Whose Life Is This, Anyway?
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My address today, which will evaluate the relationship between burn patients and the health professionals providing their care, is dedicated to the members of the American Burn Association. This relationship has undergone significant change during the past 20 years, as has the practice of medicine and the doctor-patient relationship. I hope that understanding this evolution will provide us with insight into our future needs. This past 20-year interval has been marked by significant scientific contributions, a partial definition of the limits of medical achievements, and concern over financial and other resources that impinge upon the success of burn care. I will compare what has happened in the practice of medicine during this interval and apply it specifically to the care of burn patients.

In trying to understand the patient-health care provider relationship it is important to put the essence of medicine and burn care into perspective. The following quote by the great physician Osler may be a sobering one, but I think it helps keep this relationship in the proper perspective: "Medicine is a science of uncertainty and an art of probability." Historians of health care have defined three ages of medicine: (1) the age of paternalism, spanning the era from Hippocrates to 1965, (2) the age of autonomy, from 1965 to 1985, and (3) the present age, which I term the age of Federal and bureaucratic intervention.

Age of Paternalism

The origin of paternalism for health care providers is the hippocratic oath and the Nightingale pledge. Medical paternalism, in which both doctor and nurse are viewed as parent figures responsible for the welfare of ill or injured patients, persisted until the mid-1960s. The hippocratic principle *primum non nocere*, that is, "first of all

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do no harm," and the ethical principles of malefaseance (wrongdoing) and beneficence (doing good) are the basis of paternalism. The Hippocratic oath, including the statement "I will prescribe regimen for the good of my patients according to my ability and my judgment and never do harm . . . " as well as similar charges in the Nightingale pledge were believed to invest the health care professional with the responsibility to oversee the total welfare of the patient in this perceived parent-child relationship. This role included responsibility for making and implementing therapeutic decisions for optimal patient care. Paternalism flourished during the 1950s and 1960s because of two factors: first, a rapidly improving and expanding medical care system, and second, concern that patients could not understand the impact of the new health technology on their disease processes. Doctors and nurses were perceived both by the public and by their peers as champions of health care rights, defenders of the socially and medically unfortunate, and the sole possessors of adequate understanding to evaluate new scientific developments. In 1957, the American Medical Association published a code of medical ethics outlining a program of justified paternalism that established the physician as responsible for the overall well-being of the individual patient and the community. Later revisions of this medical ethic challenged this role for the physician.

In the 1960s and early 1970s there were a number of scientific contributions and organizational developments, in terms of burn units and burn teams, which contributed to a previously unprecedented improvement in survival from severe burn injury. These phenomena encouraged paternalism. During this era, topical antibacterial agents were developed such as sulfamylon, silver sulfadiazine, and silver nitrate soaks. New formulas for burn shock resuscitation, including the Brooke formula, the Parkland formula, and hypertonic salt solutions, were implemented. These therapeutic changes had a significant favorable impact on sepsis and organ failure secondary to severe shock. Better diagnostic tests and therapy for inhalation injury contributed to improved survival of patients with this major lethal complication of thermal injury. Potent new systemic antibiotics, mechanical ventilation, and critical care units all contributed to unprecedented survival rates. Review of burn mortality statistics during this era reveals reports of survival of patients with larger and larger major burns. Since the burn team could not accurately assess the ever-improving efficacy of burn care, new techniques were tried and medical paternalism flourished. This era was marked by discovery, commitment to survival, rapidly evolving technical advances, aggressive therapeutic intervention, a sense of challenge and accomplishment, and a feeling of unlimited ability to solve the problems of burn injury patients. The burn team was in charge—and charging forward. Paternalism in burn care continued well into the 1970s.

**Age of Autonomy**

The effect of scientific technology on the practice of medicine was less dramatic in the 1970s. The realization surfaced that life could potentially be artificially supported forever, along with concern over patient rights—especially protection of handicapped, senile, and retarded patients—as well as the need for informed consent for participation in experimental treatment. For medical practice in general, the age of patient autonomy began approximately in 1965. Autonomy is defined as the capacity to think, decide, and act on the basis of thought and decision. For the practice of medicine it meant informed consent. As the need to evaluate the efficacy of experimental drugs, procedures, and other undefined therapeutic interventions increased, the importance of informed consent became a reality. Autonomy or patient self-determination then extended from experimental procedures to standard care. Ethical issues over competency, informed consent, and the right to die and to refuse life-saving treatment were widely debated during this era. Standards for judging competency, or the ability to make a self-judgment, were developed since protection of disadvantaged groups had to be ensured and some health professionals claimed that sick patients were incapable of making proper judgments. Standards for judging competency include the evidence of ability to make a choice, factual understanding of the issues, rational manipulation of information, and appreciation of the nature of the situation. Because of the wide variability of standards to determine competency, especially in making a medical decision in a life-threatening situation, a presidential commission was established that defined competency or decisional capacity as containing three parts: (1) possession of a set of values and goals, (2) the ability to communicate and understand information, and (3) the ability to reason and deliberate.

A widely accepted definition of competency was important, especially since patients were now choosing to receive new and untested treatment in desperate situations or even to refuse life-saving therapy. Sophisticated means of supporting life created new problems; that is, defining ordinary and extraordinary care became problematic, especially in the prolongation of life. Attempts to assess the value of prolonging life and to determine how to formulate these values created major conflicts in both the ethical and medical literature. Defining death and dying became difficult, especially in patients with organ failure; for example, is the patient on renal dialysis dying or not? Too, the definition of recovery created various responses: for some, recovery meant return to a former state of full health; for others, recovery meant return to a lesser state of health with a handicap; and for a few, return to spontaneous vital functions in coma was defined as recovery. Lists of medical procedures or medications have not been helpful in defining ordinary and extraordinary means of prolonging life. The moral and legal rights of health professionals to provide or not provide—or even withdraw—life support were clouded. The use of such terms as usual, unusual, useful, or useless techniques to support life was encouraged. Many treatments, however, fit two or more of these descriptions. For example, the use of intravenous fluid may be useful for dehydration secondary to diarrhea, whereas it is considered useless for a patient declared brain-dead.
A key issue during this era was the patient's right to refuse life-saving therapy in terminal diseases. Both physicians and moralists stated that competent persons with incurable terminal diseases have the right to refuse treatment for valid reasons, which may include concerns of physical suffering or mental burden. Moralists interpreted the Hippocratic premise of "do no harm" as respecting patients' rights to refuse treatment. They contended that life preservation can be doing harm if a patient has a terminal incurable disease or cannot participate even minimally in the human experience; that is, if the patient's inherent capability to respond effectively is gone.

In considering informed consent, it is worthwhile to examine the strategy for making clinical decisions. There are four factors in decision-making strategy in clinical-ethical problems in medicine: (1) medical indications, (2) the patient's preference, (3) quality of life, and (4) such external factors as family, cost issues, and societal interests. Most medical decisions are made on the basis of the first two factors—medical indications and patient preferences. Medical indications include diagnosis, therapeutic alternatives, and prognosis. A specific clinical strategy is suggested by the health care team. Since this strategy is the personal recommendation of the physician it has both objective and subjective components. The patient's preferences are then evaluated and the decision is made. When conflict over acceptable therapy arises between the health professionals and the patient, a determination of the patient's competency is made. If the medical situation is grim and the patient is unable to decide because of physical or mental incapacity, then factors of quality of life and external circumstances may come into play.

The concept of quality of life is very ambiguous. Such questions as "Is it worth it?" are posed. Attempts to define quality of life have been difficult and may not even be possible prospectively. Some have attempted to correlate quality of life with natural endowments, the physical and intellectual state of the injured or ill patient at the time of initial care. Limiting a definition of quality of life to the patient's natural endowments alone is inappropriate since it fails to take other important factors into consideration. Others have proposed the following formula: quality of life equals NE(H + S), where NE are natural endowments, H is the contribution by the family and home to the patient, and S is the contribution by society. Physicians have difficulty dealing with quality-of-life evaluations except in cases of noncurable terminal illness and brain death, since most are not trained to evaluate these phenomena. Retrospective analysis of the quality of life of ill or injured patients who have returned to society has emphasized that quality of life is most influenced by the commitment of the home, family, and society as opposed to the patient's contributions. In an attempt to blend physicians' Hippocratic obligations with patients' autonomous rights, modern bioethicists have integrated the concepts of sanctity of life and quality of life. Sanctity of life supports the obligation to preserve life at all costs when human experience is possible. Autonomy allows less than full life support when quality of life is not possible as determined by the patient, rather than the physician. The concept of the living will, the statement of a person's right to refuse treatment in incurable conditions, achieved wide acceptance in the late 1970s. Family involvement in the decision when the patient is incapable of rational thought has been an acceptable alternative for patients with documented terminal disease or brain death. However, when a patient's family is not available and terminal disease or brain death is not present, most have challenged the appropriateness of the health professional to withdraw or not provide full care since he or she serves as the only patient advocate.

The age of autonomy in burn care came later than for medical practice in general. This probably occurred primarily in the early 1970s since burn treatment, including shock resuscitation and topical therapies, was being standardized widely during this time and new critical care methodologies were being implemented. Scientific investigation of this era, which focused on a better understanding of the pathophysiology of the burn injury, included studies on the immune response and white cell function. The therapeutic implications of these investigative studies included plasma exchange therapy, early excision, immune suppression with temporary skin grafting, and the use of artificial skin. Progress in survival continued during this era. The emphasis on patient autonomy in burn care focused on informed consent for participation in experimental programs. Improved topical and systemic agents were tested and new approaches to wound management were evaluated with Institutional Review Board approval and informed patient consent.

In 1977 the concept of the patient's right to refuse usual resuscitation was suggested for patients having severe burns with unprecedented survival. Those favoring this approach provided information to the burned patient concerning the severity of the burn and the fact that patients with similar injuries had not survived. The patient then chose either standard resuscitation or no therapy except pain relief. Many questioned the ability of severely burned patients to be able to make a rational decision after a severe thermal injury. Others argued that technological progress—including the advent of synthetic skin, auto cell cultures, and new antibiotics—was evolving so rapidly that survival was still possible, even in cases of severe burns. This era was marked by intensive scientific investigation, commitment to expand burn facilities, concern for the patient and the family, high interest in burn prevention and rehabilitation, and enthusiasm for involvement in the burn problem by related service personnel such as fire fighters.

**Age of Federal and Bureaucratic Intervention**

Beginning in 1983, different concerns came to the practice of medicine. The key issues became widespread use of expensive high technology with variable effect on the quality of care, increased costs of health care, and potential for exceeding financial resources to support health care in general, specifically for those operating under federal programs. Presently 80% of health care resources,
including facilities, services, and medical research, is devoted to chronic diseases. The patient-doctor relationship with paternalism v autonomy, protection of individual rights, and other ethical issues became secondary to cost containment and federal intervention. In an effort to control increasing health care costs, a prospective payment plan was instituted using diagnosis-related groupings. This plan attempted to promote efficient care at minimal cost by providing monies based on average cost for treatment of injuries or illnesses. Other efforts to control health care costs included second-opinion programs and precertification before admission. Concerns were voiced by health care professionals about the potential adverse effects of these control mechanisms, including the erosion of the quality of care, decreased availability of health care resources, and unfavorable impact on morbidity and mortality.

The success of these programs is still being questioned. There appears to be some decrease in length of stay for certain disease processes, although in general, the overall long-term impact of DRGs on medical practice cannot be ascertained clearly. Negative effects publicized in the lay press tend to confuse the issues.

Since the prospective payment plan and DRGs are viewed only as partial solutions to health cost containment, other approaches are being considered. Health care is considered an industry and business financial management approaches have been proposed. It has been suggested that the allocation of health care dollars and the rationing of health care services could be regulated on the basis of cost-benefit analysis and cost-effectiveness ratios. Health policy makers have stated that future funding of health care should be based not only on effectiveness of care in improving mortality and morbidity, but also on its social, financial, and cost-benefit effects.

Allocation, the unequal distribution of funds and resources, is not foreign to medicine. Research support for different disease processes such as cancer, heart disease, and trauma has been allocated primarily on the basis of scientific merit and medical importance. However, medical rationing, which is providing standard health care only to selected patients, has never been a part of our health care system. The potential use of cost-benefit analysis, which defines both costs and benefits in monetary values as the basis for allocation, creates many new medical and ethical issues. It is not possible to define the monetary worth of individuals, the dollar value of their quality of life, and their present and future economic productivity. The suggested criteria for rationing standard health care include age, medical suitability, mental acuity, family involvement, willingness to cooperate in treatment regimens, economic status (that is, the patient’s net worth and income), vocational rehabilitation, previous work record, and psychiatric and intellectual status. Some criteria, such as age and medical suitability, are now considered in heart transplantation and other experimental programs. Such other criteria as economic status and vocational rehabilitation discriminate against elderly, unemployed, and handicapped persons. To even suggest that these criteria could be utilized to ration standard medical treatment is inhumane.

Those championing allocation and rationing of health service have stated that an allocation program would be developed by a committee of policy formulators, social planners, and health industry decision makers, and that rationing of health service would be implemented by the health care team.

The impact of the prospective payment plan and DRGs on burn care and burn facilities has raised great concern among burn care professionals. Five categories of DRGs for burn injuries, based on the size of the burn injury, the need for surgical procedures, and length of stay, have been developed. The financial impact of the prospective payment plan on burn treatment is not available; however, the data I will share with you are from hospitals participating in the National Coalition of Burn Center Hospitals. If one analyzes cost and reimbursement payments for burned patients fitting into DRG criteria for each category, the prospective payment appears to provide sufficient reimbursement for care. However, when the number of outliers (those falling outside the criteria for each category) is calculated, especially on a year-to-year basis, the total number of outliers is very high and has increased from 1985 to 1986. A review of the reimbursement for outliers shows significant losses. For these patients, costs exceed reimbursement by 100%. Burn injuries do not fit into the mold of a classification system, and since patients with the more severe burns are referred to burn centers, the long-term implications of the prospective payment system could lead to financial crisis for major burn centers unless adjustments are made. The concepts of allocation and rationing of burn treatment are more threatening since those who could be making financial decisions are not well informed about the significant progress that has been made in the total rehabilitation of burn patients and their reentry into society. The era, although recent and continuing, is marked by concern for the future of burn care, introspection, continued scientific progress, and caution—especially in expansion of burn services and facilities.

Meeting the Challenges

Where do we go from here? The prospective payment system, DRGs, federal and bureaucratic intervention, and other types of financial control are here to stay and may become more intense. We must plan for the present and the future.

I see three levels of involvement to meet these challenges—goals for the burn team, the burn centers, and the ABA. First, health planners emphasize that an integrated team approach is a major factor to achieve quality care and cost containment. They state the need for coordinated health care by groups of specialists practicing together, focusing on a single disease problem. We need to reinforce that the burn team has been successful for many years in integrating health professionals from many
disciplines, including physicians, nurses, occupational and physical therapists, chaplains, social workers, rehabilitation specialists, and others. A 20-year burn team experience highlights the medical importance of the burn problem and our continued commitment to this group of patients.

A modified patient-burn team relationship must be implemented to establish a balance between medical paternalism and autonomy. More than ever before the patient needs an advocate, a spokesperson, a health professional responsible for his or her well-being. The burn patient needs a new kind of paternalism—protection against inappropriate regulatory intervention and assurance of access to effective burn care. Since we have not defined the full limits of survival after a major burn, patients' rights and autonomy must be respected. New technology is improving the possibility of quality survival even in patients with the severest burns. We must provide vigorous resuscitation for all burn patients. However, we should discuss frankly which life-support alternatives should be implemented if and when irreversible changes incompatible with life should develop. Patients can participate in treatment decisions during the early phase of their care using the "living will" concept.

With the availability of computer support it is possible for burn centers to obtain outcome data in a variety of areas: morbidity and mortality statistics, financial cost-effectiveness data, burn care benefit information including return to productivity, and quality of life. Allocation of federal funds to specific programs is imminent. We must be ready with solid data that burn care programs provide a cost-effective way to return productive persons to society. Despite the demonstrated effectiveness of re-

habilitating burn victims to be productive, well-adjusted members of society, only rare studies on the long-term rehabilitation of patients and their reentry into society have been published. Quality-of-life data are needed, not only to decide who should or should not be treated, but also to prove that organized burn care is effective in solving a major health problem.

Finally, the role of the ABA, which traditionally has been primarily toward burn care education, research, and prevention, should be expanded. Involvement of our organization in burn health care policy formation has been limited, although in recent years we have established an ad hoc committee on federal issues. This committee has monitored changes in funding, the development of standards for burn centers, and other policy formation. However, there must be an even larger commitment by the ABA to the development of burn standards as well as active participation in policy formation and funding decisions. In addition to its roles in care, education, research, and prevention, the ABA must emerge at the federal level as the primary spokesperson for the burn patient, the burn team, and the burn center.

In conclusion, we are faced with potentially difficult times. However, I have confidence that the members of the ABA will meet these new challenges with the same success as has been done in the past. Although organized burn care is a young discipline in the history of medicine, the burn team has accomplished an enormous amount in the improvement of burn care. The ABA is composed of energetic, motivated, intelligent, and resourceful health care professionals who have found solutions for burn problems in the past and will continue to do so in the future.