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of subjects chose the term patient irrespective of how they were grouped. Further, the term client was disliked by almost half of those sampled, whereas there was little antipathy towards the term patient. No group had a positive attitude towards the term client.

In everyday usage the term patient is associated with a traditional relationship with a doctor, and client with a business relationship. The semantics of the term have been discussed already. The relationship between health care provider and the individual they care for is extremely complex, although an individual's preference for term of address does provide some insights into our understanding of this relationship.

The observation in our study that people over the age of 40 had a greater liking for the term patient may reflect their wish to retain traditional terminology to describe their relationship with their hospital. Furthermore, the dislike of the term client by those who are depressed may indicate a resistance to a term that lacks compassion and connotations of care. The relative acceptance of the term client by those who have had psychiatric in-patient stays may be a result of their exposure and subsequent adjustment to the term because it is commonly used by non-medical in-patient staff. It is harder to explain why men show stronger liking for the term patient than women do, and why those from a White UK background show stronger dislike for the term client.

Pimlot's introduction to *Nineteen Eighty-Four* in reference to 'Newspeak' suggested,

> "Orwell was making an observation that is as relevant to the behaviour of petty bureaucrats as of dictators, when he noted the eagerness with which truth evaders shy away from well-known words and substitute their own." (Pimlott, 1989)

According to our research, the substitution of the term client for patient has little support from the user's perspective. We feel that those who argue that the term client is empowering should demonstrate consistency with this perspective, respect the opinion of their 'clients' and return to using the term patient. Advocating alternative terminology in a psychiatric setting, despite the above evidence, demands reflection upon the source of one's objection to the clearly expressed, preferred appellation of patients.

References

DEPARTMENT OF HEALTH (1996) *Health Summary for England 1996*. London: HMSO.

GEORGE, C. R. P. (1998) Patients and clients (letter). *Medical Journal of Australia*, **149**, 568.

NAIR, B. R. (1998) Patient, client or customer. *Medical Journal of Australia*, **169**, 593.

NEUBERGER, J. & TALLIS, R. (1999) Do we need a new word for patients? *British Medical Journal*, **318**, 1756–1758.

PIMLOTT, B. (1989) Introduction. In *Nineteen Eight-Four* (G. Orwell), p. xii. London: Penguin.

UPTON, M. W., HARM-BOER, G. & NEALE, A. J. (1994) Patients or clients? A hospital survey. *Psychiatric Bulletin*, **184**, 142–143

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D. TAYLOR, L. SHAPLAND, G. LAVERICK, J. BOND AND J. MUNRO

Clozapine – a survey of patient perceptions

AIMS AND METHOD

We aimed to find out how patients on clozapine felt about clozapine treatment. A structured questionnaire was given to 1284 consecutive patients attending 27 clozapine clinics in the UK.

RESULTS

The response rate was 44.4% (570 forms returned). This cohort of responders to the questionnaire consisted, for the most part, of Caucasian males who had been taking clozapine for more than 2 years. Respondents expressed largely favourable views on clozapine treatment. For example, 86.1% claimed to feel better on clozapine and 88.6% claimed to prefer to remain on clozapine than to change to another drug. Many patients stated that they disliked having to undergo blood testing, but a large majority (87.0%) felt that the advantages of clozapine outweighed disadvantages. All other responses supported this overall favourable view of clozapine therapy.

CLINICAL IMPLICATIONS

Patients stabilised on clozapine are largely content with their treatment. These results suggest that clozapine is effective as assessed by patients' own standards and that adherence to therapy is likely to be good.

DECLARATION OF INTEREST

L.S., L.G. and J.B. are employees of Novartis Pharmaceuticals UK.

Clozapine is an established treatment for schizophrenia that is resistant to therapy with other antipsychotics. It is clearly more effective than conventional drugs in the treatment of schizophrenia (Wahlbeck *et al*, 1999) and has unarguable efficacy in treatment refractory illness (Kane *et al*, 1988). No other drug has been shown unequivocally to have comparable efficacy in this subgroup of patients (Fleischhacker, 1999; Taylor, 1999). Clozapine thus remains the drug of choice in treatment-resistant schizophrenia.

The widespread use of clozapine is very probably inhibited by its acute adverse effect burden (Dev &

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Table 1. Age of respondents (years)		
Age	*n*	%
Total	570	100.0
18 to 24	37	6.5
25 to 34	175	30.7
35 to 44	217	38.1
45 to 54	94	16.5
55 to 64	34	6.0
65 and over	7	1.2
Not reported on questionnaire	6	1.1

Krupp, 1995) and by the need for close haematological monitoring. Nevertheless, acute adverse effects are usually manageable (Naber, 1999) and patient satisfaction with treatment, although not widely evaluated, appears to be high (Wolfson & Paton, 1996). It might be concluded, therefore, that clinician expectation or observation differed importantly from patient experience and perception.

We sought to evaluate patient perceptions of treatment in a large sample of subjects attending formal clozapine clinics in UK hospitals.

The study

Questionnaires were given to 1284 consecutive patients attending 27 clozapine clinics in the UK during March–May 1999. The patients were asked by their own mental health staff to fill in questionnaire forms by themselves, but were advised to seek help when necessary from the clozapine clinic nurse. Nursing staff were asked only to provide clarification of the questions asked and not to influence patient choice in any way. Completed questionnaire forms were returned by patients before leaving the clozapine clinic. All information was provided anonymously. The questionnaire consisted mainly of questions followed by clearly stated responses, from which patients were asked to choose the one that mostly matched their view. A small number of open questions were included. A full version of the questionnaire is available from the authors upon request.

Findings

Overall, 570 forms were returned (response rate 44.4%). A small minority of forms were incomplete, but all contained part information that has been included in the data analysis. Responses to open questions were grouped by broad category for analysis.

Patient characteristics

Respondents were predominately men (63.3%) and Caucasian (89.5%), but African–Caribbeans (4.9%) and Asians (2.8%) were also represented.

The age of patient respondents ranged from 18 to over 65 years with the majority aged between 25 and 44 (Table 1).

Table 2. Reported duration of clozapine treatment		
Duration	*n*	%
Total	570	100
2 years or more	334	58.6
1–2 years	92	16.1
6 months to one year	61	10.7
Less than 6 months	77	13.5
No response given	5	0.9
Unable to remember	1	0.2

Table 3. Treatments immediately before clozapine		
Treatment	*n*	%[1]
Total	570	
Oral typical drugs[2]	465	81.6
Depot typical drugs	382	67.0
Oral atypical drugs[3]	162	28.4
None	10	1.8
No reply	80	14.0

1. Some respondents were taking more than one antipsychotic: percentage figures do not add up to 100; 51.9% of respondents reported receiving depot and oral medication simultaneously before being switched to clozapine.
2. When asked what they liked about previous treatments, 40% of respondents said that there was nothing that they liked about it and only 8.1% mentioned perceived positive effects such as control of illness. When asked what they did not like about previous treatment, 21.9% said it was ineffective and 15.1% mentioned adverse effects.
3. Atypical=olanzapine, risperidone, quetiapine, amisulpride.

Most respondents had been taking clozapine for 2 years or more (see Table 2).

Previous therapy

Patients were asked to record the medication they were receiving immediately before starting clozapine. Details are given in Table 3.

Perceptions of clozapine treatment

Respondents were broadly favourable in their views of clozapine treatment. When asked to compare clozapine with previous treatment, the overwhelming majority of respondents rated clozapine as being better (62.1% ‘much better’, 24.0% ‘slightly better’). Relatively few rated clozapine ‘about the same’ (9.8%) and a small minority felt clozapine to be ‘slightly worse’ (1.8%) or ‘much worse’ (0.9%) (*n*=570; 1.4% gave no reply). An open question on the perceived benefits of clozapine treatment revealed that efficacy benefits were most apparent: 35.4% (202 of 570 respondents) cited ‘feeling better’ as something they liked about clozapine. Relatively few (8.4%) cited improvements in tolerability. A similar open question asked patients what it was they did not like about clozapine. Blood tests were most often cited in this regard (24.2%), followed by drowsiness (13.0%) and increased salivation (9.8%). Weight gain was mentioned

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by only 5.4% of respondents (*n*=570; 19% gave no reply). A further question evaluated preference for treatment. Overall, 88.6% of respondents claimed that they would prefer to stay on clozapine, with 6.5% preferring previous treatment (*n*=570; 4.9% did not give a preference). A similar proportion (87.0%) felt that the advantages of clozapine outweighed disadvantages (*n*=570; 6.5% did not feel advantages outweighed disadvantages, 6.5% gave no reply).

These positive views were reflected in replies to question 14, which asked how patients lives had changed since starting clozapine. Overall, 57% reported finding it easier to mix with people, 42.9% said they now liked socialising, 52.9% had left hospital, 42.9% could now live in a hostel and 7.0% had obtained employment. Only 11.1% reported that their lives had not changed (*n*=570, 3% gave no reply).

Blood testing

Patients were asked whether or not they knew the reasons for blood testing with clozapine. Most (80.5%) claimed to know the reason for blood testing (17.4% claimed they did not know, 2.1% did not reply (*n*=570)). Among those claiming to know the reason for blood testing (*n*=459) 58.6% cited the need to check white cell count as the reason, with a further 10.5% mentioning the need to protect against infection and 2.4% directly citing the danger of 'neutropenia'. Overall, 6.1% did not give a reason and 12.4% gave the wrong reason. Information on blood testing had been provided by doctors (60.8%, *n*=459), nursing staff (56.9%), a relative (4.6%) and by a pharmacist (3.7%). Some 85% felt they had been given enough information about clozapine.

When asked for views on regular blood tests, 64% (*n*=570) claimed to feel that "they're OK – a necessary part of treatment" and a further 4.7% claimed to 'look forward' to blood tests. On the negative side, 28.2% claimed that they 'did not like blood tests much' or 'at all' and a further 1.6% said that blood tests made them want to stop taking clozapine.

Comments

As far as we are aware, this is the largest survey ever conducted of patient perceptions of clozapine treatment. As such, it represents a valuable insight into the experiences and feelings of those taking clozapine.

In the main, respondents were positive in their perceptions of clozapine treatment. Overall, 86.1% of patients claimed to feel better on clozapine than on previous treatments, and a substantial majority felt that the drug's advantages outweighed its disadvantages. Not surprisingly, a similar large majority claimed they would prefer to stay on clozapine rather than go back to previous treatment.

It was also encouraging to discover that most respondents knew the reasons for blood testing with clozapine and that a majority felt indifferent or positive about the necessity for them. However, an important minority of patients claimed not to like blood tests, with a small number stating that blood tests made them want to stop clozapine. Moreover, blood tests were most often given as the aspect of clozapine treatment that respondents did not like.

The large number of respondents in this survey makes more likely the probability that our results are broadly representative of clozapine patients in general. However, our response rate (44.4%) obviously represents a minority of patients surveyed, and our respondents formed something of a select group. All, by definition, were good attenders at clozapine clinics and all felt capable of or motivated to completing the questionnaire. Most were men and Caucasian and by far the majority had been on clozapine for longer than a year. It might be assumed, therefore, that our respondents are representative only of a sub-group of patients who have done well on clozapine and who undergo blood tests only monthly. (Although, an analysis of 77 patients on clozapine for less than 6 months revealed broadly similar attitudes to treatment.) It should also be noted that our questionnaire is not yet validated as a precise tool for evaluating patient perceptions.

In conclusion, in our somewhat select cohort of clozapine patients, clozapine was widely felt by respondents to be more effective than previous treatments. The need for blood tests was viewed negatively by some but, overall, patients expressed a clear preference for clozapine over former therapies. Future research should address perceptions of patients less well established on clozapine undergoing more frequent blood testing.

References

DEV, V. J. & KRUPP, P. (1995) Adverse event profile and safety of clozapine. *Reviews in Contemporary Pharmacotherapy*, **6**, 197–208.

FLEISCHHACKER, W. W. (1999) Clozapine: a comparison with other novel antipsychotics. *Journal of Clinical Psychiatry*, **60** (Suppl. 1), 30–34.

KANE, J., HONIGFIELD, G., SINGER, J., *et al* (1988) Clozaril collaborative study. *Archives of General Psychiatry*, **45**, 789–796.

NABER, D. (1999) Optimizing clozapine treatment. *Journal of Clinical Psychiatry*, **60**, 35–38.

TAYLOR, D. (1999) Treatment of refractory schizophrenia. *Pharmaceutical Journal*, (suppl. 1), 2–4.

WAHLBECK, K., CHEINE, M., ESSALI, A., *et al* (1999) Evidence of clozapine's effectiveness in schizophrenia: a systematic review and meta-analysis of randomized trials. *American Journal of Psychiatry*, **156**, 990–999.

WOLFSON, P. M. & PATON, C. (1996) Clozapine audit: what to do patients and relatives think? *Journal of Mental Health*, **5**, 267–273.

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