

## **The Right of Psychiatric Patients to Refuse Medication: Where Should Social Workers Stand?**

**Kia J. Bentley**

**T**he expanding role of social workers in the management of psychiatric patients' psychotropic medications (Bentley, Rosenson, & Zito, 1990; Davidson & Jamison, 1983; Gerhart & Brooks, 1983), as well as the developing debate over the appropriate stance of social work with regard to these medications (Cohen, 1988, 1989; Johnson, 1989), mandates the profession's attention to the complex ethical, legal, and philosophical arguments regarding where social workers should stand on psychiatric patients' right to refuse medication.

Relying on legal principles, specific case law, and social work's *Code of Ethics* (National Association of Social Workers, 1990), this article offers a rationale for social workers to be proponents of the right of psychiatric patients to refuse medication and demonstrates that this position makes sense for the profession legally, empirically, and ethically. Organized around the two preeminent value positions of the profession, self-determination and respecting the dignity and uniqueness of individuals, the article addresses the differences among competence, commitment, and mental illness; the right to privacy; and the prohibition against cruel and unusual punishment. It also reviews professional motivations in relation to both sides of the controversy and presents a position for the social work profession that stands for balance and common sense.

### **Social Workers as Proponents of the Right to Refuse Medication**

There is almost unanimous agreement among professionals, as well as among patients and their families, that a psychiatric patient does not have the right to refuse medication in a bona fide extreme emergency—that is, when the patient is “*presently* violent or self-destructive” and the state's interest is “grave and *immediate*” (Weiner, 1985, p. 346, italics added) or when there is a “*substantial likelihood of extreme violence, personal injury or attempted suicide*” (Judge Tauro, quoted in Ford, 1980, p. 337, italics added). Those in the field have seen such cases: The young man in the emergency room, acutely and severely psychotic, flail-

ing his arms, fighting off the staff, and speaking incoherently, for one example.

Unfortunately, many now wish to expand the interpretation of “emergency” to encompass essentially all refusals by patients that conflict with professional judgment. A patient's right to refuse medication is often portrayed as illogical, contradictory, and even unethical. The two key premises of this article, which point to the fallacies of these arguments, are that respecting the dignity and uniqueness of the individual and respecting the individual's right to self-determination mandate recognition of the right to refuse medication.

### **Major Premises**

#### **Respecting the Dignity and Uniqueness of the Individual**

*Corollary 1: Advocating for Fair Procedural Guidelines.* The due process and equal protection clauses of the 14th Amendment, which state that governmental processes and procedures should be fair and impartial, have been the “primary constitutional basis for recognizing the right to refuse medication” (Weiner, 1985, p. 343). Both state and federal courts have consistently ruled that it is unfair to allow forced medication without adequate procedural safeguards (*Davis v. Hubbard*, 1980; *In re K.K.B.*, 1980; “Involuntarily Committed Mental Patients,” 1986; *Jamison v. Farabee*, 1983; *Rennie v. Klein*, 1983; *Rivers v. Katz*, 1986; *Rogers v. Commissioner*, 1983; *Rogers v. Okin*, 1980).

In the words of the judge in the *Davis v. Hubbard* (1980) decision, “forced drugging of a patient for the purpose of doing good *absent* a determination that a person is not capable of rationally deciding what is good for himself” (p. 936) cannot exist. Unfortunately, with some of the so-called procedural safeguards, the right to refuse medication is tantamount merely to the right to have a second opinion (Stone, 1981).

*Corollary 2: Recognizing the Right to Privacy.* The right to privacy, or “the right to be left alone” (Malmquist, 1979), has been cited as another basis for recognizing the right to refuse medication. As Judge Tauro noted (quoted in Gutheil, 1980),

Whatever powers the Constitution has granted our government, involuntary mind control is not one of them. . . . The fact that mind control takes place in a mental institution in the form of medically sound treatment of mental disease [does not warrant] an unsanctioned intrusion of the integrity of a human being. (p. 327)

*Corollary 3: Insisting That Intentional Treatment with Medication without Permission Is Battery.* Illegal touching is a tort violation and "still an accepted legal grounds" (Stone, 1981, p. 358) for malpractice.

*Corollary 4: Defining "Good" Treatment as Treatment for Which the Patient Grants Permission.* Casual or unintended denial of the right to refuse medication occurs when patients are not allowed the same access to informed consent procedures as are medical patients, for example. It is common knowledge among mental health professionals that the doctrine of informed consent is almost always ignored in treating mental patients in hospitals (Stone, 1981). In both the legal and the professional arenas, ignorance of proper consent procedures is negligence.

*Corollary 5: Acknowledging That Medications Have Not Always Been Used Just to Treat.* Numerous examples exist in the literature—and certainly hundreds more in the memories of patients—in which drugs have been used to punish patients. For example, *Knecht v. Gillman* (1973) concerned the use of a drug to induce vomiting when a patient broke simple rules on the hospital unit. Drugs have also been used for social control, such as when patients were given a drug that induced respiratory arrest and paralysis (Malmquist, 1979). Consequently the prohibition against cruel and unusual punishment has been cited in several right-to-refuse-medication cases.

*Corollary 6: Respecting the Religious Beliefs of Patients.* In *Winters v. Miller* (1971), the judge ruled that the states did not have a compelling interest in overriding a patient's refusal of medication because of her religious beliefs. Malmquist (1979) noted that the others could easily extend this argument to anyone who has a "sincere and deeply felt opposition" (p. 353) to medication.

*Corollary 7: Holding Fast to the Presumption of Competence among Psychiatric Patients.* The central issue with regard to the refusal of medications is the extent to which mental illness impairs the ability to decide about treatment. Although the courts have unani-

mously affirmed that the competence of mental patients should be presumed unless patients have been adjudicated otherwise (*Rogers v. Commissioner*, 1983) and the psychiatric literature continues to support empirically the reality of competence (Weiner, 1985), some believe that all mentally ill people are incompetent. For example, a vocal opponent of the right to refuse medication has speculated that at least half the mentally ill patients are likely to be incompetent and, thus, that the presumption of competence is "a dubious claim" (Gutheil, 1985, p. 37). Bentley (1991) and others (Roth, Meisel, & Lidz, 1977) have pointed out that equating mental illness, or even involuntary admission, with incompetence leads to an intolerable "global indictment" of the population by characterizing them as inept and unfit and may lead to unnecessary or inappropriate decision making by third parties.

It could be argued that it is irrelevant whether mentally ill people are competent. In a criminal case, for example, it is irrelevant whether the accused is guilty because the presumption of innocence establishes the extent and direction of the burden of proof. The presumption of competence, likewise, is

essential in ensuring a just system of checks and balances.

### **Respecting the Individual's Right to Self-determination**

*Corollary 1: Believing Patients When They Report That Side Effects Are the Major Factor in Their Refusal.* Opponents of the right to refuse medication believe that patients do so for "illness-related" reasons, that is, as part of their mental illness. Studies from the 1960s concluded that patients' refusal was related to intrapsychic conflict (for a review, see Van Putten, 1974). Even a recent study of 378 patients in a maximum-security forensic hospital concluded that the primary reason for patients' refusal of medication was denial of their illness (Rodenhauser, Schwenker, & Khamis, 1987). However, the reasons for refusal were obtained not by asking patients directly but by interpreting the chart recordings of nurses.

Opponents of the right to refuse medication have also stated that patients do so because the medication erases the so-called positive aspects of being psychotic and points up the patients' reluctance to face reality (Appelbaum & Gutheil, 1980). In several court cases, however, there simply was never enough evidence

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(from the experts, from the literature, or from patients' testimony) (Cole, 1982) to support what could be called the myth of irrationality. Instead, disabling side effects have been one of the most consistent reasons for refusal (Van Putten, 1974), and patients' subjective responses about how the medication made them feel was the most powerful predictor of compliance over a two-week period (Van Putten, May, Marder, & Wittmann, 1981).

What are the side effects of medication that patients commonly report "keeps me closed in," "makes me feel spacey," "slows my thinking," and "makes me confused" and that have been described as "neuroleptic-induced anguish" (Hogarty, cited in Van Putten & Marder, 1987)? They include akathisia (restlessness) and akinesia (lack of spontaneity), as well as parkinsonism (drooling, stiffness, tremors, and a shuffling gait), muscle spasms, drowsiness, weakness, blurred vision, decreased sexual desire, constipation or diarrhea, and rashes (Van Putten & Marder, 1987).

The severest side effect, however, is tardive dyskinesia, which involves grotesque, often embarrassing, involuntary movements of the lips and mouth; is irreversible; and affects an estimated 20 to 60 percent of chronic mental patients. Another severe side effect, for which young men on high-potency drugs seem to be most at risk, is neuroleptic malignant syndrome, characterized by fever, rigidity, stupor, increased pulse, increased respiration, and sweating (Bassuk, Schoonover, & Gelenberg, 1983).

The point is not to overemphasize the risk of psychotropic drugs, whose benefits admittedly help hundreds of thousands of mental patients to manage in the community. The point is that for some patients, the side effects are too severe to offset the benefits.

*Corollary 2: Advocating for Fair Substitute Judgment, When Necessary.* Another disturbing common assumption is that declaring a patient incompetent to decide about treatment is tantamount to granting permission to treat the patient involuntarily. This assumption circumvents the need to appoint an appropriate guardian and, even more disturbing, ignores what the patient would have wanted if she or he was competent to decide.

The courts have been clear on this point. The opinions of all patients, including incompetent ones, should be seriously considered with regard to treatment or dispositional decisions (Stone, 1981). Two cases come to mind. *In re Boyd* (1980) concerned a patient whose refusal was upheld because it was based on religious beliefs even though he was adjudicated incompetent. *In re Guardianship of Richard Roe III* (1981), an appointed guardian was prevented from allowing physicians to medicate an incompetent patient forcibly because an

analysis of what the patient would have wanted revealed that he would refuse if he was allowed or able to decide. This decision was not necessarily in the patient's best interest; rather, the expressed preference of the patient was the number one criterion.

*Corollary 3: Recognizing That Occasionally, but Not as Often as Some Claim, the Consequences of Patient Refusals Will Be Negative.* Those who oppose the right to refuse medication portray refusers as irrational, psychotic, assaultive, paranoid, and dangerous individuals who bring fear and chaos to hospital wards and contribute to the excessive cost of care by extending their hospital stays. The evidence does not support these contentions.

Zito, Rott, Mitchell, and Roering (1985) found persistent "refusers no more assaultive or combative than consenters" (p. 822). Van Putten, Crumpton, and Yale (1976) stated that refusal could not be attributed to paranoia. Rodenhauer et al. (1987) reported that the length of hospital stays of refusers who were medicated against their will was no shorter than that of refusers who were not medicated. Evidence such as this led Brooks (1987) and Cole (1982) to conclude that fears of violence, destruction, and chaos are invalid. Grandiosity seems to be the only consistent variable associated with refusal (Marder et al., 1984; Schwartz, Vingiano, & Perez, 1988; Van Putten et al., 1976).

Interestingly, in the study by Schwartz et al. (1988), cited frequently by opponents, which found that 17 of 24 patients felt that overriding their refusal might be appropriate, the seven who did not express this sentiment were labeled by the researchers as grandiose and engaging in denial. This reader was tempted to question whether the researchers engaged in circular reasoning. Perhaps the researcher labeled the patients as grandiose and in denial because they refused their medication, rather than finding that they refused their medication because they were grandiose and in denial.

### **"Best Interests" and Balance**

Supporting a psychiatric patient's right to refuse medication makes sense for social workers legally, empirically, and ethically, especially in light of the profession's mandate to respect an individual's dignity and worth and right to self-determination. Many constituent groups can agree on the expansion of the right to treatment, for example, but differ over the right to refuse it. Why are there such differences of opinion? Some have implied that the issue is not patients' rights or the "best interests" of patients, but simply another battle for authority between the psychiatric and the legal professions (Brown, 1985). This battle is clearly apparent in arguments regarding whether competence should be a

clinical or a judicial decision (see, for example, Michels, 1982; Schwartz et al., 1988).

It has also been said that the more professionals can portray themselves as acting in the best interests of patients, the more they will be able to expand their power base, status, and position (Brown, 1985). Indeed, some have accused psychiatry of overemphasizing medication to remain dominant in the field (Scheff, 1976). On the other hand, psychiatrists have accused patients' rights advocates and the courts of being "cavalier in their lack of concern" and "probably biased" (Gutheil, 1985, p. 37). Patients have reminded both groups that slavemasters thought of themselves as benevolent as well (Chamberlin, 1982).

The growing family movement may have joined with psychiatrists in portraying civil libertarians and patients' advocates as standing against those who "really" care about patients. Rosenson and Kasten (1991) wrote, "Unfortunately, patients' rights advocates can be more concerned about what they deem to be autonomy than about the patient's best interest" (p. 3). This author, however, believes that patients should "own" their best interests and that social workers should stand for balance. As Gerhart and Brooks (1983) stated, social workers can play an important role in providing "an effective balance between protecting the rights of decision making . . . versus their need for medication" (p. 457). But what is meant by balance?

First, this author does not agree with Cohen's (1988) statement that "encouraging the use of drugs in another human being immediately creates issues of authority and coercion which vitiate . . . the values of temporarily feeling better" (p. 579). Rather, she believed, as did Davidson and Jamison (1983), that psychotropic medications should be "cautiously" accepted. There is more than sufficient evidence for encouraging mentally ill patients to use psychotropic medications, the effectiveness of which has been firmly established. Indeed, the use of these medications is an ethical, humane alternative to deterioration. When medications are used properly, most patients are helped, families are relieved, and hospital stays are shortened.

Social workers, however, should also stand for the right of patients to choose or reject medication. A bothersome assumption in the literature is the notion that a patient's refusal of medication is a refusal of all

treatment. As Gutheil (1985) stated, allowing patients to be committed and then refusing medication is "forcing custodial care" (p. 38). It is as if medication is the only known treatment. This is clearly an example of reductionist thinking that is commonly found in the medical profession. When a patient refuses medication, social workers should advocate for the increased use of psychosocial means of rehabilitation, such as skills training, case management, and problem solving. In devising his professional strategy for dealing with patients' refusal of medication, one psychiatrist wrote of his patience and ongoing collaboration with his patients: "I respected each patient's right to refuse [medication] while insistently keeping alive the possibility that they may decide to accept [it]" (Geller, 1982, p. 113).

Social workers are in a unique position to negotiate with clients, to empathize with their dilemmas, to educate them about mental illness and medication, to help them cope with side effects and symptoms, to teach them skills in decision making, and to utilize cognitive and behavioral strategies to enhance their compliance (Bentley et al., 1990). Making treatment available and creating alternative strategies are appropriate roles; forcing treatment is not.

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they as individuals or the profession as a whole may experience some negative professional consequences for their advocacy, from being discredited to being accused of using patients' rights issues to increase their own power (Brown, 1985). The struggle will be worth it. Patients have not, as was predicted more than a decade ago, "rotted with their rights on" (Appelbaum & Gutheil, 1979). Rather, the fight for the right of psychiatric patients to refuse medication is already credited with helping reduce dosages, polypharmacy, and inappropriate administration and increase patients' participation in treatment (Brooks, 1987). ■

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