

A Study of the Right to Refuse Treatment

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On June 18, 1982, the United States Supreme Court issued its long-awaited opinion in the "right to refuse treatment" case *Mills* (previously *Okin*) v. *Rogers*.¹ The Supreme Court stated that the case posed a substantive issue, "a definition of [a] protected constitutional interest, as well as identification of the conditions under which competing state interests might outweigh it," and a procedural issue, "the minimum procedures required by the Constitution for determining that the individual's liberty interest actually is outweighed in a particular instance."²

The Court noted that both these issues were heavily affected by state as well as federal law. The federal Constitution defines minimal liberty interests, while a state may go beyond these minimal rights. Because of the heavy involvement of state interests, the Court decided that the issues it identified must be resolved in light of an intervening Massachusetts Supreme Judicial Court decision, *Guardianship of Roe*, which held that a person has a protected liberty interest in "decid[ing] for himself whether to submit to the serious and potentially harmful medical treatment that is represented by the administration of antipsychotic drugs."³ The Massachusetts Court "required a *judicial* determination of substituted judgment [as opposed to that of a court-appointed guardian] before drugs could be administered [involuntarily] in a particular instance, except possibly in cases of medical emergency."⁴

The Supreme Court believed that *Roe III* recognizes rights under Massachusetts law "that are broader than those protected directly by the Constitution of the United States."⁵ Although *Roe* applied to an outpatient who had been declared incompetent, the United States Supreme Court thought it may also apply to inpatients. The case *Mills v. Rogers* was remanded to the Court of Appeals for the First Circuit; the latter Court's decision in the case was vacated.

The Supreme Court does not directly articulate the federal Constitutional requirements for protecting the liberty interest of an involuntarily hospitalized mentally ill person. However, it quoted from two prior cases, *Addington v. Texas* and *Parham v. J.R.*⁶ In *Addington*, the Court ruled that "clear-and-convincing" rather than "beyond-a-reasonable-doubt" evidence was sufficient to hospitalize a mentally ill person against his will. The Court commented that "because a person 'who is suffering from a debilitating mental illness' is not 'wholly at liberty,' and because the com-

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plexities of psychiatric diagnosis 'render certainties virtually beyond reach,' 'practical considerations' may require 'a compromise between what it is possible to prove and what protects the rights of the individual.'⁷

In *Parham*, the Court held that the constitutional rights of minors are not violated when their parents "voluntarily" admit them to facilities for the mentally retarded, as long as sufficient administrative procedures are available to review the appropriateness of the admission. In that case, the Court noted that "[c]ourts must not 'unduly burden the legitimate efforts of the states to deal with difficult social problems. The judicial model for factfinding for all constitutionally protected interests, regardless of their nature, can turn rational decisionmaking into an unmanageable enterprise.'⁸

The Court also quoted from *Youngberg v. Romeo*, a "right to habilitation" case. Here, it commented "[t]here certainly is no reason to think judges or juries are better qualified than appropriate professionals in making treatment decisions."⁹

The Court avoided uttering any clearcut articulation of the so-called "right to refuse treatment." However, the *Rogers* opinion strongly implies the following principles, which should be clues as to the constitutional appropriateness of states' approaches to the issue of the right to refuse treatment.

1. The mentally ill, including those hospitalized involuntarily, and those declared incompetent, do have certain liberty interests, which are protected by the federal Constitution.
2. The so-called "right to refuse treatment" is not specifically identified as a protected interest; however, the Court recognizes that other liberty interests "are implicated by the involuntary administration of antipsychotic drugs."¹⁰
3. Administrative (as opposed to judicial) procedures are sufficient to protect any federal Constitutional interests that may be affected by the involuntary administration of antipsychotic medication to a patient who has been involuntarily admitted to a psychiatric facility.
4. A state is free to impose more stringent substantive rights and procedural requirements, including the right to a judicial determination of the need for involuntary medication.

Prior case and statutory law in various jurisdictions had approached the "right to refuse treatment" in various ways. Involuntary hospitalization does not automatically deprive a patient of the right to refuse treatment.¹¹ An involuntarily hospitalized patient may be medicated against his/her will only if he/she has been declared incompetent, or an emergency situation is present.¹² The definition of "emergency" has moderated from solely a serious risk of harm to self or others to inclusion of the risk of serious deterioration of patient's condition.¹³ An involuntarily hospitalized patient may be medicated against his/her will in a nonemergency situation that presents a "sufficient threat of danger of physical harm."¹⁴ Finally, in a jurisdiction that requires a judicial determination of dangerousness plus incompetence for involuntary hospitalization, the hospitalization itself is

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sufficient grounds for medication of a patient against his or her will.¹⁵

These alternatives must be evaluated in light of the Supreme Court's findings in *Mills v. Rogers*. It would appear that all the approaches are constitutionally valid, since they depend on judicial determination of incompetency and/or the need for involuntary hospitalization and/or medication.

Nonjudicial procedures for determining the need for involuntary medication also may meet the criteria alluded to in *Rogers* as long as sufficient administrative procedural protections are provided. New York State has taken the administrative route to deal with the right to refuse treatment. Since 1975, state regulations have provided a mechanism for the administrative review of any patient's refusal of treatment.¹⁶ The right to refuse treatment is further protected by the presence of attorneys, social workers, and paralegals of the Mental Health Information Service (MHIS) in each state psychiatric hospital. The MHIS staffs are employed by the court system, not the Department of Mental Hygiene. They are articulate, independent, and frequently aggressive advocates of the rights of all hospitalized patients.

The New York State administrative procedure includes several levels of review.

1. If the patient refuses medication, the necessity for treatment is first reviewed by the head of the service.
2. If the patient still refuses treatment, the need for medication is then reviewed by the facility director.
3. If the patient continues to refuse medication, appeal may be made to the Regional Director of the state Office for Mental Health. An independent psychiatric evaluation is made to assist the Regional Director in making a determination of the need for involuntary treatment.
4. If the patient still refuses to accept medication, he or she may go to court to challenge the administrative decision.

All refusals of electroconvulsive therapy (ECT) or surgery, as well as the need for such treatment for patients who have been declared incompetent, are heard directly by the court, rather than through the administrative process.¹⁷

Patients may be treated against their will on an emergency basis only "where the treatment is necessary to avoid serious harm to life or limb of the patients themselves."¹⁸

The "patients' rights movement" has brought about tremendous changes in the care and treatment of the mentally ill. Since the mid-1960s, a number of significant court cases have established the state's obligation to provide care for patients involuntarily hospitalized for treatment of mental illness, the state's obligation to provide this care in the "least restrictive environment" necessary to protect the patient or the public, and the patient's right, under certain circumstances, to refuse treatment recommended by the treating staff.¹⁹

The issue of the "right to refuse treatment" has alarmed many psychia-

trists.²⁰ They see a logical inconsistency between the state's involuntary hospitalization laws, which usually require a determination that the patient is unwilling or unable to seek care voluntarily, and the courts' decisions that these same patients have the right to decide whether to accept medication and other treatment prescribed by the treating psychiatrist. They also are concerned about restrictions placed on treatment staff, who must now frequently determine whether a patient will be dangerous to self or others before they can medicate involuntary patients against their will. In addition, they are concerned about the effects on a patient's well-being if a court hearing or administrative review must be scheduled and conducted before treatment can begin.

Despite concerns raised over the effects on patient care of the right to refuse treatment, few published reports, other than anecdotes, address the issue empirically. Appelbaum and Gutheil studied 40 inpatient medication refusers.²¹ Refusers were categorized as situational, stereotypic, or symptomatic. Two patients were concerned with side effects of medication. Five patients refused because they said they had a legal right to do so.

Van Patten *et al.*, in a study of 29 "habitual drug-refuser" and 30 "drug-complier" chronic schizophrenic outpatients, found the refusers demonstrating an "ego-syntonic grandiose psychosis," while the accepters were characterized by depression, anxiety, and absence of grandiosity. They concluded that "there exists a group of chronic schizophrenic patients who never become reconciled to the need for antipsychotic drug treatment and who cannot tolerate the drug-induced reality contact" (even when failure to take prescribed medication inevitably leads to rehospitalization).²²

Marder *et al.* studied 15 schizophrenic voluntary patients who refused psychotropic medication and compared them with 15 voluntary patients who accepted medication.²³ Refusers were more hostile, uncooperative, suspicious, and displayed more unusual thought content than compliers.

Lacoursiere raised concerns over clinical factors arising from the right to refuse treatment, including therapeutic time lag, deterioration time lag, and withdrawal symptoms.²⁴

None of these studies squarely address the clinical consequences of patients' exercise of the right to refuse treatment. We describe a study that addresses some of these consequences.

Methods and Procedure

All patients at a state-funded 150 bed community mental health center hospital (with admissions in 1981 of 1,187) who had received a formal administrative review and/or a court hearing resulting from refusal to accept somatic treatment were identified. Two psychiatric patients who had court hearings consequent to refusal to accept surgical treatment (in both cases breast biopsies for cancer) were excluded from this study. Ten patients were identified who had been admitted to the hospital between mid-1980 and the end of 1981. A control group of ten patients matched for age, sex, diagnosis, and legal status on admission were identified. The patients in the control

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group were admitted to the hospital during the same period, and an attempt was made to match for inpatient unit although this was not done completely. All patients in the control group, as far as we could determine by thorough review of their hospital charts, were compliant with treatment prescribed and had not, at least during the hospital admission examined, refused somatic treatment. (A number of patients whose charts had been reviewed but rejected for inclusion in the control group were found to have been noncompliant, but in their cases neither patient nor staff requested a formal review.) The posthospital courses of the refusers and control patients were examined for evidence of rehospitalization and compliance with outpatient appointments and medication taking.

Outcome of Reviews and Hearings

In five cases the hospital director agreed with psychiatrists' decisions to treat. In one case he overturned the psychiatrist's decision to treat. In five cases the regional director upheld the facility director's decision to treat. In no case did the regional director overturn his decision to treat. In both court hearings (one for ECT and one for antipsychotic medication), the court ruled that the patients' wish not to receive treatment be respected. In one case the court also ordered that the patient be released from the hospital. One patient accepted ECT when application to court was made. The application was withdrawn. Another patient began taking medication when the court changed her hospital status from voluntary to involuntary.

Thus of the seven patient refusers who were ultimately treated none progressed to the level of court hearing. Two patients received involuntary medication (because of threatening behavior or agitation) while administrative review was in process. One of these patients was urged by a MHIS lawyer to accept medication after the regional director upheld the hospital director's decision to treat. One patient whom the hospital director ruled should not receive involuntary medication, received antipsychotic drugs for agitation on several occasions against his will or took it under threat of forcible injection. Of the three patients whose wish not to be treated was upheld, two were discharged immediately after the decision. One is still in the hospital (and continued to refuse ECT but is beginning to accept some fluids and solid food).

Analysis of Data and Results

The data were examined for face validity. More sophisticated statistical analysis was felt to be inappropriate because of the small number of subjects in the experimental and control groups.

The ten "refusers" ranged from 19 to 54 years of age with a mean age of 31.1. There were six men ranging in age from 21 to 38 (mean 27.7) and four women ranging in age from 19 to 54 (mean 36.3). Admitting diagnoses were: schizophrenic disorder, paranoid type (4); schizophrenic disorder, undifferentiated type (2); bipolar, manic (1); bipolar, depressed (1); bipolar mixed

with psychotic features (1); and one patient who initially received the diagnosis schizophrenic disorder that was later changed to bipolar, manic. All patients were on involuntary hospitalized status at the time they received administrative review or court hearing; however, two women patients had been admitted to the hospital on "voluntary" status. The kind of treatment refused was antipsychotic medication (8 patients) and ECT (2 patients). One "manic" patient refused to take antipsychotic medication but asked for and received lithium carbonate (which did not control his psychosis). A depressed patient was unable to tolerate antidepressant medication (which she seemed willing to accept) because of severe hypotensive side effects but refused ECT, which was felt by her treaters to be the treatment of choice.

Reasons for refusing treatment included the following: four patients complained of unacceptable side effects ("harmful to my health" with actual evidence of early tardive dyskinesia; "blurred vision"; "confused feelings"; "sick to my stomach"). Two patients believed that taking medication was an admission that something was wrong with them or that they were ill. One of these patients stated as his reason for not taking medication that "my family insists there is nothing wrong with me." The other added that he believed he was being "controlled by medication" and he disliked the feeling of being controlled.

One patient gave a reason, which was part of a delusional belief, that "I am allergic to all chemicals as they affect my brain cells." A depressed patient refused medication and ECT, along with all food and drink perhaps secondary to a "wish to die." Almost all patients had had considerable experience with antipsychotic medication and side effects prior to this hospitalization.

Discussion of Results

Comparing the hospital stays of the refuser group with the control (nonrefuser) group, we found that while the refuser group had a length of hospital stay totaling 1,183 days (mean 118 days), the control group stayed a total of 600 days (mean 60). The difference between the two can be readily accounted for by the amount of time the refuser group spent in the hospital between time of refusal and the ultimate decision to treat or not to treat. This totaled 522 days, which when subtracted from 1,183, leaves 661 days—very close to the control group length of stay. As indicated in the Table, the mean time for the administrative process was 52.2 days, which accounts for the major portion of the refusers increased length of hospital stay (mean of 66 days, as opposed to 60 days for compliers).

Comparing terms of hospital course, one finds the refusal group contains one patient who showed marked symptom improvement, four patients who showed substantial improvement, four patients who showed slight or questionable improvement, and one who became substantially worse.

In the control group were six patients who improved substantially, three

Table. Summary of Results

	Refusers	Compliers
Length of stay	1,183 days (mean 118)	600 days (mean 60)
Time between refusal and decision to treat	522 days (mean 52.2)	
Corrected length of stay	661 days	600 days
Hospital Course		
Marked improvement	1	
Definite improvement	4	6
Slight improvement	4	3
Definitely worse	1	1
Post-hospital course		
Readmitted to Hospital	5	6
Died	1	
Still in hospital (never discharged)	1	
Remained out of hospital	3	4
Length of time out of hospital before rehospitalization	972 days (mean 194)	565 days (mean 94)

who showed slight or questionable improvement, and one who became decidedly worse.

Posthospital course showed few significant differences between the two groups. Of the group of refusers, five patients were readmitted to the hospital during the follow-up period, one died in an automobile accident, and one was never discharged from the hospital.

Three patients remain out of the hospital: one is living in a halfway house, one is being followed by a private psychiatrist with frequent visits to the Emergency Room, and one is being followed by the Community Mental Health Center Outpatient Clinic with good compliance with medication but with only marginal adjustment.

In the nonrefuser group six patients were readmitted to the hospital: one is in family care, two are being followed in CMHC Outpatient Clinic—one was discharged and lost to follow-up but was not, to our knowledge rehospitalized, one is being followed by a private practitioner.

Comparing the five patient refusers who have been readmitted to the hospital with the six control patients also readmitted to the hospital during the follow-up period, we find that the first group of patients stayed out of hospital for a total of 972 days (mean of 194), before readmission. For the control group the total time out of hospital before readmission was 565 days (mean 94).

There is no difference between the two groups in amount of compliance with medication after discharge from hospital and only a slight correlation between taking medication and staying out of hospital (some patients in both groups who had good compliance were rehospitalized, but for others stopping medication was followed shortly by rehospitalization).

Conclusions

The patients we were able to identify through administrative review

records as treatment refusers are merely the proverbial tip of the iceberg. Refusal is probably not the rare occurrence it appears to be in this study. Patients who wish not to take medication but are coerced into taking it are virtually impossible to identify (except by witnessing the event). Charts do not accurately reflect these events.

Conclusions from this study must be tentative and provisional because of the relatively small number of patients studied. An incidental finding was that only one patient in each group was recorded as having been violent toward staff or patients during the period of study. This is in contrast to other investigators' observations that involuntarily medicated patients are frequently dangerous patients. In all cases in this study the decision to treat against the wishes of the patient was made (rightly or wrongly) on the basis that the patient's disorder was treatable and therefore should be treated.

In general, the two groups were found to be remarkably similar in all important outcome measures. Even length of stay in hospital was very comparable after correcting for the delay caused by the administrative review process. Lengthened hospital stays for refusers have economic consequences in that they increase the cost of hospitalization. When added to the cost of review and court hearing process, staff time, and so on, the increased cost is not negligible. However, in our opinion, cost should not be the determining factor since we are dealing with important legal and constitutional issues. The only marked difference between the two groups was in time out of hospital before readmission (refuser group nearly double that of compliers). This suggests that the refusers as a group did at least as well as the control group and perhaps somewhat better when measured on the basis of rehospitalization data. If this is a valid conclusion, can it be accounted for by the fact that the refusers stayed in the hospital longer as a group than did the compliers? Glick *et al.*²⁵ studied this question and concluded there is no essential difference in outcome between short stay and long stay hospitalized patients.

Looking at the refuser group more closely, we found that it appears the patients who never received treatment did not do very well (one died, one was never discharged, and one had made marginal adjustment outside the hospital with frequent visits to the emergency service). However, those patients, who after administrative review (usually several steps) decided to accept treatment, did somewhat better posthospital than did the complier group of patients. Perhaps the former patients retained a healthy skepticism about doctors, medicine, and psychiatry and some sense of themselves as not without power and control over their lives. These qualities may have helped the "refusers" to better cope with life outside the hospital. In contrast, those patients, who when they found themselves in hospital, uncritically put themselves in the hands of the clinicians assigned to them, may have been less well equipped for life outside the hospital.

Another possible explanation of the different outcome in the two groups is that the refusers were "healthier" to begin with.²⁶ Controlling for age, sex, and diagnosis does not necessarily rule out this possibility. A more

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in-depth evaluation of the patient would need to be done to rule out this possibility.

Closer examination of treatment-refusing patients might reveal other important differences. For example, might not some patient refusal represent a relatively healthy expression of autonomous strivings, while others are driven to refuse by delusional necessity? Should this be the case, it would certainly follow that these two types of patients should be approached very differently in our attempts to be helpful.

It would appear that New York's system of safeguards for psychiatric patients who do not wish to accept somatic treatment recommended by their physicians works reasonably well. Those patients who initially refuse but are convinced after the sometimes lengthy review process to reverse their opposition, do at least as well and probably better outside of the hospital than those involuntarily hospitalized patients who do not oppose their treatment. The increased length of stay and the concomitant increase in hospital cost is probably a small price to pay for allowing these patients to maintain some sense of autonomy, which is useful for coping with life outside of the hospital. However, in times of fiscal retrenchment, small prices do not come cheap.

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