Burn Rehabilitation: Our Unanswered Challenge
The 1992 Presidential Address to the American Burn Association

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My fellow members of the American Burn Association, it has indeed been a joy to preside as your president for the past 12 months. It is an honor that certainly highlights my academic life. This year has also been a challenge, because we are living during a time of national debate in health care that goes to the very heart of what we do as professionals and that threatens both us and our patients. As Charles Dickens said in the beginning of A Tale of Two Cities, "It was the best of times, it was the worst of times." Twenty-five years ago the bylaws of this association were founded, and 24 years ago the first meeting was held. The emphasis was on acute care, antibacterial therapy, biologic dressings, and inhalation injury. The Evans Lecture was on tangential excision. Mortality curves were frightening. Now, 24 years later, the mortality curves have dramatically improved, and the "median lethal dose" for patients without inhalation injury is burns covering about 70% of total body surface area. This should be a time for rejoicing, for patting ourselves on the back for a job well done, and for looking forward with confidence and vigor to the last leg of the race, which is effective rehabilitation of patients who have sustained thermal injury. It is the worst of times in that the media discussions about health care glorify emotion over logic and make many of us believe that the result will undo what we have achieved. Will we be able to finish the race? Will we be given the funds to continue our work in acute care, and will we be given the support to rehabilitate patients and help them back into society? Burn units are closing, emergency departments are turning away trauma cases, and job lines for therapists and nurses are being cut. Each day brings a new panacea and a new set of solutions that are withdrawn and denounced the following day. So-called improved use of services is being used to mask a pell-mell approach to health care rationing. The press is questioning whether improved technology combined with the physician's oath to do his or her best leads to a "no cost is too great to save a life" mentality. The press also wonders whether the technology is driving the system or whether the medical needs are driving the technology. In 1987 the state of Oregon challenged our precepts of giving the best care to every patient by instituting health care rationing. The Legislature curtailed funding for organ transplantation, choosing to give extended Medicaid coverage for basic health care to 1500 more people rather than to fund transplantation for 34 patients. Many beneficial or lifesaving procedures were placed at a lower priority than routine procedures such as dental care and headache treatment. When Coby Howard, a young Oregon patient with leukemia, died in the midst of a fund-raising to provide him with a marrow transplant, he became the first known and documented death in this country resulting from governmental health care rationing. In medicine we realize the rules of the game had changed. Achieving an excellent result was no longer enough. We would not have to fight the pathology and the health care system to help our patients. Amazingly the health care of the elderly is under attack. Daniel Callahan of the Hastings Institute suggested curtailing treatment of the elderly in his widely publicized book Setting Limits. The party line is that these funds could be directed to people earlier in their lives. Remember, if you will, this is a country that 30 years ago established Medicare to improve the care to the elderly. Using age as a reason to limit health care is simply discriminatory, and it contravenes basic fundamental democratic principles. Imagine if we used skin color or sex to limit health care. Why have the elderly become targeted? The ugly reality is that our society emphasizes youth and devalues the aged. Since 1980 the US Congress has cut $20 billion from Medicare Part A, which pays hospitals, and $14 billion from Medicare Part B, which pays physicians. Continued cost-

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cutting schemes place an unfair burden on the poor and the elderly, who make up the majority of our patients. Expenditure targets represent true rationing, and people are denied care that they desperately need. If we do not speak now, how long will it be before we are told who will receive burn care and how much?

Americans have always valued the importance of the individual and of autonomy, self-determination, and justice for all. Now we are being told that the three choices on which to spend our money are arms, housing, or health care. We are being told to ignore the religious considerations that have shaped our lives and our country. The Judeo-Christian belief has always been that the justice of God is displayed in the care of the poor, the marginal, the neglected, the widows, and the orphans. Deuteronomy 15:11 teaches us that "thou shalt open thine hand unto thy brother, to the needy, and to thine poor in thy land." Every axiom of rationing makes us break these religious laws.

Thomas Nickles, Attorney and Director of Government Affairs for the American College of Emergency Physicians, was quoted as saying, "There is no health policy in Washington, there is a budget policy." We simply are not in a high profile, sexy, glorified part of medicine. We are a subspecialty of trauma that is extremely costly and visually disgusting to many. Our patients are often the disenfranchised and are the least powerful in society. I challenge you that the race is not over and that in the fight ahead, we will simply have to be more aware, more astute, more responsible, and more in control of objective, scientific data to receive our share of the funding to rehabilitate our patients so they can be participants rather than victims.

If the monetary cost of our job is more important than our performance, let us study the cost of rehabilitation. One would think that these numbers are available, but they are not. When our efforts to locate the statistics failed, we turned to our members in Washington who represent the National Burn Coalition, and they sought to find out the cost. They went to many major agencies and found no data. In fact, they were told that because burn rehabilitation is excluded from the diagnosis-related group system, rehabilitation procedures are reported only by CPT codes. A research effort from our own institution in New York also met with failure. The costs of burn rehabilitation are both direct and indirect. They include the cost of medical treatment and the economic loss to the injured patient. Direct costs include hospital (inpatient and outpatient services) and professional costs for reconstruction and rehabilitation. Indirect costs include loss of salary, loss of property or materials, and economic loss to the patient's employer. That might also include costs incurred by the patient to an outside agency, costs of babysitters, costs of staying in a motel while having outpatient therapy, or the cost of going to therapy. We failed in our attempt to do this project with other hospitals, because hospitals bill in different ways that cannot be reconciled.

In our own state of New York the Department of Public Health ceased funding for burn statistical research in 1970. Many of the insurance companies were not finished computerizing their facilities, which made data retrieval complicated and time-consuming. When we requested help from more than 200 companies, all but two gave us negative responses, indicating that their search would be a manual one and would be too costly to the company. At this time, in the midst of a recession and frantic competition for research and clinical dollars, there is an appalling lack of retrievable information regarding what we do, whether it be acute care or rehabilitation costs.

Who will step forward and be responsible in providing the hard data that this government is going to demand for burn care? Donald Trunkey, the chairman of surgery at the University of Oregon and well known to all of you for his work in trauma, wrote a most provocative article in the March 1990 issue of The American College of Surgeons Bulletin entitled "What's Wrong With Trauma Care?" The leading problem, he felt, was our abdication of leadership and our unwillingness to pay the spiritual price to see trauma problems through to their resolution. He noted that about 75% of our country was still unprotected by trauma systems and that where trauma systems were in place, survival statistics improved. The rehabilitation of trauma patients is a reachable goal if we want it. Trunkey castigated all of us in our unwillingness to participate, to cooperate with other institutions to develop criteria for care, and to jump to the forefront in demanding quality assurance rather than having outsiders enter our hospitals and tell us what quality assurance should be. He pointed out the failure of our medical societies to recognize the importance of trauma education, research, and clinical care. Lest we think that Trunkey's comments are too harsh, it certainly would strike politicians, lawmakers, laymen, and other physicians as somewhat bizarre that we are capable of sophisticated studies that result in the culturing of skin in a laboratory but that we are unable to follow up our pa-
patients once they leave the hospital. Our research is incredibly creative in developing chemotherapeutic agents and studying the mechanism of shock, but we become incompetent when designing studies to test outcomes and results. The more logical reason is lack of interest on our part. I challenge you that the day has gone by when that response will suffice. If we are not interested, who will be? Will Coby Howard be an example for us or a role model for those who want to deny burn care and critical care to our patients because there is a lack of follow-up data indicating that what we do really makes a difference.

It is certainly inappropriate to blame only the federal or state governments for their mixed priorities. Professionals in burn care have failed in developing quality rehabilitation studies. Yes, it is true that there have been guiding lights who have done thoughtful work, like Phala Helm, Lee Boden, Mary Knudsen-Cooper, Suzanne Henderson, Randy May, and Steve Fischer, but an overall view of the literature is far from impressive. As Molt noted, most of these post-world War II studies have suffered from the problems of small samples, a lack of control groups, the use of unclear terminology, a failure to separate children and adults, and a true lack of prospective studies that have adequate preburn background data. Far too often a significant number of patients become lost to follow-up. There is not even an agreement on what effect the size and depth of burn have on outcomes. Perhaps this is because we have been unable to agree from unit to unit on total body burn size. Thus comparison of data from studies between and among institutions is extremely difficult. No agreement exists on what measures a successful outcome. We have discovered in our own research that even people with very small burns can have big problems after discharge and can be slower to return to school or work than individuals with large total body burns.

Voicing approval of burn rehabilitation is akin to a vote of motherhood and apple pie. Most people believe that rehabilitation begins the day the patient enters the hospital and continues until he or she is followed through the outpatient clinic. All evidence would suggest that the reality is something very different. In 1983 Randy May and the Committee on Organization and Delivery of Burn Care did a very thorough survey of burn rehabilitation efforts practiced in the United States. The findings were most disturbing. The study found a very poor team effort in most burn centers, with few weekly rehabilitation meetings in the units. Rehabilitation was still seen as a functional and structural outcome rendered by surgeons, physical therapists, and occupational therapists. The emphasis was on a surgical procedure, a splint, or a particular exercise. There was minimal effort to finish the rehabilitation effort. For instance, a plastic surgeon may have operated on a patient, but only one fifth of the units had a cosmetologist to optimize outcome. Considering that disfigurement is a major problem with patients with burns, this is remarkable. More than 64% of the respondents did not have any burn rehabilitation beds. More than 50% of the units did not have any affiliated rehabilitation facility for their patients to go to after discharge from the acute care center. Is it any wonder that our follow-up is so poor? Forty-three percent of the respondents noted that they readmitted their patients to other facilities when rehabilitation and reconstruction were necessary, thus leading to very mediocre follow-up. Length of time for follow-up was also most interesting. Follow-up for adults lasted from 15 to 24 months, and for children it lasted about 29 months. This is ridiculously short follow-up when we consider that a study at the University of Michigan found that these patients were at risk for about 5 years after thermal injury. The efforts in psychologic rehabilitation of the patients were particularly poor. Psychiatrists and psychologists were used sporadically and on a consultative basis regardless of the size of the unit. No optimal or minimal amount of psychiatric intervention was known. The availability of vocational/rehabilitative equipment in only 50% of the centers certainly does not indicate a serious commitment to returning patients to employment. A follow-up of this study done by Fred Cromes and Phala Helm was presented at the ABA meeting in Las Vegas in March 1990. They found that although physical therapy was available in 96% of the responding facilities, psychiatric or psychologic services were available in only 45% of the units, suggesting once again a very mechanistic approach to rehabilitation and less sensitivity to psychosocial problems. It was encouraging to note that no differences were found in the rehabilitation personnel or full-time equivalents when facilities of different sizes were compared. Therefore Helm concluded that perhaps some consensus has evolved for minimum guidelines of burn rehabilitation care and delivery. There is agreement in this new survey that rehabilitation should include multiple disciplines, long-term follow-up by physicians for longer than 24 months, weekly inpatient conferences and outpatient clinics, and staff and patient educational conferences. Helms and Kromis, in turn, used the survey to suggest minimum guidelines for care in a 10-bed unit. These guidelines included the following employee require-
ments: (1) physical therapy, two and a half full-time equivalents; (2) occupational therapy, two full-time equivalents; (3) social work, one full-time equivalent; and (4) psychology/psychiatry support, one fourth of a full-time equivalent.

It was the apparent lack of attention to psychosocial issues of rehabilitation that led the Committee on Organization Delivery of Burn Care to review the literature since 1955 and to report to the Board. Findings of the Committee indicated that most articles in print dealt with the patient, family, and staff during hospitalization only. Only 25% of these articles addressed discharge and family concerns during the subsequent years. A review of the research articles showed that only 33% examined outpatient adjustments and functioning of the patient. Significantly, most were written after 1979. The earlier literature emphasized psychosocial forces as being important in burn recovery and paid little attention to the interaction of the physical and psychosocial factors. What is not clearly defined anywhere in the literature is the normal reaction to burn trauma. When does a normal reaction develop into a problem? Few studies put the patient's progress into any kind of perspective by interrelating various periods such as preinjury, acute burn, and rehabilitation phases. It is obvious that the rehabilitation phase is the most neglected, and objective data on this phase are limited. Most follow-up studies are retrospective and are not longitudinal, prospective studies. The Committee was concerned that the literature revealed that we had not progressed beyond merely identifying a set of psychosocial problems accompanying burn injury. Most of the literature had a definite psychiatric orientation, and theory and research from the behavioral sciences was not reflected in the psychosocial literature. Much of the literature of the last 20 years is purely descriptive.

In 1984 Mary Knudsen Cooper tried to identify the unique research priorities in the behavioral areas for burn patients. She noted that many people incorrectly believe that disfigurement rather than physical disability is the greatest source of adjustment problems. Actually, it is the social support of the family that is the most important predictor of ultimate adjustment. She clearly outlined the difficulties in doing research in burn patients: (1) The population of patients is very heterogeneous with regard to age. (2) Special problems exist in terms of physical sequelae, such as disfigurement, amputation, hypertrophic scarring, contractures, sensory loss, skin hypersensitivity, peripheral neuropathy, pulmonary insufficiency, and heat intolerance. (3) Patients often suffer little physical disability, but disfigurement can be a major problem. (4) Recovery takes a long time—5 to 10 years for adults and twice as long for children. (5) Many patients are lost to follow-up, and little is known about the rehabilitation problems.

Many challenges exist in conducting good psychosocial research. This research requires large populations, a large number of interrelated variables that are difficult to control, and much data that demand statistical manipulation. Trained interviewers, data collection people, and access to a large computer must be available. There should be outside consultants to develop an appropriate research design. Many psychosocial professionals are overworked and simply have no research background. Why has psychosocial research ignored the contribution of the social sciences and the research methodologies of sociology and anthropology? Social science research emphasized the interaction of large numbers of variables in explaining dependent variables such as rehabilitation outcome. Anthropologic field techniques based on in-depth interviews are invaluable in developing questionnaires and standardized research instruments that are specific to certain populations such as burn patients. It is not just the size, depth, or location of the burn that is important. Multiple regression techniques must be used to assess the contributions of a number of variables.

Perhaps our quest for objective data would be simplified if at any point we were able to reach a consensus on the definition of burn rehabilitation. In 1984 the Committee on Organization Delivery of Burn Care was faced with the question "Should outcome evaluation address levels of disability or functional ability?" and "Is this evaluation a one-time assessment at the end of rehabilitation or a series of assessments over time?" The Committee believed that the goal of rehabilitation is to restore a person with temporary or permanent losses to his or her maximum functional capacity. Thus when functional ability stops improving and all rehabilitation options are exhausted, rehabilitation is complete and final outcome status is determined. In measuring functional capacity over time the Committee suggested that the patient should be assessed at discharge and then at 2-month intervals until rehabilitation is completed.

When is rehabilitation completed? We must determine whether the problem is treatable or not treatable. When the number of treatable problems approaches zero, rehabilitation is complete; that is, maximum functional ability has been achieved. The Committee tried to develop a score or index that was indicative of functional status and not just of what
the burn patient could not do. Thus the idea for a burn rehabilitation index is not to be confused with disability ratings. The burn rehabilitation index becomes a functional ability rating. Criticisms of the burn rehabilitation index by burn centers was most interesting. It was believed that it was too complex and time-consuming to fill out. People seemed not to appreciate that the total evaluation of burn rehabilitation progress is inherently complex and time-consuming. There are no shortcuts. One only has to fill out a Social Security disability application to appreciate that fact.

Other criticisms of the index were that it did not address long-term recovery. It is interesting that long-term recovery has never been addressed by burn researchers and clinicians. Perhaps those reviewing the rehabilitation index did not realize that the Committee was attempting to emphasize what a patient could do rather than what he or she could not do. This is not semantics. It has profound psychologic significance. The Committee was viewing the injured person not as a victim or chronically ill patient but as a potential participant in the world at large. Significantly, the index was abandoned because of a lack of support.

A stroke of good fortune occurred for the burn community when the Consolidated Omnibus Budget Reconciliation Act of 1985 required the Secretary of Health and Human Services to appoint a special Disability Advisory Council to study and make recommendations about the medical and vocational aspects of disability under Titles II and XVI of the Social Security Act (SSA). The Council submitted its written report in March 1988. Otis R. Bowen, Secretary of Health and Human Services, said in a letter to President Bush, "Our purpose should be to encourage people with disabilities to attain their fullest potential to insure that the government's programs of assistance do not discourage disabled people from working." How well do we succeed in reaching this lofty goal? The Committee's views were that people with disabilities have the same rights and obligations as their respective workers and as the nondisabled. Programs serving people with disabilities should encourage work. Programs for the disabled should not function as programs of retirement or take the disabled out of the work force. The program should operate with the premise that many people with disabilities want to work again.

The Council found that features of the disability income (DI) and social security income (SSI) programs work against this goal. DI was designed to make monthly payments to insured workers who become totally and permanently disabled. The SSI and SSA work benefits were to go to employees under the age of 65 who were forced into premature retirement because of disability. It would seem the program goals were to help those permanently and totally unable to work because of medically defined conditions. The SSI program extended help to indigent people and to those who are blind or otherwise disabled. But a second part of the legislation that created the DI program directed SSA to refer applicants for vocational rehabilitation (VR). Congress obviously expected some people to go back to work after receiving VR services. It is hard to reconcile this concept with the perception of DI as a program of "premature retirement because of a disability." There is widespread confusion between the payment of premature retirement pensions and the encouragement of beneficiaries to get VR and go back to work. The patients are confused. To qualify for benefits they have to prove they are incapable of employment. The process is long, cumbersome, and difficult. If the patient does succeed in getting benefits, he is told that regular and substantial earnings could cause payments to be suspended. Yet he is also referred to VR services. Beneficiaries are sent mixed signals. They must prove that their impairments prevent them from working for at least 12 months for them to be awarded the benefits, then they are encouraged to return to work and to forfeit their benefits. Many patients view their impairments as permanent and therefore believe that there entitlement to benefits should be permanent. Thus patients are suspicious of VR. They will stop getting benefits only if they go to work. Therefore there is a disincentive to work.

The Council recommended that the SSA's program for people with disabilities be changed substantially to place emphasis on helping beneficiaries return to work rather than on declaring them unable to work. Most importantly the Council found that they were frustrated by the lack of data essential to the formulation of a sound health care policy. Therefore, instead of making recommendations on how to change DI and SSI, they recommended demonstration projects that test changes to examine alternatives to the DI and SSI programs.

The Council found that the SSA's current VR program had a negligible impact on increasing the capacity of beneficiaries to return to work. Many beneficiaries who have the potential for gainful employment are not being enrolled in the VR programs and are thus being denied the means of improving the quality of their lives. The SSA does not routinely
gather experimental data on which to validate its current VR referral criteria. It does not maintain any direct management control over VR programs except through reimbursement. It is not tracking persons referred for VR services to see if the services are actually requested or provided and to ensure that the benefits are suspended to recipients who refuse to participate without good cause. Differences in the goals of the SSA and the federal/state VR programs must be recognized, but the present SSA system for VR referral and reimbursement does not promote competition among service providers or involvement of employers or unions. If there were an impetus to push this program by increasing competition and the involvement of the public and private agencies, employers, and unions, there would be more interest in achieving job goals.

The work incentives provisions for DI beneficiaries have not been broadly used and can be strengthened. The loss of benefits is a concern of the beneficiary. This fear is partly due to a lack of understanding of how entitlement of benefits is protected under the current law. The SSA can improve this situation by improving public information. The level of monthly earnings that constitutes substantial gainful activity for workers with disabilities (more than $300) is too low and should be raised. The process of disability determination to provide the patient with cash and medical benefits is too often delayed. The variation of allowance rates between states and the volatility of these rates over time raise questions about the integrity and fairness of the disability program. Rates in these programs should not vary appreciably between states. The lack of uniformity in the application of eligibility standards stems from (1) lack of specificity in the rules used for determining disability, (2) an inadequately controlled federal/state arrangement for administering the DI and SSI programs, and (3) an appeals process that fails to encourage the development of complete and correct evidence early in the process.

The Council noted that the federal government now spends nearly $66 billion annually through more than 40 programs that help people with disabilities. With all of these programs this Blue Ribbon Council concluded the job is still not being done well. What can the burn team do to be responsive and helpful to the patient who is caught in the bureaucracy and who needs benefits to take the next step toward rehabilitation? First, we must be informed and attentive. Competition for benefits is fierce; and proper documentation of disability is important. A thoughtful and complete report can greatly improve a patient's chances of obtaining fair and appropriate benefits and can hasten approval of the application. Inaccurate reports can backfire. The SSA has a strong incentive to deny disability claims on any technical grounds, because there are many claims and resources are limited. In the 3 years studied, burns accounted for fewer than 1% of all disability claims allowed by Social Security. Medical reports that do not meet SSA standards can be devastating. The SSA wants answers to the following questions: (1) Is there one or more medically determinable impairments? (2) Does this impairment or combination of impairments significantly limit the patient's physical or mental ability to perform substantial gainful work? (3) Has significant impairment lasted or can it be expected to last continuously for at least 12 months? (4) Is it expected to result in death? A well-written report by the treating physician is given more weight and consideration than the reports written by the physicians working for the SSA or by the government medical reviewer.

If achieving a good rehabilitation result is of paramount importance, then it is astonishing that more people do not become knowledgeable about disability determination. I would strongly recommend reading the chapter by Steve Fisher in the book *Burn Rehabilitation* that he and Phala Helm edited about the rehabilitation of burn injuries. Basic differences between permanent impairment and permanent disability are confusing to many individuals. The same impairment in different states gets different ratings by workmen's compensation insurance. This is a true problem. Most states do not even mention burns in their workmen's compensation laws. Nine states provide a compensation for scars if the disfigurement involves the face and head, and two states pay for disfigurement only if it specifically causes loss of function of a part. Permanent impairment is a purely medical condition that pertains to a functional abnormality after maximum medical rehabilitation, whereas permanent disability is not a purely medical condition. Permanent disability is when an individual's ability to engage in gainful activity is reduced or is absent because of his or her impairment. Only the physician determines permanent impairment. Impairment is the truly important factor in determining disability. It is usually measurable and objective. Patients with burns are hard to assess. Objective parameters such as loss of structural integrity, loss of functional capability, and persistent pain can be substantiated. These patients do have certain unique problems that are a bit difficult to quantify. The patients often have heat and cold intolerance, sensitivity
to light, changes in sweating patterns, decreased strength and coordination, and the presence of contractures, all which must be documented in a report. No percent of impairment exists for scarring, but if it affects the sweat glands, and hair and nail growth, it can lead to impairment. Disfigurement may lead to psychologic components that can be rated.

Thus there are objective, thoughtful ways of evaluating working adults. Lee Bowden and others have studied the factors influencing the patient's return to employment after burn injury and have attempted to quantify them. In a 1989 prospective study of 155 adult patients with burns who had been employed before their injury, the average time from the occurrence of the burn injury to the patient's return to work was 63 days. The average time from the patient's discharge to his or her return to work was 42 days, an improvement over previous years. The size and depth of the burn, the occurrence of hand burns, the age of the patient, and the type of job significantly influenced return to employment.

If successful rehabilitation is multifactorial, then one cannot overemphasize the effect of strong social support from family, friends, and peers. Cobb's basic thesis is that social support helps the patient to cope with crisis and to adapt to change. This is certainly the most likely explanation for why people who are expected to do extremely poorly, instead rally and surprise all of us by moving forward, whereas others with small injuries seem to falter by the wayside. When we try to determine what variables affect rehabilitation results, self-esteem certainly stands out. Studies have been done to determine self-esteem in patients with severe burns, and it has been found in several studies that men who have sustained thermal injury seem to have a higher sense of self-esteem than women with like injuries. This is believed to be partly due to the problems of disfigurement. Our society places such a high value on appearances for women that they understandably worry more about disfigurement than men. The age when one is burned also affects self-esteem. Studies found that those patients who were burned between the ages of birth and 10 years had a lower sense of self-esteem than those burned between the ages of 20 and 49 years. In the very young severe burns that result in disfigurement most assuredly cause problems as compared with those in older individuals who have a more secure or developed sense of self. A major difficulty in doing prospective studies in these young patients seems to be a lack of follow-up. Why? In a study of 109 patients, Knudsen-Cooper's group had lost 28 to follow-up by the third year. She identified variables that seemed to influence follow-up. Some of these were the patient's age, race, sex, marital status, type of employment and health insurance, financial status, and state of mental health. She found that follow-up participation was highly correlated to the patient's type of health insurance. Patient's with workmen's compensation were likely to finish follow-up because of the financial benefits coming to them. It is interesting to note that those with workmen's compensation insurance took much longer to go back to work in several studies. They simply were being taken care of by the system, and they were in no rush to get back to work. Who were the people who were lost to follow-up quickly? The various groups included those without workmen's compensation insurance, those who lived far away, those with minor facial disfigurement (because there was less incentive to come back for reconstructive surgery), and African-Americans. Rehabilitation is a long process. One cannot formulate conclusions until 3 to 5 years after discharge. Thus retrospective studies that have short follow-ups or that have prospective studies based on the first 1½ years after discharge are inadequate. Longitudinal studies dealing with adults should last about 5 years. Longer studies are probably needed for children, because developmental stages are encountered.

It is not the purpose of this talk to delve into the nuts and bolts of rehabilitation. It is the philosophy that has been written about by Phala Helm and others that is so important. Too much emphasis has been placed on isolated mechanical acts such as the proper splint, the proper exercise, and even the operations of choice. Rather, the emphasis must be on a team approach, with a true communication among all disciplines. There must be a regular conference for the entire team to review the patient's care and to discuss discharge planning and the expected problems confronting the patient. Thus Helm emphasized four principles of management: (1) setting of priorities, (2) proper timing of various programs, (3) flexibility of the program, and (4) total patient involvement.

It is likewise reasonable to emphasize rehabilitation by dividing the patient's care into the acute, subacute, and convalescent phases. The convalescent phase deals with the treatment of muscle weakness, the prevention of contractures, and the prophylactic conditioning of the skin to prevent blister formation, ulceration, excessive dryness, and hypertrophic scarring. Considering that the skin is the organ most injured in a burn situation, one should be aware of the benefits of massage, the effects of paraffin treatment, the effects of stretching, and so on. The pre-
vention and treatment of hypertrophic scarring are still in the experimental stage. The use and efficacy of elastic pressure, stretch garments, and othotics remain a fertile area for investigation. It is astonishing how primitive and sparse the research has been on the deconditioning and reconditioning of the individual who has sustained a thermal injury. Richard Edlich wrote about the cardiovascular rehabilitation of patients with burns in 1990, and he is a plastic surgeon, not a cardiologist or psychiatrist. He rightly noted that the bedridden patient with burn injuries rapidly deconditions and experiences a decrease in vigor, endurance, and work capacity. Confinement to bed for 2 weeks results in a decrease in oxygen consumption of about 25% and decreases in stroke volume and cardiac output. He recommended a program that involved exercise, education, and counseling. In a center at the University of Virginia patients were placed in a program in which they progressed from sitting in a chair (to overcome the effects of gravity) to participating in the activities of daily living and then to using a treadmill and bike. Before the patients were discharged exercise tests were done to formulate discharge planning. Goals of the early outpatient phase were to reverse the physical deconditioning and to improve functional capacity. Dr. Gillon Ward and his team identified the value of isokinetic exercise and testing in determining back-to-work status. Ward emphasized that although range of motion is important, it is overemphasized; by itself it is an incomplete guide to a patient's potential. Musculoskeletal dysfunction can be due to immobilization or abnormal posturing. Ward emphasized the differences between isotonic and isometric exercises versus isokinetic exercises. He was able to produce an increase in the patients' strength, endurance, and power with the use of a Cibex-2. In a controlled study he found that those individuals who were doing only isometric and isotonic exercises had significant deficits despite their normal range of motion. Thus, in activities that stressed high speed the control group did not do well, whereas the group trained with isokinetic exercises did do well.

Part of the in-hospital planning is the anticipation of the adjustments and adaptations that the thermally injured patients will have to make on discharge. These patients have a multifaceted identity crisis. They have to adjust to changes in appearance, body strength, capacity to work, and responses that others have to them. Thirty percent of these patients have emotional problems resulting from their injury, the most common being traumatic neuroses and chronic depression. Burn injuries frequently alter marital relationships. Women who have been injured sometimes have problems enjoying sex, because they no longer feel attractive or desirable. Their capacity to have orgasm is often lost. If the man is injured, financial hardships and role reversal often occur, because the wife becomes the new breadwinner for the family.

Once the patient is out the door of the nurturing burn center, he or she must cope with an incredibly destructive and distortive value system that links beauty with good and ugly with evil. This is seen in our literature and on television. Can one forget Quasimoto, who was evil and ugly? We are told that beauty is only skin-deep. But what we see in advertisements, on television, and in the movies tells us something very different. The men and women reporting the evening news have never been burned or scarred.

A fascinating insight into Hollywood's view of the survivor of burn injuries can be obtained from your local video store, where the movie Darkman can be rented. This recent hit movie shows that we have not come very far in addressing the problem of disfigurement. The injured protagonist wears black, gradually assumes the worst character flaws of his tormentors, and by the end of the movie is condemned for life as an outcast.

During the weekly rehabilitation rounds, psychologic concerns can be communicated among the family, the patient, and the burn team. These groups can also discuss certain problems that may occur after the patient is discharged. Having the family meet patients who have been rehabilitated can be helpful. Before the patient is discharged weekend passes allow him or her to analyze the problems that may occur at home and recount them with the staff.

The effect of disfigurement on children and adolescents cannot be disregarded. Goldberg's studies compared a group of adolescents who had facial burns with a group of adolescents who had heart disease. He found that children with heart disease did better on their vocational aspirations, career plans, self-image, and work values. A visible, physical disability severely affects adolescence. Bernstein also showed that facial disfigurement caused long-term emotional problems in children because many came from lower socioeconomic groups that have poor housing, unstable family situations, and minimal educational and vocational opportunities. He was fearful for the future of these children. That future has never been followed up. Suzanne Cahnert at the Boston Shriners Hospital rightly emphasized the need for a strong liaison between the hospital staff, the school, and the
family in the attempt to rehabilitate children. Marion Doctor has taught us that true commitment to rehabilitation is a year-round job. She and Jeffrey Heinrich have done much with their summer camps to demonstrate the potential for rehabilitation in children with burns. Unfortunately, none of this work has been followed long enough to be able to truly assess it, alter it, and test its validity. For example, the Shriners Hospitals have done magnificent work in the salvage of children with thermal injuries, but it is very disappointing that they have yet to produce prospective longitudinal studies about what happens to these children. In 1986 David Herndon reported on 22 children, 12 of whom were survivors of burns that covered 89% of total body surface area. Eighty-two percent of these were third-degree burns. This study indicates truly outstanding acute care. Herndon was very disturbed at the high incidence of hearing loss in these children that resulted from lifesaving medication. In five of these 12 survivors the hearing loss caused educational and communicational handicaps. It would be fascinating to hear Herndon's follow-up report 10 years from now, because only one of these children was an adolescent at the time of the study.

The vocational rehabilitation counselor can make a major imprint on the discharge planning process and can markedly improve the end result. Past research in the work patterns of patients with burns is extraordinarily limited. Very few papers exist on specific vocational interventions and their effectiveness. Burn recovery research has been purely descriptive, not scientific. It has been been static and has not spanned all phases of recovery. Minimal work has been done on relating psychosocial factors to the physical aspects of burn injury. The skillful rehabilitation counselor can make the difference between a patient losing or not losing his job. A patient may not need new job training. He or she may simply need an individual to intercede with the patient's previous employer to adapt the patient's old job to his new impairment.

One should follow the model of Simmons and study the patient's preinjury status, the extent and nature of the injury, and the patient's psychosocial reactions to the injury. This work has not been done. We need to know the patient's preinjury status, preexisting medical and/or psychiatric problems, motivational background, and belief system. Therefore the staff should interview the patient and the family to learn the cultural and family background and the patient's personality factors. Was the patient self-motivated or excessively dependent? Did the patient have a history of alcohol or drug abuse? The patient's work history is extremely important and is a good way to identify psychosocial barriers to employment. According to several studies, the nature of the burn injury and its complications requires about 50% of patients who have healed to change jobs.

The employer and the vocational counselor must realize that patients need long-term follow-up. Most will need readmissions for reconstruction and time off from work. They may have to wear splints on the job, and they may periodically have changes in function and strength during their phase of reconstructive surgery.

The emotional adjustment of the patient on his return to work has not been well studied. The counselor must impress on the patient that despite physical problems, he or she will be able to work. The counselor must explain to the patient the abilities he or she has that have been preserved to help maintain the patient's self-esteem. Society fails miserably in this quest, because the employers, the lawyers, and the Social Security Administration tend to emphasize what a patient cannot do rather than what a patient is still able to do.

The rehabilitation counselor must link the severity of injury to the patient's social adjustment, which may be more predictive of successful rehabilitation than the level of residual function. The counselor must do a vocational assessment to find out if there are any functional impairments or deficits that preclude the patient's return to work. The counselor must stress the patient's assets and not just his or her liabilities.

In this assessment there must be (1) data collection, that is, the facts that are known about the patient plus the results of special tests, such as work evaluation and vocational interest tests, (2) assessment of physical capabilities, and (3) analysis of current employment. The counselor must discover what attributes the patient had on the previous job that he or she can use on another job? A job analysis and a plan are crucial. The patient may be able, with the employer's help, to adapt to the job so that he or she can still do it.

A decision must be made regarding the patient's old job, new job, or possibility of retirement. Will the employer take him or her back? The patient must be aware of his or her rights under the workmen's compensation laws. Will the employer's workmen's compensation payment go up? It varies in different states. What is the employer's liability in hiring an injured person?
Why does a patient want to stay in a sick role and become a "career patient"? This is a subject that is fertile for research. The "whole man" concept is that one does not treat the disease but the individual who is suffering from the effects of an injury. There are multiple reasons for a patient not wanting to go back to work. Little correlation exists between the patient's physical impairment, his functional limitations, and his employment. What happens? How do impairments become limitations of activity and how do limitations evolve into behavioral patterns, which are called disabilities? The employer may not want the patient back. The employee wants to receive a medical disability. There may be legal issues in processing a claim. The family may be too supportive of the patient's sickness, and the patient receives advantages that he has never had before. There may be policies regarding sick leave, disability, and retirement that act as economic disincentives. The patient may indeed get no more money by returning to work than by staying home. It is the role of the counselor to educate the patient so that he or she can understand the differences between disability and handicaps. Education helps to prevent false expectations and claims.

This past year members of the Panel on Rehabilitation of Injuries issued their position paper as solicited by the Division of Injury Control and the Center for Disease Control. This panel obviously dealt not only with burns but also with how burn injuries related to other major categories requiring extensive rehabilitation. The Committee noted that the goal of the Center for Disease Control was to establish by the year 2000 a cost-effective system of rehabilitation that would permit the injured person to achieve optimal health in a noninstitutional lifestyle.

The Panel noted that the centers are usually directed by plastic surgeons or general surgeons and that at only a few centers do physiatrists work closely with the burn team and follow these patients after discharge. It was particularly striking that physiatrists and allied health professionals were usually not exposed to burn rehabilitation during their training or did not receive any formal education in burn care. This Committee was frustrated by the fact that data on burns described mortality and morbidity, but except for rare reports, there were no scientific data on rehabilitation, complications during acute care, or discharge. There are no good data on rehabilitation outcomes, long-term sequelae, the effective quality of life, or the cost of care for inpatient or outpatient rehabilitation. This panel also noted that 33% of the centers that had fewer than 81 admissions each year did not have outpatient rehabilitation programs. Interestingly 20% of burn centers with 81 to 120 admissions per year did not have any outpatient rehabilitation.

The panel recognized that the problems confronting researchers in the area of pathophysiology are abundant:

**Hypertrophic Scarring.** No adequate animal model exists on which to test modalities of treatment.

**Contractures.** Few studies have compared the effectiveness of various treatment modalities.

**Peripheral and Central Nervous System.** Peripheral neuropathy occurred in up to 29% of the patients with burns covering more than 20% of total body surface area. The cause of this neuropathy is yet to be determined. The pathologic mechanism of burns in the central nervous system needs to be described.

**Muscloskeletal Changes.** These are devastating in children. They include bone growth disturbances, kyphotic deformities, scoliotic deformities, heterotopic ossification, and joint dislocation. Minimal work has been done in these areas.

**Rehabilitation Interventions and Outcomes.** The Committee noted that few clinical studies compared various treatment techniques and determined the best protocols. Dissemination of information about successful therapies was limited. No universally accepted functional recovery measurement exists to evaluate outcomes. Innovative patterns of ambulatory care that various specialists of the burn team can deliver for nonhospitalized patients need to be developed. The psychosocial family needs of children and adults with burns have to be addressed. Rehabilitation facilities need to be used more frequently. It was significant that in a review of discharge diagnoses in 46,666 patients and 119 rehabilitation facilities, only 0.8% of the diagnoses were burn injuries. The Committee noted that longitudinal research is needed to document the problems that patients with burns face after functional recovery. Multiple burn centers have to be involved with common protocols.

**Service Delivery Issues.** There is a marked need for improved training. A major barrier in burn rehabilitation is the lack of trained personnel, especially physiatrists and allied health care personnel.

Public awareness needs to be awakened to understand the social, emotional, and occupational problems that face the patient with burns. The Committee
noted that standards of care need to be set. Comprehensive patient care that is standardized for the ABA and that has guidelines for treatment and rehabilitation of the patient with burns needs to be developed. Outcome criteria should be identified. We need to ensure delivery of quality burn care rehabilitation and to aid and educate third-party payers by supporting appropriate therapies. My recommendations to correct many of the problems I have mentioned are not complex, and the solutions are obtainable. First, a Blue Ribbon Committee of impartial government and civilian scientists should study how 40 different agencies are presently spending the $66 billion dollars on rehabilitation. After waste from overlap and duplication is identified, the sources of potential funding should be publicized within the ABA and to all of the appropriate government agencies funding burn rehabilitation. The titles of funded grants should be disseminated within the agencies to avoid future overlap. I suggest that our membership and the government respond to the criticisms and suggestions of the panel on Rehabilitation of Injuries and the Disability Advisory Council.

It is obvious that the future for burn rehabilitation research is going to be much more focused and definable. In the past there has been uncertainty in the rehabilitation field as to what is a successful outcome. There has been an inability to describe an individual's function level in a meaningful way. It has been difficult to develop a workable scoring system that accurately defines function. In the ABA this year, Region VII is developing a multicenter program that will study outcomes and quality assurance. At the national level outcomes research is being driven and fueled by the fear of health care rationing. Joseph Weinberg talked about this very issue in the October 1990 New England Journal of Medicine. He noted that all of the agencies dealing with health care policy and research that were established by the 101st Congress promote research or medical outcomes and provide guidelines for practice. He felt that this would help sort out what did and did not work with patient populations. Assessment teams can study common conditions and alternative treatments. For instance, the American Urologic Association has responded positively in helping to plan a randomized clinical trial in 20 centers to evaluate mortality after prostatectomy and to study new treatment options. After the Association has ascertained what treatments work, alternate treatments will not be entertained by third-party payers.

This past February a small workshop was held in Washington with members of the ABA who have a long history of commitment to rehabilitation and with representatives of the National Institute for Disability and Rehabilitation Research (NIDRR). The purpose of the 1½-day meeting was to improve communication, to make the NIDRR aware of what the concerns of the ABA were, and to inform the ABA of what the NIDRR was interested in funding. The meeting was most productive. We were asked to relate to our membership the desire of the NIDRR to do something positive now. The institute is committed to funding quality burn research for rehabilitation. Funds are available for fellowships, demonstration projects, and model systems of injury such as the Spinal Cord Program. It was pointed out to us that on two occasions in the 1970s the National Institutes of Health had funded work of this sort at Galveston and the University of Michigan. Clinical research was completed, papers were published, and nothing further happened. Paul Thomas of the NIDRR noted that Washington waited for efforts toward further research, but they were not forthcoming. Implementation of what had been achieved did not happen. Everyone at this meeting believed that a real window of opportunity exists at this time and that we need to move forward. Rehabilitation is a large, glaring area where quality work remains to be done. It has lagged behind other disciplines such as the spinal cord program. The gauntlet has been laid down, and the challenge has been made. The NIDRR realizes that we are capable of solving problems in rehabilitation. Do we have the will to do so? Do we have the interest to convert our patients into participants? Will we be able to delete the phrase "burn victims" from our conversation? Will we prove Donald Trunkey wrong and seize the reigns of responsibility? Will we remember Coby Howard? The future is ours to decide.