

Out-patients' perceptions of the clinical and psychosocial effects of neuroleptic medication

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While research into the effectiveness of neuroleptic medication consistently demonstrates its value in improving psychotic symptoms, and in the prevention of relapse, the treatment continues to generate controversy. Indeed, McClelland (1989) has recently asserted that this treatment of choice is “an indispensable evil”; “indispensable” by virtue of its clinical effectiveness, and “evil” because of the wide range of adverse and distressing side effects experienced by patients.

Apart from lay critics, who emphasise the distressing side effects, the long-term complications of maintenance antipsychotic therapy also prompts serious soul-searching by clinicians who continually face the dilemma of whether, in some cases, the “cure” might indeed be worse than the “disease” (see Gardos & Cole, 1976)? Since clinical research in psychiatry is inevitably complex, and individual calculations of benefit to risk ratio in need of constant review, the addition of further variables might be considered only with reluctance. One variable, however, which has tended to be overlooked in shaping clinicians' decisions about treatment has been the patients' own attitudes to medication. Since failure to take medication, for whatever reason, creates severe management problems, particularly when patients are being maintained in the community, it seems vital that clinicians have some knowledge of their patients' attitudes to medication in the frankest possible terms. An analysis of some of the data derived from the present study sheds some light on this subject.

The study

The survey from which this brief report is derived investigated schizophrenia sufferers' perceptions of the extent and quality of various kinds of medical and social support that they received. This report focuses on their attitudes to antipsychotic medication. Questionnaires were sent to those members of a rapidly growing voluntary association in the north-west catering for sufferers and their families. At the time of the study this association had 192 members registered as sufferers. Without any follow-up, 138

questionnaires were returned, providing a response rate of 72%. After scrutiny, 132 questionnaires, completed by subjects who indicated that they had received a diagnosis of schizophrenia, were found to be suitable for this part of the analysis. The sample is not representative, with bias in favour of men and the higher socio-economic groups.

Findings

Attitudes to treatment

Treatment by neuroleptic drugs is clearly the foundation of therapy. Less than 4% of the respondents indicated that they had not received this treatment. Given the controversy surrounding the administration of neuroleptic drugs, the fact that 84% of subjects who had received this medication, described it as “helpful” was quite unexpected. Indeed, only 7% indicated that drug treatment was “unhelpful” to them. Non-compliance would not seem to be an important issue for the vast majority of members of this particular voluntary association.

That sufferers are painfully aware of the damaging side-effects of anti-psychotic medication is, however, quite clear from the reservations and qualifications expressed in their responses to the open-ended items inviting them to write about the factors which help them cope with their illness. What is strikingly evident is that, on balance, the overwhelming majority were favourably disposed to medication, despite the undesirable side-effects.

A selection of responses, quoted verbatim, illustrates this:

“They're by no means ideal (due to side effects) but knowing by experience a life without these drugs is horrific I have to count my blessings”.

“All things considered, I now have to settle for the fact that any sort of life is only possible for me if I continue to take my medication and accept it for what it is – ‘a crutch’. Not a pleasant thought but at least it is there”.

“I seem damned to a life dependent on drugs. I console myself with the thought that without them, live (sic) would be like hell on earth because that is what it was before they found out what was wrong with me. They are

like vitamins to a space traveller. Without them he could not survive”.

One of the sections in the questionnaire contained a number of items relating to coping with schizophrenia. The responses to an open-ended item: “What do you find useful in helping you *cope* with your illness?” reinforces the positive contribution of medication in the lives of many. Without prompting, 31% wrote about the value of medication. This factor ranked second only to “family support”, which was mentioned by 33% of the respondents.

Recovering from schizophrenia

Again, without any form of prompting, when asked: “Which single factor do you think has helped your recovery most?”, 30% of the sample mentioned medication, more than for any other single factor. Many sufferers were convinced that their medication was the single most important factor in their recovery, e.g.:

“I think that the commencement of moderate injections on a fortnightly basis, helped me to recover most. Without this, and the other supports I have and still receive, the treatment would have been ineffectual. My mother said that once the moderate was given me, I began to improve and eventually became recognisable as the child she had known and brought up.”

“Medication because without it I would not be able to function at any level.”

“The depixol injections. . . They gave me confidence, although I realised other factors were also important I think the drugs are the most important single factor in my recovery.”

“Drugs in small doses, because they help me to live as normal a life as possible as they stop my hallucinations and delusions.”

The responses to the question “Which single factor do you think has *hindered* your recovery most?” again seemed to go some way towards vindicating the long-term use of antipsychotic drugs, with only 14% of the sample (n=115) claiming that medication actually hindered their recovery.

Comment

The study was designed in such a fashion as to allow those schizophrenia sufferers who felt able to provide their own authentic and, as far as possible, unstructured attitudes, perceptions, and feelings, about certain facets of living with schizophrenia the opportunity to express them freely. The majority of subjects who chose to mention the place of medication in their lives, on balance, referred to it in a positive rather than a negative light. We would argue that their non-scientific, yet deeply personal, reactions should be treated with commensurate respect by the proponents and opponents of pharmacological treatment alike. Since women were under-represented in the sample it is pertinent to point out that Hogarty *et al* (1974) found that although drug therapy is more effective than placebo in both sexes, the size of the difference is significantly greater for women than men ($P < 0.01$). It can be inferred, therefore, that since medication seems to be more effective for women, the generally favourable responses to drug treatment reported here cannot be an artifact of sex bias. The message from this study for clinicians who shoulder the responsibility for administering antipsychotic medication would seem to be proceed with caution. Patients understand the fine balance between costs and benefits better than many of you imagine.

References

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