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cited in Portney – 30% permanently affected memory (3)
74% memory problems

Patients' Experiences of and Attitudes to Electroconvulsive Therapy

year or more later

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INTRODUCTION

We would like to present the results of a study that was carried out in Edinburgh, in the late 1970s. At the time it represented the first systematic attempt to assess patients' experiences and views of electroconvulsive therapy (ECT). Gomez (1975) had looked at side effects but confined her questioning to a period 24 hours after the treatment.[3] A large number of other studies had asked systematically about side effects but not about attitudes. Hillard and Folger (1977) compared two wards, one that was a high user and one a low user of ECT.[4] They confined their questioning of patients to side effects and to the use of semantic differentials such as how good, how fast acting, how strong the treatment was.

However, our study had been carried out at a time when there was considerable media interest in ECT. Most of this had been critical, uninformed, and anecdotal. The authors were stimulated to carry out the study following a British Broadcasting Company television program, in which we had both taken part and which had been edited in such a way as to be highly critical of ECT. In particular, it stressed that all of the patients whom the BBC team had interviewed had dreaded ECT and feared it more than anything else they had ever experienced. Bird (1979) attempted to assess the effect this program had on patients' attitudes,[1] in a small study carried out in Bristol, United Kingdom.

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 6 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 outpatient 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 semistructured interview based on a questionnaire. They were allowed to talk spontaneously about their views and experiences of ECT for about five minutes and were 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.

At that time the Royal Edinburgh Hospital admitted approximately 2500 patients per annum. In 1976, 714 had a diagnosis of some type of depression or of puerperal psychosis. Almost all fell into 3 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 1 in 15 inpatients received a course of ECT. ECT is little used as a treatment for other psychiatric conditions. At the time of the study bilateral ECT was routinely given unless the consultant specifically requested unilateral treatment. Very little outpatient ECT was given, though in a few cases ECT that had been started on an inpatient basis was continued on an outpatient basis.

ECT was given in two places in the hospital. In the main hospital a separate ECT suite was used and the 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 anesthetist. 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 1977–78, 12 were dead, 25 were over 70, and 27 had left the Edinburgh area. This left 119 people available for interview, of whom we interviewed 106 (89%). Sixty patients who had had ECT in 1971 formed a subsidiary sample. The two samples were analyzed 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, 3 were still in treatment at the hospital but refused to be interviewed for research purposes. All 3 were said by the

TABLE 1. Background Details of the Two Samples[a]

	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 treatments	52%	49%
25–50 treatments	12%	21%
51 or more treatments	5%	5%
Range of experience	1–75	1–93
Mean total of treatments ever received	16	18

[a] n = 183 for 1976, but only 106 interviewed; n = 60 for 1971.

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 1. 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.

TABLE 2. Percentage Distribution of Diagnosis for First Course of ECT[a]

	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

[a] n = 243 for 1976; n = 60 for 1971.

TABLE 3. Reason in Case Notes for ECT Ending[a]

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	0.5%
Major complication	0.0%
Other reason or not specified	3.3%

[a] $n = 183 + 60$.

The distribution about the mean was skewed. Over half those interviewed 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 2. 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 3. In 74% 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 a subsequent illness, and in two there was only a partial response, the depression continued, and suicide occurred 9 months and 11 months later.

In six cases death appeared to have been from causes entirely unrelated to ECT. They all occurred six 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 13th treatment. Postmortem showed a myocardial infarction. She had had one previous infarct. A 76-year-old woman also died 48 hours after her 13th ECT. Postmortem showed a myocardial infarction 24–48 hours old. Both patients were taking a tricyclic drug at the time.

Patients' Experiences of the Treatment

Details of this are given in TABLE 4. Only 21% of patients felt they had been given an adequate explanation of the treatment before it began. Forty-nine percent were sure

TABLE 4a. Adequacy of Explanation Given before Treatment[a]

	Percent
Adequate	20.6
No explanation	49.1
Inadequate	8.5
Misleading	0
Can't remember if any explanation given	12.1
Other	3
Don't know	6.6

[a] $n = 166$.

TABLE 4b. Do You Remember How You Felt before Your First Treatment?[a]

	Percent
Very anxious and frightened	16.3
Slightly anxious and frightened	23.5
No particular feelings	22.9
Reassured; pleased that treatment was starting	22.9
Can't remember	5.4
Other	5.4

[a] $n = 166$.

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 percent said that 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% described feeling very anxious or frightened and a further 23.5% feeling slightly anxious. Forty-six percent 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 said spontaneously they were afraid of the unknown or afraid of the anesthetic.

The responses to specific questions about brain damage, fear of epilepsy, worry about electricity, worry about being made unconscious, etc., are listed in TABLE 5. It can be seen that worry about possible brain damage was the most common fear, but even then 77% 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 4d), 50% of subjects felt that going to the dentist was more upsetting or frightening.

Specific parts of the treatment procedure, listed in TABLE 4c, seemed to arouse little feeling in subjects, and most found them neutral. We optimistically asked whether any aspect of the treatment was pleasant. Thirty-two percent of subjects thought that the sensation of falling asleep was a pleasant one, and 27% commented on the staff being pleasant. No aspect of the treatment was rated as unpleasant by more than 30% of the subjects.

Side Effects

Details of the side effects are given in TABLE 6. It should be noted that these are side effects remembered approximately a year afterwards.

TABLE 4c. Experience of Various Parts of the Treatment (Percentages)[a]

Aspect of Treatment	Pleasant	Neutral	Unpleasant	Don't Know
Premedication	2.4	77.1	15.7	4.8
Waiting for treatment in the morning	1.2	74.7	19.9	4.2
ECT staff	26.5	65.7	3.0	4.8
Anesthetic 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 a few hours after each treatment	6.0	69.9	17.5	6.6

[a] $n = 166$.

TABLE 4d. 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	80.0	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		3.0
	Less		52.7
	About the same		32.1
	Not upsetting at all		9.7
	Don't know		2.4

Twenty percent reported remembering no side effects whatsoever. Memory impairment was clearly the most troublesome, with 50% of the total sample mentioning this as the worst side effect. Forty-one percent mentioned memory impairment spontaneously when asked about side effects, and a further 23% when prompted, making 74 percent 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% of subjects. Fifteen percent of the total sample thought it was the most troublesome unwanted effect.

When asked to respond to a series of statements about ECT, 30% agreed with the statement that their memory had never returned to normal afterwards though 12% felt their memory was better now than it had ever been. Twenty-eight percent felt that ECT caused permanent change to memory, and 22% that ECT had no effect on memory at all. (See TABLES 7 and 8.)

There were single complaints of neck stiffness, skin burns, increased sweating, and

TABLE 5. Fears and Worries about ECT[a]

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 while 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%

[a]$n = 166$.

TABLE 6. Side Effects Remembered

Patients' Reports of Worst Side Effect	$n = 166$		$n = 243$[a]
	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	

[a]This column is side effects recorded at the time by the staff, for comparison.

muscle aches. One man complained of choking and said he had been too lightly anesthetized on one occasion.

Did Patients Find the Treatment Helpful?

Details regarding helpfulness of treatment are given in TABLE 9. Altogether 78% 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 quite upsetting and blamed his present state on ECT.

Although 78% of people said it had helped them, only 65% 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% said so. When asked if they would recommend it to a friend if a psychiatrist advised the friend to have it, 65% said yes, but 24% didn't know, and 11.4% said definitely no.

Few people believed that the effect of ECT had been permanent. Thirty-five percent believed the beneficial effects had lasted for a year or more, 15% that they had

TABLE 7. Patients' Estimates 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 8. Opinions on Memory Impairment

Statement	Responses		
	Agree	Disagree	Don't Know
My memory has never returned to normal after ECT	30%	61.3%	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 9. How Helpful Was the Treatment?[a]

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	9.0%
	1 year or more	34.9%
	6–12 months	15.1%
	Less than 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	20.0%
ECT gets you better quicker than drugs	Agree	65.6%
	Disagree	14.4%
	Don't know	19.4%

[a] $n = 166$.

lasted from six months to a year, 13% less than six months, and 2.4% thought they had relapsed immediately.

Did Patients Understand the Treatment?

Fifteen percent of those interviewed appeared to have a full understanding of what the treatment involved (see TABLE 10). They knew about the anesthetic, that the electrodes were applied to the head, and that the object was to produce an epileptic fit. Thirty percent had a partial understanding. They knew about the anesthetic, 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 while 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 medical electrode was implanted in the head during the treatment.

TABLE 10. Patients' Understanding of Treatment[a]

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%

[a] $n = 166$.

Patients' Consent to ECT

From the medical case notes, we determined that 76% of patients had signed the consent form themselves (TABLE 11). We tried to determine whether patients felt they had been coerced into having ECT, persuaded against their judgment, or compelled to have ECT when they definitely did not want it. Some patients (7.8%) 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 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 percent said that they wouldn't have been able to say no, either becau

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 percent 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% 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 pressured 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 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 11. Consent Procedure

1. Who signed the consent form? (n = 166)	
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% as against 8%. Slightly more men than women said that their memory had not been impaired at all (41% as against 32%), 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 percent said they wouldn't have ECT again (26% in bilateral group), 33% said it helped them a lot (61% in bilateral group), 28% thought they shouldn't have been given ECT (9% in 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:

1. ECT is dangerous and shouldn't be used: agree 6.9%, disagree 76.9%, don't know 16.2%
2. ECT is given to too many people: agree 6.2%, disagree 30.6%, don't know 63.1%
3. ECT is often given to people who don't need it: agree 8.7%, disagree 29.4%, don't know 61.9%.

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 was a significant number of people in the midground 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% 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 would certainly be well worthwhile repeating the study now that nearly all of the patients in our hospital get unilateral, nondominant ECT.

We feel more confident about our results than we did in 1980 because two further studies have found strikingly similar results. Kerr *et al.* (1982) interviewed 178 subjects and compared three groups: patients who had had ECT, individuals visiting patients in hospital who had had ECT, and individuals visiting non-ECT patients.[6] Many of the results were similar to ours, and there was a general tendency for those patients who had had ECT to be less afraid and feel more positive about the treatment than either of the visitor groups. Hughes and Barraclough (1981) used a questionnaire based on our own and interviewed a sample in Southampton, United Kingdom, at the opposite end of the country to Edinburgh.[5] Their results were strikingly similar to ours.

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[2] and had 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 preexisting 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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