Long-Term, Assenting Psychiatric Patients: Decisional Capacity and the Quality of Care

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The objectives of this study were (1) to investigate whether the relationship between functional decisional capacity and the resulting quality of treatment posited by the informed consent theory is found in clinical practice; and (2) to describe the range of decisional impairments found in long-term psychiatric inpatients who comply with prescribed treatment. Eighty-eight long-term, compliant, psychiatric inpatients, in two public hospitals, who were prescribed antipsychotic medications were assessed. Following a formal assessment of decisional capacity, subjects were categorized according to level of impairment, using a hierarchical scheme. All subjects were evaluated for the presence of abnormal involuntary movements. The appropriateness of treatment with antipsychotic medications was determined using accepted clinical guidelines. Patients with more serious impairments of decisional capacity were more likely to receive inappropriate treatment with antipsychotic medication; and serious impairments of decisional capacity were common. The study lends empirical support to one of the bases of the doctrine of informed consent: the notion that capable patient involvement in decisionmaking plays an important role in checking the judgments of treating physicians. Remedial measures are needed to protect long-term psychiatric inpatients with impaired decisional capacity from receiving inappropriate treatment.

The advent of the doctrine of informed consent stands as a landmark legal development that has dramatically altered the doctor-patient relationship in the last generation.[1,2] A sizable body of literature has developed that explores the legal, theoretical, and practical dimensions of the informed consent doctrine. However, the empirical study of informed consent and patients' decisionmaking has received little attention.[3]

There are two main strands of informed consent theory; each has implications for empirical research. First, the informed consent of patients is thought to serve as a check on the judgments of their physicians.[4–7] Therefore, patients with greater decisional capacity will make superior

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choices regarding treatment, and receive better medical care, when given a range of qualitatively different alternatives. The second, and arguably the primary, function of informed consent is to protect the individual's autonomy—the patient's right to determine the course of treatment—independent of objective or professional judgments.[4-6]

Stanley[7] and coworkers compared the decisions made by mentally ill and nonmentally ill subjects who were asked to consent to a series of hypothetical studies with varying degrees of potential risk and benefit. No differences were found between the groups in the frequency of consent for each hypothetical study; both groups were more likely to consent to higher benefit and lower risk research. Their level of psychopathology, as measured by the Brief Psychiatric Rating Scale,[8] did not influence the subjects' willingness to consent. This study suggests that mentally ill people do not differ significantly from healthy people in risk-aversion to research. However, to date, there is no empirical work that focuses on the relationship between decisionmaking and functional decisional capacity, rather than the degree of psychopathology. Research has neither examined actual patient decisions and the quality of treatment administered as a result, nor focused on clinical care, particularly the capacity of patients to distinguish appropriate from inappropriate treatment.

The treatment of long-term psychiatric inpatients provides an opportunity to study the relationship between decisional capacities and quality of care. Decisional incapacities are likely to be common in this group. Beck and Staffin[9] found that among long-term psychiatric patients who assented to treatment (the term "assent" is used to indicate compliance on the part of patients unable to give competent consent), 80 percent were not knowledgeable about the risks and benefits of their medication, and the majority of these patients could not be educated to understand this information. This finding has recently been replicated.[10]

The study of the decisionmaking capacities of long-term, assenting psychiatric inpatients is important, independent of the potential contribution to the understanding of informed consent theory. The acceptance of assent to treatment has been a prevalent, although unacknowledged, policy of psychiatric facilities for many years. This unwritten policy has been shaped by legal developments (the shift to a presumption of competence of psychiatric patients) and by the practical difficulties of implementing surrogate decisionmaking procedures.[11] However, commentators have called for greater legal protection of elderly, nonprotesting patients based, in part, on concerns about impaired decisionmaking capacities in this population.[9, 11-14] Currently, only a few states have procedures for reviewing the hospitalization and treatment of long-term, assenting patients.[4, 9, 11, 15]

The current study addressed two objectives. The primary objective was to test the relationship of patients' functional decisional capacity and quality of treatment posited by informed consent theory. The secondary objective of the study was to describe the range of decisionmaking capacities found among long-term psychiatric inpatients.

Method

In *Rogers v. Commissioner* (1983), the Massachusetts Supreme Judicial Court found that committed psychiatric patients have the right to refuse antipsychotic treatment in the absence of an emergency; refusal can only be overridden following a judicial finding of incompetence and the court's substituted judgment—based on review of the risks and benefits—that the patient would accept the treatment, if competent. Furthermore, the Court found that a patient's acceptance of treatment must be a competent decision in order to be valid; the decision to treat assenting, incompetent patients must be submitted for judicial review as well.[16] Implementation of the *Rogers* decision entailed the right to legal counsel and other rights attendant to an adversarial process. In addition, courts were empowered to appoint guardians *ad litem* and independent psychiatric experts. To bring state mental health facilities into compliance with the *Rogers* decision, additional resources were allocated to the Legal Department of the Massachusetts Department of Mental Health; attorneys, legal assistants, secretarial staff, and psychiatric consultants were employed to process the increased number of petitions anticipated.[17]

Data were collected between 1986 and 1989 on all patients referred to a single psychiatric consultant (S.K.H) with subspecialty training in legal psychiatry and psychopharmacology. The referred patients were hospitalized in two state hospital facilities with a total census of approximately 700, about one-third of the total state hospital census in Massachusetts during this period.[18] Thus, the subjects comprise a convenience study group, not a random sample.

The treating psychiatrists referred patients who met two criteria: (1) they were compliant with prescribed antipsychotic medications; and (2) they were thought by the treating psychiatrist to be incompetent to consent to treatment. Referred patients were residents on intermediate and long-term wards. A consultation consisted of a review of all available records, a discussion with the treating psychiatrist and ward staff, and an evaluation of the patient. The evaluation consisted of a clinical interview, a formal assessment of decisional capacity, and an examination for signs of involuntary movements.

The consultant reviewed all available records to obtain a longitudinal view of the patients' presentations, and history of treatment and responses to medications, and symptomatology. All medication records were carefully examined for indications of past efforts to taper or to discontinue medications. Treating psychiatrists provided their rationale for the prescribed treatment and clarified any ambiguities in the documentation. Diagnosis, prescribed medications, pertinent history, length of hospitalization, commitment status, and demographic information were recorded.

The clinical interview focused on verifying symptoms of psychosis, past and present, and establishing a DSM-III-R diagnosis.

The assessment of decisional capacity consisted of disclosure of information regarding potential benefits, risks (including tardive dyskinesia), and alternatives to medications. The informing process was individualized, with the goal being to maximize the patient's understanding of the material. Information was presented multiple times, the patients' questions were answered, and efforts were made to rectify misunderstandings. The patients' understanding of the information was assessed intermittently during the disclosure, to minimize confusion. Patients' understanding was assessed by asking them to paraphrase the disclosed information. At the time of the assessment, a judgment was made about whether the patients had the decisional capacity to consent to antipsychotic medication as required under the *Rogers* decision. Judgments about decisional capacity were based on individualized assessments performed by the consultant, who employed the model described by Appelbaum and Roth.[19] As first conceptualized, the dimensions of decisional capacity—evidencing a choice, understanding of information, rational manipulation of information, and appreciation—formed a hierarchy. For those patients judged by the consultant to lack the capacity to consent to treatment, the lowest dimension of decisional capacity failed was recorded for each patient.

At the time of the evaluation, patients were assessed for involuntary movements, using the standardized protocol of the Abnormal Involuntary Movement Scale.[20]

Judgments about the appropriateness of antipsychotic medication were based on consideration of clinical guidelines in general use at the time. Prescription of antipsychotic medication was judged to be inappropriate in the following circumstances: (1) in the absence of an attempt to taper the dosage for more than one year without clinical justification; (2) routine (nonemergency) administration for nonpsychotic disorders; and (3) daily doses exceeding recommended ranges.[21] The use of antipsychotic medications was not identified as inappropriate until treating psychiatrists had the opportunity to explain the nonstandard usage on clinical grounds.

All of the above data were recorded at the time of the assessment on a form designed to facilitate the drafting of petitions.

Results

Study Group Characteristics Eighty-eight assenting patients were referred for evaluation. The study group is described in Tables 1 and 2.

The patients' conditions were chronic, as demonstrated by the very long mean length of the current hospitalization of more than 13 years. Many patients had multiple prior admissions; a substantial number had been institutionalized since childhood.

The primary diagnoses made at the time of assessment are described in Table 1. Patients with developmental disorders had a variety of underlying organic disorders, including phenylketonuria, tuberous sclerosis, neurofibromatosis, and Sturge-Weber syndrome; all had significant behavioral disturbances that had led to chronic hospitalization.

The frequency and severity of abnormal involuntary movements found in the study group is consistent with previous

Table 1
Study Group Characteristics[a]

Age, mean ± SD years	47.7 ± 15.7
Sex, No. (%)	
Male	49 (55.7)
Female	39 (44.3)
Race, No. (%)	
White	84 (95.5)
Black	2 (2.3)
Hispanic	2 (2.3)
Diagnosis, No. (%)	
Schizophrenia	48 (54.5)
Mental retardation/ developmental	31 (35.2)
Bipolar, manic	9 (10.2)
Hospitalization status	
Voluntary	69 (82.1)
Involuntary civil	14 (16.7)
Forensic	1 (1.2)
Hospitalization, mean ± SD months	162.4 ± 189.1
Tardive dyskinesia, No. (%)	
None	38 (52.1)
Minimal	17 (23.3)
Mild	13 (17.8)
Moderate	4 (5.5)
Severe	1 (1.4)

[a] N = 88; numbers vary to reflect missing data.

Table 2
Clinical Assessment of Capacity to Consent to Treatment

Decisional capacity, No. (%)	
Possesses capacity	14 (15.9)
Lacks capacity	74 (84.1)
Level of decisional incapacity, No. (%)	
Unable to evidence a choice, mute	15 (20.3)
Unable to evidence a choice, other	10 (13.5)
Unable to understand	32 (43.2)
Unable to manipulate information	0 (0.0)
Unable to appreciate	17 (23.0)

reports regarding long-term patients (Table 1).

Decisional Capacity A substantial majority (84%) of patients referred were judged to lack capacity to consent on examination (Table 2). It must be emphasized, however, that this does not reflect a true prevalence of decisional incapacity on these wards; patients were only referred if their treating psychiatrists thought that they lacked the capacity to consent to treatment.

Of the patients deemed to lack decisional capacity, 25 patients (33.8%) failed to achieve the minimal level of decisional capacity of "evidencing a choice." In 15 cases this resulted from severe cognitive deficits that rendered the patients permanently mute. The remaining 10 patients were able to speak, but their responses were irrelevant or devoid of content. These patients accepted medication passively, but they did not appear to be making a meaningful choice.

Thirty-two patients (43.2%) were able to express a choice, but failed to understand the requisite information necessary to give an informed consent; they failed to understand the benefits or the risks of treatment, including the increasing risk over time of developing tardive dyskinesia. The absence of cases of failure at the level of "rational manipulation of information" may be attributable to the inherent difficulty, and implicit manipulation of information, necessary to successfully understand the cumulative risk of antipsychotic treatment.

Seventeen patients (23%) who understood and were able to rationally manipulate information were unable "to appreciate" (i.e., they were unable to apply the information meaningfully to their own circumstances). In every instance this inability was the result of denial of illness.

Quality of Care In 50 cases (56.8%) antipsychotic medications, according to established clinical guidelines, had been prescribed inappropriately. The treating psychiatrist did not attempt to justify the treatment as an unconventional clinical approach to a patient's symptoms in any of the cases; and, in the opinion of the consultant, in none of the cases could the treatment be justified as unconventional.

In the study group, a variety of inappropriate prescribing practices were found (in some cases, more than one reason was found for characterizing the treatment as inappropriate). By far the most common inappropriate practice was failure to reduce dosages periodically; this was found in 45 of the 50 cases identified. Practitioners failed to follow guidelines indicating that yearly attempts should be made to taper antipsychotic medications on inpatient units.[21] These deviations from the guidelines did not represent unconventional treatment approaches. To the contrary, treating psychiatrists acknowledged either that they had never previously considered reducing medication dosages or that they agreed that reductions were indicated, but ward staff had persuaded them not to "rock the boat" with attempts to taper dosage. In 25 cases the patient had been placed on antipsychotic medications 10 to 33 years before the evaluation, with no attempt to taper the medication dose in the intervening years.

Thirty-one of these patients who were receiving antipsychotic medication (35.2%) did not suffer from a psychotic disorder. These cases do not represent diagnostic disagreement between the author and the treating psychiatrist; the antipsychotic medications were classified as inappropriate when they had been prescribed for management reasons, on a long-term basis, with no attempt to address the patients' behavior through alternative medications or nonpharmacological interventions, such as behavioral programs. In many instances antipsychotic medications had been maintained despite their ineffectiveness in controlling targeted behaviors.

Thirteen patients (14.8%) were grossly overmedicated with antipsychotic medications. These patients all received doses well outside recommended ranges and had significant clinical signs of sedation, akathisia, or rigidity. Geriatric patients, who generally require lower doses of antipsychotic medications, tended to be the most overmedicated; as much as 100 mg per day of haloperidol had been prescribed for elderly patients.

Chi-square tests revealed that patients receiving inappropriate care were more likely to be voluntary patients (93.6%, n = 44, compared to 67.6%, n = 25; $\chi^2 = 9.58$, $df = 1$, $p < .002$), and were more likely to be mute (28%, n = 14, compared to 2.6%, n = 1; $\chi^2 = 9.83$, $df = 1$, $p < .002$). Two-tailed Student t tests revealed that patients receiving inappropriate care were older than patients receiving appropriate care (mean ± SD was 53.0 ± 15.0 years old compared to 40.8 ± 13.9; $t = 3.88$, $df = 86$, $p < .001$) and had longer hospitalizations (mean ± SD was 248.3 ± 204.7 months compared to 49.4 ± 74.4; $t = 5.71$, $df = 86$, $p < .001$; the median lengths of stay were 230.0 and 16.5 months, respectively).

There were also significant diagnostic differences between the groups ($\chi^2 = 16.00$, $df = 2$, $p < .001$). Among patients who received inappropriate treatment with antipsychotic medications, 52 percent (n = 26) had mental retardation or developmental disorder diagnoses; the remainder had diagnoses of schizophrenia (44%, n = 22) and bipolar disorder (4%, n = 2). Patients who received appropriate treatment were more likely to have diagnoses of schizophrenia (68.4%, n = 26) and bipolar disorder (18.4%, n = 7); the remainder had diagnoses of mental retardation or developmental disorder (13.2%, n = 5).

Systematically collected follow-up data regarding the outcome of the consultations are not available. However, one author (S.K.H) had continuing involvement as a consulting psychopharmacologist in a subset of cases. In these cases, treating psychiatrists were successful in reducing dosages markedly and, in some cases, in discontinuing treatment with antipsychotic medications altogether.

Decisional Capacity and Quality of Care Patients who were judged to lack capacity to consent were more likely than patients with capacity to consent to receive inappropriate treatment with antipsychotic medications (63.5%, n = 47, compared to 21.4%, n = 3 ($\chi^2 = 8.50$, $df = 1$, $p < .005$)). The level of capacity to consent was also significantly associated with quality of care: patients who failed the lower standards were significantly more likely to receive inappropriate care (patients failing to evidence a choice, 88.0%, n = 22; understanding, 65.6%, n = 21; appreciation, 23.5%, n = 4 ($\chi^2 = 18.26$, $df = 2$, $p < .001$)).

Discussion

Our findings have implications for informed consent theory, long-term psychiatric patients, and future research.

Informed Consent Theory The ability of patients to check doctors' judgments through autonomous reasoning is thought to be a function of their capacity to understand the nature and consequences of treatment. It is posited that patients with greater decisional capacities are better able to check doctors' recommendations.[4–7]

The finding that decisional capacity correlates with a greater likelihood of quality care lends empirical support to the premise that capable patient involvement is an important check on a physician's judgment. At least in this setting, our findings seem to undermine physicians' arguments that informed consent is an unnecessary intrusion into the doctor-patient relationship, which interferes with the provision of effective treatment.

Long-Term Psychiatric Patients The findings of this study suggest that a segment of the population of long-term, assenting patients have substantial impairments of their decisional capacities. However, caution should be taken in interpreting our data and generalizing the findings. Our subjects did not represent a random sample of long-term, assenting patients; patients were referred and included in the study because the treating psychiatrists suspected incompetence. Our group, therefore, included no patients who were thought to be competent. The frequency of inappropriate treatment of patients thought to be competent remains unknown.

Furthermore, it is likely that clinicians questioned compliant patients' capacity to consent when impairments were obvious; more subtle impairments may have been overlooked. Thus, our study group overrepresents patients with severe impairments in decisionmaking capacity. A comparison of the lengths of stay of our subjects with those reported in a comprehensive summary of long-term patients in Massachusetts state hospitals during this period indicates that our study group overrepresents the most extreme segment of the long-stay patient population.[18] Subjects in our study comprised less than 5 percent of all patients in the state hospitalized for less than 10 years during the time span of data collection; however, subjects with stays exceeding 20 years (n = 25) constituted about 40 percent of the state total. Thus, clinicians' concerns about decisionmaking capacity appeared to be more frequent among longer-stay patients.

Absent a representative sample of long-term, assenting patients, it is not possible to draw conclusions about the association of decisionmaking capacity (or other variables) with appropriate treatment for this group.

Although our study group is not a random sample of long-term, assenting patients, it does represent a clinically and legally important population: long-term patients who are thought to be incompetent by treating clinicians.

The majority of the patients in our study group were judged to lack the capacity to consent to the treatment they were receiving. Many of the impairments found in their decisional capacity were severe. One-third of the subjects could not indicate a choice (some were mute), and received treatment passively. These patients were not able to participate in decisions regarding their treatment. Patients' compliance in these cases failed as a means of assuring quality care, and their nonobjection to treatment cannot be viewed as vindicating autonomy interests.

Nearly one-quarter of the group reported that they did not suffer from a mental illness or disorder, yet complied with treatment. It is not possible to determine what proportion, if any, of these patients denied illness at evaluation although they actually believed they were ill. But for those patients whose denial of illness was delusional in nature, compliance with treatment cannot be viewed as furthering self-determination.

The remainder of the study sample—more than 40 percent—chose to accept the prescribed treatment but could not understand the essential benefits or risks of antipsychotic medication. For these patients, the crucial question is whether their defective understanding was nevertheless sufficient to enable them to make decisions that furthered their interests. Our findings suggest that their understanding was insufficient; nearly two-thirds received inappropriate care.

Our study raises concern about the quality of treatment of chronically ill psychiatric patients. We have previously noted limits on generalizing our findings due to subject recruitment procedures. However, particular caution should be taken in interpreting the findings regarding treatment quality. Many factors contribute to quality of treatment; most relate to the adequacy of funding for treatment. The patients in this study were drawn from state hospitals that were underfunded and, as a result, understaffed. It is likely that appropriate treatment would be pervasive in facilities with adequate resources.

Implications for Research The findings of our study are preliminary and must be replicated before conclusions can be reached with confidence. It would be valuable for researchers to investigate the processes by which more capable patients influence treatment and the reasons less capable patients are unable to do so. Furthermore, within levels of decisional competence it would be important to compare patients who receive appropriate care with those who receive inappropriate care in an effort to uncover factors other than competence that may influence the quality of care. There may be some third factor, such as treatment futility, that underlies both impaired decisional capacity and inappropriate treatment. Future research should employ designs that provide for variation in the quality of treatment options or outcomes; without variation in quality, it is not possible to investigate the correlation of decisional capacity and actual decisionmaking. Finally, with the recent development of research instruments for the structured assessment of treatment decisionmaking capacities, future studies will not have to rely on nonstandardized interviews.[22–25]

It is important to note that our findings carry no implications regarding effective methods for improving treatment; there has been minimal research concerning this issue. Judicial mechanisms grounded in the principles of informed consent have proved to have little substantive value as a means of reviewing the quality of treatment provided to psychiatric patients.[15, 26–27] In addition, the intrusiveness, the costs, and the delays attendant to pursuing formal judicial review make this option unattractive and economically unfeasible. Informal and innovative methods of surrogate decisionmaking have been suggested as alternatives to traditional guardianship proceedings.[4, 6] For example, the institutional review of competence has been endorsed by a President's Commission as a model of providing prompt and meaningful determinations. Future research should examine the effectiveness and the costs of these models as a means of assuring quality care.

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