



August 1987

Special Supplement: Ethical and Policy Issues in Rehabilitation Medicine

Arthur L. Caplan
University of Pennsylvania, caplan@mail.med.upenn.edu

Daniel Callahan
The Hastings Center

Janet Haas
Moss Rehabilitation Hospital

Follow this and additional works at: https://repository.upenn.edu/bioethics_papers

Recommended Citation

Caplan, A. L., Callahan, D., & Haas, J. (1987). Special Supplement: Ethical and Policy Issues in Rehabilitation Medicine. Retrieved from https://repository.upenn.edu/bioethics_papers/3

© The Hastings Center. Reprinted by permission. This article originally appeared in the *Hastings Center Report*, Volume 17, Issue 4, August 1987, pages 1-20. Publisher URL: <http://www.thehastingscenter.org/publications/hcr/hcr.asp>

This paper is posted at ScholarlyCommons. https://repository.upenn.edu/bioethics_papers/3
For more information, please contact repository@pobox.upenn.edu.

Special Supplement: Ethical and Policy Issues in Rehabilitation Medicine

Abstract

The field of medical rehabilitation is relatively new, a product in great part of the rapid developments in medical science during and after the Second World War. Until recently, the ethical problems of this new field were neglected. There seemed to be more pressing concerns as rehabilitation medicine struggled to establish itself, sometimes in the face of considerable skepticism or hostility. There also seemed no pressing moral questions of the kind and intensity to be encountered, say, in high technology acute care medicine or genetic engineering. With eyes focused on the dramatic and wrenching problems, those in biomedical ethics could and did easily overlook the quiet, less obtrusive, issues of rehabilitation.

Comments

© The Hastings Center. Reprinted by permission. This article originally appeared in the *Hastings Center Report*, Volume 17, Issue 4, August 1987, pages 1-20. Publisher URL: <http://www.thehastingscenter.org/publications/hcr/hcr.asp>



Special Supplement: Ethical & Policy Issues in Rehabilitation Medicine

Arthur L. Caplan; Daniel Callahan; Janet Haas

The Hastings Center Report, Vol. 17, No. 4. (Aug. - Sep., 1987), pp. 1-20.

Stable URL:

<http://links.jstor.org/sici?sici=0093-0334%28198708%2F09%2917%3A4%3C1%3ASSE%26PI%3E2.0.CO%3B2-G>

The Hastings Center Report is currently published by The Hastings Center.

Your use of the JSTOR archive indicates your acceptance of JSTOR's Terms and Conditions of Use, available at <http://www.jstor.org/about/terms.html>. JSTOR's Terms and Conditions of Use provides, in part, that unless you have obtained prior permission, you may not download an entire issue of a journal or multiple copies of articles, and you may use content in the JSTOR archive only for your personal, non-commercial use.

Please contact the publisher regarding any further use of this work. Publisher contact information may be obtained at <http://www.jstor.org/journals/hastings.html>.

Each copy of any part of a JSTOR transmission must contain the same copyright notice that appears on the screen or printed page of such transmission.

JSTOR is an independent not-for-profit organization dedicated to and preserving a digital archive of scholarly journals. For more information regarding JSTOR, please contact support@jstor.org.

Ethical & Policy Issues in Rehabilitation Medicine

**by Arthur L. Caplan,
Daniel Callahan
and Janet Haas**

**A Hastings Center Report
Special Supplement/August 1987**

This Special Supplement was derived from The Hastings Center project on Ethical Issues in Rehabilitation Medicine, which was supported by a grant from the Mabel Pew Myrin Trust. This Special Supplement was edited by Margaret Fletcher Stack. Contents copyright 1987 by The Hastings Center. All rights reserved.

The field of medical rehabilitation is relatively new, a product in great part of the rapid developments of medical science during and after the Second World War. Until recently, the ethical problems of this new field were neglected. There seemed to be more pressing concerns as rehabilitation medicine struggled to establish itself, sometimes in the face of considerable skepticism or hostility. There also seemed no pressing moral questions of the kind and intensity to be encountered, say, in high-technology acute care medicine or genetic engineering. With eyes focused on the dramatic and wrenching problems, those in biomedical ethics could and did easily overlook the quiet, less obtrusive issues of rehabilitation.

With the support of a grant from the Mabel Pew Myrin Trust, The Hastings Center set out in 1985 to rectify that situation. Various friends and colleagues in rehabilitation medicine had for some time been pointing out to us the wide array of moral issues confronting the field. They ranged from some familiar issues at the clinical level—informed consent, truth-telling, paternalism—to some no less familiar at the societal level, such as the allocation of scarce resources. Yet if these issues were, in one way, familiar, their context was different from acute care medicine, often strikingly so. Rehabilitation therapy is a long process, often allowing much time for the moral struggles to unfold and play themselves out. There is a great need for active patient participation in his or her own treatment as well. Use of treatment teams and the frequent need for family involvement add their own special ingredients to the medical and ethical mix.

To explore the issues, the Center assembled a group of practitioners in the field, Hastings Center staff members, and individuals experienced in other areas of medical ethics. For project participants, there was a difficult and extended period of exploration and analysis; the issues were surely there, but they were not always easy to define with precision or to pursue with vigor. Unlike other areas of medical ethics, there was little pre-existing literature, no specialists in the moral problems, and no tradition or history of interdisciplinary work between rehabilitation and ethics. It was, in many ways, one of the hardest projects ever

mounted by the Center, not simply because the moral problems encountered were complex, which they were, but because they often seemed elusive. We ended the project with a sense that we had made some progress, but humbled that we had made less progress than we would have liked. There is still much work to be done.

The report that follows was written by Arthur Caplan and Daniel Callahan, assisted by Dr. Janet Haas of the Moss Rehabilitation Hospital in Philadelphia. It owes much, however, to the project participants, who gave gladly of their time, research, and insights. A separate collection of papers and case studies developed by them is being prepared for publication. We acknowledge with gratitude their help. We no less want to acknowledge the support of the Mabel Pew Myrin Trust.

—Daniel Callahan
—Director

PROJECT PARTICIPANTS

Thomas Anderson, Medical Director of Head Injuries Systems, New Medico, Lynn, MA

Adrienne Asch, Teachers College, Columbia University, NY

Edward Berkowitz, Director of History & Public Policy Programs, George Washington University, Washington, DC

Daniel Callahan, Director, The Hastings Center

Arthur L. Caplan, former Associate Director, The Hastings Center

Cynthia Cohen, Associate for Ethical Studies, The Hastings Center

Gerben DeJong, Director of Research, National Rehabilitation Hospital, Washington DC

Strachan Donnelley, Director of Education, The Hastings Center

Count Gibson, Chairman, Department of Family, Community and Preventive Medicine, Stanford University School of Medicine, Palo Alto, CA

Willard Gaylin, President, The Hastings Center

Richard Goldberg, Director of Research & Evaluation, West Ros Park Mental Health Center, Roslyndale, MA

Willard Green, Director of the Medical Humanities Program, Hahnemann Medical School, Philadelphia, PA

Janet Haas, Moss Rehabilitation Hospital, Philadelphia, PA

Paul Homer, Assistant to the Director, The Hastings Center

Bruce Jennings, Associate for Policy Studies, The Hastings Center

Caroline McCagg, Associate Director, The Johnson Rehabilitation Institute, Edison, NJ

Ruth Purtilo, Chairman, Department of Medical Jurisprudence and Humanities, University of Nebraska Medical Center, Omaha

Mary Romano, Director of Social Work, National Rehabilitation Hospital, Washington, DC

June Rothberg, Vice President for Academic Administration, Adelphi University, Garden City, NY

Martha Taylor Sarno, Director of Speech Pathology, Rusk Institute of Rehabilitation Medicine, NY

Deborah A. Stone, David R. Pokross Chair in Law & Social Policy, Heller School, Brandeis University, Waltham, MA

Harold Wilke, Director, Healing Community, White Plains, NY

As part of the overall project on ethics and rehabilitation, a series of case studies, with accompanying commentaries, was developed. These are available in a photoduplicated form at a nominal price and are suitable for teaching and other instructional purposes. Write to: Publications Department, The Hastings Center, 255 Elm Road, Briarcliff Manor, NY 10510 for further information.

Until recently the ethical issues in the field of medical rehabilitation had received relatively little explicit attention. Most clinical practitioners or scholars in philosophy, theology, law and the social sciences focused their analyses of moral problems in health care almost exclusively on emergency or acute medical interventions.

In part, such neglect may be a result of the fact that rehabilitation is a relatively new specialty within the realm of health care. Rehabilitation only began as a distinct field during World War II when such pioneers as Howard A. Rusk and Henry Kessler, building on the work of Frank Krusen, demonstrated the efficacy of rehabilitation to return soldiers to active duty rather than mere convalescence. The medical specialty was created in 1947 with the formation of the American Board of Physical Medicine under the guidance of Frank Krusen. To date, fewer than three thousand physicians are certified as specialists in rehabilitation medicine.

However, the newness of the field is not an entirely satisfactory explanation for such analytical neglect. Other recently developed areas of health care such as neonatology have produced a great deal of ethical discussion. Obviously, there must be other factors that have caused ethicists and practitioners to overlook rehabilitation medicine.

Rehabilitative therapy depends upon the efforts of many different health care specialists, both physicians and non-physicians. Their efforts frequently extend over long periods of time. Moreover, rehabilitation rarely results in dramatic "cures." Normally, it does not make extensive use of life-saving technologies. Without the use of these dramatic interventions, the moral questions become more amorphous, less obviously responsive to established ethical paradigms.

Those most often in need of rehabilitative services are those already undervalued by the society. Many are elderly. Some have congenital disabilities. A large proportion are unable to work. In a society that places great value on youth, vigor, and industriousness, and manifests an ongoing trust in the power of science and medicine to reverse the effects of disease and disability, there are powerful stigmas and little prestige associated with patients who lack both highly valued characteristics and the capacity for cure.

In spite of these obstacles, in the past few years there has been a significant increase of interest within and outside the field of rehabilitation medicine in ethical issues. In part, this reflects changes in social attitudes toward disability. Some of the stigma associated with physical and mental impairment has begun to wane as a result of concerted efforts by consumer advocacy groups,

rehabilitation professionals and self-help organizations such as the Independent Living Movement.

In part, the sudden spurt of interest in rehabilitation ethics is a response to increasing pressures to contain costs. Discussions about the desirability of introducing some form of prospective payment or capitation-based financing into rehabilitation have encouraged professionals in the field to examine seriously their moral obligations both to their patients and to society.

And, in part, because persons with severe neurological injuries can survive for increasingly longer periods of time, rehabilitation professionals must begin to address the moral dilemmas raised by treating patients whose capacity for independent living or autonomous behavior may be moderately or severely impaired. While small in overall numbers, the class of patients receiving rehabilitation who are brain injured are highly visible to providers, administrators and third party payers in terms of both costs and the level of resources they utilize.

It is clear, then, that medical rehabilitation differs in many important respects from emergency or acute medical care. It is also clear that interest in the unique ethical issues of rehabilitation is on the rise. It is, therefore, essential both for bioethicists and for those who deliver or receive rehabilitative services to identify the salient moral dilemmas and to determine whether ethical analysis based on emergency or acute care paradigms is adequate.

Rehabilitation Today

What Sorts of Services Are Provided and By Whom?

It has been said that rehabilitation is a medical specialty lacking an age, organ, technology or appendage to define it. Those providing rehabilitative therapy must treat the whole person rather than discrete physical, emotional or sensory dysfunctions. They also wish to provide treatment that addresses the individual needs of particular patients. In the words of Howard Rusk, the goals of rehabilitation are to restore persons "to optimal self-sufficiency and functional performance." To accomplish these goals involves the provision of a broad range of services including medical and nursing care, psychological counseling, family and social services, vocational assessment and management, sexual counseling, reconstructive surgical interventions, electrodiagnosis, massage, exercise, training to carry out activities necessary for daily living such as cooking and grooming, and the provision of prosthetic and orthotic devices.

Services are provided by a diverse group of professionals. A single patient might be treated by

a variety of specialists including a physiatrist (a physician specializing in rehabilitation), medical consultants, one or more physical therapists, a speech pathologist, an occupational therapist, a psychologist, a psychiatrist, a social worker, a vocational counselor, a recreation therapist, a large number of nurses with various degrees of specialty training, and, if the person is treated in a teaching facility, a host of students. The term "team approach" has been coined to indicate the variety of specialists involved in the provision of coordinated rehabilitative services.

A team model requires various specialists to provide different types of care in order to restore or compensate for loss of function. A physiatrist coordinates the activities of all medical specialists and works with the team to formulate and monitor each patient's plan of care. In some facilities a case manager, often a social worker, also is responsible for monitoring care and formulating a post-hospital or continued care plan. This carefully coordinated multidisciplinary approach to the provision of care, involving the sharing of responsibility and authority among a broad spectrum of health care professionals, has few analogues in other areas of health care.

Who Are the Patients?

Approximately one third of those who receive rehabilitative care have some form of neurological impairment most often caused by automobile accidents, falls, swimming mishaps, industrial accidents or gunshot wounds, injuries to the spinal cord, and strokes. The percentage of those with strokes has been declining in recent years. The number of patients requiring rehabilitation for neurological dysfunction as a result of injuries to the head, spinal cord, or both, is growing at a rapid rate. Other major causes of neurological impairment include multiple sclerosis, Parkinson's disease, cerebral palsy and muscular dystrophy.

Another third of patients who receive rehabilitative treatment have musculoskeletal impairments including arthritis, traumatic skeletal injuries, and amputation. The remainder have varied impairments associated with cancer, chronic heart and lung diseases, and diabetes.

With the introduction of antibiotics and life-support technologies, larger numbers of rehabilitation patients are elderly, having survived illnesses that would have once proven fatal. In addition, a growing proportion of those requiring rehabilitative assistance are children, many of whom have survived life-threatening diseases or congenital anomalies because of improvements in neonatal and pediatric intensive care.

How Is Rehabilitative Care Paid For?

The financing schemes that have evolved for those requiring medical rehabilitative services present a complex and confusing bureaucratic array. As a rule, reimbursement by third parties tends to cover only acute, short term hospital stays, thereby creating many gaps in the coverage presently available for reimbursing the costs of rehabilitative services.

Some private medical insurance policies cover only those costs incurred in acute care hospital settings. A small number of insurance firms have begun to write policies to provide for out-patient services and long-term care but even these policies usually have time limits for benefits that are far less than the amount of time necessary for adequate rehabilitation to be completed. Some private accident insurance policies and some group health plans also cover rehabilitation, but again often with strict limits on the amount, setting and duration of care that is compensable. Many prepaid medical plans do not cover rehabilitation services.

Most older Americans and those who are disabled, defined as those who have received Social Security Disability benefits for two years, find the primary source of payment for their medical care in the Medicare program. Medicare has two parts: Part A (Hospital insurance) and Part B (Medical insurance). Each part has a yearly deductible; in 1987 it is \$520 in Part A and \$75 in Part B.

Part A covers medically necessary care in a hospital. Sixty days of care are covered in full, the next thirty days are partially covered with a co-payment requirement of \$65 per day. Those eligible for Medicare may also draw upon a one time allotment of an additional 60 days of care with a co-payment, in 1987, of \$260 per day.

Part A of Medicare covers the costs of rehabilitation provided in a hospital setting, including therapies and drugs, within the coverage periods of the program. The costs of medical equipment can be reimbursed if the equipment is ordered and delivered to the patient in the hospital during the time period of coverage.

Part B of Medicare is optional; potential beneficiaries or their employers may enroll for a monthly fee of approximately eighteen dollars. Part B covers outpatient care at a rate between 68% to 80% of costs. Patients are responsible for paying the balance. Part B will cover doctors fees as well as those services provided by skilled professionals such as nurses, physical therapists or speech therapists both in the hospital and the home.

The major source of funding for the poor is Medicaid. Eligibility for this program is determined

by a means test. The income requirements and extent of coverage are determined by individual states that administer this program.

Those seeking eligibility under the program are required to be poor or become poor by spending down their resources to reach the indigency level defined by the state in which they reside. Many elderly persons must expend all of their resources in order to obtain coverage beyond that allowed in Medicare from Medicaid.

Medicaid coverage varies enormously from state to state. In some states Medicaid will pay for an unlimited number of days in a hospital or nursing home. In others, limits may be as low as fourteen days of coverage.

In many states Medicaid will not pay the costs of wheelchairs and other forms of equipment. In others the program will pay for some home care and some forms of equipment.

Public insurance for in- and out-patient rehabilitation, medical equipment, home care and nursing home care exists in limited form and varies enormously from state to state. Eligibility for publicly funded insurance often requires patients to impoverish themselves.

Concerns about the cost of health care, both acute and long term, have led many within the field of health care to reexamine the level of support that ought to be made available for those seeking rehabilitative services. In attempting to decide the level of support that society ought to provide, it is necessary to understand the nature of the aims and goals that providers and patients bring to this phase of care. In large measure, social consensus as to the desirability and feasibility of attaining the goals set by those who provide rehabilitation determines the availability of public reimbursement for this type of care.

Goals In Rehabilitation Medicine

Rehabilitation differs from other areas of health care with respect to the models of care that guide the efforts of health care professionals in dealing with patients. While scholars within and outside the health care professions have made numerous efforts to expand the standard view of health care in acute care settings, what is often referred to as the "medical model" remains influential in many areas of medicine.

The medical model of disease focuses upon the medical response to the sudden and unexpected onset of serious and often life-threatening disease or injury. The disease or injury is almost always the result of infection, accident or unanticipated physiological failure.

Illness—the perception on the part of the patient that something is wrong or abnormal—is understood to be the outcome or product of disease. While it is possible on the medical model for there to be disease present without the symptoms of illness, as in the early stages of breast cancer or hypertension, the converse situation, illness without disease or injury, is viewed with much skepticism.

The goals of care that dominate rehabilitation medicine, while sometimes overlapping those expressed in the medical model, are frequently far broader in scope.

The reductionist view of disease implicit in the traditional medical model has prompted some to argue that values or ethics play no role whatsoever in the definition of disease. While values may play a role in understanding illness, disease can be defined as either any deviation from statistically normal parameters of organic functioning or, as any deviation from species-typical functioning.

On the traditional medical model, there is no need to ascertain the patient's values or, for that matter, anyone else's values in the course of making a diagnosis. One simply detects abnormalities of physical functioning that are, on occasion, not even detectable by the patient, and then undertakes a series of interventions calculated to reverse or obviate organic dysfunction. On the medical model, disease is seen as a process that affects individual persons who then become the locus of medical attention and intervention.

The physician plays a critical role in this model of care in terms of both expertise and accountability. The patient expects the physician to use the knowledge and skill available in the various specialties of medical science to reverse the course of pathological processes in the body or the mind. Anything less than 'cure' is viewed in a negative light by both health care providers and patients.

The goals of care that dominate rehabilitation medicine, while sometimes overlapping those expressed in the medical model, are frequently far broader in scope. In medical rehabilitation professionals are more likely to assume that they are dealing with dysfunctions that are chronic, irreversible at the physiological level, relatively stable but, nevertheless, disabling. The subjective experience of illness helps guide the course of rehabil-

itative care. Patients play a crucial role in informing the health care team as to the extent to which any impairments that are present produce dysfunction or disability.

While rehabilitative interventions focus on the patient, providers also try to contend with the interaction of pathology and environment since extrinsic factors may exacerbate disability or produce additional handicaps.

Health care professionals in rehabilitation often see themselves as teachers or educators. They view themselves as responsible for teaching patients adaptive strategies and techniques for carrying out the activities of daily life and for maintaining health.

The traditional medical model tends to depict patients as the passive recipients of medical interventions. On the rehabilitative model, patients are commonly viewed as active agents who must participate in their own care, e.g., learning particular exercises intended to strengthen muscles damaged by injury or disease.

The goals of health care in the medical model are to remove or reverse physiological pathology in order to restore normal or typical functioning in organs or organ systems. Medical rehabilitation includes these goals when possible but also seeks to reestablish emotional well being, preserve residual function, prevent disabling complications and to develop compensatory functional capacities needed for carrying out daily activities.

Acute care and rehabilitation may be seen as two endpoints across a spectrum or range of goals within health care. In acute care more emphasis is given to cure. In rehabilitation the goal of interventions is "care-driven"—health professionals try to teach patients and their families how best to accommodate to and make the most of the consequences of chronic impairment.

Values play an important role in diagnosis or treatment in rehabilitation. Impairments in speech, vision, learning ability or memory have different meanings for patients who are children, adults who are the sole sources of financial support for others, or those who are in their post-retirement years. The degree to which a particular patient can tolerate pain, cooperate with a treatment plan, or feels handicapped in carrying out certain activities powerfully influences the course of care for each patient. The values of health care professionals and their patients, while not always explicitly acknowledged, are inextricably present at every step in the formulation of treatment plans.

Phrases such as quality of life, ability to work, ability to live on one's own, ability to resume an active life, and independent living, which only occasionally manifest themselves in the emergency

room or intensive care unit, are present at all times in the construction of a diagnosis and the subsequent formulation of a treatment plan in rehabilitation settings. Quality of life considerations play a key role in guiding the course of rehabilitation.

The fact that medical care in rehabilitation is unavoidably value-laden creates a variety of ethical questions of a kind that rarely arise when health care providers and patients agree about the goal of care. Since patients and providers bring different values to the rehabilitation setting and evaluate outcomes differently according to their individual norms, disagreements may arise concerning goals or the priority that ought to be assigned to achieving particular goals.

Disagreement can take many forms; between providers and patient, between patient and family, or among the various members of the rehabilitation team itself. Third-party payers and government officials may also advance values for the provision of rehabilitation, perhaps values that elicit little enthusiasm among providers or patients, i.e., ability to work. Of course patients, families and providers do not always disagree about the goals that ought to guide the formulation of treatment plans. But the absence of a single overriding goal—cure—means that the values of providers, patients and families are more likely to collide in the rehabilitation setting.

An especially important ethical challenge confronting health care providers in rehabilitation settings is to obtain agreement from those in their care as to what abilities and capacities constitute an acceptable quality of life. Patients who place high value on work, on hobbies, on communication, may have goals that are unrealistic or impossible to obtain to a degree consistent with their level of physiological impairment. Providers therefore must not only restore function to the extent possible, but also convince patients to reevaluate functional abilities or capacities in light of irreversible impairment, e.g., using a wheelchair for mobility rather than walking. The process of achieving accommodation between patients, their families and friends, and providers as to what constitutes an acceptable quality of life is one of the most arduous tasks faced by those involved in rehabilitation medicine.

While it is often said that the concept of "quality of life" is too ambiguous to admit of consensus, rehabilitation professionals have little difficulty in identifying central components of this concept. Rehabilitation programs, at least in the initial stages of treatment, stress the importance of the acquisition of skills that will permit independent living, work, and mobility. However, the emphasis placed on these particular goals is very much a function of the social

and economic realities that face those with chronic impairments and disabilities.

In a society that values autonomy and independence and that frowns upon dependence on either charity or assistance from others, great stress must be given to the restoration of physical and social skills that will maximize the prospect for independent living. In a society that emphasizes the importance of work and employment in establishing both personal identity and dignity, efforts must be made to teach adaptive skills that will contribute to the possibility that those of non-retirement age will be able to find some sort of remunerative employment.

Obviously, the values expressed in the ways in which the quality of life is understood in rehabilitation are highly sensitive to existing social mores and attitudes. One of the major, if relatively unexamined, ethical challenges facing those in rehabilitation is the degree to which they must orient their treatment regimens to reflect the realities that confront those who have various degrees of functional impairment.

Should rehabilitation specialists try to restore mobility to persons who ultimately must return to a world not readily accessible to those who rely upon canes or wheelchairs? Should rehabilitation specialists stress the value of work in designing treatment plans for patients for whom employment may not be of great personal value? And ought rehabilitation specialists advocate the availability of more assistance to those who are homebound rather than to teach people to live as independently as they can without the assistance of others?

Because many of the disabilities requiring medical rehabilitation are preventable, professionals also may have an obligation to take an advocacy role concerning the prevention of impairment, e.g., helmet laws, the use of air bags in automobiles, the installation of special lanes for bicycles on city streets. While acute health care professionals are appropriately concerned with prevention, the obligation for rehabilitation professionals appears to be especially compelling.

The Selection of Patients

Decisions to Admit Patients to Rehabilitation

One of the most distinctive aspects of rehabilitation in the United States is that practitioners choose their patients. Disabled Americans are not, in general, entitled to reimbursement for rehabilitative care. Nevertheless, historically, the supply of such care has fallen short of the demand for it. Clinical practitioners faced with the reality of a

demand that exceeds supply have had to review potential patients in order to select those who would receive treatment.

Generally speaking, decisions as to whether rehabilitation will be initiated involve a two stage process. Most of those who receive rehabilitative care are referred by physicians practicing in acute care settings. Once a referral is made, a decision must then be made as to whether a patient is an appropriate candidate for rehabilitation.

Some physicians do not consider rehabilitation as an option with the result that physiatrists are not always given the opportunity to consider the possibility of transferring a patient to a rehabilitative setting. The selection is difficult to challenge either by the patient or members of the rehabilitation team since no formal mechanisms exist for review of decisions at this stage of the rehabilitation process.

Once a referral has been made, it is usually a physiatrist who screens potential candidates for rehabilitation. The information used to make initiation of treatment decisions is derived from patient records, consultation with other physicians who have already treated the patient in acute or emergency settings, and usually, but not necessarily, direct physical examination of the candidate. Unfortunately, communication between physicians in acute and rehabilitation settings is not always as comprehensive as it ought to be.

When referrals are made, physiatrists consider a variety of medical and nonmedical factors in determining whether or not to initiate rehabilitation. In the area of nonmedical factors, potential candidates will have their financial and insurance status reviewed by administrative personnel. Social workers may review a potential candidate's family or social situation. The primary reason for such an assessment is to insure that the disposition of the patient will not be a problem once rehabilitation has been completed.

Among medical factors, diagnosis and prognosis are paramount considerations. Some physicians believe that persons with particular types of impairments, such as those resulting from stroke or spinal cord injuries, are likely to demonstrate functional gains from rehabilitation. Other diseases such as Alzheimer's or terminal stages of cancer are viewed by some as being less amenable to successful intervention and therefore of lower priority in access to treatment.

Relatively minor impairments in cognitive or sensory capacities may be given great weight since these deficits may significantly impair the patient's ability to participate in a rehabilitation program. Or the physician may believe that the degree of effort and amount of resources necessary to help patients

cope with cognitive or sensory dysfunction may be so large as to diminish the availability of resources for other patients.

It is clear that the field of rehabilitation must make a concerted effort to subject its practices and techniques to carefully controlled clinical trials.

Other factors that bear on decisions to initiate care are: the amount of progress that a patient is likely to be able to make, the age of the patient, and the ability to learn. Patients who are seen as capable of achieving great improvement, even if they begin with high degrees of dysfunction, are likely to be given preference in access over other patients for whom the level of improvement that is possible may be less even if they initially start with higher degrees of function.

Age is viewed as relevant for two reasons. First, younger patients are believed to have greater capacities for regaining lost function simply as a result of greater physiological malleability. Second, younger patients may receive priority over older patients in receiving access to rehabilitative care on the grounds that the net benefits are likely to be greater in terms of length and quality of life. This is so for the simple reason that younger candidates will, in all likelihood, live longer than older candidates.

Some third-party payers require that patients seeking admission to rehabilitation programs demonstrate "vocational potential." They believe that such an ability must be present since part of the overall goal of treatment in some facilities is the restoration of the ability to work.

The ability to pay is a powerful determinant of access to services. Institutions often convey information to admitting physicians as to the financial needs of the hospital. Unless a facility receives public funds, financial clearance is a necessary first step for admission at many facilities.

Some facilities do designate a few beds as "Medicaid beds." Once these are filled, no other Medicaid dependent patients are admitted. Institutions may also wish physicians to give preference in admissions to those with more comprehensive forms of insurance or those for whom discharge is unlikely to be a problem. Institutions providing rehabilitation services are accorded a wide degree of authority concerning admissions by government and regulatory agencies.

The dominant factors that seem to guide physicians in the admissions process are efficiency, potential for benefit, potential for success, the anticipated burden that will be placed on staff members in the provision of care, and the ability to pay. The way in which these factors are applied varies greatly from physician to physician and facility to facility.

The degree of freedom accorded providers to make judgments regarding access to rehabilitation carries with it the danger that subjectivity or bias may enter into the decision. Physicians have enormous discretion in making admissions decisions since there is no formal, or public set of criteria governing the decisions that are made. Few checks and balances exist to modulate the effects of personal or professional bias.

Patients may not be told about the reasons for their rejection by particular facilities. Sometimes when reasons are given they are not always accurate or complete.

It is clear that the field of rehabilitation must make a concerted effort to subject its practices and techniques to carefully controlled clinical trials. Those involved in making admissions decisions must be encouraged to provide written documentation of their decisions and the reasons for them. Periodically, such information ought to be made available to other members of the rehabilitation team for assessment and discussion. Greater efforts must be made to study the admissions process and to communicate the factors involved to the public. This information would help explain why candidates are or are not accepted at particular facilities. It might also provide a necessary system of checks and balances to assure those in need of care that they have an equitable opportunity to receive it.

Decisions to Initiate a Specific Course of Care

Those admitted for a course of care in medical rehabilitation settings are frequently advised that they must take an active role in determining the goals of their treatment. Candidates are usually eager to participate in the formulation of a treatment plan that meets their own desires and values. This is especially so since most patients come from acute care settings where they have occupied an essentially passive role vis-à-vis their own treatment.

Team members approach the initial determination of goals with different assumptions from patients and their families. Professionals are keenly aware of the central importance of patients adjusting to the realities imposed by impairment. However, to some extent the nature of these realities are products of economic, social, and physical constraints that

able-bodied society imposes upon those who have impairments.

The desirability of involving patients in taking responsibility for their own treatment is necessarily tempered by the recognition that society is not always willing to provide the social, architectural, recreational, and vocational resources that would allow those with impairments to take full advantage of their abilities and capacities. To date, in some facilities, the practice of rehabilitation is characterized by a willingness to accept the constraints imposed by society and to initiate courses of treatment that reflect these boundaries. But it is not clear that patients ought to be persuaded to accept such limits or to what extent persuasion lapses over into coercion in attempting to formulate a treatment plan to which provider and patient can both agree.

In some facilities patients are encouraged and taught to be advocates for their interests, to agitate for changes in social and public policy through community involvement. But in other institutions little concern is manifest for coping with or modifying the social and economic barriers that those with disabilities often face upon discharge from a rehabilitation setting.

Ethical Issues In Provider/Patient Relationships

The nature of the moral rules and principles that ought to govern relationships between health care providers and their patients is one that has received a great deal of attention in the literature of bioethics. Most of the discussion of provider/patient relationships presumes a situation in which a physician is the sole provider of care. It is also presumed that each patient must reach some accommodation with his or her physician as to the type and intensity of care that will be given.

In the interaction between doctor and patient, ethical questions arise regarding what moral rules ought to govern the exchange of information and, ultimately, the provision of services by the physician to the patient. Central to the moral dimensions of this relationship are such topics as truth-telling, informed consent, privacy, confidentiality, and the responsibility to continue care once a relationship has been initiated.

The Traditional Model: Medical Paternalism

Historically, discussions of the ethics of provider/patient relationships presumed a relationship between a treating physician and a patient seeking care. The medical profession articulated a number of codes of conduct intended to provide guidance as to physician responsibilities in providing care.

The moral requirements reflected in documents as diverse as the Hippocratic Oath and the American Medical Association's *Principles of Medical Ethics* enjoined physicians to act only so as to "benefit" patients and to "do no harm" or "keep patients from harm." Physicians were held to be bound by the principles of beneficence, the duty to help those in need, and nonmaleficence, the duty not to harm those seeking care. These principles were seen as sufficient for constituting the framework within which physicians and patients ought to interact.

On this model, which dominated the practice of medicine well into the twentieth century, physicians made decisions about what care was in the patient's best interest. Patients had the right to end a medical relationship, but physicians were obligated to provide patients only with information that, in their medical judgment, they needed to know.

Medical paternalism casts the physician in the role of the zealous advocate of the patient's best interests. It is the physician who is in the best position, as a consequence of specialized knowledge, skills and clinical experience, to determine which medical interventions are most appropriate.

The Contractual Model

A number of critics of medical paternalism, both within and outside of medicine, have argued for a more egalitarian model of physician/patient relationships. They believe that physician/patient relationships ought to be seen as based upon a contract between parties who are on an equal footing.

On the contractual model of doctor/patient relationships, physicians are morally responsible for providing care, but only such care as is desired or requested by patients. The desire to be beneficent in the provision of medical care is, on the contractual model of physician/patient relationships, limited by respect for the autonomy of individual patients. Patients may, if they choose, reject care that is known to be beneficial as long as such refusals are based upon voluntary informed choice.

The doctrine that has emerged as the guarantee of individual patient autonomy on the contractual model is informed consent. Patients have an absolute right to make informed choices about the kind and degree of care they wish to receive. While physicians are under no obligation to comply with the wishes of patients when they are at variance with their reasonable medical judgment, they cannot undertake any interventions without the express permission of the patient.

American courts have, in the past thirty years, shown a willingness to codify the right of patients

to retain authority over their medical care. A number of state courts have explicitly acknowledged that patients have a right to be informed of the risks and benefits associated with various courses of medical care. In most court cases, the standard of informed consent has been interpreted as what a reasonable patient would want to know.

As the contractual model has come to have greater significance in medicine, there has been a steady shift in clinical practice toward the recognition of a presumptive duty to share information about diagnoses and prognoses with patients. If it is true that patients ought to have the right to control their medical care, if respect for autonomy carries more moral weight than the obligation of beneficence when these moral principles come into conflict, then patients have a right to know and physicians a duty to tell the truth.

If a patient is mentally competent, as reflected in an ability to understand and deliberate about information concerning the risks, benefits and consequences of medical treatment or the failure to initiate treatment, then patients have the right to make choices about each and every aspect of their medical care. Differences of opinion between patient and physician are not in and of themselves sufficient grounds for challenging patient competency.

The contractual model of physician/patient interrelationships assigns a high value to confidentiality and privacy. It is the patient who can and should decide who will have access, if anyone may, to information about his or her diagnosis and medical care.

Does the Contractual Model Apply in Rehabilitation?

Informed consent is a much more problematic concept in the context of rehabilitation. While health care providers in the field of rehabilitation recognize the importance of informed consent in principle, in practice they are not always thorough in their efforts to obtain consent.

For example, in some cases a patient may sign a consent form for surgery or the provision of medications as a part of the development of a treatment plan in rehabilitation, but never be asked to provide consent for such interventions as physical therapy, occupational therapy, or vocational counseling. Consent may be obtained early on in the course of rehabilitative care for a particular treatment regimen, but, although such care may extend over months or years, no further attempts may be made to reaffirm patient consent.

The contractual model of informed consent takes the one-on-one relationship between a physician

and a patient as paradigmatic of medical practice. But in rehabilitation patients rarely receive care from a single physician. Candidates must deal with a host of health care providers of differing backgrounds, types of expertise and personal values. It is not surprising that the contractual model and its linchpin, the doctrine of informed consent, encounter practical difficulties given such a complex set of provider/patient relationships.

It has been noted already that patients and their families must assume active roles in the provision of care if the efforts of rehabilitation specialists are to be maximally efficacious. Provider/patient relationships must, as a result, reflect the involvement of third parties—spouses, children, parents, friends, etc.—whose role is simply not acknowledged in the contractual view of provider/patient relationships. Issues of privacy and confidentiality are made far more complex by the practical realities associated with the involvement of many parties, both medical and nonmedical, in the provision of care.

Moreover, many professionals in rehabilitation would readily acknowledge the priority that ought to be accorded the principle of respect for patient autonomy. But their clinical experience with patients who have suffered severely disabling injuries or diseases makes them skeptical about the ability patients possess to make informed, deliberative and reasoned choices concerning the risks and benefits of treatment.

The competency of patients in the earliest stages of rehabilitative care is called into question on three grounds. First, many rehabilitation professionals do not believe that patients can fully appreciate the risks and benefits of rehabilitative care. They will note that it may take weeks or even months for a patient to begin to understand the ways in which rehabilitation may make it possible to cope with severe disability.

Second, even when there is no doubt that patients who are entering a rehabilitation program are mentally and emotionally competent, experienced clinicians may still be reluctant to honor patient initiated refusals of care. It is not clear that a person who has lost the use of his or her limbs, cannot speak or be understood, or who has been disfigured by a burn or other injury can immediately adjust to the challenge to self-identity implicit in irreversibly disabling injury or disease.

Third, surrogate decision makers such as a spouse or parent have a similar problem adjusting to the patient's new identity and future limitations. From experience rehabilitation specialists have noted that even family members cannot project what the patient's wishes will be in the months and years ahead. The fact that most patients who initially refuse

care change their minds and begin to participate actively in rehabilitation therapy makes many rehabilitation specialists reluctant to honor the choices and requests that patients or their families make at the beginning of a course of rehabilitation. Time must be given for those who suddenly find themselves impaired or disabled to absorb the reality of disability into their sense of personal identity.

The contractual model presumes that the patient is both competent to make rational decisions and willing to do so. Rehabilitation professionals are often faced with the challenge of trying to restore or encourage autonomous behavior in patients who are depressed or demoralized by the severity of their impairments. The trauma of sudden, severe, and incurable disability leaves some patients emotionally unwilling to try and make decisions for themselves even though they retain the cognitive capacities to do so.

The capacity for free, voluntary choices may have to be facilitated in patients since it may be unrealistic to expect such capacities to be present in those who have suffered grievous and irreversible impairments. The challenge facing medical professionals in rehabilitation is frequently not how to respect autonomy, or whether to obtain informed consent at every stage in the rehabilitative process but, rather, what steps and activities, and with what degree of persuasion or even coercion, are morally permissible in the hope of restoring autonomy.

Moreover a greater latitude in physician paternalism seems justified when physicians and other health care providers know from previous clinical experience that a process of accommodation and acceptance is necessary in order to allow patients to come to grips with the reality of irreversible impairments. The fact that time is essential in allowing patients to accommodate to the reality of impairment is further confirmed by the fact that some patients report the need to undergo just such a cooling off or accommodation process in learning to accept chronic impairments resulting from disease or injuries.

The Educational Model

Thus the contractual model is difficult to implement for all patients in all phases of rehabilitation. The contractual model is strongly linked to the provision of a highly specific course of care at a specific time by a physician. The concreteness and time-frame presumed within the model are rarely present within rehabilitation.

Provider/patient interactions in rehabilitation require a model of care that is sensitive to the evolving capacities and adaptations that take place

between providers and patients over long periods of time.

An "educational model" might be more appropriate to the rehabilitation setting. On such a model, health care providers are allowed more leeway in the initial phases of care to act in a parental manner toward certain patients. They have the right to initially ignore or override patient or family choices concerning the course of care for those who are suddenly or unexpectedly severely impaired in the interest of restoring or maximizing the long-term autonomy of rehabilitation candidates.

If autonomy consists of the ability to make informed, voluntary choices about the course and direction of one's own life then it is necessary for persons to understand fully the options and opportunities that are available to them. When the onset of impairment is sudden and unexpected, it may take time for persons and their families and friends to comprehend and adapt to the reality of their condition. While such persons may be competent to make decisions, they may not fully understand or be prepared to listen to the information that health care providers or those with impairments wish to convey. In this sense, it may be necessary to allow for an infringement of autonomy in the short run in order to insure that subsequent choices are truly reflective of informed, voluntary deliberation.

This means that for some patients the initial stages of rehabilitation are sometimes characterized by paternalistic interventions that would be viewed as ethically unacceptable in the light of prevailing analyses of the ethics of provider/patient relationships. At the same time, this model requires that mechanisms be created for monitoring the capacities and abilities of patients to make autonomous choices and that provisions be created for restoring autonomous control to patients once they have had the opportunity to accommodate themselves to the realities of chronic impairment and disability.

One such mechanism might consist of regularly scheduled meetings between patients, families and team members in order to assure constant feedback between professional points of view and patient perspectives. Another might be the creation of an independent committee to review the course of care for every patient in a rehabilitation setting in order to ensure that confidentiality, privacy, and autonomy are respected to a degree consistent with maximal accommodation to chronic impairment.

An educational model will require health care professionals to state clearly to patients upon acceptance into a rehabilitation program that they will be interacting with a diverse team of health care professionals who share responsibility for the

formulation of treatment goals and the monitoring of progress toward meeting these goals. Patients and their families must understand that rehabilitation teams are less hierarchical in their sharing of responsibility and authority than is the case in other areas of health care. At the same time, patients must understand who is responsible at any given time for coordinating the efforts of the team and who holds ultimate responsibility for team management.

Patients should be informed that they have the right to request changes in the composition of the team to the extent that is practically possible in light of constraints on resources and the needs of other patients. They must also recognize that from the start of a rehabilitation program, other persons including family members will have access to information about their diagnosis and prognosis. Agreement should be reached on the degree to which family members will be given a say in the direction of treatment plans and the rationale for such involvement.

Patients also must understand that confidentiality and privacy will be protected but that the realities of a team approach to care require that many persons have access to patient diagnoses and records. The rights of third-party payers to request information concerning the course of care, including psychosocial information, must be explained clearly to both patients and their families.

Patients also should be told that team members must make determinations concerning access to care and the termination of care that are sensitive to the needs of other patients. They should understand as soon as they are capable of doing so that their continuation in a treatment program will depend in part on factors that go beyond the question of whether further benefits can be obtained by the continuation of rehabilitation efforts. They also should be told about the nature of their rights to request continuation of care and the options that are available to them to seek care from other providers in other settings.

The model proposed here is one of an evolving relationship between providers and patients. Its scope is restricted to those patients who have no prior experience with impairment or disability. Its earliest stages are characterized by assigning a higher priority to beneficence than to respect for autonomy. The model requires, however, that efforts to identify and assess levels of competency and autonomy be ongoing and zealous; once it is clear that patients have had an opportunity to accommodate to the realities of their functional impairments, their right to control the direction and composition of their rehabilitative care will be restored to them to the extent consistent with the overall needs of

other patients requiring the services of the rehabilitation team.

Implications of An Educational Model: The Termination of Treatment

One of the most controversial issues in all of bioethics is that of when, if ever, treatment ought to be withdrawn from patients. In the context of acute medical care, ethical discussions focus on the authority that patients should have to refuse treatment, the ways in which competency will be determined in deciding whether to honor patient directives that treatment be withdrawn or foregone, the definition of what constitutes a medical treatment and the type of procedural review and oversight necessary for protecting patient interests and welfare where termination of treatment decisions are being considered.

In rehabilitation medicine, decisions to terminate care for a patient are usually made without the pressure of time that constrains those decision-makers in acute or emergency settings. Once a course of rehabilitation therapy has been initiated, there is usually time to discuss and reflect upon questions concerning the termination of treatment.

Termination of care in the rehabilitation context frequently involve decisions about when to transfer a patient from an acute rehabilitation unit or specialized institution to another setting. Once treatment has started, the vast majority of termination of treatment decisions arise when professionals believe that further gains in the restoration of function are not likely within a particular institutional setting or in the context of a particular course of therapy.

The paradigmatic models of termination of treatment decisions in the literature of bioethics are those cases where competent or incompetent patients diagnosed as terminally ill request the withdrawal of various forms of life-supporting technologies such as respirators, antibiotics, cardiopulmonary resuscitation, or the provision of food and fluids. Much of the ethical discussion has focussed on the basis for determining the competency of patients to make such requests. In cases where patients are manifestly incompetent, then moral debate centers on the questions of who should make decisions to withdraw life-supporting technologies and what standards should guide decision-makers faced with such choices.

The single most distinctive feature of termination of treatment decisions in rehabilitation medicine is that they are almost always initiated by health care professionals rather than by patients or their families. Indeed, just as patients are often unaware

of decisions concerning their admissibility for a course of rehabilitative care, they are usually not actively involved in the initial decision to consider the matter of terminating care. Increasingly, financial constraints such as limits on insurance coverage or pressures to utilize scarce resources for other patients are the catalysts that compel a rehabilitation professional to consider ending care for a particular patient.

The premiere criterion for guiding decisions concerning the termination of care on the part of rehabilitation professionals is whether a patient has reached a "plateau" in terms of progress toward the goals in his or her treatment plan. Patients in institutional rehabilitation settings are expected to make constant and steady progress toward attaining the goals established by the rehabilitation team. When progress slows significantly—for example, when a patient has regained a significant degree of mobility in a particular joint—members of the health care team may raise questions as to whether further efforts at therapy are worthwhile.

The concept of plateauing is one that seems particularly unique to rehabilitation medicine. Few medical specialties attempt to assess the desirability of continuing medical treatment on the basis of either the rate of progress that patients demonstrate or the degree of progress likely to be obtained if care is continued.

The fact that termination of treatment decisions are usually triggered by professional assessments of progress rather than patient requests means that the moral judgments and values of the members of the rehabilitation team play an extremely important role in the determination of whether plateauing has occurred. Values enter into such determinations in a variety of ways.

If a patient is viewed as non-compliant, poorly motivated, or as having unmanageable behavioral or emotional problems, the rehabilitation team may decide to examine plateauing. Those patients whose financial resources are limited may reach a plateau sooner than other patients who are enjoying similar rates of progress, but have greater financial resources available. The subjective judgments of team members about the ability of a patient to cope with impairments outside the rehabilitation setting strongly influence the kinds of assessments made about the rate of progress of the patient.

One of the major ethical flaws in the current procedures followed by many rehabilitation teams for assessing patient progress is a failure to inform patients and their families in a thorough and clear manner about the criteria used to decide when rehabilitative care should end in a particular setting. More specifically, patients and their families

frequently do not fully understand the kinds of progress and the rates of progress that are viewed by professionals as requisite and sufficient for the continuation of care. Nor are patients and their families always aware of financial considerations or that constraints on the availability of resources may and probably will play a role in decisions as to when the rate of progress shown by a patient no longer justifies the continuation of further efforts at rehabilitation.

The single most distinctive feature of termination of treatment decisions in rehabilitation medicine is that they are almost always initiated by health care professionals rather than by patients or their families.

The failure to inform patients fully about the factors that prompt consideration of termination of treatment decisions among members of the rehabilitation team, the lines of responsibility and authority among team members in making evaluations of progress toward treatment goals and the kind of evidence used to assess the desirability of continuing care leaves patients and their families in an especially vulnerable position.

An educational model of professional/patient relationships allows professionals a great deal of discretion early on in the course of treatment of some patients. Such a model permits the initiation of care for brief periods of time for those who initially refuse care, on the grounds that early intervention is critical to the efficacy of rehabilitation interventions, and that many patients need time to accommodate to the possibilities and opportunities associated with permanent impairments of physical or cognitive functioning.

But the educational model requires that health care professionals strive to restore autonomy to patients as rapidly as they can. Rehabilitation professionals must devise procedures whereby authentic autonomous choices can be recognized and heeded after a reasonable period of time has passed to allow patients to accommodate to the reality of incurable impairment. There is no ethical justification on this model, and certainly not in the standard view of professional/patient relationships, for excluding competent patients from any aspect of the decision-making process surrounding the termination of care in rehabilitation.

Indeed, rehabilitation professionals have a strong moral duty to seek actively the involvement of patients and their families in decisions to end care, particularly since such decisions are almost always

arrived at through the assessments and concerns of team members rather than patient requests. If rehabilitation professionals are the only persons who can monitor and assess patient progress, then surely patients have a right to know exactly what standard or standards will be used for making such determinations and the sorts of evidence that will be brought to bear in deciding whether the standard has been satisfied.

Efforts to enhance informed participation by patients and their families in termination of treatment decisions must be supplemented by efforts on the part of rehabilitation teams to systematically collect and document information concerning patient progress and plateauing. In many instances, the data that initiates discussions of stopping care rests upon statements or claims made at weekly patient conferences or in casual conversations among team members. Decisions to stop care are too important to leave to informal or casual mechanisms.

Family Duties and Rights

Family members play crucial roles in rehabilitation medicine. In the earliest phases of rehabilitation, the presence of a secure and stable spouse or family is often a critical variable in influencing rehabilitation professionals' decisions concerning the selection of patients for a course of rehabilitation therapy. When decisions are made to terminate care they are often influenced by a patient's willingness or eagerness to return to his or her family and by the family's willingness to undertake care for the patient in the home.

The pivotal role assigned to family members in the rehabilitation process raises important challenges to current perceptions of confidentiality and privacy in medical ethics. Most analyses of confidentiality and privacy maintain that information concerning diagnosis and prognosis is not to be shared with third parties, including family members, unless and until explicit permission has been sought and granted from a patient. But the amount of time involved in the usual course of medical rehabilitation and the important roles that family members are asked or seek to play may require rehabilitation professionals to disclose information to family members in a manner that in other contexts would be considered at best inadvisable and at worst unethical.

The prominent role accorded family members imposes special obligations on rehabilitation professionals. They must make every effort early on in the course of care to identify the nature of the relationships that exist between patients and their

families. They must try to ascertain which family members, if any, have ongoing relationships of intimacy and trust with a patient. If patients have close bonds with family members, they should be informed that, for various reasons, it may prove necessary to share information about their diagnosis and prognosis with such individuals. At the same time, family members must be given honest and accurate information about the roles they may be asked to play during the course of rehabilitative care and the choices they will face at the conclusion of rehabilitation efforts.

The need to clarify the moral framework that ought to guide the relationships team members have with patients and their families is made more acute by recent discussions about the desirability of shifting the provision of medical rehabilitation for many patients from institutional to home settings. The desirability of home care seems to rest on three separate ethical values.

First, patients themselves often prefer to reside at home rather than in institutional settings. Second, rehabilitation professionals believe that patient autonomy is enhanced by early discharge to home settings. There is a fear that patients who remain too long in institutional settings will find it more difficult to adjust to life outside the institution. And third, the provision of rehabilitative services in the home or to those who live at home may prove to be an attractive way to reduce the costs associated with hospital or institutional care.

Economic considerations have dominated public policy discussions of the desirability of home care in rehabilitation. Since there are few carefully designed empirical studies of the impact of home care on patient functioning and satisfaction, and since it is, in any event, difficult to know how much weight to assign patient preferences with respect to the setting in which care is delivered, public discourse about the role of families tends to revolve around cost/benefit projections of the savings to be obtained either by discharging patients home more quickly or by delivering services customarily given in hospitals or institutions on an outpatient, ambulatory basis. The level of interest present in professional and public policy discussions in delivering more services in the home or to those who reside at home makes it imperative that the nature and source of moral obligations of family members to provide care be carefully examined.

Despite the diversity of opinions and values that exist in American society about the importance of the family and the obligations, rights and responsibilities that inhere in this social institution, there is widespread consensus as to the existence of an obligation on the part of family members to assist

each other when the need for help exists. Parents are expected to help their young children, children are viewed as responsible for providing for the welfare of their elderly parents, and spouses are seen as responsible for assisting each other when problems, medical or otherwise, arise.

The vexing moral dilemma in thinking about familial obligations is not whether a moral foundation is present to ground minimal obligations between family members, but what limits can be set on the degree of obligation family members have. Are there boundaries beyond which health care professionals or public officials cannot in good conscience expect a family member to go? Are there certain tasks so onerous that no policy-maker could legitimately expect a family to feel obligated to undertake, much less for the state to mandate or enforce their discharge? And even if a mother or a husband were willing to care at home for a family member requiring long and arduous rehabilitative care as a consequence of injury to the spinal cord or massive burns, are there certain tasks that ought not to be asked of anyone by health professionals or those who formulate public policy?

The question of the limits, if any, which constrain the obligations of family members to help one another forces a confrontation with the question of whether the relationships that family members have with each other are special or unique. An important psychological reality associated with membership in a loving family or family-like relationship is that membership in a family, either through birth or adoption, or as a result of a voluntary choice as exemplified in marriage, or the decision to reside with another person over a sustained length of time, creates a unique form of interdependency.

Those who have permanent impairments as a result of injuries, diseases or congenital anomalies often require the help of others. Frequently, this assistance can and, if special skill or expertise is required, must be provided by health care professionals. But for those who have long-standing, intimate relationships, there comes a time when the provision of care by strangers will not suffice. For those who are members of families require not only care but care provided by particular persons—the members of their family.

If it is true that patients who have loving relationships with others depend upon family efforts to enhance their chances of gaining access to care, for encouragement in carrying out their treatments, and for assistance once their treatment regimen has ended, then the degree of obligation consonant with family membership is complicated by the special needs those with chronic impairments have to be

accepted and cared for by their families. Those with chronic impairment need to regain more than physical or cognitive abilities. They also need to restore their emotional attachments. As a result, the families and friends of those with chronic impairments face unique demands of concern and affection that only they can fulfill.

It is difficult to imagine any theory of morality imposing demands upon family members that are so burdensome as to make the continuation of the family impossible. Similarly, it is difficult to imagine a moral argument that would make it obligatory for a family member to sacrifice everything, all projects, all prospects of personal enjoyment, all fiscal and emotional resources to meet the needs of another member. In great measure, the limits of family obligation are determined by the degree of sacrifice that an obligation imposes on an individual or the threat it poses to the integrity of the family as a whole.

Once it is admitted that family members can meet certain needs that rehabilitation patients have and that they are the only persons who can meet them, certain ethical implications would seem to follow. While health care professionals should not expect moral heroism from families, they do need to explain to them the unique capability they possess in providing care to those with chronic impairment. The capacity of family members to care for their loved ones also would allow for greater degrees of moral suasion on the part of rehabilitation professionals to elicit the sense of obligation to help that family members feel.

At the same time, if family members are to play pivotal roles in the provision of care to those requiring ongoing rehabilitation, then society has a duty to minimize the level of burden imposed on family members who wish to fulfill their obligations to those who need their care. Family members are often willing and eager to help. But their goodwill should not be used as a rationale to avoid allocating insufficient societal resources.

Family members who are called upon to aid patients discharged from institutional rehabilitation settings need both financial and psychological support services. Moreover, it is appropriate for the community to recognize their efforts to fulfill their moral obligations. The provision of services to families may entail costs that make home care a less attractive alternative in the eyes of some public officials. But, rehabilitation professionals who believe that the home is the best setting for enhancing the autonomy of patients and their quality of life should attend to the ethical implications such an approach has for families rather than the financial consequences for society.

Professional and Practice Issues

As previously noted, rehabilitation is unique in the delivery of care by a team of professionals. The utilization of teams of professionals gained popularity during and after World War II. The underlying rationale was that a team approach would provide better coordinated and more comprehensive care than could be given by individual professionals acting independently.

Proponents of a team approach also argued that this form of the delivery of care would result in a more efficient utilization of services. Schedules could be organized and resources provided more efficiently if health care professionals coordinated their efforts.

Finally, a team approach, in which members shared responsibility for care, was seen as consistent with the interdisciplinary, multiprofessional requirements of rehabilitative programs directed toward all aspects of the patient. The members of a team who shared responsibilities for care were likely to have greater respect for the expertise and skills of colleagues than was evident in more traditional, physician-dominated health care.

Teams and Patient Care

One of the more potentially confusing aspects of rehabilitation for new patients and their families is learning to adjust to the interdisciplinary approach used in the delivery of care. Patients usually enter rehabilitation from acute care settings. While many professionals participate in the care of patients in acute care settings, ultimately treatment is directed by a particular physician who is seen as responsible for the quality of care that is provided.

Patients admitted as candidates into rehabilitation programs must readjust their expectations and attitudes to accommodate the commitment of health care professionals to a less hierarchical, coordinated team approach. Patients and their families may not understand who is in charge of their care, or may want to impose a particular conception of professional accountability upon a group of health care providers who are committed to a different manner of providing care. Unfortunately, not all rehabilitation teams are as conscientious as they should be in educating patients, families and friends about the organization and structure of team-based care.

In addition, not all teams function in the same way in rehabilitation. Some operate with a physiatrist who acts as a kind of "captain" of the team. Others attempt a more egalitarian sharing of responsibility among team members with shared authority and accountability for decision-making. Patients may

seek to ally themselves with one or another member of the team. In doing so, they may provoke friction among the team itself depending upon the style of management that predominates in a given setting. Team members should be willing to accommodate their preferred style of team management to the desires of particular patients to the extent that the ability of the team to provide care for other patients is not affected adversely.

The members of a successfully functioning team inevitably develop strong feelings of loyalty to other team members. These are individuals who must work closely with one another over long periods of time, and it is natural that when this work is done well fidelity to one's colleagues is both expected and desired.

However, team loyalty poses potential ethical problems for team/patient relationships. Whereas health care professionals in many domains of health care see part of their professional responsibility as acting as monitors of the overall quality of care being provided to patients, it may be very difficult for the member of a team to pursue this objective within the context of a team. Team members may be viewed as disloyal or unethical if they raise issues about the competency of team members or the adequacy of a treatment plan directly with patients. Patients may expect that, if the members of a team say they are to be treated as co-equals in terms of their responsibility for care, they will be able to interact with the team by selecting anyone of the team's members as their advocate, when in fact this may not be so.

Another distinctive aspect of team care is the role team members assign to themselves as providers of care. Health care professionals in rehabilitation often say that they see themselves as educators, teachers, or guides in helping their patients undergo treatment.

But the emphasis upon patient responsibility inherent in the role of teacher or guide is not always consistent with the bureaucratic and efficiency requirements of effectively coordinating the activities of a large number of people. Patients may be told that they must set their own goals and strive to fulfill them, but it is also true that they must do so within the constraints of a team responsible for meeting the health care needs of many patients.

Patients in some rehabilitation units or specialized institutional facilities often are placed on fairly rigid schedules. There are almost always institutional policies governing such areas of daily living as eating, smoking, dressing, television viewing, exercise, and visiting hours that admit of little if any modification or individualization. Despite the fact that team members pride themselves on providing care to the

whole patient in an individualized manner that relies on the active participation of patients, many social and economic factors associated with the provision of care by large groups of people in institutional settings are at odds with these aspirations. There is an inevitable tension, exacerbated in recent years by growing concerns about the need to control the high cost of health care, between the desire to have patients take responsibility for their own care, and institutional interests in seeing that care is provided in a manner that is efficient and cost-effective.

Team-based care may well be the most useful mode for delivering the services of large numbers of professionals to individual patients. But those in rehabilitation must be careful not to allow the rhetoric that surrounds the justification of a team approach to obscure some of the tensions that arise when the desire to maximize patient responsibility and participation come into conflict with the need to provide services in an efficient manner.

Interprofessional Issues

Conflicts about the lines of authority between professionals and patients are not the only ethical problems that arise when care is delivered by a team. Inevitably, conflicts of authority and responsibility arise between various members of the team. While ideally teams should function as tightly coordinated groups providing multifaceted individualized courses of treatment, this ideal can be compromised when team members disagree as to the goals appropriate for particular patients or when different members of the team set different priorities among the various goals appropriate for particular patients.

Conflicts between team members over scheduling of treatments, rest periods and free time are a frequent occurrence in rehabilitation facilities. When patients arrive late for appointments or when therapists cancel sessions at the last minute, resentments can arise among team members.

Professional responsibility requires that individual professionals resolve their interprofessional conflicts in light of the needs and interests of their patients. Teams must therefore have administrative mechanisms for the rapid identification and resolution of interprofessional conflict. More importantly, they must routinize these mechanisms so that problems are not allowed to fester in ways that compromise the access patients have to treatment or the quality of care they receive. Team members have an ethical obligation to insure that all members are accountable for their actions to the entire team and a responsibility to insure that effective administrative mechanisms exist for insuring accountability. Each member of the team must be prepared to instigate

discussion and review of individual professional behavior when it is at variance with their perception of the care that is in a particular patient's best interest.

Resource Allocation for Medical Rehabilitation

The ethical issues arising at the level of public policy with respect to rehabilitation are no less complex than exist in other areas of health care. With nearly thirty million Americans claiming some level of disability or handicapping condition, and one in ten Americans under retirement age claiming a level of disability sufficient to impair their ability to work, the potential pool of rehabilitation patients is enormous. While precise numbers are difficult to obtain, the number of persons actually receiving medical rehabilitation services is far below the number who might benefit from access to care.

The issue of access is complicated by the high costs associated with providing medical treatment to those with severely disabling injuries or diseases. For example, the average costs associated with the medical rehabilitation of patients who have permanent impairments as a result of head or spinal cord injuries is one hundred thousand dollars. Since there are at least fifty thousand new cases each year of permanently disabling head or spinal cord trauma, the costs associated with rehabilitation for these patients are at least five billion dollars every year. Additional costs are incurred as a result of loss of wages and the need to provide social and income support.

While precise numbers are difficult to obtain, the number of persons actually receiving medical rehabilitation services is far below the number who might benefit from access to care.

As more and more individuals survive spinal cord injuries, head trauma, the life-threatening risks of congenital anomalies and prematurity at birth, as a larger and larger proportion of the American population lives into their seventies, eighties and nineties, the demand for rehabilitation services will continue to escalate. To date, medicine and society have not openly grappled with the moral question of whether those who are rescued or saved by acute care medicine have a legitimate claim to receive the follow-up rehabilitative services that will enhance their capacity to cope with disability. However, whether a decision to rescue does or does not confer a right on the part of those who are saved to an

adequate level of follow-up care, it would seem to make sense on utilitarian grounds to insure that efforts at acute care are coordinated with adequate levels of medical rehabilitation.

In recent years rehabilitation hospitals and long-term care facilities have been exempt from some of the efforts to control the escalation of health care costs. They have been specifically excluded from the newly created prospective payment schemes in public and private health insurance. However, as the number of public and private facilities claiming to offer rehabilitative services has escalated, perhaps in response to the perception that greater profits can be earned in the context of rehabilitation than are available in other domains of health care, pressure has grown on those who administer federal health care programs such as Medicare to include rehabilitation as a part of prospective payment. Many rehabilitation professionals are deeply concerned that a reimbursement system designed to meet the contingencies of acute care practice can only be implemented in the context of treating those with chronic disabilities by compromising the quality of care that is provided.

In order to secure increases in public funding, those who would argue that society has failed in its obligation to provide adequate access to minimal levels of medical rehabilitation must be prepared to demonstrate that more patients need medical rehabilitation and that medical rehabilitation is efficacious. Unfortunately, those within the field of medical rehabilitation have not always sought or received sufficient funding to permit efforts to accurately assess levels of need and, more importantly, to demonstrate through controlled scientific trials that the techniques and practices of rehabilitation are indeed efficacious.

If rehabilitation is to retain its relatively privileged status in relation to efforts at cost-containment, and if appeals for greater resources for medical rehabilitation are to be heeded, then those in the field have an ethical obligation to demonstrate the need for and the efficacy of the skills, techniques and technologies that are currently being utilized. Current estimates of need are closely linked to current patterns of utilization. But these estimates reveal little about who might benefit if more resources were allocated to medical rehabilitation.

At a time when competition for resources in health care is especially fierce, there is insufficient funding available for the collection and analysis of data in a systematic fashion concerning the efficacy of rehabilitation interventions. Since a key element in eliciting a sense of obligation on the part of the public to provide greater access to and a higher quality of rehabilitative care is to show that medical

rehabilitation is beneficial, the demonstration of efficacy is one of the strongest obligations health professionals in the field have relative to matters of resource allocation.

Pedagogical Issues

While a number of institutions and professional societies have made some concerted efforts in recent years to introduce topics in ethics into their educational programs, a great deal remains to be done if the ethical issues facing practitioners in rehabilitation medicine at the clinical and policy levels are to be adequately addressed. These efforts must be made in a number of different educational settings.

Training Professionals

Very few professional schools in medicine, nursing, allied health, or social work offer courses in the area of rehabilitation ethics. In part, this is a result of the fact that there is little in the way of case materials or substantive articles that take rehabilitation medicine as their focus. In part, faculty members have not been encouraged to make ethics a focus of research or teaching.

If rehabilitation ethics is to be taken seriously as a necessary and vital component of the education of students in professional school settings, then faculty members must be encouraged and given time to acquire the knowledge required to teach the subject. Debates over who should teach courses or where in the curriculum they should be offered are less important than whether competent and committed professionals are available to do the teaching.

While accrediting agencies in rehabilitation do not place an emphasis on formal teaching in ethics, it is interesting to note that some professions such as nursing have chosen to do so. Similarly, specialties such as internal medicine, family medicine, and pediatrics have introduced an ethics requirement into their board certification processes.

Ironically, requirements concerning ethical conduct were once a part of the certification process for rehabilitation professionals but legal concerns regarding liability appear to have led to their removal as a formal educational requirement. Serious consideration should be given by appropriate groups within rehabilitation to the desirability of adding formal certification requirements in the area of ethics for both schools and specialty training programs as the availability of teaching materials and qualified instructors in the area of rehabilitation ethics increases.

Continuing Education

There are a variety of settings in which greater attention can be directed toward ethical issues in rehabilitation. Journal editors should encourage more writing on both clinical and policy topics bearing on ethics and medical rehabilitation. Conference organizers at the local, national and international levels should solicit symposia and panel discussions of appropriate topics.

The introduction of ethics committees at many institutions provides a useful forum for the discussion of ethical issues in clinical rehabilitation. Frequently, these groups are assigned the task of sponsoring workshops or rounds on medical ethics. Rehabilitation professionals should work closely with these committees to facilitate more attention to ethical problems of the sort that arise in medical rehabilitation.

Finally, rehabilitation professionals must work more closely with groups and organizations in the community to facilitate discussions of ethical issues in rehabilitation. Trustees, patient and family advocacy groups, and staff and officials from major charitable organizations need to be educated as to the nature of the ethical challenges now confronting and soon to be confronting providers and patients in rehabilitation medicine.

Greater efforts need to be made within the bioethics community to incorporate rehabilitation medicine into ongoing research, teaching, and professional society activities. The emphasis on acute and emergency medicine so much in evidence in the current literature of bioethics needs to be supplemented with more cases and analyses based on problems arising in the context of rehabilitation and related areas of chronic care medicine.

Selected References

Books

George Agich, ed., *Responsibility in Health Care* (Boston: D. Reidel, 1982).

Norman Daniels, *Just Health Care* (New York: Cambridge University Press, 1985).

Myron G. Eisenberg, LaFaye C. Sutkin, and Mary A. Jansen, eds., *Chronic Illness and Disability through the Life Span* (New York: Springer, 1984).

Frederic J. Kottke, G. Keith Stillwell, and Justus F. Lehmann, eds., *Krusen's Handbook of Physical Medicine and Rehabilitation* (Philadelphia: W.B. Saunders, 1982), 3rd edition.

Pedro J. Lecca and John S. McNeill, *Interdisciplinary Team Practice: Issues and Trends* (New York: Praeger Publishers, 1985).

Howard A. Rusk, *A World to Care For* (New York: Random House, 1972).

T. Franklin Williams, ed., *Rehabilitation in the Aging* (New York: Raven, 1984).

Articles

Thomas P. Anderson, "Rehabilitation: Management and the Rehab Team," in J. Bosmajion, ed., *Medical Rehabilitation* (Baltimore: Williams & Wilkins, 1984), pp. 144-51.

Edward Berkowitz, "The Federal Government and the Emergence of Rehabilitation Medicine," *The Historian* 43 (1981), 530-45.

William E. Fordyce, "On Interdisciplinary Peers," *Archives of Physical Medicine and Rehabilitation* 62 (1981), 51-53.

William M. Fowler, "Viability of Physical Medicine and Rehabilitation," *Archives of Physical Medicine and Rehabilitation* 63 (1982), 1-5.

Murray M. Freed, "Quality of Life: The Physician's Dilemma," *Archives of Physical Medicine and Rehabilitation* 65 (1984), 109-11.

Janet F. Haas, "Ethics in Rehabilitation Medicine," *Archives of Physical Medicine and Rehabilitation* 67:4 (1986), 270-71.

Lauro S. Halstead, "Team Care in Chronic Illness: A Critical Review of the Literature of the Past 25 Years," *Archives of Physical Medicine and Rehabilitation* 57 (1976), 507-11.

M.V. Johnston and R.A. Keith, "Cost-Benefits of Medical Rehabilitation: Review and Critique," *Archives of Physical Medicine and Rehabilitation* 64 (1983), 147-54.

Justus F. Lehmann, "Rehabilitation Medicine: Past, Present, and Future," *Archives of Physical Medicine and Rehabilitation* 61 (1980), 291-97.

John L. Melvin, "Interdisciplinary and Multidisciplinary Activities and the ACRM," *Archives of Physical Medicine and Rehabilitation* 61 (1980), 379-80.

Ruth Purtilo, "The Health Care Team," in *Health Professional-Patient Interaction* (Philadelphia: W.B. Saunders, 1984), 30-37.

June S. Rothberg, "The Rehabilitation Team: Future Directions," *Archives of Physical Medicine and Rehabilitation* 62 (1981), 407-10.



255 Elm Rd.
Briarcliff Manor, NY 10510

The Hastings Center, founded in 1969, is a nonprofit and nonpartisan research and educational organization devoted to ethical problems in biology, medicine, the social and behavioral sciences, and the professions.

The Center carries out an active research program on timely and crucial subjects. Working in a variety of fields—law, medicine, science, philosophy, religion, among others—its research work strives to provide non-partisan information, analysis, and recommendations. A resident staff, elected Fellows, and invited consultants form the nucleus of each research group.

The Center is presently engaged in ethical problems of aging, AIDS, care of the dying and termination of treatment, care of defective newborns, organ transplantation, chronic illness, artificial reproduction, and the study of professional ethics.

The *Hastings Center Report* is sent bimonthly to Associate Members of the Hastings Center. Membership is open to professionals and interested laypersons; annual dues are \$38 for individuals, \$31 for full-time students (applicable for two years only), and \$48 for institutions and libraries.

Additional copies of this Special Supplement are available from the Publications Department, The Hastings Center, 255 Elm Road, Briarcliff Manor, NY 10510. Prices are \$4.00 each for 1-9 copies; \$3.00 each for 10-29 copies; and \$2.50 each for 30-100 copies. For prices on orders over 100 copies, contact the Publications Department.