

Patients' Rights and the Psychiatrist's Dilemma*

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The psychiatrist has traditionally viewed himself as the patient's advocate, friend, and confidant, as well as his physician. Therefore it is no surprise that mental health professionals should feel anger, disappointment, and resentment as a result of the recent flurry of patients' rights litigation and legislation which is so dramatically changing psychiatric practice. Psychiatrists, like other physicians, had grown to expect their clients to accept and follow clinical judgments without question, and were therefore unprepared for recent public requirements of increased accountability for effectiveness and appropriateness of treatment, and unprepared for patients' demands for participation in all treatment decisions.

As an outgrowth of the patients' rights and consumer movement of the late '60s and early '70s, the doctor-patient relationship has been significantly altered and expanded. No longer is it acceptable for the physician unilaterally to decide upon treatment with the patient accepting the role of passive recipient of care. Other forces now impinge upon the interactions between doctor and patient, and have created a pentagonal relationship consisting of providers, consumers, third-party insurers, the judiciary, and public regulators and law makers, including Federal and State legislatures, professional licensing and accreditation boards, etc. The interaction among these forces generally affects the availability, quality, and nature of mental health services, and, more specifically, the role the mental health professional has in delivering them.¹

Psychiatrists, like other health professionals, often have resented the intrusion of government, third-party insurers, and especially the judicial system into the mental health field. Many doctors complain about increased paperwork, limitations on flexibility in treatment decisions, the loss of necessary care for patients in need of help ("dying with their rights on"), etc. Although these complaints may be valid, it must not be forgotten that the conditions which have existed within the mental health system during much of the past one hundred years have warranted the public's demand for increased accountability and judicial purview. That demand also signals the imperative need for psychiatry to set its own house in order, rather than have changes foisted upon it.

Historically, American society has tended to ignore, to mistreat, or to exclude from view the mentally ill citizen. In colonial times, the mentally ill were frequently beaten and were driven from town to town or placed in "poor houses." During the 19th century, care improved somewhat with the establishment of small rural asylums and other institutions where "moral" treatment was provided. The goal was to restore the mentally ill person to normal functioning or, failing that, at least to isolate him and his deviant behavior from the rest of society. To carry out this mission, government, through its commitment laws, gave a relatively free hand in treating the mentally ill to the only group willing to accept responsibility for their care — the earliest mental health professionals.² This period also marked the beginnings of organized psychiatry. Those early psychiatric physicians, charged by the public with caring for the mentally ill, created in 1844 the

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Association of Medical Superintendents of American Institutions for the Insane, which later evolved into the American Psychiatric Association.³

Unfortunately, for many reasons, the improvements promised by moral treatment and rural asylums were unfulfilled. State hospitals soon became overcrowded, understaffed, and inadequately funded. The great experiment in humane treatment of mentally ill ended, however, when society lost interest in committing the necessary resources to treat adequately the handicapped population. The age of custodialism and warehousing of the mentally ill continued well into the 1950s, when the number of hospitalized mentally ill exceeded 550,000 patients.⁴ The steady deterioration of conditions in institutions was interrupted only sporadically by brief periods of exposé, public indignation, and short-lived improvement programs.

More recently, with the development of new psychotropic medication, emphasis on community rather than institutional care, increased public concern about civil rights, and growing tolerance of deviant behavior, the population of the hospitalized mentally ill has dropped to 220,000. This process of deinstitutionalization, however, has not always proceeded smoothly. Frequently patient discharges from hospitals have occurred precipitously, without adequate aftercare. In addition, communities have protested becoming "dumping grounds" for patients ill prepared to adjust to the demands of community living (*Stoner v. Miller*).⁵ Within the institution, patients left behind have also continued to suffer from widespread abuses and violations of their clinical and legal rights. While conditions are better now than they were during the snakepit days of the 1920s, serious inadequacies continue to exist. Part of the explanation for these continuing problems lies in the fact that many institutions had earlier undergone such drastic deterioration that even significant upgrading of staff and physical plants has been insufficient to provide high quality care. For example, while in the past, five psychiatrists might have had to treat 3,000 patients, even the tripling of the staff to 15 and halving the patient population to 1,500 may still not be adequate to meet the needs of the mentally ill patients.

The intrusion of new legal requirements and regulations upon psychiatry has not occurred in a vacuum. As noted previously, many state governments, reflecting the priorities of their citizens, had permitted institutions for the mentally ill to deteriorate. Recruitment became increasingly difficult, and those psychiatrists who remained in public service accepted the custodial role placed on them by the public, and did the best they could with limited resources. When the patients' rights movement began spotlighting the inadequacy of care within the mental health system, many psychiatrists became defensive and resisted attempts to make care more responsive to patient needs.⁶ Much of the blame for the inadequacies of the mental health system has been directed at psychiatry, which in the public's view was nominally responsible for the care of the mentally ill. The defensiveness of psychiatrists and their inability to convince the public that they were capable of assuring the adequacy and appropriateness of care, as well as capable of policing the actions of their colleagues through peer review, has led to their becoming excellent scapegoats.

While the defensiveness is understandable — nobody likes to be criticized — and the objection to close peer review is historically rooted, these explanations do not change the fact that if American psychiatry had taken more responsibility for stopping the serious abuses that have taken place in the name of institutional care, both the patients and the profession would have been better served. Although psychiatry is frequently identified as the culprit and enemy of patients' rights, greater blame might be justifiably placed on the public for failing adequately to support high quality care, and the judiciary for failing in its responsibility to monitor more closely the condition of those citizens whose liberty had been abridged in commitment proceedings.

Recent suits in Wisconsin have spotlighted the failings of some judges to adequately protect patients' rights through ignoring or undercutting existing legislated safeguards.⁷

Far too often judges and attorneys accepted without question the pledges of mental health professionals that a given patient would be better off and would receive treatment if hospitalized. Attorneys frequently did not cross-examine institutional witnesses. They also failed to seek less restrictive alternatives to hospitalization or to obtain independent expert testimony. Still, despite the failings of the judicial system and the neglect of the public and its governmental leadership, the conditions in many mental hospitals have been so terrible that even with distribution of responsibility, psychiatry still receives substantial blame for its role in maintaining inadequate, dangerous, and nontherapeutic institutions.

A brief description of some of the institutional conditions to which citizens of the United States have been subjected would be valuable at this point. During the course of the *Wyatt v. Stickney*⁸ trial, which involved the Alabama Mental System, it was established that the State legislature had seriously underfunded the mental retardation center (Parlow) and the Bryce Hospital. As a result of lack of funds, leading to severe understaffing, it was not possible for the staff at Parlow to provide care on an individual basis. They did not pick up toys; they locked up toilet paper because patients tended to strew it all around the facilities. Therefore, the patients were dirty at the end of the day, and to handle this problem, because the facility was understaffed, patients were used to strip each other and line each other up, much as is done in a car wash. Retarded patients were then handed high pressure water hoses as other residents walked through this water-works. On one occasion, a patient died when the hose was inserted into his rectum and the water was turned on. Another mentally retarded resident in a wheel chair died when boiling water was turned on and his testicles were scalded off. Children in this facility were strapped to their beds in spread-eagle fashion each night so that they could be better controlled and watched. Testimony at the trial indicated that from time to time when parents and guardians took their children or wards home for the weekend, they would call the hospital and say that the patient was lying on his bed at home in spread-eagle fashion, crying. On such occasions the hospital staff would instruct the parents that "if they would just tie the patient down, he would stop crying — he was used to that kind of treatment and that is what he was waiting for."⁹

For the situation described in *Wyatt*, there can be no clinical defense. It is useless for psychiatry to try to defend facilities which, in the words of a past American Psychiatric Association President, "are bankrupt beyond repair."¹⁰ Efforts can more productively be directed toward the establishment of recognizable standards of treatment, toward the development of mechanisms for assuring that patients are being adequately and appropriately treated, and toward the *utilization* of the legal system as a tool to improve patient care.

The legal system, after years of all but ignoring the status and treatment of civilly committed citizens, has begun to establish procedures aimed at protecting this handicapped population from abuse. This growing legal activism reflects the public's demands for a more responsive health care system, the disillusionment bred from the too-frequent overselling of the effectiveness of psychiatric treatment, and the revulsion from the reports of the abuses of psychiatric care. The courts have shown little enthusiasm about promulgating minimum standards under which treatment would be possible, but have accepted the responsibility of doing so, since it has become clear that such standards will not be readily forthcoming from mental health professionals.

The increased scrutiny of their actions by the judiciary, however, is making many psychiatrists, in the words of Jonas Rappoport, M.D., "feel beleagued." They feel, with some justification, that they are being made scapegoats for society's neglect of its mentally ill citizens and are being hamstrung in their practice as the result of the suits brought by attorneys many of whose attitudes toward mental illness are reflective of Szasz' anti-institutional biases. Psychiatry, however, cannot abandon its responsibility to the mentally ill, even if the law at times makes its task the more difficult. What it must do

is acquire a better understanding of the changing demands and expectations of its clients and of its new legal obligations and responsibilities.

Despite the belief of some psychiatrists that the mental health system is being singled out for special scrutiny by society and the legal profession, patients' rights is actually part of a far broader consumer movement, seeking higher standards of accountability from all providers of services — be they television repairmen, Senators, or physicians. Consumerism began as a movement to protect consumers from exploitation in the profit-making marketplace, but it soon became obvious that neglect of human rights and serious abuses were also occurring in nonprofit, charitable, and humanitarian service organizations ranging from schools to hospitals.

Patients within an institution experience a double limitation on their rights — one created by their disabilities and the other by the very organization of an institutional system. While the actual disability which requires residential care may limit a patient somewhat, the prejudging of his capacities by the staff may constitute a far greater obstacle. In the mental health facility, this means that the simplest request — for aspirin for headache, the right to call home, etc. — is subject to evaluation, interpretation, and possible rejection if it is viewed as "not in the patient's interest." Even in the most enlightened institutions, there will inevitably be a strain between the needs of the individual to live a life without outside domination and the institution's needs to deliver services efficiently. Within a mental health institution or any other long-term care facility, such organizational factors can be dehumanizing, and promote frustration, resignation and despair.¹¹

What are these rights that patients are demanding and for which lawyers are bringing suit? Are they so unacceptable to psychiatry that they must be resisted at all counts? Some patients' rights groups have sought legislation to guarantee the rights of all patients. Others, including Assistant U.S. Attorney General Stanley Pottinger, Esq. have declared such bills of rights as irrelevant, since patients already have such rights and *more* under the Constitution — the problem is not granting rights but protecting them.¹² For the sake of better understanding patients' demands, some of the most frequently articulated rights will be examined.

While many patients' bills of rights have been proposed, including one by the American Hospital Association, the publication in the Federal Register of rights of patients in skilled nursing facilities, etc., the following digest of rights and freedoms can be viewed as essential in balancing clinical needs with the legal rights of patients.* The first right can be summed up by the phrase, "to be treated with dignity and respect by service providers, and to have one's humanity recognized throughout the course of treatment." The second is the right to freedom from unnecessary hospitalization. Although mental health professionals tend to view hospitalization as more benign than do patients, they must bear in mind the disruptive and painful aspects of hospital care. In the case of certain high risk groups, such as the elderly, institutionalization may be tantamount to a death sentence. (More than 10 percent of the elderly die within 30 days of being institutionalized in a long-term care facility.¹³) The third right is to be free from unnecessary treatment. Not everyone seeking treatment is really in need, and recent reports have indicated that psychotherapy may actually be harmful to some patients.¹⁴ The fourth is the right to information about treatment — including treatment philosophy, style, duration, and likely outcome. Most skilled psychiatrists look upon the process of explaining the details of the proposed treatment, including information about the most likely side effects, as an integral part of treatment itself. The problem usually occurs when a psychiatrist is charged with the care of too many patients, or insists on underestimating his client's capacity and right to make his own decision.¹⁵ The fifth right concerns the privilege of confidentiality which belongs to the patient. This right tends to be universally accented in medicine, although it may be weakened by demands for

*See the Appendix for a concise listing of these rights and freedoms.

information by third-party insurers and some court decisions (Tarasoff) which require psychiatrists to report certain information, such as the potential dangerousness of a client, to the police authorities.¹⁶ The sixth basic right deals with the quality of the services that a patient receives. Although some might argue the point, in psychiatry as in the rest of medicine where the basic dictum is *non noceri* — to do no harm — it would often have been better not to hospitalize a mentally ill patient rather than subject him to inadequate or harmful treatment in an overcrowded and understaffed facility. The seventh right is the right to mental health services when and where they are needed. The failure of society to make mental health services available in sufficient quantity and quality to meet the needs of its citizens represents a sad commentary on health care priorities. The eighth right is the guaranteed opportunity for a patient to participate in treatment decisions which affect him, and to be actively involved in the establishment of priorities. Psychiatrists and other members of the health community have tended to perceive themselves as determining and serving the public's best interest through a "doctor knows best" philosophy. There has been the tendency to forget that practicing medicine is a privilege, not a right, granted by society. This privilege must be earned initially and reaffirmed by responsible and reasonable behavior. The ninth right patients are seeking is the right to redress for grievances. In the area of rights, many professional grievance and ethics committees have failed adequately to protect hospitalized mentally ill patients. Where were these committees when Kenneth Donaldson, who was clearly not dangerous and able to live in the community, was denied for 15 years the right to return home, move to a halfway house, or live with a concerned friend?¹⁷ Educational requirements and degrees do not guarantee ethical or competent behavior. Through more effective and continuous peer review the psychiatric profession can save itself from the growing number of restrictions placed on medical practice by the courts, and simultaneously establish a mechanism for protecting the public from harm.

A final element needed by patients to assure that they are getting appropriate and humane treatment is patient advocacy. The right to have a patient advocate who is accountable only to the patient, and whose salary, hiring, and firing are not the responsibility of the hospital administration, can help make patients' rights a reality rather than a philosophical or legal fiction. Such advocates would be able to involve themselves at the patients' request in all aspects of care and would have the right to obtain consultation with other doctors and to examine medical records as necessary. To meet these multifaceted requirements, patient advocates should have legal and clinical experience. Such advocates might be found among forensic psychiatrists or created through a team approach involving a forensic psychiatrist, a concerned private citizen or former patient, and an attorney. This team could help to assure that clinical needs are being met, that legal rights are respected, and that ancillary matters such as housing, business, and marital issues are being handled properly.

Mental health advocacy provides a unique mechanism by which psychiatry can respond constructively and effectively to the dilemma of delivery of mental health care in a system increasingly influenced by legal requirements and consumer demand. Advocacy can become the method by which the psychiatrist, lawyer, and patient or patient representative can work cooperatively instead of antagonistically in meeting a patient's wishes, needs, and rights.

While a comprehensive advocacy program has been described more extensively elsewhere, briefly it might consist of a tripartite system of patients' representatives, lawyers, and an ombudsman, with psychiatrists participating in the activities of each component.¹⁸ The primary element in the program is the patients' representative, who will be concerned with screening patients for such matters as the appropriateness of commitment, of guardianship, of conditions for forced medication and other forms of treatment, and of transfer or release to large institutions. The patient's representative will also devote his or her efforts to preserving the "right to non-institutionalization"

whenever possible, and to arranging when appropriate the transfer of patient to other mental health personnel in the community.

The second portion of the program involves the legal advocates. They are necessary in handling the multitudinous legal problems of an indigent or deprived population. In carrying out his role, the legal advocate will use the skills of his profession, bringing court action on behalf of a patient against the institution, filing class action suits, and lodging complaints regarding specific violations of patients' rights in order to secure redress. (The active involvement of mental health staff in assisting attorneys to represent their clients' wishes goes a long way toward assuring that alternative clinical regimens have been explored. The attorney's main task, however, is to be available as a last resort for serious problems which the patient's representative has failed to solve through less formal adjustment mechanisms.)

The third element in a comprehensive advocacy program, especially relevant for a mental health system undergoing rapid change, is the ombudsman. The ombudsman could address problems throughout the entire mental health system. His role would not be the resolution of individual complaints; rather, with his broad investigatory ability, independence, and objectivity, he could make recommendations to correct the system's malfunctioning.

This model for patient advocacy can be helpful in preventing the unfortunate situation of the patient being caught in a tug of war between two opposing forces — the psychiatric and legal professions — battling for his custody. Such a comprehensive advocacy program can become an important and lasting alternative to litigation and can help to create a mediated, flexible system of care for the mentally ill.

The legal system has inexorably intertwined itself with the mental health system, and although there will be many areas of incompatibility, attempts by psychiatry to wrest itself free will be costly and futile. The legal system must recognize its limitations when dealing with diagnosis and treatment of medical illnesses, just as psychiatry will have to accept greater public scrutiny and directing of its priorities.

After 200 years of working to improve the conditions of the mentally ill, American psychiatrists must not abandon their advocate role to either the legal profession or the consumer group, nor renounce their obligations as physicians to treat the whole patient within the context of his clinical and legal rights. Psychiatrists must strive to help the legal system understand the problems and needs of patients from a clinical perspective and make sure that these needs are properly reflected in any judicial decision. By working with the law and with concerned citizens, psychiatrists will be participating in the creation of a more responsive and effective mental health system. Its ultimate success or failure, however, will depend on how well mental health professionals have succeeded in convincing the public, legal professionals, and patient's representative of the importance of simultaneously meeting clinical needs through adequate financing, recruitment of quality staff, etc., while assuring rights guaranteed by the Constitution.

References

- 1 Kopolow L: Patients' rights and psychiatric practice. Presented at APA Convention, Miami, 1976
- 2 Rothman D: *Discovery of the Asylum*. Little, Brown and Co., Boston, 1971
- 3 Friedman A, Kaplan H: *Comprehensive Textbook of Psychiatry*. Williams and Wilkins Co., Baltimore, 1967
- 4 Witkin M: *State and County Mental Hospitals, United States 1973-74*. DHEW Publication No. (ADM) 76-301, 1976
- 5 *Stoner v. Miller*, 373 F Supp. 177 (E.D. N.Y. 1974)
- 6 Liebensohn Z: *Defensive psychiatry*. Unpublished paper presented at Dartmouth Symposium on Law and the Mental Health Professions, Aug. 1976
- 7 *State of Wisconsin ex rel v. Edwin A. Mundy*, Case No. 441-417, Circuit Court of Milwaukee County, Wisconsin
- 8 *Wyatt v. Stickney*, 325 F. Supp. 781 (Md. Ala. 1971)
- 9 *Ibid.*

- 10 Solomon HC: Presidential address to American Psychiatric Association. *Am J Psychiat* 115, July 1958.
- 11 Annas G, Healey J: The patients' rights advocate. *Vanderbilt Law Rev* 27, 1974
- 12 Pottinger J S: The role of the judiciary in safeguarding patients' rights. Presented at APA Convention, Miami, 1976
- 13 Statistical Note 74, DHEW No. (HSM) 73-9005, 1973
- 14 Parloff M: Can psychotherapy harm anyone? Interview, *ADAMHA News*, 11: 20 (Oct. 1, 1976)
- 15 Liebensohn, *op cit.* n. 6
- 16 *Tarasoff v. Regents of University of California*, 529 P. 2d 553 (S. CF Cal. 1974)
- 17 *Donaldson v. O'Connor*, 493 F. 2d 507 (5th Cir. 1974)
- 18 Kopolow L *et al.*: *Mental Health Advocacy: An Emerging Force in Consumers' Rights*. Washington, D.C.: Government Printing Office, 1977 (in press)

Appendix: Patients' Rights

- I. The right to be treated with dignity and respect by service providers and to have one's humanity recognized throughout the course of treatment.
- II. The freedom from unnecessary hospitalization.
- III. The freedom from unnecessary treatments.
- IV. The right to information about one's treatment — including treatment philosophy, style, duration, cost, and likely outcome.
- V. The right to confidentiality.
- VI. The right to high quality and effective services.
- VII. The right to have services available when and where needed.
- VIII. The right to participate actively in treatment decisions and in the establishment of priorities.
- IX. The right to redress for grievances.
- X. The right to the assistance of a patient advocate.