Brit. J. Psychiat. (1980), 137, 8–16

ECT: I. Patients' Experiences and Attitudes

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SUMMARY One hundred and sixty-six patients who had ECT in either 1971 or 1976 were interviewed. The 1976 sample represented 89 per cent of those available for interview. Their experiences of ECT and their attitudes to it are described. They found ECT a helpful treatment and not particularly frightening, but side-effects, especially memory impairment, were frequent.

We have not found any systematic attempts in the literature to assess patients' experience or views of ECT. Gomez (1975) looked at side-effects but confined questioning to a period 24 hours after the treatment. A number of other studies which compared the effects of unilateral and bilateral ECT on cognitive function included questions on side-effects. There have been some anecdotal reports in the general press, usually along the lines that ECT was a terrifying or damaging treatment. Following a *Panorama* (BBC TV) programme on ECT in 1977 Julian Mounter wrote in *The Listener* "I spoke to more than 50 ECT patients, and almost all of them said they dreaded it more than anything else they had ever experienced". Bird (1979) attempted to assess the effect this programme had on patients' attitudes.

In view of the increasing number of adverse anecdotal reports we felt it would be useful to interview a representative sample of patients who had had a course of ECT and find out what they thought.

Methods

Sample—We attempted to interview all the patients under the age of 70 who had had ECT during one year (1976) in the Royal Edinburgh Hospital. We tried to interview people approximately one year after their last ECT, but some had had a second course of treatment during the year and were interviewed within six months while others, being difficult to contact, were not interviewed until 18 months after their last course. The interviewing took place between February 1977 and October 1978.

Because the study was conducted alongside another investigation concerned with epilepsy following ECT, a number of patients were interviewed who had had ECT in 1971, i.e. six years earlier. No attempt was made to contact everyone who had had ECT in 1971 but it was felt useful to include this group to see if attitudes changed with the passage of time.

Each patient of the sample was sent a letter explaining the nature of the study and asking them to come for an out-patient interview. Those who did not respond were sent a second appointment enclosing a small questionnaire and a stamped addressed envelope. The few who still did not come were visited at home, where possible with prior telephone contact.

Interview schedule—Patients were given a semi-structured interview based on a questionnaire. They were allowed to talk spontaneously about their views and experience of ECT for about five minutes and then asked for specific details about the number and timing of their treatments, why they were given ECT, their psychiatric symptoms at the time, why the treatment was stopped, their experience of the treatment sessions themselves, the side-effects that they experienced, whether the treatment helped them, whether they would have it again, and whether they gave consent to the treatment. Finally, they were asked to respond to a number of statements by either agreeing, disagreeing or saying 'don't know'. Further details of specific questions are given in the results section.

Details about number and timing of treatments, psychiatric diagnosis and type of ECT were also obtained from case-notes and ECT records.

Background Information

The Royal Edinburgh Hospital admits approximately 2,500 patients per annum. In 1976 714 had a diagnosis of some type of depression or of puerperal psychosis. Almost all fell into three ICD–8 categories, (296.2 manic-depression depressed type, 300.4 depressive neurosis, or 296.1 manic-depression manic type). One hundred and eighty three patients had a course of ECT. These figures would indicate that approximately one in fifteen in-patients, and one in five depressed in-patients receive a course of ECT. ECT is little used as a treatment for other psychiatric conditions. Bilateral ECT is routinely given unless the consultant specifically requests unilateral treatment. Very little out-patient ECT is given, though in a few cases ECT which has been started as an in-patient is continued on an out-patient basis.

At the time of the study ECT was given in two places in the hospital. In the main hospital a separate ECT suite was used and patients were fasted overnight in their wards, given atropine premedication at 40 minutes and then brought down to the ECT suite by a ward nurse at approximately 15 to 30 minutes before each treatment. There were separate waiting, treatment and recovery rooms. In the other area (Craig House) ECT was given in the patient's ward. This usually involved clearing a side room or four-bedded ward. The ECT was given by the ward doctor and a visiting anaesthetist. In both areas ECT was routinely given twice-weekly but could be given three times weekly if this was specifically requested.

Results

One hundred and eighty three patients received one or more courses of ECT during 1976 and constituted the main sample. At enquiry in 1977-8, 12 were dead (see below), 25 were over 70 and 27 had left the Edinburgh area. This left 119 people available for interview, of whom we interviewed 106 (89 per cent). Sixty patients who had had ECT in 1971 formed a subsidiary sample. The two samples were analysed separately but are reported here together as no differences were found between the two. The combined sample was thus 166.

Of the 13 patients who were not interviewed three were still in treatment at the hospital but refused to be interviewed for research purposes. All three were said by the doctors treating them to be somewhat hostile to doctors in general, but they had not made any specific comments about ECT. The remaining 10 patients could not be traced.

The treatments

Many subjects had little idea how many treatments or how many courses of ECT they had had, and the information they gave was quite unreliable when checked against case-note records. The details of background variables and actual experience of ECT are summarized in Table I. It can be seen that there was a wide range of experience. A few people had had only a single ECT treatment and one lady had had as many as 93 treatments in her lifetime, spread over 14 courses. The average number of treatments of those interviewed were 16 for the 1976 group and 18 for the 1971 group. The distribution about the mean was skewed. Over half those intervewed had had only a single course of ECT, usually of five to eight treatments. Details of the diagnoses obtained from the case-notes are given in Table II. The main difference between the two years is that fewer schizophrenic patients were given ECT in 1976.

The reasons given in the case-notes for treatment being stopped are given in Table III. In 74 per cent this was because improvement was felt to be satisfactory or sufficient.

Causes of death

Twelve patients had died before they could be interviewed. Four had committed suicide. In two there was a good response to ECT and the suicide occurred during another illness, and in two there was only a partial response, the depression continued and suicide occurred nine months and eleven months later.

TABLE I

Background details of the two samples (N = 183 for 1976, but only 106 interviewed; N = 60 for 1971)

		1976	1971
Mean age		50	54
Sex ratio: M:F		1.46:1	1.4:1
Marital status:	Single	24%	21%
	Married	57%	67%
	Widowed	15%	8%
	Divorced	4%	3%
Social class	1	4%	16%
	2	21%	23%
	3	35%	23%
	4	24%	25%
	5	16%	13%
Bilateral ECT		81%	96.7%
Unilateral ECT		19%	3.3%
Experience of ECT during lifetime			
6 or less treatments		31%	25%
7–24	,,	52%	49%
25–50	,,	12%	21%
51 or more	,,	5%	5%
Range of experience		1–75	1–93
Mean total of treatments ever received		16	18

TABLE II

Percentage distribution of diagnoses for 1st course of ECT (N = 243 for 1976; N = 60 for 1971

Year	1976	1971
Unipolar depression	67.6	62.3
Bipolar illness depressed	14.5	16.4
Bipolar illness manic or hypomanic	3.9	1.6
Schizophrenic	5.0	16.4
Puerperal psychosis	3.4	0
Miscellaneous or unspecified psychosis	1.1	1.6
Other diagnoses	3.9	1.6

TABLE III

Reason in case-notes for ECT ending (N = 183 + 60)

Sufficient or satisfactory improvement	73.7%
Not sufficient improvement to justify continued treatment	13.6%
Hypomanic reaction	3.7%
Side effects	2.9%
Patient refused further treatment and/or took own discharge	1.6%
Death	0.4%
Major complication	Nil
Other reason or not specified	3.3%

In 6 cases death appeared to have been from causes entirely unrelated to ECT. They all occurred 6 months or more after treatment. In the remaining two cases death may have been related to ECT. A 69 year old woman died 24 hours after her thirteenth treatment. Post-mortem showed a myocardial infarction. She had had one previous infarct. A 76 year old woman also died 48 hours after her thirteenth ECT. Post-mortem showed a myocardial infarction 24–48 hours old. Both patients were taking a tricyclic drug at the time.

Patients' experience of the treatment

Details of this are given in Table IV. Only 21 per cent of patients felt they had been given an adequate explanation of the treatment before it began. Forty-nine per cent were sure they had been given no explanation at all and stuck to this view even when it was suggested to them that they might have forgotten. Twelve per cent said they couldn't remember being given any explanation but one might have been given.

When asked how they felt before their first ECT treatment 16 per cent described feeling very anxious or frightened and a further 23.5 per cent feeling slightly anxious. Forty-six per cent said that they either had no particular feelings one way or the other or felt reassured that some new action was being taken, or an effective treatment instigated. Most found it difficult to say why they had been afraid, though a few

TABLE IV

Patients' experience of ECT

(a) Adequacy of explanation given before treatment (N = 166)

Adequate	20.6%
No explanation	49.1%
Inadequate	8.5%
Misleading	—
Can't remember if explanation given	12.1%
Other	3%
Don't know	6.6%

(b) Do you remember how you felt before your first treatment? (N = 166)

Very anxious and frightened	16.3%
Slightly anxious and frightened	23.5%
No particular feelings	22.9%
Pleased treatment starting	22.9%
Can't remember	5.4%
Other	5.4%

(c) Experience of various parts of the treatment (N = 166)

Aspect of treatment	Pleasant	Neutral	Unpleasant	Don't know
Premedication	2.4%	77.1%	15.7%	4.8%
Waiting for treatment	1.2	74.7	19.9	4.2
ECT staff	26.5	65.7	3.0	4.8
Anaesthetic injections	5.4	83.7	6.6	4.2
Falling asleep	31.9	54.8	8.4	4.8
Waking up	10.8	63.9	20.5	4.8
Recovery period for few hours after each treatment	6.0	69.9	17.5	6.6

(d) Response to statements about experience of ECT

	Statement	Percentage answering Agree	Disagree	Don't know
1	I was so upset by the treatment I'd be reluctant to have it again	13.1%	80%	6.9%
2	If necessary I'd readily have the treatment again	59.4	34.4	6.2
3	More explanation should be given to patients about the treatment	51.2	30.6	18.1
4	ECT is a frightening treatment to have	38.7	45.0	15.6
5	How did ECT compare with going to the dentist?	More upsetting		18.3%
		Less upsetting		49.4
		About the same		32.3
6	How frightening or upsetting was ECT compared with what you expected?	More		3%
		Less		52.7
		About the same		32.1
		Not upsetting at all		9.7
		Don't know		2.4

said spontaneously they were afraid of the unknown or afraid of the anaesthetic.

The responses to specific questions about brain damage, fear of epilepsy, worry about electricity, worry about being made unconscious etc. are listed in Table V. It can be seen that worry about possible brain damage was the commonest fear, but even then 77 per cent of patients had not thought about this at all. We did not come across anybody who had bizarre ideas about what happened during ECT and our general impression was that patients did not find it particularly frightening. When asked to compare it with a trip to the dentist, (see Table IVd), 50 per cent of subjects felt that going to the dentist was more upsetting or frightening.

Specific parts of the treatment procedure, listed in Table IVc, seemed to arouse little feeling in subjects, and most found them neutral. We optimistically asked whether any of the aspect of treatment was pleasant. Thirty-two per cent of subjects thought that the sensation of falling asleep was a pleasant one and 27 per cent commented on the staff being pleasant. No aspect of the treatment was rated as unpleasant by more than 30 per cent of the subjects.

Side-effects

Details of these are given in Table VI. It should be noted that these are side-effects remembered approximately a year afterwards.

Twenty per cent reported remembering no side-effects whatsoever. Memory impairment was clearly the most troublesome with 50 per cent of the total sample mentioning this as the worst side-effect. Forty-one per cent mentioned memory impairment spontaneously when asked about side-effects and a further 23 per cent when prompted, making 74 per cent of the whole sample who reported some memory disturbance.

The only other side-effect commonly reported was headache occurring at the time of treatment. This was reported by 48 per cent of subjects. Fifteen per cent of the total sample thought it was the most troublesome unwanted effect.

When asked to respond to a series of statements about ECT, 30 per cent agreed with the statement that their memory had never returned to normal afterwards though 12 per cent felt their memory was better now than it had ever been. Twenty-eight per cent felt that ECT caused permanent change to memory and 22 per cent that ECT had no effect on memory at all.

There were single complaints of neck stiffness, skin burns, increased sleepiness, increased sweating and muscle aches. One man complained of choking and said he had been too lightly anaesthetized on one occasion.

Did patients find the treatment helpful?

Details are given in Table IX. Altogether 78 per cent of subjects thought that ECT had helped them either a little or a lot. Only one person thought that ECT had made him much worse. He was a young electrical engineer who had developed a schizophrenic illness. Because of his trade he had considerable respect for electricity and had found the whole experience

TABLE V
Fears and worries about ECT
(N = 166)

Worry or fear	Not at all	A little	A lot
About being made unconscious	80.6%	11.9%	7.5%
About losing control of bladder, or embarrassing things happening whilst unconscious	83.7	9.4	6.9
That electricity was used in the treatment	76.9	13.1	10.0
About having a fit or a turn	90.9	4.2	3.8
Of possible brain damage as a result of the treatment	76.9	13.1	10.0

quite upsetting and blamed his present state on ECT.

Although 78 per cent of people said it had helped them, only 65 per cent were willing to say that they would have ECT again. This discrepancy appeared to be due to two factors. A number could not imagine themselves getting depressed again and therefore could not believe that they would ever need more ECT. Others had clearly been put off by the side-effects and 13 per cent said so. When asked if they would recommend it to a friend if a psychiatrist advised the friend to have it 65 per cent said yes, but 24 per cent didn't know, and 11.4 per cent said definitely no.

Few people believed that the effect of ECT had been permanent. Thirty-five per cent believed the beneficial effects had lasted for a year or more, 15 per cent that they had lasted from 6 months to a year, 13 per cent less than 6 months and 2.4 per cent thought they had relapsed immediately.

TABLE VI

Side effects remembered (for comparison, side effects recorded at the time by the staff, on the right)

Patients' report of worst side effect	N = 166		N = 243
	N	Percentage	Percentage
Memory impairment	83	50%	7%
Headache	26	15.6	16
Other side effects	8	4.8	14
Confusion	6	3.6	9
Dizziness	3	1.8	
Vomiting	2	1.2	
Don't know	4	2.4	
No side effects at all	33	19.8	

Did patients understand the treatment?

Fifteen per cent of those interviewed appeared to have a full understanding of what the treatment involved. They knew about the anaesthetic, that electrodes were applied to the head and that the object was to produce an epileptic fit. Thirty per cent had a partial understanding. They knew about the anaesthetic, they knew that electricity was used and that it was applied somewhere around the head. They said they were put to sleep but then had no idea of what happened to them whilst they were asleep. Only four patients described false ideas. One believed that patients were naked when they had the treatment and another that some sort of metal electrode was implanted in the head during the treatment.

TABLE VII

Patients' estimate of severity

	Total percentage reporting symptom	Percentage who reported symptom spontaneously	Percentage who reported when prompted	Percentage who thought symptom severe	Percentage who thought symptom mild
Memory impairment	63.9%	41%	22.9%	25.3%	38.6%
Headache	47.6	24.7	22.9	19.2	28.4
Confusion	26.5	4.8	21.7	9.0	17.5
Clumsiness	9.0	2.4	6.6	3.6	5.4
Nausea or vomiting	4.2	2.4	1.8	2.8	1.4
Eyesight problems	4.2	2.2	2.0	2.2	2.0
Other side effects	12.0	10.8	1.2	3.6	8.4

TABLE VIII
Opinions on memory impairment

Statement	Percentage responses: Agree	Disagree	Don't know
My memory has never returned to normal after ECT	30%	63.1%	6.9%
My memory now is better than ever it has been	11.9	84.4	3.7
ECT is helpful but the side effects are severe	15.6	77.5	6.9
ECT has no effect on memory at all	21.9	73.7	4.3
ECT causes permanent changes to memory	28.1	63.7	8.1

TABLE IX
How helpful was the treatment?
(N = 166)

How much did ECT help you?	A lot	57.2%
	A little	20.5
	No change	18.7
	A little worse	2.4
	Much worse	0.6
In what way did it help?	Less depressed	50.6%
	Less anxious	6.0
	Made me forget	1.2
	Gave me a jolt	0.6
	Other explanation	19.3
	Didn't help	21.1
	Don't know	1.2
Has the effect lasted?	Permanently	9%
	1 year or more	34.9
	6–12 months	15.1
	<6 months	12.7
	Immediate relapse	2.4
	Not applicable	24.7
	Don't know	1.2
ECT is a helpful and useful procedure	Agree	79.5%
	Disagree	14.3
	Don't know	6.2
ECT works for a short while but the effects don't last	Agree	65.6%
	Disagree	14.4
	Don't know	20
ECT gets you better quicker than drugs	Agree	65.6%
	Disagree	14.4
	Don't know	19.4

Patients' consent to ECT

From the medical case-notes we determined that 76 per cent of patients had signed the consent form themselves (Table XI). We tried to determine whether patients felt they had been coerced into having ECT, persuaded against their judgement, or compelled to have ECT when they definitely did not want it. 7.8 per cent felt that they shouldn't have been given ECT but in most of these this was because they felt the treatment did them little or no good. Only two patients said that they clearly remembered being given ECT against their specific wishes. One of these had been helped by the treatment and was now glad she had received it. We also asked everyone whether they felt that if they had not wanted ECT they could have refused it at the time, and whether they thought their decision would have been respected by their doctors. A third said they could have said no and they felt they would have been obeyed. Twenty-three per cent said that they wouldn't have been able to say no, either because they couldn't imagine themselves saying no to a doctor or because they were in no fit state at the time to make a decision. Forty per cent said that they didn't know what would have happened or didn't understand the question. We then asked an open-ended question about whether in general they felt the consent procedures for ECT were adequate. In 90 per cent of cases the reply was yes or that it wasn't really the patient's decision, i.e. that it was up to the doctor to decide and for the patient to do as the doctor recommended.

Two people said they had been pressurized into signing the consent form. One man said he was 'conned'. "They said I wouldn't get out if I didn't have it!" The other, a woman, said she felt that the doctors had already decided she was going to get ECT and it was futile her resisting.

We found this area of the questionnaire the most unsatisfactory and we were left with the clear impression that patients would agree to almost anything a doctor suggested. Many people could not remember ever having signed a consent form, didn't regard it as particularly important and seemed quite happy to have other people, such as relatives, give consent on their behalf.

TABLE X
Patients' understanding of treatment
(N = 166)

1. What does the treatment involve?		
	No understanding	30.1%
	Partial understanding	43.4
	Full understanding	22.9
	False ideas	2.4
	Wouldn't answer	1.2
2. Why is the treatment given?		
	No idea	16.4%
	For depression	61.2
	For anxiety	5.5
	Other reasons	14.5
	Wouldn't answer	2.4
3. How does the treatment work?		
	No idea	38.8%
	Gives you a jolt or a shock	32.7
	Makes you forget	7.3
	Other explanation	14.5
	Doesn't work	5.5
	Wouldn't answer	1.2

TABLE XI
Consent procedure

1. Who signed the consent form? (N = 266)	Information on whole sample from notes.	
	Patient alone	76.1%
	Relative alone	11.9%
	Both relative and patient	11.5%

No form could be found in notes for one patient.

2. Do you think you could have refused to have ECT if you had wanted to?		
	Yes	33.7%
	No	23.1%
	Don't know	40.0%
	Other replies	3.1%

Factors affecting attitudes

More women than men found the treatment very frightening, 20 per cent as against 8 per cent. Slightly more men than women said that their memory had not been impaired at all (41 per cent as against 32 per cent), otherwise there were no sex differences. The amount of previous experience of ECT did not appear to alter attitudes, nor did attitudes either mellow or harden with time. The 1971 group did not complain either more or less than the 1976 group and they did not report that ECT had been any more or less helpful.

The number of people who had unilateral ECT was small and some of them had had bilateral treatment on other occasions. Their views differed markedly from the bilateral group. Fifty per cent said they wouldn't have ECT again (26 per cent in bilateral group), 33 per cent said it helped them a lot (61 per cent in bilateral group), 28 per cent thought they shouldn't have been given ECT (9 per cent bilateral group). We think that the most likely explanation for this negative view is not that unilateral ECT is a more unpleasant treatment but that these patients already had adverse views and were therefore selected by their consultants for unilateral treatment although in this hospital bilateral ECT is the usual procedure.

An alternative explanation is that unilateral ECT doesn't work as well, and therefore more people complained; however the numbers of treatments given and the therapeutic outcome recorded in the notes did not differ between unilateral and bilateral groups.

Finally, patients were asked the following: ECT is dangerous and shouldn't be used: agree 6.9 per cent, disagree 76.9 per cent, don't know 16.2 per cent. ECT is given to too many people: agree 6.2 per cent, disagree 30.6 per cent, don't know 63.1 per cent. ECT is often given to people who don't need it: agree 8.7 per cent, disagree 29.4 per cent, don't know 61.9 per cent. The commonest reply to the second and third questions was in fact that it was "up to the doctors, and I'm not qualified to say".

Discussion

We are aware that the main criticism of this study is that it was carried out by psychiatrists in a psychiatric hospital. It is obviously going to be difficult to come back to a hospital where you have been treated and criticize the treatment that you were given in a face-to-face meeting

with a doctor. It is not easy to see a way round this. It would clearly not be possible to release details of a group of patients' treatments to lay persons so that they could undertake such a study. Even if this were possible we imagine that the response rate to a questionnaire administered by strangers would be much lower. It was our impression that those patients who had strong views spoke out with little inhibition. What is less certain is whether there were a significant number of people in the mid-ground who felt more upset by ECT than they were prepared to tell us.

Given these reservations a number of definite results are apparent. The majority of patients did not find the treatment unduly upsetting or frightening, nor was it a painful or unpleasant experience. Most felt it helped them and hardly any felt it had made them worse. In general then, most patients had very positive views about ECT.

We were surprised by the large number who complained of memory impairment. Many of them did so spontaneously without being prompted, and a striking 30 per cent felt that their memory had been permanently affected, although the majority meant by this that they had permanent gaps in their memory around the time of treatment, not that their ability to learn new material was impaired. It may be that this high level of memory complaint is due to most people having had bilateral ECT.

It is clear that patients wish to be told more about the treatment. It so happened that one of us had interviewed a number of these patients before they started ECT in 1976 in connection with another study (Freeman *et al*, 1978) and given them quite detailed explanations of what the treatment involved, yet several of these were adamant that they had never been given any explanation. It might, therefore, be beneficial to patients to give them a *second* explanation of the treatment after they have completed the course and are symptomatically improved.

It is worrying that two patients from the 1976 sample died during a course of ECT. Both were elderly females, had pre-existing cardiac disease, were taking tricyclic antidepressants, had longer than usual courses of ECT and died of myocardial infarctions which were clinically silent until death. It is not possible to draw firm conclusions from two cases but they raise the question whether in such 'at risk' patients ECT and tricyclics should be given together.

Finally, we would like to emphasize the great trust that patients put in doctors. The majority of subjects in this study were more than happy to leave all decisions about their treatment to a doctor. There was hardly any concern about consent procedures being inadequate. This is perhaps best illustrated by two patients who misunderstood the initial appointment letter and came fully prepared to commence a course of ECT. Neither had been near the hospital for nine months and both were quite symptom-free.

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The addresses of the authors are given at the end of Paper III.

Part damage is docility