

Long-stay psychiatric patients' knowledge and experience in the use of their ANTIPSYCHOTIC MEDICATION

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AIM — To determine the knowledge and experience in the use of antipsychotic medication in long-stay patients based in a specialist psychiatric hospital.

DESIGN — Patient questionnaire, movement disorder rating scales, side effects checklist and consultant psychiatrist questionnaire.

SETTING — St Andrew's Hospital, Northampton, a 400-bed tertiary referral psychiatric hospital. The study was carried out between December 1999 and April 2000.

OUTCOME MEASURES — Patients' self-reported knowledge and opinions, as well as recall of information provided by their psychiatrist. Patients' perceptions of choice as regards taking medication, requests for further information and experiences of side effects. Psychiatrists' reports of what they had told their patients.

RESULTS — In total, 29 out of 54 potential subjects (54 per cent) agreed to take part. Most patients were aware that their antipsychotics were being prescribed for symptoms of mental illness but they did not always believe the explanation given to them by their psychiatrist. Patients had relatively little knowledge of the side effects of these drugs, and many did not recognise the side effects as being due to medication. Only 14 per cent knew the nature and cause of tardive dyskinesia and only 17 per cent of psychiatrists said they had told their patients about tardive dyskinesia. Just over half of the patients requested more information about their medication.

CONCLUSIONS — Patients' knowledge of their antipsychotic medication was fairly limited. Recommendations are made with the aims of increasing patients' knowledge about their medication and detecting and treating side effects early.

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Earlier surveys of traditional, long-stay psychiatric inpatients have reported low levels of patient knowledge and understanding about antipsychotic medication, commonly combined with a lack of insight.^{1,2} However, it has been demonstrated that patient knowledge can be increased by appropriate education. For example, rehabilitation patients with schizophrenia showed an increase in knowledge about illness and treatment following education sessions.³

Although some studies have reported that providing patients with information about their medication and its side effects can enhance their knowledge,^{4,5} other studies have reported poor retention of new information in patients with schizophrenia, which the authors attributed to the cognitive deficits associated with chronic schizophrenia.⁶⁻⁸

While antipsychotic medication is of great benefit in relieving the positive symptoms of schizophrenia and other psychotic illnesses, it can cause a wide variety of unpleasant side effects. Typical antipsychotics are associated with motor side effects, such as akathisia, parkinsonism and tardive dyskinesia. These movement disorders stigmatise patients and can cause considerable distress. In the case of tardive dyskinesia, the movements are potentially irreversible. The newer atypical antipsychotics have a different profile of side effects, including weight gain and sedation. It is generally felt that these side effects are more acceptable to patients than those associated with older, typical antipsychotics.

There is no consensus as to how much patients should be told about side effects, and doctors have anxieties about providing patients with information about side effects. A survey of psychiatrists found that over half were concerned that providing patients with knowledge about tardive dyskinesia would reduce compliance and only 15 per cent said that they always informed those patients at risk of developing tardive dyskinesia about this side effect.⁹ Guidance to all doctors provided by the General Medical Council states that doctors have a duty to inform patients about the purpose of any treatment, including the common and serious side effects.¹⁰ For psychiatrists, it is considered good practice to inform patients of the nature, likely

effects and risks of treatment.¹¹ If information is to be withheld from patients, the reason for doing so should be documented in the case notes. Failure to inform patients about side effects could lead to litigation.

This project was carried out following a complaint by a patient that they had not been warned about a rare but stigmatising and disabling motor side effect of their antipsychotic medication. The principal aims of the study were to determine the level of knowledge about antipsychotic medication, including side effects, among a sample of the hospital's long-stay patients, and to evaluate the side effects experienced by these patients. We were particularly interested in patients' knowledge and experience of side effects and whether or not any current side effects appeared to be an influence on their motivation to continue with antipsychotic medication.

METHOD

Approval for the study was obtained from the St Andrew's Hospital, Northampton, research committee.

The subjects were inpatients at St Andrew's Hospital, or resident in one of the hospital's hostels, aged 18 to 65 years old, who were suffering from a functional psychiatric disorder and had been receiving one or more regular antipsychotic drugs for at least the past four weeks. Patients could speak English and were able to give written, informed consent to take part in the study.

Patients were excluded from the study if they were suffering from developmental disability, acquired brain injury or organic brain disease, as the presence of movement disorders in these subjects could confound the assessment of drug-induced movement disorders and these subjects were also unlikely to be able to give informed consent for the study. Patients currently receiving mood stabilisers, anticonvulsants and antidepressants were excluded, as side effects from these medicines overlap with those caused by antipsychotics (for example, tremor, dyskinesia, weight gain, constipation and sedation).

Ward pharmacists identified all subjects who qualified for inclusion in the study by

examining the prescription charts and case notes. Antipsychotic drugs were described as typical or atypical antipsychotics using the classification given in the British National Formulary (BNF).¹²

Of the 54 potential subjects, 29 (54 per cent) agreed to participate and completed the assessment. The reasons for non-participation in the study (n=25) were: considered clinically unfit to participate by medical or nursing staff (10), refused (nine), did not complete the assessment (five) and unavailable (one). Patients were interviewed between December 7, 1999 and April 17, 2000 by JS (pharmacist) with RC (pharmacist) or HH (physiotherapist).

The study sample was compared with the total hospital population of patients who were taking regular antipsychotic medication in July, 1998 (n=190), using the data set compiled for the Royal College of Psychiatrists' national audit of antipsychotic prescribing, as detailed information on the total hospital population receiving antipsychotic medication at the time of this study was not readily available.

Assessment instruments: Assessment instruments included patient interviews,

movement disorder rating scales, side effects checklist, prescribing details and information from consultant psychiatrists.

Patient interview Knowledge of antipsychotic medication was assessed by means of a semi-structured interview schedule developed by the research team for this study. The schedule includes enquiries into the following areas: patients' knowledge of their current antipsychotic medication, patients' recall of information provided by the psychiatrist about their antipsychotics (including the likely effects, side effects and the effect of stopping the medicines), patients' understanding and belief in this information, other sources of information about medication, details of current side effects and knowledge of tardive dyskinesia.

Movement disorder rating scales The following three movement disorder rating scales were completed for each patient: Extrapyramidal Rating Scale (EPRS),¹³ a version of a scale for rating tardive dyskinesia¹⁴ modified by Halstead *et al*¹⁵ (to allow separate ratings of choreiform and dystonic movements, tics, stereotypies and mannerisms), and the Barnes rating scale for drug-induced

akathisia.¹⁶ Two of the assessors had previous experience in the use of these rating scales and were working in the St Andrew's movement disorder clinic. All three assessors received training in the assessment of movement disorders from an expert practitioner in the field (S. Halstead¹⁵). The presence and severity of movement disorders in each patient was recorded independently by two assessors and the final ratings were agreed following discussion at the time of the assessment.

Side effects checklist "A checklist for patients on antipsychotic medication" (antipsychotic side effects checklist [ASC]¹⁷) was given to patients to complete at the end of the interview. The ASC was developed by psychiatrists in the UK and USA with the aim of facilitating communication between patients and their psychiatrists about the side effects of antipsychotic medication. It consists of a list of 19 questions about current side effects, and asks patients to indicate if they have experienced these problems recently and if they would like to discuss their side effects with a nurse or a doctor. This particular scale was used as it is easily understood, simple and brief.

Case note and prescribing details

Demographic, clinical and Mental Health Act (MHA) information was obtained from the case notes and the details of current antipsychotic medication from the prescription chart. The current dose of each regular antipsychotic was expressed as a percentage of its maximum dose as stated in the BNE. Where a patient was prescribed multiple antipsychotics, the percentages were added together to give a total percentage dose.¹⁸ "As required" or *prn* prescriptions were not included in the calculation of total percentage dose. High dose antipsychotic prescribing was defined as a total percentage dose greater than 100 per cent.

Information from consultant psychiatrists

The patients' consultant psychiatrists were each sent a questionnaire asking about the information they had given to the patients concerning their antipsychotic medication. Where patients had recently changed their consultant (three cases), the previous consultant was also sent a copy of the questionnaire. The patients' current psychiatrists were asked to provide ICD-10 diagnoses for each patient.

Statistical analysis Statistical analyses were carried out using the Statistical Package for the Social Sciences¹⁹ (SPSS) and Epi Info.²⁰ The chi-squared

Table 1: Comparison of study sample with those eligible but not included in the study

Comparators	Study sample (n=29)	Eligible but not included (n=25)	Results of significance test
Mean age (years)	38.6	34.2	Mann-Whitney U test, z=-1.989, P<0.05
Sex:			
Male	23	22	Fisher's exact test, P=0.48 (not significant)
Female	6	3	
Ethnic origin:			
Caucasian	24	15	Chi-squared test = 2.42, P=0.12 (not significant)
Non-caucasian	5	10	
Legal status:			
Informal	3	2	Fisher's exact test, P=1.0 (not significant)
Detained	26	23	
Consent to treatment status: (n = 26)		(n = 23)	
MHA Form 38	20	13	Chi-squared test = 1.48, P=0.22 (not significant)
MHA Form 39	6	10	
Primary diagnosis			
Schizophrenia*	29	23	Fisher's exact test, P=0.21 (not significant)
Other diagnoses	0	2	
Prescribed clozapine			
Yes	15	10	Chi-squared test = 0.35, P=0.55 (not significant)
No	14	15	
Mean total percentage dose of regular antipsychotics	87.4	95.9	Mann-Whitney U test, z=-0.677, P=0.50 (not significant)
Antipsychotics			
High dose	9	9	Chi-squared test = 0.15, P=0.70 (not significant)
Not high dose	20	16	

*ICD-10 codes F20-29 (schizophrenia, schizotypal and delusional disorders)

Table 2: Comparison of study sample with total hospital population prescribed antipsychotics

Comparators	Study sample (n=29)	Total hospital population (n=190)*	Results of significance test
Mean age (years)	38.6	42.8	Mann-Whitney U test, $z=-0.124, P=0.90$ (not significant)
Sex:			
Male	23	123	Chi-squared test = 2.41, $P=0.12$ (not significant)
Female	6	67	
Ethnic origin:			
Caucasian	24	158	Chi-squared test = 0.92, $P=0.34$ (not significant)
Non-caucasian	5	23	
Not known		9	
Legal status:			
Informal	3	55	Fisher's exact test, $P<0.05$
Detained	26	135	
Primary diagnosis:			
Schizophrenia†	29	104	Fisher's exact test, $P<0.0001$
Other diagnoses	0	86	
Prescribed clozapine:			
Yes	15	27	Chi-squared test = 22.8, $P<0.0001$
No	14	163	
Mean total percentage dose of regular antipsychotics	87.4	74.7	Mann-Whitney U test, $z=-2.121, P<0.05$
Antipsychotics			
High dose	9	46	Chi-square = 0.62, $P=0.43$ (not significant)
Not high dose	20	144	

*Total hospital population in July, 1998 who were prescribed regular antipsychotic medication

†ICD-10 codes F20-29 (schizophrenia, schizotypal and delusional disorders)

test (with Yates's correction where appropriate), Fisher's test of exact probability and Mann-Whitney U statistical tests were used.

RESULTS

Of the 29 patients included in the study, 23 were male and six female. The mean age was 38.6 years (median 36, range 21-60). There were 24 (83 per cent) Caucasian patients. All patients had a primary diagnosis of schizophrenia, schizotypal or delusional disorders (ICD-10 codes F20-29). Twenty-one patients (72 per cent) were being treated in locked wards.

The mean length of stay at St Andrew's Hospital was 3.7 years (median 2.8 years, range 0.5 years to 11.2 years), although many patients were already in another hospital before they were transferred to St Andrew's. Three patients (10 per cent) were informal and 26 (90 per cent) were detained under the MHA. Each of the patients' consultant psychiatrists acted as the responsible medical officer (RMO) under the MHA. Of the detained patients, 20 consented to receive their medication and this was certified on an MHA Form 38 (after three months of treatment under the MHA, if the patient consents to take the treatment, the RMO signs an MHA Form 38) and six

patients required a second opinion (because either they lacked the mental capacity to consent or they refused the treatment), their treatment being authorised by a Second Opinion Appointed Doctor on an MHA Form 39.

The mean total percentage dose of regular antipsychotics was 87.4 per cent (median 75 per cent, range 38-185 per cent). Nine patients (31 per cent) were receiving high dose antipsychotic medication. Fifteen patients (52 per cent) were prescribed clozapine, 11 as monotherapy and four in combination with other antipsychotic drugs. Eight patients (28 per cent) were prescribed atypical antipsychotics other than clozapine, in two cases as monotherapy. Sixteen patients (55 per cent) were receiving typical antipsychotics, in four cases as monotherapy. Seventeen patients (59 per cent) were receiving one regular antipsychotic, 10 (34 per cent) were receiving two different antipsychotics and two (7 per cent) were receiving three.

The study sample was compared with the remaining subjects who were eligible for the study but did not take part. The study sample did not differ from the non-included patients in terms of the following characteristics: sex; ethnic origin; legal status; consent to treatment status (MHA Form 38 or 39);

primary diagnosis of schizophrenia or related illness (ICD-10, codes F20-29) compared with all other diagnoses; proportion receiving clozapine; total percentage dose of regular antipsychotic medication; and proportion receiving high dose antipsychotic medication (Table 1, p167). However, the patients in the study sample were older than the non-included patients (mean age 38.6 years versus 34.2 years) (Mann-Whitney U test, $z=-1.989, P<0.05$).

The study sample did not differ from the rest of the hospital population prescribed antipsychotics in terms of age, sex, ethnic origin, or the proportion receiving high dose antipsychotic medication (Table 2). The study sample was significantly more likely to be detained (90 per cent versus 71 per cent, Fisher's exact test $P<0.05$), to have a primary diagnosis of schizophrenia (100 per cent versus 55 per cent, Fisher's exact test $P<0.0001$), to be receiving clozapine (52 per cent versus 14 per cent, chi-squared test = 22.8, $P<0.0001$) and to be on a higher total percentage dose of regular antipsychotics (mean dose 87.4 per cent versus 74.7 per cent) (Mann-Whitney U test, $z=-2.121, P<0.05$).

Knowledge of antipsychotics Eighteen patients (62 per cent) could correctly name the number of antipsychotic medicines they were taking regularly (Table 3, p170). Sixteen patients (55 per cent) knew the names of their antipsychotic drugs and a further eight (28 per cent) were able to name them when prompted. Twenty patients (69 per cent) were aware that their antipsychotics were being prescribed for mental illness or symptoms of mental illness. Ten (34 per cent) specifically mentioned schizophrenia and a further four (14 per cent) cited mental illnesses, while another six (21 per cent) described mental symptoms, for example "people with outbursts, violence, cutting wrists", "for the voices" and "bad thoughts".

Recall of information from psychiatrist Nearly 70 per cent (20 patients) said that their psychiatrist had told them why they needed to take antipsychotic medication. Of these, eight mentioned schizophrenia and three mentioned depression. A further eight gave highly personal answers relating to their

own experience of the effect of medication on their mental experiences, for example, "to stabilise me, keep me functioning well", "to keep my blood pressure down and keep thoughts normal" and "because I was mentally ill and it brings stability". One patient said he was taking antipsychotic medication "because he [the psychiatrist] thinks I hear voices". Five of the 20 patients (25 per cent) did not understand or believe the explanation proffered.

Nearly 60 per cent (17 patients) said that they had been told they would get ill again if they did not take their medication but of these, only 12 (71 per cent) believed what they had been told. Of the 11 patients who said they had not been informed about the consequences of stopping medication, four were aware that they could relapse and two insisted they did not need medication.

Patients' perception of choice Seven patients (24 per cent) believed they did have a choice about whether or not they took their medication. These are some of their comments: "Yes, he [the psychiatrist] can advise me but I can say whether I take them" (patient being treated on an MHA Form 39), "Yes I do, the doctor said it was good for me" (informal patient) and, "Yes, chances are, though, they would put me back on section" (informal patient). Of the 19 patients who said that they had no choice but to take their medication, 13 were being treated on an MHA Form 38 and one was an informal patient. One patient receiving treatment on an MHA Form 38 said: "No, I will be put on a 39 if I do not take it [the medication]". Another patient, who was being treated on an MHA Form 39 said, "No, I thought I had a choice but when I tried to say no they said I had to take them".

Knowledge of side effects Of the patients, 13 (45 per cent) (nine being treated on an MHA Form 38 and one informal patient) said that they had not been told about the side effects of their antipsychotics by their psychiatrist. A further five (17 per cent) could not remember if they had been informed. The remaining 11 patients (38 per cent) said that they had been informed about one or more side effects, the most commonly cited side effect being shaking (four cases). Reference to agranulocytosis and the need for regular blood tests was made by three patients receiving clozapine: "take blood to see if it's good under the microscope", "sometimes alters blood cells" and "will take blood every week to see if enough white cells".

Other sources of patient information about side effects were: nursing staff (four cases), patient information sheet or patient video (four), other patients (three) and an advocate (one). One patient described his frustration when a fellow patient, who was

also receiving clozapine, refused to let him see an information leaflet about clozapine.

When specifically asked about tardive dyskinesia, seven patients (24 per cent) said they had heard of the condition. Five (17 per cent) patients were aware that tardive dyskinesia is a movement disorder which commonly affects the facial muscles. These are some of their replies: "involuntary movements of the face", "in your jaw", "Is that difficulty in moving?" and one patient was able to demonstrate the characteristic orofacial movements. Four (14 per cent) correctly ascribed the cause of tardive dyskinesia to medication, although another patient thought it was caused by "an attack from something in the body".

Requests for further information Just over 50 per cent (15 patients) requested more information about their antipsychotic medication. Seven (24 per cent) made specific requests for information, for example, "Can you get white Clozaril?", "Would it be possible to go to a blood test every three months?", "Yes, but do you know the long-term effects?" and "Why is it making me impotent?" Four patients (14 per cent) wanted to know how the medication worked: "How does chlorpromazine work? Does it go to the brain?", "What does it do to me?" A further three patients (10 per cent) made non-specific requests for more information, for example: "I would like a chat about the drugs".

Experience of side effects During the study, 16 patients (55 per cent) said that they were suffering from side effects which they believed were caused by their antipsychotic medication. They were asked to name the worst side effect they had experienced then or within the previous month. The most common were motor side effects (five) and excessive salivation (four). Nine patients (31 per cent) had told staff about the side effect and nine (31 per cent) said that the side effect was so bad that they wanted to stop taking the medication.

Movement disorders Ten patients (34 per cent) were assessed as having one or more movement disorders as follows: parkinsonism (four patients), orofacial tardive dyskinesia (four), trunk-limb tardive dyskinesia (two), akathisia (one) and pseudoakathisia (one). Before the movement disorder assessment, nine patients said that they were suffering from a movement side effect but only four of these were found to have a movement disorder at assessment. Of the six patients with a movement disorder of which they were not aware, three had tardive dyskinesia, two parkinsonism and one had pseudoakathisia. Of the five patients with tardive dyskinesia, none was aware that they had the condition, only two had heard of tardive dyskinesia and these

two also knew that it was caused by antipsychotic medication.

Checklist for patients Patients reported a mean of 6.2 (median 6, range 1-14) difficulties or problems on the ASC (see Table 4, p171). The most commonly reported problems were: low energy (16 cases), drowsiness (15), blurred vision (15), constipation (13) and forgetfulness (13). As regards the four items on the ASC which relate to motor side effects (difficulties with movement, muscle stiffness, trembling or shaking and restlessness), 19 patients (66 per cent) reported having at least one of these problems. Only six patients (21 per cent) stated that they would like to discuss any of the identified problems with a nurse or a doctor.

Information from psychiatrists All 29 questionnaires were completed. For 26 patients (90 per cent), the consultant psychiatrists said that there had been a discussion about side effects within the previous 12 months. The psychiatrists said that they had told patients about tardive dyskinesia in five cases (17 per cent). Information about side effects had not been withheld from any patient, although in two cases, the psychiatrists believed that the patients' mental states made meaningful discussion impossible. In 21 cases (72 per cent) the psychiatrists considered the patient had been fully informed about side effects, although in five cases (17 per cent), the psychiatrists doubted the patient's ability to understand or retain the information. However, when rating the risk of reduced compliance if the patient was then to be fully informed about the side effects of their antipsychotic medication, seven (24 per cent) rated the risk as "considerable" or "moderate" and 17 (59 per cent) as "small" or "no risk".

DISCUSSION

In this sample of inpatients who were receiving antipsychotic medication, more than half knew the general nature and likely effects of their antipsychotic drugs. However, patients did not always believe the explanations given to them by their psychiatrist. Patients were less knowledgeable about the side effects of their medication, with just over a third being able to recall a side effect that their psychiatrist had told them about. Only a quarter had heard of tardive dyskinesia, despite the fact that all of them were being, or had been, treated with typical antipsychotics.

The study sample appeared broadly representative of those patients fitting the study inclusion criteria, although some eligible patients were too mentally unwell to take part in the study. The study sample was not, however, representative of the total population receiving antipsychotic medication, as would be expected in view of the

Table 3: Responses from patient interview

Question	Response	No	%
1. How many antipsychotic medicines are you taking regularly?	Correct answer	18	62.1
	Incorrect answer	4	13.8
	Don't know or unable to answer	7	24.1
2. What are the names of the antipsychotic drugs you are taking?	Correct spontaneous answer	16	55.2
	Correct answer with prompting	8	27.6
	Don't know or incomplete or incorrect answer	5	17.2
3. What do you think your antipsychotic drugs are usually prescribed for?	Schizophrenia	10	34.5
	Mental illness	4	13.8
	Mental symptoms	6	20.7
	Unclear or don't know	9	31.0
4. Has your psychiatrist told you why you need to take your antipsychotic medication?	Yes	20	69.0
	No	5	17.2
	Don't know or can't remember	4	13.8
5. What did your psychiatrist say (for those answering "yes" to question 4)?	Schizophrenia	8	40.0
	Depression	3	15.0
	Personal answers related to effect of medication on their mental experiences	8	40.0
	Other	1	5.0
6. Do you understand this explanation (for those answering "yes" to question 4)?	Yes	15	75.0
	No	5	25.0
7. Do you believe this information (for those answering "yes" to question 4)?	Yes	14	70.0
	No	5	25.0
	Don't know	1	5.0
8. Has your psychiatrist told you what will happen if you don't take the medication?	Yes	17	58.6
	No	11	37.9
	Can't remember	1	3.4
9. What did your psychiatrist say (for those that answered "yes" to question 8)	"Get ill again"	17	100
10. Do you believe your psychiatrist (for those that answered "yes" to question 8)?	Yes	12	70.6
	No	5	29.4
11. What do you think would happen if you did not take your medication (for those answering "no" or "can't remember" to question 8)?	Would get ill again	4	33.3
	Don't know	3	25.0
	Don't need medicine	2	16.7
	Other	3	25.0
12. Do you have a choice about whether or not to take the medication?	Yes	7	24.1
	No	19	65.5
	Don't know or other	3	10.3
13. What side effects of your antipsychotics has your psychiatrist told you about?	Informed about one or more side effects	11	37.9
	None	13	44.8
	Can't remember	5	17.2
14. Have you received information about side effects from another source? (some had more than one source)	No	17	58.6
	Nurse	4	13.8
	Patient information sheet or video	4	13.8
	Other patients	3	10.3
	Advocate	1	3.4
	Don't know or can't remember	2	6.9
15. Have you heard about tardive dyskinesia?	Yes	7	24.1
	No	22	75.9
16. Is there anything else you would like to know about your antipsychotics?	Yes	15	51.7
	No	13	44.8
	No answer	1	3.4
17. What would you like to know (for those that answered "yes" to question 16)?	Specific requests for information	7	46.7
	Effects of drugs	4	26.7
	General information	3	20.0
	Other	1	6.7
18. What is the worst side effect you have experienced from your medication now or in the past month?	Yes (could name worst side effect)	16	55.2
	No side effects named	13	44.8
19. Do you think you have any motor side effects now or in the past month?	Yes	9	31.0
	No	19	65.5
	Don't know	1	3.4

Table 4: Problems experienced by patients on the checklist for antipsychotic medication

Problem	Patients reporting they have had this problem recently		Patients who would like to discuss this problem with a nurse or doctor	
	n	%	n	%
Too much spit	18	62.1	1	3.4
Low in energy	16	55.2	4	13.8
Drowsiness	15	51.7	1	3.4
Blurred vision	15	51.7	0	
Constipation	13	44.8	0	
Forgetful	13	44.8	1	3.4
Muscles trembling or shaking	12	41.4	0	
Weight gain	12	41.4	1	3.4
Restlessness	11	37.9	1	3.4
Problems with concentration	10	34.5	0	
Difficulties with movement	9	31.0	0	
Muscle stiffness	9	31.0	1	3.4
Feeling depressed	9	31.0	1	3.4
Difficulty in sleeping	7	24.1	1	3.4
Dry mouth	5	17.2	0	
Sexual problems	4	13.8	1	3.4
Difficulty in passing urine	2	6.9	0	
Changes in periods	0		0	

inclusion and exclusion criteria for the study. Unlike the rest of the hospital population of patients prescribed antipsychotics, all the patients in the study sample had schizophrenia or a related psychotic illness, and a high proportion were receiving the atypical antipsychotic, clozapine, which is only licensed for use in treatment-resistant schizophrenia. Patients in the study sample were also receiving higher doses of antipsychotic drugs than the rest of the hospital population.

Antipsychotics are used in the treatment of many other mental disorders, for example affective (mood) and organic disorders, but patients with these diagnoses did not meet the inclusion criteria for the study. For example, patients with affective disorders were excluded if they were being treated with mood stabilising or antidepressant drugs. Adolescent and elderly patients were also excluded from the study. For this reason, the findings of this study cannot be readily extrapolated to the whole inpatient population.

The study sample had relatively little knowledge about side effects and just over half reported side effects when asked directly at the interview. This contrasted with the large numbers of problems detected by the ASC antipsychotic checklist and suggests that patients may commonly be experiencing side effects from their antipsychotic medication but do not recognise them as such.

Day *et al*¹ found that patients reported high levels of side effects on a side effect rating scale (Liverpool University neuroleptic side effect rating scale [LUNSERS]) but

were unlikely to attribute side effects to antipsychotic medication. In our study, only four of the 10 patients with a movement disorder were aware of their involuntary movements and none of the patients with tardive dyskinesia was aware that they had this side effect. Caracci *et al*²² found only 25 per cent of patients with movement disorders were aware of the movements and this lack of awareness was associated with lack of insight and longer duration of mental illness.

The patients in this study had limited knowledge about side effects and many wanted to know more about their medication. In several instances the patient's consultant psychiatrist felt that if the patient was fully informed about side effects, there was a risk that compliance would fall. However, some studies have shown that informing patients with schizophrenia about side effects does not reduce compliance,^{3-5,7} and there is evidence that when information about medication is combined with behavioural interventions, compliance can be increased.²³

We are unaware of any published reports on forensic patients (ie, patients who have committed, or who have the potential to commit, violent offences to others) or on inpatients, and there is a need for an intervention study examining the effect on clinical outcome and compliance of medication education in these groups of patients.

In this study, 20 of the 26 detained patients were being treated on MHA Form 38, which meant that their consultant psychiatrists had certified that they could give

valid consent to treatment with antipsychotic medication. On the basis of our findings about the patients' level of knowledge and understanding of their medication, it is likely that few would fulfil the MHA code of practice¹¹ criteria for consent, namely, being "able to understand the purpose, nature, likely effects and risks of the treatment". In addition, most patients surveyed felt that they had no choice but to take their medication. This raises the issue of whether detained patients can give valid consent for their treatment or whether a second opinion should be sought more often than is currently the practice. Detained patients' capacity and consent to treatment with medication is of great practical as well as legal importance to clinicians and deserves further study.

Patients with chronic schizophrenia have difficulty in retaining educational material about their medication.^{6-8,22} In this study, several psychiatrists commented that although they felt patients had been informed about their medication, they had doubts about how much the patients had remembered. This suggests that, in order to increase patients' knowledge, repeated exposure to education about their medication over time is required. Written information that patients can refer to at a later date is also likely to be beneficial. For example, the United Kingdom Psychiatric Pharmacists' Group has produced an excellent series of patient-friendly leaflets about a range of psychotropic medication.

It is known that patients are most receptive to information when it is given informally and in the context of a good therapeutic relationship.⁷ In a study carried out by Dorevitch *et al*,²⁴ long-term monitoring and education sessions run by a clinical pharmacist for patients with chronic schizophrenia resulted in improved clinical outcome and compliance over a 10-year period. However, other professionals, provided they have the necessary knowledge base and good relationship with the patient, are also in a good position to educate patients and improve compliance.

As a result of this study, as well as a review of the literature and the authors' knowledge of examples of good practice in other hospitals, the following recommendations regarding patients at St Andrew's Hospital were made. These suggestions primarily relate to patients with schizophrenia who are prescribed antipsychotic drugs, but the basic principles apply to all patients receiving medication.

The aims of these recommendations are to:

- ensure patients are adequately informed about the possible side effects of their medication, and that when they consent to treatment their consent is fully informed

Panel: Recommendations

Increasing patients' knowledge of their medication:

1. Information about medication should be readily available in all areas of the hospital used by patients. Patients should be advised that they can request the manufacturer's patient information leaflet of any drug that they are prescribed.
2. Information should be appropriate to the individual patient's level of understanding. Thus, a range of leaflets should be available to meet the needs of patients with a wide range of cognitive abilities.
3. Staff should encourage and motivate patients to be better informed about their medication. Key workers have a close working relationship with patients and are therefore in a good position to discuss medication as part of the patient's care plan, particularly before care programme approach meetings, and also to assess the patient's level of knowledge and understanding. Patients may benefit from informal discussions with pharmacists, or from more formalised medication sessions as part of patient programmes.
4. Educational material needs to be presented repeatedly. It is important to provide appropriate written information, which patients can keep and refer to at a later date.

Consent to treatment:

5. It is the RMO's responsibility to check that patients being treated on MHA

Form 38 are able to give valid consent to treatment with the medication prescribed. At the same time as completing Form 38, the RMO should make a contemporaneous case note entry detailing the patient's capacity and consent to treatment.

6. If information about side effects has been deliberately withheld from a patient on clinical grounds, then this fact and the reason for withholding the information should be documented by the RMO in the patient's case notes.
7. Patients' consent to treatment status can vary with their mental state and nursing staff should alert the RMO if they become aware that a patient on a Form 38 requires excessive persuasion to take their medication or is refusing doses.

Monitoring side effects:

8. As patients spontaneously report a low level of side effects, clinicians should consider using screening checklists, such as the ASC, to identify possible medication-related problems.
9. Patients at risk of developing movement disorders should be assessed for the presence of movement disorders on an annual basis using appropriate rating scales. Those patients with movement disorders may benefit from referral to a specialist movement disorder clinic.
10. Clinicians need to review patients' prescriptions in the light of serious or persistently troublesome side effects.

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REFERENCES

1. Geller J. State hospital patients and their medication: do they know what they take? *Am J Psychiatry* 1982;139:611-5.
2. Macpherson R, Double D, Rowlands R, Harrison D. Long-term psychiatric patients' understanding of neuroleptic medication. *Hospital and Community Psychiatry* 1993;44:71-3.
3. Macpherson R, Jerrom B, Hughes A. A controlled study of education about drug treatment in schizophrenia. *Br J Psychiatry* 1996;168:709-17.
4. Kleinman M, Schachter D, Koritar E. Informed consent and tardive dyskinesia. *Am J Psychiatry* 1989;146:902-4.
5. Chaplin R, Kent A. Informing patients about

tardive dyskinesia. *Br J Psychiatry* 1998;172:78-81.

6. Jaffe R. Informed consent: recall about tardive dyskinesia. *Compr Psychiatry* 1981;22:434-7.
7. Munetz M, Roth L. Informing patients about tardive dyskinesia. *Arch Gen Psychiatry* 1985;42:866-71.
8. Ganguli R, Raghu U. Tardive dyskinesia, impaired recall and informed consent. *J Clin Psychiatry* 1985;46:434-5.
9. Chaplin R, Potter M. Tardive dyskinesia: screening and risk disclosure. *Psychiatr Bull* 1996;20:714-6.
10. General Medical Council. Seeking patients' consent: the ethical considerations. London: GMC; 1998.
11. Department of Health and Welsh Office. Code of Practice Mental Health Act 1983. London: The Stationery Office; 1999, p67.
12. British National Formulary Number 40. London: British Medical Association and Royal Pharmaceutical Society of Great Britain; 2000.
13. Simpson G, Angus J. A rating scale for extrapyramidal side effects. *Acta Psychiatr Scand* 1970;212 (Suppl 44): 11-9.
14. Barnes T, Trauer T. Reliability and validity of a tardive dyskinesia videotape rating technique. *Br J Psychiatry* 1982;140:508-15.
15. Halstead S, Barnes T, Speller J. Akathisia prevalence and associated dysphoria in an inpatient population with chronic schizophrenia. *Br J Psychiatry* 1994;164:177-83.
16. Barnes T. A rating scale for drug-induced akathisia. *Br J Psychiatry* 1989;154: 672-76.
17. Dott S. Clear perspectives: management issues in schizophrenia. AstraZeneca and Shire Hall International; 1999, p12-9.
18. Yorston G, Pinney A. Chlorpromazine equivalents and percentage of British National Formulary maximum recommended dose in patients receiving high dose antipsychotics. *Psychiatr Bull* 2000;24:130-2.
19. Statistical package for the social sciences base users guide. New Jersey: Prentice Hall; 1999.
20. Dean A, Dean J, Coulombier D, Brendel K, Smith D, Burton A et al. Epi Info Version 6: A word processing database and statistics program for epidemiology on microcomputers. Atlanta: Centers for Disease Control and Prevention; 1994.
21. Day J, Kinderman P, Bentall R. A comparison of patients' and prescribers' beliefs about neuroleptic side-effects: prevalence, distress and causation. *Acta Psychiatr Scand* 1998;97:93-7.
22. Caracci G, Mukherjee S, Roth S, Decina P. Subjective awareness of abnormal involuntary movements in chronic schizophrenia patients. *Am J Psychiatry* 1990;147:295-8.
23. Merinder L. Patient education in schizophrenia: a review. *Acta Psychiatr Scand* 2000;102:98-106.
24. Dorevitch A, Aronson R, Zilberman L. Medication maintenance of chronic schizophrenic outpatients by a psychiatric pharmacist: 10-year follow-up study. *J Clin Pharm Ther* 1993;18:183-6.

- reduce the risk of possible litigation by patients who develop side effects such as tardive dyskinesia
- detect side effects at an early stage so that appropriate action can be taken
- improve the therapeutic alliance between patients and clinicians.

More detailed information about these recommendations can be seen in the panel.

CONCLUSION

Long-stay patients' knowledge of their antipsychotic medication, including side effects such as tardive dyskinesia, is limited and could be improved by patient education. There is a need for a greater awareness of and treatment of the side effects experienced by patients. Psychiatrists have concerns that informing patients about side effects will reduce their compliance with treatment, although research evidence suggests that this is not the case.