

Patients' perceptions and knowledge of electroconvulsive therapy

KATY MALCOLM, Senior Registrar in Adult Psychiatry, Northern General Hospital, Sheffield

Most research on electroconvulsive therapy (ECT) has focused on technical aspects, such as indications for treatment, efficacy, side effects of treatment, and theories of mechanism of action. Little investigation has been made of the attitudes and experience of patients receiving ECT and less regarding patients' understanding and knowledge of this treatment. Earlier studies have looked at specific aspects of patients' perceptions of ECT, such as subjective side effects, (Gomez, 1975), or the effect of the media on attitudes towards ECT (Bird, 1979). Other studies have investigated these and related issues more comprehensively (Freeman & Kendell, 1980; Hughes *et al.*, 1980). These studies were carried out some time after the ECT course had been completed; in some cases, over a year. It may be that patients' perception and knowledge of ECT are different before and after treatment. Attitudes and knowledge may also change or fade over time.

In the present study, patients' perceptions and knowledge of ECT were examined before and after treatment. In this way, a comparison could be made of patients' attitudes before treatment in relation to their actual experience of treatment, and an assessment could be made of their general knowledge of the ECT procedure shortly after this had been explained to them.

The study

One hundred patients from the Northern General Hospital and Middlewood Hospital, Sheffield, who were due to receive ECT were interviewed by the author before and after treatment using a semi-structured interview based on a questionnaire. Consecutive patients were interviewed until the total of 100 was reached over a time period between February 1986 and March 1987. The first interview took place before treatment but after consent had been sought. A further interview was held during the week following completion of the course of ECT.

Patients were asked a series of questions before treatment concerning their knowledge of ECT, their satisfaction with the explanation and consent procedure, and their anxieties about the impending

treatment. No attempt was made to influence the explanations given to the patients which were conducted according to the usual clinical practice of the doctors involved. After treatment, they were again questioned about their attitudes towards and experiences of treatment. Information concerning diagnosis, previous ECT treatment and conduct and outcome of the present course of ECT was extracted from the case-notes.

The findings

One hundred and two patients received ECT in the time period studied, but two were unable to complete the interview; one refused and one remained mute throughout the interview.

Of the remaining 100 patients, 32 were men and 68 were women. The mean age of the group was 68.5 years (range 20 to 92 years); 59 patients were over 65. Forty-eight patients had received one or more previous courses of ECT. The case-note diagnoses for the group were depressive disorder in 95 patients, schizophrenia in four patients and dementia in one patient. It was not possible to make definitive diagnoses according to predetermined criteria such as DSM-III owing to lack of information in the casenotes. Of those with depressive disorder, only 19% were reported to have delusions. Ninety-five patients were receiving psychotropic drugs, mostly anti-depressants, prior to ECT. Ninety-three continued to receive psychotropic medication during the ECT and ninety-four received continuation treatment immediately after the course of ECT. Eighty-nine subjects were in-patients, six attended as out-patients and five attended as day-patients.

Seventy-three patients had bilateral ECT, 21 received unilateral ECT and six had a mixture of both. The mean number of treatments was 7.5 (range 1–15). Seventy-nine patients received ECT twice a week and two had ECT three times a week. Ten patients had between one and three 'extra' treatments administered approximately one week after the bulk of their course had been completed.

Eleven patients received ECT under the emergency provisions of Section 62 of the Mental Health Act

1983. Of these, one patient had two emergency treatments, and a further patient had three such treatments. A further 16 patients refused treatment and were given it compulsorily after a second opinion had been obtained. Of the remaining patients who consented to treatment, 65 were informal and eight were detained under the Mental Health Act.

Reasons for discontinuing ECT were as follows: 70 patients were reported in the case-notes to have improved. Thirteen were reported to show no improvement by the end of treatment. Six patients refused further treatment, four became hypomanic, two suffered severe post-ECT confusional states, and five had treatment stopped due to the development of physical problems. Of these, two had myocardial infarctions, two developed jaundice, and one developed intestinal obstruction necessitating surgery.

Problems noted during the administration of ECT were missed fits in 18 patients, and single cases of spontaneous seizure following ECT, prolonged seizure during ECT, hypersensitivity to scoline resulting in slow recovery, and a case of one patient waking up during ECT. One patient aspirated vomit twice on successive occasions and had to be transferred to the intensive care unit. She continued to the end of the course of ECT on recovery from her physical problems.

Knowledge of the procedure prior to treatment (Table I)

Most patients (89) knew that a general anaesthetic was involved, but less than half the patients were aware of other crucial information regarding ECT, including the fact that electrodes are used and an electric current passed through the brain. Only 16 patients knew that a convulsion was induced, some

making comments such as "they would stop the treatment if you had a seizure", and "I am sure the doctors would never do that to me". There was a poor awareness of the number of treatments and treatment intervals, a common misconception being that only one treatment was involved. Forty per cent of patients thought that the treatment would prevent future episodes of depression. Breakdown of the data by age showed that the under 65s were much better informed than the elderly patients, particularly with regard to the fact that electrodes were used, a current passed and a convulsion occurred. Men tended to have more overall knowledge than women. Knowledge was not greatly improved by previous exposure to ECT, although not surprisingly people who had previous ECT treatment were less inclined to the opinion that it is preventive. Patients who consented to treatment had better overall knowledge than those who refused.

Explanation and consent

Thirty-five patients received ECT under the Mental Health Act (1983). Eight of these patients consented to the procedure, but their consent was not felt to be valid. Five patients initially consented but later withdrew their consent and were given ECT under the Act.

Thus, the majority of patients consented to treatment despite their lack of factual knowledge about it. Just over half (51) thought they had received an adequate explanation of the procedure. The remainder consented despite their feeling that the explanation had been inadequate. Thirty-three patients said that they had not received any explanation of the procedure but only 12 of these felt this to be unsatisfactory. The remainder made observations such as "I am happy to let the doctor decide

TABLE I
Knowledge about ECT prior to treatment

	TOTAL	Age		Sex		Consent	
		>65	<65	M	F	YES	NO
Number of patients	100	59	41	32	68	73	27
General anaesthetic	89	84.7	95.1	100	83.8	97.3	66.7
Electrodes	42	23.7	68.3	53.1	36.8	46.6	29.6
Current passed	44	23.7	73.2	50	41.1	50.7	25.9
Convulsion	16	1.7	36.6	25	11.8	19.2	7.4
Treatment number	8	3.4	14.6	15.6	4.4	11.0	0
Treatment interval	6	3.4	9.7	9.4	4.4	8.2	0
Preventive	40	42.4	36.6	46.9	36.8	53.4	3.7

Figures are percentages. Data subdivided by age, sex, previous treatment with ECT, and whether or not the patient consented to treatment.

what is best for me". Age, sex, and previous exposure to ECT made little difference to the perceived adequacy of the explanation but, not unexpectedly, patients who had consented were more likely to be satisfied with the explanation than those who refused (58.9% v. 29.6%).

Forty-nine patients, of whom 29 had consented to ECT, thought they were unable to refuse ECT and six did not know whether it was possible to refuse. Forty-five patients, of whom 39 consented to the procedure, said it was possible to refuse ECT but often commented that it was futile to refuse as they would end up getting treatment anyway. Many fewer patients over the age of 65 were aware of the possibility of refusing ECT than those under 65 (27.1% v. 70.7%). Men tended to be more aware of the possibility than women (56.3% v. 39.7%).

Thirty-six patients said the explanation had made them more anxious prior to treatment, and six said it had made them less anxious. The remaining majority (56) said it had made no difference to their level of anxiety.

Attitudes and perceptions towards ECT prior to treatment

Sixty patients said they felt frightened about their impending treatment when asked. More patients

under 65 were fearful than those over 65 (78.1% v. 47.5%), and more patients who had refused ECT were fearful than those who consented (70.4% v. 56.2%). A previous history of ECT did not seem to influence fears prior to treatment.

Patients were asked with the aid of a check-list whether they feared particular parts of the treatment (Table II). Thirty-two patients mentioned fears not specified on the check-list. The commonest of these, reported by 11 patients, was the shame of facing friends and relatives after treatment which they viewed as stigmatising. A few patients had unusual fears, for example that brain surgery would be performed on them while they were anaesthetised for ECT. Only five patients had no worries about their treatment.

The experiences and perceptions of ECT after treatment

Fifty-five patients said that they had found the treatment frightening when asked. Patients under 65 tended to find the treatment more frightening than those over 65 (63.4% v. 49.2%) as did those who refused treatment relative to those who had consented (66.7% v. 50.7%). The history of previous ECT did not seem to greatly affect whether the current treatment course was experienced as frightening.

TABLE II
Fears reported by patients before and after a course of ECT

<i>Before treatment</i> Check-list item	<i>Number</i>	<i>After treatment</i> Check-list item	<i>Number</i>
Brain damage	53	Waiting for treatment	75
Losing memory	46	Injections	39
Not knowing what is going to happen	40	Being with other patients waiting for treatment	36
Pain	39	General anaesthetic	26
General anaesthetic	34	Being with other patients during recovery from treatment	26
Having a personality change	33	Anaesthetic mask on face	19
Becoming a zombie	32	Waking up after treatment	17
Dying	31	Seeing treatment equipment laid out	15
Injections	27	Hearing people talking in background during treatment	15
Having a heart attack	21	Journey back to ward after treatment	15
Electricity	17	Being wheeled on trolley into treatment suite	4
Being unconscious	16	Staff attitude during treatment	0
Being seen by strangers while unconscious	13		
Having a seizure	10		
Having too much shock	9		
Biting tongue	7		
Not being unconscious during treatment	6		
Breaking bones or teeth	5		
Vomiting	4		
Developing epilepsy	3		

Figures are numbers of patients (total $N = 100$).

A check-list was again used to determine whether particular parts of the procedure were experienced as frightening or worrying (Table II). Again, some fears were mentioned that were not specified on the check-list. Five patients were alarmed to discover that they would have more than one treatment. Individual patients reported other fears such as being afraid that their relatives would be told that they had had ECT, or that ward staff were bad tempered on ECT days because they were so busy accompanying patients to the ECT Suite. Four patients reported pleasant aspects to the treatment, such as drifting off to sleep or amnesia, which made them forget their worries.

Fifty-two patients reported side effects which they associated with ECT. The commonest of these was an adverse effect on memory, mentioned by 31 patients. Other complaints mentioned by between three and five patients were of permanent or temporary headache following treatment, slowing of thought processes and disorientation. Two patients said that the treatment had made them worse. The five patients who experienced physical problems requiring cessation of ECT all attributed these problems to the ECT procedures.

Comment

As in previous studies, (Bird, 1979; Freeman & Kendell, 1980; Hughes *et al.*, 1980), few patients had fully understood the nature of their treatment. This was so even though they had apparently been given a full explanation shortly before they were questioned about the extent of their knowledge of the treatment. There are various possible explanations for this finding. The patients may have forgotten the explanation, or not understood it at the time, or the explanation may not have been as comprehensive as it should have been.

Some sub-groups of patients had notably less knowledge than others. The over 65 age group knew considerably less. Whether they were less capable of understanding and retaining the information, or whether they had a less than adequate explanation, is unclear. It appeared that the elderly were more inclined to trust blindly the doctors and they may therefore have not been so motivated to understand and retain information given. Those who refused to consent to ECT knew less about it. This may have been because they were less able to understand, perhaps because of a more disturbed mental state, or it is also possible that increased knowledge makes people more likely to consent to treatment. Previous exposure to ECT did not improve knowledge of the technicalities of the treatment.

Although knowledge about the treatment was poor, 73% consented and just over half thought the explanation adequate. However, when challenged with the check-list 40% admitted to anxiety about

their uncertainty as to what was going to happen to them. This accords with the finding of Kerr *et al.* (1982), that 55.9% of patients reported that "patients are never told what is going on". Some of those who said that they had received no explanation, particularly those over 65, seemed to think this was a satisfactory state of affairs. Elderly patients appeared to have greater faith in the doctor doing what was in their best interest, and they also felt less able to refuse ECT. Younger people were more knowledgeable, more apprehensive and less satisfied with the explanation they received.

A high proportion of the group (60%) admitted to being afraid before treatment, especially those below the age of 65. Nearly as many patients still felt frightened after their treatment. These figures are higher than those reported by Hughes *et al.* (1980) and Freeman & Kendell (1980). However, in the latter studies patients were being asked to recall emotions after a considerable time period had elapsed. The present data, however, accord with those of Spencer (1968) who found that more than half the patients given ECT had adverse feelings about the treatment ranging from dislike to dread.

The commonest specific anxieties prior to ECT, such as fears of brain damage and memory loss, point the way to the possible improvement of the explanation which is given by focusing on these areas of anxiety, and giving more detailed information. Few patients feared such things as electricity or having a convulsion, but this may simply be a function of their lack of knowledge that these things actually happen during the treatment.

Aspects of treatment which were reported as frightening in the interview conducted after ECT also provides some indication of how procedures might be improved. Waiting for treatment is by far the most anxious time, and other features which could be modified included being with other patients waiting for ECT, being with other patients during recovery from ECT, and hearing people talking in the background during treatment. It should be possible for patients to be individually called up for treatment instead of waiting with other patients who are in a distressed state. It would seem important to minimise waiting time, which includes promptness on the part of the anaesthetist and the psychiatrist carrying out the treatment.

Finally, it should be noted that in this series of patients there was a significant morbidity associated with ECT, including two myocardial infarctions in elderly patients. The commonly held view that ECT is the safest treatment for severe depression in the elderly has recently been challenged (Malcolm & Peet, 1988), particularly in view of the greatly improved cardiovascular safety of the 'second generation' antidepressants relative to the older tricyclic drugs.

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The role of the satellite clinic in reaching intravenous drug users at risk from HIV

ROSIE M. COLEMAN, Registrar; DAVID CURTIS, Registrar; and MARGARET SHARPE, Clinic Nurse, Department of Psychiatry, University College and Middlesex School of Medicine, London

The arrival of HIV has challenged the traditional services for intravenous drug users providing the impetus to re-examine working practices. Only 10% of intravenous drug users attend hospital based treatment centres offering out-patient programmes based on reducing doses of oral methadone with an ultimate goal of abstinence (Hartnoll *et al*, 1985), yet for public health programmes designed to limit the spread of HIV it is important to increase the contact between high-risk groups and health professionals. Satellite clinics originally introduced to provide low cost help for drug users at a more local level may also be effective as a means of reaching intravenous drug users at high risk of HIV who would otherwise not be exposed to treatment and health education. Strang has described how a satellite clinic may be established with few resources, with staff who can be supervised by more senior workers at a central site (Strang & Creed, 1985). In this study the client groups of a satellite clinic and a conventional drug dependency unit were compared in order to characterise the clientele of the satellite clinic and to discover whether it was indeed fulfilling a useful role in terms of attracting such high-risk individuals for treatment.

Drug Indicators Project has already demonstrated that attenders at the satellite clinic are more likely to abuse a variety of drugs and have more drug-related social problems than the drug dependency unit attenders (Daviaud, 1987), and Dolans has shown that these two factors are linked with an increased

rate of needle-sharing among intravenous drug users (Dolans *et al*, 1987). Accordingly it might be expected that there would be more needle-sharing among the satellite clinic attenders, and so this and other risk factors for HIV infection were specifically investigated in the two clinic populations. Demographic and other variables were also investigated to aid comparison of the two samples with each other and with subjects of other studies.

Description of the easy access satellite clinic (Rathbone Place)

In 1985 Rathbone Place Clinic was set up in a Probation Office. It was hoped it would reach clients who did not attend hospital based drug treatment centres, in particular the homeless drug users living around the West End for whom no treatment service provision had been made and who lived by theft, prostitution and drug related activities, thus bringing them in frequent contact with the law. The clinic is staffed by an experienced nurse and a psychiatric trainee and is run once a week. The links with probation officers (two of whom have a brief to work with drug users) are good and there is close involvement with Narcotics Anonymous, who provide counselling and a meeting on the same day that the clinic is open.

The clinic is run on a walk-in basis and provides counselling, advice on treatment, methadone reduction programmes, health education and condoms.