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— Contributors—

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Where We Are

Introduction

Statement of the Problem

Rehabilitation involves restoring an injured person's altered physiologic, psychologic, and social functioning as closely as possible to its original state. The ultimate goal of rehabilitation for persons with disabling injuries is to achieve optimal health and personal autonomy so they can live an independent and noninstitutional lifestyle.

In recent years, improvements in injury prevention, emergency medical services, trauma systems, and medical and surgical management of persons with injuries have resulted in more people surviving all injuries and more people surviving severe injuries.

These improvements in prevention and medical care have increased the demands on rehabilitative systems of care. Each year more than 200,000 people require extensive rehabilitation services as a result of spinal cord injuries (SCIs), traumatic brain injuries (TBIs), and burns. Limb and extremity injuries, injuries to the face and eyes, and polytrauma add considerably to demands for rehabilitative services.

Unfortunately, rehabilitation services are not available to all who need them for two primary reasons. First, comprehensive rehabilitation services are not available in all regions of the country. Although some areas have excellent systems of rehabilitative care for severe injuries that result from burns, SCI, or TBI, only about 20% of people with spinal cord injuries are actually treated in a comprehensive system of care. The second problem is cost. Some injured persons are unable to pay for comprehensive rehabilitation services. In addition, third party payers (private insurance carriers, Medicaid and Medicare, and workers' compensation insurers) tend to support therapies on the basis of cost and expediency rather than efficacy.

Our panel made a major effort to develop an agenda for rehabilitation services, research, and policy for the next decade. We believe that our agenda — combined with concurrent and parallel efforts by the National Institutes of Health, the National Council on Disability, the National Institute for Disability and Rehabilitation Research, and the Institute of Medicine — will significantly advance the availability and quality of comprehensive rehabilitation services for those with a disabling injury.

We are encouraged that progress toward improved rehabilitation is already under way. The recent passage of the Americans with Disabilities Act (ADA) recognizes — for the first time

— the rights of a person with a disability to have access to full employment and to therapies that will make them independent. The ADA will have a significant impact on employers, educational institutions, persons with disabilities, and our Nation. We urge prompt and vigorous implementation of the provisions of the ADA.

We are also encouraged by the recent publication of *Disability in America* by the Institute of Medicine. This report documents the impact of disability in America and presents an extremely useful framework for understanding the disabling process better and for developing strategies to intervene in this process. We urge careful reading of this report.

The recommendations expressed in this paper are based on the following three principles:

- To integrate rehabilitation successfully into injury control programs, policymakers and the general public must understand that rehabilitation services represent one phase in a continuum of care that begins when the injury occurs and may continue for life.
- To deliver comprehensive rehabilitation services, a coordinated team of rehabilitation specialists must work in concert with the persons who have disabling injuries and with their families.
- To achieve optimal health, personal autonomy, and independence for seriously injured people, we need to establish by the end of this decade, a cost-effective system of rehabilitation care.

Our goal is ambitious. It will require substantial financial commitment, innovative thinking, and cooperation among specialists. It will require reorganizing health services delivery, developing new systems of health care financing, conducting new basic science and clinical research, and establishing new methods to critically evaluate rehabilitation services. The cost of reaching our goal will be great, but we believe that the financing can be found. Our goal can be met only through a collaborative and collegial effort among researchers, clinicians, consumers, families, communities, and public and private agencies.

Key Terms and Definitions

Associated injury: An injury that occurs when the primary injury occurs.

Comprehensive medical rehabilitation: Coordinated multidisciplinary rehabilitation services provided in an inpatient or outpatient setting under the direction of a qualified physician. These services are designed to obtain for the patient the highest attainable levels of personal independence, health, and productivity.

Condition: A person's medically diagnosed physical or psychological situation.

Disability: Inability or limitation in performing the socially defined activities and roles expected of people in a social and physical environment.

Functional limitation: Restriction or inability, which results from impairment, to perform an action or activity in the manner or within the range considered normal.

Impairment: All mental, emotional, physiological, or anatomical losses or abnormalities, including pain and those not attributable to an active pathologic condition.

Limb and extremity injury: Traumatic injury to the limbs, which could involve muscles, bones, joints, soft tissues or peripheral nerves.

Pathologic condition: Interruption or interference in normal bodily processes or structures.

Polytrauma: Potentially life-threatening or disability-producing injury to more than one major body region or organ system.

Primary injury: The injury with the greatest consequence to the person, within a particular context of care. For example, when a polytrauma patient is first injured, the primary injury could be a cardiac contusion; after acute medical care is complete, the primary injury could be a spinal cord injury.

Public health surveillance: The ongoing systematic collection, analysis, and interpretation of health data needed for planning, implementing, and evaluating public health programs.

Rehabilitation services: Care and treatment provided by professionals from the disciplines of medicine, physical therapy, occupational therapy, speech and language pathology, rehabilitation nursing, orthotics and prosthetics, rehabilitation engineering, psychology, social work, recreational therapy, and vocational counseling.

Secondary condition: Any pathologic condition that begins as a result of a previous condition. (In this document, the first condition is always understood to be an injury.)

Spinal cord injury (SCI): Injury to neurologic structures contained in the spinal cord that may cause motor or sensory impairment, or bowel or bladder dysfunction.

Standard of care: A health care practice that is expected in defined circumstances.

Traumatic brain injury (TBI): An insult to the brain (not of a degenerative or congenital nature) that may produce a diminished or altered state of consciousness and that results in temporarily or permanently impaired cognitive or perceptual abilities or physical function.

Spinal Cord Injury

Dimensions of the Problem

Recent estimates of the prevalence of spinal cord injury (SCI) range from 177,000 to 200,000 people. As recently as World War II, practically all those who sustained a spinal cord injury died; today, life expectancy for all but the most catastrophically injured can approach normal. Advances in the management of cardiorespiratory complications (the leading cause of death among children and adults with SCI) are expected to increase the number of people with SCI who survive. Each year, 10,000 to 20,000 persons in the United States receive a spinal cord injury, resulting in 30 to 35 additional persons per million population who need rehabilitation services for SCI.

More than 80% of people with new SCIs are men, and about 60% of these men are from 16 to 30 years of age when the injury occurs (1). Among young men, motor vehicle crashes, often involving alcohol use, account for more than half of the SCIs. Among people older than 60 years of age, more than half of the SCIs result from falls.

About 75% to 80% of people with acute traumatic SCI experience some degree of permanent impairment despite optimal medical and rehabilitation management. Neurologic impairment is more often incomplete among older people. Among older persons, impairment and disability may be greater because of preinjury conditions that interfere with the person's physiologic and psychologic ability to adapt to spinal paralysis. Most people with SCI have disabilities that interfere with major life activities such as walking, bowel and bladder control, and employment, disabilities that result in a life-long need for assistance with daily activities. Regretfully, the postinjury vocational outcome of SCI patients is less than desirable, as evidenced by data showing that as long as 5 years after injury, only 20% of patients who received comprehensive care in model SCI care systems are employed. Little is known about the relationship between rehabilitation outcomes and injury etiology, alcohol use, or other behavioral risk factors related to cause of injury. The effects of age, gender, and psychosocial factors on rehabilitation outcomes have not been well described (2).

The average annual direct costs of initial medical and rehabilitation care in a model SCI system during 1988-1989 ranged from $71,980 for a patient with incomplete paraplegia to $153,312 for a patient with complete quadriplegia. Lifetime direct costs for a single case of complete quadriplegia are now estimated at $571,584, and lost earnings are estimated at more than $308,054 (3). The total annual economic burden for SCI patients in the United States has been estimated at about $6.2 billion (3).

In 1988, the Council of State and Territorial Epidemiologists selected SCI as the first injury to be included in public health surveillance by state departments of public health. Because states faced multiple financial, organizational, and methodological barriers to obtaining accurate surveillance data on SCIs, only a few states have begun surveillance efforts.

Complete case ascertainment, the need for monitoring mandatory reporting, and unreliable and undetailed medical records are some of the problems preventing effective implementation of SCI surveillance in states. New strategies are being developed and tested.

Pathophysiology

Currently, our understanding of the determinants of clinical recovery from acute SCI is rudimentary. Clinical prognosis is best determined by the degree to which motor and sensory function is preserved or improves during the days immediately following injury. Severe mechanical forces applied to the spinal cord are followed by microcellular and neurochemical changes, creating a microenvironment in the damaged area of the spinal cord that inhibits or prevents regrowth of nerve axons. Intensive basic science research is being conducted to understand the neurophysiologic changes that follow sudden mechanical forces being applied to the spinal cord. Some believe that early removal of any structures such as bone or foreign bodies that cause continued mechanical compression on the spinal cord, particularly after reduction of an associated spinal fracture, improves recovery (4), although no controlled-series studies on the efficacy of this treatment strategy exist. Results of one recent study showed that the early administration of high doses of steroid is associated with a significant rate of improvement in semiobjective clinical measures of motor and sensory function (5). Further contributions to clinical recovery that result from basic science research on nerve regeneration will be incremental, and use of these new findings will need to be combined with currently known medical and rehabilitative techniques to enhance functional recovery.

The impact of the psychological and pathophysiologic aspects of aging on people with SCI has not been adequately studied. A person's age when SCI occurs and the duration of an SCI may synergistically affect the rate of degenerative changes in different organ systems and may affect a person's life-long functional performance.

Rehabilitation Interventions and Outcomes

Since 1971, the National Institute of Disability and Rehabilitation Research (NIDRR), Department of Education, has supported the Model SCI Systems Program, which has collected extensive descriptive data about people with SCI, treatment, and SCI outcomes during and following the injured person's participation in specially designed model systems of care. A 1989 national consensus conference provided SCI experts an opportunity to examine various research results documenting the efficacy of this model care system (3). Results of one study (3) showed that patients treated in model SCI systems had shorter hospital stays and were more often discharged to community living situations than a comparison group of persons treated in nonmodel SCI system hospitals. Patients with neurologically complete quadriplegia treated in model SCI systems gained significant functional independence sooner after injury, a result that reduces costs. Researchers compared two groups of SCI patients for secondary complications that developed during initial hospitalization. They found that the group of SCI patients admitted immediately to model SCI systems had a significantly lower prevalence of contractures, heterotopic

ossification, atelectasis, urosepsis, and pressure sores than SCI patients admitted 2 to 60 days after injury.

Little is known about the epidemiology of secondary conditions that develop during the lives of people with SCI. Only recently have more than a few persons with SCI begun surviving more than 30 years (3), and the impact of effective rehabilitation on the occurrence of secondary conditions during a lifetime has not been fully evaluated. Recent clinical reports have described the onset and treatment of many secondary conditions such as pressure sores and urinary tract infections. Other common problems are infertility among many male SCI patients, intractable pain, contractures, and fractures due to osteoporosis. Clinical depression is probably increased, and suicide may be five times more prevalent as a cause of death in the spinal-injured population than in able-bodied populations. Although effective treatment for many of these conditions is available, more knowledge is needed about preventive interventions, including the timing, intensity, and mix of interventions. The delivery of rehabilitation services as soon as possible is also important. Delayed or ineffective treatment results in additional disability that affects the quality of life and functional independence of people with SCI. We believe that, ideally, rehabilitation should not only begin as soon as possible after the acute injury, but should continue throughout the injured person's lifetime.

Service Delivery Issues

Not enough comprehensive clinical rehabilitation programs can fully apply the rehabilitation methods developed and demonstrated in the Model SCI Systems Program. Although, in certain regions, these programs have a high capture rate of patients with acute traumatic SCI, overall less than 20% of all people with SCI are treated in these systems. Furthermore, only about half of all persons with SCI are treated at some time by physicians who are members of the American Spinal Cord Injury Association, a multispecialty physician organization devoted to improved care and treatment for people with SCI. The number of experienced rehabilitation professionals in allied health fields is also inadequate to meet the needs of persons with SCI.

Helping people achieve an independent lifestyle following injury is a major objective of rehabilitation. Since SCI patients typically are cognitively intact young people, they are an ideal group in which to demonstrate methods for achieving independent living. Independent living centers, various state vocational agencies, and other independent organizations offer attractive models for providing cost-effective services to people with SCI. We must evaluate the effectiveness and costs of training injured people to live independently at centers. A key to effective rehabilitation is to involve the family of an injured person in the support and delivery of services. Another key element in rehabilitation is to provide training to help persons with SCI get full employment.

Funding Issues

Many people have inadequate or no third-party medical insurance (private insurance, Medicare or Medicaid, or workers' compensation). Universal and more uniform insurance coverage for rehabilitation services can help increase the availability of specialized care for people with SCI throughout the country. Treatments, outcomes, and cost-benefit analyses of various mixes of inpatient, outpatient, and home care services need to be examined. At present, the mix of the level and location of rehabilitative services is strongly driven by reimbursement mechanisms rather than by effectiveness or cost-benefit analyses. For example, one objective of the Model SCI System Program has been to begin rehabilitation services immediately after injury, blending acute medical care with early rehabilitation care in specialized SCI units or programs. Although data support this method as cost-efficient, the current reimbursement system makes achieving these objectives difficult. The most effective mix of acute care and rehabilitative services during the acute phase of SCI needs to be determined. Standards of care should be developed to balance cost, effectiveness, and various treatment modalities. Acute and rehabilitative care settings and systems that most cost-effectively lead to optimal outcomes must be characterized. Incentives are needed to improve coordination between acute-medical and rehabilitative services to people with SCI, both during initial hospitalization and during follow-up.

Advances in adaptive equipment technology have greatly expanded opportunities for people with extensive paralysis to increase their productivity and independence. The cost of this technology, however, often makes it inaccessible to people who need it, and obtaining funding for adaptive equipment is difficult. In addition, information about the availability and benefit of new equipment is inadequately disseminated among professional, payer, and consumer groups. Financial constraints also can limit the availability of affordable barrier-free housing and transportation systems, optimal public school services, and personal care attendants.

Traumatic Brain Injury

Dimensions of the Problem

The true annual incidence of traumatic brain injury (TBI) in the United States is unknown because no reliable systems of surveillance are established in any state. In addition, coding problems are significant because ICD-9 coding does not have a specific code for TBI. The results of a 1985 survey of central nervous system injuries found 225 TBIs per 100,000 population, of which 5% to 10% (20 per 100,000) were fatal (6). About 20% to 40% of the people with nonfatal TBIs did not seek medical care. Of those who received medical care, only 40% to 60% were hospitalized.

Each year in the United States, about 70,000 head injuries are classified as moderate to severe. Persons with moderate to severe TBI will live the rest of their lives with a combina-

tion of cognitive, physical, behavioral, and emotional deficits and will require long-term rehabilitation services. Almost no data are available on so-called mild TBI or on the impact of mild TBI on a person's capacity to function normally. The peak incidence of TBI occurs among adolescents and young adults [from 15 to 24 years old (6)]. TBI is two to three times more common among men than women. Patients with TBIs often are single and in lower socioeconomic groups. Many persons with TBI have a history of alcohol or drug use and may have undergone psychiatric care before their head injuries occurred (7). Motor vehicle crashes and falls are leading causes of TBI. Clearly, the most effective way to prevent disability is to prevent TBI from occurring in the first place. Mandatory seat-belt and motorcycle-helmet laws, air-bags, and bicycle-helmet usage are examples of primary prevention strategies.

Pathophysiology

The pathophysiologic changes to the brain that result from TBI begin at impact. Contusions are a type of focal brain injury that can occur beneath sites of impact or skull fracture. They also occur as a result of the brain gliding over the irregular surfaces of the base of the skull, especially at the frontal and temporal regions. Other focal brain injuries occur as a result of laceration of blood vessels, which then bleed into surrounding tissue to cause epidural, subdural, or intracerebral hematomas. Rotational acceleration can cause movement between different components of the brain tissue itself; such movement results in concussion and shear injury or diffuse axonal injury. In the latter type of injury, delayed degeneration of injured brain cells occurs.

As contusions and hematomas enlarge, intracranial pressure rises. This rise, in turn, causes brain displacement, potential tissue necrosis, and obstruction of venous blood flow. These events further increase the pressure, compromise cerebral blood flow, and promote an ischemic condition that worsens the original injury and can lead to cerebral infarction. The ischemia can be aggravated by extracranial factors, such as hypoxia due to respiratory failure or hypotension due to blood loss.

Intracranial pressure is managed by such advanced assessment techniques as magnetic resonance imaging, computerized axial tomography, and intracranial pressure monitors. In addition, acute neurosurgical treatment includes techniques such as positioning, hyperventilation, sedation, diuretics, ventricular drainage, and paralyzation. Aggressive early surgical decompression of mass lesions and surgical treatment of hydrocephalus have resulted in decreased damage due to the effects of increased intracranial pressures. Basic research on delayed cellular damage and the development of medications to diminish cell death are needed to minimize the neurological dysfunction after TBI.

Rehabilitation Interventions and Outcomes

Rehabilitation for people with TBI differs from general rehabilitation because of the longer recovery course after severe head injury and because of different stages of recovery associated with different profiles of physical and cognitive impairments. The optimal

approach to rehabilitation for people with TBI is to adapt treatment as each major stage of impairment occurs and to prepare patients and families for the next stage of recovery. Physical problems often include extracranial injuries (both soft tissue and skeletal fractures) and motor impairment; later, spasticity and heterotopic ossification often develop. In the early phases of recovery, aggressive rehabilitation efforts that prevent contractures will frequently minimize later disability. Patients who engage in passive range-of-motion exercises twice a day have fewer contractures (8). Aggressive, nonpharmacologic management of spasticity with the use of inhibitive casts and nerve blocks also will decrease the likelihood of contracture formation (9).

Cognitive rehabilitation is a specialized type of rehabilitation for patients who are disabled primarily as a result of impairments in memory, judgment, and other cognitive functions. In the past few years, cognitive rehabilitation has become increasingly controversial because of the proliferation of costly, time-consuming, and unproven treatments. Results demonstrating the effectiveness of cognitive rehabilitation are, at best, preliminary. There is clear evidence, however, that patients can improve function through compensatory strategies, and many can be retrained to return to work or school (10-12). The patient's level of cognitive and behavioral functioning is usually the major factor in outcome and can be used to determine realistic goals for the patient (13). Family intervention with adequate information and support is important to the patient's recovery and should start as soon as possible (14).

Service Delivery Issues

The usual course of treatment in comprehensive rehabilitation begins with the rehabilitation team evaluating the patient's strengths and deficits, establishing overall rehabilitation goals, and estimating the expected length of stay. Treating cognitive impairments is an interdisciplinary process. Since rehabilitating people with TBI is likely to extend beyond acute care hospitalization, it is important that team members and potential community service providers, including school personnel in the case of children with TBI, be identified and invited to participate in any discussions about long-range goals and treatments. This comprehensive approach is especially important in rehabilitating children with TBI whose developmental, educational, and social needs are especially sensitive.

Controlled efficacy studies of specialized rehabilitation programs are needed. Uncontrolled study results have shown that large improvements in function can occur during initial rehabilitation (15), but the evaluation of treatment effects is confounded by rapid spontaneous recovery following traumatic brain injury. The National Institute for Disability and Rehabilitation Research (NIDRR) is presently supporting the development of five model systems of care for people with TBI. Unique to these systems is a common standardized method of collecting data that should facilitate comparisons of treatment efficacy among various rehabilitation facilities.

Funding Issues

To provide the best possible outcome for patients with TBI, we must (a) develop a national network of Level I trauma care systems with well integrated rehabilitation programs and (b) fund rehabilitation services and acute care services. Funding for custodial and long-term care is often needed for people with TBI, since they have often incurred those injuries in their teens or early twenties, have near-normal life spans, and often survive the death of the family member who was the primary care giver. Additional funding is needed to train health professionals, special education teachers, and personal care givers.

Burns

Dimensions of the Problem

Each year, about 1% of the population of the United States receives a burn injury. About half of these injuries will require medical attention or be severe enough to restrict daily activities in the home, school, or workplace. One-fourth of these injuries require confinement in bed. Hospital admissions for burns are estimated to be between 70,000 and 108,000 a year; about 20% of those admitted are children. On the basis of data for 1965 to 1979 from the National Burn Information Exchange (NBIE), 18% of 37,442 patients were older than 50 years and 10% were older than 60 years.

Each year between 6,500 and 12,000 people die from burns. The most common groups burned are children (ages 2 to 4 years), young adults (ages 17 to 25 years), and males of any age.

The United States now has 198 burn units with 2,243 specialized burn-care beds. About one-third of all patients who are hospitalized for burns are treated in these centers. In general, burn centers are directed by plastic or general surgeons. Only at a few burn centers do physicians with specialty training in physical medicine and rehabilitation (physiatrists) work closely with the burn team and follow up with burned patients after their hospital discharge. During their formal education, physiatrists and allied health professionals are usually not trained in the treatment of burns or rehabilitation of burned patients. Most of their education about burn rehabilitation must occur on the job and during professional seminars.

Most data collected about burns are on mortality and morbidity. No data exist on rehabilitation outcomes, long-term sequelae to burn injuries that affect quality of life, the cost of care for inpatient or outpatient rehabilitation, or (except for a few reports) rehabilitation complications during acute care or at hospital discharge.

Outpatient rehabilitation programs are not always available in burn centers. Of centers with fewer than 81 admissions each year, 33% do not have outpatient rehabilitation programs. Of burn centers with 81 to 120 admissions each year, 20% do not have such programs, and of those with more than 121 admissions, 12% do not. Accurate information is needed on the cost of rehabilitative care, including ways to lower those costs, such as increasing productivity by distributing the peak service demand for services over 24 hours, using part-time employees, and diversifying.

Pathophysiology

Hypertrophic scarring: Hypertrophic scarring creates a major cosmetic problem, can cause severe contractures, and may be the most challenging aspect of rehabilitating a burn patient. The lack of adequate animal models on which to test the various therapeutic modalities has limited study of burn scar development.

Contractures: A burn wound will shorten until it meets an opposing force. Often, the shortening force can be so severe that it dislocates joints. A variety of treatment techniques is needed to manage burned-skin contractures because they differ from other types of contractures. For example, since burns may cover an entire limb, contractures may affect more than one joint. No studies have compared the effectiveness of various treatment methods.

Peripheral and central nervous system: Few investigations have assessed the implications of peripheral and central nervous system involvement in the burn-injured patient. Neurological problems in burn patients can result from various etiologies, many of which are preventable with proper precautions. Peripheral neuropathy is a common neurological problem that occurs in 15% to 29% of patients with burns on more than 20% of their total body surface (16); however, its etiology is unknown. Electrical burns produce many neurological complications and sequelae. The pathophysiological mechanism of burns on the central nervous system needs to be described.

Musculoskeletal changes: Bone and joint changes have been reported in 2% to 5% of severely burned patients. These musculoskeletal changes are particularly devastating when they occur among children, for whom they can cause bone-growth disturbances, kyphotic deformities, scoliotic deformities, heterotopic ossification, and joint dislocation.

Rehabilitation Interventions and Outcomes

Few clinical studies have compared treatment techniques to determine what protocols are best. In addition, little information about successful therapies is available, and no universally accepted measurement of functional recovery exists.

Although burn care is mostly centered around inpatient burn units and centers, outpatient care is growing in importance. Use of alternative care locations, such as intermediate care

facilities and the patient's home, may permit earlier discharge than the use of hospitals alone. Innovative patterns of ambulatory care by which various specialists of the burn team can deliver patient care need to be developed. In all rehabilitation models, caregivers must address the psychosocial needs of children and adults with burns as well as the needs of their families. Burn patients also need to use existing rehabilitation facilities more frequently. A review of discharge diagnoses on 46,667 patients in 119 rehabilitation facilities showed that only 0.8% of the diagnoses were burn injuries.

We need longitudinal research to document the problems that burn patients face after recovery. Such research should involve many burn centers, each using the same protocol so that an adequate number of patients can be studied to obtain valuable information for planning a burn patient's future and for predicting costs of care.

Service Delivery Issues

Training: A major problem for burn rehabilitation is the lack of trained personnel, particularly physiatrists. Generally, physiatry residents do not study burn care. The shortage of allied health personnel trained in burn rehabilitation is also acute.

Public awareness: The public's failure to understand the social, emotional, and occupational problems that face burn patients after healing is especially critical in the workplace and for children and adolescents returning to school.

Standards of care: Members of the American Burn Association agree that a comprehensive model of standards or guidelines for treating and rehabilitating burn patients should be developed and outcome criteria identified. Such a model is needed (a) to assure the delivery of quality burn rehabilitation services and (b) to aid third-party payers in supporting appropriate therapies.

Other issues: Very few burn patients receive Social Security benefits. On a national basis, the percentage of disability claims paid to burn patients by Social Security from 1981 to 1983 was less than 1%. A universal approach is needed for retraining persons whose burns do not permit them to return to their previous type of employment. Burn patients often are forced to seek employment that does not require their full capabilities and does not provide sufficient income to support themselves or their families. These people need social security and vocational rehabilitation services.

Limb Injuries

Dimensions of the Problem

Each year an estimated 986,000 people are admitted to a hospital for treatment of an injury to a limb; they account for nearly half of all hospital trauma admissions. Costs associated with initial hospital treatment alone amount to $5.1 billion (1985 dollars). Injuries to lower limbs account for most admissions (696,000 per year or 70% of all admissions for limb injuries). People 65 years and older are at particularly high risk of being hospitalized for treatment of a lower limb injury; they account for a disproportionate share (40%) of all hospitalizations for lower limb injuries (17).

Although current data on limb injuries do not specify etiology, severity, place of occurrence, or treatment, we know that significant causes of limb injury are sports, leisure, and home activities and trauma resulting from motor vehicle crashes. As the population ages, falls among the elderly that result in injury will become an increasing problem. The sequelae of massive limb trauma, which may be amputation, also need further study.

Pathophysiology

The pathophysiology of bone healing is not well understood. The relationship between weight-bearing and internal fixation is unclear, and more research is also needed to help clarify the value of adjunctive therapies, such as electrical stimulation, in improving bone healing. Surgery to repair blood vessels is highly effective, but research into improving peripheral nerve repair has not received much attention in the past 10 years. The ability to move skin and soft tissue to enhance tissue coverage has improved, but repair techniques for ligaments are still evolving. Immobilization as a treatment for limb injury is not ideal, because muscle weakness, fibrous tissue contractures, and cardiopulmonary deconditioning are all inevitable complications. The patient's loss of energy is the cost of accommodating an immobilized limb. Walking with crutches to avoid putting weight on a limb raises the heart rate 25%. Using a fracture brace instead of the traditional cast minimizes the loss of energy and periarticular fibrosis.

Rehabilitation

Rehabilitation has not played a major role in the management of limb fractures, except when the limb is amputated. The traditional model for managing limb injuries involves primary care by an orthopedist, with occasional assistance from vascular and plastic surgeons. Follow-up is provided on an outpatient basis, which allows the patient to set the rehabilitation pace. Care is focused on healing the primary pathologic condition, and little attention is given to traditional concerns of rehabilitation such as employment problems and social reintegration.

The trend toward increasing the number of trauma centers provides an opportunity for early involvement of the rehabilitation team in acute care settings. Although many

rehabilitation therapy protocols need to be evaluated, information about factors that influence a patient's return to work following hospitalization for limb injury is emerging. In one study of outcomes following limb injuries, results showed that of patients with Abbreviated Injury Scores (AISs) of 1 or 2, 44% were back at work 6 months after injury, and 65% 1 year after injury (18). Of the patients with more severe limb injuries (AISs of 3 or more), 28% were back at work 6 months after injury, and 54% 12 months after injury. Especially striking is the high percentage of less severely injured workers who were not working after 1 year. Factors that correlated positively with patients returning to work were quantity and quality of vocational rehabilitation, preinjury personality traits, and involvement of the family in the recovery program. Negatively correlated factors were low income and low education, which may reflect limited resources for rehabilitation care.

Service Delivery Issues

One major problem in limb injury rehabilitation is clinical care providers' lack of awareness that rehabilitation can improve limb injury outcome. Another problem involves deciding when is the best time to begin rehabilitation. Including rehabilitation as an element in trauma centers is advantageous. For example, psychologists and other counseling professionals can help patients return to work early, and these professionals can also contribute to more efficient coordination of community services. Patients who can return to work, even though they do not work full time, may have improved recoveries. There is evidence that if a person fails to return to work by 6 months postinjury, the likelihood of that person ever returning to work is reduced (18).

Funding Issues

For work-related injuries, most phases of treatment are funded satisfactorily. For injuries occurring during a leisure activity, treatment is generally reimbursed through third-party payers who may not adequately cover a patient's rehabilitation needs. Assistive medical equipment, other than such simple items as crutches, may not be covered by health insurance and therefore unavailable to some injured persons.

Back Injuries

Dimension of the Problem

Musculoskeletal injury to the spinal column is also an important source of impairment and disability, especially among workers. Although exact figures on the numbers of back injuries that occur each year are not available, one can estimate the problem by determining the number of people who complain about low back pain and the number of workers' compensation claims filed for back injuries.

About 5.2 million Americans are disabled by low back pain; half of them are chronically disabled (19). The annual costs of compensable low back pain have been estimated at $11 billion (in 1986 dollars). Low back pain is the most common cause of work disability among adults less than 45 years of age and the third most important cause of disability among those 45 years or older (19). The rate of disabling low back pain increased 14-fold from 1970 to 1981 (20). Each year about 5% of the population complains of low back pain. Because of the difficulty in making a differential diagnosis, it is unknown to what extent reported symptoms of back pain are due to an acute sudden injury, to cumulative trauma to the spine as a result of repeated heavy physical work, or to congenital anomalies and chronic medical conditions. In general, an exact diagnosis is made for only 10% to 15% of all patients with low back complaints (20).

Work-related back injuries account for about one-fifth of all workers' compensation claims (21). The annual incidence rate of compensable back injuries among all industrial workers has been estimated to be 2%, although these rates vary considerably by industry and occupation, with highest rates reported among machine operators, truck drivers, and nurses (21). Estimates of the back injury problem that are based on workers' compensation claims are generally low since many workers who experience a back injury do not file a claim or are not covered under state programs. Claims data do, however, provide important information on the incidence of serious back injury and can be used to design and target prevention programs.

Three-quarters of all claims for back injury are filed by men. The average age of the back injury claimant is 35 to 40 years (21).

Overexertion, including lifting, pulling, and throwing, is the most common cause of back injury. In many cases, however, back pain is not associated with a sudden injury; rather, it is the result of cumulative spinal damage due to heavy physical work. This is especially true if workers lift more than their capacity.

Treatment

The treatment for back injury, and low back pain generally, is not standardized and ranges from conservative therapies to surgery (22). In general, little scientific evidence supports the choice of a particular clinical strategy (23). Published reports of clinical studies are few because of the lack of appropriate controls and random assignment of patients to alternative therapies, reliance on short-term follow-up evaluations, and poor standardization of both treatments and evaluation. In addition, many studies lack clear and precise criteria for particular patients; the result is that study populations are heterogeneous with regard both to etiology of low back pain and to sociodemographic factors (24). The lack of scientific evidence to support alternative therapies has led to wide variations in treatment practices for both acute and chronic low back pain.

It is important to distinguish between acute and chronic back pain. Acute back pain is generally defined as lasting less than 12 weeks, and chronic low back pain as lasting more than 12 weeks.

The prognosis for acute low back pain is generally favorable. About 90% of all cases of acute low back pain are resolved within 6 to 12 weeks (22). Although bed rest, often in combination with analgesic medication, is regarded as the principal therapy for acute low back pain, little scientific evidence supports the efficacy of this approach. Prolonged bed rest can be harmful and may promote chronic pain and disability (25). One study found that patients who were prescribed 2 rather than 7 days of bed rest did equally well in terms of functional, physiologic, and perceived outcomes. Further, the group for whom only 2 days of rest were prescribed missed 45% fewer days of work (26). The role of various types of exercise and physical therapy in treating acute lower back pain is even more controversial. Evidence is growing, however, to indicate that activity is not harmful for acute back pain patients and that an active rehabilitation program and early return to work can improve function and reduce pain (22). Surgery is rarely indicated for relief of acute low back pain except for a small percentage of patients with unrelenting sciatica.

Although only 5% of all cases of low back pain are chronic, these cases account for approximately 85% of the costs associated with low back pain (27, 28). The available statistics on long-term recovery from chronic back pain are discouraging. In general, 40% of patients who have been disabled because of lower back pain for 6 months eventually recover; this figure drops to only 20% if the disability persists for up to 1 year (29-31). Most patients with low back pain are managed conservatively with anti-inflammatory medication and an exercise program. The indications for surgical treatment are vague and imprecise. Many experts would agree that back surgery in this country is performed too frequently, with poor, or at best, equivocal, results.

Interventions

Recent studies have emphasized the potential benefits of functional restoration programs that emphasize physical reconditioning and pain relief. In these programs, patients are educated and counseled in order to enhance their motivation to work and to teach them ways to deal with their impairment and avoid further injury. One study found that 87% of persons enrolled in a multidisciplinary functional restoration program were actively working after 2 years, compared with only 41% of comparable patients not enrolled in the program. The comparison group, moreover, made physician visits at a rate five times higher than the treatment group, and twice as many in the comparison group had additional spine surgery (32). These results are promising; further evaluation of the costs and benefits of similar programs should be given high priority.

The role of back schools in relieving symptoms and preventing recurrent episodes among workers with low back pain needs to be further evaluated. These schools, originally developed in Sweden, combine an exercise program with education and counseling on

ergonomics (33). Although the effectiveness of back schools has been questioned, one study demonstrated that a program at one such school was effective for workers with severe chronic pain (34, 35).

Training

To improve the medical treatment of back injury, health professionals who routinely see patients with complaints of low back pain must have appropriate training in the assessment and management of pain behavior (36). Health professionals must be able to integrate and coordinate different modalities of care, such as medication, exercise, and surgery. Too often, the first physician to evaluate a back patient has had little training or education in pain management. Typically, orthopedic surgeons and neurosurgeons are consulted, even though surgery is indicated in only 1% to 2% of all cases. Physiatrists, given their training in the management of musculoskeletal disorders and pain, should be more broadly involved in the treatment of back pain.

Other factors besides medical treatment play important roles in a patient's recovery from back injury (20). Among the factors shown to affect the outcome (including the extent and rate of return to productive work) are the patient's educational background and vocational resources, other personal and psychosocial factors, and the type and security of the job the patient held when injured. Some researchers believe that the type and amount of compensation received influence a patient's return to work, although the few studies that have addressed these issues report conflicting results. The role of income replacement programs as work disincentives is complex and depends on numerous factors, including type of job and salary, job satisfaction, program rules and procedures, and the willingness of an employer to hire persons with disabilities. Workers' compensation programs and laws should be reviewed to determine whether they inhibit successful rehabilitation of injured workers. More study is needed to determine how multiple factors interact to impede a timely return to work after back injury. The Americans with Disabilities Act, which becomes effective in July 1992, should help to eliminate employment discrimination for people with disabilities.

Medicine and the allied health professions that focus on occupational rehabilitation are fragmented in their approach to service delivery. Occupational or industrial medicine has existed for several decades as a recognized medical specialty, but the discipline has not grown sufficiently to meet demands for services. Similarly, occupational medicine has not been well-integrated with physical medicine, rehabilitation, or orthopedic surgery.

Facial and Eye Injuries and Polytrauma

Significant disability and the need for rehabilitation services are associated with injuries other than those in the major categories of SCI, TBI, limb injury, back injury, and burns. Most notably, these include injuries to the face and eye.

Facial and Eye Injuries

Although injuries to the face and eye are rarely life-threatening, they can result in significant temporary or permanent impairment. Each year an estimated 85,000 people are hospitalized for treatment of a significant injury to the face or eye (37). Eye injury is the primary diagnosis in 33,000 hospitalizations (38). An additional 9 million injuries occur that result in treatment on an outpatient basis or result in one or more days of restricted activity (Ellen MacKenzie, The Johns Hopkins University, unpublished data, 1990). Impairments resulting from these injuries include disfigurement (scars, deformities of the face and jaw, missing or maloccluded teeth), visual impairment and blindness, chronic obstructed nasal lacermal passages or chronic sinusitis, anosmia (loss of sense of smell), and impairments such as difficulty chewing or temporal mandibular joint arthritis.

Of particular importance in terms of long-term impairment and disability are ocular injuries, an important cause of blindness and vision loss in the United States. Although good information about the consequences of these injuries is unavailable, estimates of the number of people visually impaired as a result of ocular trauma are as high as one million, nearly 80% of whom are blind in one eye. Eye injury is the leading cause of monocular blindness in the United States and is second only to cataracts as the most common cause of visual impairment (39). Although no segment of society escapes the risk of eye injury, eye injuries are especially frequent among young adults, with 64% of all ocular trauma occurring to persons younger than 30 years of age (U.S. Eye Injury Registry, Birmingham, AL, unpublished data).

There is much controversy about the leading causes of ocular injuries. Some studies focus on injuries in the home, during sports, at work, or resulting from motor vehicle crashes; other studies point out that assault accounts for a significant proportion of eye trauma (38, 39).

Little is known about the long-term functional consequences of eye trauma. Severe visual impairment often affects ability to read, drive, walk, pursue hobbies and sports, and interact socially because of their difficulty in recognizing and acknowledging friends and because of their concerns about their appearance.

Although significant strides have been made in developing aids and devices to assist people with visual impairments, programs and policies must ensure that this technology is financially accessible to all who need it. Research is needed to further evaluate artificial vision devices for the blind. Rehabilitation services for the visually impaired must emphasize the importance of creative job placement — that is, taking advantage of individual skills and

talents as opposed to placing people in stereotypic jobs for blind and visually impaired people. We need to give special attention to equipping the person with visual impairment with the skills necessary to undertake activities of daily living such as working and driving, to providing adequate services for families of injured patients, to developing creative rehabilitation programs, and to researching the prevention of ocular injuries.

Polytrauma

Many injured persons are best categorized as polytrauma patients, (i.e., patients who sustain injuries to more than one body system). Because combinations of injuries among polytrauma patients vary, the rehabilitation strategies required are varied and complex.

Multiple injuries occur most frequently as the result of motor vehicle crashes. Approximately half of all people injured as the result of police-reported crashes had multiple injuries. The average number of injuries is 2.5 per injured person.

For polytrauma patients, physicians often have difficulty deciding which is the primary injury. For example, which specialized services are most appropriate for SCI or TBI if a person has both? Recent studies suggest that more than 80% of patients with severe TBI also sustain injuries to other body systems (6). The frequency of problems associated with managing selected conditions in polytrauma patients has not been adequately determined. Polytrauma injuries often associated with TBI include fractures to the spine and extremities, soft tissue injuries to the chest and abdomen, and peripheral nerve injuries (1). About 10% of all SCI patients have an associated TBI. Associated injuries in TBI patients, especially skeletal fractures, complicate recovery and result in greater disability.

One organizational problem occurs when people with severe primary injuries in an organ system and relatively minor TBIs or SCIs are not referred for rehabilitation services by trauma specialists who are intent on managing the primary injury. Recent evidence has suggested that up to half of patients with SCI may also sustain a mild head injury. Patients need to have these mild head injuries diagnosed and rehabilitation therapy set up to ensure optimal recovery and quality of life.

Little is known about the effects of general debilitation and associated cardiovascular and neuromuscular deconditioning that can occur in multiple trauma patients with severe injuries to the abdomen and thorax. Although advances have been made in techniques for nutritional support of patients who have severe abdominal injuries, objective measurements are needed to assess the relative importance of maintaining optimal nutrition and its effect on rehabilitation goals.

Few trauma programs routinely include rehabilitative services, except for patients with specific injuries such as TBIs and SCIs. Several organizational problems within the health care system contribute to the lack of routine referrals for rehabilitation services for patients with polytrauma injuries, although many of these patients will have long-term disability and could benefit from comprehensive medical rehabilitation.

Where We Want To Be

Introduction

Rehabilitation after injury can greatly improve a patient's chance of achieving optimal health, personal autonomy, and reemployment; rehabilitation techniques mitigate impairments, reduce residual disabilities, and help the patient maintain function. Unfortunately, rehabilitative services are not available throughout the country, nor are all services accessible financially to all who need them. Some clinical rehabilitation therapies have been inadequately evaluated, and others are determined by the cost to third-party payers rather than efficacy. Although great progress has been made in developing and delivering rehabilitative services, many improvements are still needed. Everyone, especially children and the elderly, must benefit from currently available rehabilitation techniques; and research, both basic and applied, must be financially supported. **Our goal is to establish, by the year 2000, a cost-effective system of rehabilitation care that will permit an injured person with a disabling injury to achieve optimal health, personal autonomy, and an independent, noninstitutional lifestyle. A cost-effective system of rehabilitative care will help achieve an important objective of *Healthy People 2000*, namely the reduction of secondary disabilities as a result of head and spinal cord injuries.**

To develop this ideal system of rehabilitation care, we have recommendations in six major areas: basic science research, injury and rehabilitation surveillance, information dissemination and technology transfer, rehabilitation services capacity, health services research models, and training. Financial support for implementing these recommendations must come from public, philanthropic, and corporate sources. These recommendations should be addressed through a collaborative and interdisciplinary effort by clinicians, researchers, public health practitioners, patients and their families, policymakers, and the public.

Basic Research

The knowledge base on which injury rehabilitation rests is too small. Support of research in the basic mechanisms of tissue function and dysfunction is essential to provide a basis for understanding and applying rehabilitation therapies. Recently, the National Institutes of Health (NIH) convened a group of more than 100 experts in rehabilitation medicine, behavioral and social sciences, allied health, nursing, and health services research to help determine what research is needed to build a strong foundation for rehabilitation services. The resulting task force report recommended that a solid program of basic science research and outcome research needed to be developed. In addition, research must be undertaken to validate outcomes associated with new and old forms of treatment. Recently, the National Center for Medical Rehabilitation Research was established within the NIH to

develop a program of basic research in rehabilitation. **We strongly endorse the recommendations of the NIH task force report and the establishment of the National Center for Medical Rehabilitation Research and recommend establishing a cohesive research program in all areas of injury, ranging from basic science to ways that persons with injuries can function in the community.**

Injury and Rehabilitation Surveillance

To develop an effective system of rehabilitative care, we need objective evaluation of preventive strategies and clinical management. Sound decisions about clinical care strategies, preventive interventions, and cost and treatment options depend on developing measurement systems that generate a population-based, patient-oriented data base that contains information on etiology, risk factors, treatment, and outcome. The field of rehabilitation has been hampered by lack of objective tools with which to measure outcomes. **We recommend developing a clinical care data base from the records of all injured people. The data base would include epidemiologic information on etiology, risk factors, treatment, outcomes, and costs.** Developing this data base will require (a) innovative approaches to collecting data from health departments, hospitals, trauma centers, private care providers, and patients, and (b) improved cause-of-injury codes in patient records. Specialized registries; mandatory reporting; and evaluation of insurance, medical examiner, and coroner data will be needed. Issues such as confidentiality, participation, and data linkage also need to be addressed. Despite the difficulty in collecting these data, we must make every effort to do so, because they are necessary to evaluate the effectiveness of various therapies, to establish the direction for research aimed at prevention, and to reduce secondary complications.

Information Dissemination and Technology Transfer

For rehabilitation programs to be successful, up-to-date knowledge must be available to the providers of rehabilitation services, to persons with disabling injuries, to families of injured persons, and to the community, We believe strongly that the transfer of information from the researcher to clinical and public health programs and to the general public is critical to the development of our proposed model system. In addition, information about gaps in knowledge, effective and ineffective strategies, and new and emerging problems must be made known to the researcher. Information about successful patient- and community-based prevention and care strategies must be shared with injured persons, their families, and their medical providers. **We recommend that high priority be given to information dissemination and technology transfer among researchers, clinicians, health providers, injured persons and their families, and the community.**

Increased Capacity for Rehabilitation Services Delivery

At virtually every level, rehabilitation services are insufficient to meet the needs of injured Americans. This problem has two aspects: geographical distribution of services and their affordability. The development of Model Spinal Cord Injury (SCI) Care Systems during the past two decades demonstrates that effective systems of care can be provided by using existing clinical and prevention knowledge. In these model systems, cooperative, integrated systems of care have made rehabilitative medical services more readily available. **We propose that systems of care be developed for people with any injury that produces significant limitations in function and that the effectiveness of these systems be evaluated.** Groups using innovative approaches to delivering rehabilitative care, such as home care agencies, public school systems, independent living centers, and state agencies for vocational rehabilitation, should be encouraged and their effectiveness in delivering rehabilitation services should be objectively evaluated. Guidelines for clinical rehabilitation of injured patients will be developed from these models and can serve as the basis for intervention at all treatment facilities.

Research on Clinical and Health Services

Many interventions outside the medical model play vital roles in the outcomes and quality of life of people with disabilities. **We recommend that health systems research models, incorporating a variety of innovative and traditional approaches, be used to address issues such as access to and payment for services, the cost-benefit analysis of rehabilitation services, reemployment training and back-to-work incentives, and combinations of traditional and nontraditional rehabilitation services and therapeutic methods.**

Training

There are shortages of trained medical, allied health, and nonmedical personnel in medical rehabilitation. **We strongly believe that more trained personnel are needed in all areas of rehabilitation (including research, clinical care, and personal services) to ensure the development of model systems of rehabilitative care.** This training should be at the medical-student, resident, and fellow levels. Nursing, behavioral science, and allied health programs should include general and specialized training in injury rehabilitation, and continuing education in rehabilitation should be provided to medical practitioners. Attracting and training nonprofessional staff members is also important. A specific critical need is the development of formal methods to train, support, and certify personal care attendants and other nonprofessional care providers who are vitally important to the continuing success of rehabilitative efforts for persons who can never achieve physical independence in daily living activities. Special training for family members of injured persons also needs to be addressed.

By strengthening these six areas, our goal of creating a cost-effective system of rehabilitative care can be achieved in this decade. Achieving that goal, however, will be difficult and costly, but we strongly believe that a cooperative and well-planned approach can achieve much and ultimately be worth the cost.

How We Get There

Introduction

Three issues relating to evaluation impede the development of model systems of rehabilitation care: (a) the absence of objective methods for measuring functional recovery, (b) the lack of suitable comparison groups, and (c) the sheer complexity of clinical care evaluation studies.

There are few objective measurements of functional recovery. Such measurements have many uses for researchers studying cost-effectiveness, designing optimum mixes of inpatient and outpatient rehabilitation services, or measuring the effectiveness of various interventions. Measurements of functional recovery should be on three levels:

- **Motor, cognitive, and sensory impairment.** The rehabilitation field needs practical clinical measures of motor, cognitive, and sensory impairments that are sufficiently sensitive to changes and that produce results with practical meaning for clinicians and patients.
- **Functional capacity.** Functional capacity relates to a patient's general health (including cardiopulmonary fitness, cognitive ability, and pain) and to neuromuscular impairments of strength, joint mobility, and control.
- **Functional performance.** Functional performance involves the injured person's activities and is related to the severity of impairment and functional capacity. It is also influenced by environmental, cognitive, and emotional factors.

To build functional capacity, many rehabilitative services use physical restoration techniques, skill training, and education. In comprehensive medical rehabilitation programs, however, an interdisciplinary approach is used to address all aspects of physical health and environmental, psychological, and sociocultural factors that build functional performance.

Semiobjective measures of functional performance, such as ordinal scales for scoring a patient's ability to complete common activities of daily living, were first developed more than 20 years ago. Recently, however, the Functional Independence Measure (FIM) has been developed (40), and it may prove capable of measuring the effectiveness of many rehabilitation strategies. FIM's validity, reliability, and usefulness in cost-effectiveness studies have yet to be fully determined. Ways to assess the functional demands of a task and an individual's capacity with regard to that task need to be developed. Measuring the functional capacity of children is particularly challenging, since their functional capacity changes with development.

Another constraint to conducting and interpreting the results of outcome studies is the dearth of suitable comparison groups. Acquiring comparison data on a sufficient number of patients who received fragmented or potentially inadequate rehabilitation services has not been possible. One way to obtain sufficient comparison data would be to mandate a national surveillance system whereby all cases would be reported to a governmental or research organization not concerned with clinical service. Such a system may also resolve similar problems with longitudinal follow-up of populations with injury-related disabilities over their lifetime.

Three other problems encountered in studies to measure the effectiveness of various forms of rehabilitative care involve the sheer complexity of such studies. The first problem is the difficulty, already noted, of establishing a comparison group. Referral of patients to specialized or general centers involves many factors, such as the patient's ability to pay and the accessibility to such centers. Those factors can influence the numbers and types of patients in treatment and the makeup of the comparison groups. Second, because of existing payment systems, patients may receive care in a variety of settings that range from optimum to minimum standards of care. Finally, the evaluation of rehabilitation outcomes may require long-term follow-up studies of up to 10 to 20 years of continuous observation. These studies are costly and logistically complicated.

Specific Recommendations

Several federal agencies currently have programs concerned with rehabilitation services and research. Among them are the National Institutes of Health, the National Council on Disability, the National Institute of Disability and Rehabilitation Research, the Centers for Disease Control, the Agency for Health Care Policy and Research, the Department of Veterans Affairs, the Food and Drug Administration, and the Health Care Financing Administration. Other public organizations such as the Institute of Medicine, the National Head Injury Foundation, and the American Spinal Cord Injury Association are intensely involved in issues related to care, research, and policy on rehabilitation. Although this list does not include all groups involved in rehabilitation, it demonstrates that there is indeed a broad national interest in rehabilitation.

In making the following recommendations, the panel believes that some may be ideally carried out by one, several, or all of the agencies listed previously. Recommending which organization(s) should undertake these activities is, however, beyond the scope of this panel. We suggest that consideration be given to developing an intergovernmental committee to coordinate the implementation of these recommendations.

Basic Research

- Address and appropriately support research on injury conditions that require rehabilitation.
- Consider increases in research budgets of federal agencies to support significant, long-term, basic research studies of rehabilitation issues such as central nervous system regeneration, mechanisms of both normal and injured tissue function, and the impact of pharmacological agents on healing, pain, and bone biology.

Injury and Rehabilitation Surveillance

- Establish a longitudinal population-based surveillance system to determine the incidence, prevalence, etiology, and risk factors for specified impairments, functional limitations, and disabilities resulting from injury. This surveillance system should be designed as a partnership of federal and state public health and research practitioners, clinical research facilities, and rehabilitation agencies.
- Draft model legislation to mandate state-based public health surveillance of injuries that result in disabilities. Link this system to existing trauma registries and include relevant information on rehabilitation. Give special consideration to models for surveillance that can be supported by revenues generated from special-use taxes, such as those on cigarettes or alcohol.
- Develop a burn surveillance system to link causal and short- and long-term outcome information. This system would require the close cooperation of health departments, burn centers, and rehabilitation facilities.
- Conduct a national survey of persons with disabilities to collect more detailed information on injury-related disabilities.

Information Dissemination and Technology Transfer

- Develop and fund a cooperative effort to transfer research information among government agencies and private agencies involved in rehabilitation. Focus on collecting current and pertinent basic, applied, and clinical research findings and disseminating them to clinicians and other health care providers.
- Develop a coordinated approach to educate third-party payers about the complex rehabilitation needs of injured patients.
- Develop and implement a strategy to improve the quality of published rehabilitation research reports. Various professional associations concerned with rehabilitation services should work to improve the peer-review process, evaluate research protocols, and provide support for collecting rehabilitation information.
- Develop resource and information guides for persons with injuries so that those who need rehabilitation and their families can have a better understanding of the latest research and services provided by comprehensive rehabilitation.

- Hold consensus conferences supported by various professional associations to develop minimum clinical treatment guidelines for each major area in injury-related rehabilitation. Make these guidelines available to persons with disabilities, the clinical care community, and the general public.

Increased Capacity for Rehabilitation Services Delivery

- Support nontraditional models for providing rehabilitation services such as independent living centers, improve training and referral systems, and provide more personal care attendants.

- Develop model burn injury centers similar to model SCI and TBI centers.

- Develop a system for the uniform delivery of personal assistance services. This system should, at a minimum, serve all people of any age, regardless of income, include respite and emergency assistance care, not create disincentives to employment, and have a training component for consumers, personal care attendants, payers, and administrators.

- Consider increasing the funds for model SCI and TBI systems of care to demonstrate that rehabilitation care for specific disabilities can be made universally available throughout the United States.

- Establish disability and injury prevention programs in each state health department.

Research on Clinical and Health Services

- Increase support for clinical research and clinical trials on improved approaches to comprehensive rehabilitation. This research should focus on injured persons of all ages and should include an examination of early rehabilitative interventions and the contributions made by all rehabilitation-related professions such as physiatry, physical therapy, clinical psychology, social work, and dentistry.

- Conduct population-based and longitudinal studies to better establish the prognoses and medical rehabilitation needs of patients with traumatic brain injury, spinal cord injury, and burns.

- Develop an inventory of all rehabilitation facilities to determine their location, the population served, and disease categories dealt with. Consider ways to upgrade facilities with the goal of making them model treatment centers.

- Fund research and demonstration projects that focus on strategies to enhance living with the long-term consequences of disability. Include important psychosocial components such as stress management, psychosocial integration into the community, vocational guidance and training, and independent living services (e.g., personal care attendants, peer counseling, and transportation).

- Support research to assess the strengths and weaknesses of various service delivery models for providing designated services to persons disabled because of injury.

- Initiate research on alternate models of health care and rehabilitation services that could complement traditional medical models.

- Identify new research paradigms and statistical methods to assess the complex interactions among multiple impairments, functional limitations, and disabilities.

- Support research of secondary conditions that develop after the acute phase of rehabilitation and throughout the lives of people with residual disabilities. Such studies are needed to understand the long-term sequelae of injury, the outcomes of rehabilitative services, and what new services (such as health promotion), if any, are needed to enhance the health, productivity, and quality of life of persons with disabilities.

- Develop a strategy to evaluate national health care funding mechanisms for rehabilitative services, especially with respect to the needs of persons who are disabled because of injury. Consider developing guidelines or single points of access that would meet the lifelong needs of these people.

- Induce third-party payers such as workers' compensation programs, insurance providers, and Medicare and Medicaid programs to support service demonstration programs that permit people with disabilities to maintain eligibility for Social Security and Supplemental Security Income after they return to work.

- Adopt the nomenclature recommended by the Institute of Medicine in its report, *Disability in America: Toward a National Agenda for Prevention*. The report describes a model with four related but distinct concepts: pathology, impairment, functional limitation, and disability.

Training

- Add courses on caring for people with disabling injuries to the curriculums of nursing, physical therapy, and occupational therapy schools.

- Include the principles and practices of rehabilitation in the training of physicians, especially of physicians involved with people requiring acute care for burn or extremity injuries.

- Increase support for predoctoral and postdoctoral training for people who wish to specialize in the clinical and research aspects of rehabilitation services.

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