At Issue: Management of Medication Noncompliance in Schizophrenia by Families in India

by Tirupati N. Srinivasan and Rangaswamy Thara

Abstract

Noncompliance with medication during a symptomatic phase is a common problem in the treatment of schizophrenia patients. In India, a majority of patients live with their families and those families supervise patients’ medication intake. In a study of patients attending an urban outpatient care center in India, it was noted that when the patients were acutely ill and refused to take medication, the families administered medication to them without patients’ knowledge, under the supervision of the psychiatrist. This method had been practiced by families in half the cases of patient noncompliance. Many families felt that there was no other viable alternative under the circumstances. Only a minority of patients was aware of having received medication through this method, and many of them reacted negatively to it. However, the patients were subsequently taking treatment voluntarily following the reduction in the severity of the behavioral disorder with the involuntary treatment. The issues involved in this form of treatment are discussed with regard to the social and health care environment in the country.

Keywords: Medication compliance, involuntary treatment, outpatient, schizophrenia, India.


Patients who do not follow the treatment schedule and drug regimens prescribed to them by physicians can be described as noncompliant or nonadherent (Razali and Yahya 1995). Poor medication compliance is a problem in all areas of medicine, and psychiatry is no exception (Nageotte et al. 1997). By its very nature, psychiatric illness that impairs judgment, insight, and stability places psychiatric patients at increased risk for medication noncompliance (Kane 1985).

Noncompliance may occur in up to 50 percent of patients with schizophrenia who are prescribed neuroleptics (Bebbington 1995). Even higher rates of noncompliance (73%) have been reported (Razali and Yahya 1995). Patients with schizophrenia are particularly vulnerable to relapse following medication noncompliance (Johnson et al. 1983; Rajkumar and Thara 1989). The costs of poor compliance to sufferers and to society are considerable, and effective ways of improving compliance are a crucial part of good management (Bebbington 1995). Therefore, improving medication compliance in persons with schizophrenia holds the potential for reducing the morbidity and suffering of patients and their families, in addition to decreasing the cost of rehospitalization (Nageotte et al. 1997).

Studies on medication compliance in schizophrenia have often dealt with its role in relapse prevention after recovery from an episode. Often, refusal of medication is encountered during the acute phases of the illness, at the onset, or during a relapse. As patients are acutely symptomatic during these periods, medication refusal can entail harm to the patients and others around them, in terms of not only safety but also the social and emotional consequences of the psychotic behavior. Such a crisis situation calls for immediate steps to control the psychotic symptoms. Under these circumstances hospitalization and administration of medication to such patients, with family or legal sanction, is a standard approach in most health...
Care settings. The growing emphasis on community care has underlined the significance of patient-family interactions in this aspect of treatment. Families have been oriented toward increasing medication compliance through psychoeducational programs (Goldstein 1994).

Health care seeking in India for schizophrenia is based on some realities. First, the patient typically lives with his or her family, like most other persons in the country. Second, the predominant and often only method of treatment for a majority of patients takes place in the outpatient setting (Agarwal and Gupta 1999). The lack of adequate inpatient facilities and health care services at the community level places the brunt of caring for the acutely ill schizophrenia patient on the family. Given this scenario, a strategy that can help the family to administer medication to the acutely disturbed noncompliant patient at home is called for.

During the last 16 years of work at Schizophrenia Research Foundation (SCARF), a nongovernmental organization located in Chennai in southern India, we had noted that a number of schizophrenia patients had received medication from relatives without their consent and knowledge during acute phases of illness. This was almost always done upon the advice of their psychiatrist. Antipsychotic agents in colorless and tasteless liquid or tablet form were mixed into beverages or food of the patients in the advised doses. Once the acute symptoms were controlled with this treatment, the patient was prescribed oral medication that he or she took voluntarily. As this practice seemed to be a fairly common mode of intervention, we aimed to study the prevalence of this practice among family members treating noncompliant schizophrenia patients; here, we will refer to the practice as family management of noncompliance (FMN).

The factors related to the practice and the consequences of such administration of medication were studied. We present our observations and discuss the issues involved in this method of involuntary outpatient treatment of patients.

Method

Study Population. The study was conducted at SCARF. This center provides outpatient treatment and rehabilitation as well as residential care facilities for schizophrenia patients. The outpatients attending the center formed the study group. All these patients lived with their families in the city of Chennai and its suburbs. They were diagnosed as having schizophrenia using DSM-IV criteria and had been ill for at least 2 years. Diagnosis was made by mental status examination and review of medical history records. The study was conducted over a period of 1 year from 1999 to 2000.

Family Interview. A key relative, a family member living continuously with the patient in the same household (usually a parent or spouse), was interviewed. Sociodemographic information was recorded. A short questionnaire was administered that elicited information on the following details regarding FMN:

1. experience of noncompliance in the form of refusal by the patient to take medication orally at the onset of illness, during a relapse, or both
2. doctors' advice to administer medication without the patient’s knowledge
3. (if advice followed) the person who administered the medication, the form of medication, and the duration of such treatment
4. the effect of treatment on overall behavior (The effect on behavior was assessed by the overall change in the severity of behavior as perceived by the family. Two types of change were scored, namely, “no change or worsened” and “reduced severity.”)
5. the reaction of the patient when the patient realized he or she was receiving medication by this method
6. the key relatives' opinions about giving medication without the patient’s knowledge

Results

The total number of patients studied was 254. There was a history of noncompliance with oral medication in 148 (58%) patients during the course of their illness. Sixty-two of them (42%) took medication subsequently; various strategies, including waiting, pleading, coercing, and threatening, were used. The other 86 (58%) refused medication, and all methods adopted by the family failed. Twelve of them were admitted to a hospital, where the doctor administered parenteral medication for control of acute symptoms. The remaining 74 (50% of the noncompliant patients) were treated as outpatients and given medication at least once without their knowledge by the family members under the psychiatrist’s advice. Subsequent data pertain to this group of 74 patients who received FMN. All of them received the medication during an acute symptomatic phase of the illness, 24 (32%) at the onset of illness, 24 (32%) at a relapse, and 26 (36%) during both phases. The treatment was given for a few days (less than a fortnight) in 57 patients (77%), for a few weeks to months in 7 (9%), and for a year or more in 10 (14%). The medication was given by parents for 38 patients, by the spouse for 15, and by other relatives (siblings or children) for 21 patients. Oral preparations of neuroleptics (liquid or tablet form of chlorpromazine, haloperidol, or risperidone) were used.

Patients who were given FMN were compared with those who were not. There were no differences in gender, marital status, education, or employment status (for males)
of the patients in the two groups. About 90 percent of all the families were from lower and middle economic strata.

**Effect of FMN.** In a great majority of patients who were given involuntary medication \((n = 67, 91\%)\), the family observed a reduction in severity of symptoms that was said to have helped them convince the patient to take oral medication subsequently. FMN had no effect on the symptoms in the other seven patients, who had to be treated by other means, including parenteral medication by the psychiatrist. Adverse events like drowsiness and extrapyramidal symptoms attributable to the administered drug were noted in 10 patients.

**Reaction of the Patients to FMN.** In 19 (26\%) cases the families reported that the patient became aware of FMN at a later date. Families of 55 (74\%) patients were not sure of the patient's state of awareness about FMN and did not want to explore it with the patient. In the patients who were aware of the treatment, anger and resentment toward the family was the common reaction, expressed by 12 of them. The other 7 were said to have accepted it without any reaction.

**Caregiver Reaction to FMN.** There were three types of reactions from the key relatives toward the method they had adopted. More than half of them \((n = 41, 55\%)\) felt it was the right action under the circumstances. All the families of patients who later became aware of the treatment felt this way. The feeling that the method was not the ideal but was probably the most practical one in the absence of any alternatives at the moment of crisis was expressed by 30 (41\%) respondents. Only 3 (4\%) felt that they should not have administered the medications that way even if there had been no alternative.

**Discussion**

Administration of antipsychotic medication by family members under medical advice to noncompliant patients with schizophrenia without the patient's knowledge was observed to be common in the population we studied. Half of the families whose ill members refused to take medication had resorted to this form of treatment. Gender, marital status, education, or employment status of the patients did not relate to the use of this method. The treatment was often given for a few days, but a few received it for more than a year. The treatment was effective in most patients, reducing the severity of symptoms, which in turn seemed to have facilitated further voluntary intake of medication by the patient. Many patients never became aware of the treatment they had received, but in those who did come to know about it, hostility toward the family was a common reaction. However, even these patients continued to be on regular treatment voluntarily after the initial reaction. Most of the families felt it was the right step taken when the patient was acutely disturbed, and only a few expressed the feeling that they should not have resorted to FMN.

**Risks and Benefits of FMN.** The benefits derived for the patient and the family in terms of rapid control of symptoms, facilitation of further treatment, and avoidance of the cumbersome and costly process of hospitalization seem relevant. The negative consequences of surreptitious treatment in terms of serious adverse effects were not found to be high. The prolonged use of FMN, extending for years in some cases, causes concern. However, the benefits of such treatment in at least some patients seem to far outweigh other considerations, as exemplified in the following case description.

After becoming severely ill and refusing to undergo treatment, a 30-year-old woman with paranoid schizophrenia was sent back to her parents in India by her husband living abroad. Her parents were advised to try FMN. After nearly 15 months of FMN she remitted fully and returned to normal functioning. It was then explained to her that she had been given treatment without her knowledge. She had no adverse reaction and began to take the medicines voluntarily. When this report was made, she had been on continued medication for 3 years and had rejoined her husband.

Below, some FMN issues are considered from the perspectives of the patient, the family, the professional, and ethics.

**Patient Perspective.** A variety of experiences of patients undergoing involuntary treatment have been studied. Although the treatment was viewed negatively by nearly half of patients with severe mental disorders who had experienced forced treatment of one form or other, they retrospectively felt that the forced treatment was in their best interest (Adams and Hafner 1991; Lucksted and Coursey 1995; Naber et al. 1996). Many respondents believed that pressure or force has an appropriate role in psychiatric treatment, although most wished to maintain the right to refuse treatment that they considered not in their best interest (Lucksted and Coursey 1995). Only patients with good insight into their disease were able to accept the involuntary treatment, retrospectively, as positive (Naber et al. 1996). In this study only a minority became aware of the involuntary treatment, and although their reaction was often negative, it had not affected their adherence to treatment subsequently. The general impression was that involuntary treatment is viewed positively by many patients in the long run even though they felt aggrieved about it during the early stages.
Family Perspective. The role of the family in caring for the mentally ill in India needs due consideration. The family in India plays a major role in health seeking for its constituents (Nunley 1998). Any intervention planned for the patient should take into account the family’s considerable influence over many aspects of patient management, including outpatient consultation and continuing care (Nunley 1998; Padmavati et al. 1998). As mentioned in the introduction, the entire responsibility for meeting all patient needs—namely medical, social, and economic—rests with the family, given the status of health care services. The families, consequently, face a great degree of burden and distress. Hospitalization is a less preferred method of treating an acutely ill patient. More important, the families often do not feel, as they did in our study, the need for hospitalization as they are prepared for and prefer treating the patient at home.

The issue of families’ reaction to FMN needs examination. The position taken by the families regarding FMN came out when the possible “wrong” in giving medication to patients without consent was discussed with some of them. The families opined that the health of the patient was uppermost in their minds and that because they were acting on medical advice, they had no reason to dispute this method of treatment. As the method led to improvement and facilitated further treatment without any danger to the patient and avoided the difficulties of other alternatives, their action was justified in their minds. It should be noted that the opinion expressed by the families about the “rightness” of the method adopted could be so because it was post hoc. Their opinion at the time they were actually giving medication could have been different. The key relative’s apprehension about exploring the reaction of the patient who was unaware of having received FMN does indicate that involuntary medication of the patient had been far from easy for the families to do. They had to choose the easier of two difficult options, treat voluntarily or hospitalize without the patient’s consent.

Professional Perspective. On general principle, competent adult patients may ethically and legally refuse treatment, totally or partially. The doctor often faces an emergency situation when faced with a health condition like psychosis or another medical disorder in which there is an imminent threat to the patient’s health that would increase without immediate treatment and the patient is not able to provide an express consent. Under such circumstances, public policy and law support an assumption of implied consent for initiation of medical care (Crimmins 1992; Rice 1992). When patient’s intentions are unknown, they should be clarified by a responsible surrogate decision maker. This surrogate can authorize the physician to override the patient’s decisions if the physician believes that the patient’s expressed preferences are not consistent with the patient’s actual goals (Casarett and Ross 1997). What applies to initiating treatment to a medically ill person unable to consent to treatment should also be relevant to a person whose judgment is impaired because of a psychiatric disorder like schizophrenia. In our patients it was not merely the family consenting on behalf of the patient to treat the patient but actually administering the drugs to the patient. In this context, it is to be noted that the family in India would be involved in administering medication even if the patient was volunteering to take the medication. The ultimate responsibility, without doubt, rested with the psychiatrist under whose supervision medication was administered. It was important that the psychiatrist had accurately documented that an actual emergency existed requiring immediate administration of medication, that there was an inability to obtain express consent from the patient, and that there was some responsible authority/surrogate authorized to give consent on the patient’s behalf and to administer the medication. Psychiatrists must be vigilant about protecting the patient from any ulterior and harmful motives on the part of the surrogate who gives the medication.

Ethical Perspective. Growing concern for involuntary patients’ civil rights has engendered criticism of psychiatry. Several mutually reinforcing and, at times, conflicting ethical principles are involved in the involuntary treatment of patients: beneficence (do good and no harm), utilitarianism (benefits must outweigh costs), and respect for persons. The administration of treatment to schizophrenia patients without their expressed knowledge is an ethical issue involving these three principles. The first two principles are addressed here, as the FMN mode of treatment helped many patients recover from the illness enough to voluntarily participate in further treatment, without many negative effects and at a low cost, both financial and emotional. With regard to the principle of respect for persons, it could be argued that treatment of a competent person with psychosis against his or her will may be beneficial clinically but fails to respect the person’s right to make his or her own decisions. The counter is to say that effective treatment of severely disturbed psychotic patients, whose awareness and judgment are impaired and who are not competent to make decisions regarding treatment because of the illness, is showing respect for the affected person by restoring his or her capacity for self-determination and psychological freedom. It would not be proper to overemphasize the apparent liberty of ill persons at the expense of allowing them to go untreated and suffer the consequences of not being able to obtain medical help for themselves. The Hawaii declaration of the World Psychiatric Association provided guidelines for treating a patient who...
cannot express his or her own wishes regarding treatment and cannot see what is in his or her best interests owing to the psychiatric illness. The guidelines suggest that compulsory treatment may or should be given provided it is done in the best interests of the patient (cited in Agarwal and Gupta 1999).

There are limitations to the interpretations that can be made from the study’s observations. The retrospective nature of the study entails recall bias, especially with regard to the reaction of the patient to the treatment and adverse events experienced because of the drug. The information gathered does not indicate which type of patient benefits most from the treatment. Notwithstanding the report’s methodological flaws, we would like the reader to focus on the issues related to the common practice of involuntary treatment of schizophrenia patients by the family in a situation where the alternative modes of treatment are unavailable and not preferred. There is bound to be an ongoing debate over the rights of the patients who refuse medication and the benefits of restoring them to functioning by involuntary treatment. In many nations of the developing world, where economic needs often assume priority and are critical for day-to-day living, it can be expected that FMN will continue as a viable solution for the acutely disturbed patient and the family.

References


The Authors

Tirupati N. Srinivasan, M.D., is Consultant Psychiatrist, and Rangaswamy Thara, M.D., Ph.D., is Director, Schizophrenia Research Foundation, Chennai, India.