

# Medication refusal among patients treated in a community mental health rehabilitation service

Rob Macpherson, Minh Alexander and W. Jerrom

**Aims and method** This study aimed to examine medication refusal and its associated variables in a representative sample of patients on the Gloucester rehabilitation service case register. One hundred and seventy-four of 199 patients on the Gloucester rehabilitation register were surveyed. Insight, cognitive function, knowledge of treatment, psychopathology and patient satisfaction were independently rated.

**Results** Thirty-five per cent of patients had refused treatment in the past month. Negative attitudes to treatment and historical indices of non-compliance were associated, identifying a consistent core of patients at continuing risk of refusal. However of refusers, 84% were persuaded within one month to take treatment, mostly by their community keyworker. Treatment refusal was associated with diagnosis of affective disorder, higher Brief Psychiatric Rating Scale score and failure to use a dosett dispenser, but not with insight, cognitive function, satisfaction with treatment, knowledge of treatment, a range of illness and demographic factors or any particular treatment type.

**Clinical implications** Drug refusal was evidently mostly managed by community keyworkers, and without recourse to the Mental Health Act. Simple techniques such as the use of dosett dispenser may be valuable. Problems of communicating with the severely mentally ill about their long-term treatment were discussed.

Relapse prevention is at the core of modern psychiatric practice. Immeasurable human suffering and enormous cost to society result from relapse (Kissling, 1994). Following a psychotic or affective episode, continuing drug treatment will roughly half the risk of relapse over the next year. Poor compliance has been cited as a prominent reason for treatment resistance in schizophrenia (Barnes & Pantelis, 1992), up to 80% of psychotic patients failing to comply with their treatment (Corrigan *et al.*, 1990). Putative reasons for non-compliance including side-effects of treatment, the complexity of the drug regime, lack of social

supervision, more severe psychopathology and the doctor's attitude, were identified in an early paper by Blackwell (1972). Kemp *et al.* (1996) have argued that psychotic patients often fail to accept treatment that may help them "largely because of their illness", and have presented promising results from new therapeutic approaches, targeting compliance problems, with techniques such as motivational interviewing.

Methodological problems are inevitable in compliance research, which generally involves the inference of non-compliance with treatment from indirect measures of patient behaviour, and in which the patient's report implicitly cannot be relied on. It is possible to distinguish treatment refusal as a sub-group of non-compliance problems, most of which are probably passive and 'partial', meaning a failure to take some but not all the medication. Studying treatment refusal has theoretical advantages, being more reliably based on the professional's account and arguably representing the type of problematic patient attitude more likely to lead to a requirement for compulsory treatment.

The present study aimed to examine rates of drug refusal and compliance problems in a representative group of patients with severe mental illness of varying aetiology, being treated largely in community settings. The study aimed also to assess the relationship between compliance problems and relevant clinical factors.

## The study

This study was carried out as part of a larger examination of patient satisfaction (Macpherson *et al.*, 1998). One hundred and seventy-four of 199 patients on the Gloucester rehabilitation register were surveyed. The work of the rehabilitation service studied is focused on challenging behaviour in severe mental health, and is inevitably biased towards problems such as treatment refusal. Two research assistants

assessed all patients in their home settings, with the following instruments:

- (a) The Insight Scale (Birchwood *et al.* 1993), a seven-item interview scale deriving total insight scores ranging zero to 14.
- (b) The abbreviated Roth Hopkins Scale (Blessed & Thompson, 1987) for cognitive function.
- (c) Patient satisfaction was measured as the total of six satisfaction domain scores, on a scale designed by R. M. (Macpherson *et al.* 1997).
- (d) An abbreviated form of the Understanding of Medication Questionnaire (Macpherson *et al.* 1996) was used for knowledge of treatment, referring to the patient's main (in his/her view) psychiatric medication.
- (e) The Brief Psychiatric Rating Scale (BPRS; Overall & Gorham, 1964) was used to rate psychopathology.

#### Compliance with medication

The compliance sub-scale of the Insight Scale (Birchwood *et al.* 1993), range zero to four, was rated by research assistants.

Keyworkers identified whether their patients had refused treatment (defined as explicitly and actively declining treatment in communication with the keyworker) over the past month. Where refusal had occurred, its outcome was recorded by keyworkers on a seven-point scale, giving a spectrum of outcomes from being persuaded immediately to take the treatment, to continued refusal for the full month of treatment. Keyworkers also rated the patient's predominant attitude to treatment over the previous month as 'actively pursued', 'passively accepted', 'actively refused', following a modified form of Van Putten's (1974) method. Keyworkers also rated the patient's acceptance of treatment over the past month as: 'always', 'usually', 'not usually' or 'never'.

In addition to current compliance difficulties, keyworkers recorded the number of compliance-related admissions over the course of the patient's illness.

Data were entered in to the SPSS computer package for statistical analysis.

#### Findings

Full results were obtained for 174 of 199 patients (87% response rate). Patient diagnostic, demographic and illness related details are listed in Table 1.

The sample comprised 124/174 (68%) male subjects, aged mean 49.6 years (range 18 to 72 years, *s.d.* 14.2). One hundred and sixty-six (45%) patients were Caucasian, the remaining

eight being Afro-Caribbean (7) and Asian (1). Seven patients were being treated under the Mental Health Act (1983), four conditionally discharged under Section 37/41, and three patients on Section 3.

#### Treatment data

All patients were taking psychotropic medication. One hundred and fifty-seven (90%) were on antipsychotic medication, of whom 53 (34%) were on depot, 52 (33%) on oral medication and 52 (33%) on oral plus depot antipsychotics. Thirty-two patients (18%) were on 'atypical' antipsychotics (clozapine/risperidone). Forty-two patients (24%) were taking lithium and 40 (22%) carbamazepine. Twenty-nine (17%) were on antidepressants. In 32 cases (18%) medication was administered by dosett dispenser. Treatment was supervised by: professionals, 76 (44%); non-professional carers, 42 (24%); family, 10 (6%); and the patient him/herself, 46 (26%).

Table 1 Demographic and illness related data in study group

Variable	Mean
Years since first illness (range, <i>s.d.</i> )	22.3 (1–55, 12.8)
Years in psychiatric hospital (range, <i>s.d.</i> )	11.1 (0–46, 13.1)
Brief Psychiatric Rating Scale (range, <i>s.d.</i> )	24.5 (2–66, 12.2)
Roth Hopkins score (range, <i>s.d.</i> )	7.5 (0–10, 2.4)
Social Function Scale score (range, <i>s.d.</i> )	16.3 (0–24, 4.8)
Insight Scale (range, <i>s.d.</i> )	10.7 (0–16, 4.0)
Modified Understanding of Medication Questionnaire score (range, <i>s.d.</i> )	9.2 (0–18, 5.4)
Patient total satisfaction score (range, <i>s.d.</i> )	15.2 (6–31, 5.5)
Accommodation type	
Hospital	6 (3%)
Psychiatric nursing home	27 (16%)
General nursing home	22 (13%)
Supported lodgings	68 (39%)
Group homes	16 (9%)
With family	10 (6%)
Independent	25 (14%)
Diagnosis	
Schizophrenia	105 (60%)
Schizoaffective disorder	13 (7%)
Mood (affective) disorder	18 (10%)
Dementia/other chronic organic brain disease	15 (9%)
Obsessive-compulsive disorder	9 (5%)
Other neuroses	4 (2%)
Personality disorder	10 (6%)

*Illness histories*

Duration of time since first psychiatric illness was mean 22.3 years (range 1 to 55 years, s.d. 12.8). Patients had spent a mean of 11.1 years (range 0 to 46, s.d. 13.1) in psychiatric hospital. Only three patients (2%) had never been admitted to psychiatric hospital, the mean number of admissions being 4.4 (range 0 to 29, s.d. 4.5). Fifty-three (30%) patients had been admitted on Section, mean number of Section admissions being 1.0 (range 0 to 10, s.d. 1.8).

*Compliance-related data*

Thirty-five per cent (61/174) had refused treatment at least once over the past month. Of refusers, 48% (29/61) were persuaded to take treatment immediately by keyworkers. Twenty-three per cent (14/61) were persuaded over the next month by keyworkers, a further 5% (3/61) at lower dose. Eight per cent (5/61) were persuaded to continue treatment following medical review, 10 patients (16% of refusers, 6% of total sample) continuing to refuse treatment through this time scale, despite any efforts made.

Keyworkers reported their patients' acceptance of treatment over the past month as: always, 117 (67%); usually, 50 (29%); not usually, 7 (4%); never, 0.

Keyworkers rated their patients' main attitude to treatment over the past month as: actively pursued, 71 (41%); passively accepted, 97 (56%); actively refused, 6 (3%).

Thirty-two per cent (56/174) of patients had a history of compliance-related admissions, mean 0.67 (range 0 to 10, s.d. 1.43) admissions per patient.

Predominant attitude to medication was significantly correlated with acceptance of medication and with the compliance sub-scale of the Insight Scale (Kendall's tau,  $r=0.27$ ,  $P<0.001$ ;  $r=-0.19$ ,  $P=0.004$ ). Acceptance of medication was significantly correlated with the compliance sub-scale (Kendall's tau,  $r=-0.29$ ,  $P<0.001$ ).

*Associations of treatment refusal*

Drug refusal was significantly related to more negative attitude to treatment (Kendall's tau,  $r=0.24$ ,  $P=0.001$ ), see Table 2. There was no association between treatment refusal and gender, race, current Section status, accommodation type, mode of supervision of medication, or any particular current medication including oral/depot antipsychotic, atypical antipsychotic, antidepressant, lithium or carbamazepine ( $\chi^2$  tests). Treatment refusal distributed significantly differently by diagnosis, being more likely with a diagnosis of affective disorder, and less likely with 'other' diagnosis (mainly primary substance misuse and various neurotic conditions)

Table 2 Association of drug refusal with attitude to treatment

Treatment refusal	Patient attitude to treatment		
	Actively pursued treatment	Passively accepted treatment	Actively refused treatment
Yes	2	53	6
No	69	44	0

( $\chi^2=18.5$ ,  $P=0.002$ ). Treatment refusal was less common in the group given a medidose to help take their medication ( $\chi^2=5.5$ ,  $P=0.02$ ). See Table 3 for distribution of refusal by diagnosis, use of medidose and accommodation type.

Drug refusal was associated with significantly greater compliance-related and Section admissions, and higher BPRS score (Mann-Whitney  $U$ -tests,  $z=-2.8$ ,  $P=0.004$ ;  $z=2.5$ ,  $P=0.01$  respectively), but not with age, total years since illness started, Insight Score, Roth Hopkins Score or modified Understanding of Medication Questionnaire score. Total satisfaction score and the satisfaction with treatment sub-scale scores were similar in the treatment refusal and accepting groups (Mann-Whitney  $U$ -tests in all cases).

Table 3 Distribution of drug refusal according to diagnosis, current accommodation type and use of dosett dispenser

	Did not Refused	% refusing by group
Diagnosis		
Schizophrenia	30	29
Schizoaffective disorder	6	50
Affective disorder	9	64
Organic disorder	5	38
Obsessional disorder	4	44
Personality disorder	4	40
Other	0	0
Accommodation type		
Hospital	2	33
Psychiatric NH	11	41
Residential/medical NH	10	43
Supported lodgings	17	25
Group home	6	35
With family	5	50
Independent	9	36
Other	1	25
Use of Dosett dispenser		
Dosett dispenser in use	5	16
Dosett dispenser not in use	53	37

NH, nursing home

## Comment

The results of this study should be treated with some caution, as the population may be biased in favour of drug refusers; patients in the care of a rehabilitation service may have more severe, resistant illnesses, and drug refusal may be more common than in general psychiatric populations. The service studied has an assertive outreach policy; periods of drug refusal are anticipated and do not cause discharge from the service. The response rate was high, suggesting the results are at least representative in this type of population, although as non-participation resulted mainly from non-cooperation, the rate of treatment refusal may be slightly underestimated.

Around a third of the patients had refused their treatment in the month prior to assessment. This rate appears high, but is in keeping with a previous finding (Macpherson *et al.*, 1997) of 24% over a two-week period. Marder *et al.* (1984) found that 15 of 31 psychiatric inpatients said they would, if permitted, refuse treatment. The demonstration of higher rates of refusal in hospital is not surprising, particularly as patients in hospital may be detained. While high rates of refusal appear alarming, the keyworkers' reports of the consequences of refusal are illuminating: half the refusers were persuaded immediately, and 84% within a month, to take their treatment. Although multi-disciplinary reviews contributed to the persuasion, the keyworkers were mostly responsible. Evidently, there is a spectrum of patient attitudes, ranging from intermittent refusal responding to reassurance and encouragement, to a more persistent and trenchant refusal expressed by a small proportion of patients (roughly 6% in the present sample). It is also encouraging, and will be of no surprise to clinicians, that the great majority of patients were persuaded to take their treatment by explanation, education and encouragement, and without recourse to compulsory treatment. The crucial role of the community keyworker, with a good relationship with the patient, is emphasised.

Treatment refusal was not associated with any particular psychiatric treatment. Neither was it associated with duration of treatment, cognitive function or satisfaction with or knowledge of treatment. More severe psychopathology on the BPRS and diagnosis of affective disorder were associated with refusal, both findings previously demonstrated (Marder *et al.*, 1984; Zito *et al.*, 1985). Although the association between refusal and affective diagnosis should be viewed with some caution in this population, which may for example include abnormally severe and difficult to treat depressives, it seems likely that even in

chronic conditions, episodic mood disorder may account for treatment refusal. The link between current and historical indicators of refusal suggests that there is a sub-group of patients who persistently and predictably maintain treatment refusal over time, presumably the familiar 'revolving door' patient who improves with compulsory treatment in hospital and then relapses after discharge due to non-compliance. These findings could be construed to argue for a community treatment order (as proposed by the Royal College of Psychiatrists, 1987), in that this group is easily identifiable and could in theory be maintained well and relapse free, with compulsory community treatment. However, these results show that most refusing patients can be persuaded, and the effect of more formalised compliance-promoting therapies shows great potential (Kemp *et al.*, 1996). The feasibility of forcing treatment on highly resistive patients in the community is questionable. Logically, as half our patients are in reality partially complying with their treatment, we must dispense with the myth of full compliance in favour of practice which aims for sufficient compliance to prevent relapse.

Finding that depot antipsychotic was not more (or less) associated with drug refusal was interesting, and reinforces previously expressed concern (Babiker, 1986) about the use of depot treatment in situations where compliance is problematic. It is as easy to say no to tablets or injections. More positive was the finding that the use of a dosett dispenser to administer medication was associated with lower treatment refusal. Although a causal relationship cannot be inferred from these cross-sectional findings, it is implied that aids to memory and compliance training may have a secondary effect on improving attitudes and minimising refusal. It is surprising that a device so simple and cheap, and apparently effective, should not have passed in to more routine use.

We were surprised that there was no relationship between satisfaction with drug treatment and drug refusal. Finding a meaningful way to communicate with patients about these issues is a difficult problem, and the validity of satisfaction ratings is inevitably questionable in populations where insight is expected to be impaired.

The results of this study suggest a need for regular discussion with patients about their attitudes to treatment, its perceived value and the risks of non-compliance. Our experience is that patients with severe mental illness are surprisingly open to this approach, and the potential for longer-term intervention packages targeted at improving understanding and attitudes to drug treatment is increasingly clear.

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\*Rob Macpherson, Consultant Rehabilitation/General Psychiatrist, Wotton Lawn, Horton Road, Gloucester GL1 3PX; Minh Alexander, Senior Registrar in General Psychiatry, Royal United Hospital; W. Jerrom, Head of Clinical Psychology Services, United Bristol Healthcare Trust, Barrow Hospital, Bristol

\*Correspondence

## Model of forensic psychiatric community care

Mary C. Whittle and Mark D. Scally

**Aims and method** The paper describes the establishment of a specialist forensic team providing an integrated model of forensic community psychiatric care.

**Results** A description is provided of the problems encountered in setting up and running the service and of the ways in which those problems were managed.

**Clinical implications** The integrated model has the advantage of minimising stigma, providing support and education for staff and enabling forensic expenditure to be provided for a wider group of patients and staff than would otherwise be possible.

Developments in community forensic psychiatry have been hampered by the reluctance of forensic psychiatrists to develop integrated

services with general and community psychiatry. Forensic services continue to focus on a parallel system of secure hospital care and remain aloof from local mental health services (Grounds, 1996). Rehabilitation of forensic patients has been hampered by the lack of community services suitable for their needs (MacCulloch & Bailey, 1991; Parry, 1991). However, the impetus to develop community forensic psychiatric services is increasing. The public remains concerned about violence by mentally ill persons in the community (Ritchie *et al*, 1994). Community psychiatrists and purchasing authorities are becoming more assertive in seeking forensic advice, particularly for patients on supervision registers (McCarthy *et al*, 1995).