terminated during the 1980–1981 reviews and who appealed this decision; the case was later expanded into a class action suit. Oral

arguments were heard in the Eighth Circuit Appeals Court in June 1984, but the judge deferred issuing a decision until the parties had a chance to come to an agreement. On July 11, the parties to the case signed such an agreement, known as a consent decree; the court accepted the agreement a week later, followed shortly by the Secretary's dissemination of this approved standard to SSA disability adjudicators in the Eighth Circuit.

The consent decree to which the Secretary and the plaintiffs agreed set forth the following standard on the evaluation of pain as a disability:

• Although the claimant has the burden of proving that the disability results from a medically determinable physical or mental impairment, there need not be direct medical evidence of the cause and effect between the impairment and the subjective effects of pain.

• The absence of objective medical evidence is only one factor to be considered in making the disability determination.

• The adjudicator must give full consideration to all evidence and testimony regarding the subjective complaints.

• The adjudicator cannot accept or reject subjective complaints based solely on his personal observations.

This agreement was based primarily on the SSA's 1982 ruling, SSR-82-58, which the Secretary acknowledged in the agreement might have been misinterpreted by some SSA adjudicators.

P.L. 98-460, the Social Security Disability Benefits Reform Act of 1984, was passed in October and took effect in November. It included a section on the evaluation of pain and other subjective complaints that essentially incorporated the standard agreed to by the Secretary in July. The judge's decision on *Polaski* v. *Heckler* was issued on December 31, 1984, and included the determination that the agreement and the statute are not substantially different in their handling of pain.

Since the agreement and the codification of the standard in P.L. 98-460, there have been cases appealed to the courts by claimants who were denied after applying for benefits primarily on the basis of pain. However, a review of the cases indicates that the SSA's decisions have been overturned infrequently. The Polaski standard and the law appear to have better defined the criteria for evaluating pain and thus to have decreased the disagreement between the SSA and the federal courts.

## COMPARISON WITH OTHER DISABILITY COMPENSATION PROGRAMS

Programs in the United States and in other countries have developed a variety of ways to deal with compensation for disability that
may or may not pay specific attention to pain complaints. This section briefly describes procedures of the Veterans Administration (VA), the Workers' Compensation system, private disability insurance carriers, and programs in Western Europe in order to provide some points of comparison with the SSA disability system. Table 3-3 presents a synopsis of the four major disability compensation programs in this country.

## **Veterans Administration**

The VA has two programs for the compensation of disability. One is the service-connected compensation program, an entitlement program for which a veteran is eligible simply by a determination of disability; there is no means test and no requirement of an inability to work. A veteran can be compensated for any disabling physical or mental impairment sustained in the course of his or her military service. The amount of compensation depends on the percentage of disability determined by the VA's administrative process. Separate ratings are assigned to each impairment, and a total rating is reached by means of a formula that takes into account the interactive as well as the additive effects of multiple impairments.

Non-service-connected pension benefits may be payable for an impairment sustained after military service. Benefits under this program are available only when the veteran is determined to be totally and permanently disabled and unable to work at a substantial gainful level as a result. An individual must be adjudged at least 60 percent disabled, using the VA rating system, in order to be considered "totally" disabled and eligible for this program.

Legislation pertaining to the VA disability compensation programs defines total and permanent disability in the following way:

•  $\dots$  (1) any disability which is sufficient to render it impossible for the average person to follow a substantially gainful occupation, but only if it is reasonably certain that such disability will continue throughout the life of the disabled person; or

• ... (2) any disease or disorder determined by the Administrator to be of such a nature or extent as to justify a determination that persons suffering therefrom are permanently and totally disabled. 35 USC 502(a)

In 1985 there were almost 4 million veterans receiving benefits for disabilities—2.3 million were service connected and 1.6 million were non-service connected. About 60 percent of the VA's fiscal year (FY) 1985 budget was allocated to disability benefits, with \$9 billion paid for service-connected disabilities and \$6 billion for non-service-connected disabilities (Swansburg, 1985).

The VA provides a broad array of benefits to its disability recipients. In addition to monthly cash benefits, disabled veterans are eligible to receive medical treatment at VA facilities, prosthetic devices, an allowance for modifications to homes and automobiles if required by the disability, and vocational rehabilitation services. Vocational rehabilitation is not mandatory in order to receive or continue receiving benefits. It consists of counseling, job training or retraining, and job placement assistance.

#### The Role of Pain

The VA does not consider pain in and of itself disabling. Federal regulations delineate the role of pain in assessing disability as follows:

Disability of the musculoskeletal system is primarily the inability, due to damage or infection in parts of the system, to perform the normal working movements of the body with normal excursion, strength, speech, coordination and endurance.... The functional loss may be due to absence of part, or all, of the necessary bones, joints and muscles, or associated structures... or it may be due to pain, supported by adequate pathology and evidenced by the visible behavior of the claimant. (38 CFR 4.40)

In evaluating disability claimants, the examining VA physician is instructed to furnish "in addition to the etiological, anatomical, pathological, laboratory and prognostic data required for ordinary medical classification, full descriptions of the effects of disability upon the person's ordinary activity" (38 CFR 4.10). When evaluating a disorder that includes significant pain, the physician is further instructed to request the veteran to describe the pain, any limitation of function that results from the pain, the duration of the pain, and other findings associated with the pain (e.g., fatigue, weakness, swelling, or tenderness). Findings on the presence of pain, as well as the limitations that the pain imposes, are factors in the determination of the percentage of disability. As the regulations indicate, disability can be found to be caused by pain as long as there is adequate underlying pathology, but pain in excess of the underlying disorder is not considered independently.

#### Workers' Compensation

Workers' Compensation programs are state-run programs and there is much variability among them. The common element is the intent to

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Program	Application and Appeal Proceas	Types of Benefits Available	Length of Benefits
Social Security (SSDI/SSI)	Administrative: Initial consideration Reconsideration Appeals Council Judicial: Federal District Court Circuit Court Supreme Court	Cash; insurance-type benefit for SSDI, based on work prescription; welfare-type benefit for SSI, based on means and resources; Medicare/Medicaid; and vocational rehabilitation	Indefinitely or until claimant's condition is found to have improved or claimant returns to work
Workers' Compensation	Administrative: Insurance company WC Board or Division <sup>a</sup> Judicial: State Trial Court (superior) State Supreme Court	Cash; insurance-type benefit, based on most recent earnings; associated medical expenses; and rehabilitation services	Indefinitely until disability has ended, which can be shown at annual recertification examinations or through successful vocational rehabilitation
Veterans Administration	Administrative: Local rating board Secondary rating board <sup>a</sup> Board of Veteran's Appeals <sup>a</sup> (No judicial review)	Cash; insurance-type benefit for SC compensation; income supplement benefit for NSC pension; medical treatment at VA hospital; prosthetic devices; housing and auto modification allowance; and rehabilitation services	Indefinitely <i>after</i> reexamination has shown that disability has stabilized
Private sector	Administrative: Insurance company Possibly an insurance commission Judicial: State Trial Court (superior) as a contract action	Cash: insurance-type benefit, based on contract language and most recent earnings; and rehabilitation services	For the peried specified in the contract or until a company- required examination determines that disability has ended

TABLE 3-3 Synopsis of Four Major U.S. Disability Programs

	Definition of Disability	Consideration of Pain	Rehabilitation
Social Security (SSDI/SSI)	"An inability to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment which has lasted no less than 12 months." Can be further defined by ace. education or shility	Considered and given credence but only insofar as it relates to an underlying physical and/or mental impairment	Not required for initiation or continuation of benefits Option of trial work period
Workers' Compensation	Immediate inability, because of work- related injury, to perform gainful activity, as defined by one's most recent occupation. Can be further expanded by factors relating to employability	Considered to the extent that the treating or examining M.D. asserts that it creates the disability where the impairment was insufficient or where it is a sign of an unstable impairment or where it prevents antiained annowment	Not required for initiation or continuation of benefits Payments generally available if elected by employee Note exceptions: Florida, Oregon, and New Hampshire
Veterans Administration	Service-connected—a formulaic percentage of physical or mental impairment arising during the course of military service and expected to continue for the veteran's lifetime Non-service-connected—a formulaic percentage of physical or mental impairment that results in an inability to engage in gainful activity, which is evidenced through the average impairment of earnings that defect causes; sepected to continue for the evenese, or iferino.	Not generally considered except as a manifestation of a physical or mental impairment. Not an independent disability	Not required for initiation or continuation of benefita Extensive counseling, training, and placement program available
Private sector	Inability because of physical or mental impairment to engage in gainful activity as evidenced through inability to engage in any occupation that the seasonably suited for by age, education, and experience. Specific language may vary given different contracts and different companies	Considered and given credence as an exacerbating factor insofar as it relates to an underlying physical or mental impairment	Not required for initiation or continuation of benefits Payment for and/or maintenance of disabled status during participation may be included in the contract
NOTE: ALJ =	administrative law judge. NSC = non-service	connected. SC = service connected. SSI = Su	pplemental Security Income. SSDI = Social

Security Disability Insurance. WC = Workers' Compensation. <sup>a</sup> De novo review.

compensate disability arising in the course of one's employment. Workers' Compensation programs provide three kinds of benefits: death benefits to an employee's survivors; wage-loss payments due to disability; and payment of hospital, medical, and rehabilitation expenses occasioned by a work-related injury. Formulas for calculating death benefits and weekly compensation rates differ significantly from one state to the next.

Although the SSA requires that a person be unable to engage in any kind of substantial gainful employment, most Workers' Compensation systems require only that the employee be unable either to perform his or her former employment or to obtain other employment suitable to his or her qualifications and training. The ability to perform work at a lower activity level is usually not a consideration in the award of Workers' Compensation benefits.

Workers' Compensation systems provide for four categories of compensable medical disability: temporary total, temporary partial, permanent partial, and permanent total. The two temporary categories have been the least controversial because they are characterized by the expectation of a return to work after a period of recuperation; the controversy that does arise surrounds determining the appropriate length of the recuperative period. The question has usually been resolved by defining the end of the healing period as the time when maximum medical improvement has been achieved, as determined by the treating physician.

In theory, the underlying notion supporting Workers' Compensation systems is that the employee eventually will return to work; state compensation boards often attempt to impress upon the employee the value of rehabilitation. Willingness to participate in a rehabilitation program is usually not mandatory in order to qualify for benefits; however, a few states have instituted obligatory completion of a rehabilitation program after benefits have begun. There has been a trend toward the revision of state laws to provide for the expectation of a return to work rather than for the long-term receipt of benefits.

## The Role of Pain

In state compensation systems, the emphasis is usually not on the continuing presence of pain but on the stabilization of the underlying disorder. Larson (1980) notes, "[t]he persistence of pain may not of itself prevent a finding that the healing period is over, even if the intensity of the pain fluctuates from time to time, provided again that the underlying condition is stable." When a claimant reports subjective complaints of unknown etiology, there is little chance of receiving Workers' Compensation benefits. However, when there is substantial pain and at least some underlying pathology capable of producing the pain, the disabling effect of the pain is taken into account (Swansburg, 1985). As with Social Security disability, such cases are among those that are appealed to the courts and that are sometimes overturned on appeal.

#### **Private Disability Insurance**

Income replacement is the benefit generally available under private disability insurance programs (see Soule, 1984). A disability insurance policy is an agreement between parties that a particular amount will be paid periodically if the claimant becomes disabled. Health care and hospitalization are not generally included in these contracts. Rehabilitation services may or may not be provided depending on the insurance company and the type of policy. Benefits are usually provided for stated periods of time ranging from a few months to the attainment of a particular age. Insurance carriers may offer disability coverage to individuals and to groups. Most policies include a clause that a beneficiary may be required to be reexamined periodically by a physician of the insurance company's choice, in order to be sure that the individual is still eligible for compensation.

Because each company issues its own policies, disability is defined in a variety of ways. The elements that vary among criteria include: the degree of impairment covered (e.g., partial, total, or residual), the degree of vocational impairment required (e.g., inability to perform one's usual occupation), and the expected duration of disability (e.g., permanent, more than a particular number of months, etc.).

Carriers of policies that allow for rehabilitation benefits will pay for services not otherwise covered by health care insurance, provided that an acceptable plan of rehabilitation has been agreed to by the insured, the treating physician, the rehabilitation facility, and the carrier. Although an intent to participate in rehabilitation is not required to initiate or continue benefits, such an intent is considered evidence of the claimant's motivation. The insurance company itself may become involved in rehabilitation efforts by referring claimants to a thirdparty rehabilitation counselor or center or, in some cases, by providing its own rehabilitation centers.

## The Role of Pain

Insurance companies require medical documentation of treatment for any condition held to be causing disability; reports from the treating physician, laboratory results, and hospital records are generally sufficient. In some cases, however, including those in which pain is significant, companies may require disability examiners to see the claimant face to face (Deal, 1985). The examiner may seek information about the claimant's personal stability, home life, marriage, work history, and relationships. The examiner may ask the claimant's treating physician about the pain's relation to any underlying injury or illness. The examiner may also arrange for an independent physical or psychiatric examination of the claimant.

The level of correspondence required between pain and underlying pathology tends to be somewhat lower and less restrictive in most private disability insurance than it is in the SSA system. Still, a claimant whose complaints are subjective only, with little or no detected pathology, has small chance of compensation (Swansburg, 1985).

#### **Disability Compensation Programs in Western Europe**

Similar variety exists between the SSA programs and disability compensation programs in other countries (see Wegner, 1986). European policies toward the disabled focus principally on the assessment of earnings capacity rather than on a strict medical definition of disability. Individuals need not be totally incapable of earning a living in order to qualify for benefits. European systems also provide temporary disability benefits, preferring to maintain individuals on temporary disability rather than labeling them as "permanently disabled," in order to encourage rehabilitation efforts. Another major difference is that in European countries the health, unemployment, disability, and retirement insurance systems are usually coordinated and also may be linked to medical and vocational rehabilitation, including job retraining. The decision about eligibility for disability benefits is usually made only after efforts have been made to rehabilitate the individual and return him or her to gainful employment in his or her previous job or a new one.

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## **4** Conflicts and Contradictions in the Disability Program

s discussed in Chapter 2, multiple forces coalesced to produce the Social Security disability program, and many participants at several levels are responsible for determining eligibility for the program. Multiple forces continue to operate, some working to keep the program within its established boundaries and others pushing against these boundaries, such that there is continual tension among various elements within the program as well as between various external forces and the program (Stone, 1984). This chapter examines the tensions and inconsistencies among the statutory, regulatory, medical, judicial, and programmatic perspectives on disability, highlighting those aspects that relate most directly to the claimant whose chronic pain is not fully substantiated by objective clinical evidence. By so doing it further elucidates the complexities of the issues and provides a more complete context for drawing conclusions about the way in which chronic pain complaints are evaluated in the program and for making recommendations for changes.

There are at least four major reasons why disability determinations will always be subject to differences of opinion and will always contain an important element of subjectivity. First, disability is a complex phenomenon. The inability to work is determined not simply by anatomy, physiology, or mental status, but also by the interplay of these factors with an individual's education, work experience, psychological predispositions, social situation, and the available job opportunities. Judgments based on a combination of so many factors are necessarily open to wide variation.

Second, some of the inconsistencies in how the statutes and regulations are interpreted and applied to individual cases clearly derive from the number of people and offices involved at various levels of review. There are more than 1.300 district and branch offices with more than 19,000 people to help claimants complete the proper forms to file their claims. The actual initial and reconsideration decisions are made in more than 100 offices across the country by about 4.300 disability examiners and 1,400 physicians under contract to the Social Security Administration (SSA). For those cases that are appealed there are more than 130 hearing offices with approximately 700 administrative law judges (ALJs) and as many or more decision writers to assist them. The 20-member Appeals Council is assisted by 324 analysts. Federal quality review of disability decisions is carried out in 10 SSA offices by more than 500 examiners and medical consultants. Finally, there are the federal district courts. With so many people involved in making decisions about anything, there are bound to be inconsistencies, even if the nature of the decisions were relatively objective. In determining eligibility for disability benefits, even the most carefully delineated standards and decision-making rules cannot eliminate all of the inconsistencies because there will always be an element of human judgment required.

Third, some of the inconsistencies and tensions derive from differences in the institutional perspectives of the various participants in the decision-making process, either because of the nature of their stake in the decision or because of their disciplinary training and biases. For example, program administrators are likely to have a very different set of goals and underlying rationales for their behavior than physicians, who are oriented to serving their patients/clients (Mashaw, 1983). Thus, although the basic rules are the same at all levels of review, the perspectives of the participants and the nature of the evidence at each level differ enough to cause inconsistencies. Thus, tensions are created among the various levels and between the SSA and Congress.

Finally, in determining eligibility for disability the basic decision is inherently value laden: to what extent does *this* claimant deserve social aid? No matter how much we try to reduce this question to well-specified medical and vocational criteria, the moral dimension remains. "[T]he question in the end is a value conflict about the distribution of resources. The question is not just what the claimant's skills, impairments, experience, and so forth are, but whether persons with that particular set of characteristics *ought* to have access to public support" (Mashaw, 1983). In recent years there has been considerable discussion, especially in the health insurance arena, about the role of personal responsibility and eligibility for benefits. Some people believe that certain potentially health-compromising behaviors, such as smoking, should be cause to charge higher premiums or even to deny coverage for health problems associated with those behaviors. In the disability arena, too, some people believe that certain individuals inflict problems on themselves or that they can control their problems. Alcoholism, drug addiction, and other mental health problems are sometimes viewed in this way, as are incapacitating symptoms in the absence of clinical signs of disease. At one end of the spectrum of value-laden opinion, some people believe that individuals suffering from these problems should be excluded from receiving benefits. At the other end of the spectrum is the view that personal responsibility for one's disabilities is irrelevant to the need for benefits, and that decisionmakers should base determinations on the current status and capacity of the individual, without regard for the cause and etiology of any condition.

#### CONGRESS AND THE SOCIAL SECURITY ADMINISTRATION

The SSA is a bureaucratic entity whose existence and jurisdiction has been mandated by Congress. Like other agencies, its job is to implement government programs fairly through the agency functions of investigation, rulemaking, and adjudication. Although Congress establishes the parameters of bureaucratic activity in statutes, the agencies develop the rules and regulations by which the program mission is to be carried out.

The policy implementation role of agencies requires interpreting and translating congressional intent into workable administrative policies and procedures that can be applied to individual cases through adjudication. In executing these functions, there is often room for agencies to exercise their own discretion. In the case of the authorizing statute for the disability program, Congress linked medical condition to employability but did not distinguish clearly between those who cannot perform work functions because of their conditions and those who might be able to work but are unemployable because of their conditions (Mashaw, 1983). Thus, interpretation of the statute, coupled with the necessarily pragmatic orientation of those charged with developing administrative guidelines for the day-to-day program operation, may result in agencies viewing or carrying out their missions somewhat differently than Congress intended (Cofer, 1985).

Periodically Congress chastizes the SSA for awarding too many claims and for allowing too much subjectivity into the decision-making

process. Yet the statutory definition of disability is ambiguous enough to allow many interpretations. Furthermore, at every step in the decision-making process, judgments are called for-an element of human judgment is built in. Mashaw (1983) notes that the judgments become more and more discretionary as one moves through the sequential evaluation from "meets the listings" to "equals the listings" and on to the assessment of vocational criteria. The listings themselves contain a mixture of objective standards ("fixation of the spine at 30° or more from neutral position"), criteria requiring some judgment ("abnormal apophyseal articulations as shown by x-ray" [emphasis added]), and highly discretionary criteria ("appropriate sensory or motor loss" [emphasis added]). There was very substantial growth in the proportion of disability awards made on the basis of the more judgmental categories between 1960 and 1975 (going from about 30 percent to 70 percent of awards being based on "equals" the listings and vocational factors (Subcommittee on Social Security, 1976); after 1975 the trend reversed, and today about half the awards are based on these categories). The increased reliance on discretionary criteria paralleled the growth in the disability program's expenditures during the same period, and hence became an easy target for criticism of the SSA by Congress. Other factors that have influenced both the overall increase in applications and awards and the basis for them include population growth (particularly among the elderly) and rising unemployment rates that make it more difficult for marginally disabled people to find jobs (Heaney, 1984; Howards et al., 1980).

## **TENSIONS WITHIN THE PROGRAM**

#### **Medical Definitions Versus Functional Concept**

Within the disability program itself there are two major sources of tension. The first stems from the fact that medical evaluations are relied on to draw conclusions about work capacity. The "listings" discussed in Chapter 3 are essentially medical diagnoses and clinical findings, and most of the evidence used to determine eligibility for disability benefits is medical. A presumption about occupational fitness and employability is made by program administrators based on data provided by physicians, usually in the absence of an actual assessment of work-related functional capacities.

As discussed in subsequent chapters of this report, there is substantial individual variation in terms of tolerance for pain and other symptoms and in terms of the amount and nature of dysfunction caused by the same level and severity of symptoms. Many factors interact in complex ways to influence individual tolerance, motivation, and functional capacities such that some people are able to work in the face of severe symptoms and others are unable to work when confronted with less severe symptoms. Thus, the presumption of a simple relation between medical signs and symptoms on the one hand and the ability to work on the other will always result in some errors of judgment. Some people who can work will be found eligible for disability benefits and some who cannot work will be denied benefits.

#### **Income Support Versus Rehabilitation**

The second major tension is between the income maintenance and rehabilitation goals of the program. The report of the HHS Commission on the Evaluation of Pain (U.S. Department of Health and Human Services, 1987) notes that although "the primary mission of the disability program is to pay monthly benefits to those found to be disabled, a subsidiary objective is to help restore disabled individuals to productive activity." As an income support program, disability insurance must take care not to undermine work incentives. For this purpose the eligibility criteria must be strict (see Chapter 2). As a rehabilitation program, disability insurance must take care not to undermine the potential for effective rehabilitation. For this purpose, eligibility determination should occur as soon as possible after the onset of illness or injury and should encourage claimants to view themselves as able to work, rather than as totally unable to work.

The SSA's definition of disability is deliberately restrictive. The Social Security disability system is not designed for partially disabled people or for people who are expected to recover quickly. Yet within the program there exist numerous rehabilitation provisions. These provisions are presumably designed to encourage and facilitate rehabilitation and yet they seem at odds with the basic definition of disability. There appears to be a serious "catch-22"-to be eligible for disability benefits a claimant must prove that he or she is unable to engage in any substantial gainful employment that exists in the national economy because of a medical impairment that is expected to either last for at least 12 months or to end in death. To be eligible for rehabilitation, a claimant must demonstrate both the potential for work and that rehabilitation would be beneficial. In light of these conflicting requirements, it does not seem surprising that the rehabilitation provisions are rarely used and that few people ever go off the disability rolls by returning to work. Furthermore, the same claimant can be found both not disabled according to SSA criteria *and* not eligible for rehabilitation services because he or she is too impaired to profit from them.

The rehabilitation provisions themselves contain some conflicting messages to the state agencies charged with providing services. The SSA pays state vocational rehabilitation agencies by the case for services rendered to people who subsequently return to work for a continuous period of 9 months. Given the stringent eligibility criteria to receive disability benefits and the often long delays between the application for and granting of benefits, it would seem that as a group these people are a poor risk for rehabilitation. Under these conditions, there is little incentive for state agencies to accept the risk of payment after the fact for successes only.

As the Pain Commission (U.S. Department of Health and Human Services, 1987) stated, the need to vigorously "prove and re-prove" one's disability under the current system works against the rehabilitation provisions. The beneficiaries themselves may have little incentive to try to be rehabilitated after being found "disabled." Not only have many of these people had to work hard to produce the necessary evidence for their cases, but they have also typically waited a long time for the process to be completed. The elapsed time between initially filing a claim and eventually being found eligible for benefits can easily exceed 2 years if there are appeals. During this time the claimant's health may have deteriorated. At that point, the likelihood of successful rehabilitation may have significantly diminished, even in those whose motivation has remained strong.

## Physicians, Claimants, and Administrators

Clinical assessments play a very different role in medical practice than they do in eligibility determinations. The physician's role and relationship to the patient in a purely clinical situation is to diagnose and treat the patient. By contrast, in a gatekeeping situation, the physician's job is to evaluate a patient for an employer (e.g., to determine suitability for a job), for a private insurance company (to assess actuarial risk), for the armed services (to determine suitability for military service), or for a public program dispensing money on the basis of medical criteria (Stone, 1979).

The SSA uses physicians in three different ways, each with different formal relationships to the SSA bureaucracy. First, the SSA relies on information from a patient's own physician. Most claimants have seen one or more physicians for their condition before they apply for benefits, and the medical records are a crucial part of the claimant's file. Other than filling out forms, these physicians usually have no relationship with the SSA. These doctors are selected by the claimant, and are generally paid by the patient or the patient's insurer.

The second tier is made up of consultative physicians. These are doctors in private practice who examine applicants at the SSA's request to provide additional medical evidence deemed necessary for a decision that is not available in the treating of physician's records. Consultative physicians are not full-time or salaried employees of the SSA; instead, they are paid by the SSA for each examination. Some of these physicians perform just one or only a few examinations each year. Others do an extensive amount of work for the state Disability Determination Service (DDS), however, so there is often a continuing relationship between the state agency and the consultative physician; there is rarely a continuing relationship between an applicant and a consultative physician.

Third are the physicians directly employed by the state DDS who serve on the disability determination teams. These physicians never see applicants in person; they only review the records of examinations from the treating and consultative physicians. From these records, staff physicians, in collaboration with other members of the determination teams, make eligibility decisions.

Physicians in these three roles have different relationships with SSA administrators and with patients/claimants, and may have different perspectives on disability issues. This variation is a source of tension among physicians, between physicians and patients/claimants, and between physicians and the program administrators.

Treating physicians, like claimants, have no inherent interest in the overall size or expenditures of public programs. Because theirs is an individualistic view, there is no reason to expect that treating doctors have taken broad programmatic interest into account in assessing the patient's medical condition and functional levels.

Unlike program administrators for whom "reliance on nonreplicable, nonreviewable *judgement* or *intuition* [is seen] as a singularly unattractive methodology for decisions" (Mashaw, 1983), health care professionals routinely are expected to exercise informed judgment. Decision making in the absence of complete facts and intuitive assessments of patients based on observation are integral to the practice of medicine. As discussed in Chapter 2, medical professionals have been given a central role in the disability determination process that is articulated in law and defined in regulations. Yet some observers worry that treating physicians may too easily consider patients impaired, because their first priority is to help and be an advocate for their patients. Whether they are too lenient or not depends on one's point of view; that physicians are advocates for their patients' well-being is as it should be. From the perspective of the treating physicians, "disability decisions [are] viewed not as attempts to establish the truth or falsity of some state of the world, but rather as prognoses of the likely effects of disease or trauma on functioning, and as efforts to support the client while pursuing therapeutic and vocational prospects" (Mashaw, 1983).

One countervailing force that may operate to make some physicians conservative in their judgments of disability is the damage such a label can do to a person. Especially in the SSA disability system, where disability is defined as the total inability to work and has an implied permanence, such a label might undermine further medical efforts and the patient's will to improve.

Although intuition would suggest that personal physicians are more lenient and the SSA's consultant physicians more stringent in their judgments, there are few data to support this claim. In fact, one study found that consultative physicians thought 48 percent of a sample of disability claimants could work, whereas treating physicians thought that 55 percent of the sample could work (Carey and Handler, 1986). Regardless of the evidence, physicians and administrators within the SSA *believe* that treating doctors do not understand the program criteria adequately and that they *are* more lenient. These beliefs are the source of some further strain between the medical community and the SSA. What is known empirically is that just as some claimants shop for doctors in an effort to find physicians to certify their disabilities, so too do some program administrators (public and private) seek consultative examinations to find reasons for not certifying claimants as disabled (Stone, 1984).

The nature of the disability may also exert a differential impact on the judgment of treating physicians and SSA personnel. Patients with cardiovascular problems, for example, appear to elicit higher levels of perceived legitimacy than those with low back problems or mental disability. In a study by Nagi (1969), the vast majority of coronary disease patients judged disabled by a clinical team were also found unfit for work by the disability examiners, but less than half of the patients with low back problems similarly judged by the clinical team were found disabled by disability examiners. Furthermore, Nagi found that among patients with modest physical impairments, those with minimal psychological limitations were more likely to be found disabled than those with severe psychological limitations.

Physicians who work for the SSA (like company doctors and those

employed by HMOs and other organizations) may have conflicting loyalties. As members of the medical profession, they have been taught to promote their patient's welfare. Even if they only see the patient once for a consultative examination, physicians may feel an obligation to serve the patient well. On the other hand, because they are paid by the SSA, they may feel some loyalty to their employer and to the system as a whole. Like disability evaluators generally, physicians employed by the SSA in whatever capacity may be influenced by the political and bureaucratic climate, especially as that affects the quality assessment reevaluations of their cases. Whether the emphasis is on too many allowances or too few, or on too much time being taken to process the claims, all of these messages affect the context within which judgments are made.

Furthermore, being in a gatekeeping role may compromise (or be seen as compromising) autonomy and profoundly affect the doctorpatient relationship, transforming it from one based on mutual trust to one permeated with mutual distrust. When serving a gatekeeping role to disability benefits, doctors are believed to be more likely to question the claimants' credibility and motivation than when they are in only a clinical role (Stone, 1979, 1984). This transformation (or even the potential transformation) of the doctor-patient relationship has important ethical implications. Limits on trust as a result of the perception of dual loyalties on the part of providers, or as a consequence of the fact that medical consultations are required rather than chosen, effectively eliminate informed consent as a means of protecting those who must enter into a system of medical screening and eligibility determination.

## Administrative Law Judges Versus Program Administrators

A claimant who has been denied benefits at the initial and reconsideration levels of administrative review can request a hearing before an ALJ. This level of review differs in many important ways from both the lower and the higher levels of review. Most significantly, only at the ALJ hearings is the claimant seen face to face by a decisionmaker. Both the lower levels of administrative review and the higher levels of judicial review in the federal courts rely on the written record alone in making determinations about eligibility for benefits. Other differences derive from the training and expertise of the more than 700 ALJs, the nature of the hearing and the evidence allowed, and the multiple roles and concurrent pressures on the judges.

ALJs are federally appointed and permanently assigned to an agency. Permanent assignment is controversial for what appear to be

contradictory reasons. Although it is meant to ensure that the judges have the in-depth expertise necessary to understand the agency's functions and rules, some observers worry that permanent appointment, without fear of firing or concern about reelection, encourages independent decision making. Others have worried that being permanently assigned to an agency may compromise the ALJs' impartiality and independence, because they become loyal to the agency and because they are financially dependent on it as their effective employer (Cofer, 1985).

The ALJs have a difficult task that involves juggling three roles simultaneously. Their job is not only to represent the agency's interest, but also in effect to represent the claimant and to be an impartial decisionmaker by equitably balancing the competing interests of the claimant and the agency. Typically when disability cases come to the ALJs the records are so incomplete that there is an inadequate basis for decision making. Thus, one of the important tasks of the ALJs and their staffs is developing the record; it is in this sense that ALJs serve as the claimant's advocate.

A considerable amount of tension exists between the SSA and the ALJs in part because the rate of reversal at this level averages about 50 percent and because of substantial variation in the rates of reversal among the judges themselves. The inconsistencies among the ALJs (reversal rates range from 10 to 90 percent) are most troublesome because there is no obvious explanation for such wide variation other than to attribute it to differences in personal opinion and values (Cofer, 1985). The high average rate of reversals is also of concern. In both instances, observers worry that inappropriate subjectivity enters into decisions; hence, there is an implicit questioning of the accuracy and appropriateness of the judges decisions (Mashaw et al., 1978). As emphasized throughout this report, pain is subjective and there is no entirely objective way to measure it (see Chapters 7 and 11 especially). The real issue should not be how to eliminate subjectivity from the assessment process, but how to factor subjective elements into the determination process in a more reliable and valid manner. Although subjectivity is clearly one reason for the high reversal rate, there are several other reasons as well.

First, when cases arrive before the ALJs they are frequently incomplete. In developing the cases and completing the record, it is not unusual for the judges to uncover new evidence—evidence that was not considered or was not available at the state determination level. Second, in the time that elapses between the reconsideration and the ALJ review (which often exceeds one year), claimants' conditions can, and often do, deteriorate. Third, the cases heard by the ALJs are unlikely to be straightforward or easy to adjudicate. "The ALJs principally hear cases which lie close enough to the statutory definition of disability to require human judgement to make the determination. Therefore, accuracy becomes less empirical, and more subjective, in these cases" (Cofer, 1985). Given that the cases reviewed by the ALJs are close to the line, and given the further development of the evidentiary record, face-to-face encounters, and elapsed time between the lower denial and the ALJ hearing during which the impairment may have progressed, it is not surprising, or necessarily inappropriate, that a substantial proportion of decisions are overturned (Mashaw et al., 1978).

## THE FEDERAL COURTS AND CHRONIC DISABLING PAIN

Congressional debate on the Social Security Disability Benefits Reform Act of 1984 (P.L. 98-460) included discussion about the way the federal district courts handled allegations of chronic pain and how the rulings were creating tensions between the courts and both the Congress and the SSA. Several concerns were aired during this debate: first, some members of Congress thought the courts were exercising excessive influence in defining standards by which to assess chronic disabling pain; second, pain decisions varied widely from circuit to circuit, suggesting that the law was not being uniformly interpreted or applied; third, the courts were accused of going beyond what Congress intended by giving too much weight to claimants' allegations, thereby broadening and redefining statutory definitions; and fourth, by comparison, some members of Congress thought the SSA's rulings were too restrictive, such that some pain claimants were being improperly denied benefits (Subcommittee on Social Security of the Committee on Ways and Means, 1981; Collins and Erfle, 1985). As described in Chapter 3, in an effort to clarify its intent, and as part of the 1984 amendments, Congress legislated a statutory standard for evaluating chronic disabling pain.

Once having exhausted all administrative remedies, a claimant can appeal an unfavorable disability decision for federal court review. Ordinarily, the federal district court is a trial court; however, for Social Security disability cases the federal district court acts as an appellate forum. As such, the federal court carries out a "paper review" of the record as it was developed in lower levels; the judge never sees the claimant face to face and therefore is precluded from making a firsthand assessment of the claimant's (or the witness') credibility. The role of the federal district court in Social Security determinations is not to readjudicate the facts, but to examine the record and assess what is essentially a single (albeit often multifaceted) legal issue: is the Secretary's decision supported by substantial evidence?

In actual practice the evidence is often reexamined. What is required for a federal judge to overturn an ALJ's decision is the invalidation of the *process* used by the ALJ to evaluate the specific facts of the situation. Once the process of assessment is negated, then the facts are left open for the application of relevant statutory interpretation by the federal judge. Claimants' advocates must present the legal arguments regarding substantial evidence. Because the most effective arguments tend to be tightly interwoven with and supported by the facts of the case, the federal judge is given the unofficial opportunity to review the evidentiary record, while articulating a decision founded in legal principle.

Significant controversy can develop among the courts, the Congress, and the SSA when federal courts repeatedly overrule ALJs' decisions. Often new policy is developed through incremental changes progressively articulated in case law (see Chapter 3). Although the court's only function is to interpret and apply existing law, not to rewrite it, continuing interpretation necessarily leads to expanded application of statutes, which may go beyond Congress' original intent. Conversely, it has been argued that the SSA has been excessively restrictive in promulgating internal rulings and agency regulations that allegedly ignore congressional intent. This is a constant theme in the political discussion of all judicial behavior, not only in disability benefit adjudication. In this respect the disability area only manifests what is a much larger, more enduring tension between the legislative and judicial branches.

Another type of tension is created when a federal court bases its decision on earlier case law that interpreted relevant statutes, regulations, or rulings differently from the Secretary's stated policies. In recent years the Secretary has agreed to implement the decision rendered by the court for the particular claimant, but has refused to apply that decision to other claimants. Therefore, each claimant with a similar impairment or disability has had to appeal his or her case through federal court. This policy of the Secretary, termed "nonacquiescence," was the official position of the Secretary until the 1984 amendments.

Finally, conflict is created between the judiciary and the SSA because of inconsistencies in decisions from the various U.S. Circuit Courts of Appeal. Each federal judicial circuit operates as an autonomous unit to the extent that it is not in conflict with the Supreme Court. Although claimants' advocates often quote the law of other circuits and one circuit may find another's decision satisfactory and opt to use it as precedent, no circuit is required to adopt the case law decisions of another circuit. Adoption of a particular new standard is entirely discretionary by the court. This situation, coupled with the agency's policy of nonacquiescence, wreaks havoc on disability program administrators. In the absence of common, consistent disability determination standards, federal circuit court judges have attempted to articulate what they consider to be workable and fair guidelines. Thus, at the federal court level, as at all the other levels of review, human judgment plays a part.

## **COMPENSATION AND INCENTIVES**

In addition to the tensions that are specific to the SSA disability system, there is a controversial question associated with transfer payments of all kinds: do monetary payments undermine motivation? A pervasive conventional wisdom (at least as old as sixteenth-century English poor law) holds that income maintenance payments in any form—public assistance, industrial injury insurance, veterans payments, or disability pensions—undermine the motivation to work, and therefore reduce the labor supply and ultimately national productivity. In terms of disability payments, three types of incentive effects are often postulated:

1. that the availability of disability benefits acts as an incentive for workers with marginal disabilities to drop out of the labor force and seek disability benefits instead;

2. that the receipt of disability benefits acts as a disincentive for the recipient to return to work; and

3. that the receipt or potential receipt (e.g., a pending application) of disability compensation acts as a disincentive to rehabilitation.

If disability payments have any of these negative effects, then there is a conflict between two competing social goals: (1) providing economic security to disabled people, and (2) both returning as many people as possible to productive work through rehabilitation and keeping as many people as possible in the work force.

This topic generated considerable discussion in our committee meetings. The intensity of the debate is indicative of its centrality in larger questions of social philosophy (see Chapter 2). Although committee members agreed that the general theory plays a dominant role in public policy precisely because it amounts to a conventional wisdom, members disagreed about the correctness of the theory of disincentives in general, about the three specific propositions, and about the quality of social science evidence supporting or refuting any of the propositions.

In the economic choice framework, nonmonetary incentives are viewed as relatively less important than monetary rewards. This model assumes that "the individual rationally compares [the] expected income flows [from disability benefits and from work] and selects the option which maximizes his expected income" (Haveman et al., 1984). A worker who is potentially eligible for disability benefits (because of a condition that might meet the eligibility requirements) faces a choice between continuing in the labor market or applying for disability benefits. In the second version of the theory, a worker already on the disability rolls faces a choice between keeping the level of income provided by the program or returning to the labor force. In the third version, in which the impact of disability benefits on rehabilitation is at issue, no such model of conscious choice is specified, but the underlying assumption in this version is that the financial gains from remaining disabled exert a negative influenceperhaps unconsciously-on the patient's desire to regain skills and functional abilities. A number of economic studies find some support for these theories (Luft, 1978; Berkowitz et al., 1976; Parsons 1980a,b; Leonard, 1979). (See Chapter 5.)

This same theme is found in the literature on the rehabilitation of chronic pain patients. Many studies use some form of "compensation" as an independent variable to test the hypothesis that receiving benefits impedes rehabilitation. Whereas several studies find that rehabilitation outcomes are less good for people who are receiving benefits or have claims pending (Krusen and Ford, 1958; Herman and Baptiste, 1981; Guck et al., 1986), other, often more methodologically sophisticated, studies do not (Rosomoff et al., 1981; Trief and Stein, 1985; Chapman et al., 1981; Brena et al., 1981). As discussed in detail in Chapter 12, virtually all of these studies suffer from severe methodological shortcomings that render the findings inconclusive.

In a society such as ours in which the work ethic is strong and a sense of personal worth derives from work, it is likely that most people would prefer to work than to receive "handouts." Thus, although it seems clear that economic forces influence work-related behaviors (including disability), the committee was not satisfied that a narrow theory of incentives focused exclusively on income adequately accounted for the observed behaviors. In fact, most economists postulate that behavior is influenced by a more sophisticated cost-benefit calculus that takes account of the broader work environment.

#### **Importance of Job Satisfaction**

The majority of people who report themselves as disabled do work (Wolfe, 1979). Therefore, what needs explaining is why some workers, for whom disability benefits might represent a net economic gain, remain in the labor force while others do not. Many committee members felt that certain types of unpleasant or low status jobs push people out of the labor force at the first opportunity, rather than disability benefits exerting a "pull" on people. This is borne out in several studies from the United States and abroad (see Chapter 6). A study by Yelin and his associates (1980) found that work disability for people with rheumatoid arthritis was predicted by social characteristics of the workplace more than by any other factors, including medical factors and physical demands of the job. Control over the pace of work was found to be especially important. Swedish data indicate that monotonous, boring work is significantly related to job dissatisfaction and disability rates (Svensson and Andersson, 1983).

The econometric and rehabilitation studies do not distinguish bluefrom white-collar jobs, much less more refined categories of occupational characteristics or worker satisfaction. Committee members pointed out that a common pattern among professionals is to continue working long past the date when relatively generous retirement benefits are available. The decision to leave the labor force, therefore, probably depends as much on the more intangible benefits (or lack of them) a job provides as on the monetary rewards.

#### **Program Rules as an Explanation of Labor Supply**

For recipients of Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI), program rules constraining work effort could account for the low rates of return to work as well as the putative attractiveness of disability benefits. A person earning more than \$300 per month not only loses disability benefits but eventually also loses Medicare or Medicaid coverage. For people living at a bare subsistence level (which includes most disability beneficiaries), the risk of losing both income and health insurance may be too great a gamble (Berkowitz, 1981). Although the trial work period represents an attempt to deal with this problem, very few people take advantage of it. It simply may not address the basic disincentives and constraints on returning to the work force we have identified.

Other rules that could explain much of the increased rate of application to the Social Security disability programs are the requirements of many state general assistance and Aid to Families with Dependent Children (AFDC) programs. During the period from the mid 1960s to the early 1980s, many of these programs began to require that applicants for general assistance and/or AFDC file an application with the Social Security disability programs; these state programs were eager to shift costs out of the state budgets and onto the federal treasury. Hence, some (perhaps large) portion of the increase in disability applications in the period when benefit levels were also increasing must be attributed to government-mandated behavior rather than to individual choice.

## **Employment Opportunity as a Determinant of Labor Supply**

A critical factor that is often overlooked in discussions of disability benefits and work disincentives is whether, in fact, jobs are available. Although economic analyses include attention to employment opportunity, econometric studies typically use national or regional unemployment rates as an independent variable. Few studies control for the availability of jobs reasonably near home for a person with a particular handicap. It may well be that people do not participate in the labor force only when they cannot get in. In that case, they are not "choosing" a disability benefit over a potential wage, but rather they are forced to accept disability benefits because they simply cannot get a job. There is substantial evidence that people with nondisabling medical conditions are less likely to be hired than healthy workers, and that people with chronic conditions and severe handicaps have a much lower likelihood of finding employment (Weinstock and Haft, 1974; Rothstein, 1983; Stone, 1987). From the employer's perspective there are perceived risks in hiring or reemploying impaired people. which may include higher insurance premiums.

In summary, economic and rehabilitation studies show an aggregate effect of compensation and other factors on labor force participation. This effect is complex and its causes are difficult to sort out. In the absence of more detailed and precise studies, the committee found that the available data could neither adequately explain the observed relation, nor unequivocally answer the question of whether disability benefits are a disincentive to work and rehabilitation.

#### CONCLUSIONS

It is clear that the task of determining eligibility for disability is generally difficult and that making such decisions on the basis of symptom complaints, such as pain, that are not fully substantiated by clinical findings is especially difficult. These difficulties derive from the inherent elusiveness of the concept of "disability," from deliberate ambiguities in the statutory definition, from the multiplicity of perspectives and goals at each level of review and appeal, from the limitations of medical science, and from the necessary and appropriate reliance on human judgment. Taken together, these elements of the decision-making process explain why there are inconsistencies and conflicts between and among the individuals and institutions charged with making disability determinations.

The committee believes that the goal should not be to eliminate the tensions and inconsistencies, because to a large extent these are evidence that an appropriate system of checks and balances is operating. Instead, the goal should be to ensure a decision-making process that is as accurate and fair as possible. Human judgment and subjectivity are inherent in that process and appropriate to determinations that require a combination of so many different kinds of information medical, psychosocial, functional, and vocational. However, even subjective determinations can be made more valid and reliable (see Chapter 11). Furthermore, although subjectivity is an easy target for criticism, as this analysis illustrates, it is only one of many contributory factors to the observed inconsistencies and strains in the system.

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## PART II THE EXTENT AND COST OF THE PROBLEM





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# 5 Economic Issues and the Cost of Disability

**E** conomic studies have contributed substantially to the understanding of many disability issues. However, there have been no systematic economic inquiries into the problem pain presents to disability systems. The reason is an absence of data because of the many conceptual and measurement problems mentioned in earlier chapters and discussed at length in the remainder of this volume. Although we can say little about the economics of *pain*, the committee thought it important to include some material on the economics of *disability* in order to understand the larger context of disability programs and the pain problem. This chapter summarizes current disability-related expenditures and recent trends, and presents an overview of some economic explanations for the observed growth of the Social Security Administration (SSA) disability programs. It is not possible to know what proportion of disability expenditures is attributable to pain claimants and beneficiaries.

The economic analysis of disability starts at the micro or individual level with the basic notion that disability (i.e., the inability to work or engage in one's accustomed role because of a medically definable impairment) causes losses to the individual and to the economy. In addition to monetary losses in earnings, losses in satisfaction and other aspects of well-being are also considered. Economic studies seek to understand how economic and other incentives motivate observed behaviors.

At the macro or economy-wide level, economists try to explain trends in disability expenditures (and in the prevalence of disability), and seek to identify cost-effective changes in the disability programs that

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would limit the prevalence of disability while maximizing efficiency and preserving equity and adequacy. Thus, in examining total disability expenditures, economists pose several questions. Given the distribution of these expenditures, for cash payments, medical care, and direct services, would some other distribution better meet social and programmatic objectives? Could the level of transfer payments and medical care costs be reduced by preventing disabilities in the first place or by rehabilitating disabled persons? Would some change in the incentives or disincentives that govern decision making improve the efficiency of the system? Are the levels of benefits high enough to provide an adequate replacement income for those who cannot work and not so high that they discourage people who can work from doing so?

## **DISABILITY EXPENDITURES**

Although the costs to disabled persons of their diminished well-being cannot be accurately measured, disability program expenditures can be estimated. There are many programs and policies to serve disabled workers. They differ in terms of their eligibility criteria, the extent to which the receipt of benefits is subject to a means test, the limits on the level of market earnings allowed for continuation of benefits, and the degree to which these benefits are taxable. As discussed in Chapter 2, these programs also differ in their philosophy toward the disabled, which, in turn, dictates the nature of their program response. Whereas some responses are "ameliorative," others are "corrective" (Haveman et al., 1984a,b). Among the ameliorative government programs are those that provide payments for income support and medical care. By contrast, corrective responses are designed to enhance the individual's ability to return to work and to reduce or remove the disabling effects of the individual's impairment. Training through vocational rehabilitation, sheltered workshops, programs for job accommodation, and employment subsidies may be provided.

## **Cash Transfers**

Cash (or transfer) payment programs can be divided into three categories: social and private insurance, indemnity, and income support. Social and private insurance programs maintain incomes of persons who have had their usual and regular earnings interrupted because they are work disabled. Social Security Disability Insurance (SSDI) is the largest government program targeted to the long-term

Program	Amount		
Social insurance (SSDI)	\$18.8		
Private insurance	18.0		
Indemnity payments (WC, VA, auto, other)	23.3		
Income support (SSI, VA, AFDC)	7.3		
Total	\$67.4		

TABLE 5-1Cash Disability Transfer Payments inFiscal Year 1982 (billions)

NOTE: AFDC = Aid to Families with Dependent Children; SSDI = Social Security Disability Insurance; SSI = Supplemental Security Income; VA = Veterans Administration; and WC = Workers' Compensation.

disabled population. In 1982, \$18.8 billion was paid out to beneficiaries and their dependents. Another almost \$18 billion was paid out by various private insurance programs, including individually purchased policies and group plans offered by employers.

The largest indemnity program is Workers' Compensation, which pays workers for injuries "arising out of and in the course of" employment (Berkowitz, 1985). These programs provide cash benefits, medical care, and rehabilitation services. In fiscal 1982 Workers' Compensation expenditures amounted to \$7.3 billion. Another indemnity-like government disability program is the Veterans Administration (VA) program, which accounted for \$6.1 billion. Disability transfer payments resulting from automotive-related bodily injuries accounted for \$4 billion, and indemnity transfers resulting from other bodily injuries amounted to another \$5.9 billion in fiscal 1982.

The third category of transfer payments are the income support programs for the disabled "needy" who are subject to a financial means test in order to qualify. These include SSA's Supplemental Security Income (SSI) program, needy and disabled veterans, and recipients of welfare payments from Aid to Families with Dependent Children who live in households headed by a disabled person. Total disability transfer payments are summarized in Table 5-1.

## **Medical Care**

Medical care costs associated with the various disability transfers totaled almost \$52 billion in 1982. The social insurance category includes only the Medicare program, which, since 1973, has covered SSDI recipients. In 1982, hospital and supplementary medical insur-

Program	Amount		
Social insurance (Medicare)	\$ 9.8		
Private insurance	24.0		
Indemnity (VA, WC, torts)	6.4		
Income support (Medicaid)	11.7		
Total	\$51.9		

TABLE 5-2Medical Care Payments for DisabledPersons in Fiscal Year 1982 (billions)

NOTE: VA = Veterans Administration; WC = Workers' Compensation.

ance payments by Medicare for SSDI beneficiaries (and persons in the special End Stage Renal Disease Program) totaled \$9.8 billion.

Estimating the proportion of total expenditures by private insurers attributable to medical care usage by disabled persons because of their disabling conditions is difficult. The best estimate is that private and employer-provided insurance paid \$24 billion in fiscal 1982 for disability-related medical expenses.

Indemnity medical payments from the veterans programs, federal and state workers' compensation programs, and tort settlements are estimated at \$6.4 billion. Medicaid accounted for nearly all the \$11.7 billion medical care expenditures to the disabled in the income support category. Total medical care costs are summarized in Table 5-2.

### **Direct Services**

Direct services provided to disabled persons include vocational rehabilitation provided by the states under a joint federal-state program and a separate vocational rehabilitation program for veterans; various other services for disabled veterans, including appropriately adapted vehicles, prosthetic appliances, and domiciliary care; and government services for the deaf, blind, mentally ill, and developmentally impaired. In addition to the direct services provided to the disabled only, under Title XX some disabled people are eligible for benefits from general federal programs that provide food stamps and social services. Finally, there are a number of employment assistance programs for handicapped federal government workers and others that are designed to return people to the labor market or encourage their initial entry. Table 5-3 summarizes expenditures for direct services to the disabled in FY 1982.

The estimate of \$3.0 billion for all direct services probably underes-

Program	Amount
Vocational rehabilitation and education	\$1.1
Veterans programs	0.4
Services for persons with specific impairments	0.1
General federal programs	1.1
Employment assistance programs	0.3
Total	\$3.0

TABLE 5-3Direct Services Expenditures for FiscalYear 1982 (billions)

timates the total because the costs associated with the many private sector accommodations for disabled employees and the expenditures of community groups are not included.

## **TRENDS IN EXPENDITURES**

Between 1970 and 1982, estimated total disability expenditures from all sources for members of the population age 18 to 64 years old more than doubled, from \$60.2 billion to \$121.5 billion in real 1982 dollars (see Table 5-4). These costs increased as transfer payments and medical care payments escalated. Between 1970 and 1978, the number of SSDI recipients nearly doubled, from 1.5 million to 2.9 million (Reno and Price, 1985).

Economists try to explain such patterns with statistical modeling techniques. Such modeling requires certain assumptions and simplifications that may not appropriately reflect all the circumstances of particular individuals or groups. For example, in exploring the relation between the rates of unemployment and disability, studies that use national or statewide figures may not reflect local employment circumstances. One of the primary economic assumptions is that people make rational choices in order to maximize their well-being. Although recognizing that income is only one aspect of well-being, economic models typically use income as a proxy for well-being because it can be counted and measured more easily than other factors like job satisfaction. The assumption that people behave rationally may not be true for all individuals, including people with pain symptoms.

Numerous possible explanations of these trend data can be set forth. One possibility is that a backlog of need is being met more appropriately in recent years than formerly—that is, a more realistic proportion of the disabled population is now seeking and receiving benefits. A contributory factor could be greater publicity about disability pro-

Year	Transfer Program Payments		Medical Care Payments		Costs of Direct Services		Total	
	Current dollars	1982 dollars	Current dollars	1982 dollars	Current dollars	1982 dollars	Current dollars	1982 dollars
1970	15,230	37,793	7,968	19,773	1,053	2,613	24,251	60,179
1975	31,470	56,341	16,158	28,928	2,308	4,132	49,936	89,402
1976	35,533	60,146	19,547	33,087	2,554	4,323	57,634	97,555
1977	41,411	65,847	22,821	36,287	2,887	4,591	67,119	106,725
1978	45,700	67,532	27,353	40,420	2,877	4,251	75,930	112,204
1979	52,188	69,184	31,651	41,959	3,344	4,433	87,183	115,577
1980	58,335	68,160	36,399	42,529	3,395	3,967	98,129	114,656
1981	64,068	67,903	44,051	46,688	3,415	3,619	111,534	118,210
1982	67,377	67,377	51,197	51,1 <b>97</b>	2,950	2,950	121,524	121,524

TABLE 5-4Total Disability Expenditures, from all Sources for thePopulation Ages 18–64, 1970–1982 (millions)

SOURCE: Berkowitz, Monroe, 1985, Disability Expenditures, 1970-1982, Tables 7, 9, and 11.

grams, including more active social work and legal advice. Additionally, both the absolute and relative number of people who are medically impaired, and hence eligible for disability benefits, may be rising sharply. Although the population is aging, the elderly (who are most likely to be work disabled by virture of a medical impairment) are not covered by SSDI. Nonetheless, this demographic trend may account for some of the increase in the 55- to 64-year-old group, but it is not sufficient to account for the magnitude of the overall increase. Furthermore, it is impossible to account for such a rapid rise in expenditures on medical grounds alone. No epidemic swept the country during those years leaving in its wake vast numbers of disabled persons. To explain changes of such magnitude requires an understanding of disability as a complex socioeconomic phenomenon.

One such explanation for the rapid increase in expenditures is that the number of people who identify themselves as disabled fluctuates with changing economic conditions. Several types of evidence support this view. As discussed in Chapter 4, various features of the labor market and the disability programs influence rates of disability and hence expenditures. In the United States the disability program is not used explicitly to counteract unemployment, but the labor market appears to influence application rates. Even if the disability program were administered in exactly the same way over the period of a business cycle, economists would expect the number of applicants to vary in accordance with changing economic activity, especially local unemployment rates (Lando, 1979).

The ratio of benefits to anticipated earnings also appears to influence people's decisions to seek disability benefits. Economic studies use regression analyses to estimate the relative contribution of different factors (e.g., age structure of the population, unemployment rate, and disability benefit levels) to rates of application to the Social Security disability insurance programs. The most sophisticated of these studies use some measure of the relative value of disability benefits compared with earnings to determine the effects of disability benefits on labor force participation. A common measure in recent studies is the replacement rate, the ratio of average disability award to average wage. Estimates of the elasticity of the labor supply for every 10 percent increase in disability benefits range from -0.3 percent (Parsons, 1980a,b) to -0.0003 percent (Haveman and Wolfe, 1983). (This means that for every 10 percent increase in the replacement rate, aggregate labor supply drops by 0.3 percent or 0.0003 percent.) In general, later studies have found smaller effects of disability benefits on labor supply.

In addition to economic influences, the increased use of medical screening by employers may contribute to the increase in disability applications. Employers use medical screening both to reduce their future costs (e.g., health insurance and disability payments) and to increase the safety of the work environment by taking employee health into account in job placement and hiring. Such screening results in the exclusion of some individuals who are able to work, but who are perceived as being "high-risk" workers by potential employers (Stone, 1987). An examination of the characteristics of the disabled population, which elucidates some of these hypotheses, follows.

## **Disabled Persons**

### A Note About Measurement

Information about the prevalence of disability is available from a variety of sources, including the U.S. Department of Labor, the SSA, other disability programs, and special surveys of samples of the general population (Haber, 1984). Although the definition of disability generally includes the inability to work, the specific definition used in each data set varies considerably. Each program has its own definition of disability, usually linking it to a medical impairment, which is variously defined. Surveys that ask respondents whether they are limited in the amount or kind of work they can do because of a health
condition are subject to individual interpretation. Moreover, that kind of question may provide a very different estimate of the number of disabled people than the actual number known to have withdrawn from the labor force—which may, in turn, be significantly different from the number of people receiving disability benefits. Long- and short-term disability are not always distinguished. Among older workers it may be impossible to distinguish disability withdrawals from the labor force and withdrawals for other reasons.

For all of these reasons, the number of disabled people cannot be estimated precisely. The best we can do is to calculate the number using the sources most appropriate to the particular question of interest—that is, the number of people receiving benefits, the number who consider themselves disabled, or the number who have stopped working because of a medical condition. These same kinds of definitional and measurement problems hinder our ability to count the number of pain-disabled people with precision (see Chapter 6).

#### Number and Characteristics of the Disabled

Estimates of the proportion of disabled people in the noninstitutionalized population from 18- to 64-years old range from 4.4 percent to 8.9 percent. The best estimate of the number of severely disabled people (defined as those not working or not working regularly) is 5.8 percent based on the 1978 Social Security Survey (Haber, 1984). This is more than 8 million people. Work disability increases systematically with age. Controlling for age, work disability decreases with education. Generally, blacks are more likely to be work disabled than whites, with black women more likely to be disabled than black men; among whites, men are more likely to be disabled than women.

That the prevalence of disability increases with age is neither surprising nor troubling. Both morbidity and the prevalence of potentially disabling conditions (e.g., visual and hearing impairments, circulatory and respiratory conditions) increase with age. The relation between education and disability is another matter. It is likely that those with less schooling work in jobs that involve greater risk of occupational injury or illness. Furthermore, these jobs are likely to require more physical exertion. The same condition that may force a manual laborer to withdraw from the labor force may be only an inconvenience to an office worker. Finally, individuals with less education may face more restricted occupational choices than those with more education.

#### **Benefit Levels and Beneficiaries**

The number of beneficiaries appears to be positively related to the level of benefits in a number of ways. As discussed in Chapter 4, the level of benefits is believed to provide an incentive for people to claim disability if that level is higher than expected earnings (Addison, 1981; Painter, 1980). In 1982, monthly SSDI benefits averaged \$413 for all disabled workers and \$812 for workers with families (Reno and Price. 1985). Nearly one-fourth of the newly disabled workers were receiving more in SSDI benefits than they had earned while working (Lando et al., 1979, 1982). Observers agree that as benefit levels increase, the number of people in the labor force decreases, although they disagree on the magnitude of the relation (Leonard, 1979; Parsons, 1980a,b; Slade, 1984; Haveman and Wolfe, 1983). Furthermore, in addition to cash benefits, the disabled are eligible for medical benefits. Although a disabled person may be persuaded to give up a monthly disability check for labor market earnings, he or she may be more cautious about relinquishing Medicare eligibility if faced with an unknown future medical liability.

Treitel (1979) and Berkowitz et al. (1976) found that as the benefits to income replacement ratio increased, the likelihood that a recipient of SSDI benefits would leave the disability rolls declined. Economists also assert that the decision to apply for benefits is influenced more by the *level* of benefits than by the probability of *acceptance* into the program (Halpern and Hausman, 1984).

In any society there are individuals on the margins; whether they persist in attempting to work or seek release depends to some extent on the mix of incentives and disincentives. As noted in Chapter 4, most people who report being disabled do continue to work. Some of these people might meet the disability eligibility criteria, but for various reasons do not apply for benefits even if working is difficult. Were this situation to change, perhaps because of deterioration in health or job skills as they grow older or because of some shift in the business cycle, these people might be more likely to apply. Economic incentives clearly affect application rates, but they are not the only influence. Features of the disability program also are important to consider.

#### **Program Influences**

The rapid growth in the number of SSDI beneficiaries between 1970 and 1978 is probably due in part to some administrative changes in the program. These changes included more lenient application of eligibility criteria, cutbacks in federal reviews of the state agencies that administer the SSDI program, and a reduction in the number of continuing eligibility reviews (Weaver, 1986). The growth led to congressional action to step up continuing reviews, which resulted in many people being taken off the rolls, which in turn led to substantial public pressure and the subsequent reinstatement of benefits to many.

The problems remain. The federal disability program is still criticized for denying benefits to some people who really need them, while allowing others on the rolls who are capable of working. As discussed in the previous chapter, because disability is a judgment, some errors are inevitable. The extent of such errors in the system as a whole is unknown. Furthermore, given the present size and complexity of the Social Security program, one would not want to recommend major changes in the system without being fairly certain that such changes would lead to significant improvement at acceptable costs.

#### **Program Efficiency**

Efficiency refers to meeting particular defined objectives at the lowest possible cost. Assuming there were a method for ascertaining the correctness of the decisions in light of the operational criteria, the efficient solution would be one that, with a given amount of funds, maximized the number of correct decisions and minimized the number of incorrect decisions. The efficiency test becomes more complicated if we assume that certain errors are worse than others and seek to eliminate egregious errors, such as denying benefits to the older, uneducated paraplegic, while perhaps tolerating marginal errors, such as denying benefits to the middle-class, educated applicant with low back pain.

As discussed in earlier chapters, the sheer size of the work load faced by the Social Security disability program boggles the imagination. It would be extremely inefficient to require a thorough examination and evaluation of each applicant for disability benefits. The program necessarily operates by using administratively feasible tests that are proxies for the existence of "disability." The less rigorous the criteria, the greater the pool of potential applicants and the greater the ratio of allowances to denials. Almost 4 percent of the program costs are spent on administration. The administration of the program is expensive, not only because of its size but also because of the complexity of its administrative structure and eligibility rules. In 1977, the average cost of processing a case was \$105; in 1985 the average cost was \$342. The cost of processing cases has been growing in both absolute terms and as a percentage of contributions to the trust fund from which disability payments are made.

#### PREVENTING DISABILITY BY REALLOCATING FUNDS

It is often alleged that if more money were spent on prevention we would not have to spend as much on disability payments. Indeed, the usual and historical rationale for public support of rehabilitation services is that they are a good investment. The present value of an \$800 per month SSDI award to a 25-year-old beneficiary with a family is estimated at \$188,000. If at least some of this amount could be saved by providing rehabilitation services, such expenditures would be worthwhile.

In fact, each of the benefit programs uses rehabilitation to some extent, but expenditures for direct services, including rehabilitation, appear to be decreasing relative to cash transfers and medical care expenditures. It is estimated that 4.2 percent of all disability expenditures in 1970 were for direct services of all kinds. By 1982, the amount spent for direct services was an even smaller proportion of the total disability dollar. Largely because of the rapid increases in medical care payments, the proportion of total disability expenditures allocated to direct services had shrunk to 2.4 percent.

Not enough is known about prevention and rehabilitation to warrant making major changes in the distribution of disability expenditures at this time. As discussed in later chapters in this volume, this lack of knowledge is especially apparent in the area of preventing and rehabilitating people with chronic pain. We do not know how to identify people early who are likely to develop chronic disabling problems, and we know little about the efficacy of specific interventions in preventing functional impairment or restoring function. Thus, although in theory it would seem worthwhile to spend on a case until the marginal dollar expended on rehabilitation equaled a dollar in benefits, at this point in time we lack sufficient knowledge to do this efficiently. We do not know which individuals will improve and which will not. Furthermore, from a cost-benefit standpoint, just as we could spend too little on rehabilitation, we could also spend too much. The experiences in the Workers' Compensation jurisdictions of California, where costs soared after the introduction of compulsory rehabilitation, and Washington state, where the rehabilitation statute was amended to cut down on services because of high costs, illustrate some of the problems involved with increasing rehabilitation efforts (Berkowitz, 1986).

Prevention requires a good deal more information than simply knowing how much it is rational to spend. Both clinical and economic

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analyses are needed. What types of interventions yield what types of benefits? Do employers have sufficient incentives to prevent the worker on a short-term sickness benefit program from moving onto the long-term rolls and eventually to the Social Security disability system? If early intervention is indicated to prevent long-term disability, is it possible to identify potential candidates in a cost-efficient manner?

#### THE ECONOMICS OF PAIN: GAPS IN THE LITERATURE

As mentioned previously, there appear to have been no systematic economic inquiries into the pain issue. Given additional resources for data collection, would it be possible to collect reliable data that could aid in some cost estimates or help isolate the pain phenomenon in the disability eligibility determination process? In most benefit programs, pain itself is not taken into consideration. It may be a component in any one of a number of preliminary stages of eligibility determination, be it the classification of the medical condition or as contributory to the impairment or the nature and extent of functional limitation. The problem for the SSA is not with pain in general or with pain associated with well-documented anatomical abnormalities or disease processes. It is pain and its associated functional limitations that are not fully explained by clinical findings. This complicates data collection activities substantially.

In terms of the costs associated with chronic pain, a few speculative observations can be offered. First, people with chronic pain of uncertain origin are known to be heavy users of health care services (see Chapters 8 and 10). Thus, their medical care costs are likely to be relatively high compared with those of people with some other conditions. Second, the costs associated with the assessment of claimants with pain and other symptom complaints that cannot be readily explained are likely to be higher than for claimants with obvious medical conditions. Administrative costs of consultative examinations and tests, as well as appeals through the system, contribute to the high costs of processing these claims. Finally, given the elasticity in the system associated with changing economic and political conditions, allowance rates for symptom complaints such as chronic pain may vary more than for more clear-cut impairments.

#### CONCLUSIONS

Examination of the basic trends in disability, be they the fluctuations of cash benefits over time or the distribution of disabled persons by age or educational level, leads to the conclusion that disability cannot be understood solely as a medical phenomenon. Economic conditions, individuals' options and motivations, and program features such as the level of benefits all exert an influence on the number of disabled people. No matter what the eligibility criteria, it is likely that a number of people in the population could qualify, but for various reasons they do not apply; it is also likely that some people who deserve benefits apply and are found ineligible.

The purpose of the Social Security disability system is to pay a portion of predisability wages as an income maintenance benefit to those who are "truly" disabled. Yet there is no one truly disabled state; each program chooses its eligibility criteria in light of the program's purposes, and designs a determination process to fit within its time and income restraints. Pain is an especially challenging problem, because the more subjective the complaint, the more expensive it becomes to establish its relation to the inability to work. The field is ripe for controlled experiments and demonstrations that could provide information about efficiently and fairly evaluating claimants, selecting potential beneficiaries for preventive efforts, and determining the mix of services that can equitably and efficiently encourage return to substantial gainful activity.

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## **6** The Epidemiology of Chronic Pain and Work Disability

This chapter examines the frequency and distribution of chronic pain in the population and its relation to work disability and medical care utilization. The epidemiological literature on chronic pain, like that in some other disciplines, suffers from a lack of consensus about basic definitions and from inconsistencies in measurement which make it difficult to compare studies and to generate precise numbers. Keeping in mind that among the claimants who are most troublesome for the disability insurers are those who have pain and associated impairment that cannot fully be accounted for by clinical findings, there are several pieces of epidemiological data that would be useful. What are the numbers and characteristics of people with:

• chronic pain (and what kinds of pain do they have)?

• chronic pain not correlated with objective clinical findings?

• severe chronic pain with important dysfunction and impairment? and

• of those with any of the three abovementioned conditions, how many apply for Social Security Administration (SSA) disability benefits, how many get them, and what are their characteristics?

Such data would allow estimates of the size of the population at risk, and hence provide a basis for estimating the costs associated with any proposed changes in the way pain is handled by the SSA.

Although there are no complete answers to the abovementioned questions, studies carried out after 1970 in working age populations in

the United States and other countries provide some useful information. Studies of pain occurrence in populations, in groups of patients, and in groups of workers form the basis for the estimates in this chapter. Seventeen pertinent studies from the United States, Canada, and Western Europe were located, 15 of which examined low back pain alone, the most common chronic pain. These studies are summarized in Table 6-1.

#### **METHODOLOGICAL ISSUES**

Variations in operational definitions of chronic pain, measures of its severity, sampling frameworks, data collection techniques, and survey response rates make comparisons between epidemiological surveys difficult.

#### **Definitions and Measures of Chronic Pain**

The many inconsistent definitions of pain, chronic pain, and severity of pain used in epidemiological surveys reflect the uncertainty about pain and its nature discussed throughout this volume. Pain was defined by the patient's perception or recognition in all of the studies reviewed in this chapter. People reported verbally whether or not they "had" pain. This is consistent with the notion that pain is a subjective phenomenon, most accurately measured by the verbal communications or nonverbal behaviors of the individual in pain.

Most of the studies reviewed here attempted to obtain measures of pain occurring during the whole previous year, and some even reported the prevalence of pain during the entire lifetime. The majority of these papers neglect to mention that such recalled historical information may greatly distort estimates of pain occurrence. One obstacle to measurement that is basic to the nature of pain is the completeness with which pain is often forgotten once it is over. Whereas current pain may be measurable with some validity, the threshold of recall of previous pain probably varies with the recentness of the episode, the severity of the symptom when it was present, associated events such as surgery, and the persistence of the probing questions in the interviewing process (Bierring-Sorensen, 1982).

There is no agreed-upon operational definition of chronic pain in the studies reviewed. Terms such as "frequent" (Reisbord and Greenland, 1985) or "serious" (Enquete Santé Canada, 1981) pain are poor proxies for chronicity. Such definitions are likely to have low reliability because individuals will vary in their concepts of these terms. In the Nuprin Pain Report (Louis Harris, 1985) respondents were asked to report roughly how many days during the previous 12 months they had different kinds of pain. (Data are given for 1–5 days, 6–10 days, 11–30 days, 31–100 days, and >100 days.) From these data chronic pain could be arbitrarily defined as pain on more than 30 days or more than 100 days. The frequency of work disability due to pain may be estimated from the Nuprin study from the reported number of days during the previous 12 months respondents had such severe pains that they "could not work or engage in routine activities."

Different aspects of pain and disability were measured in the various surveys. The two national health surveys (Drury, 1984; Enquete Santé Canada, 1981) asked respondents whether they had a number of specific conditions usually associated with pain, among them impairment of the back or spine. The Nuprin Pain Report, on the other hand, although not as rigorous as the National Health Surveys in its survey methods, contains a considerable amount of information on the frequency of pains of different kinds (Louis Harris, 1985).

#### **Study Samples**

Data in the studies reviewed here are drawn from samples of national populations, communities, patients, and workers. Results from these four types of samples are not strictly comparable because the category "workers" does not include some people who already are disabled and out of the labor force, the category "patients" exclude those who do not go to doctors, and people in particular geographic communities may have relevant attributes not found in other places.

#### **Methods of Data Collection**

All 17 surveys were cross-sectional in nature. Data were collected by several means. The American and Canadian national surveys were done by interviewing respondents in their homes (Drury, 1984; Enquete Santé Canada, 1981). Information was obtained by telephone interviews in the Nuprin study (Louis Harris, 1985). These kinds of surveys are likely to lead to underreporting (Kelsey et al., 1979).

Among the regional studies, pain data were obtained from surveys conducted for other purposes in Columbus and Dayton, Ohio (Nagi et al., 1973; Reisbord and Greenland, 1985) and from interviews and actual physical examinations in Glostrup, Denmark (Bierring-Sorensen, 1982), Göteborg, Sweden (Svensson and Andersson, 1982; Svensson, 1982), and Zoetermeer, the Netherlands (Valkenburg and

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	Frequency (%)	6.9		1.3		2.6	0.6		11.8		13.9	13.8	13.3	9.9	4.0			3.7	1.9	2.0
	Measure of Frequency	Prevalence/year	Prevalence/year of back impairment with ≥1 day in	bed Prevalence/vear of hack	impairment with $\geq$ one visit	to the doctor Annual incidence of new back	impairments	Point prevalence: data are only available combined with serious limb and joint	conditions	Prevalence/year for people 18– 65 years old having pain >30 davs/year	Backaches	Joint pain	Headaches	Muscle pains	Stomach pains	Premenstrual or menstrual	pain (percentage of	women)	Dental pain	Other types of pain
Back Pain	Definition of Pain	Diagnostic condition usually	associated with pain; impairment of back or	spine				Present serious condition with back or spine		No. of days in pain during previous year										
s of Pain and Low ]	Method of Data Collection	Home interview;	participation rate not reported					Home interview; participation rate about 85%		Telephone survey; participation rate not stated										
TABLE 6-1 Recent Survey	Jample	NATTONAL SAMPLES 1. National Health Interview	Survey. Sample of U.S. vopulation, 1979–1981. Rates	are given for all persons >18 years old (Dmiry, 1984)				<ol> <li>Canada Health Survey.</li> <li>Sample of 31,668 Canadians, 1978–1979. Rates are given for</li> </ol>	all persons 15–64 years old Enquete Santé Canada, 1981)	3. Nuprin Pain Report, onducted by Louis Harris, 1985. Samule of 1 254	Americans >18 years old	Louis Harris and Associates,	1985)							

					14.2	10.5	15.4	8.9	8.4		7.4	3.6	ļ		17.9		4.2			2.6	17.9					
Prevalence of inability to work	or engage in routine	activities ≥1 day/year due to	pain (including people >65	years old):	Backaches	Joint pain	Headaches	Muscle pains	Stomach pains	Premenstrual or menstrual	pain	Dental pain	Other pain		Prevalence	Prevalence with back pain and	moderate work limitations	Prevalence with back pain and severe work limitations	(unable to work for health	reasons)	Prevalence/year					
															Often bothered by pain in	the back					Frequent back pain during	previous year				
															Home interview; data	collected for	disability survey;	participation rate not stated			Method not stated;	data collected for	health insurance	reasons;	participation rate	not stated
														<b>REGIONAL SAMPLES</b>	1. Sample of 1,136 persons in	Columbus, Ohio, 18-64 years	old, about 1970 (Nagi et al.,	1973)			2. Sample of 2,792 persons in	Dayton, Ohio, >18 years old,	undersampling of group >65	years old, 1973 (Reisbord and	Greenland, 1985)	

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TABLE 6-1 (Continued)				
Sample	Method of Data Collection	Definition of Pain	Measure of Frequency	Frequency (%)
<ol> <li>Census of 928 persons 30, 40, 50, and 60 years old in Glostrup Municipally near Copenhagen, 1977 (Bierring-</li> </ol>	Physical exam, questionnaire, and follow-up questionnaire 1	Having pain or trouble with lower back	Lifetime incidence Prevalence/year Point prevalence Incidence/year of new cases	62.0 44.9 6.3
Sorensen, 1982)	year later; participation rate 82%		Incidence of new cases in those not having had problems in earlier life	16.5
<ol> <li>Sample of 940 men 40-47</li> <li>years old in Göteborg, Sweden, 1978 (Svensson, 1982: Svensson</li> </ol>	Physical exam, questionnaire, interview:	Having low back pain	Lifetime incidence Point prevalence "Present" incidence of new	61.0 31.4
and Andersson, 1982, 1983)	participation rate 76%; further data obtained from		cases Prevalence with back pain- caused moderate (occasional)	2.1
	register of Public Health Insurance Office		interference with work Prevalence with back pain- caused severe interference	13.9
			with work Prevalence with back pain- caused disablement for work	4.2 3.6
<ol> <li>Sample of 6,584 people</li> <li>≥20 years old in Zoetermeer, the Netherlands, 1975–1978</li> </ol>	Physical exam, questionnaire; participation rate	Low back pain ever	Lifetime incidence Men Women	51.1 57.8
(Valkenburg and Haanen, 1982)	78%	Low back pain now	Point prevalence Men Women	22.2 30.2
		Ever unfit for work due to low back nain	Men Women	24.3 19.5
		Ever changed jobs due to low back pain	Men Women	4.2

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PATIENT SAMPLES				
1. National Ambulatory	Record forms	Visit for back symptoms	Percentage of visits to	
Medical Care Survey USA, 1977–1978. Patients of 6,007	completed by physicians		physician for back symptoms	2.8"
physicians in the American				
Medical Assoc. and American Osteonathic Assoc (98 355				
visits) (Cypress, 1983)				
2. National Ambulatory	Record forms	Visit for back symptoms	Percentage of visits for back	
Medical Care Survey, 1981	completed by	1	symptoms	1.8
(NCHS, 1983)	physicians			
3. National Ambulatory	Record forms	Visit for new pain	Percentage of visits for new	
Medical Care Survey, 1980-	completed by		pain	6.1
1981 (NCHS, 1984)	physicians		Percentage of visits for new	
	•		back pain	0.9
4. Sample of 1,221 male	Mail questionnaire;	Ever experienced low back	Lifetime incidence of moderate	
patients 18–55 years old seen	response rate 67%	pain	pain	46.3
in family practice facility in			Lifetime incidence of severe	
Burlington, Vermont, 1975–			pain	23.6
1978 (Frymoyer et al., 1983)			1	
5. 827 patients $>18$ years	Telephone survey,	Often troubled by any pain	Prevalence of any pain	16
old seen in group family	then interview;	<b>Experienced</b> noteworthy	Incidence/2 weeks of new pain	
practice in Burlington, Ontario,	participation rate	pain in last 2 weeks	(not often troubled by pain)	5
E 1115 notionto attending	Comment of anticols.	Defined attending Dain	Documents of motion to with low	
o. 1,110 patients attended Oxford Regional Pain Relief	maintained records	rauenu auenum ram Relief Unit	rercentage of partents with 10w back pain	$26.2^{b}$
Unit, 1982 (McQuay, 1985)				

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TABLE U-1 (COMMUNUM)				
Sample	Method of Data Collection	Definition of Pain	Measure of Frequency	Frequency (%)
WORKER SAMPLES 1. 12,125 coal miners in South Yorkshire, 1976–1977 (Afacan, 1982)	Medical record survey	Absence from work due to back lesion for at least one spell (average duration of absence spell = 21.2 days)	Prevalence/year	14.8
2. 38,250,100 workers in 26 states belonging to the Bureau of Labor Statistics' Supplementary Data System, 1979 (Klein et al. 1984)	Survey of records of Workers' Compensation claims	Workers' Compensation claim due to strains/ sprains of the back (16.7% of all claims)	Prevalence/year	0.75
3. Quebec workers, 1981 (Spitzer and Task Force, 1986)	Survey of Workmen's Compensation claims	Workmen's Compensation claim due to back pain with at least 1 day's absence from work (16.6% of claims)	Incidence/year	1.4 <sup>c</sup>
<sup>a</sup> Second leading symptomatic	reason for visit.			

TABLE 6-1 (Continued)

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b Most common condition.
 <sup>c</sup> 0.5% frequency in women, 1.9% in men.

Haanen, 1982). The Glostrup study is unique in that all of the subjects were followed up by questionnaires a year later. The Göteborg study is also noteworthy, because it compared respondents with nonrespondents using the register of the Public Health Insurance Office. More nonrespondents (59 percent) than respondents (49 percent) were found to have been off work during the preceding 3 years. A sizeable proportion of respondents, moreover, had been "sicklisted" for low back pain when they said that they had not been (27 percent). The authors concluded that low back pain incidence and prevalence rates are underestimated when they are based on interview findings.

#### PAIN AND ITS CONSEQUENCES

Some information can be gleaned from the epidemiological studies about the kinds of pain people experience, the incidence and prevalence of pain and its associated outcomes, and the frequency of health services utilization for pain complaints.

#### What Kinds of Chronic Pain Do People Have?

Information about what kinds of pain people have is found primarily in the Nuprin Pain Report and in one Canadian study (Crook et al., 1984). Most of the other studies are restricted to back pain. The common types of pain are headache, backache, muscle pain, joint pain, stomach pain, premenstrual or menstrual pain, and dental pain. The Nuprin study classified only 2 percent of people as having other types of pains. Chronic pain was arbitrarily defined as having pain for more than 30 days during the year. Table 6-1 shows that back pain, joint pain, and headache each occurred in about 1 in 7 people (13–14 percent), whereas chronic muscle pain occurred in 1 in 10 people, and other types of chronic pain occurred in less than 1 in 20 people (2–4 percent).

Findings from the Burlington, Ontario, patient survey are in agreement (Crook et al., 1984). Chronic pain was defined as "persistent" pain and was categorized by body area. In terms of occurrence, back pain ranked first, lower extremity pain second, and head or face pain third. Eighty-three percent of people reporting persistent pain said they had had the pain longer than a year.

One of the critical questions about back pain is what proportion of people with it go on to chronicity and work disability. The Quebec Task Force (Spitzer and Task Force, 1986) reviewed the records of 3,000 workers in Quebec (a random sample of the entire 1981 cohort of 58,000 cases of "disorders of the vertebral column") who reported an

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incident of occupational back problems. This was done in order to see what happened to these people over the next 4 years. Within 1 month, 74 percent of the sample was back at work and used no further medical care for their back problems. Between the 2nd and 5th months after the onset of back pain, an additional 19 percent returned to work. Most important, only 7.4 percent of the patients were disabled for more than 6 months; but this small group of chronic pain patients accounted for 70 percent of lost work days in 1981, for 73 percent of medical care costs, and for 76 percent of compensation payments made to beneficiaries who had problems associated with the vertebral column.

#### **Incidence and Prevalence of Relevant Outcomes\***

An estimated 10–15 percent of adults have some work disability due to back pain in any given year. The leading causes of disability in people in their working years are musculoskeletal conditions such as low back pain, joint pain, arthritis, and rheumatism (Kelsey et al., 1979; U.S. Department of Health and Human Services, 1980). Swedish National Health Insurance data show that between 9 and 19.5 percent of all sickness-absence days from work are associated with back complaints (Svensson and Andersson, 1982; Svensson, 1982). This percentage is unquestionably higher than for any other class of health problems and is unlikely to be explained by methodological inconsistencies or shortcomings. Almost 17 percent of workers' compensation claims in the United States and in Quebec are due to back problems (Klein et al., 1984; Spitzer and Task Force, 1986).

The authors of the Nuprin Pain Report projected the number of days lost from work or usual occupation to the total U.S. adult population (including those more than 65 years of age, which inflates the figures somewhat). Back pain ranked first at 1.3 billion person-days lost, joint pain was second at 1.0 billion person-days lost, and headache was third at 0.6 billion person-days lost.

The incidence of new back pain was measured in three surveys. A relatively low annual incidence rate (0.6 percent) is reported in the National Health Interview Study (Drury, 1984). The present incidence of new back pain was found to be 2.1 percent in the Göteborg survey (Svensson and Andersson, 1982; Svensson, 1982). The annual inci-

<sup>\*</sup>Incidence refers to the number of new cases of a disease or condition occurring in the population during a specified period of time. Prevalence refers to the total number of cases of the condition present in the population at a particular time.

dence of new back pain was reported to be 6.3 percent in the Glostrup survey (Bierring-Sorensen, 1982). The validity of incidence rates derived from cross-sectional surveys is questionable. We have no information about work disability caused by new back pain.

Estimates of annual prevalence rates for work disability caused by back pain were reported in several surveys (Svensson and Andersson, 1982; Svensson, 1982; Drury, 1984; Louis Harris, 1985; Nagi et al., 1973). Work disability attests to a certain degree of pain severity. Furthermore, because absence from work is an objectively verifiable behavior rather than a subjectively remembered sensation, it is a reasonably reliable proxy for other outcomes of interest and complements them. Unfortunately, most of the surveys use "one or more bed days" or self-reports of the number of days per year respondents were unable to work or engage in routine activities as proxies for calculating the prevalence of work disability. Neither measure adequately describes a chronic problem and both are subject to problems of recall.

The National Health Interview Survey of the adult U.S. population reported a 1.3 percent annual prevalence of back impairment with one or more days in bed (Drury, 1984). This value is considerably lower than the 14.2 percent of Americans "unable to work or engage in routine activities one or more days per year" given in the Nuprin report (Louis Harris, 1985). The Columbus, Ohio, survey (Nagi et al., 1973) reported that 2.6 percent of people had severe work limitations linked to back pain and a further 4.2 percent reported moderate work limitations.

Both the National Health and the Columbus surveys, however, were conducted for many purposes. Their estimates could be low because of respondents' recall failure when attention was not focused on back pain. Data from the 1978 Göteborg survey, on the other hand, were collected expressly for the purpose of investigating back pain; they yield high estimates of back pain prevalence. "Moderate" interference with work associated with back pain occurred in 13.9 percent of the sample and "severe" interference or "complete disablement" occurred in another 7.8 percent (Svensson and Andersson, 1982; Svensson, 1982).

#### **Back Pain and Medical Care**

As discussed elsewhere in this report, some people have considerable pain in the absence of clinical findings accounting for it, whereas others have clear anatomical abnormalities without pain. This discrepancy between objective abnormalities and existing complaints is shown

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clearly in two studies. In one study, disc herniation and vertebral fracture accounted for only 3 percent of sickness absence episodes for back pain (Svensson and Andersson, 1982; Svensson, 1982). A considerable number of people in another survey had radiological abnormalities of the spine but no complaints of pain (Valkenburg and Haanen, 1982). Disc degeneration and rigid lumbar segments normally occur with aging, but the reported relation of back pain with age is inconsistent. Mechanic and Angel (in press) report that although clinical findings increase with age, the relation between age and self-reported pain, controlling for clinical findings, decreases with age. This suggests that pain may be expected, more acceptable, and hence less noteworthy in the context of aging. (See Chapter 8 for a discussion of psychosocial influences on the perception of symptoms and illness behavior.)

The magnitude of the back pain problem compared with other illnesses is highlighted by the National Medical Surveys (Cypress, 1983; National Center for Health Statistics, 1983, 1984). Pain and back pain are among the leading symptomatic reasons for visits to physicians. In 1977–1978 and 1980, 2.8 percent and 1.8 percent of visits, respectively, were for back symptoms. In 1980–1981, 6.1 percent of physician visits—70 million—were attributed to new pain, of which 10 million were for new back pain. Low back pain was the chief reason for visits to the Oxford Regional Pain Relief Unit in 1982 (Frymoyer et al., 1983). Although 30 percent of people with more than occasional backache (>5 days per year) did not consult a doctor for their pain, 41 percent saw one or two doctors, and 29 percent saw three or more doctors (Louis Harris, 1985).

#### **Descriptive Epidemiology of Chronic Pain and Disability**

#### Trends in Time

There appears to be an increase on the relative frequency of back pain-caused work disability over time. In England, a 22 percent increase in the number of episodes of back trouble and a 30 percent increase in their duration was noted between 1961 and 1967 (Wood, 1970). In Quebec, physiotherapy treatments have increased dramatically; about 40 percent of these treatments are for conditions affecting the spinal column (Spitzer and Task Force, 1986). In the United States, disability as reported in the National Health Interview Surveys increased substantially from 1966 to 1976, and musculoskeletal disorders were responsible for a considerable portion of this increase (Colvez and Blanchet, 1981).

#### Demographic Factors, Pain, and Work Disability

The incidence of new low back trouble was highest in relatively young adults in the Glostrup survey, the sole source of age- and sexspecific incidence rates in a general population. Eleven percent of 30year-olds developed new back trouble in the course of a year. In comparison, only 3-6 percent of men and women 40, 50, and 60 years old developed new back pain. This difference remained when incidence rates were calculated excluding those who had had back pain earlier in life.

In the two studies in Ohio, age-specific prevalence rates of back pain were 30-70 percent higher in people aged 35-64 years than in those aged 18-34 years (Nagi et al., 1973; Reisbord and Greenland, 1985). Back pain and chronic joint pain for more than 30 days per year was highest in the 50- to 64-year-old respondents in the Nuprin Pain Survey. This increasing prevalence of back pain with age was found only in women, however, in the Glostrup and Zoetermeer surveys. Combining all age groups, women appear to have a slightly higher prevalence of back pain than men (Louis Harris, 1985; Nagi et al., 1973; Reisbord and Greenland, 1985).

Age- and sex-specific rates of disablement for work associated with back pain are also given by the survey of workmen's compensation claims in Quebec (Spitzer and Task Force, 1986). Although not representative of the general population, demographic data on workers is pertinent to the question of who claims Social Security disability benefits. Claiming compensation for at least 1 day's absence from work for back pain during 1981 in all age groups in Quebec were 0.5 percent of women workers and 1.9 percent of men. Although three times more claims were made by men than by women overall, in the 45- to 64-year-old age group, women made almost as many claims as men. The majority of claims were made by men and women younger than 45 years of age (82 percent). A sizeable proportion (28 percent) were submitted by people under 25 years old.

In summary, most people have back pain at some time in their lives. Young adults have the highest incidence of new back pain. Older women, on the other hand, have the highest prevalence of chronic back pain and of chronic joint pain. Few data are available on the frequency of work disability related to pain, but it appears from the Quebec data that compensation for at least 1 day's absence from work for back pain is claimed by men more than by women, and mostly by people who are quite young.

Data on the rate of occurrence of back pain by race are given in three U.S. surveys (Louis Harris, 1985; Nagi et al., 1973; Reisbord and

Greenland, 1985). Striking differences are not indicated by any of the data, although blacks in the Nuprin study had less chronic back pain than whites and somewhat less chronic joint pain. No information is available on pain-caused work disability by race.

Marital status was associated with recurring back pain in two American studies (Nagi et al., 1973; Reisbord and Greenland, 1985) but was not related to the occurrence of back pain in the Swedish study (Svensson and Andersson, 1982; Svensson, 1982). In both the Columbus and Dayton surveys 18 percent of married people had frequent back pain, whereas higher rates were found in separated, widowed, and divorced people (24–30 percent in Columbus, 25–37 percent in Dayton) and lower rates occurred in never-married people (9 percent in Columbus, 11 percent in Dayton). Marital status was not reported in the Nuprin study.

#### **Physical Factors**

Certain individuals may be predisposed to chronic back pain because of the shape of their bodies. We have little information on such possibly predisposing factors as constitution, height, degree of obesity, physical fitness, and flexibility or suppleness. Tallness is associated with back pain in some studies (Andersson, 1981).

The association of physical effort with back pain also is unclear, although many studies report the frequency of back pain in various work places (Spitzer and Task Force, 1986; Anderson, 1976; Andersson, 1981). Associations have been reported between back pain and six types of physical work, all of which affect the load on the spine (Andersson, 1981). These six factors are physically heavy work in general, static work postures, frequent bending and twisting, lifting and forceful movements, repetitive work, and vibrations.

Because several of these factors often are present at the same time, multivariate analyses are required to know which associations are important. Such methods were used to analyze the work characteristics of the 40- to 47-year-old men in the Göteborg survey (Svensson and Andersson, 1983). Although the reported physical demand, posture, and amount of lifting at work were all associated with a history of back pain in univariate analyses, only lifting was significantly associated with back pain in the multivariate analysis.

Yelin and his colleagues (1980) also used multivariate methods in their study of work disability in 180 people after diagnosis of rheumatoid arthritis. No one physical characteristic of a job correlated significantly with whether these people remained employed. Physical effort of work was not an important predictor of work disability in people with rheumatoid arthritis.

#### Socioeconomic Status

Socioeconomic factors were associated with back pain in the surveys in which they were measured. Although not entirely consistent, the data indicate that back pain may be more likely to become a chronic problem in people of lower socioeconomic status. People with less than a high school education had more chronic back pain in three American surveys (Louis Harris, 1985; Nagi et al., 1973; Reisbord and Greenland, 1985). In the Nuprin survey (Louis Harris, 1985) 23 percent of respondents with less than a high school education had more than 30 days of back pain in the year, compared with 11–13 percent of high school and college graduates. Similarly, in both Columbus (Nagi et al., 1973) and Dayton (Reisbord and Greenland, 1985), about twice as many respondents with less than a high school education had frequent back pain as compared with those with a high school education or more (25–30 percent vs. 12–16 percent and 23–25 percent vs. 12–18 percent, respectively).

Back pain was not associated with educational level in either the Göteborg survey of 40- to 47-year-old men (Svensson and Andersson, 1982; Svensson, 1982) or in the Zoetermeer survey of adult men and women (Valkenburg and Haanen, 1982). When accompanied by objective clinical signs such as radiating leg pain and muscle spasm, back pain did tend to be associated with education level in Zoetermeer. (In this survey one-quarter of the men and women having back pain had such signs.) Men and women with less education (advanced primary education or less) tended to have disc prolapse more frequently than those with more education (2–3 percent vs. 0–2 percent); they also tended to have clinically evident lumbago more frequently (4–7 percent vs. 0–4 percent). The disparity between American and European studies could be due to the different definitions of back pain. Only frequent or chronic back pain appears to be associated with lack of education.

Low occupational status was also related to back pain. In most surveys (Nagi et al., 1973; Reisbord and Greenland, 1985; Svensson and Andersson, 1982; Svensson, 1982) laborers and blue-collar workers were about one-and-one-half to two times more likely to have back pain than white-collar workers. It should be noted that socioeconomic factors are not independent in their influence. Those with lower levels of education are more likely to have jobs of lower status, and those jobs

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are more likely to require physical activity that may be more conducive to back pain or injury.

#### **Psychosocial Factors**

As discussed elsewhere in this report (see especially Chapters 8 and 9), a host of psychosocial factors influence the course and outcomes of chronic pain. Some epidemiological work includes exploration of these associations. In the Columbus survey (Nagi et al., 1973), people with frequent back pain more often reported that they had trouble getting to sleep, were bothered with nervousness, felt restless and tense, had trouble getting up in the morning, and had trouble with sweating hands. From this cross-sectional study, however, it cannot be determined whether these factors were present before or began after the onset of back pain.

There is some fairly good evidence that the psychosocial nature of the work environment is linked both to back pain and to work disability. In the Göteborg survey, several work environment factors were found to be associated with a history of low back pain in univariate analyses (Svensson and Andersson, 1983). The factors reported were monotonous or boring work, diminished work satisfaction, decreased potential to influence the work situation, and less demand on concentration. Monotonous and/or boring work, as graded by the workers on a four-level scale, remained significantly associated with a history of back pain in a multivariate analysis.

In the study by Yelin and his colleagues (1980) of work disability after the diagnosis of rheumatoid arthritis, the social characteristics of the workplace predicted cessation of employment twice as well as personal or medical factors. Two important workplace factors were control over the pace of work and self-employment. Two rival hypotheses are suggested to explain these findings: "Because of ... fluctuations in symptoms, the ability to fit the work schedule around the illness through control over the pace and time of work and activities of the job is crucial to the continued employment of persons with rheumatoid arthritis." Alternatively, "it is interesting to speculate as to whether those who control the pace of work, or have flexible schedules of work, are more satisfied with their jobs and are, therefore, more willing to push on to continue working, whereas those who lack control on the job are more willing to take the disability route." These findings suggest that in addition to individually targeted medical interventions, more attention should be paid to the social characteristics of the workplace.

#### **RESEARCH AGENDA**

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Considering the number of people affected with chronic pain and the magnitude of its personal and social consequences, surprisingly little valid information is available. Some possible reasons for the paucity of longitudinal studies, interdisciplinary research, and research specifically focused on the nexus between chronic pain and disability include institutional and disciplinary constraints as well as lack of funding. Much work remains to be done before rational policies based on scientific studies can be proposed to ameliorate the problem of chronic pain and related work disability.

#### **Epidemiological Studies**

Most of the descriptive epidemiological work and the surveys reported to date are cross-sectional studies. As a result, virtually nothing can be said about cause and effect. The single most important recommendation made in the context of a research agenda is to begin now with at least one prospective, longitudinal study of a nationally representative sample. This might be a single uncontrolled cohort (like the Framingham study of cardiovascular diseases), or a comparison study with two or more carefully delineated cohorts. These could be:

1. An unselected geographically defined population cohort. Such a cohort would include individuals free of disease or injury or symptoms related to pain and disability. The geographically defined cohort could permit inclusion of individuals with a history of or current minor injury, disability, or disease because strict exclusion of people from the population simply on grounds of a history of pain or disability might create a highly selected, unrepresentative cohort for purposes of generalization.

2. A clinically defined cohort. Such a cohort might include a sample of people with particular diseases, new injuries, or episodes of disability. These persons would then be followed to determine the natural history of chronic patterns of symptoms, disease, or disability. A combination of geographical and clinical criteria might be used (i.e., all new cases of neck injuries in three states).

3. Special approaches to cohort delineation. The cohort could be defined by occupation groups known to be at high risk for chronic disabling pain, given the interest in work-related disability and the need for follow-ups of considerable length. Cohorts might also be defined by age group or compensation status.

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Concurrent, prospective epidemiological studies would help to identify determinants of chronicity and impairment *before* such unfavorable outcomes are manifested. In a clinically defined inception cohort, for instance, we could determine which individuals with low back pain eventually develop chronic pain and chronic disability. Today we know only that fewer than 8 percent of such individuals are likely to develop chronic pain. Faced with a new case, the clinician or investigator currently has no way of predicting whether that person is likely to go on to chronic status or not. Cohort studies can help answer some of these questions and generate focused hypotheses for other types of studies. Most important, they could point the way to designing preventive measures and directing therapeutic efforts toward those people most likely to need and benefit from such interventions.

Because longitudinal follow-up studies require considerable time and money, complementary methods should be pursued as well. Case-referent (or case-control) studies, in which "cases" are defined by manifestation of the outcome of interest and "referent" subjects are defined by its absence, permit exploration of the role of suspected risk factors for chronic pain. If two or more well-conducted case-referent studies point in the same direction and are sustained by evolving data from cohort work, the concordance might permit better judgment of the effectiveness of preventive measures and the importance of risk factors and risk markers among people who first experience a problem potentially leading to a chronic condition. It should be noted that the cross-sectional studies that have been done, although leaving many questions unanswered, have provided what little valuable information we now have. New cross-sectional studies can and will answer specific questions and help to generate hypotheses for other strategies of investigation.

#### **Methodological Research**

The development and standardization of concepts of chronic pain measurement are critical. The assessment of phenomena such as pain that have few or no directly observable components, the standardization of measurement of relevant clinical phenomena, the validation of indexes and scales of attributes such as quality of life, and even the establishment of minimum standards for recording relevant clinical and social information are neglected in much of the epidemiological and clinical literature. It is not glamourous to do or support methodological research, but without such work one risks conducting uninterpretable and inconclusive investigations. Priority should be given to developing a small but valid armamentarium of data-gathering instruments and measuring techniques with as much care as is used in the laboratory sciences.

Innovative dependent variables need to be developed and measured in standardized ways. Health status measures and indexes of the quality of life, measures of concordance or discordance of seeking compensation with objective evidence of physical disorder or disability, and measures of the style and content of clinicians' interventions are needed. Lastly, the very large array of interventions for disorders associated with chronic pain and disability, and the even larger array of combinations and permutations of such interventions, should be standardized in a relatively small set of packages that can be defined operationally, so that interventions are replicable and comparable from one study to the next.

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### PART III INFLUENCES ON PAIN AND PAIN BEHAVIOR



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# 7 The Anatomy and Physiology of Pain

Pain is a subjective experience with two complementary aspects: one is a localized sensation in a particular body part; the other is an unpleasant quality of varying severity commonly associated with behaviors directed at relieving or terminating the experience.

Pain has much in common with other sensory modalities (National Academy of Sciences, 1985). First, there are specific pain receptors. These are nerve endings, present in most body tissues, that only respond to damaging or potentially damaging stimuli. Second, the messages initiated by these noxious stimuli are transmitted by specific, identified nerves to the spinal cord. The sensitive nerve ending in the tissue and the nerve attached to it together form a unit called the primary afferent nociceptor. The primary afferent nociceptor contacts second-order pain-transmission neurons in the spinal cord. The secondorder cells relay the message through well-defined pathways to higher centers, including the brain stem reticular formation, thalamus, somatosensory cortex, and limbic system. It is thought that the processes underlying pain perception involve primarily the thalamus and cortex.

In this chapter we review the anatomy and physiology of pain pathways. We also discuss some of the physiological processes that modify the pain experience and that may contribute to the development of chronicity. For obvious reasons, most of this information comes from animal experiments. However, in recent years, experimental studies of human subjects using physiological, pharmacological, and psychophysical methods indicate that much of what has been learned in animals is applicable to humans (National Academy of Sciences, 1985). Research into basic mechanisms underlying pain is an increasingly exciting and promising area. However, most of what is known about the anatomy and physiology of pain is from studies of experimentally induced cutaneous (skin) pain, while most clinical pain arises from deep tissues. Thus, while experimental studies provide fairly good models for acute pain, they are poor models for clinical syndromes of chronic pain. Not only do they provide little information about the muscles, joints, and tendons that are most often affected by chronically painful conditions, but they do not address the vast array of psychosocial factors that influence the pain experience profoundly. To improve our understanding and treatment of pain we will need better animal models of human pain and better tools for studying clinical pain.

#### PAIN PROCESSES

Figure 7-1 illustrates the major components of the brain systems involved in processing pain-related information. There are four major processes: transduction, transmission, modulation, and perception. Transduction refers to the processes by which tissue-damaging stimuli activate nerve endings. Transmission refers to the relay functions by which the message is carried from the site of tissue injury to the brain regions underlying perception. Modulation is a recently discovered neural process that acts specifically to reduce activity in the transmission system. Perception is the subjective awareness produced by sensory signals; it involves the integration of many sensory messages into a coherent and meaningful whole. Perception is a complex function of several processes, including attention, expectation, and interpretation.

Transduction, transmission, and modulation are neural processes that can be studied objectively using methods that involve direct observation. In contrast, although there is unquestionably a neural basis for it, the awareness of pain is a perception and, therefore, subjective, so it cannot be directly and objectively measured. Even if we could measure the activity of pain-transmission neurons in another person, concluding that that person feels pain would require an inference based on indirect evidence.

#### Transduction

Three types of stimuli can activate pain receptors in peripheral tissues: mechanical (pressure, pinch), heat, and chemical. Mechanical



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FIGURE 7-1 Diagrammatic outline of the major neural structures relevant to pain. The sequence of events leading to pain perception begins in the transmission system with transduction (lower left), in which a noxious stimulus produces nerve impulses in the primary afferent nociceptor. These impulses are conducted to the spinal cord, where the primary afferent nociceptors contact the central paintransmission cells. The central pain-transmission cells relay the message to the thalamus either directly via the spinothalamic tract or indirectly via the reticular formation and the reticulothalamic pathway. From the thalamus, the message is relayed to the cerebral cortex. (DRG: dorsal root ganglion.) The pain-modulation system has inputs from the frontal association cortex and the hypothalamus (H). The outflow is through the midbrain and medulla to the dorsal horn of the spinal cord, where it inhibits pain-transmission cells, thereby reducing the intensity of perceived pain.

and heat stimuli are usually brief, whereas chemical stimuli are usually long lasting. Nothing is known about how these stimuli activate nociceptors. The nociceptive nerve endings are so small and scattered that they are difficult to find, let alone study. Nonetheless, there have been some studies of the effects of chemicals on the firing frequency of identified primary afferent nociceptors. A variety of pain-producing chemicals activate or sensitize primary afferent nociceptors (Bisgaard and Kristensen, 1985; Juan and Lembeck, 1974; Keele, 1966). Some of them, such as potassium, histamine, and serotonin, may be released by damaged tissue cells or by the circulating blood cells that migrate out of blood vessels into the area of tissue damage. Other chemicals, such as bradykinin, prostaglandins, and leukotrienes, are synthesized by enzymes activated by tissue damage (Armstrong, 1970; Ferreira, 1972; Moncada et al., 1985; Vane, 1971). All of these pain-producing chemicals are found in increased concentrations in regions of inflammation as well as pain. Obviously, the process of transduction involves a host of chemical processes that probably act together to activate the primary afferent nociceptor. In theory, any of these substances could be measured to give an estimate of the peripheral stimulus for pain. In practice, such assays are not available to clinicians.

It should be pointed out that most of our knowledge of primary afferent nociceptors is derived from studies of cutaneous nerves. Although this work is of general importance, the bulk of clinically significant pain is generated by processes in deep musculoskeletal or visceral tissues. Scientists are beginning to study the stimuli that activate nociceptors in these deep tissues (Cervero, 1982, 1985; Coggeshall et al., 1983; National Academy of Sciences, 1985). In muscle, there are primary afferent nociceptors that respond to pressure, muscle contraction, and irritating chemicals (Kumazawa and Mizumura, 1977; Mense and Meyer, 1985; Mense and Stahnke, 1983). Muscle contraction under conditions of ischemia is an especially potent stimulus for some of these nociceptors.

Despite progress in our understanding of the physiology of musculoskeletal nociceptors, we still know very little about the mechanisms underlying common clinical problems such as low back pain. Even when there is degeneration of the spine and compression of a nerve root—a condition generally acknowledged to be extremely painful—we do not know which nociceptors are activated or how they are activated. Neither do we know what it is about the process that leads to pain.

#### Transmission

#### Peripheral Nervous System

The nociceptive message is transmitted from the periphery to the central nervous system by the axon of the primary afferent nociceptor. This neuron has its cell body in the dorsal root ganglion and a long process, the axon, that divides and sends one branch out to the



FIGURE 7-2 The primary afferent nociceptor. This is the route by which the central nervous system is informed of impending or actual tissue damage. Its peripheral process runs in peripheral nerves, and its peripheral terminals are present in most body structures. These terminals are sensitive to noxious heat, mechanical stimulation, and/or pain-producing chemicals. The central process enters the spinal cord via the dorsal root and terminates on central pain-transmission cells that relay the information to higher centers. Both peripheral and central processes are maintained by the cell body in the dorsal root ganglion, which is near, but not in, the spinal cord.

periphery and one into the spinal cord (Figure 7-2). The axons of primary afferent nociceptors are relatively thin and conduct impulses slowly.

It is possible to place an electrode into a human peripheral nerve and record the activity of primary afferent nociceptors (Fitzgerald and Lynn, 1977; Torebjork and Hallin, 1973). The nociceptor is characterized by its response to noxious heat, pressure, or chemical stimuli. The "pain" message is coded in the pattern and frequency of impulses in the axons of the primary afferent nociceptors. There is a direct relation between the intensity of the stimulus and the frequency of nociceptor discharge (Figure 7-3). Furthermore, combined neurophysiological and psychophysical studies in humans have shown a direct relation between discharge frequency in a primary afferent nociceptor and the reported intensity of pain (Fitzgerald and Lynn, 1977; LaMotte et al., 1983). Blocking transmission in the small-diameter axons of the nociceptors blocks pain, whereas blocking activity of the largerdiameter axons in a peripheral nerve does not. These identified primary afferent nociceptors are thus necessary for detecting noxious stimuli.

Monitoring activity in identified primary afferent nociceptors is a potential tool for the evaluation of certain types of clinical pain. In fact, this method has been used clinically to demonstrate pain-producing neural activity arising from a damaged nerve (Nystrom and Hagbarth, 1981). At present, this method should be considered just a research tool; however, it is technically feasible and is of great potential value



FIGURE 7-3 The relation of discharge frequency in primary afferent nociceptors to subjective pain intensity in human subjects. Top left: The skin of human subjects was subjected to brief, calibrated temperature increases. Subjects began to identify the temperature as painful at about  $45^{\circ}$ C; with increasing temperature, the reported pain intensity also increased. Top right: Using the same range of temperatures, discharge in primate primary afferent nociceptors (with unmyelinated axons) was recorded. These afferents were not active prior to stimulation and only began to fire at temperatures near the human pain threshold. The increase in their firing is quite similar to the increase in subjective pain ratings of human subjects across the same temperature range (Lamotte and Campbell, 1978). (C-PMN: C-polymodal nociceptor.) Bottom: Identified unmyelinated afferents were recorded in awake human subjects. In these subjects, calibrated thermal stimuli were delivered to the skin region innervated by the nerves that were recorded. Nociceptor discharge and subjective pain intensity were measured concurrently. There is a direct, though nonlinear relation between them (Gybels et al., 1979).

for evaluating pain patients. It raises the possibility of actually demonstrating nociceptor activity coming from a painful area. This method could be an advance over other correlative techniques for assessing pain because it measures the presumed noxious input, that is, the neural activity that ordinarily causes pain. Most of the other measures assess responses that could be, but are not necessarily, caused by noxious stimuli.

It is important to point out that (1) there can be pain without activity in primary afferent nociceptors, and (2) there can be activity in primary afferent nociceptors without pain. These phenomena occur when there has been damage to the central or peripheral nervous systems. In addition, the modulating system can suppress central transmission of activity elicited by nociceptor input. Thus, there is a variable relation between nociceptor input and perceived pain intensity. For this reason the method of recording primary afferent nociceptors could be used to confirm the presence of an input, but it could not be used to prove that pain was not present.

Besides these theoretical limitations of trying to assess subjective pain intensity by recording primary afferent nociceptors, there are important practical problems in measuring either pain-producing substances or primary afferent nociceptor activity. One is that the largest group of patients disabled by pain localize it to musculoskeletal structures in the lower back. Because the nerves innervating these structures are not near the skin, they are difficult to find. Another problem is that pain arising from deep structures is often felt at sites distant from where the tissue damage occurs. In contrast to the pain produced by skin damage, which is sharp or burning and well localized to the site of injury, the pain that arises from deep tissue injury is generally aching, dull, and poorly localized (Lewis, 1942). When the damage to deep tissues is severe or long lasting, the sensation it produces may be misperceived as arising from a site that is distant from the actual site of damage (Head, 1893; Kellgren, 1938; Lewis, 1942; Sinclair et al., 1948). This phenomenon, known as referred pain, helps to explain the frequent discrepancy between physical findings and patient complaints. The mechanism of referred pain is unknown for any particular case.

Referred pain can be a major source of confusion in the examination of patients complaining primarily of pain. The fact that pain is referred from visceral internal organs to somatic body structures is well known and commonly used by physicians. For example, the pain of a heart attack is not always localized to the heart but commonly is felt diffusely in the chest, the left arm, and sometimes in the upper
abdomen. Less widely recognized is the fact that irritable spots, such as myofascial trigger points, in skeletal muscles also cause feelings of pain in locations distant from the irritable spot. This was demonstrated experimentally in muscle and fascia by Kellgren in the late 1930s (Kellgren, 1938). Specific patterns of pain referred from particular muscles have been described clinically (Travell and Rinzler, 1952; Travell and Simons, 1983). (See Chapter 10 and Appendix.)

At least four physiological mechanisms have been proposed to explain referred pain: (1) activity in sympathetic nerves, (2) peripheral branching of primary afferent nociceptors, (3) convergence projection, and (4) convergence facilitation. The latter two involve primarily central nervous system mechanisms.

1. Sympathetic nerves may cause referred pain by releasing substances that sensitize primary afferent nerve endings in the region of referred pain (Procacci and Zoppi, 1981), or possibly by restricting the flow of blood in the vessels that nourish the sensory nerve fiber itself.

2. Peripheral branching of a nerve to separate parts of the body causes the brain to misinterpret messages originating from nerve endings in one part of the body as coming from the nerve branch supplying the other part of the body.

3. According to the convergence-projection hypothesis, a single nerve cell in the spinal cord receives nociceptive input both from the internal organs and from nociceptors coming from the skin and muscles. The brain has no way of distinguishing whether the excitation arose from the somatic structures or from the visceral organs. It is proposed that the brain interprets any such messages as coming from skin and muscle nerves rather than from an internal organ. The convergence of visceral and somatic sensory inputs onto pain projection neurons in the spinal cord has been demonstrated (Milne et al., 1981; Foreman et al., 1979).

4. According to the convergence-facilitation hypothesis, the background (resting) activity of pain projection neurons in the spinal cord that receive input from one somatic region is amplified (facilitated) in the spinal cord by activity arising in nociceptors originating in another region of the body. In this model, nociceptors producing the background activity originate in the region of perceived pain and tenderness; the nerve activity producing the facilitation originates elsewhere, for example, at a myofascial trigger point. This convergence-facilitation mechanism is of clinical interest because one would expect that blocking sensory input in the reference zone with cold or a local anesthetic should provide temporary pain relief. One would not expect such relief according to the convergenceprojection theory. Clinical experiments have demonstrated both kinds of responses.

This phenomenon of referred pain can present a serious problem to both patients and physicians when it goes unrecognized. Because the source of the pain lies overlooked at a distant location, the lack of any demonstrable lesion at the site of pain and tenderness often leads to the suspicion that the pain has a strong psychological component. When health professionals insist that there is no reason for the pain, patients sometimes begin to wonder whether the pain is "all in their head." As is discussed in later chapters, this can exacerbate anxiety and other psychological reactions to the pain, is likely to frustrate both the doctor and the patient, and may lead to "doctor shopping" and inappropriate treatment.

# Pain Pathways in the Central Nervous System

Primary afferent nociceptors transmit impulses into the spinal cord (or if they arise from the head, into the medulla oblongata of the brain stem). In the spinal cord, the primary afferent nociceptors terminate near second-order nerve cells in the dorsal horn of the gray matter (Willis, 1985). The primary afferent nociceptors release chemical transmitter substances from their spinal terminals. These transmitters activate the second-order pain-transmission cells. The identity of these transmitters has not been established, but candidates include small polypeptides such as substance P and somatostatin, as well as amino acids such as glutamic or aspartic acid.

The axons of some of these second-order cells cross over to the opposite side of the spinal cord and project for long distances to the brain stem and thalamus. The pathway for pain transmission lies in the anterolateral quadrant of the spinal cord. Most of our information about the anatomy and physiology of pain-transmission pathways in the central nervous system is derived from animal studies. However, it is known that in humans, lesions of this anterolateral pathway permanently impairs pain sensation and that electrical stimulation of it produces pain (Cassinari and Pagni, 1969; White et al., 1950; Willis, 1985).

There are two major targets for ascending nociceptive axons in the anterolateral quadrant of the spinal cord: the thalamus and the medial reticular formation of the brain stem. Our knowledge is most extensive for the spinal cells whose axons project directly to the thalamus, that is, the spinothalamic tract cells. The spinothalamic pathway is implicated in human pain perception because lesions of it, at any level, produce lasting impairments of pain sensation.

Studies of the properties of spinothalamic tract cells have been carried out in several species. In all these species, a major proportion of spinothalamic neurons respond maximally to noxious stimulation. Furthermore, there is a direct relationship in spinothalamic tract cells of firing frequency to stimulus intensities in the noxious range for human subjects (Kenshalo et al., 1980; Willis, 1985). These observations, coupled with decades of careful clinical studies, strongly implicate the spinothalamic tract as a major pathway for pain in humans.

The other major ascending nociceptive pathway in the anterolateral quadrant is the spinoreticular tract. The medullary reticular formation receives a major direct projection from the spinal cord as well as from branches of some of the spinal neurons that project to the thalamus (Kevetter and Willis, 1984; Mehler, 1962).

At the thalamic level, pain pathways have two major sites of termination: ventrocaudal and medial. The ventrocaudal thalamus receives nociceptive input directly from projecting spinal neurons. Neurons in the ventrocaudal thalamus project directly to the somatosensory cortex (Willis, 1985). The medial thalamus receives some indirect input from the spinal cord, but in addition, it receives a major input from the region of the brain stem reticular formation to which the nociceptive spinoreticular neurons project. The medial thalamus projects to widespread areas of the forebrain, including the somatosensory cortex (Jones and Leavitt, 1974). Thus there are two major ascending pathways for pain: a direct lateral spinothalamic pathway and an indirect medial spinoreticulothalamic pathway. It is thought that the lateral pathway from the spinal cord to the ventrocaudal thalamus and to the cortex is responsible primarily for sharp, well-localized pains that arise near the body surface. In contrast, the medial spinoreticulothalamic pathway responds more to stimuli of deep somatic and visceral structures.

There is some evidence for further functional differences between medial and lateral thalamic pathways. Lesions of the ventrocaudal thalamus and somatosensory cortex produce long-lasting deficits in the sensory aspects of pain that are very similar to those produced by lesions of the anterolateral spinal cord pathway. Lesions of the medial thalamus have very little effect on pain sensation per se; pain threshold is unaffected, as are the other sensory aspects of the pain experience. In contrast, the emotional or reactive aspects may be totally abolished (Barber, 1959).

#### Sensory Versus Affective Aspects of Pain

The processes set in motion by noxious stimuli can be divided into two broad categories. On one hand, there are the sensory processes that lead to the detection and identification of the stimulus. On the other hand, presumably because of the tissue-damaging potential of the noxious stimulus, aversive behavioral sequelae such as withdrawal and escape can terminate the stimulus and protect the organism. Correlated with these two categories of response are two subjective aspects of pain: sensory and affective.

The sensory aspects concern detecting, localizing, assessing the intensity of, and identifying the stimulus. Focusing on the sensory aspects, a person might describe his or her pain as a mild burning pain located on the back of the hand. In contrast, the affective or unpleasantness aspect of pain correlates with the aversive drive to terminate the noxious stimulus and is described by terms that are not specifically tied to a sensory experience, for example, nagging, uncomfortable, or excruciating. The affective aspects would also be accompanied by mood changes such as anxiety and depression, which are usually considered psychological rather than sensory.

The difference between the sensory and affective aspects of pain can be illustrated further by distinguishing between pain threshold and pain tolerance. For example, if one delivers calibrated thermal stimuli to the skin, most people will report that the sensation becomes painful over a narrow range of skin temperatures (43-46°C) (LaMotte et al., 1983; Willis, 1985). The temperature that is called painful 50 percent of the time would be the pain detection or sensory threshold.

In contrast to this relatively reproducible pain-detection threshold, tolerance for pain differs widely among individuals. For example, subjects immersing their hands in ice water fall into distinct groups those who keep their hands in for over 5 minutes and those who pull them out after less than 90 seconds (Turk and Kerns, 1983–1984). The tolerance for pain is a complex function that may be modified by personality traits, attitudes, previous experience, economic factors, gender, and the particular circumstance under which the pain is experienced. Tolerance may be thought of as a response threshold. Pain of a certain intensity and duration may be ignored, whereas a somewhat more intense pain might induce some people to take painkillers, stay home from work, or consult a physician. The particular behavior elicited by pain of a given intensity is highly individual and greatly influenced by what the patient believes will be helpful and how serious he or she thinks the situation is. For example, most people with headaches do not seek medical attention because headaches are not considered indicative of serious disease (and usually are not). In contrast, a person whose father died recently from a brain tumor might be very frightened by even a mild headache and seek medical attention (see Chapter 8).

Tolerance is also tied to the cognitive and affective aspects of pain. For patients with cancer, pain may be a sign that the tumor has recurred or spread and that death is near. For such patients, the suffering is due not only to the pain's intensity but also to its meaning. Anguish, suffering, and anxiety commonly accompany pain.

In the 1950s many patients with severe pain due to malignancy were given frontal lobotomies (Barber, 1959). These operations disrupt the projections to the frontal lobe from the medial spinoreticulothalamic pathway. In such patients, pain intensity and threshold were unaffected, but the emotional aspects (suffering and anguish) were abolished. Unfortunately, the severe personality changes that accompanied the elimination of suffering made this an unacceptable approach to the treatment of pain. However, these clinical observations show that the affective component of pain has a separate anatomical substrate from the sensory component.

# Modulation

The abovementioned processes were discussed in terms of a highly reliable pain-transmission system, the assumption being that pain intensity is a direct function of nociceptor activity. In fact, the excellent correlation among stimulus intensity, impulses in primary afferent nociceptors, and reported pain intensity demonstrated in human subjects under experimental conditions often does not apply to the clinical situation. The most remarkable observations are those in which patients subjected to injuries that ought to be very painful report no significant pain (Beecher, 1959).

An hypothesis for spontaneous analgesia emerged when it was discovered that electrical stimulation of certain brain regions blocks responses to noxious stimulation in laboratory animals (Basbaum and Fields, 1978). This phenomenon, stimulation-produced analgesia (SPA), became more than a laboratory curiosity when it was shown that stimulating homologous brain regions provided relief for patients suffering from chronic pain (Hosobuchi et al., 1977; Richardson and •

Akil, 1977). SPA has been demonstrated in a variety of animal species and in hundreds of patients.

SPA can be elicited from well-defined brain stem sites. A body of evidence now indicates that SPA is mediated by a discrete neuronal network running from the midbrain to the medulla and then to the spinal cord (Figure 7-1) (Basbaum and Fields, 1978, 1984). This descending, pain-modulating pathway projects to regions of the spinal cord that contain pain-transmission neurons. Stimulation at brain stem sites that produce behavioral analgesia also selectively inhibits identified nociceptive spinothalamic tract neurons. This inhibition may underly the behavioral analgesia produced by brain stem stimulation.

In addition to electrical stimulation, the analgesia network can be activated by morphine and other opiate analgesic drugs (Yaksh, 1978). The brain stem sites for SPA and the spinal cord are both sensitive to directly applied opiates. The weight of evidence indicates that opiates produce analgesia in part by activating these pain-modulating networks.

One of the most important discoveries in pain research was that the brain contains substances that have the same pharmacological properties as plant-derived opiates and synthetic opioid drugs. These substances, called endogenous opioid peptides, are present within nerve cells of the peripheral and central nervous systems (Palkovits, 1984). Of particular importance for our discussion is the presence in high concentrations of these peptides in those brain stem sites implicated in pain suppression (Basbaum and Fields, 1984). As discussed in Chapter 9, these findings have led to some promising new psychopharmacological applications.

Studies of this endorphin-mediated analgesia system in laboratory animals have shown that it can be activated by a variety of stressful manipulations, including painful stimuli (Basbaum and Fields, 1984). Clinical studies indicate that it is activated after surgery and can have a significant analgesic effect (Fields and Levine, 1984; Levine et al., 1979). The important point is that there is a well-defined network for controlling pain transmission. Current evidence indicates that this network accounts for some of the striking variability of reported pain intensity in different patients who have had apparently similar noxious stimuli.

It has been suggested that failure of the pain-suppression system accounts for certain types of chronic pain states (Sicuteri et al., 1984; Terenius, 1985), but most pain experts consider this conclusion premature. Much more work is needed to determine the extent to which this pain-modulating network operates on chronic pain.

# PHYSIOLOGICAL PROCESSES THAT ENHANCE PAIN AND MAY LEAD TO CHRONICITY

One of the most troublesome issues for patients, clinicians, and disability examiners is how to account for pain experiences that seem disproportionate to physical findings or objectively verifiable disease or injury. Although it is well known and well accepted that various psychosocial factors may enhance pain, the role of several physiological processes in amplifying and maintaining pain is perhaps not adequately taken into account when assessing patients' complaints.

# Sensitization

Tissue damage initiates a variety of processes that sustain and amplify pain. With repeated stimuli, the thresholds of primary afferent nociceptors progressively decrease, so that normally innocuous stimuli become painful (Campbell et al., 1979; Gybels et al., 1979; LaMotte et al., 1983). For some primary afferent nociceptors, repeated noxious stimuli may induce continuous activity lasting for hours (National Academy of Sciences, 1985). The most familiar example of this is sunburn, in which the skin becomes a source of pain; hot water applied to the skin is perceived as unbearably painful and a friendly slap on the back is excruciating. Other examples are the tenderness of a sprained ankle or an arthritic joint. In these situations it'is painful to bear weight or even move the affected joint. Sensitization is a major feature of many and perhaps most clinically significant pains, but its cellular mechanism is unknown.

# Hyperactivity of the Sympathetic Nervous System: Reflex Sympathetic Dystrophy

Patients with relatively minor injuries occasionally develop pain disproportionate to their injuries. Such pain often becomes progressively worse rather than following the usual course of lessening with time. It is important to stress that the pain persists well beyond the time when the original tissue-damaging process has ended. Furthermore, the location of the pain may be quite different from the site of the precipitating pathology.

In some of these patients hyperactivity of the sympathetic nervous system clearly plays a major role in sustaining the pain because selective blockade of the sympathetic outflow produces immediate and dramatic relief. The pain is usually accompanied by signs of sympa-



FIGURE 7-4 Reflex activation of nociceptors in self-sustaining pain. There are two important reflex pathways for pain. The top loop illustrates the sympathetic component. Nociceptor input activates sympathetic reflexes, which activate or sensitize nociceptor terminals. The bottom loop illustrates the muscle contraction loop. Nociceptors induce muscle contraction, which, in some patients, activates muscle nociceptors that feed back into the same reflex to sustain muscle contraction and pain.

thetic hyperactivity, such as a cold (vasoconstricted), sweaty limb. In addition, the skin may be hypersensitive to touch, as if the nociceptors were sensitized. With time, osteoporosis, arthritis, and muscle atrophy may set in and a permanent impairment of function may ensue. This condition, called *reflex sympathetic dystrophy*, usually responds to sympathetic blocks and physical therapy (De Takats, 1937; Livingston, 1943; Procacci et al., 1975). Physiological studies in animals indicate that the sympathetic outflow can induce discharge of primary afferent nociceptors. This is most prominent in damaged and regenerating afferents (Devor, 1984) but also occurs in undamaged, sensitized afferents (Roberts, 1986) (Figure 7-4).

The reflex sympathetic dystrophy syndrome is relatively uncommon in its full-blown form, but sympathetic activity could be a common factor in sustaining or amplifying pain that would ordinarily fade as the injured tissues heal. If this were the case, local signs of increased sympathetic activity could help provide objective evidence that a pain-producing pathological process is present.

#### **Muscle Contraction**

Nociceptor activity results in sustained contraction in muscles. In limbs, this muscle contraction produces flexion, a form of primitive withdrawal that is presumably a protective movement. Disease in the abdominal viscera (e.g., gut, liver) produces tension in the muscles of the abdominal wall. Pain arising from musculoskeletal structures also produces contraction and tenderness in other muscles innervated by the same spinal segment (Head, 1893; Kellgren, 1938).

There is some evidence that this spreading muscle contraction plays an important role in clinically significant pains. In patients with persistent pain it is common to find small areas in muscles that are quite tender. Pressure over these myofascial trigger points can reproduce the patient's pain, and locally anesthetizing the points (or other manipulations of them) can give relief lasting days to months (Simons and Travell, 1983). The physiological basis of these trigger points is unknown, but the clinical evidence suggests that they are often involved in sustaining pain in the absence of ongoing tissue damage.

### Self-Sustaining Painful Processes: Livingston's "Vicious Circle"

From the material just discussed, clinical observations clearly indicate that several processes are set in motion by tissue-damaging stimuli that activate nociceptors. In the peripheral tissues, painproducing substances are released that sensitize the nociceptors so that normally innocuous stimuli can activate them. In addition, nociceptors themselves release factors such as substance P that in turn cause vasodilation, edema, and the release of sensitizing substances from nonneural cells (Lembeck, 1983). Presumably, these processes play a role in the activation of host defenses against infection or toxins. However, they do prolong and amplify pain.

For example, a noxious stimulus to the skin would activate nociceptors. These nociceptors then activate spinal reflexes that produce sustained muscle contraction with consequent activation of muscle nociceptors (Figure 7-4). In this case, the production of a second site of noxious input in muscle is due to a spinal reflex. In some cases (e.g., reflex sympathetic dystrophy), the nociceptive input also activates the sympathetic nervous system, which can feed back to the periphery to sensitize or even activate nociceptive primary afferents. Livingston (1943) was the first to emphasize the clinical importance of these positive feedback loops; that is, the pain produces muscle contraction and sympathetic outflow that in turn activate nociceptors, which produce more sympathetic outflow and muscle contraction, and so on (Figure 7-4). The point is that painful injuries set in motion secondary processes, not associated with tissue damage, that cause a prolongation and spread of nociceptive input and may contribute to chronicity. These secondary processes set up foci of nociceptive input that are independent of the original site of injury. The pain acquires, so to speak, a life of its own.

Although there is no question that these factors contribute to the pain in some cases, it is not clear what proportion of patients with chronic pain have it because of these factors. This would obviously be an important area for future research on chronic pain.

### Neuropathic Pain

Damage to the peripheral or central nervous systems can produce chronic pain. For example, in some diseases that affect peripheral nerves, such as diabetes mellitus or alcohol toxicity, pain is very common. Traumatic injury to a peripheral nerve is rarely painful, but when it is, it may be dramatically so. Causalgia (heat pain) is an example of pain induced by traumatic injury to a peripheral nerve. Causalgia is a syndrome characterized by severe burning pain and signs of sympathetic nervous system hyperactivity (Mitchell, 1965; Roberts, 1986). Similarly, lesions of the central nervous system are rarely painful, but when they are, the pain is severe and resistant to treatment (Cassinari and Pagni, 1969; Riddoch, 1938).

There are certain characteristics of neuropathic pain. It frequently begins several days to weeks after the injury that produces it and tends to worsen before stabilizing. It is usually accompanied by sensory abnormalities, including, paradoxically, deficits in pain sensation and painful hyperreactivity to ordinarily innocuous stimuli (Noordenbos, 1959; Ochoa, 1982).

The mechanisms of neuropathic pain are not completely understood, but there are several factors that could contribute to them (Ochoa, 1982). Damaged primary afferents, presumably including nociceptors, acquire certain properties when they begin to regenerate. These include spontaneous activity, mechanical sensitivity, and sensitivity to sympathetic nervous system activity (Ochoa, 1982; Scadding, 1981). Note that under these circumstances there can be pain either without any stimulus or with a very gentle, non-tissue-damaging stimulus.

In addition to the peripheral sources of pain, damage to primary afferents produces changes in the pain-transmission neurons to which they project in the central nervous system. These cells become spontaneously active and could be a source of pain, again in the absence of any noxious stimuli (Lombard and Larabi, 1983; Roberts, 1986).

Trigeminal neuralgia and post-herpetic neuralgia are among the most common types of neuropathic pains. These conditions tend to strike older individuals, many of whom are retired. This may be why patients with pains that are obviously neuropathic account for only a small proportion of those who seek disability benefits. On the other hand, some patients with low back pain might have an element of nerve damage that adds to the painfulness of their problem as well as to its chronicity and resistance to conventional treatment. Further research on this issue is clearly needed, as are better methods for detecting injuries to nerves that innervate deep structures.

# **Acute Versus Chronic Pain**

Is there any physiological basis for differentiating between acute and chronic pain? Little is known about the effects of prolonged pain on the central nervous system. There is some evidence that the transition from acute pain to chronic pain alters patients' neurophysiology in a way that makes them somewhat different from people with acute pain. In arthritic rats, for example, there are changes in the peripheral nerves that alter their range of response to applied stimuli, and there may be changes in the central pathways for pain transmission as well (Guilbaud et al., 1985; Kayser and Guilbaud, 1984). Experiments with rats in which nerves have been injured and observed over time have shown changes in the central nervous system, but it is not known how these changes relate to pain (Markus et al., 1984).

People with recurrent headaches, arthritis, low back pain, angina, or low-grade malignancies may have had pain for years. The complaints, treatment, and patients' reactions may be different for each of these conditions. In some cases, psychological factors loom large. These factors are particularly prominent in patients with low back pain, facial pain, and headaches and seem to be more prominent the longer the pain persists.

Psychological and somatic factors are not completely separate in maintaining pain. For example, stress and anxiety increase both muscle contraction and sympathetic outflow and would be expected to exacerbate any ongoing pain problem to which they contribute. Conversely, any treatment that induces relaxation will reduce these factors and lessen pain. This may be one important connection between the psychosocial and the somatic factors that influence pain tolerance.

# POTENTIAL METHODS OF PHYSIOLOGICAL MONITORING

In this chapter we have briefly surveyed the anatomy, physiology, and pharmacology of nociceptive transduction, transmission, and modulation. These are objective and potentially observable phenomena initiated by stimuli that damage or threaten tissue.

As we learn more about the transduction process, it may be feasible to measure the concentration of substances in regions of ongoing tissue damage that activate or sensitize primary afferent nociceptors. This could give an estimate of the level of stimulation of chemically sensitive nociceptors. The most promising technique at present is direct recording of the electrical activity in primary afferents. This is technically feasible and has been used in research, but it is not presently available for general clinical use.

The monitoring of central pain transmission pathways is not practical with the technology available. Although it is theoretically possible, recording single units within the human nervous system requires a potentially dangerous surgical procedure. Multiunit, or evokedpotential, studies do not have the required specificity or spatial resolution to permit collecting meaningful data about clinical pain. It is technically possible to measure the chemicals released at spinal synapses by primary afferent nociceptors. If the concentration of such chemicals in the cerebrospinal fluid could be shown to correlate with either the activity of the primary afferent nociceptors or with the severity of clinical pain, this could provide evidence similar to that derived from recording the activity of the primary afferents. However, at the present time, the transmitter or transmitters for the primary afferent nociceptors are unknown.

Another approach is to use positron emission tomography (PET) to monitor metabolic activity in central nervous system pain pathways. PET is a noninvasive scanning technique that can provide evidence of focal brain activity and of the concentration of certain chemicals. This technique requires that enough neurons be active in a large enough region for a long enough period of time to be detected. Because of the topographical organization of the cortex, this technique might be used to monitor the somatosensory cortex. A precise map of the body surface spreads over many millimeters of the cortex. Representation of the face

and hand on this map is very large, so it might be possible to detect ongoing activity produced by nociceptive input from these regions. At present, there is no evidence that such measurements show anything in patients with chronic pain.

Indirect measures, such as those of sympathetic nervous system activity (skin temperature or skin resistance) or of muscle contraction in painful areas might be helpful in providing objective evidence of sustained nociceptive input. The measurement of skin temperature over extensive areas of the body surface, thermography, is being used clinically but is still not widely accepted as a reliable indicator of pain. Although they are simple, painless, and safe indicators of sympathetic function, indirect measures of painful input like thermography could be misleading. Sympathetic changes could be produced by nonspecific factors such as surprise or anxiety that do not involve pain. On the other hand, if the changes in sympathetic activity are highly localized, persistent, and consistent with the reported location of the patients' pain, routine evaluation of sympathetic function with techniques like thermography in patients with chronic pain might provide clues about the mechanisms sustaining the pain.

Ultimately, the presence of pain in another individual is always inferred. Even if we could measure pain directly, such a measure would not be adequate to describe the experience of pain, and it is the experience that affects functioning, including the ability to work.

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# 8 Illness Behavior and the Experience of Pain

hronic pain is experienced not only as bodily discomfort but also as fears about the future, work impairment, threats to family bonds and activities, and assaults on the priorities of one's daily life. How an individual reacts to physical symptoms-be they pain or any other symptom-depends on his or her past experience with illness, personality and coping styles, familial and cultural norms, and current interpersonal interactions. How symptoms are perceived and the meaning attributed to them may, in turn, powerfully influence their subsequent intensity and duration, the nature and extent of help-seeking behavior, and whether the person comes to view him- or herself as sick, impaired, and deserving of disability benefits. As emphasized throughout this volume, chronic pain is not an entity, but a process. Furthermore, it is simultaneously a physiological and psychosocial process. The Social Security Administration (SSA) specifically asked the Institute of Medicine (IOM) study committee to address the psychosocial aspects of the pain experience and to describe how the concept of illness behavior provides a framework for understanding the observed discrepancies between the clinical manifestations of pain and the behaviors of people with pain.

# **ILLNESS BEHAVIOR: AN INTEGRATING CONCEPT**

Much research and clinical experience with pain have demonstrated that there is no clear relation between the amount of tissue damage and the degree of discomfort or functional disability reported by the patient. The nature of the pain and its underlying physiological factors affect the course from acute pain to chronic pain to functional disability. Yet for many, and perhaps most, of those who go through this process, psychosocial factors are inextricably intertwined with physiological change and may even be primary (Better et al., 1979; Brena et al., 1979; Brena and Chapman, 1984; Carron et al., 1985; Dworkin et al., 1985; White, 1966). The marked variability in individual behavior, despite the similarity of symptoms and pathophysiological processes, reflects major differences in psychological and cognitive predispositions as well as prevailing sociocultural norms.

The concept of illness behavior provides a useful way of understanding and describing the many psychosocial influences that affect how people monitor their bodies, define and interpret their symptoms, come to view themselves as sick and disabled, take remedial action, and use lay and professional sources of help (Mechanic, 1978). The concept draws on psychological theories of perception, cognition, and meaning attribution and on theories of social relationships. A crucial premise in the study of illness behavior is that illness, as well as the illness experience, are shaped by psychological, social, and cultural factors irrespective of the genetic, physiological, or other biological bases of disease. Hence, as used here, illness and disease are distinct. Disease refers to a specific clinical entity characterized by a disturbance in the structure or function of any part, organ, or system of the body. Illness is a broader concept that refers to any condition that a person views as sickness (Eisenberg, 1977). Whereas the magnitude, severity, persistence, and character of symptoms affect and establish limits for personal and social definitions of illness, there is considerable variability in what is perceived, how it is defined, the interventions that are considered and used, and the outcomes of illness. Thus, illness behavior is a dynamic response to changing bodily sensations. It reflects not only the individual's psychological predisposition, but also the broader socioeconomic and cultural context within which the individual lives. For the physician, as well as the disability examiner and the law courts, much of what is involved in understanding a person's complaints of chronic disabling pain that seem disproportionate to objective clinical findings may be clarified by the concept of illness behavior. This concept also helps to explain why some people who have wellsubstantiated diagnoses of painful diseases and obvious physical limitations continue their usual routines and push themselves to perform beyond the levels observers might expect.

Since the term "illness behavior" was first introduced (Mechanic, 1962), the concept has been widely adopted and adapted, and, in the

committee's view, sometimes misused. Illness behavior is neither a disease nor a diagnosis. Neither is it static; it is a process that unfolds over time as people struggle to achieve some accommodation or mastery over their health problems. In the committee's view, the term "abnormal illness behavior" is likely to be confusing because it suggests a simple dichotomy—normal and abnormal—rather than a range of behaviors that are highly individualistic and variable. For the purposes of medical treatment and rehabilitation, it is important to understand each particular behavior. Lumping behaviors together under a convenient rubric may obscure crucial distinctions.

# THE PROCESS OF ILLNESS BEHAVIOR

Although illness behavior is best conceptualized as a process, it is important to note that it usually does not proceed in a straight path from one well-defined stage to another. Rather, there are likely to be bidirectional interactions between four elements—symptom perception, symptom interpretation, symptom expression, and coping behaviors.

# **Symptom Perception**

The process of illness behavior usually begins when a noticeable change in bodily function is interpreted as a symptom of ill health. Symptoms are necessarily experienced against the background of a particular individual's ordinary functioning. All of us know how our bodies behave in the multitude of circumstances that make up our daily lives. If we choose to focus on our bodies for a few minutes we become aware of sensations associated with breathing and moving that we normally do not notice. At other times, changes in functioning may be readily apparent but their proximate cause is so obviously not an illness that we do not call these altered sensations symptoms. After physical exertion, for example, our increased respiratory rates, difficulty breathing, muscle fatigue, and the like may be experienced as discomfort or even as pain, but they are unlikely to be perceived as "symptoms." Consciously or unconsciously we "cognitively packaged" the changes in functioning and attributed them to our recent exertion. In the course of our daily lives we constantly interpret bodily sensations and assign meaning to them, often without being aware of it (Pennebaker, 1982).

For a change in functioning to be interpreted as a symptom it must have evoked concern that the alteration is somehow not normal and is not readily accounted for except in the framework of illness. The perception of a sensation as a symptom of ill health involves categorizing the experience and assigning meaning to it. Our past repertoire of experience with our own and others' illnesses provides the basis for making such interpretations. These interpretations then affect our perceptions such that the processes of perceiving and assigning meaning to symptoms become intertwined with values and beliefs and influence each other (Cassell, 1985).

Attention (selecting and integrating sensory input from the external and internal environments) plays a major role in the experience of pain. A cardinal characteristic of pain is that it has a unique ability to captivate and hold one's attention. The patient who has suffered a significant injury or disease and fears a recurrence of the pathology may be constantly on the alert for any physical signs or pains associated with the feared disorder. Another curious property of pain is that attention directed to it typically exaggerates its aversiveness (Pennebaker and Epstein, 1983). As individuals think about their pain, it tends to become more intense and disabling, whereas distraction and meaningful activity are likely to reduce the salience of pain experiences. Thus, some people believe that as activities (including work) become more rewarding and stimulating, people will be less likely to focus attention on themselves and their incapacities. On the other hand, because pain is distracting, it may make work and other activities seem less rewarding and stimulating. The degree of awareness of one's own pain may vary from a near denial of its presence to an almost total preoccupation with it, and the reasons for attending to pain may vary. Pain itself may become the focus of the self and self-identity, or may, however uncomfortable, be viewed as tangential to personhood. One of the most powerful influences on the way in which symptoms are perceived and the amount of attention paid to them is the meaning attributed to those symptoms.

# **Meaning Attribution**

Meaning attribution about the cause and likely outcome of symptoms is influenced by a host of psychosocial and cultural factors as well as by a person's prior experience with illness. Assigning meaning to symptoms can be a conscious process that helps people structure the experience, or it may occur outside of awareness. A person's report of symptoms inevitably reflects not only the nature of the experience but also its significance to that person. A person's assessment of meaning may be as important to symptom formation as the disturbances in functioning for which the meaning is invoked (Cassell, 1985). The meanings given by a patient to an accident, sickness, personal suffering, or the relentless presence of pain affect subsequent illness behavior and help to order experience in several ways (Engel, 1959; Taylor, 1983). First, meaning is associated with a sense of coherence or purpose for life events. Patients seek to comprehend why an accident or sickness has occurred and what impact it has had and will have in the future. Causal attributions are formed by patients to account for current unfortunate circumstances. These formulations shape the meaning of the situation and can open or close options for actively dealing with it or the feelings it evokes.

Second, the ability to assign meaning to an illness or to symptoms has been found to enhance some patients' sense of self-mastery over a problem or crisis (Lewis, 1982). For example, the limitations imposed on a patient's lifestyle by chronic pain may be significantly attenuated if the patient believes that he or she can control the pain or can, despite the pain, undertake activities without harm (Averill, 1973). In contrast, it has been observed that patients who believe that they have little or no control over their health and well-being work less effectively with health care providers to achieve rehabilitation (Pilowsky, 1984).

Finally, the personal meaning of an illness or symptom may affect self-esteem either positively or negatively. Becoming an invalid, even briefly, can be a blow to a person's self-esteem. Similarly, being unemployable or forced to accept employment at a lower wage or job status because of pain can be demeaning. However, for some patients embracing the sick role is seen as an elevation in status. These people value the nurturance and special consideration of friends, family, and neighbors that follow injury and the development of chronic pain. Personal meanings are likely to be influenced by the shared meanings of the group to which the individual belongs. Studies of various socioeconomic, cultural, and religious groups reveal that the meanings associated with pain tend to vary by group membership (McKinlay, 1975; Zborowski, 1952; Zola, 1966) and by the structural characteristics of ethnic and cultural groups (Suchman, 1965, 1966).

The meaning attributed to pain influences whether or not suffering occurs. Although suffering and pain are often associated with one another, they are distinct phenomena. First, the degree of suffering is not necessarily related to the degree of pain. People may tolerate severe pain without suffering if they understand (1) the source of the pain, (2) that it is not dire, (3) that it will end, and (4) if means exist to control it. Second, suffering commonly occurs in the absence of any physical distress, for example, in someone who is anticipating the return of a terrible pain even though the pain is not currently present, or when one is unable to help a loved one in pain. For some people, pain and suffering have religious and moral significance. The Judeo-Christian tradition has attempted to interpret the moral significance of suffering in numerous texts. Some people view pain and suffering as tests or trials of their moral worth. Others view them as conditions that may purify or "cleanse" the character or soul. Health care providers need to be sensitive to the possible clinical significance such interpretations can have both for patients and providers in the treatment of chronic pain (Cassell, 1982).

The interpretation of symptoms and the meaning assigned to them may have a profound influence on coping responses. Whether or not people who perceive a change in their physical functioning attribute the alteration to sickness will obviously influence their help-seeking behaviors. Particular meanings may result in more or less productive responses that may affect patients' rehabilitation potential. The expression and communication of pain in the family and other social settings is also influenced by the meaning attributed to the symptom.

### **Expression and Communication**

Although pain is subjective, it is the outward expression-the observable illness behaviors-of the patient in pain (rather than any subjective state or physiological indicator) that defines the severity of the problem for others. Particular words chosen by the person to describe his or her pain let others know about the experience. Movements and body postures, as well as nonverbal vocalizations (sighing, groaning) are also powerful indicators of pain states. Body language expressive of pain may include posturing, bracing, grimacing, rubbing, gasping, or withdrawal from normal activity. Facial expression is a principal cue for caregivers' perception of patient distress, which influences the level of concern expressed for the patient (Le Resche and Dworkin, 1984; von Baeyer et al., 1984). The method of pain expression influences how the individual is judged by others. While those who appear more stoical and less histrionic may have their pain taken more seriously by caregivers, it is also possible that they may be taken less seriously and receive less attention from caregivers than patients who express pain more vocally or dramatically. As discussed later in this chapter, because pain expression is influenced by familial and cultural norms, it may not be a good indicator of severity.

# Help-Seeking Behavior and Other Coping Responses

Like all the other aspects of illness behavior, how people cope with their pain or other symptoms is determined in many ways and varies from person to person. Coping responses may be more or less adaptive and more or less consciously motivated. Although some people may deny their symptoms and diseases, others may exaggerate them.

The abnormal functioning that occurs in chronic illness leads inevitably to compensatory behavior that may have positive or negative effects on subsequent symptoms and functional levels. One group of compensatory mechanisms serves to avoid unpleasant symptoms. For example, guarding a painful joint reduces its activity, which leads to increasing involuntary immobility (the origin of the common condition called "frozen shoulder"). Similarly, reduced physical activity will eventually decrease the effective muscle mass, which makes physical activity more difficult. On another level, the sick person may develop reclusive behaviors that further exaggerate the social loss of being ill.

Another group of compensatory mechanisms assists in attempts to maintain normality. So-called "overuse syndromes," for example, refer to the damage done to alternate muscle groups or joints that were used to restore lost function (e.g., walking) and have sustained too much activity. Symptom avoidance and compensatory mechanisms may aggravate the illness and produce further losses, but they may also, if used properly, facilitate coping and continued effective functioning. Thus, compensatory behaviors, initiated in response to symptoms and altered functioning, also affect subsequent functioning. As such, these compensatory mechanisms may contribute to the self-sustaining nature of chronic illness.

Malingering is an extreme example of a consciously motivated coping response. We all engage in malingering to some extent when, for example, we take a day off from work because we are not feeling entirely well but, in fact, are probably not too sick to continue our usual routines. Malingering in the sense of deliberately feigning sickness solely for the purpose of gain over a long period of time is probably uncommon, and experienced clinicians believe they can identify such behavior. There is no evidence that malingering is common in the SSA disability context.

Most people who experience symptoms and fear they are sick visit doctors. For the chronic pain patient and for health professionals, such encounters can be frustrating because the symptom is often so very difficult to diagnose and treat. The absence of a diagnosable disease does not mean the absence of abnormalities, disturbances, or alterations in bodily functions. Thus, severe illness, illness behavior, and suffering can exist in the absence of a diagnosable disease. Effective treatment of patients with chronic pain requires that health care professionals view illness broadly and not only in terms of a narrow disease model (see Chapter 10).

Some proportion of people with chronic pain use alternative care systems either in lieu of or as adjuncts to the traditional medical care system. Although it is known that musculoskeletal complaints, including pain, are a common reason for choosing alternative therapies, particularly chiropractic care, it is not known what proportion of patients with these complaints use alternative practitioners.

Some alternative practices have developed as a reaction to what a number of people perceive to be shortcomings in traditional medical care. The holistic health care and self-care movements are examples of such alternative approaches, and both of them receive considerable support from some physicians for much of their work and for their basic philosophies. The holistic health care movement emphasizes mind-body unity and positive health enhancement (Inglis and West, 1983) and integrates traditional practices of Eastern mysticism into medical programs for pain and stress relief (Benson, 1975). Holistic health care practitioners believe that analgesics should be used only minimally (Mattson, 1982), but little is known about how pain is treated in holistic health care centers. The self-care movement emphasizes the individual's role in risk avoidance and decision making. self-monitoring and diagnosis, self-treatment, and medication. Little is known about the effectiveness of the self-care approach in ameliorating chronic pain. As discussed previously, however, feeling in control of one's symptoms and illness is likely to promote better coping skills and may therefore be beneficial.

Numerous folk and religious healing traditions exist in the United States. A survey of a metropolitan suburb located 130 types of alternative healers (McGuire, 1983). In the past, scholars attributed whatever effectiveness these forms of healing may have to suggestion, catharsis, or a placebo effect. More recent research suggests that religious and folk practices may be effective insofar as they take into account essential psychosocial factors, such as patients' explanatory models of illness, that are often neglected by conventional medicine (Kleinman and Sung, 1979). In addition, these modes may help alter the meaning of illness in such a way as to allow a different and more healthy response (Csordas, 1983; Bourguignon, 1976; Frank, 1973). These observations suggest the need for research on how the transformation of the meaning of illness may contribute to the amelioration of pain and impairment, not only in religious and folk healing but also in conventional medical care.

Two specific alternative treatment modalities deserve mention. Acupuncture, a specific technique of Chinese traditional medicine, has acquired notable publicity in the last decade, although the extent of its use is not known. Findings from clinical and experimental studies of acupuncture analgesia are inconclusive (Hu, 1974). Comparison of actual and simulated (placebo) acupuncture in patients with shoulder pain (bursitis or tendonitis) demonstrated that a positive or negative therapeutic milieu determined the therapeutic response rather than the actual or simulated treatment itself (Berk et al., 1977). Several authors have discussed possible neurophysiological and psychological mechanisms (Lewith and Kenyon, 1984) and the merits of acupuncture for chronic pain (Lee, 1975; Kepes et al., 1976), but, in general, this explanatory literature leans heavily on notions of suggestibility. Good outcome studies are lacking.

Finally, chiropractors, who are licensed in all 50 states and are covered by Medicare, Medicaid, and most private insurers, treat over 7.5 million patients each year (Caplan, 1984), most of whom have musculoskeletal complaints, including pain. Those who seek care from chiropractors are more likely than other people to seek care from physicians too-they tend to be frequent users of health care services of various types, perhaps partly because of the nature of their symptoms (Cleary, 1982). Some observers report that chiropractic treatment is effective for short-term relief of back, neck, and other musculoskeletal problems, as well as for headaches (Coulehan, 1985b; Klein and Sobel, 1985). The therapeutic milieu and the chiropractor-patient relationship are believed to be significant determinants of treatment effectiveness (Coulehan, 1985a; Cowie and Roebuck, 1975; Skipper, 1978). More research on the effectiveness of chiropractic is warranted in view of the fact that so many patients use it (National Institutes of Health, 1975).

# THE INFLUENCE OF PERSONALITY, FAMILIAL, AND SOCIOCULTURAL FACTORS ON ILLNESS BEHAVIOR

All aspects of illness behavior can be influenced in important ways by an individual's personality, by his or her family, and by the broader sociocultural environment in which he or she lives.

# **Personality and Illness Behavior**

Personality, chronic pain, and illness behavior interact in complex ways that are not fully understood. Both normal and abnormal influences of personality on the etiology and maintenance of symptoms and on illness behavior have been identified. In the next chapter, "Psychiatric Aspects of Chronic Pain," we explore pathological aspects of personality; here the focus is on normal tendencies that are related to personality and coping styles. Of particular importance for understanding chronic pain is the process known as somatization.

Somatization is the expression of psychosocial problems in bodily complaints. It is a communication process in which headaches, back and other pain, as well as a great variety of other symptoms—all of which usually have some physiological basis—become an alternative means for expressing personal problems and interpersonal tensions. In social systems and families in which psychological or social distress is neither authorized nor responded to, the somatic communication of such problems may be one of the only means by which interpersonal negotiations can encompass these issues (albeit usually indirectly) (Mechanic, 1972). Therefore, somatization is a dimension of illness behavior that holds special relevance for the appreciation of the broader context of chronic pain. It does not connote malingering or willful exaggeration.

The cross-cultural literature discloses that in all societies the body serves to some extent to register, express, and negotiate life difficulties (Good, 1977; Kleinman and Kleinman, 1985). Moreover, as is true of other illness behaviors, people learn to somatize in ways that are understood by others and sanctioned as appropriate. Somatization, like language, is a learned form of expression modeled for us by parents, friends and the media. Communicating indirectly about problems in a marriage, a job, or a community via headaches, backaches, abdominal cramps, and other forms of pain usually is not only more acceptable than direct complaints, but often is more effective in obtaining help, gaining time off or away, and changing difficult relationships and life circumstances (Kirmayer, 1984). Somatization in this perspective is not an abnormal process but a mode of attempted adaptation to the social environment and a mode created and made available by the culture or social group, not by the individual. Preexisting symptoms may be amplified or exacerbated by the psychophysiology of stress; the unintentional mislabeling of normal physiological changes; the presence of other pathology; and changes in endocrine, cardiovascular, and gastrointestinal functioning and in the autonomic nervous system (Kleinman, 1986).

Somatization is common in all societies but may become even more frequent for groups and individuals under greater socioeconomic and political pressures, such as in situations of unemployment, migration

and refugeehood, and under local conditions of powerlessness and oppression (Lock, in press). From a sociocultural perspective, the sources of somatization result from a combination of the large social forces (economic system, historical circumstances, political pressures, or cultural norms) and the local social situation (family, work, or community) that places certain individuals and categories of individuals at greater risk for disease, distress, and demoralization. Interaction between these social conditions and the physical and mental state of a particular person provides the basis for symptom amplification and the possibility of a resulting disability.

Furthermore, as discussed elsewhere in this report, health professionals and the disability system may unintentionally contribute to somatization (and other illness behaviors). By focusing narrowly on patients' bodily complaints, by ordering numerous tests to try to confirm a physical diagnosis, and by questioning the validity of patients' complaints that are not clearly accounted for by a diagnosis. health care professionals may encourage the conscious or unconscious elaboration of symptoms (Barsky, 1979) (see Chapter 10). Some observers believe that disability programs may also contribute to chronic amplification of physical complaints through their eligibility requirements that emphasize the physical manifestations of disease or injury (Katon et al., 1982, 1984) and their economic rewards (see Chapter 4). For the patient, inappropriate medical care may result in polypharmacy, drug dependence, dangerous and unnecessary surgery, and illness directly attributable to medical intervention (iatrogenesis).

# **Family Influences**

The family typically has a profound influence on the health, illness trajectories, symptom expression, and coping behaviors of its members. Problems and stress within the family may contribute to the development of illness and may affect its expression. Ways of coping with and communicating about illness and symptoms may be learned from other family members, and health care usually begins in the family. Several findings support the hypothesis that the family is an important factor in the etiology and maintenance of pain.

There is evidence that chronic pain problems are much more frequent in some families than in others (Violon, 1985), but the reasons for this are not well understood. As discussed in Chapter 9, chronic pain patients are more likely than others in the population to have had parents or other family members with chronic pain conditions (Apley, 1975; Gentry et al., 1974; Turk et al., 1985). Clinical observations indicate that chronic pain patients are more likely to have suffered physical or emotional abuse than have others (Engel, 1959) and that chronic pain patients frequently come from families with a history of depression, alcoholism, and spouse abuse (Blumer and Heilbronn, 1982). There is disagreement about whether there is a genetic component that predisposes some people to chronic pain (Apley, 1975; Craig, 1980; Edwards et al., 1985; Violon and Giurgea, 1984; Christensen and Mortensen, 1975).

The hypothesis that pain is an illness behavior learned in the family is less controversial than the genetic hypothesis. Two types of learning may occur-modeling (copying or imitating a behavior pattern exhibited by another person in a similar circumstance; see Bandura, 1969) and conditioning or operant learning (in which rewards for particular behaviors reinforce them). Part of children's socialization includes learning about appropriate illness behavior. Thus, children learn their pain responses in part from their parents' examples and rearing methods. Conditioning may occur naturally and without planning, and even without the awareness of the individual. The most fundamental concept in operant learning is that any behavior followed by an event favorable to the individual is increasingly likely to occur again when a similar situation arises. Thus, for example, the presence of rewarding events that occur in association with pain behavior may increase the frequency and intensity of pain expression; similarly, eliminating such rewards may reduce pain expressions from the patient's behavioral repertoire. Rewards for pain patients often consist of attention. nurturance, sympathy, time out from unpleasant obligations, and, sometimes, financial compensation. For patients who are chronically deprived of normal attention and understanding from family members or associates, the expectation of these rewards may result in a dramatic reaction to injury and persistent and dramatic expressions of pain (Fordyce, 1976; Kremer et al., 1985). In contrast to the behavioral view of pain is the psychodynamic view that pain may serve an intrapsychic (as opposed to an interpersonal) need. According to this view, simply limiting reinforcement will not in itself solve the problem. In fact, it may exacerbate it by causing the individual to feel more neglected and despondent.

Sometimes pain is used as a way to avoid facing other problems in family relationships, especially between spouses. In such cases an unconscious collusion between the spouse and the pain patient may develop to maintain the pain behavior. Because so much time and energy is taken up with the pain problem, other aspects of life and relationships can be ignored. Pain and illness can also be used, often

without awareness, to avoid intimacy (Roy, 1984; Waring, 1982). In these cases, chronic pain and illness may stabilize a family that is experiencing difficulties in its interpersonal relationships or is stressed by features of its socioeconomic environment. For some families, attending to the illness of one of its members may be the only way the family can continue to function (Minuchin, 1974).

As discussed previously, somatization is a particular form of illness behavior that is likely to be reinforced in some families, especially those in which the recognition and open expression of feelings is discouraged and in which tensions among family members can only be expressed indirectly through somatic complaints.

There is a great deal of literature indicating that chronic illness in one member of a family adversely affects other members as well (e.g., Lask and Matthew, 1979; Shambaugh and Kanter, 1969). Increased stressrelated complaints and illnesses in the spouse and other household members have been very commonly reported after the development of chronic pain in a family member (Shanfield et al., 1979; Flor and Turk, 1985). Factors contributing to the development of such illnesses among family members may include increased responsibilities for the rest of the family when one member is incapacitated by pain, alteration in roles, or financial problems as a result of a member not being able to work.

The importance of family influences on the development and maintenance of chronic pain and pain behavior raises questions about the possibility of intervening to prevent the development of a pain problem or to help prevent an acute situation from becoming chronic. Some researchers and therapists have observed that successful therapy is very difficult to achieve when both members of a couple are heavily involved in maintaining the pain behavior (Roy, 1985). Good, wellcontrolled research is lacking in this area.

#### **Cultural Influences**

Culture is the integrated pattern of learned behavior accumulated over generations and transmitted to the young or to newcomers in a group. It is a major constituent of human personality and the organized web of associations that we call community. "Culture" is an abstract way of characterizing the ways of adapting to the environment that individuals share. Culture affects every aspect of behavior. It determines not only how we perceive and react to physical dysfunction and personal distress but also what aspects of personal experience and behavior are understood as problems of health and illness (Kleinman, 1980). Patterns of health and illness behavior, which develop first in the family, vary for men and women and for different social classes and ethnic groups. In Western society men are expected to be stoical and willing to accept pain and discomfort; women are less inhibited in expressing their distress. Such cultural learning may account for the fact that women report more symptoms and use more medical services than men. Persons in higher social classes are more likely to become knowledgeable about health and disease and to develop preventive health patterns than their lower-class counterparts. Most dramatic, however, are the variations among ethnic subcultures and the manner in which they view illness and use health services.

Response to pain and distress is influenced by cultural conditioning. Although physiological pain thresholds do not appear to differ substantially from culture to culture (Lipton and Marbach, 1984; Garron and Leavitt, 1979), reaction to pain varies and reflects the beliefs of the group (Zola, 1966; Winsberg and Greenlick, 1967). It has been observed, for example, that some ethnic groups, such as Italians and Jews, are likely to be expressive about pain, and some, such as the Irish, are likely to learn a pattern of denial. Moreover, despite the similarity of response, Italians seem more concerned with pain itself, whereas Jews are more likely to worry about the significance of pain for their future well-being (Zborowski, 1952, 1969).

Studies of chronic pain have tended to emphasize ethnic differences in people's reactions to pain rather than analyzing how culture shapes the experience. Understanding such differences adds to the ability of professionals to relate to patients in a meaningful way and to gain rapport with them. One study, for example, found that physicians at the Massachusetts General Hospital—a Harvard-affiliated institution—confused the learned emotionality of Italian patients with psychiatric symptoms (Zola, 1963). These patients, part of a culture that encourages the open expression of distress, often express their symptoms with much affect. Those unfamiliar with Italian culture can confuse the cultural mode of expression (the affect associated with the report of symptoms) with the severity of the symptoms being reported, and especially careful clinical assessment is essential. Clinicians must also be aware of their own cultural prejudices and recognize that patients' pain expressions will vary.

This example also illustrates the difficulty of using cultural or ethnic differences as markers because clearly it is inappropriate to generalize from group observations to the individual patient. There is a great deal of variation in all groups, and patients must be individually evaluated. Understanding cultural differences assists physicians in their individual inquiries and may help direct their questioning of patients. Yet, such information is never appropriate for prediction in individual instances and should not be used in this way. Clearly, culture exerts a powerful influence on pain expression and other illness behaviors. However, knowledge of these influences can only serve to sensitize clinicians to inquire more carefully and listen more attentively in sorting out (to the extent possible) how much a patient's responses derive from underlying disease and how much from the sociocultural situation.

# CONCLUSIONS

By examining various psychological, familial, social, and cultural influences on illness behavior, we have tried to illustrate the many sources of variation observed in chronic pain patients. Responses to alterations in bodily functions are consciously and unconsciously determined by a complex web of interacting influences. No one variable will ever fully account for the patient's experience with pain and illness. There also is no one-to-one correlation between pain behavior and disease and no single psychological profile of chronic pain patients. Social factors may strongly influence pain behavior but they are not fully determinative; culture and ethnicity may determine certain components of the pain experience, but cultural characteristics must be understood as general patterns that may or may not be relevant in the case of any particular individual. Not everyone responds in culturally predictable ways; neither can it be assumed that each social or cultural group is unique.

There can be no clear-cut manual of responses to pain patients of particular sociodemographic, occupational, or cultural groups for use by health care providers or disability evaluators. Understanding that these and other characteristics can influence the perception of symptoms, the meaning attributed to them, and how they are expressed and coped with sensitizes health care professionals and disability examiners to potential sources of variation. It can lead to better history taking and communication about illness and treatment, but it does not provide a formula for how to interpret and treat patients' complaints or illness behaviors (see Chapter 10). Illness behavior is useful for understanding observed differences. The fact that individuals perceive, interpret, express, and cope with their pain in different ways does not in itself address the question of who should receive disability benefits. As discussed in Chapters 2 and 4, that is ultimately a political and moral issue about which societies must decide.

What this chapter suggests for the disability system is the impor-

tance of conducting assessments of individual claimants that are broad enough to take account of the experience of the individual. Simply knowing a person's diagnosis is unlikely to be a good proxy for presuming a particular level of impairment. The meaning of the illness and the experience of the individual are crucial to assessing functional capacities and limitations.

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# 9 Psychiatric Aspects of Chronic Pain

The previous chapter dealt with normal social and psychological processes that influence the course and expression of chronic pain. There is also evidence that chronic pain is associated with mental disorders and substance abuse, although the nature of the relation, especially in terms of cause and effect, is often unclear. Just as there is diversity among chronic pain patients in general, so, too, are individuals with chronic pain and psychiatric disorders a heterogeneous group: many have affective disorders (particularly depression); others suffer from substance abuse, personality disorders, and various somatoform disorders such as conversion, hypochondriasis, and somatization disorder (not to be confused with "somatization" as a normal process, as discussed in Chapter 8). In some patients, certain of these varied disorders may be secondary to chronic pain, but in others they predate the onset of pain or reflect alternative expressions of the same underlying psychobiological disorder. Whatever their etiological significance, each of these psychiatric disorders may exacerbate the pain condition and impede recovery. Identification and treatment of any mental disorder or substance abuse problem that may be present is essential to the successful rehabilitation of individuals with chronic pain. At the same time, clinicians must be careful not to presume that chronic pain complaints that cannot be accounted for readily by physiological findings are due to psychiatric disorders. As discussed in Chapter 10, clinical assessments performed very early in the course of a disease may not reveal the underlying cause of pain. Thus, it is important to pursue both physiological and
psychological assessments to make certain not to overlook important diagnoses that may account for the pain either alone or in combination.

### EPIDEMIOLOGY OF CERTAIN PSYCHIATRIC DISORDERS

Depression is one of the most pervasive and, paradoxically, least well diagnosed and treated conditions confronting medical practitioners. As a syndrome it is often associated with symptoms of anxiety. The National Institute of Mental Health (NIMH) Epidemiological Catchment Area (ECA) project, a community population survey conducted in five areas of the United States using a structured diagnostic interview with community residents, has provided useful data on the prevalence of various mental disorders (Regier et al., 1984; Myers et al., 1984; Robins et al., 1984; Blazer et al., 1985). Six-month prevalence of affective disorders ranged from 4.6 to 6.5 percent in three ECA sites; prevalence of anxiety/somatoform disorders varied far more widely, from 6.6 to 14.9 percent (largely because of differences across sites in rates of phobic disorders). We can thus conclude that depression is a common illness. Anxiety and somatoform disorders are even more common.

Several studies from the ECA project show that individuals with affective disorders seek medical care more often than individuals without psychiatric disorders, they often seek care for medical or somatic symptoms (including pain) rather than for psychiatric symptoms, and they often are only seen in the general medical care sector (Shapiro et al., 1984; Horgan, 1975; Regier et al., 1978). Weissman et al. (1981) also have identified increased use of both general health and mental health services by those with depression, but they noted that the overall proportion of those who receive any treatment at all directed toward their mental disorder is low. Keller et al. (1982) report that even among those who do receive some treatment for depression it is likely to be inadequate. Finally, those with depression who do not receive treatment for their emotional problems make relatively frequent visits to nonpsychiatric physicians. Depressed individuals use health and mental care services more than most individuals with other diagnosable psychiatric disorders.

Surveys of medical clinic populations corroborate the findings from the epidemiological studies. For example, in one study of a primary care clinic, 35 percent of the study group exhibited at least one psychiatric disorder at one of two interviews conducted 6 months apart (Kessler et al., 1985). Various studies have identified between 10 and 40 percent of ambulatory medical patients as depressed on standard-

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ized rating scales or structured diagnostic interviews (Glass et al., 1978; Nielsen and Williams, 1980; Goldberg, 1979). The higher rates may be associated with the use of screening instruments that score somatic symptoms as part of depression (see last section of this chapter). The highest reported rates (approaching 50 percent of patients seen in ambulatory practice) probably reflect an intermixture of depressive, anxiety, and somatic symptoms. Studies using standardized diagnostic interviews, such as the Schedule for Affective Disorders and Schizophrenia (SADS), report a lower but still significant prevalence of major depression in medical clinic populations. Despite differences in the methodologies, all of these studies document that psychiatric disorders, when present in patients seen in medical clinics, are not routinely diagnosed or appropriately treated. It appears that like their patients, physicians in these settings tend to focus on "medical" or somatic symptoms rather than recognizing emotional factors or psychiatric disorders.

### CHRONIC PAIN, DEPRESSION, AND ANXIETY

A substantial amount of research has explored the possible relation between depressive disorders and chronic pain (Gupta, 1986). Studies have reported widely varying prevalence of both depressive symptoms and diagnosable depression in pain patients (10-87 percent), as well as widely varying prevalence of pain symptoms in clinically depressed patients (27-100 percent) (Romano and Turner, 1985). Discrepancies in the reported prevalence of depression in patients with chronic pain result from the use of different instruments to measure depression with varying sensitivity and specificity (Rodin and Voshart, 1986). These discrepancies also result from a failure to distinguish between the presence of various depressive symptoms (e.g., tearfulness, sadness, diminished interest in activities, etc.) and the presence of a specific affective disorder, particularly diagnosable major depression (a relatively well-defined syndrome characterized by prolonged disturbance of mood or pervasive lack of interest or pleasure; the presence of many other cognitive, vegetative, and psychological symptoms of depression associated with alterations of brain neurotransmitters and hormonal systems; as well as disturbances of the autonomic nervous system. circadian rhythm, and rapid eye movements during sleep) (American Psychiatric Association, 1980). In a recent study of 283 consecutive admissions to a comprehensive pain center, extensive psychiatric evaluations based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) (American Psychiatric Association, 1980) re-

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vealed that half of the men and almost two-thirds of the women suffered from affective disorders and that anxiety disorders were present in 59 percent of men and 66 percent of women (Fishbain et al., 1986). Thus, the preponderance of studies suggest that there is a considerable association between chronic pain, depressive symptoms, and major depression (Romano and Turner, 1985). This association can be conceptualized in a number of different ways.

### Chronic Pain, Depression, and Somatoform Disorders

The essential features of somatoform disorders "are physical symptoms suggesting physical disorder . . . for which there are no demonstrable organic findings or known physiological mechanisms and for which there is positive evidence, or a strong presumption, that the symptoms are linked to psychological factors or conflicts" (American Psychiatric Association, 1980). Several specific syndromes are classified as somatoform disorders, including hypochondriasis, conversion disorder, psychogenic pain disorder, and somatization disorder. Unlike malingering, the symptom production in somatoform disorders is not under voluntary control.

One way of conceptualizing the association between chronic pain and depression is to consider chronic pain as a particular type of somatization—the expression of feelings through bodily complaints. including pain; somatization often occurs in the absence of conscious awareness of the underlying feelings. Blumer and Heilbronn (1982) describe a "pain prone disorder" as a variant of a depressive disorder. They identify a constellation of (1) somatic complaints, including continuous pain of obscure origin, hypochondriacal preoccupation, and desire for surgery combined with (2) depression as evinced by anergia, fatigue, anhedonia, insomnia, and depressed or despairing mood with (3) certain personality factors. They characterize these patients as solid citizens who deny conflicts, idealize self and family, and were "workaholics" prior to the onset of pain. Further, such individuals tend to have a family history of depression and alcoholism and commonly have family members who are handicapped or afflicted with chronic pain.

Chronic pain is considered by some authors to be the most common form of somatization in American society (Katon et al., 1984). As discussed in the previous chapter, everyone somatizes to some extent, but in some individuals and cultural groups the tendency to somatize is more exaggerated than in others. This *tendency to somatize* is different from *somatization disorder*, a specific clinical syndrome.

Somatization disorder (formerly subsumed under the term hysteria) is a chronic psychiatric condition beginning before age 30, more commonly in women than men, in which the sick person has many physical complaints and impairments either in the absence of organic pathology or greatly in excess of the degree of pathology. Somatization disorder has rather rigid and lengthy diagnostic criteria (14 symptoms from various body systems). The symptoms are multiple, shifting, and often vague, affecting a number of organ systems (gastrointestinal, cardiopulmonary, neurological, or reproductive). Pain is a frequent complaint, as are depressive symptoms. Usually the affected person repeatedly seeks medical care (American Psychiatric Association, 1980). Many chronic pain patients involved in the disability process have traits of this disorder without meeting the full DSM-III criteria. Fishbain and his colleagues (1986) made the diagnosis of somatization disorder in 0.6 percent of men and 8 percent of women in their study of 283 admissions to the University of Miami Comprehensive Pain Clinic. Similarly, Reich and colleagues (1983) diagnosed somatization disorder in none of the men and in 12 percent of the women in a series of 43 consecutive chronic pain patients who had not responded well to conventional treatment.

In the absence of coexisting major depression, clinicians have found that pharmacological interventions and psychodynamic psychotherapies are often of little value in the treatment of somatization disorder. There are reports, however, that certain modifications in psychodynamic psychotherapy do seem useful-especially in the treatment for patients with alexithymia (an inability to perceive and express the mental component of their feeling state) (Krystal, 1979). A cognitive and behavioral approach may also be helpful (Katon et al., 1982a,b). A central goal in the management of somatization disorder is to keep these patients from unnecessary surgery, expensive and potentially dangerous tests, and polypharmacy with untoward side effects and potential addiction to analgesics or sedatives. Such an approach requires primary care physicians to be well-informed, empathic, and protective. The utility of making the diagnosis of somatization disorder is to prevent these problems as well as unnecessary costs to the patient and the medical care system.

Several other somatoform disorders may be present in patients with pain. Some people with *conversion disorder* (characterized by an involuntary "loss or alteration in physical functioning that suggests physical disorder but which instead is apparently an expression of a psychological conflict or need"; American Psychiatric Association, 1980) have chronic pain as a symptom, although if pain were the only symptom, the diagnosis would not be appropriate. In Fishbain and his colleagues' (1986) study, this was the most common somatoform disorder diagnosed (42 percent of men and 32 percent of women). On the other hand, Reich and colleagues (1983) found only 2 cases out of their series of 43 pain patients (less than 5 percent).

A predominant complaint of pain "in the absence of adequate physical findings and in association with evidence of the etiological role of psychological factors," but without other mental disorder, is the essential feature of psychogenic pain disorder. There has been considerable controversy about the implications of this diagnosis when used in clinical care; it will be replaced with the more neutral term "somatoform pain disorder" when DSM-III is revised by the American Psychiatric Association in 1987. Because the establishment of the diagnosis rests heavily on the exclusion of all organic causes for pain. there is great variability in the frequency with which it is used. For example, at the University of California at Davis, 20 percent of men and 32 percent of women with chronic pain were diagnosed with psychogenic pain disorder (Reich et al., 1983). However, at the University of Miami, where 85 percent of pain patients were given an "organic treatment diagnosis" of myofascial pain syndrome, none of the women and only 0.6 percent of the men were classified as having psychogenic pain disorder (Fishbain et al., 1986). On the basis of their own clinical experience, members of the Commission on the Evaluation of Pain and of the Institute of Medicine (IOM) study committee believed this diagnosis to be relatively uncommon in adults and not often very useful. Furthermore, the Social Security Administration (SSA) reports that the diagnosis of psychogenic pain is rarely the basis for disability determinations.

Hypochondriasis is another somatoform disorder that may involve pain. "The essential feature is a clinical picture in which the predominant disturbance is an unrealistic interpretation of physical signs or sensations as abnormal, leading to preoccupation with the fear or belief of having a serious disease" (American Psychiatric Association, 1980). Thus, hypochondriasis is distinguished from somatization disorder by the fear of disease rather than the amplification and generation of symptoms. What Pilowsky (1967, 1978) terms "abnormal illness behavior" is an extreme form of hypochondriasis produced primarily by the social environment. Although it is widely considered to be a common disorder in general medical practice, less than 1 percent of the patients in the Miami pain center study were given this diagnosis (Fishbain et al., 1986). Seven percent of the patients in the California study met the criteria for this disorder (Reich et al., 1983). As noted previously, all of these conditions are distinguished from factitious disorder and malingering. Somatoform disorders involve the involuntary (i.e., not consciously motivated) production of symptoms, but in factitious disorders and malingering the patient experiences voluntary control of symptoms. *Factitious disorder* involves the intentional production or feigning of physical or psychological symptoms, including pain. There is a psychological urge to make oneself ill and assume the sick role. Often these patients migrate from one medical agency to another. Unlike malingering there are no external incentives for this behavior, such as economic gain. It is a rare cause of chronic pain. Long-term psychotherapy may be helpful—if the person will stay in it—because such patients usually have severe personality disorders or other mental disorders.

*Malingering* is the intentional production of false symptoms motivated by external incentives, such as avoiding military duty or work, obtaining financial compensation or drugs, and so on. Pain experts believe malingering is uncommon and can be detected, but there is virtually no systematic research on this topic.

The taxonomy of somatoform disorders is controversial, and the criteria for these diagnoses are being revised by the American Psychiatric Association. They represent a group of empirically derived diagnoses with somewhat arbitrary symptoms, they are not theoretically based, and they all assume that a thorough and adequate physical examination has ruled out organic disease or anatomical abnormalities that would account for the symptomatology. Furthermore, clinical experience with chronic pain patients suggests that the diagnoses are not very useful or appropriate. Most chronic pain patients have some physical findings, even if they are only minimal. Their very presence, however, makes the diagnosis of psychogenic pain disorder inappropriate. Because few chronic pain patients have nosophobia, the diagnosis of hypochondriasis is inappropriate. Very few pain patients meet the stringent criteria for somatization disorder. That leaves a catch-all category-atypical somatoform disorders-that has no criteria and therefore is not a useful diagnosis.

### A Neurobiological View of Chronic Pain and Depression

An alternative, although perhaps complementary, way of conceptualizing the relation between chronic pain and depression is to regard them as having common neurobiological mechanisms. Alterations in the neurotransmitters serotonin and norepinephrine have been implicated in various forms of depressive illness. These also have been

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shown to play critical roles in the mediation of opiate- and stimulationproduced analgesia in pain modulation. For example, manipulations that decrease serotonergic function also decrease analgesia (Samanin et al., 1970; Messing et al., 1976; Akil and Mayer 1972). Conversely, enhanced serotonergic function also increases antinociceptive effects (Samanin and Valzelli, 1971; Sewell and Spencer, 1974; Sternbach et al., 1976; Modigh, 1973). The effects of norepinephrine are different in the brain than in the spinal cord. In the brain, norepinephrine appears to have effects on analgesia that are opposite to serotonin: Decreased noradrenergic function causes increased analgesia, whereas decreased analgesia results from direct intracerebroventricular injection of norepinephrine (Akil and Liebeskind, 1975). Studies with agonists and antagonists of dopamine, from which norepinephrine is synthesized, indicate that it has analgesia-enhancing effects (Pasternak, 1982). There is also evidence implicating other neurotransmitters and neuropeptides (e.g., acetylcholine,  $\gamma$ -aminobutyric acid, and substance P) (Gebhart, 1983). Research in this area is yielding important insights about the neurobiology of pain and depression. Studies of family members of patients with chronic pain could be particularly useful in determining the extent to which chronic pain and depression share common neurobiological mechanisms.

### **Depression as a Consequence of Chronic Pain**

In addition to depression as a contributory cause of pain and depression as a neurobiological companion to pain, a third way of conceptualizing the relation between chronic pain and depression is to regard depression as resulting from inescapable chronic pain-that is. depression results from learned helplessness and demoralization. Pelz and Merskey (1982) demonstrated that for some chronic pain patients there are long-term psychological effects, including depression, and that the rates and nature of these effects are not different in patients either receiving or not receiving disability payments. The findings in one study (Blumer et al., 1982) that patients with chronic pain from rheumatoid arthritis suffered less depression than patients with idiopathic chronic pain might argue against this interpretation because both groups suffered from prolonged pain. It is possible, however, that the rheumatoid arthritis patients suffered less pain, received more relief from treatment, and received fewer opiates than patients with idiopathic chronic pain. Additionally, rheumatoid arthritis patients may be somewhat protected from demoralization and adverse social consequences because the diagnosis and source of their pain is known.

Prospective studies of the incidence of depression (the new occurrence of depression) in chronic pain patients with no previous history of depressive episodes would help to determine the extent to which depression is secondary to chronic pain.

### **Depressive Symptoms as a Consequence of Drug Therapy**

Because chronic pain is often so difficult to diagnose and treat effectively, patients frequently seek care from multiple providers and are likely to become involved in polypharmacy. Indeed, as discussed in Chapter 12, often the first step in rehabilitation in multidisciplinary pain clinics is to wean patients from their multiple and high doses of drugs. Drugs clearly can be useful in the treatment of chronic pain (Portenoy and Foley, 1986), often providing the relief needed to carry on normal activities, but they may also produce side effects, which at the very least should be monitored and which may be cause to alter therapeutic regimens.

Many patients experience depressive symptoms, sometimes of great severity, as the inadvertent result of the medication prescribed to relieve their pain and related symptoms (Hall et al., 1980; Perl et al., 1980). Depressed mentation, mental clouding, and sedation are common. The three types of medication with a substantial risk of adverse alterations of mood and functioning are opiate analgesics, benzodiazepines, and barbiturate and nonbarbiturate hypnotics. Overuse of opiate analgesics, even when it does not lead to frank addiction, may cause depressed mood and other untoward side effects. When benzodiazepines are used (to relieve muscle tension, anxiety, or insomnia) the effects on mood and functioning may go undetected by health care personnel. Vigilance about drug dependence, adverse side effects. and prolonged withdrawal syndromes is a well-established practice in the prescription of opiates and barbiturates-but is much less so with other classes of drugs used with pain patients. For example, many people in pain have a very difficult time sleeping and greatly overuse nighttime sedative-hypnotic drugs. Some of these drugs, especially certain benzodiazepines, are very long acting and can adversely affect daytime mood, cognition, and coordination. Once again, the patient and physician may not be alert to this possibility, because the medication is prescribed at night and is not one of the heavily controlled "dangerous" substances like the opiate analgesics, which are classified as narcotics (Institute of Medicine, 1979; Solomon et al., 1979; Busto et al., 1986; Hendler, 1981). (See Chapter 10 for additional information about commonly prescribed drugs for pain.)

### **TREATMENT OF DEPRESSIVE DISORDERS IN THE CHRONIC** PAIN PATIENT

Even if depression in patients with chronic pain is only a fortuitous finding (resulting from a referral bias), which seems unlikely, treatment of depression in chronic pain patients may be an essential component of successful rehabilitation (Aronoff, 1981). An untreated major depression is likely not only to exacerbate the chronic pain but also to interfere with the success of other treatments for pain. Consideration of the various ways of conceptualizing the relation between chronic pain and depression has important implications for treatment. For example, to the extent that depression results from demoralization and learned helplessness, both of which are frequent concomitants of chronic pain, successful treatment of pain would be expected to ameliorate depression (Kramlinger et al., 1983).

### **Psychotherapeutic Treatment**

Numerous psychotherapeutic approaches have been used with depressed patients, including those with chronic pain. Although detailed discussion of these techniques goes beyond the scope of this volume. several approaches deserve mention. In recent years there has been a growing interest in the development of short-term psychotherapeutic treatment with well-defined therapeutic goals and techniques that can be evaluated by specific criteria and that allow for comparisons among various approaches. For example, the NIMH Collaborative Study of Depression compared the effectiveness of drug treatment and brief psychotherapy in a randomized controlled study. At the end of 16 weeks there were no statistically significant differences between a fixed dose of Imipramine, interpersonal psychotherapy, and cognitive therapy for the outpatient treatment of depression. Imipramine was superior to placebo treatment, and all three treatments were superior to "routine clinical management." While Imipramine worked faster than the psychotherapeutic modalities to relieve depressive symptoms, ultimately all three modalities achieved similar results (Elkin et al., 1986).

Interpersonal therapy is based on a model postulating that depression results from difficulties in interpersonal relationships. The task of interpersonal therapy is to identify the specific, current relationship difficulties or patterns of relating that are damaging to the patient's self-esteem, and to enable the patient to learn alternative ways of interacting that may lead to improved relationships and to an improved mood. Cognitive therapy is based on a model that views depression as resulting from faulty cognitions about the self and others (including negative self-images) and faulty beliefs about the future. The task of cognitive therapy is to identify these faulty cognitions, to enable the patient to recognize that the thoughts are mistaken, and to substitute alternative cognitive structures that can lead to improved affective and behavioral responses. In combination with behavioral therapies, cognitive therapy has been found useful in the treatment of chronic pain patients (Turner, 1982; Turner and Chapman, 1982). The cognitive-behavioral approach to chronic pain teaches patients specific cognitive skills (e.g., anticipating the occurrence of pain and diverting attention to nonpainful thoughts) and helps the patient to become aware of psychosocial influences that affect the pain experience, all of which may allow better coping with pain (Turk and Meichenbaum, 1984; Weisenberg, 1984).

Clinical practice suggests that the combined use of various psychotherapeutic techniques aimed at ameliorating specific difficulties (e.g., self-image, faulty cognitive structures, and interpersonal difficulties), in addition to pharmacological interventions aimed at ameliorating vegetative symptoms, is efficacious (Klerman et al., 1984; Hamburg et al., 1982).

### **Psychopharmacological Treatment of Pain**

It is often observed clinically that when pain occurs as a symptom of a primary psychiatric disorder, successful pharmacological treatment directed at the disorder itself is accompanied by alleviation of the pain. Response of a primary depressive disorder to antidepressant drugs, for example, will generally include a parallel improvement in any painrelated complaints that may be symptomatic manifestations of the depression. Thus, in their conceptualization of "pain prone disorder" as a variant of depression, Blumer and Heilbronn (1982) view the response of the pain to antidepressants as related to the response of the syndrome as a whole to these drugs. Similarly, improvement in psychotic symptoms that take the form of pain-related complaints (e.g., somatic delusions or tactile hallucinations) accompanies the global response of psychotic syndromes to neuroleptic (antipsychotic) drugs.

Apart from their efficacy in relieving pain that is clearly secondary to primary psychiatric disorders, psychotropic drugs have been found to have more general benefits in the relief of chronic pain (Goodman and Charney, 1985). The adaptation of newer strategies from mainstream psychopharmacology, such as the systematic evaluation of combination

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and augmentation approaches (Price, in press), promises to further enhance the therapeutic armamentarium against pain disorders.

The most widely used psychotropic drugs in the management of chronic pain are antidepressants, primarily of the tricyclic class. Both uncontrolled and controlled studies support the efficacy of these agents in a variety of pain syndromes (France et al., 1984). Efficacy has been demonstrated both concurrently with and independent of antidepressant actions per se (Feinmann, 1985). In most cases, the analgesic effects of antidepressants occur more rapidly and at lower doses than the antidepressant actions. The profound effects of these drugs on the serotonergic and noradrenergic systems, both implicated in pain mediation, probably account for their analgesic properties. However, some antidepressants may interact more directly with endogenous opioid systems (Isenberg and Cicero, 1984).

Psychopharmacological treatment of chronic anxiety associated with pain has led to the use of a variety of agents, both on the basis of their phenomenological effects (anxiety reduction) and their neurochemical actions. For example, anxiolytic drugs, particularly benzodiazepines, are used adjunctively in the management of many medical and psychiatric disorders in which anxiety is prominent. There is little controlled evidence to support their efficacy in treating pain conditions, except for short-term muscle relaxation. Clinical authorities are virtually unanimous in cautioning against their long-term use (Stimmel, 1983; Hendler, 1981). Used inappropriately, these drugs can cause cognitive impairment in conjunction with physiological and psychological dependence, thereby complicating other pharmacological and nonpharmacological treatment interventions. In selected cases, however, the circumscribed use of benzodiazepines for managing concomitant anxiety may be justified. The use of barbiturates and related compounds for this purpose is rarely warranted, given the greater potential for abuse and toxicity of these agents (Worz, 1983).

Neuroleptics (antipsychotic drugs), particularly phenothiazines and butyrophenones, have been proposed as analgesic and anesthetic adjuvants since their discovery. Although many anecdotal reports of efficacy have been published, the number of controlled studies is surprisingly small (Foley, 1985; Stimmel, 1983). (One phenothiazine, methotrimeprazine, is specifically marketed as an analgesic and may have some unique properties in this regard, although even here the evidence is weak.) Dopamine antagonism is believed to underlie the action of these drugs in relieving symptoms of psychosis, but their analgesic properties may depend more on their interactions with pain-modulation pathways in the central nervous system, especially the serotonergic, noradrenergic, and endogenous opioid systems (Gebhart, 1983).

Sporadic reports have claimed analgesic efficacy for other classes of psychotropic drugs, such as lithium and stimulants, but their clinical use for this indication is not common. Suggestions that amine precursors, such as tryptophan and L-Dopa, might also be of benefit are presently unsubstantiated.

### ADDICTION AND ALCOHOLISM

Significant rates of alcoholism and drug abuse are found among chronic pain patients (Schottenfeld, 1986). Maruta et al. (1979) at the Mayo Clinic reported that 24 percent of a consecutive series of patients referred for the treatment of chronic pain were addicted to prescription drugs and another 41 percent were misusing medication to such an extent that they were classified as drug abusers. In a recent Scandinavian study (Sandstrom et al., 1984), 50 patients with chronic low back pain were compared with a group matched for age, sex, and socioeconomic status. Of 34 male chronic pain patients, 14 had previously sought alcohol treatment (41 percent) as contrasted to only 6 of 34 controls (18 percent). Low back pain patients, particularly men, are often found to have higher rates of alcoholism than control populations; and disabled low back pain patients have higher rates than nondisabled patients. Longitudinal studies would be useful to determine whether alcoholism contributes to disability, is an associated noncontributory factor, or increases with disability duration.

Patients with substance abuse disorders often have associated depression (Weissman et al., 1977; Rounsaville et al., 1982; Kamerow et al., 1986). Weissman and Myers (1980) identified 15 percent of alcoholics as having coexisting major depression. Of those patients, they identified approximately 40 percent as having depression secondary to the alcoholism. The prevalence of major depression in a study of 533 opiate addicts was 24 percent (Rounsaville et al., 1982). The data indicate clearly that these problems are interconnected—depression and anxiety states, depression and drug dependency, substance abuse and depression, and all of these with chronic pain. However, the role of alcohol and other substance abuse in the genesis and maintenance of chronic pain is poorly understood.

Treatment considerations regarding alcoholism or drug abuse and/or dependency in patients with chronic pain are similar to the considerations for the treatment of depression in these patients. Regardless of whether substance abuse is a cause, an effect, or merely a fortuitous

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concomitant feature of chronic pain, recognition and treatment of substance abuse disorders is likely to be an essential component of successful rehabilitation of the chronic pain patient. Depressive symptoms are likely to resolve spontaneously after relatively short (1 month) periods of abstinence from the abused substance (Jaffe and Ciraulo, 1986). Mutual help groups like Alcoholics Anonymous and family or group therapy may be helpful in treatment. Use of naltrexone (a pure opiate antagonist) in the treatment of formerly opiate-addicted chronic pain patients is more controversial both because of the theoretical possibility that opioid blockade might exacerbate chronic pain (by disabling the endogenous mechanisms for pain modulation) and because of the practical difficulty in convincing some patients with chronic pain to accept complete abstinence from any use of opiate analgesics.

### PERSONALITY FACTORS AND CHRONIC PAIN

Personality and chronic pain are certainly interactive. Yet as is true of the relation between other psychological and psychiatric factors discussed in this chapter and elsewhere in this volume, the nature of the association is not well understood. The extent to which welldefined personality factors in chronic pain patients precede the development of symptoms or are highlighted and amplified by pain and reflect learned behaviors remains unclear. There is a fairly large psychodynamic literature that suggests that certain personality traits and mental mechanisms (e.g., dependence, identification, and low self-esteem) place people with particular personality types at risk for chronic pain and other problems of somatization (Engel, 1959; Blumer and Heilbronn, 1981). This literature emphasizes that pain and its relief are essential elements in the caregiver-child interaction, and that this interaction around the child's pain, distress, and crying may form the prototype for later interactions. Although learning theorists and proponents of operant conditioning for the treatment of chronic pain focus on rewards and sanctions for pain behavior in current relationships, old patterns of interaction deriving from early childhood (e.g., sympathetic identification with significant others) may persist with great saliency and continue to affect pain behavior in adult life. There is evidence that in families in which there is physical and/or sexual abuse, children grow up being more susceptible to symptoms of depression. These children may develop persistent personality patterns reflecting somatic preoccupation, feelings of inadequacy, and anxiety (Robins, 1983).

There has been little systematic research on the relation among childhood experience, personality development, and chronic pain, although numerous studies have found significant correlations between chronic pain and various personality traits and psychodynamics currently operating in the individual, such as unconscious guilt. Investigators have consistently noted that disabled patients with low back pain have abnormally high scores on the hypochondriasis and hysteria subscales of the Minnesota Multiphasic Personality Inventory (MMPI) (Chapman and Brena, 1982; Southwick and White, 1983; Trief and Stein, 1985). Attempts have been made to correlate disability status to these subscales of the MMPI as well. At least one study found that disabled low back pain patients scored higher on these subscales than nondisabled low back patients (Frymover et al., 1985). Scores on the MMPI have also been used to predict treatment responses. Higher levels of hysteria and hypochondriasis are associated with poorer outcomes in a number of studies of rehabilitation and surgery (Southwick and White, 1983).

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Clinical data and psychological tests have been used to describe various personality factors associated with chronic pain. Again, these data do not identify whether the personality factors antedate or result from the pain experience. On the basis of a comprehensive literature review of the use of psychological tests with chronic back pain patients, Southwick and White (1983) identified a composite psychological profile of these patients that differentiates them from others. They are described as being more extroverted, more demanding, somatically preoccupied, dependent, anxious, and as feeling inadequate and inferior. Whittington (1985) described such patients as dependent but noncompliant, passive, and as feeling a sense of entitlement. He claims that many patients are bitter, even paranoid, and often abuse drugs and alcohol. As mentioned earlier, Blumer and Heilbronn identify their pain prone syndrome as occurring in "solid citizens" who deny conflicts, idealize family relationships, and are workaholics until the onset of pain. They also identify these patients as having excessive unmet dependency needs. Blazer (1980-1981) describes the tendency for individuals with strong investments in themselves, their appearance, and their body to decompensate after an injury that threatens their sense of invulnerability-that is, to regress and become withdrawn, demanding, dependent, and angry.

From these studies emerge common personality factors associated with chronic pain, particularly in those patients who respond poorly to treatment. It is not known the extent to which the described behaviors reflect exaggerated preexisting personality factors or a more complex interaction between the underlying condition, sociopsychological factors, and learned behaviors that lead to similar personality types as a result of chronic pain.

Psychodynamic psychotherapy is currently the treatment of choice for many of the personality disorders, but for chronic pain patients, who tend to be focused on their pain and reluctant to view problems psychologically, psychodynamic psychotherapy may not be possible. Chronic pain patients may be more amenable to "supportive" psychotherapies, which encourage patients to use their previous coping strategies and defenses against feelings of inadequacy and vulnerability and that enable patients to reestablish a stable sense of self-esteem and to recognize and tolerate conflicts around dependency and aggression. Pilowsky (1976) has suggested that traditional psychotherapeutic techniques have considerable utility in the treatment of chronic pain patients. These techniques may be particularly helpful in breaking the cycle, so often seen for help-rejecting patients, of clinicians becoming increasingly frustrated and angry and ultimately rejecting the patient because of the patient's failure to improve. Most of the cognitive and behavioral approaches to treatment may be facilitated in the context of a supportive psychotherapy.

### **RESEARCH ON PSYCHIATRIC ASPECTS OF CHRONIC PAIN**

Assessment of the contribution of psychiatric disorders to disabling chronic pain conditions is limited by shortcomings in the methods and instruments used. The MMPI, the Cornell Medical Index, and the Hopkins Symptom Checklist-90, for example, are relatively widely used but nonspecific instruments for measuring psychological traits and emotional distress. The definitions of various types of psychological distress in many of the scales in these instruments include the presence of somatic symptoms, thus confounding, rather than clarifying, the relation between psychological and physical symptoms. In other words, a person suffering from chronic pain will automatically score high on a number of psychological measures of distress, including many depression scales.

Endicott (1984) has developed criteria specifically designed for medical patients to more accurately assess depression in cancer patients. Similarly, Clark and his colleagues (1983) have identified special cognitive and affective symptoms of depression that discriminate severe depression in a medical sample. Over the past decade the field of psychiatric epidemiology has begun to change dramatically as there has been a shift away from nonspecific instruments to instruments that enable one to focus on specific diagnostic conditions. Adapting such instruments to studies of medical patients, especially pain patients, may lead to more precise identification of psychiatric factors in patients with chronic pain. Studies of depression in pain patients are often further confounded by imprecision in diagnosis (including inadequate distinctions between symptoms and disorder) and by sampling bias. Studies of personality factors often suffer from the same sources of error.

Throughout this volume the lack of prospective cohort studies is noted. Such studies are crucial to determining causal relations among the many variables that influence the chronic pain/disability trajectory. Current attempts to prescribe effective treatment interventions (Feinmann, 1985; Morris and Randolph, 1984; Turner and Romano, 1984) for the admixture of symptomatic, characterological, and substance abuse problems are impeded by an insufficient understanding of the extent to which these conditions are either the cause or the consequence of pain and disability. Furthermore, the problem of sorting out the interactions between chronic pain and psychiatric factors is further confounded by the impact of the many sociocultural, economic, job-related, and normal psychological factors related to the chronic pain and disability process discussed in Chapter 8. All of these factors together influence the process and help account for the extraordinary diversity found in this group of patients.

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# $_{\text{part}} IV$

### ASSESSING AND TREATING PAIN AND DYSFUNCTION



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## 10 Chronic Pain in Medical Practice

Previous chapters have examined the multifaceted nature of chronic pain and the complex interactions among physiological, psychosocial, and psychiatric factors that contribute to its development and maintenance over time. This chapter examines chronic pain and chronic pain patients from the perspective of the physicians who are called on for diagnosis and treatment. Particular emphasis is placed on the viewpoints of primary care physicians (who handle about three-fifths of treated back pain cases) and orthopedists (who handle about one-quarter) (Cypress, 1983).

The focus of this chapter is on the assessment and treatment of pain in clinical settings, not on the assessment of pain primarily for certification, although the records from treating physicians may be used later in disability determinations. In decisions about disability or about diagnosis and treatment, physicians have similar pressures and incentives for accurate diagnosis. However, the doctor-patient relationship in the two settings often differs. In the clinical setting, it is assumed that the patient has come for an explanation (diagnosis) of the cause of the pain and for treatment that will relieve it and that the patient seeks relief. The complaint is usually taken at face value. These are not necessarily the ground rules of the relationship when the focus is on certification. Under those circumstances, there is a greater tendency to challenge the claimant's credibility and motivation in complaining of pain and disability.

Back pain has been selected as the primary focus of this chapter

because (1) more clinical, epidemiological, and administrative information is available on it than for other pain sites; (2) musculoskeletal pain, especially chronic low back pain, is the most common of the problematic cases for the disability system; and (3) back pain is illustrative of many of the clinical issues surrounding the chronic pain state in general (Drossman, 1982).

### **CLINICAL DECISION MAKING**

Clinical decision making is a process that unfolds over time. It is influenced by physicians' training and experience, as well as by treatment outcomes for individual patients over time. Clinical texts recommend a particular diagnostic sequence for low back pain that is usually based on a fairly narrow medical model that assumes, implicitly or explicitly, that pain complaints can be accounted for by disease or anatomical abnormalities. However, as will be discussed, most back pain is not attributable to a particular diagnosis. The initial course of treatment for back pain is usually targeted directly at symptom relief. If improvement does not result, physicians become more uncertain about the cause of the complaint and typically expand their inquiries. Instead of focusing primarily on the symptom, their attention shifts to the patient with the complaint. Additional observation of the patient and other diagnostic pursuits are oriented to identifying psychological, family, workplace, and other social and behavioral factors that may be affecting the pain. Treatment at this stage may include referrals to specialists, including mental health professionals, for specific psychosocial interventions. As discussed throughout this volume, given the nature of chronic illness generally, and chronic pain specifically, this broader "biopsychosocial" model is likely to uncover important clues to the etiology and maintenance of the pain complaint that may be significant for successful treatment and rehabilitation.

### **The Diagnostic Process**

The medical paradigm is relied on to provide the logic for clinical decision making. A basic premise of the medical model is that symptoms are the expression of anatomical, physiological, or biochemical abnormalities indicative of disease. The assumptions on which the model is based help to define the steps clinicians should take in order to make a medical diagnosis.

In the case of back pain, diagnostic studies are undertaken to determine specific medical disorders that may account for it, including (1) acute or chronic low back strain, (2) lumbar disc disease, (3) lumbar facet arthritis, (4) spinal stenosis, (5) mechanical instability, (6) spinal infection or tumor, and (7) systemic disease processes or other nonspinal problems with pain referred to the back. The clinical definitions of these disorders (e.g., their symptoms, physical signs, laboratory and imaging findings), delimit the scope of a diagnostic workup. Thus, the patient's complaint of "back pain" is explored by a series of clinical acts: (1) history-taking and (2) physical examination, followed in some cases by (3) x rays of the lumbar spine, (4) various laboratory tests, and (5) special imaging of the spinal canal by myelography, computerized axial tomography (CAT), and nuclear magnetic resonance (NMR).

1. History-taking. Traditional teaching emphasizes the importance of a careful medical history focused on the chronic pain complaint as a symptom of specific back disorders. To illustrate, Wilson and Levine (1972), writing about history-taking in Arthritis and Allied Conditions, advise

a carefully taken history will help greatly to ascertain cause.

A general appraisal should include sex, age, race, economic and social background, past medical history and a general system review. The type of work and daily habits are important to ascertain. Relevant points in the family history should be sought. An analysis of the pain itself is then necessary, and should proceed along two lines: one concerned with the chronological aspect . . . the other with the character.

Although the text suggests that demographic characteristics of the patient should be elicited, the more important dynamic and social psychological factors in the development of pain are not specified. The major advice given in this and other texts (Cailliet, 1981) is to expand the "analysis of the pain itself"—its quality, subjective and sensory dimensions—namely, "the character" of the pain sensation.

In actual practice, however, medical interviews characteristically are highly focused and limited to back symptoms along with the other symptoms of back disorders that may suggest an etiology, such as sciatica in patients with lumbar disc disease. As a result of these narrowly focused medical interviews, the context of the pain complaint (namely, the personal situation of the patient in work, career, and personal and family life) is not regularly elicited. Generally, unless the patient fails to respond to an initial course of treatment, psychosocial and cultural factors that may help explain the development of pain or the nature of the patient's pain report, pain response, and illness behavior are not explored.

2. The Physical Examination. In low back pain, careful physical examination of the back is advised, including an assessment of back

and joint motions, a neurological examination, as well as observation of muscle bulk with strength testing and careful palpation of the back and legs (including muscles, sciatic and femoral nerves). Tension signs must be tested. The appropriateness and consistency of patient responses should be carefully observed and nonorganic signs looked for (Waddell, 1979). The physical examination provides information that x rays and other tests do not on (1) the degree of functional impairment; (2) the patient's physical responses as "pain behaviors," such as posture and limited motion; and (3) the disorder producing the pain, such as an absent ankle jerk and sensory impairment in the distribution of the sciatic nerve suggesting nerve root compression (Barr, 1947), or trigger point tenderness suggesting referred or myofascial pain (Simons and Travell, 1983).

A thorough physical examination can provide valuable diagnostic information that cannot be obtained in any other way. Yet physicians often conduct only brief physical examinations and move quickly to order tests not only for diagnostic purposes but also to satisfy patients' demands for the latest technology. Tests are also ordered to document information that may be demanded in malpractice actions, because the economic incentives are greater for doing tests and procedures than for interviewing or physical examinations, and because testing procedures may have some placebo effect in relieving pain symptoms and dysfunction (Sox et al., 1981).

3. X Rays of the Lumbar Spine. Films of the lumbar spine are often the next diagnostic study performed, despite the fact that in 95 percent of cases they do not provide diagnostic information (Deyo and Diehl, 1986a; Scavone et al., 1981). Even though x rays are of limited value for diagnosing back pain, it is appropriate to order them to assure that no relatively rare but very important condition, such as metastatic tumors and spinal abnormalities, has been overlooked that could be causing pain. Repeated x rays are generally not appropriate.

4. Laboratory Tests. Blood tests are diagnostic tools that are largely confirmatory and supplementary indicators of inflammation, infection, metabolic and neoplastic disease (e.g., the altered immune globulins of multiple myeloma), or electrolyte imbalances.

5. Special Techniques. When routine, standard x-ray films are negative, the CAT scan may occasionally localize a ruptured intervertebral disc or uncover other important diagnostic considerations such as spinal stenosis. Among the techniques that sometimes provide useful diagnostic information are special imaging of the spinal canal by myelography and NMR, as well as nerve conduction tests, electromyography, and thermography. These two to five diagnostic steps are the usual number and sequence of studies that the physician pursues to define the medical diagnosis of chronic low back pain (Hendler, 1981; Hendler et al., 1982). These diagnostic studies often uncover one or more of the disorders that are believed to cause *acute* low back pain, but the mechanism is rarely confirmed because that pain is usually self-limited and resolves spontaneously (Nachemson, 1976). In *chronic* low back pain the diagnostic explanation is more elusive and only occasionally can be inferred from these studies and from the outcomes of therapeutic interventions. Indeed, the predictive power of these examinations and tests (their sensitivity and specificity) is surprisingly low. A definitive diagnosis can only be expected in 5–10 percent of patients with chronic low back pain (White and Gordon, 1982; Dodge and Cleve, 1953).

### Treatment of the Pain and the Disorder: The Medical Model

In the treatment of chronic low back pain by primary care physicians and specialists, such as orthopedists, neurologists, neurosurgeons, rheumatologists, physiatrists, and physical therapists, numerous therapeutic modalities have been used (Deyo, 1983):

1. bed rest or restricted activity (Deyo et al., 1986);

2. oral drugs such as analgesics, muscle relaxants, and antidepressants (Fields and Levine, 1984);

3. exercises;

4. physical therapy with cold, heat, and/or massage (Gibson et al., 1985);

5. corsets (Coxhead et al., 1981);

6. traction (Coxhead et al., 1981);

7. trigger point injections with local anesthetics; stretch and spray (Simons and Travell, 1983; Sola, 1985);

- 8. injections of parenteral and epidural steroids (Urban, 1984)
- 9. intradiscal chymopapain injection (Smith, 1964);
- 10. diathermy (Gibson et al., 1985);
- 11. transcutaneous nerve stimulation;
- 12. biofeedback and behavioral modification (Fordyce, 1976); and
- 13. surgery.

The choice of therapies from this list is likely to vary, depending in part on physicians' and physical therapists' individual preferences (Nelson, 1986). The sequence and combination of therapies also vary. Some are used earlier and others later in the course of chronic pain when initial treatment fails.

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In general, outcomes from these many medical therapies remain uncertain. In part, these uncertain outcomes may be due to the natural history of back pain as observed by clinicians, who note that acute low back pain (or acute exacerbations of chronic low back pain) usually remit in 2 weeks regardless of the mode of treatment (Nachemson, 1976). Thus, time is an important variable in studies of the outcome of any treatment. Further, few treatments have been tested for efficacy in double-blind studies (Deyo, 1983). Even if clinical trials were to demonstrate the benefit of specific treatment modalities, therapeutic choices would still depend heavily on the individual views of practitioners and their interactions with patients, who themselves have notions of appropriate treatment regardless of what the doctor recommends.

Despite the variations in choices of specific therapy, the literature indicates that, initially at least, three therapeutic approaches are most commonly suggested for the relief of low back pain: analgesics, rest or restricted activity, and physical therapy (Cypress, 1983; Knapp and Koch, 1984; Gagnon, 1986; Gilbert et al., 1985). If these interventions do not provide relief, then the physician often entertains a second order of diagnostic questions about the patient's pain complaints and a second order of treatment, which may include surgery.

## DIAGNOSING AND MANAGING THE PATIENT WITH PAIN: AN EXPANDED MODEL

Conventional understandings of disease fail to explain why people may be disabled by pain in the absence of a disease process that adequately accounts for the severity of symptoms. Physicians are trained to identify discrete diseases to the extent possible. They try to translate the patient's symptom complaint into signs of disease. Unfortunately, there is not necessarily a one-to-one correspondence, especially for chronic pain (Cassell, 1985). First, the same symptom can be caused by many different pathological states. One can experience back pain, for example, from arthritis, disc disease, muscle strain, or various kinds of malignancies. Second, a single disease, such as rheumatoid arthritis, can have widely disparate symptom constellations in addition to pain. Third, not only is there not always a strong correlation between the intensity of symptoms and the severity of pathology, but extensive pathology may exist in the absence of any symptoms at all. Hypertension, lung cancer, and lumbar disc disease are examples of serious diseases whose pathology may not cause any symptoms until the disease is quite advanced.

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When an initial course of treatment has failed, physicians are likely to expand their inquiries in order to discover "what the patient is like" (McCormick, 1986). Even if a diagnosis has been identified, if initial treatment has failed, the diagnosis alone is viewed as insufficient because it is unable to completely explain the pain or to provide the basis for practical relief. New clinical questions about the patient (his or her personality, affect, attributions, previous life events, and current stressful situations) have their origins in the physician's diagnostic uncertainty, concern about the patient's behaviors (persistence of pain complaints and failure to improve with treatment, seemingly low tolerance for pain, frequent requests for medical help and drugs, and work absences), and sometimes concern about the authenticity of the complaint.

These clinical concerns about the patient are not new. Writing about pain in 1911, Cabot noted

In many cases a strong neurotic element can be traced—the mental or nervous weakness acting on the back through a reduction of muscle tone. Flabby mind, flabby muscles and unsupported joints, pain. Doubtless any of these factors . . . may so activate the ache. I do not think anyone knows much about it.

Fortunately, such complete ignorance and uncertainty reflected in this old text are far less common among practitioners today. Indeed, the modern clinical literature clearly recognizes the important contributions of psychosocial and situational factors to the etiology and maintenance of pain, although, as discussed in Chapter 9, distinguishing psychological reactions to pain from primary psychological disturbance is often difficult.

At this stage the physician may refer the patient to a specialist in psychiatry, social work, or clinical psychology for intervention that may be psychodynamic, psychophysiological, or behavioral. The treatment focus shifts from attempts to relieve the pain directly to trying to resolve psychosocial issues that may be contributing to the continuation, severity, and disabling effects of the patient's pain. Referrals may also be made to multidisciplinary pain clinics for a combination of psychosocial and physical treatment. The value of all these approaches (psychosocial and physical) in effectively relieving chronic pain has rarely been demonstrated in controlled studies.

### WHY IS THE DIAGNOSIS OF CHRONIC PAIN SO ELUSIVE?

In chronic musculoskeletal pain, such as chronic back pain, proving the presence of a "name" disease (e.g., a ruptured intervertebral disc)

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is seldom possible despite the use of sophisticated diagnostic techniques. This disturbing fact has led to considerable disagreement among the various specialists concerned with back pain. In addition to the inadequacies of a narrow medical model, there may be several other reasons why a diagnosis is not found:

1. the disease or pathophysiological process is as yet unknown—it has not been identified by medical science;

2. the pain is caused by a disease process that is well known, but the diagnosis is difficult to establish or has been overlooked; and

3. some physicians believe certain pathophysiological processes exist and are a cause of pain, but other physicians do not accept the existence of such processes or do not believe that they explain the pain.

Such controversies over the source of chronic back pain and the resultant wide divergence of treatment methods cause difficulties for the insurance industry, Workers' Compensation systems, and the Social Security Disability program. This divergence is also likely to confuse the many individual patients whose pain continues unexplained, unabated, and ineffectively treated.

### **Unknown Disease Processes**

If the patient has a disease that is, as yet, unrecognized, or one for which no specific diagnostic test has been developed, it will be impossible to make a diagnosis. The possibility that patients may be enduring chronic pain because of deficiencies in medical knowledge should make clinicians very cautious in disparaging their complaints or attributing their suffering to purely psychological causes. Even when chronic pain arises from disease processes that are not understood, it remains possible and necessary to provide adequate pain relief and to teach the patient how best to carry on despite the pain. In these circumstances, however, attention to contributory psychosocial factors may be extremely important in the effective management of pain.

### **Overlooked Diagnoses**

It is unusual but not rare for patients who have been in pain for prolonged periods to be referred for evaluation to specialized treatment centers, where they are then found to have diseases that can be definitively diagnosed and often treated. These diagnoses include spinal stenosis, tumors, true intervertebral disc disease, infection, and other diseases that are uncommon causes of back pain. The diagnosis in such patients may have been overlooked because the original diagnostic evaluation was inadequate or because it took place so early in the disease process that identification was not possible (see, for example, Hall et al., 1978; Koranyi, 1979; Ananth, 1984). When patients have been complaining of pain for a long time, their physicians may become frustrated or impatient with the persistent pain. When that happens, diagnostic efforts frequently cease and a diagnosable disease can be overlooked. As difficult as it may be, such patients should be repeatedly queried for changes in their symptoms and examined carefully for changes in their physical findings. As will be discussed, certain diagnoses—such as myofascial trigger points, fibromyalgia (fibrositis), and articular dysfunction—are considered by some physicians to be common and remediable sources of pain, whereas others either do not accept them or are unaware of these conditions and the manner by which they are diagnosed and treated.

### **Controversial Diagnoses**

The majority of patients with chronic back pain are cared for by internists or family practitioners whose conceptions of etiology are similar to those of orthopedics. The traditional understanding of the field of orthopedics (and neurosurgery) about back pain centers on the axial skeleton and its associated joint and neurological structures.

There is no question that the pressure on the spinal nerve root that results when an intervertebral disc (the cartilaginous pad that cushions the space between the vertebrae) ruptures and is extruded from its proper position can be a consistent and diagnosable cause of leg and back pain. Further, the pain that occurs in a classical acute rupture of an intervertebral disc displays a pattern that is explainable by the anatomy of the bony and nerve structures of the back. In addition, the pain may be accompanied by other evidence of pressure on the nerve root, such as loss of sensation or muscle weakness. Surgical removal of the afflicted disc in such circumstances is often followed by complete relief of symptoms. In the overwhelming majority of instances of acute or chronic back pain, however, there is little or no correlation between the extent of disc disease and the severity of the pain. Furthermore, as noted previously, only in a small proportion of chronic pain cases is any clear diagnosis of disease or anatomical abnormality made.

In light of the difficulties in diagnosing and treating back pain according to traditional models, clinicians have searched for alternative explanations. Over the past several decades, new views of the pathogenesis of acute and chronic back pain have arisen that concentrate on back structures other than the axial skeleton. One such understanding, held by increasing numbers of specialists in rehabilitation medicine, is based on the view that myofascial trigger points and referred muscular pain (myofascial pain syndrome) are a major cause of pain. In this view, the primary difficulty in chronic back pain lies in the muscles, not in the axial skeleton or associated joints; muscular dysfunction is believed to frequently play an essential part in chronic back pain even when disc disease is present.

Some clinicians agree with this view and others disagree. Indeed, the study committee's discussion of this topic was very heated. Although all the clinicians acknowledged the existence of muscular involvement in back pain, some expressed strong doubts about the existence of myofascial trigger points. Similarly, others expressed strong doubts that the orthopedic view of the pathogenesis of back pain is correct. Although advocates of the view that trigger points and referred pain are primary elements in the pathogenesis of many common pain symptoms acknowledged the absence of controlled clinical trials for this (and most other interventions for back pain), they pointed to a rapidly growing literature reporting that the diagnosis is useful and common (Fishbain et al., 1986; Fricton et al., 1985b; Skootsky, 1986) and asserted that efficacious treatment approaches have been developed.

The committee did not reach agreement on this. Because of the debate and in light of the increasing prominence of myofascial pain syndrome in clinical reports, the committee believed that the topic and the controversy—should be brought to the attention of clinicians and researchers.

### Myofascial Trigger Point Syndromes\*

Proponents believe that trigger points develop in the following way: Because the muscles are not stretched through their normal range of motion (from misuse, lack of exercise, mechanical overload, or recurrent minor injury), they shorten. During subsequent muscular activity at work or while exercising, the muscles are repeatedly strained, which may induce further shortening. It is believed that trigger points are produced in the strained and repeatedly injured muscles. Trigger points that arise in these acutely injured muscles usually become latent trigger points after a few days of rest and protection of the

<sup>\*</sup> For a more detailed discussion, see the Appendix.

muscle from mechanical overload. Those who consider that myofascial syndromes are a common source of chronic back pain suggest that alternation between the active and latent status of the trigger point is the usual basis of recurrent or chronic musculoskeletal pain problems (Travell and Simons, 1983). In the presence of perpetuating factors (mechanical or systemic), an acute myofascial trigger point syndrome is likely to persist and become chronic despite appropriate therapy (Simons, 1985). Specific myofascial therapy includes a variety of techniques whose object is to restore the muscle to its normal length and pattern of action and to inactivate the trigger points (Travell and Simons, 1983; Sola, 1985; Lewit and Simons, 1984).

Trigger points, which may develop in any of the approximately 500 skeletal muscles, have five cardinal features that distinguish them from other musculoskeletal disorders (Travell and Simons, 1983; Simons and Travell, 1984):

1. The history of the pain is muscle oriented; the pain consistently relates to the positioning or use of specific muscles.

2. There is reproducible, exquisite spot tenderness in the muscle at the trigger point.

3. There is pain that is referred locally or at a distance on stimulation of the trigger point either mechanically or by a needle. This referred pain and tenderness is projected in a pattern characteristic of that muscle and reproduces part of the patient's complaint. Patterns of referred pain are frequently different than those expected on the basis of nerve root innervation (Travell and Rinzler, 1952; Travell, 1976).

4. There is palpable hardening of a taut band of muscle fibers passing through the tender spot in a shortened muscle (Simons, 1976).

5. There is a local twitch response of the taut band of muscle when the trigger point is stimulated by snapping palpation or needle penetration (Fricton et al., 1985a).

### Fibrositis or Fibromyalgia

Many rheumatologists and some other physicians who treat chronic musculoskeletal pain consider fibrositis (or fibromyalgia) to be a frequently overlooked source of chronic pain (Wolfe and Cathey, 1983; Bennett, 1981; Campbell et al., 1983; Yunus et al., 1982). The frequency with which fibrositis (or fibromyalgia) is diagnosed suggests that a specific entity is being described (Smythe and Moldowsky, 1977; Smythe, 1985; Bennett, 1981, 1986; Wolfe and Cathey, 1983; Yunus et al., 1982), but these terms have a checkered history of multiple meanings (Gowers, 1904; Reynolds, 1983; Yunus et al., 1982). Some physicians believe there is considerable overlap between myofascial syndromes and fibrositis (Simons, 1986) and treat them similarly. Both are treated with reassurance, physical therapy, and sometimes with analgesics. Those who are concerned with fibrositis use tender points to establish the diagnosis without regard to their relation to muscles. The management of myofascial pain syndromes focuses specifically on trigger points in muscles and the functions of those muscles.

### Articular Dysfunction

Articular dysfunction that requires mobilization or manipulation for correction is believed to be another source of acute musculoskeletal pain that is likely to become chronic if it is not appropriately treated (Bourdillon, 1983; Dvorak et al., 1985; Lewit, 1985; Maitland, 1977a,b; Mennell, 1964).

### **IMPROVING DIAGNOSIS, TREATMENT, AND PREVENTION**

From this review of physicians' decision making, of their diagnostic and therapeutic interventions, and of the shortcomings of the traditional medical approach emerge a number of suggestions for clinical practice that are likely to improve the overall management of chronic back pain, many of which are applicable to chronic pain generally.

### Diagnosis

Because the development and persistence of chronic pain (including back pain) and impairment depend so importantly on psychosocial factors, attention to these factors is essential for diagnosis, treatment, prevention, and rehabilitation.

Almost all low-back pain has a physical basis [even if it cannot be labeled with a diagnosis]; psychological ramifications are universal and commonly become more important after failed or multiple surgery [or other treatment], and social factors may contribute to [impairment], while social consequences of [impairment] are unavoidable. Although these three aspects interact and cannot truly be separated, an approximation of independent assessment is clinically useful. The aim of the assessment is to evaluate the importance and contribution of each aspect, their interplay and appropriateness, rather than to search narrowly for physical, psychological and social disease. (Waddell et al., 1979) A complete history is likely not only to aid in the diagnosis, or at least an understanding, of the cause of pain, but may also in some instances provide some pain relief. One study found that patients with intermittent chronic headaches expressed the greatest relief in those instances in which a detailed comprehensive history was taken at the onset of their illness (The Headache Study Group, in press). A careful explanation of the cause of pain can be reassuring to patients. This simple cognitive therapy, the explanation of symptoms or illness, is usually coupled with a placebo effect, such as has also been observed with diagnostic tests; both may relieve the uncertainty and anxiety associated with pain (Eisenthal et al., unpublished manuscript).

Second, a comprehensive history early in the course of the pain may reveal psychosocial or psychiatric problems, which if treated early could help to avoid chronicity. Thus, the expanded history would provide additional clues regarding the diagnosis and the basis for earlier referral to a mental health professional. Third, even if there are no mental health problems, a psychosocial history will provide a broader base for understanding the patient's pain and designing a treatment plan to address its multifaceted nature.

More attention to history-taking and to physical examination may make it less necessary to take x rays and to perform other, sometimes invasive, tests to diagnose chronic back pain. While recognizing that current reimbursement schemes do not encourage such time-intensive activities, in the long run they may prove cost effective because they may uncover clues to the pain that tests do not and point the way to appropriate treatment.

### **Treatment of Chronic Pain**

It is beyond the scope of this volume to specify treatment protocols in detail, but two general issues should be highlighted. First, as is true in medical practice generally, it is most important to treat not only the disorder but the patient and the symptom of pain as well. An expanded view of chronic pain that includes attention to psychosocial factors is likely to result in more effective treatment and prevention. Orienting medical practice to a more behavioral and preventive mode suggests some important principles in the care of pain patients:

• Detailed explanation of the cause of pain should be provided to patients, insofar as the cause is understood, while acknowledging the attributions of the patient.

• Instruction in medication use should be explicit to assure maxi-
mal control of pain with regular schedules and to avoid overprescribing.

• Return visits should be organized to reinforce suggested behaviors, provide support, and alter therapy if needed.

• Family members should be involved to help the patient control his or her pain.

• Collaborative care should be arranged when psychosocial factors require specific therapeutic interventions. Such referrals occur infrequently despite the well-documented frequency of psychosocial impairments in chronic pain patients (Sternbach, 1974) and despite the promise that such consultations hold for more comprehensive diagnosis and complementary psychosocial therapies that could aid in the treatment of chronic pain. Referral to a mental health professional or other specialist requires the primary care physician to orchestrate collaborative care. Coordination can be difficult for the solo practitioner because it requires frequent direct communication with colleagues. In multidisciplinary pain clinics and rehabilitation centers, such collaborative care usually is explicitly organized (see Chapter 12).

The second general issue regards the danger of iatrogenesis in some of the common treatments used for chronic pain. Three commonly used treatments for chronic back pain that deserve special comment are the use of bed rest, medications, and surgery.

#### Bed Rest and Restricted Activity

The time-honored prescriptions for bed rest and restricted activity lasting for weeks or months are difficult to rationalize for patients with nonradiating acute low back pain and exacerbations of chronic low back pain. These patients are usually relieved just as rapidly by a few days of rest as by much longer periods of inactivity (Deyo et al., 1986). Clinical efforts should be directed at relieving pain with mild, nonaddicting analgesics while the patient continues to be as active as possible. Inappropriate extended periods of inactivity reduce the effective muscle mass and may make the patient more vulnerable to subsequent strains. Furthermore, prescriptions for restricted activity may heighten patients' attention to and awareness of their symptoms and convince them that they are sicker than they really are. At a certain point, such a view can undermine effort and motivation and alter social interactions. Thus, there can be physical, psychological, and social iatrogenic consequences of long periods of inactivity. Most patients with chronic back pain may need to be

explicitly counseled that even if their backs hurt, such discomfort is unlikely to be harmful.

# Drug Therapy

Analgesics (narcotic and non-narcotic) and muscle relaxants (benzodiazepines and non-benzodiazepines) are very commonly prescribed for back pain. In addition, hypnotics may be used to help pain patients sleep, and antidepressants have recently begun to be prescribed for pain (see Chapter 9). Used in relatively small doses for a short period of time, these medications can often be effective, either alone or in conjunction with other therapies. Often, when pain complaints continue, increasingly powerful drugs are prescribed over long periods of time in increasingly large doses. This is particularly likely when patients have consulted multiple providers.

There is considerable controversy in the medical community about the appropriateness of long-term drug therapy with opioid analgesics for nonmalignant chronic pain. Until very recently it was generally thought that the risks of physical and psychological drug dependence, drug abuse, increased psychological distress, and impaired cognition were too great to warrant the extended use of narcotic analgesics for severe chronic pain (see, for example, Maruta et al., 1979; Maruta and Swanson, 1981; Medina and Diamond, 1977). In the last several years, however, there have been reports indicating that long-term therapy with these drugs can be successful. For example, Portenoy and Foley (1986) found that 24 out of 38 patients maintained on opioid analgesics for at least 4 years for nonmalignant chronic pain achieved "acceptable or fully adequate relief of pain." Few patients required escalating doses, management was a problem for only two patients (both of whom had a history of drug abuse), and toxicity was not a problem.

Clearly, drug therapy is an important element in the treatment of chronic pain, either alone on in conjunction with other modalities. Regardless of the type of drug prescribed or the duration of drug treatment, physicians need to be alert to the possible unintended, often adverse, side effects of drugs, including physical and psychological dependence, impaired motor coordination, altered daytime functioning, and symptoms of withdrawal when medication is discontinued. For example, symptoms of benzodiazepine withdrawal may not begin until several days after discontinuation of the medicine and therefore may not be recognized as abstinence reactions by either the patient or his or her physicians (Greenblatt et al., 1983; Schopf, 1983). More careful monitoring of the effects of medications may prevent unnecessary iatrogenic complications.

#### Surgical Treatment

Although surgical treatment can be dramatically helpful for a high percentage of patients with *acute* sciatica due to a herniated lumbar disc, resulting in prompt and effective relief of leg pain in at least 95 percent of them, not all patients with lumbar disc rupture require surgery. Even when an extruded lumbar disc is suspected, analgesics and a period of rest are indicated unless a major, progressive neurological deficit develops. Even when surgery is effective in relieving sciatica, comparisons of surgical and nonsurgical treatments reveal no differences in outcomes after 2 years (Weber, 1983).

Surgical treatment for *chronic* low back pain is less often effective than in acute sciatica, and rarely produces dramatic relief of back or leg symptoms except in problems of spinal stenosis, or in unusual abnormalities due to tumor or infection. Problems of spinal stenosis are becoming increasingly recognized and are amenable to surgical treatment in the majority of patients whose condition is confirmed by myelography, computerized body tomography, and magnetic resonance imaging. Infection, tumor, and spinal instability problems may all result in chronic back pain; and although these conditions are relatively uncommon, surgical treatment remains a definitive management. Of concern are those conditions in which the pathology demonstrated is not a clear cause for chronic low back pain, in which case surgical treatment should not be considered.

Numerous research studies and clinical observations reported in the literature indicate that surgery for chronic back pain is overused and often misused, that it is seldom any more effective than nonsurgical treatment in either the short or long term and often is less effective. and that back surgery (especially repeated surgery) frequently results in serious iatrogenesis. "With successive low-back operations, the results rapidly deteriorate . . . beyond two operations, further surgery was more likely to make the patient worse rather than better" (Waddell et al., 1979). Generally, after one unsuccessful back operation the chances of rehabilitation are significantly reduced, and after two or more failed operations it is very unlikely that operative treatment will be of value. An important exception to this general statement is when evidence is uncovered suggesting that the initial operation was not effectively designed or executed to address the known pathology. In such cases, additional surgery may be warranted and effective.

In cases of chronic intractable disabling pain in which the specific etiology cannot be determined or treated, neurosurgical procedures for

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pain relief are helpful for a few select patients. For patients with disabling pain after failed lumbar surgery, dorsal column stimulation or focal installation of spinal morphine may, in a very few cases, offer a temporary period of pain control during which some of these patients can become functional. In most medical centers, other neurosurgical operations, such as cordotomy, extensive rhizotomies, or midline myelotomy are no longer used in rehabilitative efforts for the patient disabled by chronic pain of nonmalignant origin.

In a study of work disability in newly diagnosed cases of arthritis, people who underwent surgery were less likely than others to continue working (Yelin et al., 1980). In fact, cessation of employment was predicted twice as well by having had surgery as by physicians' judgments of the initial severity of the illness. Moreover, for each therapy and drug regimen commonly prescribed by physicians for patients with arthritis, stopping work became more likely (but to a lesser degree than for surgery). Although it is possible that the need for therapy indicated severity of disease more sensitively than the physicians' reported judgment, it is also possible that in addition to providing some relief from pain, medical therapies may also have served to reinforce a lifestyle of invalidism. Thus, an important preventive measure to avoid iatrogenesis and mitigate long-term disability is to refrain from back surgery unless there is a clearly identified, surgically correctable problem and reasonable conservative treatment has failed.

# **RECOMMENDATIONS FOR CLINICAL RESEARCH**

This overview of how chronic pain is handled in clinical practice highlights a number of areas in which current practice appears to be inadequate (and perhaps harmful), and in which the rationale for physicians' behavior is based more on medical tradition than on the demonstrated efficacy of particular techniques or strategies. Pain, like insomnia and functional bowel distress, is a symptom complaint that has been relatively neglected in medical education and clinical research despite the fact that it is a common problem. In recent years there has been an increased interest in the multifaceted clinical aspects of chronic pain, but much research remains to be done. There are three broad questions for which clinical research would be particularly useful:

1. For what types of patients and in what circumstances does acute pain progress to chronic disabling pain, and can these patients at risk be identified early?

2. What specific treatment modalities are effective for which patients, and how do particular aspects of the doctor-patient relationship influence the effectiveness of treatment?

3. What are the optimal times in the pain-disability course for particular kinds of interventions?

As discussed in Chapter 6, less than 10 percent of people with acute back pain develop chronic disabling pain. If those people who are at risk for long-term illness and impairment could be identified early, it might be possible to design more effective treatment plans that could prevent long-term chronicity for at least some patients. At this time certain factors are known to be correlated with long-term problems, but they are not useful as predictive factors. More detailed patient typologies and classifications based on the development of chronic pain and disability are needed.

There is a paucity of data in the literature about the effectiveness of diagnostic tools (including the history-taking interview and physical examination) and treatment modalities for pain. The Quebec Task Force on Spinal Disorders (Spitzer and Task Force, 1986) concluded that methods of treating chronic pain are, by and large, untested in well-controlled clinical trials. Few treatments have been shown to improve the natural history of nonspecific spinal disorders. Clearly, there is a need to assess interventions in order to see what works alone or in combination and for which kinds of patients.

Among the treatments that should be evaluated are some of the alternative care therapies offered by chiropractors, holistic health care practitioners, and others that were discussed in Chapter 8. A number of questions could usefully be addressed: Do these therapies actually alleviate pain or do they alter pain perceptions or attributions so that disability is avoided despite persistent pain? Do particular forms of healing techniques preclude or interfere with medical treatment, or do they complement medical care by taking account of important psychosocial factors sometimes neglected in current medical practice? Are particular therapies effective only with individuals with certain group affiliations or personal characteristics? Do certain alternative therapies have potentially harmful effects that may exacerbate pain and disability? If, as a few studies suggest, outcomes depend on the characteristics of the provider more than on the actual techniques used, such findings may point the way to specific alterations in physician behavior or in the doctor-patient relationship that will promote rehabilitation and recovery.

Finally, there is a very critical question about the optimal timing of

interventions. Intuitively it makes sense to suggest that early attention to psychosocial problems might alter subsequent illness behaviors and mitigate the long-term negative consequences of pain. However, this has not been adequately tested. Generally, clinicians agree that the longer people have been impaired, the harder it is to treat or rehabilitate them (see Chapter 12). What is not known is whether early interventions and rehabilitation efforts prevent later problems.

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# 11 Measuring Pain and Dysfunction

This chapter explores the technical feasibility of measuring chronic pain and related dysfunction. It addresses questions of whether the severity of pain can be documented and whether the relation between pain and the ability to work can be assessed. The Social Security Administration (SSA) considers these questions to be crucial to disability evaluation of pain patients. Physiological and neurological techniques for measuring pain were described in Chapter 7; this chapter examines psychological, behavioral, and functional methods for assessing pain. Measures of conditions such as depression and anxiety are not discussed because these have been thoroughly reviewed elsewhere (see Anastasi, 1983; Evans, 1983; Lehmann, 1985; Spielberger et al., 1984). Some of the methods discussed here are appropriate for the assessment of work disability for compensation purposes; others are more appropriate for use by clinicians diagnosing and treating pain patients.

In order to pursue its mandate to conduct a state-of-the-art evaluation of pain assessment methods, the Institute of Medicine (IOM) study committee reviewed the literature and invited a panel of six experts in pain measurement and related matters to make formal presentations and participate in a discussion at one of its meetings (see list of panelists at end of chapter). Topics reviewed with the panelists included physiological measures of pain, subjective and behavioral observation techniques, assessment of the meaning of pain, physical function measures and vocational assessment in chronic pain patients, and the assessment of psychosocial and psychiatric factors in the etiology and maintenance of chronic pain and dysfunction. In later meetings the issues of assessing pain and functional capability were discussed repeatedly and considered in light of disability evaluation.

# **BASIC CONCEPTS OF MEASUREMENT**

Measurement is the process of assigning numbers to specific properties of events, processes, objects, or persons. All measurement involves error to varying degrees. Number assignment, or scaling, may involve different degrees of precision. It can be used to categorize or classify items or individuals (e.g., 1 = male, 2 = female) or to rank order them. In some cases, number assignment is sufficiently precise to justify mathematical manipulation of scores. The depth of scientific inference permitted by measurement depends on the precision of the scaling used.

In some cases the attributes or properties being measured are hypothetical, being derived from a theory or model, rather than an object or event that can be objectively observed. Human pain, like intelligence, cannot be directly observed but may be scaled along one or more dimensions in accordance with theory or highly specific models. Pain measurement is never atheoretical; every tool is rooted in a fundamental conceptualization of pain or at least certain basic assumptions that may or may not be explicitly defined by its users.

There are both medical and nonmedical conceptual models for pain. In each of these broad categories, there are several subcategories. Medical models share the basic assumption that pain is a symptom of an underlying pathology. Nonmedical models, which are largely psychological in nature, construe pain as a perception, as a behavior, or as a cognition.

The distinctions between the various models are complicated by the basic distinction between acute and chronic pain. Some models can account for one type of pain but not the other. In general, medical models are best suited for explaining acute pain problems in which pain is a direct function of nociception, whereas nonmedical models can best account for chronic pain problems in which the relation between tissue damage and pain complaint is weak or lacking. In practice, medical and nonmedical models can be, and often are, combined.

The multiplicity of models available for quantifying pain attests to the early stage of development of this area of research. The lack of a unified theoretical perspective has both advantages and disadvantages and is probably a necessary stage in the long-range development of science in this difficult area. On the positive side, the combination of medical and nonmedical models is a more powerful approach to pain assessment and control than the use of either model alone. On the practical, clinical level, measures derived from multiple models may provide a mosaic of information that promotes a clearer understanding of the patient than the medical model alone.

The primary disadvantage of variation in theoretical perspective is inconsistency in the resulting measurement technology. Operational definitions of pain vary greatly, and the data gathered by one investigator may be of little or no use to another. In addition, investigators sometimes disagree with one another about precisely what is being measured. For example, as discussed in Chapter 9, pain may be a symptom of depressive disorder, a consequence of it, or a problem that coexists with depression. Depression, then, may be an independent variable for one theorist and a dependent variable for another. The lack of consensus on the role of affect in chronic pain is a major impediment in the progress of pain measurement technology.

# **MEASUREMENT TOOLS**

Most pain measurement involves either structured self-report of pain, observation of patient behavior, or some combination of the two approaches. When self-report methods are used, instruments should (1) burden patients minimally, (2) be understood by patients, (3) yield a wide range of scores with sensitivity to analgesic intervention, and (4) demonstrate appropriate reliability and validity. Observational methods for the scaling of pain need not be understandable to the patient, but they must fulfill the other three criteria and, in addition, protect the patient's right to privacy. The major methods for scaling pain and their advantages and limitations are discussed below.

# **Measurement of Subjective Pain States**

Measurement by subjective report is by far the most common type of procedure for quantifying pain. Patients may indicate pain levels verbally, mark simple scales, or fill out complex questionnaires. In all cases, the patient determines the data.

# Self-Report: Data from Introspection

Many investigators hold that pain is inherently a private experience that can only be quantified by asking the patient to do his or her own number assignment. There are both unidimensional, or simple, scales for pain measurement and multidimensional, or complex, methods to obtain data.

## Self-Report Methods Using a Single Dimension

The simplest approach to assessing subjective pain states is the use of category scales. Usually the intensity dimension is scaled, but category methods can scale aversiveness or some other quality of pain as well. Such scales require only simple choices of the best descriptors from the patient. For example, Melzack and Torgerson (1971) introduced the following scale for pain intensity: "mild, discomforting, distressing, horrible, excruciating." Statistical treatment of category data is usually restricted to nonparametric methods, and this restrains the interpretation of the data gathered. Moreover, respondents tend to use the middle of the scale.

An alternative is the Visual Analog Scale (VAS), which usually consists of a 10-cm line anchored at one end by a label such as "no pain" and at the other end by "the worst pain imaginable" or "maximum pain." Respondents mark the line to indicate pain intensity; the mark is scored on either a 1–10 or a 1–100 scale. The Numerical Rating Scale (NRS) is a variation of the VAS in which patients rate their pain on a 0–10 or 0–100 scale that is discrete rather than continuous.

Although these tools are expedient, researchers have reported that 7 to 11 percent of patients are unable to complete the VAS or find it confusing and about 2 percent are not able to use the NRS (Kremer et al., 1980; Revill et al., 1976; Walsh, 1984). Carlsson (1983) critically reviewed the VAS as a method for scaling pain states or pain relief in chronic pain patients, and she compared different forms of the scale. Reliability, as judged from consistency of responses to two forms, was low, and Carlsson concluded that the validity of VAS procedures for chronic pain populations may be unsatisfactory.

The VAS is a straightforward, efficient tool for scaling pain, but it can fail if care is not taken to ensure accurate, valid, and reliable reporting. Such instruments will continue to be used because of their expediency, minimal respondent burden, and face validity. However, in addition to the limitations in reliability, these tools may oversimplify the pain experience.

## Self-Report of Pain in Several Dimensions

The scientific value of the VAS is restricted by its unidimensionality. Some investigators adjust for this by using more than one VAS, with each designed to assess a different dimension of pain. However, it is hard to ensure that the response to the first scale administered does not influence the response to subsequent scales (Carlsson, 1983). There are several multidimensional scales that avoid some of the problems with VAS but increase responder burden and cost more to interpret.

The McGill Pain Questionnaire (MPQ) is perhaps the most thoroughly evaluated multidimensional scaling device for pain. It is based on the vocabulary used by patients to describe various experiences of pain. The MPQ scales pain along three dimensions: sensory, affective, and evaluative. There are 20 sets of words that describe varying qualities of pain. Ten of the sets represent sensory qualities, 5 are affective, and 1 is evaluative. Each set has from two to six words that vary in intensity for the quality described by the set (e.g., from hot to searing, from annoying to unbearable). Patients are instructed to select the sets that are relevant to their pain and to circle the words that best describe it within each selected set. An adjunct test device, the Dartmouth Pain Questionnaire, has been offered to supplement the MPQ through the assessment of four additional factors, including impaired functioning (Corson and Schneider, 1984).

Many studies support the factor structure of the MPQ, its reliability, and its concurrent validity (see Syrjala and Chapman, 1984; Chapman et al., 1985). However, it places a large responder burden on the patient, some patients cannot handle the vocabulary of the instrument, and the scoring procedures available are limited (Syrjala and Chapman, 1984).

Turk, Rudy, and Salovey (1985) critically evaluated the MPQ and various approaches to scoring it. They concluded that the total score is valid as a general measure of pain severity but that individual scale scores should not be used; adequate discriminant validity to support scaling at the level of sensory, affective, and evaluative dimension subscales could not be demonstrated. Melzack has responded to these challenges by pointing out that the high intercorrelation among the factors of the MPQ does not necessarily indicate a lack of discriminant validity and by reviewing an impressive number of studies that demonstrate the discriminant capacity of the instrument (Melzack, 1985).

The West Haven-Yale Multidimensional Pain Inventory is an alternative instrument designed to be briefer and more classical in its psychometric approach to multidimensional scaling than the MPQ (Kerns et al., 1985). The 52-item inventory is divided into three parts: (1) five general dimensions of the experience of pain and suffering, interference with normal family and work functioning, and social

support; (2) patients' perceptions of the responses of others to displays of pain and suffering; and (3) the frequency of engagement in common daily activities. The instrument is derived from cognitive-behavioral theory and assesses such constructs. As such, it represents a very different approach to scaling than the MPQ.

The Brief Pain Inventory is an efficiently administered multidimensional pain questionnaire with demonstrated reliability and validity in cancer and arthritis patients (Daut et al., 1983; Cleeland, 1985). In less than 15 minutes, patients can report analgesic medication use, pain relief from drugs, beliefs about the cause of pain, qualitative descriptions of pain, areas in which pain interferes with quality of life, the pain's locus, and their worst, average, and current pain level on a 0–10 scale. This measure has proved useful as a multidimensional pain measure in patients with progressive disease.

Other approaches to the multidimensional scaling of pain have been derived from a psychophysical technique known as cross-modality matching in which a sensory experience is quantified by matching it to the experience of a precisely controlled stimulus in a different sensory modality. For example, a laboratory subject might match the intensity of a toothache produced by electrical tooth shock to the loudness of a controlled tone in decibels. Analogous methods are used for clinical pain scaling. The typical procedure involves matching words describing pain to line length or handgrip force, matching both to experimental pain, and then deriving scaling standards for the relationship of words describing pain to actual pain. The methods can then be applied to clinical pain assessment. This can be done for multiple dimensions of pain, such as intensity and unpleasantness (Gracely et al., 1979).

The Pain Perception Profile (Tursky et al., 1982) uses cross-modality matching scaling procedures. It (1) quantifies the sensation threshold; (2) uses magnitude estimation procedures to judge induced pain; (3) scales pain on intensity, reaction, and sensation dimensions using psychophysical scaling of verbal pain descriptors; and (4) permits the psychophysically scaled verbal descriptors to be used in a diary format for repeated assessment over time.

Compared to the MPQ, cross-modality scaling methods are shorter and less demanding. Yet they offer potentially more reliable and valid data than the simpler VAS scales. However, the Pain Perception Profile and Graceley's methods (Gracely et al., 1979) have not yet been validated for different patient populations. Such work would require experimental pain testing and a substantial amount of development before clinical data from a broad sample of patients could be interpreted confidently.

#### Pain as Behavior: Observational Data

#### Pain Judgments by Health Care Providers

Health care providers generally use two types of pain assessment that can be more or less structured: patient classification and observer ratings of patients' pain problems. The most basic form of observer scaling is patient classification. Typically, medical history and diagnostic data are used to categorize chronic pain patients. For example, Hammonds and Brena (1983) devised a four-category classification scheme for patients in which Class I consisted of those with high behavioral determinants and low organic determinants of pain, and Class II patients were low both on behavioral and organic determinants. Class III patients had high scores both on organic pathology and pain behaviors, and Class IV patients had high organic pathology and low pain behavior scores. Advocates of such approaches point to the value of such categorizations for screening and selecting appropriate interventions. Others, however, believe that such methods are oversimplified, that most patients do not fit neatly into a category, and that such categorization may affect the patient's care inappropriately.

When pain is directly scaled by health care providers observing the patient, simple rank-ordered category scales are typically used, such as no pain, slight pain, moderate pain, and severe pain. Often, such scales may include an evaluation of what the patient can or cannot do on certain tasks, such as bending over to pick up a weight.

There are several limitations of observer pain judgments in chronic pain settings. First, most investigators hold that such judgments are not true measurements: Pain can never be observed by another individual, it can only be inferred from a patient's actions. Second, knowledge of a patient's clinical findings can bias the pain rating. There is also the danger that raters will stereotype patients on the basis of age, sex, or race. Use of multiple raters who are trained with well-defined criteria for assessing pain can reduce these problems.

#### Measurement of Pain Behavior

Although pain may not be objective, the behaviors of patients in pain may be observed, and scored, objectively. Pain behavior is a normal response to an injurious stimulus, but when it occurs in the absence of such a stimulus or too small a stimulus, it may be described as an abnormal behavior. Behaviorists generally do not seek to infer pain from behavior; instead, they view pain behavior itself as the problem;

and it is pain behavior, rather than some hypothetical personal state, that they seek to correct therapeutically.

Patients in pain exhibit certain consistent behavior patterns. For example, studies have shown that back pain patients tend to grimace, guard their movements, rub themselves, and sigh (Keefe and Hill, 1985). When clinical pain is operationally defined in terms of such behavior patterns, objective measures can be used. Certain behavior patterns can be identified as being related to pain, quantified in terms of frequency or rate of occurrence, and assessed via direct or videotape observation of patients in selected settings performing specific tasks. Because behavioral patterns are complex, most behavioral measures are multidimensional. The identification and quantification of pain behaviors varies greatly with different types of pain problems. In general, behaviors are tallied over time and scored in terms of their frequency. Keefe and Block (1982) developed an observational scoring system for scoring pain behavior in chronic back pain patients. Guarded movement, bracing, rubbing, and sighing were assessed. These indices proved reliable, valid (in relation to reported pain), and more frequent in pain patients than in normals or depressed controls.

Keefe and Hill (1985) extended the observational approach by using a transducer placed in the patients' shoes so that walking parameters could be assessed. Patients and nonpatients were required to walk a 5-m course while being videotaped. Patients walked more slowly than normals, took smaller steps, failed to show normal symmetrical gait patterns, and exhibited more pain behaviors. This approach appears promising for assessing and objectively quantifying back pain behaviors. More generally, repeated recordings could be used to document changes in an individual patient's behavior over time for use by physicians or by disability examiners. In the latter instance, such recordings could provide some information that would otherwise be available only by a face-to-face encounter.

A major limitation of the behavioral approach is that pain behaviors are highly specific for each pain syndrome. Patients with shoulder pain or headache, for example, would probably be indistinguishable from healthy people on Keefe and Hill's (1985) test. Keefe and his colleagues (1985) undertook behavioral evaluations of patients with head and neck pain to address this issue. They found that such patients displayed their pain primarily through their facial expression rather than through guarded movements.

Broad indicators of pain behaviors with potential application to different clinical populations do not appear promising. Linton (1985) hypothesized that reported pain intensity is inversely related to general activity level in back pain patients (as measured by selfmonitoring or observed behavior in a test situation). He found no relation between the level of patient activity and chronic pain intensity. Thus, behavioral indicators appear well suited as highly specific and precise ways to quantify certain outward pain behaviors, but they may not serve well as global indicators of subjective pain intensity. Further work is needed before the behavioral approach can quantify a wide range of chronic pain problems.

#### **Mixed Methods: Self-Reports of Pain Behaviors**

One way to gather information about behavior patterns and habits is to ask the patient, his or her spouse, or some other day-to-day observer. The pain diary is perhaps the most commonly used form of behavioral self-report. A typical pain diary is a log of daily pain-relevant activity broken down into small blocks of time. Activities may be divided into sitting, walking, and reclining, with the patient filling in the specific activity under the appropriate category according to the time the activity occurred. Pain level is rated on a 0–10 scale for each hour, and medications may also be recorded.

There are several potential advantages to using a pain diary with chronic pain patients. First, because the diary is completed daily, it is not subject to distortion based on the patient's current pain experience at the time he or she is seen in the clinic. Variations in pain levels during the day and from day to day can be recorded. Second, the diary yields data on patterns of normal activity relative to patterns of pain behavior (or pain-linked inactivity) not available from other behavioral assessments. In addition, it gives information about patient behavior in the home setting. From the pain diary one can determine behavioral patterns, defined in terms of the time of day or activity, that result in high pain versus average pain levels. It can also reveal time spent in various activities or inactivity over a week and help define the relation among pain, activity, and medication use.

Two limitations should be borne in mind when considering pain diaries. First, their reliability is unknown and varies from person to person because diary data are dependent on the accuracy of recording. Second, whereas some people complete the form on a daily or hourly basis as directed, others do it incompletely or retrospectively just before their appointments. Furthermore, it is not known whether the experience of keeping a diary affects the experience of pain itself. Certainly, the diary calls attention to the pain and its influence on day-to-day activity. This issue awaits formal study.

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The pain diary method combines the simplicity and efficiency of selfreport methods with the theoretical perspective of the behaviorist. However, pain diaries presuppose that the patient (or the spouse) is a reliable and accurate historian. Ready, Sarkis, and Turner (1982) found that chronic pain patients, when asked to report medication use, gave information that was 50-60 percent below their actual drug intake. Kremer, Block, and Gaylor (1980) compared patient records with staff observations of patients' social behavior and found discrepancies. Sanders (1983) studied automatic monitoring of time spent out of bed ("uptime") in normal controls, psychiatric inpatients, and chronic back pain patients. He found moderate positive correlations between self-reports and automatic monitoring. All groups averaged less self-reported uptime than the automated report indicated, with the discrepancy being greatest for the chronic back pain patients. Thus, the validity of the mixed methods approach as a measure of pain is questionable.

## **RELATED MEASURES OF DISABILITY**

## **Pain and Functional Status**

Of primary importance in assessment both in the context of medical care and in determining eligibility for disability benefits is ascertaining whether an individual is prevented from gainful employment or otherwise normal living patterns by his or her condition. The challenge of assessing the patient's functional capability has attracted the attention of several investigators, and a few have attempted to relate pain to function.

#### **Disability Assessment**

The Northwick Park Activities of Daily Living Index has been combined with a grading system (Parish and James, 1982) to produce a way of assessing the level of functional independence of the disabled patient. Basically, the assessment procedure records whether the patient is independent or dependent on 20 different activities. There are six self-care tasks, six stages of mobility, three employment grades, and five types of domestic activity. This assessment procedure can be performed quickly and repeated as often as needed. However, it is better suited to the assessment of severely impaired individuals than to workers with pain complaints.

Jette (1980) has offered an approach to assessing the functional

capability of noninstitutionalized persons with polyarticular conditions. Activities of daily living were examined in the assessment process. Five categories (physical mobility, transfers, home chores, kitchen chores, and personal care) accounted for more than 50 percent of the variance in the data studied.

#### Sickness Impact

Persisting pain typically has a significant sickness impact on the patient. For the low back pain patient (the most-studied type of patient in the chronic pain population), this effect consists of increased hours spent reclining or in bed rest, restriction of normal social and recreational pursuits, emotional distress, and inability to maintain gainful employment. The concept of sickness impact is for most practical purposes interchangeable with that of disability.

No comprehensive, validated objective indicators of sickness impact exist. Instead, behaviorally oriented subjective report procedures (like those discussed previously) are used. Activity diaries, in which a daily record is kept of uptime/downtime, medication use, and type of activity, can be used to assess the impact of chronic pain (Follick et al., 1984). A variety of scores can be tabulated and plotted over time from diary forms, depending on their construction. However, it is possible to go well beyond the daily diary in an attempt to systematically scale physical, social, and psychological limitations imposed by (or adopted in response to) sickness.

The most fastidiously developed and fully validated of such instruments is the Sickness Impact Profile (SIP) (Bergner et al., 1981). This instrument is designed to be a general indicator of health status and health-related dysfunction rather than a pain-specific test. It can be administered by an interviewer or self-administered. Patients respond only to those sickness-related behavior change items that describe them appropriately. The SIP provides general scores along three dimensions of impairment—physical, psychosocial, and work-recreation—and 12 specific category scores that include, for example, communication, social interaction, and home management. Its measures are derived from responses to 136 items.

Follick and his colleagues (1985) investigated the SIP scores of 107 back pain patients seen at a multidisciplinary pain clinic; 75 percent of the study patients were receiving Workman's Compensation. The outcomes supported the validity of the SIP as an indicator of functional status in low back pain patients. The psychosocial dimension of the SIP was significantly correlated with the Minnesota Multiphasic Personality Inventory (MMPI); the physical dimension score was inversely related to independent measures of standing and/or walking and positively correlated with downtime. The investigators concluded that the SIP is a useful means of assessing functional impairment in back pain patients.

Charlton, Patrick, and Peach (1983) used items from an existing health survey together with items from the SIP to produce a tool for the multivariate assessment of disability. Five global classifications for items were used: physical, psychosocial, eating, communication, and work. The disability measures derived from the items related to age and number of medical conditions but not to services utilization.

Mayer and colleagues (1986) have developed a set of rehabilitationfocused tests consisting of largely objective physical function measures for use with low back pain patients. These tests, which were combined with a battery of psychologic measures, included eight categories of measurement: (1) range of motion, (2) cardiovascular fitness and muscular endurance, (3) gait speed, (4) timed simulation of daily activities, (5) static lifting, (6) lifting under load, (7) isometric and isokinetic dynamic trunk strength, and (8) a global effort rating. These measures were obtained repeatedly through the course of treatment of back pain patients and provided information on functional capacity both to the patient and surgeon. There was an initial unemployment rate of 92 percent in the sample under study, and 82 percent of patients returned to work after treatment. Although the measures derived were not direct measures of pain, but rather measures of function, they proved to be of great value in successful treatment. Despite the successful rehabilitation of patients in this study, and with a significant decrease of self-reported pain, these patients maintained a mean VAS pain report score of 77 out of a possible 150. This suggests that rehabilitation may be achieved without major pain relief.

## Assessment of Work Performance

In recent years, a considerable amount of attention has focused on the development of techniques to assess work-related function. Because direct assessment in the workplace is usually not possible (Chaffin, 1981), various work simulation strategies have been developed. The most basic approaches involve direct measures of strength or capability. For example, Harber and SooHoo (1984) used static ergonomic strength testing as part of a multidisciplinary evaluation program for occupational back pain. Lifting ability in several positions was quantified. Because it was independent of the degree of impairment, the degree of intrasubject variability could be used to detect inadequate subject efforts. This approach seems promising but falls short of true work simulation and may not be applicable to all types of occupations.

The Liberty Mutual Medical Service Center in Boston uses work simulation as part of the treatment for back pain patients (Bettencourt et al., 1986). Balance monitors, pneumatic lifting and lowering equipment, a multi-work station, a truck driving simulator, and an upper extremity work simulator are available. The goal of the program is to allow patients to improve work performance capability and stamina while they learn to live with their symptoms. The setting has not yet been a major resource for disability assessment. This type of program is consonant with the concept of work hardening as an approach to industrial rehabilitation (Matheson et al., 1985).

The adaptation of work simulation techniques to eligibility determinations for disability programs is intrinsically appealing because they offer promise to measure work-related function. However, a substantial amount of development would be required to standardize the measures and establish norms and parameters for specific kinds of jobs.

# Severity of Pain and Dysfunction

The relation between pain severity as defined by subjective report and functional capacity has not been adequately studied. However, the literature on contingency management and operant conditioning has clearly demonstrated that the relation is not simple. Patients often fail to perform normal daily functions because they believe, or they have been told by well-intentioned health care providers, that activity will exacerbate the pain and worsen their health. But for many chronic pain conditions the opposite is true: excessive rest and reclining contributes to the persistence of pain, and activity is beneficial rather than harmful to health.

Patients who undergo a rehabilitation program involving contingency management typically increase their functional capacity with programmed exercise (Fordyce, 1976; Doleys et al., 1982; Roberts, 1981). Some report that the pain disappears as normal activity increases; others report that the pain remains but fades into the background of daily life. The latter type of patient demonstrates that at least some people can function in normal daily and vocational life despite the presence of pain, once they understand and prove to themselves through experience that activity is not harmful (see

Chapter 12). Still other patients are able to live reasonably normal daily lives but find that the unique demands of their vocations (typically manual labor) exacerbate the pain. In this case, vocational rehabilitation is critical to fully successful treatment.

# FACTORS BIASING PAIN MEASUREMENT

The accurate scaling of pain in a cooperative, intelligent respondent cannot be taken for granted, and the problem of minimizing error cannot be dismissed simply because the person seems cooperative. People may knowingly or unknowingly bias their responses to any form of subjective report instrument in accordance with their beliefs, expectations, or personal goals. In addition, the test situation itself, including the attitudes and behaviors of the health care providers present, may affect the data obtained. Inaccuracy may result from distortions in memory as well as from medication toxicity. A brief description of several biasing factors follows.

## **Personal Meaning**

As discussed in Chapter 8, how people interpret their symptoms and the meaning attributed to them can have a significant impact on illness behavior, including the response to treatment. Although not designed specifically for chronic pain patients, instruments that measure the personal meaning of life events in terms of purposefulness, personal control, and self-esteem may be useful to adapt for pain patients.

The theoretical concept of coherence as defined by Antonovsky (1980) involves the sense of purpose in life. Crumbaugh's (1968) Purpose-in-Life Scale asks respondents to indicate how they perceive their personal existences and the world as meaningful or purposeful and the extent to which their lives have reasons, purposes, or goals. A 7-point ordinal scale is used; higher scores indicate greater coherence.

Personal control constructs can be assessed with instruments designed to scale "locus of control": the extent to which individuals believe they versus fate control the major events of their lives. The Multidimensional Health Locus of Control Scale (Wallston et al., 1978), for example, assesses the extent to which patients believe in a cause-effect relationship between their actions and their state of health. Three separate dimensions of locus of control are assessed: (1) internality, the extent to which health is perceived to be a function of one's behavior; (2) powerful others externality, the extent to which the actions of other people are seen as controlling one's health; and (3) chance externality, the extent to which health or lack of health can be attributed to fate. The test consists of three six-item scales. Each item requires a response on a 4-point scale ranging from "strongly agree" to "strongly disagree."

Patients' beliefs about the perceived cause, nature, and expected course and effects of pain can be assessed with Kleinman's (1980) Explanatory Model method of elicitation. When combined with a few questions from the Health Belief Model (Rosenstock, 1966) regarding perceived vulnerability to pain, it could give assessors a quick way of taking the patient's perspective into account.

## Coping

Chronic illness, including chronic pain, may be viewed as a stressor with which patients must cope (Lipowski, 1971; Lazarus and DeLongis, 1983). Coping skills are one more of the many factors that are likely to affect chronicity, functional status, and the seeking of disability benefits (Strauss, 1975; Thornbury, 1982). Lazarus and colleagues (Folkman, Schaefer and Lazarus, 1979; Lazarus and DeLongis, 1983) have offered a cognitive framework for understanding coping as a process. This model predicts that patients will tend to change their attitudes toward illness and associated life change demands over time. Working within this model, Thornbury (1982) and Moos and Tsu (1977) identified illness-related coping responses and several cognitive skills that may be used in therapy to teach patients to cope with extended illness.

Several instruments have been developed to assess coping skills. The Ways of Coping Check List was derived from Lazarus' transactional model of stress (Folkman and Lazarus, 1980) and subsequently revised (Vitaliano et al., 1985). An event is considered stressful when the patient appraises it as being potentially dangerous to his or her psychological well-being. Five scales (revised form) can account for patient coping behaviors: (1) problem-focused coping, (2) wishful thinking, (3) avoidance, (4) seeks social support, and (5) blames self.

The Coping Scale Questionnaire (Rosentiel and Keefe, 1983) asks people to rate how often they use certain strategies for coping with pain. A list of 42 strategies is provided that includes 6 different types of cognitive strategies and 1 behavioral strategy. Cognitive strategies include diversion of attention, reinterpretation of pain sensations, coping self-statements, ignoring pain, praying and hoping, and catastrophizing. The patient's belief about how much control he or she

has over pain is also recorded. Turner and Clancy (1986) used this instrument in a study of back pain patients undergoing behavioral interventions. They replicated the factor structure for the test and observed that increased praying or hoping was associated with decreased pain ratings.

# **Memory for Pain**

The ability of patients to remember pain while in a relatively pain-free state has been shown to be reasonably accurate up to a week after surgery (Hunter et al., 1979; Kwilosz et al., 1984). For pain that persists, and when measures are being compared over time, research has demonstrated that current pain intensity produces systematic distortions of memory for prior pain, independent of treatment outcome (Eich et al., 1985). This influence of current pain on memory of past pain in persistent or chronic pain situations suggests that measures derived from the patient's recollection are probably invalid and at best likely to be biased.

#### **Attributional Factors**

Patients, like people in general, tend to behave in accordance with their beliefs about the world and themselves. Moreover, behavior is accommodated to the social environment of the moment in psychiatrically normal persons. The person who believes that he or she has a serious undetected disease and who is being tested or observed by health care providers will generally act in accordance with this belief. Such a patient may unknowingly exaggerate reports of pain and related problems and will behave as he or she believes a person sick with a serious disease should. The patient who fears being labeled as a "psychogenic pain" patient may become theatrical in displaying suffering and functional impairment in the clinical setting, but when observed fortuitously in the hospital cafeteria later the same day may appear quite normal.

The opposite bias may also occur. The driven, time-obsessed executive who tends to deny disease may fail to report angina or other relevant symptoms as well as functional problems in an attempt to evade an illness assignment that would impair his or her personal and professional lifestyle. Thus, the patient's own beliefs (which may be shared by other family members) can severely bias the assessment of pain and pain-related impairment.

Similar biases may affect treatment outcome when pain patients are

subjected to surgery, drug therapy, or psychological interventions. Most of the literature in this area is concerned with the placebo effect—the tendency to report favorable outcomes in order to please the clinician, fulfill the therapeutic hopes of family or self, or achieve some other goal, such as maintaining employment. However, the opposite phenomenon also occurs; some patients fail to report therapeutic benefit when it probably has occurred. Because both pain reports and performance on function tests are voluntary efforts, patients' claims of therapeutic failure cannot be challenged. Such behavior is largely a matter of patients acting in accordance with their own beliefs about their health and roles in society and may be consciously or unconsciously motivated. Research on placebo effects has helped to emphasize the importance of the context of interventions and of the doctorpatient relationship as determinants of pain report and pain behavior.

## **Medication Toxicity**

Measurement error may also occur when the patient is toxic from excessive medication. Over months or years of seeking pain relief, some patients gradually develop toxicity from polypharmacy and medication overuse. The toxic patient often is irritable, has difficulty concentrating, is depressive, and may be lethargic (Hall et al., 1980). The data obtained from such patients are rarely reliable and are of little value if the purpose of data collection is to evaluate pain or pain relief. It is best to detoxify such individuals before attempting to evaluate their pain and its impact.

## SUMMARY

Because human pain is an area of inquiry rich in complexity and multidimensionality, it is of interest to clinical and basic scientists in a wide variety of fields. It can be studied within several different conceptual models. From the viewpoint of measurement, however, this richness is also its great deficiency. The lack of consensus among investigators on precisely how pain should be defined operationally and the conceptual tensions that emerge from different interpretations of related variables such as mood disorders engender confusion and contradiction.

A number of well-defined instruments are available for assessing pain and related variables. Each is bound to a theoretical position, and each has its strengths and weaknesses. None can yield unequivocal evidence of the presence of painful activity within the nervous system apart from the patient's report and behaviors. Most experienced clinicians tend toward the eclectic: Subjective data are used to build a broad picture of the individual patient. Decisions for diagnosis and treatment are based on interpretations drawn from patterns evident among the combined measures. Because pain levels vary so much from hour to hour and day to day, ideally, such measures would be used repeatedly in order to have a longitudinal record and to avoid making inappropriate inferences based on a single assessment.

In recent years measures of functional capability have emerged in the literature. Pain-related disability has been investigated in several studies, and it is clear that (1) there is no direct relation between severity of pain and disability and (2) some disabled pain patients can be rehabilitated when pain relief is not achieved. These findings suggest that disability status ought not to be granted on the basis of pain complaint alone. Evaluation of the candidate for disability status should include pain assessment, but this should be interpreted in the context of measures of functional capability in various realms of the claimant's life.

## IMPLICATIONS FOR SSA DISABILITY ASSESSMENT

In light of the preceding review of pain measurement, the committee agrees with the conclusion of the Pain Commission (U.S. Department of Health and Human Services, 1987) that there is no direct, objective way to measure the experience of pain. Because adequate technology for the objective assessment of chronic pain is not available, the committee believes that attempts to draw inferences about the ability of a patient to engage in gainful employment on the basis of pain measurement are futile. Instead, disability evaluation efforts should focus on pain-related dysfunction rather than on pain alone. Both multidimensional pain indices and measures of functional capacity should be obtained so that a comprehensive evaluation is performed.

#### **MEASUREMENT PANELISTS**

- Fields, Howard L., M.D., Ph.D. Professor of Neurology and Physiology, University of California, San Francisco
- Florence, David W., M.D. Director of Medical Affairs, People's Community Hospital Authority, Wayne, Michigan
- Keefe, Francis, Ph.D. Associate Professor and Director, Pain Management Program, Duke University

- Marcus-Lewis, Frances, R.N., Ph.D. Professor of Community Health Care, University of Washington School of Nursing, Seattle
- Merskey, Harold, D.M., F.R.C. Psych. Director of Education and Research, London Psychiatric Hospital, Ontario
- Sternbach, Richard A., Ph.D. Director, Pain Treatment Center, Scripps Clinical Medical Group, Inc., La Jolla, California

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# 12 Rehabilitation Approaches and Issues in Chronic Pain

A s documented throughout this report, the intensity and disabling effects of chronic pain are highly variable and unpredictable. Among the problems faced by persons with such pain are disruptions in the physical, psychological, social, and economic aspects of their lives. In their search for relief, chronic pain patients often seek care both from several different physicians and also from nontraditional healers; in addition, they may undergo numerous treatments over a period of months or years.

At some point in their quest for relief these patients may be referred to specialized pain management programs (or "pain clinics") for rehabilitation. Such programs have proliferated rapidly in the last 20 years. Although they vary greatly in terms of staffing, specific treatment orientation, and criteria for accepting patients into their programs, these pain clinics are specialized rehabilitation facilities whose approach is consistent with the basic philosophy and approach of rehabilitation medicine.

## THE REHABILITATION APPROACH

Rehabilitation medicine differs from other types of medical practice in a number of ways. A major focus is on preserving residual function and preventing secondary complications (physical, physiological, behavioral, or social) that lead to increased disability. Rehabilitation is geared to the needs of people with multifaceted problems and, therefore, tends to take a multidisciplinary approach to treatment in which experts from a number of pertinent disciplines work together to design and implement treatment plans. This conscious, focused meshing of the skills and knowledge of professionals from many fields into a multifaceted, tightly coordinated treatment approach sets rehabilitation medicine apart from the other areas of practice that deal with pain patients.

In order for a rehabilitation team to function successfully, it is believed that each member must share responsibility for addressing the patient's problems and achieving the goals established. In addition, clinicians generally find that the rehabilitation process is more successful if it includes the active participation of the patient and his or her family and if the goals are set by mutual agreement among the patient, family, and team members. The goals may include a resumption of physical and psychological well-being through increased mobility, self-care, communication, emotional and social adjustment, and return to work. Unlike some other areas of medicine that concentrate primarily on the causes and direct consequences of a specific disease or disorder, rehabilitation is directed toward an optimal resumption of performance in all aspects of daily living.

This chapter describes pain management programs and the techniques they use to rehabilitate chronic pain patients. It reviews the findings from outcome studies on the effectiveness of rehabilitation and on the relation between receipt of compensation and rehabilitation success. In addition, it raises a number of issues about rehabilitation for pain claimants in the context of the Social Security disability system.

## PAIN MANAGEMENT PROGRAMS: AN OVERVIEW

Specialized facilities for the treatment of chronic pain have originated within the past 20 years and are associated with the emergence of a medical specialty known as algology or dolorology. This specialty is devoted to the study of pain, and includes a shift in the medical conceptualization of pain as a symptom of disease to chronic pain as an independent clinical entity. It is estimated that there are more than 1,200 organized multidisciplinary pain clinics in existence today (Holzman and Turk, 1986), as well as many other small, singlediscipline practices calling themselves pain treatment facilities.

Chronic pain management programs exist in a variety of organizational settings and facilities. Many programs are university-based, operated by departments of various medical specialties. As such, they are situated in medical centers, community hospitals, rehabilitation hospitals, and the rehabilitation units of hospitals. Some are free-

standing specialized pain centers that focus exclusively or primarily on chronic pain. Programs can be voluntary (nonprofit), government-run (state or federal), or proprietary (either as an individual profit-making entity or as part of a regional or national chain).

The philosophy of most pain management programs is to look at the broad aspects of a patient's life, not just at the medical factors. Treatment is oriented toward the patient and family as a unit and concentrates on restoring functional capacity and limiting disability in all spheres of living; in doing so, this approach deemphasizes disease processes and diagnostic categories. Although pain reduction is a goal, the total alleviation of pain is less important than enabling the patient to function effectively with whatever residual pain exists.

Common criteria for admission to pain management programs include the presence of pain for at least 6 months, that the pain is not due to an active disease process for which other medical or psychiatric treatments are deemed more appropriate, and the patient's agreement to participate actively in the program and to involve his or her family members in the treatment. These programs usually design individualized patient assessments, treatments, and follow-up plans. Medication reduction, psychological treatment (directed particularly at depression and anxiety), family counseling, socialization skills, and educational or vocational counseling are emphasized. Physical treatment methods (e.g., transcutaneous electrical stimulation [TENS] and nerve blocks) and physical reactivation methods (e.g., exercise, strengthening, conditioning, postural improvement, and physical stress-reduction techniques) often are integral components of the treatment plan (Fey and Fordyce, 1983; Roberts and Reinhardt, 1980). Even pain management centers oriented to one primary treatment method tend to use supporting approaches as well. Thus, for example, in a program that espouses a "purely" behavioral approach, one is likely also to find occupational and physical therapy activities.

Despite their similar underlying philosophy, chronic pain management programs or pain clinics vary considerably. They can be roughly classified into three types, each of which may provide inpatient and/or outpatient care. (1) Comprehensive pain centers are multimodal chronic pain management programs with an integrated multidisciplinary rehabilitation approach that screen patients prior to admission and routinely include psychological assessment and patient follow-ups; (2) syndrome-oriented pain centers deal with discrete problems (e.g., headache, low back pain, or cancer pain) and may be uni- or multidisciplinary; (3) modality-oriented pain centers rely on a particular treatment (e.g., nerve blocks, psychotherapy, transcutaneous stimulation) and tend not to include extensive evaluative procedures (Csordas and Clark, 1986).

# The Need for Standards

Accompanying the rapid increase in the number of chronic pain treatment facilities are several problems for those suffering from pain, for health care providers, and for those who pay for such services. The Commission on Accreditation of Rehabilitation Facilities has begun accrediting chronic pain management programs (there were 50 accredited programs by mid-1986) (Whitacre, 1986). As is true of health care facility accreditation in general, accreditation for rehabilitation facilities is based on the availability of particular health care professionals and services, not on the quality of treatment. These standards do require individualized treatment programs, but actual performance criteria are lacking. Performance standards could help to deal with the following three issues.

1. The variation among pain treatment facilities is a substantial problem for the patient who may be inclined to consult the first pain center recommended, assuming that they are all the same. This is especially pertinent because these centers are typically the last resort for sufferers who feel they have tried everything else. The diversity of centers also poses a major challenge for research on the comparative effectiveness of pain treatment facilities.

2. As discussed in Chapter 10, health care professionals tend not to be adequately trained to manage patients with chronic pain. Thus, some pain programs are run by well-intentioned physicians or other health care professionals who nevertheless lack specific training and experience in the management of patients with chronic pain. Furthermore, there is concern that some programs are headed by untrained individuals who see the current interest in chronic pain treatment as a way to make money (Bonica, 1981). There is no easy way for either the pain sufferer or the referring physician to differentiate between the good and bad programs.

3. Properly carried out interdisciplinary rehabilitation for chronic pain can be expensive. The cost must be balanced against the patient's needs and resources, the payor of the services, the rehabilitation facility, and the overall system of health care delivery, as well as the potential economic benefit to both the patient and to society of returning an individual to work.

Establishing agreed-upon standards could help resolve all three of these issues. Patients and their health care providers must be able

to decide on the basis of clear, generally accepted criteria which programs are reputable, how the programs differ from one another, and what may be the most appropriate and cost-effective treatment program for a given individual. The committee cautions against the Social Security Administration (SSA) taking any action that could lead to the further proliferation of pain clinics or centers without first setting proper performance standards.

# **REHABILITATION TECHNIQUES FOR PATIENTS WITH** CHRONIC PAIN

The chronic pain patient of primary concern to the SSA is one in whom no organic or psychological cause has been identified that is sufficient to account for the pain. By the time the patient has been frustrated by the inability of numerous providers to identify the cause of the pain and resolve it, practitioners, employers, family members, and friends may increasingly question the "genuineness" of the pain. Even if the pain initially had a single treatable cause, with time it becomes enmeshed in a complex web of emotional, behavioral, and social interactions that defy simple solutions. The patient suffers not only from the inescapable pain, but also from the uncertainty as to what causes the pain. He or she sees frightful visions of what this unknown threat may portend for the future. The question facing pain centers is how such a patient can be rehabilitated and returned to function despite their pain.

Regardless of the specific treatment modalities used, pain centers commonly use two general strategies for rehabilitating chronic pain patients. One approach reassures the patient that the pain will not harm them. Because most practitioners do not truly understand the pain's cause, efforts to convince the patient that the pain is harmless can be difficult and can strain the patient's credulity. The other approach encourages the patient to increase his or her activity and thus discover that this additional activity does not increase their pain. Patients are likely to become more functional as they refocus their attention toward productive and rewarding activities and away from the pain. This strategy mirrors rheumatologists' treatment for patients diagnosed as having fibrositis (Bennett, 1981, 1984) or fibromyalgia (Yunus et al., 1982), diagnoses that have no commonly agreedupon or well-understood etiology (Wolfe and Cathey, 1985).

The following sections summarize seven treatment modalities used by rehabilitation programs for patients suffering from chronic pain: physical modalities, behavior modification, patient education, psychosocial rehabilitation, stress management, pain control, and vocational rehabilitation.

#### **Physical Modalities**

Nearly all chronic pain treatment programs include some form of physical treatment or an activities program administered by a physical therapist, occupational therapist, activity therapist, or specially trained nursing staff (Tyre and Anderson, 1981). These interventions are designed to alleviate pain and to increase physical functioning. A few reports simply identify physical therapy as one treatment approach without giving further details; others specify the physical modalities used. The 72 responses to a survey of the 263 U.S. centers listed in the 1979 Pain Clinic Directory of the American Society of Anesthesiologists revealed that the treatments most commonly used by physical therapists were (1) an individualized exercise program, (2) instruction in body mechanics, (3) relaxation training, (4) TENS, (5) biofeedback, and (6) group exercise (Doliber, 1984).

Nearly every chronic pain rehabilitation program incorporates some form of exercise designed to increase the patient's activity tolerance and range of motion. The exercise program may include stretching, conditioning, strengthening, relaxation, or some combination of these. Many exercises are incorporated into the patient's daily routine in the hope that the patient will continue the exercise at home after completing the program.

TENS is used, at least occasionally, in most programs. It is noninvasive, relatively inexpensive, harmless, and not likely to interfere with other treatments. Although TENS helps some chronic pain patients, how any individual patient will respond is unpredictable, and its benefit for pain relief is likely to fade with time. Comparing the efficacy of vibration with that of TENS in 267 patients with chronic pain, Lundeberg (1984) concluded that TENS was generally comparable with but not quite as effective as vibration.

Joint mobilization or manipulation is commonly practiced by physical therapists, chiropractors, some osteopaths, and a few physicians. According to patient reports, chiropractic manipulation alone for chronic back pain rarely provides more than temporary relief. Manipulation is more useful as part of a total program than as an isolated treatment approach (Klein and Sobel, 1985).

Physical therapists in over half of the 72 chronic pain programs surveyed by Doliber (1984) used hot or cold packs, massage, and/or hydrotherapy in their treatment programs. Other treatment methods
such as ultrasound, traction, and electrical stimulation were used less frequently.

Chronic pain programs usually use the various methods just mentioned in conjunction with an exercise program. Clinical experience suggests that exercise is a critical element of treatment and that the combination of exercise and other physical modalities is more effective than any single modality. In addition, there is no evidence that any one physical modality alone is totally effective in the treatment of chronic pain.

#### **Behavior Modification**

The reconceptualization of chronic pain from a disease model to a behavioral model was primarily the work of Fordyce and his colleagues (Fordyce et al., 1968). According to this model, regardless of its source, pain eventually develops a life of its own by interacting with environmental factors that reinforce pain behavior. Behavioral treatment methods attempt to improve functioning by helping patients rework and unlearn pain behaviors and by helping family members alter their responses to the patient in order to encourage better functioning. A primary goal of treatment is to demonstrate to patients that they can increase their activity levels and decrease excessive drug use without increased pain (Fordyce et al., 1985). Most pain management programs use at least some behavioral therapy, including operant conditioning, relaxation methods (biofeedback and progressive relaxation), cognitive strategies (including restructuring of thought processes or distraction), or some combination of behavioral strategies, sometimes including physical interventions (Linton, 1986). One recent study (Heinrich et al., 1985) confirmed experimentally the general impression that programs integrating physical and behavioral rehabilitation are more effective than any one approach alone.

Most behavior modification programs for pain include the following seven components, with variable emphasis from program to program.

1. The patient and health care team work together to establish goals and agree on a treatment plan. Baselines of drug usage, function, and reported pain levels are recorded.

2. "Well behaviors" (e.g., recreational exercise, hobbies, social interactions, and vocational planning) are reinforced. "Sick behaviors" (e.g., inactivity and pain complaints) are discouraged by disregarding them. Attention is paid primarily to what the patient does rather than to what the patient says. 3. Patients suffering from drug intoxication are gradually withdrawn from nonessential pain medications, including narcotics, nonnarcotic analgesics, antidepressants, muscle relaxants, tranquilizers, and sleep medications either through a "pain cocktail" or controlled decreasing dosage.

4. Daily activity quotas are established and graphed so as to increase activity levels gradually. Quotas are revised regularly to encourage progress and avoid failure. Daily graphic feedback of the activity level is considered essential to the behavior modification process.

5. A spouse, family member, roommate, or coworker is taught about pain behavior and the behavior modification approach. This person is also taught how to help replace the pain behavior with well behavior.

6. Patients are taught to generalize their well behavior by transferring it from the therapeutic setting to the patient's home and vocational setting.

7. Because of the possibility of having overlooked organic pathology that will be exacerbated by the exercise and activity program, or of ignoring a new illness, patients and physicians learn to distinguish "new" from "old" symptoms. New symptoms are investigated promptly. The patient is helped to live with old symptoms.

# **Patient Education**

Patient education takes many forms and is included in some form in most programs. It may include audiovisual presentations, literature, and discussion about such topics as the contribution of psychophysiological stress to chronic pain, the neurophysiology and anatomy of pain, the role of nutrition and being overweight, the proper use of pain medication, energy conservation, body mechanics, and postural awareness (Gottlieb et al., 1977; Graff-Radford et al., in press). Patient education is as varied as the differences among individual chronic pain patients and the emphasis of individual pain programs.

# **Psychosocial Rehabilitation**

Some chronic pain programs emphasize psychosocial rehabilitation to help the patient function better despite his or her pain. Such approaches include the following points.

• Training in coping skills to teach patients to solve problems and meet responsibilities rather than avoid them.

• Family retraining to facilitate important interpersonal responses in the modification of pain behavior. A key person is identified through whom the contribution of important others is implemented.

• Social rehabilitation to encourage and reinforce increased numbers of social contacts and activities in the therapeutic milieu and offer the completion of therapy.

• Psychotherapy is an integral component of most treatment regimes. Individual, family, and group psychotherapy may be used. The manner in which this therapy is introduced to patients as well as the patients' perceptions about its potential usefulness are usually critical to its success (Corley and Zlutnick, 1981).

#### **Stress Management**

Stress management is a common component of chronic pain rehabilitation programs. It may include relaxation training, biofeedback, and hypnosis. Relaxation training was used in most of the physical therapy programs Doliber (1984) surveyed. Doliber also noted that biofeedback is commonly used by psychologists and physical therapists. Biofeedback for reduction of muscle tension has been found helpful for upper back, neck, and shoulder pain; for tension headaches; and for jaw pain associated with teeth clenching. It is rarely helpful for low back pain (Fordyce, 1981).

# **Medical Interventions for Pain Control**

Most of the treatment strategies discussed previously focus primarily on the improvement of function. Many medical rehabilitation approaches focus on the alleviation of pain per se. The pain control treatment approaches that may be used in rehabilitation settings include stretch and spray of muscles or injection of trigger points; vibration; nonnarcotic, analgesic, and antidepressant drugs; and peripheral nerve blocks or epidural steroid injections (see Chapters 9 and 10).

#### Attention to Myofascial Trigger Points

As discussed in Chapter 10, there is still considerable controversy among physicians about the existence and treatment of myofascial trigger points. Nonetheless, some studies report that trigger points are common in chronic pain patients. Doliber (1984) found that physical therapists in 90 percent of 72 chronic pain treatment programs reported seeing patients with myofascial syndromes, but that only 56 percent reported seeing them frequently. At the pain treatment center in Miami, 85 percent of a consecutive series of almost 400 patients were found to have myofascial trigger points (Fishbain et al., 1986). There is a growing literature reporting that recognizing and dealing with the factors that perpetuate myofascial trigger points contribute to overall treatment effectiveness (Graff-Radford et al., in press).

# Use of Drugs

As discussed in Chapters 9 and 10, many different kinds of drugs are commonly prescribed for pain patients. Over time, many patients become involved in polypharmacy with multiple providers, which may produce untoward side effects. Most rehabilitation programs for chronic pain emphasize detoxification and withdrawal from nonnarcotic and antidepressant drugs; a few programs introduce drugs as a part of their treatment program. The more powerful analgesics and muscle relaxants may interfere so seriously with function that their side effects outweigh their benefits for some patients with long-standing chronic pain. Nonsteroidal anti-inflammatory drugs are considered useful in patients with primary fibromyalgia (Yunus et al., 1982; Bengtsson, 1986; Bennett, 1984), whereas myofascial pain from trigger points is rarely alleviated by these drugs (Travell and Simons, 1983).

# Nerve Blocks and Epidural Steroid Injections

Peripheral nerve blocks are commonly used by anesthesiologists diagnostically to localize the source of pain. Occasionally, a temporary diagnostic block proves therapeutic. In a controlled study, epidural steroid injections were found to relieve low back pain in twice as many of the treated patients as in controls, with a statistically significant advantage in the treatment groups at a 3-month follow-up (Dilke et al., 1973). However, these injections are rarely included as a regular part of chronic pain programs.

# **Vocational Rehabilitation**

One essential aspect of rehabilitation is vocational rehabilitation. Vocational rehabilitation is a specialized practice that focuses on occupational or work function. Generally, vocational retraining starts in the later stages of a rehabilitation program, and builds on the gains in function achieved in the restorative program. The issue of optimum timing for vocational counseling and training is raised frequently. It is generally believed that earlier and stronger emphasis on vocational factors, particularly on an early return to work, is likely to result in better outcomes (Goldberg, 1982; Gottlieb et al., 1977).

# **OUTCOMES OF PAIN MANAGEMENT PROGRAMS**

The general message from the literature on pain management programs is that they almost universally show good effects on the basis of a variety of outcome criteria. Improvement is observed in pain self-reports, measures of physical activity level, employment status, and medication use. There are, however, some important caveats regarding the design and methodology of many of these studies, especially those conducted before about 1982 (see Aronoff et al., 1983; Fey and Fordyce, 1983; Goldberg, 1982; and Linton, 1982). Some of the specific problems follow:

• Admission criteria. Pain management programs usually are quite selective and accept only about one-third of those who are referred for evaluation. Most of the studies do not describe the characteristics of those who were denied admission. Therefore, there is no way of knowing how representative of the entire pain population those persons are who participated. Generally, the patient selection criteria are not well-enough described to enable comparisons among studies. Standardized admission protocols and comparable physical, demographic, laboratory, and psychological data would be useful.

• Types of patients. Patients suffering from different types of chronic pain are often reported on within the same study without proper differentiation. It is not clear whether the conclusions drawn for some groups apply to others or whether treatments effective for one type of pain will be as effective for others. This lack of differentiation further impedes comparisons between studies.

• Control groups. Many studies lack control groups, and in other studies the groups are not truly comparable. Appropriate patients for such comparison groups are those who are untreated although eligible, or those who are treated only with drugs and/or surgery rather than in a multifaceted rehabilitation program.

• Treatment effects. The various components of treatment packages are not well-enough identified to allow an evaluation of their individual components. Thus, it is not known whether the observed outcomes are attributable to particular treatment modalities or to the interactive effects of multiple treatments. • Follow-up procedures. The length of time between the end of treatment and the follow-up evaluation varies considerably from study to study (and sometimes within a study for different groups of patients). Some follow-ups are conducted too soon after treatment to be informative about the robustness of the reported improvement. In addition, many follow-up evaluations depend on self-report measures alone rather than on more objective, standardized techniques; sometimes retrospective procedures are used, introducing the factor of memory into the ratings (see Chapter 11). Response rates for follow-up also vary considerably and are sometimes too low to generate reliable data.

• Outcome measures and criteria for success. Outcome criterion measures are often vague, are not always quantifiable, and lack consistency from study to study. The actual data are sometimes not reported, thus restricting the ability to make judgments about clinical significance. In addition, data on the psychosocial adjustment of patients are often not reported.

• Attention to vocational adjustment. There are few studies of the vocational adjustment of persons who have completed pain treatment programs (Goldberg, 1982). Those studies that are available are often too simplified and lack comparative data and control groups. Because, in the context of Social Security disability, vocational adjustment might be considered the most important measure of successful rehabilitation, the paucity of well-designed studies in this area is a major problem.

Despite these caveats about methodology, some common conclusions emerge from the outcome studies of chronic pain treatment programs (Linton, 1982).

The Operant (or Behavioral) Approach. Studies on operant conditioning generally report increased activity levels in patients, reduced medication use, and lowered subjective reports of pain. According to Linton (1986), "The question is no longer 'does it work,' but 'how well does it work, for whom, and why.'"

The Relaxation Approach. Relaxation, in the form of biofeedback alone, appears to yield mixed results. However, both progressive relaxation and relaxation as a coping strategy have been found useful in controlling reported pain intensity (Linton, 1982). It can be tentatively concluded that, as a group, patients can benefit from relaxation treatment. An advantage of these techniques is that they are relatively inexpensive and easy to administer.

The Cognitive Approach. Studies using a cognitive-behavioral approach tend to focus on acute (often laboratory-induced) pain, and few use a purely cognitive approach. No strong evidence indicates that cognitive strategies are effective as a treatment of choice for chronic pain (Linton, 1982).

The Multimodal Approach. Studies of multimodal treatment methods generally report considerable improvement at discharge and follow-up, but they have the same methodological weaknesses as the others. That is, the methods and treatments used varied significantly from study to study, making them difficult to compare. Further, usually the individual components of the treatment techniques are not described.

Recent research (roughly post-1982) into the outcome of chronic pain treatment has been much improved (Keefe and Gil, 1985; Linton, 1986). Research design and methodology is better; in addition, important advances in behavioral assessment and treatment methods have been made. A considerable amount of attention has been directed at developing reliable and objective methods for recording behavioral, cognitive, and physiological responses. There is a growing use of standardized questionnaires to assess functional status and to measure the severity and quality of pain, and of data analysis using multivariate techniques that permit simultaneous examination of the determinants of treatment response and control for status variables. Other improvements include

• increased attention to social and environmental variables that may influence behavioral responses;

• more standard methods for evaluating antecedents that may elicit maladaptive pain behavior patterns and for evaluating the consequences of changing these behaviors;

• identification of behavioral and psychological variables that may predict treatment response; and

• comparison of behavioral approaches to other treatments routinely used in the management of chronic pain.

The development of improved outpatient programs for the behavioral management of chronic pain has been described as a major advance, as these programs provide for substantial cost savings and less disruption of patients' lives (Keefe and Gil, 1985). An increased emphasis on planning for a patient's return to work, the inclusion of the spouse in the treatment program, and a focus on the collection of long-term, more objective measures of follow-up data all are important advances in pain treatment programs and research.

Yet even with these improvements in treatment and methodology, it

is important to recognize that rehabilitating chronic pain patients to their prepain level of functioning is not always possible (Linton, 1982). Some of the most successful programs evaluated in well-designed studies report 1-year success rates of about 50 percent (Cinciripini and Floreen, 1982; Gottlieb et al., 1977). Thus, complete rehabilitation of every patient is not currently a realistic goal; treatment, therefore, should be aimed at helping the patient live as normally and productively as possible. Indeed, with this in mind, the appropriate question may not be whether pain management programs are successful, but rather which programs or treatments are most (and least) successful with different types of pain patients (Aronoff et al., 1983). Research on specific components of successful programs would help to identify their most effective aspects, and comparative studies would further help to refine the programs. In addition, given the limitations of even the most successful treatment programs, the prevention of the development of chronic pain should be an important clinical research priority.

In conclusion, it now appears that although the early research efforts investigating the effectiveness of pain management programs were weak, recent work has been more scientifically rigorous. Data from these later studies continue to support the general impression that rehabilitative approaches to chronic pain are effective. However, much more work is required before any particular program or programs can be recommended as the best clinical solution(s) to the problem, either in general or for specific patients.

# EMPLOYMENT AND COMPENSATION AS INCENTIVES OR DISINCENTIVES IN OUTCOMES OF PAIN MANAGEMENT PROGRAMS

A specific question the Institute of Medicine (IOM) committee was asked to explore was whether receiving disability benefits exerts a negative influence on rehabilitation outcomes, especially on the return to work. This is part of a larger issue about the effects of monetary transfers on work incentives discussed in Chapter 4. Despite the common belief that compensation and litigation are disincentives to the successful rehabilitation of chronic pain patients, the literature increasingly reveals that there is no direct effect. Conversely, of more than passing clinical interest are the results indicating that employment continued or resumed during or immediately after the course of treatment has positive effects on rehabilitation. This information fits well with the view that early rehabilitation and treatment directed toward resumption of a normal life role is desirable.

#### **Employment as a Factor in Treatment Outcome**

Results from chronic pain program studies of the relation among compensation benefits, pending litigation, and treatment response are inconsistent. The one consistent finding is that patients who are employed at the outset of treatment appear to have better outcomes. Dworkin et al. (1985) studied the effects of compensation, litigation, and employment on the treatment responses of chronic pain patients. In a univariate analysis, there were significantly poorer outcome effects both for those receiving compensation and for those not working. However, when both variables were examined in multiple-regression analyses, only employment had a significant effect on outcomes.

Based on these findings and those of other authors (Catchlove and Cohen, 1982; Newman et al., 1978; Seres et al., 1981) indicating that employed patients have better treatment outcomes, Dworkin and his group proposed that the inconsistent results in the literature may be explained by: (1) differences among studies in the proportion of patients who are receiving compensation or have litigation pending and who are also working, (2) variability in compensation laws among states and countries, and (3) differences in the nature of pain treatment programs.

Several other studies address the issue in various ways. Catchlove and Cohen (1982) conducted a retrospective study of patients who at the outset of treatment were not working and were receiving Workers' Compensation benefits for pain. The patients in the experimental group (II) had been told that returning to work within 1-2 months of beginning treatment was an integral part of the pain treatment program. The control group (I) was made up of patients treated at the center before the requirement to return to work was part of the program. Fifty-nine percent of patients in the experimental group and only 25 percent of those in the control group returned to work during treatment. Ninety percent of the experimental patients who had returned to work on instruction were still working after an average of 9.6 months. Seventy-five percent of control patients who returned to work were still working after 20 months. On follow-up, fewer experimental patients were receiving compensation benefits. Of the patients from both groups who were not working, 65 percent continued to receive compensation. Although low back pain was the presenting symptom for 50 percent of patients in both groups, at follow-up it was found that this group was overrepresented among those who had returned to work. However, although this study demonstrates the importance of the expectation that patients will return to work. it should be noted that 40 percent of the experimental patients did not go back to work even when they had been instructed to do so.

In another study, Carron and his colleagues (1985) compared chronic low back pain patients at a pain center in the United States with those in a treatment center in New Zealand. They investigated psychosocial and economic factors that may influence disability and recovery in patients from countries with different approaches to the handling of disability compensation. The two groups were demographically similar. However, at initial contact, 49 percent of the U.S. sample were receiving financial compensation as compared with only 17 percent of the New Zealand sample; in addition, 56 percent of the U.S. patients attributed the pain to a work injury, whereas 37 percent of the New Zealanders did so. Treatment approaches at the two centers were determined to be equivalent; both were outpatient programs following an integrated treatment model based on Fordyce's (1968) behavior modification approach.

Patients were assessed by a self-administered questionnaire preand posttreatment. On the pretest, U.S. patients reported significantly greater emotional and behavioral disruption as a result of their pain; they used more medication and were more hampered in personal and vocational functioning. The amount of improvement 1 year after treatment was nearly equal in the two groups; the New Zealand group maintained its initial relative advantage. The authors attribute these differences in functioning despite the similarity in duration, frequency, and intensity of pain to the following aspects of disability management in New Zealand: (1) the availability of Worker's Compensation unrelated to on-the-job injury; (2) an absence of adversarial relationships among employer, insurer, and claimant (i.e., no-fault compensation); (3) a required rehabilitation intervention within 30 days of injury; and (4) extensive efforts to place the disabled worker in a job suited to his or her impairment, with substantial penalties for refusing such employment.

Seres, Painter, and Newman (1981) studied a patient population in which 40 percent were blue-collar workers in such occupations as construction, logging, and trucking; 84 percent were covered by some form of Workers' Compensation. Results of the study were that full-time employment was associated with maintaining or improving the ability to function; that part-time employment and student status were associated with similar although less striking results; and that not engaging in any such activities resulted in significant regression. Similarly, in an evaluation of low back pain patients 80 weeks after rehabilitation treatment, Newman and his colleagues (1978) found that full-time workers maintained the greatest gains in physical functioning and in reducing the need for medication.

It should be noted that not enough information is available in these studies to allow us to rule out the possibility that those employed, or able to return to work early in treatment, had less severe conditions than other individuals from the outset. It is not clear how these studies apply to Social Security Disability Insurance (SSDI) beneficiaries because in order to be eligible for SSA benefits one cannot be working and must be expected to be disabled for at least 1 year. Taken as a whole, however, the results of these studies seem to indicate that increased attention to vocational rehabilitation for chronic pain patients is warranted. The education of physicians and other treatment providers, the public, and the pain-impaired individual should focus on the possibility, desirability, and encouragement of those with pain returning to work and other activities. Specific instruction about self-regulation of medication and self-management of pain may help reduce illness behaviors that can lead to the inability to work and aid in the adoption of healthful, productive behaviors.

#### **Compensation Status as a Factor in Treatment Outcome**

As mentioned previously, whether the receipt of financial compensation (or the expectation of it from a pending application or legal action) is a disincentive to rehabilitation is a particularly controversial issue. The literature is equivocal on this question and neither dispels nor confirms the common perception that compensation has a negative influence on rehabilitation. Moreover, studies of this issue tend to be flawed in ways that make all conclusions and pronouncements questionable.

First, a number of different outcome measures are used. These include improvement in physical functioning, medication reduction, modification of patient attitudes, and a decrease in subjective reports of pain. Return to work is neither the exclusive nor even the major outcome criterion measure of most programs, but it is the outcome of greatest interest to disability insurers.

A second major problem with the studies is that not enough detail is given about the patients being studied to know whether their conditions were comparable at the outset. Severely disabled people who are receiving compensation may be unsuccessful in their rehabilitation attempts; less severely disabled people who are not receiving benefits may be more successful in their rehabilitation efforts. These differences are to be expected from the relative severity of the patients' conditions and are not, in themselves, proof that receiving compensation is a disincentive to rehabilitation. Not only the diagnosis but also the symptoms, functional capacities, and duration of time with the condition need to be specified and controlled in order to study this question properly.

Third, often different kinds of compensation are not distinguished. Because each disability program has different eligibility criteria, it is important to identify particular programs if one wishes to examine the question of incentives.

Studies examining the relation between compensation and treatment response in patients participating in multidisciplinary pain programs present conflicting evidence. Some studies report differences in outcome, with compensation and disability payment patients exhibiting less successful results (Block et al., 1980; Brena et al., 1979; Finneson, 1977; Fordyce, 1985; Hammonds et al., 1978; Herman and Baptiste, 1981; Krusen and Ford, 1958). However, other studies have found no significant relation between compensation and treatment outcome (Aronoff and Evans, 1982; Brena et al., 1979; Chapman et al., 1981; Leavitt et al., 1982; Melzack et al., 1985; Mendelson, 1984; Painter et al., 1980; Pelz and Merskey, 1982; Rosomoff et al., 1981; Trief and Stein, 1985).

"Compensation neurosis"\* (sometimes called accident or litigation neurosis) is a frequently mentioned concept in the literature on compensation as an influence on recovery. It has been described as a situation in which symptoms occur as a result of an injury or condition for which compensation is being sought, and in which the possibility of financial compensation is thought to be the most significant factor maintaining the symptoms (Weighill, 1983). The theory that such problems are resolved on settlement of a compensation claim is generally not supported (Mendelson, 1984; Tarsh and Royston, 1985). Furthermore, different outcomes might be expected depending on whether the compensation is in the form of monthly payments or a lump sum award. The literature typically does not differentiate between these possibilities.

# Studies Suggesting a Negative Effect of Compensation on Outcome

Krusen and Ford's 1958 study was one of the first to conclude that patients receiving Workers' Compensation did not benefit from treat-

<sup>\*</sup> It should be noted that this is not a psychiatric diagnosis but an informal term adopted by some in an attempt to explain an observed phenomenon.

ment as much as those not receiving compensation. Major design problems marred this study, primarily in that the two groups were not comparable on sex or initial diagnosis, and improvement was measured only in terms of the discontinuation of pain complaints and the subsequent resumption of normal activities, including work. In addition, because this study was done wholly through retrospective chart review, data may be tainted by the caregiver's subjective interpretations.

Hammonds, Brena, and Unikel (1978) focused on chronic pain patients for whom the primary treatment was the administration of sympathetic nerve blocks as a positive reinforcer for the achievement of particular behavioral goals. Patients receiving compensation were less likely to merit a block than were those not receiving compensation. Further, although not statistically significant, noncompensation patients decreased their semantic index of pain verbalization after they improved functionally, whereas that of compensation patients increased after treatment. The authors concluded that pain behavior is reinforced by conditioning and that financial compensation operates as a reward for the learned pain behavior. Brena, Chapman, Stegall, and Chayette (1979) drew a similar conclusion from a study of 101 patients, all of whom had pending disability cases. (Later studies by this group, however, found no significant relation between compensation and rehabilitation outcomes.)

Trief and Stein (1985) evaluated the effects of pending litigation for compensation on treatment outcomes in patients with chronic low back pain who participated in a 6-week behavioral treatment program. The patients were differentiated according to whether they had unsettled legal claims for compensation. Although both groups improved significantly as a result of treatment, there were some differences on specific measures between the two groups. Patients without pending litigation obtained significantly greater reduction on the hypochondriasis and hysteria scales of the Minnesota Multiphasic Personality Inventory (MMPI), and achieved "relatively greater," although not significantly different statistically, improvement on two out of three physical mobility behavior measures.

Block et al. (1980) reported on a study of patients divided on the basis of referral source. Patients referred from a disability program (Workers' Compensation or other), although significantly improved after a behavioral treatment program, did less well than those referred by physician specialists. In a 1981 article, more valuable for its description of an approach to the management of pain than for its research method, Herman and Baptiste found work incentive, employment, and the absence of litigation or Workers' Compensation claims to be significant in differentiating successes from failures. They concluded that the greatest deterrent to work was the "secondary gain" received or expected from Workers' Compensation and pending litigation.

In an exploratory study using discriminant analyses, Guck et al. (1986) found that age, compensation status, and education level, taken together, were significant predictors of treatment outcome. In addition, successfully treated patients tended to be younger and less likely to be receiving compensation.

### Studies Suggesting Little or No Negative Effect of Compensation

A number of studies show little difference in outcome between patients who claim compensation and those who do not when their psychological or physical states are assessed. Chapman, Brena, and Bradford (1981) found that pending or current disability claims are "not necessarily" an indication of likely treatment failure. Treatment in this study combined an operant conditioning approach emphasizing patient education and counseling in an attempt to refine internal coping mechanisms and abilities to adopt healthy life behaviors despite pain. Chapman and his colleagues (1981) studied 100 patients, at an average of 21 months posttreatment, divided into three categories of disability status: currently receiving long-term disability payments, having a pending claim for compensation, and not currently receiving or seeking compensation. They found that changes from pretreatment to follow-up were not significantly different among the three groups. Commenting that a significantly higher percentage of patients with pending disability claims returned to work compared with those currently receiving disability compensation, the authors suggest that granting open-ended disability be done cautiously so as to avoid establishing a permanent sick role. Similar findings are reported by Brena, Chapman, and Decker (1981).

Melzack et al. (1985) examined patients suffering from low back pain or other musculoskeletal pain. All were tested on the McGill Pain Assessment Questionnaire (MPQ) and the MMPI. Compensation and noncompensation patients had nearly identical pain scores and pain descriptor patterns. The groups were also similar on the MMPI pain triad (depression, hysteria, and hypochondriasis) and on several other personal variables. Significantly lower affective or evaluative MPQ scores and fewer visits to health care professionals were made by compensation patients. The authors suggest that the financial security of compensation decreases anxiety, resulting in lower affective ratings but unchanged sensory or total MPQ scores.

Rosomoff et al. (1981) looked at low back pain patients who presented

at a clinic as totally disabled; the majority were in unskilled and semiskilled jobs requiring heavy labor. At the outset, 59 percent were receiving compensation and 41 percent were not. At follow-up (an average of 11 months after the end of treatment), 86 percent of the total group and 88 percent of the compensation patients reported full levels of function. Also at follow-up, 70 percent of the entire group and 65 percent of the compensation group were "effectively and appropriately occupied," having returned to work or school or resumed their usual activities. The authors found no difference between groups and concluded that compensation status in and of itself does not affect the final outcome of patient functioning. They attribute success to early and aggressive job planning and placement as a central component of treatment.

Pelz and Merskey (1982) examined the social adjustment and psychological characteristics thought to be representative of a pain clinic population. They examined the effects on personal and social life, spontaneous descriptions of pain, the frequency of depression, and the personal characteristics of chronic pain patients. Interviewers administered the Hopkins Symptom Check List-90 and the Levine-Pilowsky Depression Questionnaire. Patients receiving compensation differed from others only in their higher somatization scores, a difference the authors suggest could have been an artifact of sampling resulting from the unequal sex ratios in the two groups.

## **REHABILITATION ISSUES IMPORTANT TO THE SSA**

#### The SSA and Vocational Rehabilitation

Administrators of the Social Security disability system historically have relied on the joint federal-state program of vocational rehabilitation to provide rehabilitation services; this has been an uneasy alliance. One reason for housing the disability determination services at the state level in the first place was to allow the state rehabilitation agencies to screen applicants for vocational rehabilitation services. Another reason was that the arrangement was thought to be cost effective. Between 1954 and 1965, legislative amendments provided both a carrot and a stick to foster rehabilitation. In 1954, when an earnings freeze for disabled workers was passed, the law required the referral of disabled workers to state vocational rehabilitation agencies. When cash benefits were introduced in 1956, a similar referral provision was included with the additional specification that benefits could be withheld or reduced if the disabled beneficiary refused rehabilitation services without good cause. The creation of a trial work period was also intended to foster rehabilitation. Despite these measures, the number of beneficiaries who were rehabilitated was small (Treitel, 1979).

In an attempt to improve SSA's performance in rehabilitating beneficiaries, Congress established the Beneficiary Rehabilitation Program (BRP) as part of the 1965 Social Security amendments. Previously, the federal government had provided 80 percent of the vocational rehabilitation funds, while the remaining 20 percent came from the states. Under the BRP, the federal government provided 100 percent of the rehabilitation funds; the goal was to stimulate the states to greater rehabilitation activity. Clients had to meet four eligibility requirements, the most important of which was that the predicted period of productive work should be long enough so that the benefits saved would offset the cost of the rehabilitation services. Initially, the maximum amount of SSDI trust funds allocated among the states was fixed at 1 percent of the year's total SSDI payments. In response to the program's encouraging start, the maximum was increased to 1.25 percent in 1973 and 1.5 percent in 1974.

The BRP ultimately failed for a number of reasons. Some observers felt that funds had been poured into the state programs faster than they could be wisely spent. The allotment for 1972 was \$40.5 million: by 1976 the amount had reached \$102.6 million. Questions were raised about the effectiveness of the program, and a number of cost-benefit analyses were conducted, with equivocal results. It was difficult to tell whether all of the clients who had been accepted into the program actually met the eligibility requirements and it was more difficult still to tell whether the recovery of the clients could be attributed to the services received. The program's objective was not to restore the client to maximum effectiveness but to enable him or her to engage in "substantial gainful activity" and hence leave the benefit rolls. In 1981, Congress effectively abandoned the BRP program; since then, state vocational rehabilitation agencies have been reimbursed only for services to federal disability beneficiaries who have been able to return to work for 9 consecutive months (Berkowitz and Fox, 1986). Less than \$1 million per year is currently appropriated to the states for this program.

# **Measurement and Evaluation of Pain**

The problem for the SSA in determining entitlement for disability benefits or remedial services for chronic pain patients appears to revolve around the difficulty—if not impossibility—of objectively measuring pain (see Chapters 7 and 11). One solution that has been proposed is to focus on the functional limitation caused by the pain that prevents the person from carrying out a fully active life. Functional limitation is more precisely describable than pain, and certain key elements of it can be measured with acceptable validity and reliability. For example, it is possible to verify alterations in the performance of the activities of daily life. Communication, self-care performance, mobility status, and social activity inside and outside the home or in the workplace could all be used to assess the disabling consequences of chronic pain.

Thus, one realistic approach in determining eligibility for the various benefits available is to define that eligibility by a more precise measurement of the components of dysfunction and disability and to use functional assessment as a surrogate for the measurement of pain. Disability level, as demonstrated by properly designed functional tests, may be the most objective and appropriate evidence of the inability to work caused by pain.

# The Question of Mandatory Rehabilitation

There appears to be a trend toward viewing rehabilitation (as defined in this chapter) as the preferred method for the treatment of patients with chronic pain. The Commission on the Evaluation of Pain subscribed to this view, although it stopped short of recommending mandatory rehabilitation for all chronic pain patients. This committee, too, feels that there would be critical problems with such a recommendation. As has been reiterated throughout this report, it is not known how many people have chronic pain or how many of them have conditions that are due to treatable but undiagnosed conditions. Further, not enough is known about existing chronic pain rehabilitation facilities in terms of their adequacy, their comparative effectiveness, or their ability to meet either strict standards or a requirement for accreditation. We do know that the number of high-quality programs with experienced staff and a focus on the Social Security population is limited and that some of the most successful programs accept only 30 to 40 percent of those referred for pain rehabilitation. We also know that combinations of treatment modalities appear to be effective, but there are insufficient data available to recommend one type of rehabilitative program over another.

Quite apart from the practical considerations, there are serious ethical problems in mandating treatment or rehabilitation in order for pain claimants to get benefits. Such a requirement would raise questions of fairness and equity: Would it be fair for pain claimants to have to meet requirements that no other claimants must meet? Conversely, would it be fair for pain claimants to receive a benefit (automatic access to rehabilitation programs) that no other claimant receives? In addition, mandatory treatment would compromise the claimants' autonomy and voluntariness, both of which are key elements in the doctrine of informed consent. Finally, the inception of mandatory rehabilitation would risk promoting a rapid proliferation of pain centers of poor quality because of the sudden availability of funds to pay for such rehabilitation efforts. For all of these reasons, the committee cannot recommend a mandatory rehabilitation requirement for SSA pain claimants.

# **Research and Demonstration Projects**

The pain management programs reviewed earlier in this chapter are restorative in their orientation and rehabilitative in their treatment approach. Despite methodological shortcomings in study designs, an increasing body of literature supports the view that comprehensive multidisciplinary rehabilitation, provided in specialized clinics, is useful in reducing the disability and dysfunction associated with chronic pain. Because the programs vary so much in the specific techniques used to rehabilitate pain patients, little is known about which treatment or set of treatments is responsible for the observed improvements. It appears that a multimodality, multidisciplinary approach is critical, but much more research is needed.

Specifically, a major research and demonstration effort is needed to assess the efficacy of comprehensive rehabilitative management services for chronic pain patients. The design should focus on clinical factors and on issues of social and economic policy. The clinical aspect should include research into the process and outcome of rehabilitative treatment studied at selected demonstration sites. The study centers should have a comprehensive interdisciplinary approach to chronic pain rehabilitation and a clear definition of the elements of the treatment process. Sites should be chosen that offer differing combinations of treatment approaches to allow a comparison of these various approaches. Common admission and outcome criteria and uniform follow-up evaluation protocols should be used at all sites.

The companion policy research effort should include attention to the possibilities that follow.

## 1. Earlier Identification and Entry into the System

Under SSA rules, a claimant cannot receive benefits until at least 5 months after the onset of a disabling condition. Furthermore, the elapsed time between initial filing and granting of benefits, especially for claimants whose level of dysfunction seems disproportionate to objective medical findings, is often a year or more. Clinicians have observed that the more time that passes, the harder it is to intervene successfully with pain patients.

A well-designed, well-evaluated demonstration project to determine the feasibility of early identification and the effects of early rehabilitation would add significantly to our current knowledge of the prediction of long-term disability, the optimal timing and content of rehabilitation, and the relative costs and benefits of early versus late intervention. In designing such a project, several difficult questions emerge.

- How does one identify people earlier?
- Who should identify them?
- What kinds of people are being sought? Can "high-risk" categories be identified?

• Who will be responsible for providing rehabilitation services and for the costs of such services?

# 2. Expansion of the Initial Assessment of Pain Claimants to Incorporate a More Functional Approach

Medical criteria are used as a basis for presuming or establishing the inability to work. Disability in excess of objective medical evidence, as is often the case with chronic pain claimants, leads to denial of benefits and to possibly unnecessary reviews and appeals. Pain claimants should be able to proceed to the stage of the evaluation process in which the ability to function in working and in performing basic activities is assessed. Such an evaluation is then directly relevant to questions about the possibility of rehabilitation for chronic pain claimants.

3. Disentangling the Current Requirements for Proof of Work Disability and the Requirements for Acceptance into Vocational Rehabilitation

The SSA's definition of disability requires the total inability to work. To be eligible for state or federal vocational rehabilitation, however, claimants must be able to demonstrate a future likelihood of employment. This is an inconsistency that must be resolved if claimant rehabilitation is to be achieved.

# 4. Coordination of Disability Benefits Programs and Rehabilitation Services

As discussed previously, although state vocational rehabilitation agencies are linked to the SSA, they treat relatively few SSDI or Supplemental Security Income beneficiaries. If rehabilitation is to be an integral part of the federal disability program, the administration and funding of these activities must be better coordinated.

## 5. Emphasis on Existing Incentives

Currently, the Social Security disability programs include provisions designed to encourage people to try to work, such as a trial work period during which disability and medical benefits continue. These features seem to be used very infrequently, at least partly because physicians, lawyers, and beneficiaries are unaware of them. A concerted educational/ information campaign should be undertaken to highlight these provisions and to encourage beneficiaries to take advantage of these opportunities.

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# PART V CONCLUSIONS AND RECOMMENDATIONS





# 13 Conclusions and Recommendations

The Social Security Administration (SSA) and the Congress have acknowledged difficulties in evaluating claimants for disability benefits whose complaints and dysfunction are not fully accounted for by clinical evidence of disease or injury. Persons with chronic pain, especially musculoskeletal back pain, are thought to constitute the largest category of such claimants.

The Institute of Medicine (IOM) was asked by the SSA to follow up on the work of the Department of Health and Human Services (HHS) Commission on the Evaluation of Pain to further elucidate the factors that influence the course of development from acute to chronic pain, to explicate the concept of illness behavior as applied to chronic pain, to review the state of the art of assessing and measuring pain, to consider making recommendations about how the SSA disability programs might better evaluate claimants with chronic pain and provide incentives for rehabilitation, and to make suggestions about research that holds promise for improving our understanding of chronic pain and the disability process.

The SSA disability program is the largest in the world. Thousands of people at the local, state, and federal levels are involved in the eligibility determination process and program administration. As discussed in Chapter 4, differences in the perspectives and goals within various program elements and among the many levels of review and adjudication create a variety of tensions and conflicts. For example, differences in the perspectives of physicians and administrators and of SSA-employed physicians and consulting physicians are likely to have a differential impact on judgments about eligibility for benefits. Furthermore, despite detailed rules and regulations for determining eligibility for benefits, subjectivity is inherent in the process. This is most striking at the administrative law judge level of appeal (the only time a claimant is seen face to face), where approximately half the decisions of the administrative paper reviews are overturned.

The entire program operates within the constraints of laws and congressional and public pressures that reflect economic conditions and societal views about the extent and nature of governmental responsibility to care for those who are unable to work (see Chapter 2). Like other cash transfer programs, there is a constant tension between forces trying to expand the program and forces trying to keep it tightly constrained. This derives in part from conflicting views about whether the provision of benefits is inherently a disincentive to work.

In conducting this study the IOM committee assumed that it was inappropriate to consider recommending changes in the legal definition of disability under which the SSA operates, which implies a total and permanent inability to work in any gainful occupation. Not only would such considerations go far beyond the study's mandate, but the definition is too central to the basic philosophy of the SSA disability program to expect Congress to seriously entertain revisions. Nonetheless, within the constraints of the existing definition of disability, the committee did explore numerous procedural issues.

In reviewing data from the SSA, hearing testimony from SSA officials and experts in pain assessment, analyzing the published literature, and in its own discussions, the study committee was struck by the complexity of the disability system and by the extraordinary complexity and multifaceted nature of chronic pain. Several crucial gaps in knowledge about chronic pain and its relation to disability bear importantly on the study mandate. These include, for example:

• inconsistencies in definitions and measurement that make it difficult to generate reliable estimates about the numbers of people in the population with chronic pain and associated dysfunction; these are the people at risk for becoming unable to work and applying for SSA disability benefits;

• lack of data about the numbers and characteristics of SSA claimants and beneficiaries in the disability program whose primary complaint is pain and how they fare over time;

• lack of reliable methods for predicting which patients with acute and subacute pain will develop chronic disabling pain; although many factors are known to correlate with chronic disabling pain, predictive models have not been developed; • untested assumptions about the ability of early treatment and rehabilitation to interrupt the course of chronic pain; although there is general agreement that the longer a person has had a chronic condition, the more difficult it is to achieve rehabilitation, there are few data that attest to the effectiveness of early intervention; and

• imperfect correspondence between severity of pain and dysfunction; people can have severe pain with minimal functional limitations or minimal pain with severe limitations.

In light of these and other considerations that will be discussed, the committee cannot responsibly make recommendations for major changes in the way the SSA disability programs operate. In the absence of more specific and refined data, the implications of such changes cannot be accurately estimated in terms of their monetary costs, administrative burden, or their effects on the fair and equitable functioning of the programs. However, the committee does recommend one important change that holds promise for improving the way the SSA handles chronic pain complaints (see Recommendation 3). Furthermore, in order to clarify a number of aspects of the problem and provide the basis for making well-informed decisions about other significant changes that might be entertained in the future, the committee recommends several demonstration projects and research studies. The committee also makes recommendations about clinical practice and the education of health professionals to improve the prevention, diagnosis, treatment, and rehabilitation of chronic pain.

On the basis of its deliberations and an analysis of the available literature, the IOM study committee makes six major recommendations.

1. The SSA should develop a better system for routine data collection and information retrieval for the disability programs in order to know more about the numbers, characteristics, and outcomes of claimants and beneficiaries generally and to know more about pain claimants and other troublesome categories of claimants specifically.

2. Neither "chronic pain syndrome" nor "illness behavior" should be added to the listings of impairments.

3. Significant pain, even in the absence of clinical findings to account for it, should trigger a functional assessment of the capacity for work.

4. The SSA should support the design and execution of two major demonstration/evaluation projects: one to develop and compare several methods for assessing pain claimants early in the evaluation process,

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and one to assess the efficacy of early multidisciplinary rehabilitation interventions with chronic pain patients.

5. The Secretary should take the lead in ensuring that a broad research initiative on pain and disability is undertaken within HHS. This should include at least one major longitudinal epidemiological study to identify the determinants of chronic disabling pain; clinical studies on the efficacy of commonly used treatment modalities and the optimal timing of interventions to prevent chronic disabling pain; methodological studies to develop and validate measures of clinical phenomena, psychosocial variables, and pertinent outcomes relevant to chronic pain and disability; and health services research to elucidate the contributions of important sociocultural variables to illness progression and illness behavior and to study the interactions of the health care delivery system and disability programs with patient/ claimant behavior.

6. The training of health care professionals should entail a comprehensive and multidisciplinary approach to patients with pain that includes attention to important psychological, social, and cultural contributions to the development of chronicity and associated illness behavior. Such an orientation is likely to improve the diagnosis, treatment, and rehabilitation of chronic pain patients and to prevent or mitigate long-term negative outcomes.

A discussion of each of these recommendations and the conclusions on which they are based follows.

# **Recommendation 1** DATA COLLECTION AT THE SSA

In the course of its activities, the committee found that specific figures and reliable estimates about the numbers and characteristics of pain claimants in the SSA disability programs and about what happened to claimants and beneficiaries over time were not available. Thus, the committee finds that routine data collection activities for the entire disability system should be improved. Recognizing that the creation of a data collection system for such a large program is a major undertaking, the committee suggests that collaboration with other government agencies, especially the National Center for Health Statistics and the Bureau of the Census, on routine and special data collection activities, might be especially useful and efficient. Better data collection and retrieval capabilities would provide valuable information to the program administrators and would also facilitate research by the agency or others. An improved data collection system would permit the SSA to define more concretely its problem with chronic pain claims. The committee recommends that the SSA commission a study to address the following questions.

• What proportion of claims are based primarily on pain?

• What proportion of pain claimants are found eligible under the existing rules and at what level of review or adjudication?

• What share of the appeals at each level are pain cases and what are the results?

• How much time elapses between the onset of chronic disabling pain and application for the disability benefits?

• Is the SSA a last resort or a first resort for chronic pain patients? To what extent do Social Security Disability Insurance pain claimants also seek and receive benefits from Workers' Compensation or other public and private disability programs?

• What happens to people with claims based primarily on pain who are denied eligibility? How many ever return to work or enter the disability system at a later time?

Expert consultation should be sought for the design of both the information system and the study to ensure their scientific validity and maximum utility to the SSA.

# **Recommendation 2** NO NEW LISTINGS FOR PAIN OR ILLNESS BEHAVIOR

"Chronic pain" alone should not be added to the SSA regulatory listing of impairments that allow a presumption of disability, nor should "chronic pain syndrome" be added to the listings. Likewise, "illness behavior" should be neither a diagnosis nor a listing.

Although acknowledging the value of the terms chronic pain syndrome and illness behavior in certain contexts, the committee has reservations about their use. First, the lack of consistent definitions of each term is likely to cause confusion and misunderstanding. Second, each term risks reifying conditions that are highly variable, thereby implying a homogeneity in patients and conditions that does not exist. As discussed in Parts III and IV of this report, chronic pain does not present a coherent, clearly defined constellation of symptoms and signs that can appropriately be called a clinical syndrome or a medical diagnosis. There has been no demonstration of a common etiology, a predictable natural history, or specific treatment for the various pain conditions that would suggest a basis for positing a single chronic pain syndrome. Therefore, the committee recommends using terms that are more specific to the particular complaints, problems, and deficits being discussed.

Similarly, the committee's judgment is that illness behavior is neither a disease nor a diagnosis. As described in Chapter 8, the term refers to a concept intended to describe the behavior of individuals responding to illness or to the belief that they are ill. All individuals exhibit such behaviors in varying ways. The concept and the perspectives associated with it facilitate appropriate inquiry and provide a framework for understanding behavior but are not intended to describe clinical status. The key variables underlying the concept are the particular types and intensity of the behavioral manifestations of illness.

The recommendation that there be no listing for chronic pain syndrome and illness behavior certainly does not mean that chronic pain, and chronically painful conditions, should be ignored in the administrative process. On the contrary, as discussed throughout this volume, the committee believes that pain should be attended to in a more thorough and systematic fashion in clinical practice and in the determination of eligibility for disability benefits.

# **Recommendation 3** SIGNIFICANT PAIN SHOULD TRIGGER AN ASSESSMENT

The committee recommends that significant pain as a primary complaint should trigger a functional assessment, even in the absence of objective clinical findings that could reasonably produce the pain. In the current sequential evaluation process (see Chapter 3), once it has been established that the claimant is not working, the second step is to determine whether the claimant has a "severe impairment" (e.g., one that interferes with the performance of basic work activities). When symptoms such as pain are alleged, there must be objective physical findings to substantiate the presence of an "impairment" (the SSA uses the term impairment to refer to both a disease and to an inability to do something that results from a disease) that could reasonably produce the symptoms. If such findings do not exist and it has been determined that there is no mental impairment (as defined in the SSA's Listing of Impairments) to account for the pain, the claim is denied on medical grounds alone without considering vocational factors. If the impairment is determined to be severe, the third step is to determine whether the impairment "meets or equals the listings." The listings include diagnoses and associated signs, symptoms, and findings, usually at a specified level of severity, all of which must be present in order to meet the listing. Many listings, such as arthritis, include pain as one criterion that must be present along with several others. If a claimant meets or equals the listings, benefits are granted; if a claimant does not satisfy the listings, the evaluation proceeds to an assessment of the claimant's residual functional capacity to perform past relevant work. It is at this fourth stage that vocational factors are considered. An assessment is made of exertional and nonexertional limitations in order to determine whether the claimant has the capacity to perform work-related physical and mental functions despite the limitations caused by a medically determinable impairment. The residual functional capacity assessment is based on a paper review of medical findings that must therefore be detailed enough to permit a medical judgment about the claimant's functional capacities.

In this sequential evaluation, a pain claimant without clinical findings to account for the symptom would be denied benefits at the second level. The committee's recommendation is for a primary complaint of pain to allow assessment of the claimant's functional capacities for work—in other words, essentially to proceed to the fourth level. The SSA's recently revised mental illness listings provide a precedent for this approach. They are based on integrated functional criteria, not simply a diagnosis, by which claimants are evaluated primarily on their ability to function in activities of daily life, including work.

Disability benefits have not been awarded on the basis of self-reported pain uncorroborated by objective findings, nor does the committee believe they should be. However, the kinds of acceptable evaluation and corroboration should not be limited to medical evidence of an underlying disease process. With or without such findings, consideration should also be given to serious functional limitations and serious problems on measures of integrated behavior. This means not only assessing physical abilities such as sitting, standing, lifting, and walking, but also examining how the limitations imposed by pain affect aspects of the individual's daily life: sleeping, eating, self care, interpersonal relationships, the ability to concentrate, and work activities. In the committee's view, an increased emphasis on functional assessment of claimants early in the evaluation process holds promise for preventing some errors of commission and omission in eligibility determinations and for averting at least some of the later appeals for higher review and adjudication. Moreover, while recognizing that government agencies and programs can never be shielded fully from politics, it is important to protect individual disability

determinations from political pressures by making judgments as scientifically and clinically sound as possible given the inherent difficulties and subjectivity involved.

# **Recommendation 4** DEMONSTRATION PROJECTS

The committee recommends two distinct but interdependent types of studies. One type is research to further scientific understanding of chronic pain and disability and to develop improved methods for conducting such studies (see Recommendation 5). The other type is demonstration projects with immediate policy relevance whose purpose is to assess the feasibility and consequences of changes in SSA procedures.

# Demonstration: The Feasibility and Consequences of Early Assessment

Because of the general lack of information about pain claimants and how best to assess them, the committee recommends that a welldesigned and well-evaluated demonstration project be undertaken by the SSA: (1) to evaluate the effects of assessing pain complaints at the initial state level of review, (2) to compare several methods of evaluating pain and associated dysfunction, and (3) to determine and compare the impact of each type of assessment on the following kinds of procedural and outcome variables:

• allowance and denial rates for pain claimants in general and to determine whether certain types of pain claimants are more likely than others to be found eligible with each method;

• appeal rates for each method among pain claimants who are found ineligible for benefits at the initial determination;

• reversal rates for cases appealed to the administrative law judge level;

- average length of time to final decision for each method;
- overall costs to the program for each method; and

• claimants' and evaluators' views of the fairness of the process, and evaluators' views of the ease with which the assessment can be done.

The recommendation for a demonstration project to evaluate various methods for assessing pain early in the eligibility determination process is based on a number of observations and conclusions. First, the IOM committee concurs with the HHS Pain Commission that pain is subjective and that there is no completely reliable or valid way to measure it. Furthermore, because pain and functional impairment are imperfectly correlated, even if there were an instrument to measure pain, it would not necessarily provide an accurate assessment of functional impairment—which should be the key to eligibility for disability benefits.

As discussed in Chapter 7, by measuring nervous system activity one can measure activity that reliably produces pain; but pain itself cannot be measured in an equivalently objective way. Because the perception of pain is subjective, it will always be an inference from neural activity or observations of behavior. Because pain cannot be measured directly, various indirect methods have been developed to assess the effect of pain as perceived by the patient or by observers. No one method is complete by itself. Each method has some positive and negative features in terms of practical considerations (e.g., how long each takes to administer, ease of interpretation, and costs) and in terms of reliability.

Second, although a number of sophisticated means of assessing chronic pain claimants have been developed, as discussed in Chapter 11, it has not been demonstrated that these methods provide more accurate measures of pain or of the relation between pain and functional impairment than some simpler methods, such as systematic observation of the claimant directly or using videotape recordings.

Third, the committee believes that assessment for clinical purposes and assessment for the purpose of certification/eligibility are and should be distinct processes. Clinical assessment is performed to diagnose and treat pain. Assessment for SSA disability screening or other certification purposes, however, is done to determine whether the claimant qualifies for benefits. While risky evaluation procedures may be acceptable in the context of treatment that includes discussion with the patient and fully informed consent, from an ethical perspective it would be inappropriate to require claimants to undergo such procedures to determine their eligibility for benefits. Furthermore, using the same personnel for treatment and for eligibility determination risks compromising the doctor-patient relationship and producing conflicting obligations for the physician. From a programmatic perspective, practical considerations, including costs, may further constrain the nature and extent of assessment.

Finally, the committee cautions that an unnecessarily sophisticated assessment process for disability determinations is likely to delay decisions and increase costs. In the interest of developing a decisionmaking process that is optimally efficient in terms of time and money,

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while at the same time rendering fair and consistent results to claimants, the committee believes that the SSA should look for methods of assessment that are as simple, valid, and equitable as possible. In light of all these considerations, the committee recommends that several methods be tested and compared at the initial determination level.

#### Simple Assessment Tool

Several states have been experimenting with various questionnaires for assessing pain at the initial determination level. In addition to recommending that such natural experiments be evaluated, the committee also recommends that one or more easily administered questionnaires or visual analogue scales be incorporated into the initial determination in a more rigorous experiment in order to test their reliability, their effects on the ratio of allowances to denials, and the practical constraints of including such instruments in this stage of the review.

#### Early Face-to-Face Hearing

Recognizing the value of observation for evaluating pain, numerous observers, including the Pain Commission and SSA program administrators, have recommended that claimants have an early face-to-face hearing at the state disability determination level rather than rely solely on a review of the medical record. The committee is aware that the SSA is currently designing a feasibility study of face-to-face assessments at the initial consideration level to assess practical and procedural issues. The IOM committee recommends a demonstration project that goes beyond procedural feasibility issues to evaluate the consequences of an early personal hearing as detailed previously, and to determine the extent to which such an approach could be standardized and would yield consistent decisions.

#### Integrated Functional Assessment

The third method to be tested is an integrated functional assessment at the initial determination level for pain claimants. In the current system, such assessments are conducted late in the evaluation process, if at all. Included are reports of the claimant, family, and former employer; the history and physical examination (which should include a neurological and musculoskeletal examination); and a psychosocial assessment, including an evaluation for possible psychiatric disorder. In addition to these elements of the evaluation, the committee recommends (1) the use of a standardized pain questionnaire or visual analogue scale to help systematize information from observation, interviews, and the physical examination and (2) an integrated functional assessment going beyond simple range of motion tests (see Chapter 11). The committee believes that there is potential for using careful description and measures of functional disturbances in performance and activities of living as surrogate variables for the severity of chronic pain conditions. This should be tested rigorously in this demonstration.

#### **Demonstration Project: Does Early Rehabilitation Work?**

The IOM committee was charged to examine possible disincentives to rehabilitation and to consider making recommendations about how rehabilitation could be better incorporated into the SSA disability programs.

#### Incentives and Disincentives for Rehabilitation

As discussed in Chapter 4, the question of whether the SSA disability system contains elements that encourage or discourage rehabilitation is part of a much larger issue about economic incentives and work. The narrower question about whether receipt of benefits is an impediment to successful treatment and rehabilitation has not been well researched. The studies reviewed in Chapter 12 on the effects of compensation on rehabilitation outcomes are too imprecise in terms of their operational definitions and measurement to draw any definite conclusions. Nonetheless, the committee notes that there are several features of the disability program itself (including its definitions, eligibility requirements, and determination procedures) that apparently work at cross-purposes to rehabilitation.

First, the committee concurs with the Pain Commission that under the current disability system the need to "prove and re-prove" one's disability is so great that it is likely to undermine claimants' subsequent motivation for rehabilitation.

Second, the requirements for proving work disability and the requirements for acceptance into rehabilitation need to be disentangled if rehabilitation is to become a realistic goal within the SSA. The SSA definition of disability requires a long-term, virtually total inability to work. To be eligible for rehabilitation, however, a claimant
must be able to demonstrate a potential to work and benefit from a rehabilitation program. These two requirements work at cross-purposes.

Third, as noted by the Pain Commission, although the Social Security disability programs include features intended to provide incentives for rehabilitation (e.g., a trial work period with continuation of disability and medical benefits), such opportunities are seldom used. This appears to be due largely to two factors: fear of losing benefits and lack of knowledge about the existence and details of such provisions. The committee strongly endorses the Pain Commission's recommendation that a concerted educational/informational campaign should be undertaken to acquaint beneficiaries, physicians, lawyers, and employers with the existing SSA provisions for rehabilitation and return to work.

Finally, although the details go well beyond the scope of this inquiry, the committee notes that the lack of coordination between agencies providing disability benefits and those providing rehabilitation services in terms of their eligibility requirements, administration, and funding does not encourage rehabilitation. Furthermore, the committee notes that several basic features of the SSA disability program, including the definition of disability and the 5-month waiting period, may preclude rehabilitation as a realistic goal on a large scale because most of those who qualify for disability may simply be too impaired to return to work.

## The HHS Pain Commission's Proposal

A key recommendation of the Pain Commission was that the SSA undertake a demonstration project "to determine what proportion of individuals determined to meet the [commission's] selection criteria for impairment due primarily to pain can be reactivated and vocationally rehabilitated through intensive treatment in appropriate treatment centers and/or vocational rehabilitation centers and the treatment modalities which achieve maximum success with these individuals." The cost-effectiveness of rehabilitating this population and of "incorporating a reactivation/vocational rehabilitation program as an integral part of case evaluation in disability claims where impairment is due primarily to pain" are to be evaluated. The commission's proposal is to test the efficacy of rehabilitation quite late in the chronic pain/disability process. The IOM committee endorses this recommendation, but also suggests that a related demonstration project should be designed to assess the effects of intervention earlier in the course of chronic pain.

#### Demonstration Project for Early Rehabilitation

By the time claimants apply for SSA disability benefits, chronicity is well established and functional impairments are severe. Early identification and rehabilitation hold promise for preventing long-term disability, which would ultimately reduce the number of claimants and beneficiaries. Thus, in the committee's view, it is appropriate for the SSA to sponsor this demonstration.

The possible value of early and active rehabilitation for pain patients should be thoroughly explored. The committee recommends a demonstration/evaluation project to identify pain patients before they apply for disability benefits and to offer them a package of multidisciplinary rehabilitation, time-limited cash benefits, and medical benefits.

Several critical questions must be addressed in planning such an effort. For example:

• When is the optimum time to identify those at risk?

• How can they be identified? What screening tools should be used? A relatively simple screening method should be developed to attempt to identify those at highest risk for long-term disability. The informed judgment of the committee is that a mobility scale may prove to be a reliable indicator of those at high risk for maintaining a chronic pain problem in the long term; such scales assess the functioning of an individual in his or her usual activities, such as working, household responsibilities, leisure activities, and use of transportation. This and other methods should be tested and compared.

• Who should identify the study population?

• What kinds of people are being sought? Are there particular categories of people, such as those with back pain of uncertain origin or those with pain and depression, for example, who are at high risk for the development and maintenance of chronic pain problems?

• What should constitute appropriate rehabilitation services and what standards should be set to allow for comparative studies?

• Who should provide rehabilitation services? Presumably a sample of multidisciplinary pain clinics would be selected, but the population of such specialized centers is difficult to define because of the variation among such centers in their approaches to pain rehabilitation.

The committee recognizes that these are difficult issues to resolve, but not prohibitively so. A well-designed, well-evaluated demonstration to develop and test methods for reliably identifying patients likely to develop chronic disabling pain and for testing the efficacy of particular rehabilitation techniques will yield invaluable information for the disability program that may suggest ways to better integrate the rehabilitation aspect of the program with the disability benefits part. For clinicians also, this demonstration is of paramount importance to the prevention, treatment, and rehabilitation of chronic pain.

## **Evaluation of the Demonstrations**

Rigorous evaluation must accompany the demonstrations if they are to provide reliable information on which to base policy decisions. Accordingly, we make the following four recommendations.

1. Plans and/or requests for proposals to execute demonstration projects should be separate from requests for proposals to evaluate those projects.

2. "Evaluators" should be investigators neither accountable nor beholden to the "demonstrators" in order to assure objectivity of the evaluation. Evaluation of demonstration projects should not be conducted by the SSA staff.

3. Requests for evaluation of proposals should require details about research design, specification and measurement of key variables, as well as criteria for success of the demonstration and of the evaluation component.

4. The evaluation should be designed and baseline data gathered before the demonstrations begin.

The committee recognizes that such evaluation is costly and could be even more expensive than the demonstration. Justification of the costs of evaluation and the time needed to do it should be linked to the resource and cost implications of widespread implementation of a successful model, or the accrued savings when an ineffective but politically appealing demonstration is shown to be worthless.

## A Note About Research with Human Subjects

The committee is aware that the Social Security Act gives the Secretary authority to suspend the normal rules for purposes of demonstration projects without institutional review board review and all that that entails. Although the federal requirements for research with human subjects are not strictly applicable to testing modifications of entitlement programs, the committee voiced concern that in implementing the demonstration projects the Secretary should be sensitive to the needs of the claimants regarding appropriate notice, information, and consent. Specifically, claimants should be informed that they are involved in a demonstration project and that the old rules and regulations do not apply; they should be informed about the new procedures and regulations. The right to appeal must be maintained. Participants should be informed of this right and how to exercise it.

In addition, the committee shares the concern of the Pain Commission about the interpretation and application of results from demonstration and research projects. Caution should be exercised in applying summary statistics and general research findings to the decisions made about individual claimants. The Social Security Act requires personalized adjudication of disability claims. Therefore, research results documenting aggregate behavior should not be the basis for denying benefits to an individual. Results of research and demonstration projects can be useful in designing an equitable system, but they must not substitute for the personal assessment and adjudication to which claimants are legally entitled.

## **Recommendation 5 RESEARCH AGENDA**

Throughout its work, the committee found critical information lacking about every aspect of the chronic pain/disability problem. Epidemiological, clinical, health services, and methodological studies are needed. Recognizing that such a broad research initiative goes far beyond the immediate concerns of the SSA, the committee recommends that the Secretary coordinate this effort within HHS in consultation with SSA officials and other federal agencies that have programs and conduct research relevant to these issues.

## **Epidemiological Initiatives**

Epidemiological initiatives should be directed primarily to a prospective study of at least two cohorts. Such a study will help elucidate the determinants of chronicity, disability, and other poor outcomes.

As discussed at length in Chapter 6, virtually all of our information about chronic pain comes from cross-sectional studies. Although recognizing that prospective studies are expensive and difficult to execute, the committee feels strongly that such a study is the only way to get the critical information needed to understand who is at risk for developing chronic pain, and hence, who is a potential claimant for disability benefits. Until the size of the universe of potential pain claimants has been estimated and their characteristics described, entertaining proposals for major changes in the disability programs would be unwise. Furthermore, such a study would point the way to the development of successful prevention strategies, including the critical issue of the optimal timing of interventions and directing efforts at those most likely to require and benefit from them.

## **Clinical Research**

Clinically, the compelling need is to demonstrate the effectiveness of commonly used therapeutic and rehabilitative interventions used singly and in various combinations. The most powerful method for investigation is the randomized controlled trial. There have been very few such studies to assess the benefits and harms of the many medications, physical therapy techniques, and surgical interventions that are frequently used for back pain. Little is known about the characteristics of those for whom particular interventions are likely to be more or less successful or about the optimal timing of specific treatment methods. Important factors such as concurrent diagnoses and compensation status have rarely been described in detail or controlled for in clinical trials. In the rehabilitation studies there are significant biases in the selection criteria for admission to programs. What happens to people who are not admitted and the effects of such a selection on outcomes have not been analyzed clearly.

As discussed in Chapter 12, none of the studies that purport to address the question of whether receipt of benefits affects rehabilitation potential has systematically examined the particular elements within the categories of "compensation" versus "no compensation" that may account for the findings in either direction. Although it is certainly possible that receiving benefits could be a deterrent to rehabilitation, as discussed in Chapters 4 and 12, many other equally plausible explanations have little to do with compensation itself.

Related to the need for clinical trials of commonly used interventions is the need to apply promising findings from laboratory research to the treatment of pain patients. A National Academy of Sciences Research Briefing Panel on Pain and Pain Management (1985) found that clinical research had lagged behind laboratory research and that there was an unfortunate delay in disseminating laboratory findings to clinical settings. The panel urged the establishment of multidisciplinary research centers to promote the development and the application of new knowledge in pain and pain control. This committee concurs and recommends that the results of basic biological, neurological, and behavioral pain research be better tested in clinical settings and used in the planning and evaluation of research on clinical management and therapeutic procedures.

Furthermore, a number of basic clinical questions about pain have yet to be adequately studied. For example, not much is known about the relation between chronic pain and the actual diagnosis given to patients, about the cause and effect relation between chronic pain and disorders such as depression and alcoholism, and about the natural histories of the various chronically painful conditions. Prospective studies—particularly cohort analytic studies—of at least several years duration are needed on the clinical disorders and psychosocial factors related to chronic pain. These could be done as part of the longitudinal cohort study discussed previously or as separate clinical studies. Well-designed cross-sectional studies with appropriate control groups would also be useful.

## **Health Services Research**

Very little is known about patterns of utilization of traditional and nontraditional health care among chronic pain patients other than the fact that care from multiple sources is often sought (see Chapters 6 and 8). Studies of the sequence of help-seeking and the effects of different kinds of care on subsequent health status for patients with various pain conditions and personal characteristics would provide valuable information about patients' decision making and about the appropriate timing of interventions. Such studies would also elucidate the process of illness behavior and hold promise for identifying critical elements or stages in the process for successful intervention.

It is generally asserted that features of the health care and disability systems, and the nature of the interactions with health care professionals and disability examiners, affect the behavior of pain patients/claimants. This assertion has not been systematically studied. Such research holds promise for discovering important clues for altering behavior, optimizing the organization and content of health services, and identifying elements of the eligibility determination process that may encourage illness behavior.

## **Improved Methodology and Multidisciplinary Research**

As discussed throughout this volume, definitions of key terms, outcome measures, follow-up periods, assessment methods, intervention strategies, and selection criteria vary widely. Most existing studies rely on small, poorly described heterogeneous samples and rarely use control groups. Progress in this field depends on developing and refining uniform definitions and approaches to measuring numerous independent and dependent variables, including patient classification, psychosocial variables, the delineation of interventions, and outcomes. Methodological research of this type is extremely sophisticated and requires input from experts in a number of disciplines in order to be effective.

Ideally, all of the studies in this research agenda would be designed and executed by multidisciplinary teams of clinicians and epidemiologists in collaboration with psychologists, sociologists, economists, policy analysts, and statisticians as appropriate to the issue being addressed. The design of the sampling frames will be particularly important in several of these studies. Recognizing that the recommended research is likely to go well beyond what the agency is able to do in-house, the committee recommends that the SSA consult with appropriate experts in research design, measurement, and statistics in planning these various studies, and that the actual studies be conducted by a multidisciplinary group of outside experts.

The research agenda recommended by this committee will facilitate judicious inquiry into important clinical and policy-relevant questions. Much of the agenda pertains to issues of prevention. Epidemiological studies to identify people at risk for chronic pain before negative outcomes are apparent, methodological research to develop and test ways of identifying people early in the pain trajectory who are likely to go on to chronicity, controlled trials of particular treatment techniques alone and in combination, and studies of the optimal times to intervene all hold promise for preventing chronic disabling pain. It is not possible to estimate the cost of this research without designing the individual studies. However, the committee notes that the cost of these studies is likely to be slight compared with the potential savings in medical care expenditures and disability benefits for chronic pain.

## Recommendation 6 EDUCATION TO IMPROVE THE CLINICAL CARE AND TREATMENT OF CHRONIC PAIN PATIENTS

Among the committee's members were clinicians and researchers knowledgeable about and experienced in the care of medical and surgical patients with pain and the course of their illnesses. There was much discussion of the appropriate and inappropriate treatment of those with chronic pain, especially musculoskeletal back pain. In addition, the committee reviewed the available epidemiological and clinical data about pain and the development of chronic pain in order to determine the range of techniques used in practice and their effectiveness in eliminating, reducing, and preventing chronic pain and associated dysfunction and disability. These activities have led to a number of conclusions about the nature of chronic pain and appropriate clinical management, and to recommendations about the postgraduate medical training of primary care practitioners and specialists.

Everyone suffers severe pain from time to time; for most of us, each episode ends with the resolution of the symptom or the disorder producing it. A small but significant proportion of individuals treated may get less than optimal relief, have recurrences, and develop chronic pain. What differentiates people who develop chronic pain, who can function with it, or who become disabled is not well understood. At the time of the first episode of pain it is difficult to predict the course of the condition for a given patient, the likelihood of recovery, the response to specific therapies, or the potential for rehabilitation and return to a more active role.

What is known is that physical, psychological, socioeconomic, cultural, and situational factors all interact to influence the development, course, and outcome of persisting pain. As discussed in Chapter 10, in order to understand and effectively manage patients with chronic conditions, a model is needed that includes attention to multiple variables including psychological, sociocultural, and behavioral factors.

Pain patients, regardless of the duration of illness, should have a comprehensive assessment. A thorough history and physical examination is needed to detect the presence of physical, neurological, or musculoskeletal abnormalities and to determine what diagnosis, if any, can be confirmed. Comprehensive clinical assessment requires a variety of measures and data. Sources of information include subjective report data, information from others close to the patient, behavioral data, organic findings, and direct observation by physicians and other professionals experienced in functional assessment. An evaluation of contributing psychosocial and behavioral factors should be conducted by collecting information on the patient's family, work, school, and community in which the pain is experienced and by which it is influenced. Using a variety of methods from many disciplines, it is possible to build a more accurate picture of the effects of pain on a patient than by relying on a single method.

Such evaluations require expertise in a number of disciplines and in skills such as functional and psychosocial assessment and neurological and musculoskeletal examinations. Currently, few individual clinicians are competent to conduct such multidisciplinary evaluations of pain patients or to recommend and coordinate appropriate therapy. The patient is typically referred to a series of experts, each of whom does part of the assessment and/or part of the treatment. Alternatively, the committee recommends that individual clinicians receive training in those aspects of the various specialty disciplines that deal with significant numbers of pain patients (e.g., orthopedics, neurology, psychiatry, anesthesiology, and physical medicine and rehabilitation). Such individual clinicians would then be qualified to conduct multifaceted evaluations, institute appropriate therapeutic measures, and coordinate treatments that are beyond their own expertise.

Practitioners must be aware that chronic pain is best understood as a process that evolves over time. The problem results from the entire progression of the patient's illness, the sociocultural context in which it occurs, and the interactions between health care professionals and patients. Health care professionals may inadvertently reinforce illness behavior. Medical interventions, whether physical, pharmacological, behavioral, psychological, or surgical, may also affect the illness' course. In the case of back pain, for example, some potentially negative effects of treatment include multiple surgery, prescription of drugs that risk further compromise of function, and excessive bed rest for patients who would do better by remaining active. Extended periods of inactivity often exacerbate the problem of back pain physically (by weakening muscles), psychologically (by making patients feel that they are sicker than they are), socially (by restricting interpersonal activities and altering family interactions), and economically (by removing them from gainful work).

In the treatment and management of chronic pain, and most particularly in rehabilitation, it is important to distinguish "hurt" from "harm." Pain patients, especially those with musculoskeletal pain, may hurt when they exercise or continue their daily routines and activities (including working), but they may not be harmed by such activity. Patients must, of course, be carefully evaluated to be sure that they do not have undiagnosed underlying disease or injury such that harm *could* occur as a result of exercise or other activity. Once this has been established, however, the committee's judgment is that patients should be encouraged to remain reasonably active despite their pain. Surgery, especially multiple operations, is rarely indicated for chronic back pain. In the long run, repeated surgery for *chronic* back pain is likely to cause more harm than benefit (see Chapter 10).

Attention must be paid to any psychological or psychiatric disorders discovered in chronic pain patients, particularly depression, anxiety, and alcoholism or other substance abuse. As discussed in Chapter 9, clinical experience suggests that treating these conditions—whether they are coexisting, contributory, or consequential—can sometimes alleviate the pain. Even in the absence of pain relief, if the accompanying mental disorder or substance abuse problem can be eased, the likelihood that the patient can be rehabilitated increases.

On the basis of the available evidence, the committee believes that practitioners are not adequately trained to manage patients with pain. despite increased attention to this area in recent years. In light of this conclusion the committee makes two recommendations. First is that a cadre of physicians should be trained in those aspects of each of the medical specialties most relevant to pain. This group of experts would then be available not only to perform the multidisciplinary assessment and treatment necessary for patients with particularly difficult pain problems, but also to help train primary care providers who handle the majority of pain complaints. Because pain patients typically first seek help from primary care providers, it is important that these health care professionals understand the nature of pain and become skilled in assessment, treatment, and referrals. Thus, the second recommendation is that organizations and boards that review postgraduate training programs for primary care providers (family physicians, internists, pediatricians, gynecologists, nurse practitioners, etc.) examine their accreditation processes to assure that these programs attend to a number of educational goals so that primary care providers:

• appreciate the complexity of the chronic pain progression and associated illness behavior and understand the contributions of psychosocial and cultural factors to the process;

• are aware of commonly overlooked psychological concomitants of pain, and physical and psychiatric disorders that may account for the pain or contribute to it significantly, and of the variety of treatment modalities that may provide pain relief;

• know about the work of practitioners in other disciplines, are able to make appropriate referrals, and can participate effectively in multidisciplinary teams;

• understand the potential for an inadvertent adverse impact of health care providers on the course of chronic pain problems and disability; and

• understand the processes by which the medical records of the treating physicians are used in the disability evaluation process to determine eligibility for disability.

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Chronic pain, especially musculoskeletal pain, is a common health problem that afflicts a substantial proportion of the adult population and interferes with every aspect of their lives. The chronic paindisability course is inextricably intertwined with social, psychological, economic, and cultural factors. As a clinical problem, chronic pain is often elusive and intractable. As a public policy problem, determining whether claimants whose pain and dysfunction are not accounted for by objective physical findings are disabled for work is difficult to do in an efficient, fair, and reliable manner. Pain is inherently subjective, there are no thoroughly reliable ways to measure it, and the correlation between the severity of pain and dysfunction is imperfect. Evaluation of pain claimants will always contain a subjective element regardless of the specificity of the rules and regulations developed to guide disability examiners.

In this report, the Institute of Medicine study committee has attempted to elucidate the issues and to provide some guidance to the Social Security Administration and other disability insurers about how pain complaints might be better handled. In addition, the committee hopes that its analysis of the many facets of chronic pain and the disability process provides useful information to researchers, clinicians, and others about this complex problem.

## APPENDIX

A description is offered here of the pathogenesis, diagnostic criteria, and treatment approaches to myofascial pain. The author, who was a member of the Institute of Medicine study committee, is one of the foremost proponents of the concept of trigger points in myofascial pain syndromes and a pioneer in developing treatment methods based on this viewpoint. As indicated in Chapter 10, the concept of myofascial trigger points is controversial and was the subject of debate by the committee.

# Myofascial Pain Syndromes Due to Trigger Points

DAVID G. SIMONS, M.D.

Myofascial trigger points are one of three musculoskeletal dysfunctions that are commonly overlooked and deserve particular attention. The other two are fibromyalgia or fibrositis, and articular dysfunction. None has a diagnostic laboratory or imaging test at this time. All three conditions presently require diagnosis by history and physical examination alone. In each case, the diagnosis would probably be missed on routine conventional examination. The examiner must know precisely what to look for, how to look for it, and then must actually be looking for it. This appendix concentrates on myofascial pain syndromes because they now appear to be the most common and the least well understood of the three conditions.

## **MYOFASCIAL PAIN SYNDROMES: HOW COMMON ARE THEY?**

Recent reports indicate that myofascial pain syndromes are likely to be the major cause of pain that brings patients to chronic pain treatment centers. Among 283 consecutive admissions to a comprehensive pain center, 85 percent were assigned a primary organic diagnosis of myofascial syndromes (Fishbain et al., 1986). This diagnosis was made independently by a neurosurgeon and a physiatrist based on physical examination for soft tissue findings as described by Travell (Travell and Rinzler, 1952; Simons and Travell, 1983). Among 296 patients referred to a dental clinic for chronic head and neck pain of at least 6 months duration, the primary diagnosis was myofascial pain syndrome in more than half (55.4 percent) of the cases. Another 21 percent had pain due to disease of the temporomandibular joint (Fricton et al., 1985).

Acute myofascial pain syndromes are also common in general medical practice. Among 61 consecutive consultation or follow-up patients in an internal medicine group practice, 10 percent of all patients and 31 percent of those presenting with a pain complaint had myofascial trigger points that were primarily responsible for their symptoms (Skootsky, 1986).

## Why Are Myofascial Pain Syndromes So Common?

Skeletal muscle is the largest organ of the body, making up nearly half of its total weight. Muscles are the motors of the body, working with and against the ubiquitous spring of gravity. They, together with cartilage, ligaments, and intervertebral discs, serve as the body's mechanical shock absorbers. Each one of approximately 500 skeletal muscles is subject to acute chronic strain and can develop myofascial trigger points, and each has its own characteristic pattern of referred pain.

Myofascial pain may occur in conjunction with other common diseases. Reynolds (1981) compared the prevalence of signs of myofascial trigger points in 14 women who had early rheumatoid arthritis with the prevalence in 18 asymptomatic control women. The women with arthritis had twice as many trigger points. Every one of the women with arthritis had myofascial signs in muscles of the shoulder girdle. He found that the myofascial trigger points in these patients with rheumatoid arthritis were a significant source of additional pain. This component of their pain could be abated or relieved only when it was recognized and managed as being myofascial in origin.

## HISTORICAL BACKGROUND

A study done by Kellgren in 1938 reported that pain was referred to remote locations from muscles throughout the body in response to intramuscular injection of hypertonic saline. This gave credibility to the large series of clinical papers published independently through the following decade by three authors on three continents. Gutstein (1938) in Europe, Kelly (1947) in Australia, and Travell (1949) in America reported that points of exquisite tenderness found in many muscles throughout the body were responsible for pain that projected to locations distant from the point of tenderness. Injecting that spot with a local anesthetic eliminated the pain. Travell and Rinzler (1952) published the first summary of the specific patterns of pain and tenderness referred from trigger points in the most commonly involved muscles throughout the body.

## NATURAL HISTORY

Myofascial pain syndromes are caused by trigger points in specific muscles (Travell and Simons, 1983). Pain due to active myofascial trigger points often begins suddenly as an acute single-muscle syndrome resulting from stress overload of the muscle. The pain also may develop insidiously because of chronic or repetitive muscle strain. In the absence of perpetuating factors, and in the presence of normal daily activities that stretch the muscle, active trigger points tend to revert to being latent trigger points.

Examples of trigger point activation by acute gross trauma are activation of longissimus trigger points in the paraspinal muscles during a fall, or activation or sternocleidomastoid trigger points in the neck during a rear-end collision (one type of whiplash injury). Sometimes the acute overload occurs during what appears to be a trivial movement, such as activation of a quadratus lumborum trigger point by bending over to one side to pick up a pin from the floor. An example of trigger point activation by microtrauma is unrelieved tension in the upper trapezius and levator scapulae muscles due to continued elevation of the shoulders to reach a high keyboard without elbow support (Travell and Simons, 1983).

The pain and tenderness referred by a trigger point is usually projected at a distance, much as the trigger of a gun that is located one place causes the bullet to impact elsewhere. Trigger points refer pain and tenderness in a reproducible pattern characteristic of each muscle. That pain and tenderness are referred from muscles in this way should be no surprise. Four well-recognized neurophysiological mechanisms account for this phenomenon of referred pain; the question is, which mechanisms are responsible in specific situations. (See Chapter 7 on the neurophysiology of pain for more detail.)

In the abovementioned examples, trigger points in the low thoracic longissimus muscle of the midback may refer pain *and tenderness* to the lower buttock, causing buttock pain when sitting. The sternoclei-

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domastoid trigger points in the neck are likely to cause headache and facial pain. Together, the upper trapezius and levator scapulae muscles of the shoulder are likely to cause pain and tenderness extending down the back of the neck from the skull, across the back of the shoulder, and down along the vertebral border of the shoulder blade (Travell and Simons, 1983).

For reasons that are not well understood, one limited group of myofascial pain patients suffer greatly and are difficult to help. They exhibit a posttraumatic hyperirritability of their nervous system and of their trigger points. Each patient has suffered trauma, usually from an automobile accident or fall, severe enough to damage the sensory pathways of the central nervous system. This damage apparently acts as an endogenous perpetuating factor susceptible to augmentation by severe pain, additional trauma, vibration, loud noises, prolonged physical activity, and emotional stress. From the date of the trauma, coping with pain typically becomes the focus of life for these patients who previously paid little attention to pain. They are unable to increase their activity substantially without increasing their pain level.

## DIAGNOSIS

Five cardinal features are characteristic of myofascial trigger points:

1. The history of the initial onset of pain and of its recurrences is strongly related to muscles. It usually relates to the length (prolonged shortening aggravates pain) and use (overload or sustained contraction) of the specific muscles involved.

2. Reproducible, exquisite spot tenderness occurs in the muscle at the trigger point.

3. Pain is referred locally or at a distance on mechanical stimulation of the trigger point. This referred pain and tenderness projects in a pattern characteristic of that muscle and reproduces part of the patient's complaint. Patterns of referred pain are frequently different than those expected on the basis of nerve root innervation (Travell and Rinzler, 1952; Travell, 1976).

4. There is palpable hardening of a taut band of muscle fibers passing through the tender spot in a shortened muscle (Simons, 1976).

5. A local twitch response of the taut band of muscle occurs when the trigger point is stimulated by snapping palpation or needle penetration.

The last two features are completely objective findings, and the local twitch response is pathognomic of a myofascial trigger point.

The lack of diagnostic laboratory studies emphasizes the importance

of looking for myofascial trigger points and knowing how to identify them by history and physical examination. Both thermography (Fischer, 1984) and pressure threshold measurements (Fischer, 1986; Reeves et al., 1986) provide objective substantiation of clinical findings associated with myofascial trigger points. The trigger point itself generally registers by thermography as a circle of cutaneous warmth 5-10 cm in diameter and is a point of measurably reduced pressure tolerance (Fischer, 1984).

A latent trigger point may have some or all of the other characteristics of an active trigger point, except that it does not cause pain with ordinary daily activities. Latent trigger points regularly cause some restriction of range of motion and are tender to digital palpation. An individual muscle may harbor latent trigger points for a period of time and then flare to become an active source of referred pain in response to stress or perpetuating factors (Travell and Simons, 1983). Latent trigger points may (although they usually do not) have all the other characteristics of active trigger points (Travell, 1976; Simons, 1985). Latent trigger points are common by early adulthood. Among 100 male and 100 female 19-year-old asymptomatic Air Force recruits, Sola and associates found focal tenderness indicative of latent trigger points in the shoulder-girdle muscles of 54 percent of the women and 45 percent of the men (Sola et al., 1955). Referred pain was demonstrated in 5 percent of these subjects. Myofascial trigger points tend to accumulate throughout a lifetime.

In the presence of sufficiently severe perpetuating factors and if left untreated, an acute myofascial pain syndrome characteristically becomes chronic. Mechanical or systemic perpetuating factors increase the susceptibility of muscles to trigger points; the severity of pain gradually increases, and less muscular activity is required to produce pain. Systemic factors increase the susceptibility of all muscles to the development of trigger points; additional muscles develop additional referred pain patterns (Travell and Simons, 1983). Disability increases unnecessarily, weaving the complex web of chronic pain through all aspects of the patient's life.

Myofascial pain is frequently overlooked in diagnosis and, as a consequence, inadequately treated. Clinicians often lack the training and experience necessary to recognize specific pain patterns referred by individual muscles, to identify trigger points by palpation, and to identify factors that may perpetuate the pain. The lack of standard diagnostic terms in this area and, until recently, of a published source consolidating the known information have contributed greatly to the problems of diagnosing and treating myofascial conditions.

Over the past century, confusion developed because successive authors recognized different, often overlapping, aspects of the condition. Many authors contributed new names; some recognized symptoms due to the involvement of muscles in one region of the body, whereas others recognized symptoms in other regions without noting their commonality. A few examples include soft-tissue rheumatism, nonarticular rheumatism, fibrositic nodules, fibrositis, fibromyalgia, myogelosis, tension headache, tendonitis, and bursitis. Each term may be used to identify at least two conditions, one of which is often a myofascial pain syndrome. Approximately 100 years of this international confusion was reviewed for muscle pain syndromes generally in 1975 (Simons, 1975, 1976), and specifically for fibrositis in 1981 (Reynolds, 1981).

## PERPETUATING FACTORS

These factors are rarely the same as the stress that activated the trigger point. Perpetuating factors may be mechanical or systemic (Fricton et al., 1985). Mechanical perpetuating factors include stressful posture and body asymmetries (Travell and Simons, 1983). For instance, a one-quarter inch discrepancy in leg length, present since childhood, may cause no symptoms until an awkward movement activates trigger points in the quadratus lumborum muscle. The resultant myofascial low back pain often persists, regardless of appropriate therapy, until the chronic excess strain on the muscle is relieved by correcting the leg length disparity (Simons and Travell, 1983).

Similarly, systemic perpetuating factors may cause minimal symptoms, including increased irritability of the muscles, that by themselves escape attention. Irritable muscles are susceptible to strain. This susceptibility leads to the activation of trigger points. In the presence of unusually severe perpetuating factors, the activity of trigger points may be exacerbated, not relieved, by specific myofascial therapy. In most cases, unless the perpetuating factors are specifically dealt with, response to myofascial therapy is temporary, lasting only a few hours or days. The identification and management of common perpetuating factors, both mechanical and systemic, have been described in detail elsewhere (Travell and Simons, 1983).

## TREATMENT

Uncomplicated myofascial pain syndromes are highly responsive to simple treatment when appropriately directed (Sola, 1985; Travell and Simons, 1983). Specific myofascial therapy includes a variety of musclestretching techniques (Lewit and Simons, 1984) and the injection of trigger points (Frost, 1986). Relief of *chronic* myofascial pain syndromes often requires resolution of *all major* perpetuating factors (they are commonly multiple) and application of myofascial therapy to the specific muscles involved. Satisfactory relief may require treatment of many muscles in several regions of the body in addition to restoration of well behaviors and a functional life-style.

Trigger points cause the muscle to become tense and shortened (Travell, 1976). Extension of the muscle to its full range of motion is blocked by pain. Any stretch technique that permits the tense shortened muscle to reach its full stretch range of motion comfortably also inactivates its trigger points. Two effective methods are stretch and spray (Travell and Simons, 1983) and postisometric relaxation (Lewit and Simons, 1984), which is similar to the contract-relax technique used by many physical therapists. A home self-stretch program often gives a patient control of the pain without drugs. Other treatments, such as muscle energy techniques, deep massage ultrasound, and specific relaxation techniques followed by stretch, are used with variable effectiveness depending on the practitioner's training and skill.

Effective local injection of trigger points depends on physical disruption of the trigger point mechanism by penetration with the needle and flushing the region with either a short-acting local anesthetic or saline. A recent study found that injecting trigger points with a prostaglandin inhibitor produced more pain relief than lidocaine (Frost, 1986). Less desirable is chemical destruction of the trigger point region with a long-acting, myotoxic local anesthetic (Travell and Simons, 1983).

The effective management of an acute single-muscle myofascial pain syndrome *without* perpetuating factors can require simply the recognition of one referred pain pattern and a knowledge of the self-stretch technique for that muscle. This basic knowledge can be used by the patient to control recurrence and prevent chronic disabling pain. Conversely, the rehabilitation of a patient with chronic complex myofascial pain syndromes may require the multiple talents of a team approach and considerable time and ingenuity.

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