Patients' knowledge and views of their depot neuroleptic medication

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Aims and method This study examined the attitudes and knowledge of patients regarding their depot neuroleptic medication. All patients were attending a community mental health centre in Clydebank, Scotland.

Results Many patients had limited knowledge of their medication, its benefits and side-effects as well as the rationale for its use. The biggest gaps were found in patients' knowledge of the long-term side-effects of their medication.

Clinical implications Our findings raise doubts as to the capacity of some patients to give informed consent to their treatment. A number of steps are outlined in order to raise patients' standard of knowledge.

Neuroleptic drugs are widely used in psychiatry, both as oral and depot preparations. Despite the advent of novel antipsychotic drugs, side-effects remain a reality for many patients who are exposed to such drugs. There is consensus that psychiatric patients should receive adequate information about their psychiatric medications, especially if these are administered on a long-term basis (Kleinman *et al*, 1993; Brabins *et al*, 1996; MacPherson *et al*, 1996). Obtaining informed consent, an issue reviewed by Brabbins *et al* (1996) not only constitutes good clinical practice, but is advisable given the possibility that psychiatric patients or their families may seek legal redress if faced with long-term adverse side-effects.

While a number of studies have examined psychiatric patients' knowledge of their neuroleptic medication (Soskis, 1978; Soskis & Jaffe, 1979; Geller, 1982; Clary *et al*, 1992; MacPherson *et al*, 1996), few studies have focused on those patients who receive depot neuroleptic medication. The aim of the present study was, therefore, to investigate further psychiatric patients' knowledge of their depot neuroleptic medication.

The study

The Goldenhill Resource Centre (GRC) offers a community psychiatric service to a population of 47 000 people who live within Clydebank, a town situated to the west of Glasgow. It offers a comprehensive range of services to its users including, for some patients, the regular administration of depot neuroleptic medication.

We assessed patients' views and knowledge of their medication by using a semi-structured interview schedule specifically designed for this purpose. Questions covered details of all psychiatric medications, perceived benefits and drawbacks of depot medication, knowledge of its potential side-effects (including long-term side-effects) as well as patients' perception of the importance of taking this medication and perceived consequences of discontinuation. We also asked patients what they would do if problems arose with their medication and what further information, if any, they would like to receive.

We decided that the following standard of knowledge would be desirable for our patients:

(a) Full knowledge of all psychiatric drugs (type, dose, dose interval).
(b) Ability to identify at least two potential benefits of depot neuroleptic medication.
(c) Knowledge that side-effects may develop.
(d) Ability to identify at least two potential side-effects of depot neuroleptic medication.
(e) Knowledge of tardive dyskinesia or what it entails.
(f) Knowledge that relapse is a possibility if depot is discontinued.
(g) Ability to name at least one person who can be approached for help and information if side-effects develop.

At the start of our survey (October 1996), we identified 69 patients who were currently receiving depot neuroleptic medication. Of those, eight patients refused to be interviewed, one patient was taken off depot medication prior to interview and one patient was unavailable for interview despite various attempts. A total of 59 patients (86% of the original sample) were thus interviewed, most of whom were out-patients,

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although three patients were interviewed while in hospital. Thirty-four (58%) were male and 25 (42%) female. The mean age was 43.8 years (s.d. 12.3, range 22–75). Diagnostic categories are summarised in Table 1.

Results

Ability to identify drugs currently taken

Twenty-six patients (44%) were able to identify correctly the name, dosage and dosage interval of all prescribed psychiatric medications (including depot medication). Thirty patients (63%) were able to identify correctly the name, dosage and dosage interval of their depot neuroleptic medication. Twenty-four patients (41%) received both depot and oral neuroleptic medication.

General views of depot medication

Twenty-three patients (39%) expressed a positive view, 17 a neutral view (29%) and 19 (32%) a negative view of their depot medication. The administration of depot neuroleptic medication was regarded as important by 42 patients (71%), but only 34 patients (58%) anticipated any negative consequences as a result of discontinuation. Thirty-four patients (58%) stated that they would continue to take their depot injections if the decision about this was entirely up to them.

Perceived benefits of depot medication

Thirteen patients (22%) were able to identify spontaneously two or more potential benefits. Twenty-seven patients (46%) identified at least one benefit and 19 patients (32%) could not identify any benefits. Benefits commonly mentioned included a calming effect, reduction of auditory hallucinations, better sleep, control of troublesome thoughts, a mood-stabilising effect and a general improvement in health.

Table 2 summarises patients' responses which were obtained when potential benefits of depot medication were systematically inquired about. On the basis of these responses, 47 patients (80%) could identify two or more benefits.

Table 1. Diagnostic categories of patients treated with neuroleptic depot medication

	n	(%)
Schizophrenia	45	(76.3)
Schizotypal disorder	1	(1.7)
Persistent delusional disorder	1	(1.7)
Schizoaffective disorder	3	(5.1)
Bipolar affective disorder	6	(10.2)
Recurrent depressive disorder	2	(3.4)
Borderline personality disorder	1	(1.7)

Table 2. Possible benefits of neuroleptic depot medication identified by patients

	n	(%)
Prevents hospitalisation	44	(75)
Calming effect	41	(70)
Prevents relapse	38	(64)
Helps with sleep	30	(51)
Stops troublesome thoughts	31	(53)
Helps getting on better with others	26	(44)
Improved self-care	26	(44)
Reduces suspiciousness	25	(42)
Helps with the voices	24	(41)
Clearer thinking	24	(41)
More drive and energy	9	(15)

Perceived drawbacks and side-effects of depot medication

Fifteen patients (25%) spontaneously identified two or more potential drawbacks of depot medication. Twenty-one patients (36%) were able to identify at least one drawback and 23 patients (39%) could identify no drawbacks at all. Commonly mentioned drawbacks included side-effects, painful injections and having to attend the depot clinic.

Forty-three patients (73%) were aware of the possibility of side-effects but only nine patients (15%) seemed aware of the possibility of long-term side-effects. Table 3 summarises patients' spontaneous responses when asked about potential side-effects. Twenty-eight patients (47%) could identify at least two side-effects, 16 patients (27%) one side-effect and 16 patients (25%) no side-effects at all. Table 4 summarises patients' responses when specifically asked about certain common side-effects. Using this approach, the number of patients who could identify at least two potential side-effects increased to 54 (92%). Only four patients (7%)

Table 3. Possible side-effects of neuroleptic depot medication spontaneously identified by patients

	n	(%)
Shakiness/trembling	10	(17)
Tiredness/sleepiness	10	(17)
Weight gain	8	(14)
Stiffness	7	(12)
Dry mouth	4	(7)
Lethargy	3	(5)
Blurring of vision	3	(5)
Increased appetite	2	(3)
Dizziness	2	(3)
Difficulties with communication	2	(3)
Vomiting	2	(3)
Hearing voices	2	(3)

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Table 4. Possible side-effects of neuroleptic depot medication identified by patients when specifically enquired about

	n	(%)
Shakiness	42	(71.2)
Drowsiness	40	(67.8)
Stiffness	37	(62.7)
Dryness of mouth	35	(59.3)
Restlessness/pacing	34	(57.6)
Weight gain	33	(55.9)
Blurring of vision	26	(44.1)
Repetitive movements	23	(39.0)
Dizziness	22	(37.3)
Muscle spasms	19	(32.2)
Sexual difficulties	18	(30.5)
Constipation	17	(28.8)
Irregular heart beat	11	(18.6)

stated that they had heard of the concept of tardive dyskinesia although 13 patients (22%) were aware of some of its features. The majority of patients (57, 97%) was able to identify at least one person who they could approach for help in case of side-effects.

Information regarding depot medication

Thirty-one patients (53%) stated that they had received adequate information on their depot neuroleptic medication. Further information was most often requested on side-effects (including long-term side-effects), mechanism of action and proposed length of treatment. Most patients (45, 76%) favoured verbally given information although written information was regarded as helpful by 41 patients (70%). The benefits of additional aids such as a video or an audio tape was endorsed by 32 (54%) and 26 patients (44%) respectively. Fewer patients showed an interest in participating in educational groups with other patients (24, 41%).

Application of standard

Five patients (8%) met all seven criteria of our standard (median score five, range 2–7). Overall attitude towards depot medication, willingness to continue with it and a view that enough information had been received was not significantly associated with these scores. Patients who viewed the administration of their depot medication as important had higher scores than those who were ambivalent or did not consider it as important (Mann–Whitney test, P=0.03).

Comment

Our results suggest that patients had variable levels of knowledge regarding their depot neuroleptic medication. While most patients were able to identify some benefits and drawbacks/common side-effects, especially when these were specifically inquired about, few patients had any knowledge of potential long-term side-effects such as tardive dyskinesia. This is worrying given that depot medication is often administered over long periods of time and raises questions with regards to patients' capacity to give informed consent.

Many patients felt that they had not received enough information on their depot medication. This may reflect the forgetting of such information, a lack of understanding of previously given information or simply the fact that sufficient information had not been given. It is beyond the scope of our inquiry to distinguish between these various possibilities.

A major concern of clinicians is the possibility that informing patients of potential side-effects of medication may lead to increased problems with adherence. Poor adherence is a major factor leading to relapse in chronic schizophrenia and if such relapses occur repeatedly, may have adverse prognostic effects. There is, however, evidence from the literature that improving patients' knowledge about their medication does not in fact lead to poorer adherence (MacPherson *et al*, 1996; Brabbins *et al*, 1996). In addition, there has been some criticism of the concept of adherence and some have argued for the adoption of a collaborative approach, namely 'concordance' (Marinker, 1997).

Few patients in our study met the knowledge standard which we had adopted at the outset. If this standard is accepted as reasonable (we would welcome comments and criticisms), then measures should be taken to improve patients' level of knowledge. We are currently considering the implementation of the following steps.

(a) As part of the depot clinic, patients will be asked regularly about side-effects (possibly by using a side-effect check-list) and will be allowed to discuss issues regarding their depot neuroleptic medication. An open out-patient clinic will be run alongside the depot clinic to allow patients easy access to medical advice if required.

(b) Patients who receive neuroleptic medication or who are commenced on such medication will also be offered a leaflet with relevant information. This will include information on treatment rationale, expected benefits as well as short and long-term side-effects. The leaflet will clearly identify members of staff which can be approached if troublesome side-effects develop. Patients will be offered an opportunity to discuss the information contained in the leaflet and to ask

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supplementary questions. Patients who do not wish to receive a leaflet or who fail to read it will be offered verbal information.

(c) In patients who in view of the severity of their illness have difficulties in assimilating or retaining information regarding their depot medication, continued efforts (including the involvement of family members) will be made to ensure an acceptable level of knowledge.

By carrying out the above steps, we are aiming to raise our patients' level of knowledge and demonstrate such raised knowledge, in due course, by repeating our survey. It is hoped that this will contribute to improved adherence to treatment. This has recently been demonstrated for 'compliance therapy' (Kemp *et al*, 1998), an approach which specifically targets patients' adherence with their treatment. Among other things, patients are invited to discuss their views of their medication, weigh up its pros and cons, learn to differentiate symptoms of their illness from side-effects and consider the consequences of not taking medication. Our patient group may also ultimately benefit from such adherence therapy.

Finally, we wish to acknowledge that we did not ask and in fact do not routinely inform patients about less common side-effects of their depot neuroleptic medication such as the neuroleptic malignant syndrome or blood dyscrasias. A patient fact sheet on depot neuroleptic medication issued by the Royal College of Psychiatrists (1993) does not mention such side-effects. This raises the question of what constitutes adequate information, an issue which is discussed by Brabbins *et al* (1996) who comment on the difficulty in "finding a balance between providing sufficient information to enable patients to give real consent and providing so much information that the patient is needlessly frightened".

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