The Right to Refuse Treatment: The Real Issue is Quality of Care

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"Legal advocates for the mentally ill have not been willing to consider seriously the needs of the mentally ill and to formulate those needs as rights. Instead, they have done the reverse. They have treated rights as if they constituted the needs of the mentally ill." (Stone, The Myth of Advocacy[1]).

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Unlike many of the other lawyers writing today on the issue of the right to refuse treatment, Professor Dix, in his response to our paper,[2] hones in immediately on the core concern: the quality of care in State institutions. He challenges us to address this issue, and we accept with pleasure, because we could not agree more that this, in fact, is the level at which the debate should take place.

Professor Dix's emphasis on the way things really are in this country's State hospitals comes closer than anything else we have read to making explicit the premise that underlies the bulk of responsible advocacy of a right to refuse treatment: the right to refuse treatment is being promulgated as an instrument designed to improve the quality of care in public mental institutions. Courts, troubled by testimony about patients who are being over-sedated, mistreated or simply ignored, are attempting to respond with one of the few tools at their disposal. They are granting patients a right to refuse because, short of taking over the hospitals themselves, they have no other way even to begin to cope with the "quality of care" issue. "If patients cannot be treated properly," the courts appear to be saying, "then, by God, we will not let them be treated at all!"

The implications of this focus on improving care for psychiatric patients are entirely congruous with the major point of our paper: the constitutional arguments that have been synthesized about the right to refuse treatment constitute a smokescreen. They have, as we demonstrated, little relevance for the patients who reject psychotropic medications, but, in addition, they

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have equally little to do with the arguments of the proponents of a right to refuse. The Constitutional arguments are being dragged into the fray, often (as with the First Amendment freedom of speech issue) in rather farfetched ways, to support the actual policy objectives of the courts and the legal activists: improving the quality of psychiatric care. (Rennie v. Klein[3], a New Jersey right to refuse case, was all-but-explicitly inspired by the poor conditions in New Jersey State hospitals.)

Once the goals of the movement to grant a right to refuse treatment are recognized, much of the rhetorical cloud that surrounds the issue can be cleared away. We can now ask directly whether invoking the right to refuse is an appropriate means of protecting psychiatric patients from the hazards of inadequate care. There appear to be at least two reasons why the answer to this question must be "No."

First, as we pointed out in our original paper, and as has been elaborated elsewhere,[4-5] the right to refuse will, if anything, probably lower the quality of psychiatric care in State institutions. This has certainly been the case at Boston State Hospital, where the use of seclusion and transfers to maximum security units have escalated as patients have exercised their right to refuse.[6-7] Psychotic patients who refuse medication on delusional grounds will not only prevent their own treatment from taking place, but will also impede and dilute the treatment of other patients, by creating chaos on the wards and diverting the attention of the treatment staff to managing the crisis at hand; thus, willing and voluntary patients will suffer impairment of the treatment they wish to receive simply because their fellow patients wish not to receive it. The legal procedures mandated by the *Rogers* courts,[8] specifically the judicial determinations of competency, have already required untold hours of clinical time and have resulted in days, and often weeks, of delay in desperately needed treatment. Hospitals in which treatment was being appropriately carried out prior to the *Rogers* decision will see the quality of care they deliver plummet; even in the worst of the public hospitals, it is hard to believe that care will actually improve as a result of treatment refusal. At best, some abuses, the extent of which has never been quantified or even systematically examined, may be prevented; at worse—since the perpetrators of such abuses pay little attention to current regulations and standards of care — not even that will be gained.

Second, if our real goal is to raise the quality of care, even a right to refuse that arguably protects some patients leaves the bulk of the problem untouched. Only a small percentage of patients refuse treatment, even when granted the right to do so, as our study showed.[9] (This finding, it should be noted, does not negate the disruptive effect that even that small group may have, nor, of course, the deleterious effect on their own treatment). What about the vast majority of State hospital patients who never challenge the care that they receive? To the extent that much of that care is substandard, the right to refuse medication protects them not at all. If we are to be concerned with the vast majority — and clearly Professor Dix is as con-

cerned with them as we are — the answer must lie in improving the quality of care for all.

That is not an easy task, but the time spent arguing about and implementing a right to refuse treatment could be better spent promoting a right to proper treatment. Adequate funding needs to be provided for State facilities, better staff must be recruited, academic affiliations must be established and mechanisms, such as peer review, must be implemented to assure the quality of care — for *all* patients. That is the proper response to the concerns that animate the right to refuse litigation, but, of course, all this would cost money, and, in any event, it remains beyond the power of the courts to implement; thus, establishing a right to refuse is a tempting — but ultimately deceptive — substitute for real reform. As we suggest, moreover, it may even defeat the very purpose for which it was forged.

Nonetheless, there do remain situations, even in an optimal system, in which patients refuse medication and a decision must be made as to how to proceed. Given the realities of the current system, in which care is often provided by an insufficient number of poorly trained and overwhelmed staff members, the possibility that involuntary medication will be used inappropriately must be considered, but the answer is not to turn to the courts, nor to rely on the chimerical notion that all we need do is assess patients' competence—a concept more nebulous by far than "dangerousness"[10,11] — in order to determine who may be treated. As Professor Dix suggests, a review of the situation by a well-trained psychiatrist out of the clinical chain of command may provide a means of protecting the refusing patient from both the possibility of mistreatment and the possibility of not being treated at all. This remedy—analogous to the customary use of a "second opinion" in good medical practice — was, in fact, a central pillar in the *Rennie* decision.[3]

In keeping with our belief that the quality of care for *all* patients — not just for refusers — should be the primary concern of the system, we note that such careful review of patients' treatment should not be limited to those patients who refuse medication. All patients have the right to the same careful consideration of their care. In the better institutions, this is already accomplished by means of regular review by supervisory psychiatrists and through consultation with visiting experts. If the argument over the right to refuse treatment provides an opening wedge for the introduction of these procedures on a universal basis for all patients, some good may yet come from all of this. At stake is not, in truth, the right to refuse treatment, but the right of every patient to receive good treatment, to reject bad treatment and to have some recourse: these are the rights that matter.

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