Patients' Rights Advocates in San Francisco

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"Patients' rights will be to the 1980's what civil rights and woman's rights were to the 60's and 70's."[1]

Patients' rights in psychiatry encompass the areas of the right to receive treatment,[2] right to refuse treatment,[3] informed consent,[4] and regulations regarding involuntary commitment.[5,6] This article focuses on the role and utilization of the patients' rights advocates that were established by California legislation. This topic should be of interest to psychiatrists and mental health professionals in other states since the California experience may portend similar developments in other parts of the country.

In California, the issues of right to refuse medication and informed consent for administration of psychotropic medications have been studied in litigation since 1978 as key issues raised in the *Jamison v. Farabee* lawsuit.[7] Regulations regarding involuntary hospitalization are contained in the Lanterman-Petris-Short Act of 1969, which is part of the California Welfare and Institutions Code. In addition, a patients' rights advocate system was established in California and this system has been functioning in San Francisco since 1978.

California legislation established the patients' rights advocate system with the purpose of ensuring that psychiatric patients in mental health facilities are afforded their "statutory and constitutional rights."[8] Each county mental health director in California designates a patients' rights advocate who is responsible for investigating complaints of patients and acting as their advocate. The mental health director of a California county may either appoint a civil service employee who is not directly participating in the mental health service delivery system or contract with a private group or private individuals to serve as patient advocates. In San Francisco, the contract was awarded to the Patients' Rights Advocacy Service through Consumers' Union. The state patients' rights advocacy office recommends that there be at least one advocate for each 500,000 individuals in the population served. With the consent of the patient, the Patients' Rights Advocate may have access to the patient's chart. The advocate receives special in-service courses which may consist of as little as 2½ days of

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training. In the California setting, many advocates have college degrees or mental health experience, although neither of these is required.

When patients are admitted to a hospital, a group home, or a day treatment center, they are given a Patients' Rights Handbook, which specifies their rights and gives the number to call if they feel that their rights are being denied. A list of rights and the complaint procedure are also posted on all wards and common living areas of facilities. Patients' rights are specified as including the right to adequate care and treatment, the right to receive treatment in the least restrictive environment, the right to be provided with mental health services without discrimination because of race, color, sex, age, or religion, the right to confidential records, the right to wear their own clothes, use their personal possessions and keep personal funds, the right to have individual storage space, the right to see visitors, the right to receive and send written unopened correspondence, and the right to have access to telephones and letter-writing materials. Patients are told that these rights cannot be denied without good cause. Patients are also told the requirements for involuntary commitment and that staff shall assist them in filing a writ of habeas corpus to the Superior Court if they want to be released. Patients are also told that they cannot be secluded or restrained without a physician's order and that they have the right to refuse to take part in research projects, psychosurgery, and electroconvulsive therapy.[8]

At this time it seems appropriate to review and question how this patients' rights advocate system is working. Is this system being properly used or abused? Are patients' rights in fact being protected?

To respond to these questions, this article presents data from the years 1982 and 1983 regarding who utilizes patients' rights advocate services and for what purposes.

Method

The San Francisco Patients' Rights Advocacy Service was asked to supply statistics for the last five years as to the utilization of the service. The director of the service advised that the most valid statistics were available for the period after August 1982, after which time the system for gathering statistics had improved. Therefore, this report focuses on September 1982 through August 1983. These statistics were gathered routinely and were sent to the California State Office of Patients' Rights. The statistics were discussed with representatives from the San Francisco Patients' Rights Advocacy Service and with mental health professionals who work in psychiatric hospitals and have had multiple contacts with the Patients' Rights Advocacy Service. Questions were asked about their assessment of the need for patients' rights advocates and about possible beneficial and harmful effects of the service as it has been functioning. Statistics were also gathered concerning the total number of inpatients in San Francisco hospitalized during this period, contacting all of the psychiatric hospitals in the city. Information was also obtained concerning the cost of the Patients' Rights Advocacy Service from the budget department of San Francisco Community Mental Health Services.

Results

Patients' Rights Advocacy Services Data In the 12-month period of this study, there were 714 calls to the Patients' Rights Advocacy Service from all San Francisco catchment districts. Demographic information about these callers is listed in Table 1. The most frequent callers were males between the ages of 19 and 59, who were hospitalized involuntarily in an acute inpatient unit, and Caucasian or whose race was unknown. The totals in each category of Table 1 are not identical inasmuch as the statistics were not gathered uniformly since it is not the primary purpose of the Patients' Rights Advocacy Service to gather statistics.

The reasons for the calls are summarized in Table 2. The general content of typical calls for the most frequent categories (averaging at least one per

Table 1. Utilizers of San Francisco Patients' Rights Advocacy Services from September 1982 to August 1983

Sex	
Male	426
Female	288
Total	714
Age	
0–18	35
19–59	543
60 and up	48
Unknown	97
Total	723
Race	
White	296
Black	88
Hispanic	46
Asian	26
Unknown	264
Total	720
Facility	
Nonhospital	303
Hospital (acute)	346
Locked facility	23
Total	672
Legal status	
Voluntary	49
Involuntary	304
Criminal justice	20
Unknown	55
Total	428

Table 2. Patients' Purpose in Contacting Patients' Rights Advocacy Services*

Release	218
Benefits/entitlements	60
Medication	40
Placement/needs housing	37
Complaints about treatment by staff or in general	30
Medical records	27
Loss of property	25
Confidentiality	23
Referral to lawyer	17
Clarification of legal status	13
Seclusion and restraint	12
LPS conservatorship	11
Complaints re medical care	10
Physical abuse	9
Denial of rights	8
Conditions at facility	8
Medi-Cal	8
Sexual abuse	7
Eviction	7
Access to treatment/services	7
Probate conservatorship	5
Referral to therapist	5
Electroconvulsive therapy	3
Access to personal funds	3
Disposition of minor	2
Board and care home dispute	2
Criminal justice problem	1

* Number of contacts in period from September 1982 to August 1983 for each category.

month) and the responses and actions of the patients' rights advocates can be summarized as follows:

Release The patient says, "I'm being detained and want to be released." The patients' rights advocate will check the patient's chart and explain the law. If the patient is involuntary, the patients' rights advocate will refer the patient to the public defender. If the patient is voluntary, the patients' rights advocate will tell the patient that he/she can leave.

Benefits/Entitlements The patient says, "My Social Security check is late," "My Social Secutity check has not arrived at the right address," or "I have appealed the cancellation of my Social Security benefits and have not won." The patients' rights advocate will usually refer the patient to legal services or the Department of Social Services.

Medication Eight-five to 90 percent of these calls are from involuntary patients. The patient says, "I don't want to take my medications," or "I want to change my medications." The patients' rights advocate generally checks the chart to see that the patient is not on huge doses of medication. (One of the patients' rights advocates told me, "I want to make sure the patient is not on 5,000 mg. Thorazine.") The patients' rights advocate will characteristically ask the patients if they want them to call their doctor. The patients will also be encouraged to file a writ of habeas corpus. There are also calls from voluntary patients who feel they have been verbally coerced into taking medication. Here, the patients' rights advocate will tell them they should not allow themselves to be coerced if they are voluntary.

Placement Needs/Housing The patient may say, "I don't want to go to a locked facility; I want a halfway house," or "I don't want to go to a locked facility in San Jose; I want a locked facility in Santa Cruz." The patients' rights advocate will encourage the patient to file a writ of habeas corpus or possibly will negotiate with the conservator for a different placement. In one case, an elderly patient needed a place to stay and the patients' rights advocate called many hotels to arrange a placement.

Complaints About Treatment by Staff or in General The patient will complain that a staff member is disrespectful or mean or that the patient was given misinformation. The patients' rights advocate will try and clarify the situation and will mediate between staff and patients. The patients' rights advocate may also encourage the patient to write a formal complaint to the director of nursing or the appropriate administrator. In one case, a patient was refused treatment in an outpatient facility because he was refusing medications. The patients' rights advocate spoke to the director of the clinic who acknowledged, "That's illegal," and said he would check into it.

Medical Records These complaints are in reference to the California state law AB-610, which gives patients access to their records. Patients may say, "I have requested my medical records and have not gotten action," or "How do I get my records"? The patients' rights advocate may go with a patient to read the medical record. If the facility does not release the record, the patients' rights advocate will write a letter to the appropriate administrator, or if not successful there to the local mental health director, and finally to the State Patients' Rights Advocacy Office.

Loss of Property The patients may claim that the staff did not return all of their belongings to them or there may be disputes about what property patients had when they left the hospital or half-way house. The patients' rights advocate will attempt to clarify and resolve this situation.

Confidentiality Patients may complain that their employer has found out that they are a psychiatric patient or the patients may complain that their doctor broke confidentiality in some other way regarding their psychiatric treatment. The patients' rights advocate will make a complaint to the doctor and/or the facility and ask, "What is being done so this won't happen again?"

Referral to Lawyer Patients' rights advocates indicate that when a legal referral is requested, they refer to low-fee or no-fee lawyers who are interested in patients' rights. In the five years of the system's operation,

Table 3. Examples of Types of Lawsuits Resulting from Patients' Rights Advocates' Referrals to Lawyers

Inappropriate eviction
Injury during restraint
Injury related to medication
Loss of property

there have been approximately 10 cases that have been brought to litigation.

Clarification of Legal Status The patient will ask, "What legal hold am I on?" The patients' rights advocate will clarify the situation.

Seclusion and Restraint The patient will say, "Seclusion was not justified." The patients' rights advocate will look at the chart and see if there is adequate documentation of clinical care issues, e.g., 15-minute checks, or reason for seclusion. If the record is not satisfactorily documented, the patients' rights advocate will discuss the issue with the staff and the administrators and, at some later time, do another follow-up review of the issue.

It is hard to gain details about all of the cases that were brought to litigation after the patients' rights advocates made a legal referral since different lawyers are involved and some of the cases are still in the courts. Nevertheless, the San Francisco Public Defender's Office was able to give me information about five of the cases which are summarized in Table 3 with details as follows:

Inappropriate Eviction An attempt was made by a residential treatment facility to evict a patient who refused to move. The patient sued the facility and won because there is a landlord-tenant relationship as well as a treatment facility relationship between patient and facility.

Injury During Restraint An elderly woman was put in a sheet pack for restraint purposes and developed medical complications. The hospital was sued for negligence with the claim that the patient was not adequately checked. There was a settlement. A patient who had a history of setting fires was put into seclusion and restraints. She had hidden a cigarette lighter in her undergarments and she seriously burned her hand and it had to be amputated. The case is still in litigation.

Medication A patient was given high doses of medication and discharged after her 72-hour involuntary hold expired. After discharge the patient developed a severe dystonic reaction of her jaw and sued the hospital for personal injury. The hospital settled the case.

Property A patient felt that she was inappropriately denied money in a private hearing and therefore she successfully brought a lawsuit to regain her money.

The patients' rights advocates feel that they provide an essential service which protects patients' rights and that their presence and interventions benefit patients therapeutically because patients feel that someone is listening to them. They believe that patients almost always tell the truth and only a minority of complaints are exaggerated. They admit that occasionally patients who really do need treatment are prematurely released from a hospital because of the action taken by the patient (e.g., filing a writ of habeas corpus) following his contact with the patients' rights advocate. They feel, however, that this is necessary to preserve the patients' civil rights.

Mental Health Professionals' Comments Five mental health professionals (two psychiatrists, one social worker, and two clinical nurse specialists) who work in psychiatric hospitals and have had multiple contacts with the Patients' Rights Advocacy Service were interviewed by me. All of the mental health professionals felt that the idea of patients' rights advocacy was generated because there have been abuses of patients in psychiatric hospitals and that the goal of the Patients' Rights Advocacy Service is to protect patients' rights. One mental health professional stated, "The need for patients' rights advocacy grew from a generally recognized concern about types of neglect, poor practices and abuses of patients—retarded, disabled, aged, infants and psychiatric—that were documented in books, reports, investigations studies, parents' groups, and lay organizations for many, many years." The mental health professionals were asked to comment about how necessary they felt this service to be, since there is legislation in California which already protects patients' rights, e.g., California AB 3454 which established mandatory certification review hearings for all involuntary patients and the medication consent forms for all voluntary patients which resulted from early negotiation of the *Jamison v. Farabee* lawsuit.[7] Also, there is an active and well-funded public defender's office which covers the mental health court in San Francisco, and the final resolution of the *Jamison v. Farabee* lawsuit established a procedure for review by an outside psychiatrist before medicating refusing, nondangerous involuntary patients; these hearings started in April 1984 at one state hospital and eventually will be extended to all hospitals.[9] The mental health professionals were of differing opinions as to the necessity of the Patients' Rights Advocacy Service, with positions ranging from the service being totally unnecessary to a belief that it was necessary to mobilize the public defender's office or the viewpoint that the patients' rights advocates offered many more important services to patients than were provided by the public defender's office. There were universally positive feelings about the social service functions provided by the advocates.

When mental health professionals were asked how they felt about the advocates reviewing medical charts, there were many reservations about the capacity of patients' rights advocates to interpret information in the chart from a knowledgeable viewpoint. They felt that patients' rights advocates misinterpret and misunderstand information in charts because they do not have adequate clinical experience. One mental health professional questioned whether a patients' rights advocate with minimal training should be making judgments about the appropriateness of dosages of medication. There was also concern about how patients' rights advocates might use sensitive and confidential information from the chart or share it with patients inappropriately.

The mental health professionals universally had concern about the potential effect of the patients' rights advocate on the doctor-patient relationship in that they saw the advocate as usually interfering with the relationship. One mental health professional stated, "If a patient reports a legitimate problem, the patients' rights advocate turns the incident into a litigious, adversarial issue rather than one of clinical problem solving. The advocate interferes with the therapeutic alliance by interjecting mistrust in someone who is already paranoid and has difficulty forming relationships with others."

One mental health professional related an incident in which a patient who was angry told the advocate that he did not like his nurse. The advocate got angry and went up to the charge nurse and said, "I think that you need to reassign this patient to another nurse." The staff felt that the advocate should have told the patient to talk directly to the nursing staff.

Another mental health professional related an incident where an advocate was on the inpatient unit when the security police were called to help restrain an agitated and belligerent patient who was threatening to attack staff. The advocate got very upset and said that the police were making the patient more agitated and the advocate tried to intervene with the patient and with the nursing staff to keep the police away from the patient. From the nursing staff's perspective, the patient was getting increasingly agitated because of the advocate's inappropriate intervention and the nursing staff felt that the advocate was putting herself, the nursing staff, and the patient at risk of bodily harm. When the incident was discussed with the advocate, she defended her actions by saying that she felt that it was her job to intervene if she felt patients' rights were being violated.

When asked whether patients' complaints were usually valid, most of the mental health professionals felt that many complaints were exaggerated; e.g., when a patient said that no one paid any attention to him. One person said patients often misperceive the situation or disagree with what they are told. Rather than dealing directly with staff, they call patients' rights advocates. Another person stated, "We hear from patients that they are being harassed by the FBI and the CIA, but we don't investigate! The patients' rights advocates' jobs are dependent on patients complaining. They have a stake in saying the complaints are valid." One mental health professional attended a patients' rights advocacy workshop and stated that the group was composed of hostile, antimental health people, many of whom were expatients who were dissatisfied with their treatment.

Most of the mental health professionals did, however, acknowledge that the existence of a patients' rights advocacy service may have made them more attentive to the issue of patients' rights and certaintly made them more careful about documenting the reasons for denial of patients' rights.

Statistics About Percentage of Inpatients Utilizing Service and About Budget To better evaluate the proportion of patients who utilize the Patients' Rights Advocacy Service, a telephone survey was conducted of every psychiatric inpatient unit in San Francisco to find out the number of admissions they have each year. It was also confirmed that, in fact, each inpatient unit routinely provides a copy of the Patients' Rights Handbook to each admission. The total number of admissions to acute psychiatric inpatient units in San Francisco in the year under study was 5,851. From the statistics gathered by the Patients' Rights Advocacy Service, it was learned that in the period of study 346 acutely hospitalized patients called. Thus, approximately 6 percent of all hospitalized patients utilize the service and 94 percent do not. (The numbers given by Patients' Rights Advocacy Services and the inpatient units probably include repeat admissions but an unduplicated count is unavailable.)

It is difficult to ascertain how many patients outside psychiatric hospitals (e.g., in group homes, day treatment programs, or outpatient departments) may receive the Patient's Rights Handbook and, therefore, are encouraged to utilize the service. Thus, although it is known that 303 nonhospitalized patients called the Patients' Rights Advocacy Service during the year under study, it is impossible to determine what percentage of nonhospitalized patients this value represents.

The public funding for the Patients' Rights Advocacy Service is $103,101 per year. If we figure that there are approximately 700 calls per year to the Patients' Rights Advocacy Service, we can see that the cost per call is approximately $147 per call.

Discussion

The data show that only 6 percent of acutely hospitalized psychiatric patients utilize the services of the patients' rights advocates and that this establishes the cost of the service at about $147 per patient contact. It seems appropriate to question whether the services are worthwhile.

From the perspective of patients' rights advocates, the patients' rights advocate system was established with the intent of protecting patients' rights. Many patients' rights advocates believe that psychiatric patients are mistreated and taken advantage of and that they need advocates to help them improve their lot.[10] Furthermore, they feel that fundamental constitutional rights are at stake: the right to be free from cruel and unusual punishment, the right to equal protection under the laws, and the right to self-determination and personal autonomy, i.e., the right to be left alone.[11]

From the above perspective, the patients' rights advocate system would appear to be functioning well. The data about the types of calls received show that the patients' rights advocates provide two functions: (1) social services to patients such as those related to problems with housing and Social Security payments and (2) monitor treatment facilities to be sure that patients' constitutional rights are not being violated.

From the perspective of patients' rights advocates, they provide important services even though only 6 percent of all hospitalized patients utilize them. The cost of $147 per call is expensive but justifiable. An analogy could be made that the fire department which is utilized by only a small fraction of the population and is an expensive service is universally recognized as an essential service. In addition, the very existence of the patients' rights advocate system and the threat of monitoring and reporting abuses may, in fact, decrease the number of abuses. This would not be reflected in the statistics about utilization but would, in fact, be an important service to patients.

From the perspective of mental health professionals, the contribution of the advocate system in helping patients obtain social services is certainly useful. The advocates may provide patient transportation, intervene with landlords, arrange for patients to get Social Security checks, and may provide other helpful services. Although social workers and other mental health professionals could provide some of these services, it is recognized that in this area of their role the advocates do fill a need.

There are divided opinions, however, as to whether the patients' rights advocates are essential to ensure patients' constitutional rights. It seems clear that opinions about necessity are partially based on opinions about the extent of abuse of psychiatric patients in different settings and on different experiences with the degree of activity and initiative by the public defender's office which is responsible for many of the same functions as the patients' rights advocates.

Furthermore, when talking about patients' rights, there is the important issue stressed by mental health professionals about the balance of constitutional rights *v.* medical needs. When patients' rights advocates encourage a voluntary patient to leave the hospital, is this really in the best interest of the patient? Advocates have treated patients' rights as if they were the needs of the mentally ill.[12] The legal and advocacy systems may fail to recognize that patients' refusal to comply with treatment may be a manifestation of their illness and that constitutional arguments serve to justify deprivation of appropriate care.[13] Severe or tragic consequences can ensue to the patient or those around him in the absence of treatment.[14] Advocates assume the authority to bring about certain actions such as the termination of treatment, yet they are not assigned any medical or legal responsibility for the negative consequences of these actions, such as having the patient's condition deteriorate.[10] In addition, the advocates are given very little training considering the nature of their involvement in important aspects of patient care and the fact that they have access to patients' charts. As has been suggested by Lamb,[10] advocates should receive more in-depth training including the experience of providing direct service to severely disturbed patients.

The other area of potential harm arising from the role of the patients' rights advocates system as revealed in this study is its possible negative effect on the therapist-patient relationship. The patients' rights advocates reinforce the idea that patients may be abused by their doctor unless the providers are vigilantly monitored. This can create an atmosphere of mistrust and an adversarial relationship.

In summary, the present patients' rights advocate system appears to have good and bad points. If the existence of a monitoring system does prevent abuse of patients, this is certainly a good thing. However, when as the result of the intervention of an advocate a patient is discharged prematurely and his condition deteriorates or he commits suicide or harms someone, these are indeed serious consequences. The patients' rights advocates should be forced to take legal responsibility for the consequences of their actions with respect to patients. They should be liable for suit just like everyone else who is involved with patient care. Perhaps this will lead to more responsible advocacy. Patients' rights advocates would be more helpful if they saw themselves as working closer with the mental health professional staff, if they learned to understand the complexity of clinical decision making, and if they had to take responsibility for their actions.

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