

RESEARCH AND EVALUATION

Eliciting users' views of ECT in two mental health trusts with a user-designed questionnaire

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Abstract

**Background:** Users' views of the process of ECT have not been systematically assessed in prospective studies.

**Aims:** (i) To determine the ability of a questionnaire to quantify user satisfaction with ECT; (ii) to elicit users' views of the treatment process; and (iii) to compare findings across two mental health trusts.

**Method:** A self-report questionnaire was designed by a mental health service user group and sent to all patients completing a course of bilateral ECT during the study period. Scored items covered preparation for treatment, information giving, consent and adverse effects. Non-scored items included questions on compulsion, previous ECT and intention to accept future treatment. Open-ended comments were invited and analysed qualitatively.

**Results:** The response rate was 41%. Users having ECT for the first time and those reporting they would 'never have ECT again' had lower care satisfaction scores and higher adverse effect scores than those who had had ECT before and those who were prepared to have ECT again. Mean care satisfaction scores differed significantly between the two trusts but reported levels of adverse effects were similar, and high, in both.

**Conclusions:** Prospective research with a user-designed scale may elicit more critical responses than clinician-designed scales used in previous studies.

**Declarations of Interest:** None

**Keywords:** ECT, user involvement, adverse effects, satisfaction.

Introduction

'Doctors who give electroconvulsive therapy (ECT) have shown remarkably little interest in their patients' views of the procedure and its effects on them' (Abrams, 1997). However, in more recent years attitudes appear to be changing (Abrams, 2002). Conventional research studies on this issue have concerned themselves either with the 'attitudes' of users towards ECT (Baxter, Roy-Byrne, Liston, & Fairbanks, 1986; Benbow, 1988; Bernstein, Beale, & Kellner, (1988); Calev et al., 1991; Cowley, 1985; Fox, 1993; Goodman, Krahn, Smith,

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No relation  
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Rummans, & Pileggi, 1999; Hillard & Folger, 1977; Kerr, McGrath, O'Kearney, & Price, 1982; Pettinati, Tamburello, Ruetsch, & Kaplan, 1994; Riordan, Barron, & Bowden, 1993; Wheeldon, Robertson, Eagles, & Reid, 1999) or the adverse effects of ECT (Freeman & Kendall, 1980; Gomez, 1975; Hughes, Barraclough, & Reeve, 1981), rather than the users' overall experience of the procedure. Studies have employed either questionnaire or interview methods but in every case these have been constructed by the researchers involved (National Institute of Clinical Excellence, 2003).

A number of surveys, published independently, have been carried out by user organizations (ECT Anonymous, 1999; MIND, 1993, 1995; Peddler, 2000; Rogers, Pilgram, & Lacey, 1993; United Kingdom Advocacy Network, 1996). However, these surveys have been criticized for the subject selection methods used that might have accounted for the usually negative responses and high rates of adverse effects reported (Wheeldon et al., 1999).

For some years we have attempted to collect outcome data from the consultant psychiatrists of users recently completing ECT with the purpose of compiling a central database on perceived clinical outcome, adverse effects and reasons for treatment termination. During an ECT audit presentation, service user representatives suggested that users receiving ECT should be similarly surveyed. This led to the development of a questionnaire by representatives from the service user group, Communicate, which was intended to form part of the routine practice of the ECT clinic in order to provide information about users' views and use this to inform ECT practice. The present study aimed (i) to determine the ability of the questionnaire to quantify user satisfaction with ECT; (ii) to elicit more general comments related to users' experiences of ECT, (iii) compare the findings in two mental health trusts in SE London employing different protocols for informing patients about the treatment

## **Method**

### *Participants*

Users completing a course of bilateral ECT at the Bethlem Royal and Maudsley Hospitals (MH), Bexley and Greenwich Hospitals (Oxleas Trust; OT) between April 1999 and June 2000 were invited to take part in a postal questionnaire survey. At the time of the study, users at MH were given verbal information about ECT prior to consent and pamphlets designed in-house were available on request. At OT, each user was given the Royal College of Psychiatrists information booklet before consent was obtained. At the time of the study, unilateral ECT was rarely prescribed in either of the Trusts.

### *Procedure*

The 20 item questionnaire was constructed by members of Communicate (the users' group at the Maudsley Hospital). For scoring purposes, the questionnaire was divided into two sections. The Care Satisfaction Scale covered the preparation for treatment, the information given, consent issues, benefits and aftercare. Most questions allowed for one of three responses. For example, 'Do you think you made a fully informed decision to have ECT?' – 'yes' (score 2), 'possibly' (score 1), 'no' (score 0). Each question was followed by an open-ended comments section. The Adverse Effects Scale, in a checklist format, was based on previous literature and patients were asked to indicate whether or not they had experienced the symptom (scoring 1 for 'yes' or 0 for 'no'). An open section allowed for the addition of



other symptoms. A number of additional items were included but not scored: whether adverse symptoms had persisted, whether any stigma had been felt as a result of having had ECT, an opened-ended item concerning the user's understanding of why they had been given ECT, the types of care they had received after ECT, whether they had had ECT before and whether they would have it again. These items were used in the qualitative analysis. At the suggestion of the local research ethics committee, the inclusion of the respondent's name was left optional and no demographic information was sought in order to preserve the respondents' confidentiality. However, an open comments section allowed respondents to add any personal details they wished. The full text of the questionnaire is given in the Appendix.

The questionnaire, a covering letter from Communicate and a pre-paid envelope were posted by the ECT Coordinators to the users' home address, approximately 6 weeks after the last treatment session. The covering letter described the rationale for the study and its origin and listed phone numbers of user groups and help lines. In the case of users who had not left hospital, the ECT Nurse Coordinators in each hospital trust delivered the questionnaire and the covering letter by hand to the users on their wards. In some cases, the ECT Coordinator assisted the user in completing the questionnaires by reading it to them. Completed questionnaires were returned to the ECT Coordinator (at MH) and the Audit Department (at OT).

#### *Data analysis*

Analysis of variance (with Scheffe's post hoc test) was used to compare mean scale scores, whether or not respondents had had ECT before, whether they had received written information about ECT and whether they would have ECT again.  $\chi^2$  and Fisher's exact tests were used to examine differences in nominal data between the two hospital trusts. Logistic regression was used to determine the variables associated with the decision not to have ECT again.

Content analysis (Bauer, 2000) of the respondents' comments was made to identify common themes and concerns. Although a 'qualitative' technique, content analysis includes frequency counts and the results are amenable to non-parametric statistical analysis. In addition, illustrative quotations which represented commonly occurring themes were compiled.

#### *Ethical approval*

The study was approved by the relevant local research ethics committees.

### **Results**

One hundred and eight people completed courses of bilateral ECT during the study period and were sent questionnaires. Table I shows the demographic and clinical data of all users receiving ECT during the study period. The only significant difference between the groups is that MH users were less likely to be White British ( $p = .001$ ). There was a tendency for MH users to be more likely to be detained under the Mental Health Act but this did not reach significance.

Forty-four questionnaires were returned completed (response rate 41%) and 34 included the respondent's name. Two questionnaires were returned blank, three users declined to accept questionnaires handed to them and two died before receiving the questionnaire. Nine users completed the questionnaires with the aid of a nurse.

Table I. Demographic and clinical data of all patients receiving bilateral ECT during the study period in each hospital trust

	Bethlem & Maudsley Trust (MH) N = 53	Oxleas Trust (OT) N = 55
% Women	83	75
% White British	71	96
% Patients detained under the Mental Health Act	26	12
% Patients returning completed questionnaires	38	44
% Patients returning named responses	26	36
Mean age (SD), years	61 (15)	63 (14)

### Quantitative analyses

Table II shows the mean scores on the Care Satisfaction Scale and the Adverse Effects Scale. Two respondents left several of these questions unanswered and their results were not included in the following analysis. Care Satisfaction Scale scores were significantly lower for users receiving the treatment for the first time ( $p = .032$ ), those who did not receive written information prior to treatment ( $p < .001$ ) and those who reported that they would definitely not have ECT again ( $p = .016$ ).

Scheffe's post hoc test revealed that those indicating that they would definitely not have ECT again had significantly lower scores on the Care Satisfaction Scale ( $p = .024$ ) and higher Adverse Effect Scale scores ( $p = .033$ ) than those responding 'possibly' or 'yes'. Those respondents who said they had had ECT before were more likely to say they would agree to it again ( $\chi^2 = 4.91$ ;  $df = 1$ ;  $p < .05$ ). Those receiving treatment at MH had lower Care Satisfaction Scales ( $p = .007$ ). No differences were found in the rate of adverse symptoms between the two trusts (Table III). There were no differences in mean Care Satisfaction Scale and Adverse Effect Scale scores between patients who perceived they had benefited from ECT and those who stated they had not. Of the patients giving their names, those stating they would never have ECT again were significantly younger than the remainder ( $54.8 \pm 16.1$  years vs.  $66.4 \pm 13.2$  years;  $F = 5.26$ ,  $df = 1, 42$ ,  $p = .0286$ ).

Logistic regression analysis confirmed that the decision to 'never' have ECT again was associated with lower Care Satisfaction scores (Exp.  $\beta = 0.853$ ,  $p = .015$ ) and higher Adverse Effect scores (Exp.  $\beta = 1.446$ ,  $p = .036$ ). A history of previous ECT, receipt of written information before treatment, and the hospital trust involved were not variables in the equation. The final model was as follows:  $-2 \text{ Log Likelihood ratio} = 38.66$ ,  $\chi^2 = 15.18$ ,  $p = .001$ .

### Qualitative analysis

Four main themes emerged from the content analysis.

#### 1. Relationship between previous ECT and future consent to ECT

Fourteen (74%) of respondents who stated they would definitely have ECT again if prescribed had had ECT before. The association was stronger in OT (10 out of 11; 91%) than in the MH (5 out of 8 63%). The impression is of a cohort of users in OT for whom ECT is a routine treatment that they are used to receiving (10 users out of 23 valid responses). Only four of the total 19 people who had ECT for the first time said they would definitely have it again, one commenting that she would if she thought it would do any good, which it had not on this occasion. Two commented that they had previously found ECT

Table II. Mean Care Satisfaction and Adverse Effect Scale scores comparing hospital trusts and clinical groups

	N	Scale scores mean (SD)	F	df	p
Care Satisfaction Scale <sup>1</sup>					
Bethlem-Maudsley Trust	19	11.5 (6.8)	7.96	1	.007
Oxleas Trust	23	16.9 (5.6)			
'Was this the first time you had ECT?' <sup>2</sup>					
Yes	19	12.0 (7.4)	4.92	1	.032
No	22	16.5 (5.5)			
'Did you receive written information?'					
Yes	18	19.2 (5.1)	27.1	1	>.001
No	24	10.4 (5.6)			
'Would you ever have ECT again?' <sup>2</sup>					
Yes	17	17.1 (6.7)	4.64	2	.016
Possibly	7	16.6 (3.8)			
No	17	10.9 (6.4)			
Adverse Effects Scale					
Bethlem-Maudsley Trust	20	4.4 (2.6)	1.09	1	.302
Oxleas Trust	24	5.3 (3.0)			
'Was this the first time you had ECT?' <sup>2</sup>					
Yes	19	5.1 (2.9)	0.03	1	.876
No	24	4.9 (2.8)			
'Did you receive written information?'					
Yes	18	5.3 (3.1)	0.514	1	.478
No	24	4.7 (2.5)			
'Would you ever have ECT again?' <sup>2</sup>					
Yes	19	3.7 (2.4)	3.71	2	.033
Possibly	7	5.0 (2.7)			
No	17	6.2 (3.0)			

<sup>1</sup>Two respondents left several items unanswered.

<sup>2</sup>One respondent left these items unanswered.

Table III. The proportion of ECT respondents reporting adverse effects at each hospital trust

Proportion reporting adverse effect	Bethlem-Maudsley Trust N=20 (%)	Oxleas Trust n=24 (%)	Fishers' exact test p
Memory disturbance	70	88	.261
Headaches	35	42	.760
Muscle pains	0	4	1.000
Muscle spasm	0	8	.493
Nausea	10	13	1.000
Confusion	60	71	.532
Drowsiness	55	46	.563
Weakness	35	17	.185
Loss of intelligence	35	46	.547

helpful in lifting depression but now found the adverse effects too disabling. "I used to find ECT very helpful in lifting my depression but the last two times I have had a lot of side effects."

## 2. The feeling of compulsion

Feeling compelled to have ECT was defined as checking both that one did not make a fully informed decision and that there was pressure or force to have it. Respondents

soon after? yes  
when?

commented, "I did not think I could refuse", or "The decision was made by others." Question 3 was not included in the definition of felt compulsion because it is clear that different respondents interpreted this question differently. Some reported being given no alternative by staff whereas others felt themselves that there was no alternative, either because ECT had worked before or because they were at the end of their tether, and prepared to try anything (cf. Johnstone, 1999).

Thirteen respondents met the definition of feeling compelled by the hospital to have the treatment. From the general comments section, only one of these was treated under a Section 58 of the MHA. Thus 12 respondents felt compelled to have the treatment even though they were not legally compelled.

As noted above, 19 of the respondents had had ECT for the first time. Nine of these (47%) felt they were compelled, seven being MH patients. Only two would countenance ECT again so it is therefore possible that these were people who resisted the treatment but felt the doctors were ultimately right in prescribing it. However, the figures suggest that most of those, in both hospitals, who were faced with a new treatment which they felt under pressure to accept with insufficient information, believed that the doctors made the wrong decision. Two of these individuals were very angry. One wrote: "It made me incontinent and screwed up my brain. I didn't know that my mother was dead until 9 or 10 months ago."

The other was a medical professional herself who had consulted widely about whether to have the treatment. She was "...very against it as I had seen ECT performed..." but felt that she had been "gently persuaded". Though reporting that she had tried to inform herself she felt at the end of the day the information was wrong because the treatment did not work and she had memory loss. Both of these respondents were very concerned about stigma, the doctor having great difficulty hiding her treatment from family and colleagues which was what she wished to do.

The other side of this pattern was that no-one who had had previous ECT, and reported they were happy to have it again in the future, felt any compulsion on this occasion.

### 3. Persistent adverse effects

As well as being asked about side-effects around the time of treatment, users were asked if any side-effects had persisted. Memory loss was the side-effect reported most frequently. "I have lost many memories." "Not just short-term memories but long term memories." "I have holes in my memory." "I have lost many memories. I don't know if it's the depression or the ECT. I also lost smell and taste."

Of the 22 respondents who reported persistent adverse effects, 18 focused on memory loss. One of these also reported nightmares and "a new fear of hospital". Others reported long-term problems were flashbacks, headaches, tremor and extreme dizziness "every day", each reported once. One person said they experienced persistent side effects but did not specify what these were.

The denominator consisted of 40 valid responses. Thus 45% of users reported persistent memory loss and 55% reported general persistent side-effects (including memory loss). However, there were OT users who experienced persistent adverse effects but appeared to believe that this was either a cost worth bearing or something they had to put up with in order to relieve depression. There were others who thought that the costs outweighed the benefits and did not want the treatment again. (One respondent, who had had no relief from her depression, but also no adverse effects, made the ironic comment "So that means it must have worked, then!").

#### 4. Putting one's trust in doctors

There was a significant minority of users in this sample who felt that they had no option but to have ECT because it was the only treatment that had worked in the past, that they were too ill or too confused to make any other decision at the time, or that they simply trusted the doctors to do what was best. Many of these users reported long-term memory loss from ECT but appeared to either believe that this was the price one paid or just did not care. When asked to record, in their own words, why they had had ECT, half used lay language, "For my nerves", "To make me better", "I was brought into the Maudsley with a blackout". A few used the terms 'depression' or 'severe depression' but others wrote that they could not remember, or that the doctor had advised it. There was a single user in the group, of Asian background, who wrote that he did not know why he had had the treatment, did not know if he had had it before and did not answer the question about whether he would have it again. As a whole, those respondents giving their names were older than the remainder and may have been untouched by more modern cynicism about the medical profession in general.

The users discussed in section 2 represented the opposing picture. They felt compelled to have the treatment and many explicitly answered question 3 (the 'no alternative' question) by writing that "I was given no alternative", two of them contrasting this with the approach of their previous consultant. Most of these users replied that they would not have ECT again and most had never had it before. In between these two groups were those who had a range of reasons for being satisfied or not and accepting the treatment or not. It should not be surprising that service users had complex views about ECT since they must have assessed their own experience against the backdrop of what they were told about it and how they were treated before, during and afterwards.

### Discussion

This is the first prospective study of users' responses to ECT which is based on a questionnaire designed by ECT users themselves. Although the response rate (41%) was rather low, it is within the range for postal surveys and the questionnaire itself appeared to be acceptable to those who completed it. In particular, the open comments section which followed each question allowed users to elaborate on their experience and a significant number chose to use this to say more about their positive or negative experience of ECT.

A substantial minority of users reported that they would not countenance ECT again, and the factors associated with this view were the feeling of compulsion, poor pre-treatment information and a higher number of adverse events. The adverse effect profiles showed a high prevalence of adverse effects, with two thirds of respondents reporting memory disturbance or confusion at the time of treatment and nearly half permanently.

#### *Relation of present study to previous work*

Rose, Wykes, Leese, Bindman, & Fleischmann (2003) have reviewed all studies attempting to ascertain users' views on ECT. This included 26 clinical studies and nine studies carried out by user groups or in collaboration with them. In the clinical attitude studies the range of users saying ECT had helped them was 56–82% whilst in the user studies the range was 28–43% (16 studies examined this question). On whether the user would have ECT again, the range for clinical studies was 59–98% although this last figure (Pettinati et al., 1992) should be treated with caution as it was the sum of two proportions. Only two user-led or collaborative studies provided information on whether users would have ECT again. The



United Kingdom Advocacy Network (1996) gives a figure of 18% and MIND (Peddler, 2000) a figure of 30%.

This suggests that there is no overlap between clinical and consumer studies on the question of benefit (although confidence intervals do overlap). A possible reason for this (Wheeldon et al., 1999) is that whilst clinical studies used prospective or retrospective designs, consumer studies have been surveys and it has been suggested that only those opposed to the treatment would be motivated to complete them. The present study is the first prospective one to be undertaken in collaboration with users. This indicates that consumer studies may elicit a different response to clinical ones even when traditional sampling methods are used. The present investigation lies closer to the range of consumer and collaborative work than it does to clinical studies on the question of helpfulness of ECT.

In the review by Rose et al. (2003) several methodological factors were found to predict satisfaction rates, including who did the interview or survey and in what setting. In many clinical studies, patients were interviewed on the ward by the treating doctor and this arrangement was associated with high satisfaction scores. It can therefore be suggested that since the present questionnaire came with a covering letter from the Communicate user group together with information on other user groups and that the questionnaire was usually completed in a setting of the user's choice, the lower levels of satisfaction that were found compared to any other prospective design is due to these factors. This argument is supported by findings from randomized designs (Clark, Scott, Boydell, & Goering, 1999; Polowycz, Brutus, Orvietto, Vidal, & Lipriana, 1992) which found that service users were more critical about treatments and services when interviewed by a fellow user. Further large scale studies are needed to elucidate whether the higher rates of dissatisfaction in consumer studies are a genuine and truer reflection of user views of ECT or simply a reflection of who responds.

Another variable which may determine satisfaction rate with ECT is the length of time that elapsed between treatment and being interviewed or completing a survey, which Rose et al. (2003) found to be the most significant methodological variable. The longer the interval, the less likely the user was to want ECT again. The present study had a shorter interval than either of the other user-led or collaborative studies and this could also be a reason why the figures are higher. If this is true the interval since treatment is a significant factor in all kinds of data—clinical attitude studies, user-led and collaborative studies and first-hand accounts. This finding may have implications beyond that of the specific field of ECT. For example, most drug trials have a follow-up period of 2 months or less.

There is evidence that adverse effects occur less often in patients receiving unilateral ECT (Hughes et al., 1981; Lisanby, Maddox, Prudic, Devanand, & Sackeim, 2000). Our study was limited to patients receiving bilateral ECT as that treatment methodology was the one employed for nearly all patients receiving ECT in the hospitals involved at the time of the study. This might also have accounted for the relatively high adverse effect scores and proportions of patients with persistent problems. However, it is our experience that users—and many psychiatrists—do not discriminate between bilateral and unilateral electrode application as a significant issue and consider ECT to be a uni-modal treatment.

Significantly, there was no association between the perceived helpfulness of ECT and the side-effect of memory loss or the findings of felt compulsion. These findings are consistent with other studies (Rose et al., 2003). Authors do, however, differ in how they interpret these figures. Of particular interest here is the more detailed analysis we were able to make about felt compulsion. It appears that some users have true faith in their doctors to do what is best and are quite happy with this. This is supported by the finding that those who have had ECT before are more willing to have it again. Others put their faith in doctors only to feel let down, and sometimes quite strongly (c.f. Johnstone, 1999). Yet others feel that they



have to do what the doctor says despite strong misgivings only to find that the treatment was not beneficial, had disabling side-effects and led to feelings of stigma. People in this position often covered their questionnaires with angry comments and they were twice as likely as the remainder to say that they would never have ECT again.

While this study provides valuable information, a major limitation was the absence of demographic details which was required by the local research ethics committee in order to preserve respondents' anonymity in the light of users' involvement with the study. However, our impression is that older people were more satisfied (despite perhaps experiencing more adverse effects) with ECT than younger users, perhaps as a result of previous beneficial experience or being more compliant with treatment. This is consistent with previous clinical surveys of older people treated with ECT (Benbow, 1988).

The low response rate to our postal questionnaire was also an issue. Higher participation, and consequently greater generalizability, might well have been obtained using direct interview methods (e.g. Wheeldon et al., 1999) but a larger study is now required to further examine the properties of the user-designed questionnaire, to determine, for example, whether it is sensitive to change occasioned by improvements in care. In the light of the recent imperative set within the UK by national guidance on ECT (National Institute of Clinical Excellence, 2003) user views will become an integral part of service provision and future planning.

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## Appendix

## Communicate Asking Patients about ECT (CAPECT)

Thank you for agreeing to complete this questionnaire. Please answer each question by circling one of the answers. There is space after each question for you to make additional comments if you wish (*not included in example*).

1. Why did you have ECT? .....	score:	2	1	0
2. Were other treatments offered to you before you had ECT? e.g. medication, talking therapies etc.		yes		no
3. Did you feel that you had no alternative but to have ECT?		yes		no
4. Did ward staff explain to you what would happen during ECT?		yes	partly	no
5. Did ward staff explain the possible side effects of ECT?		yes	partly	no
6. Did you receive any written information about ECT? e.g. hospital booklet or MIND booklet		yes		no
7. Did you have enough time to think about ECT and discuss it with your doctor or nurse before agreeing to the treatment?		yes	partly	no
8. Did you discuss your decision with anyone else? e.g. family, friends or other patients		yes	partly	no
9. Do you think you made a fully informed decision to have ECT?		yes	possibly	no
10. Did you feel pressurised or forced to have ECT?		yes	possibly	no
11. Do you think ECT helped you?		yes	partly	no
12. Do you think you were properly cared for after ECT? e.g. did anyone spend time with you if you felt confused or distressed		yes	partly	no

## Care Satisfaction Scale Total

11. Did you have any side-effects soon after the treatment? (Please circle any of the side effects you had).

memory disturbance	headaches	muscle pain	muscle spasm	nausea
confusion	drowsiness	weakness	loss of intelligence	

Any other side effects .....

## Adverse Events Scale Total (score 1 for each)

(N.B. The remaining items are not scored)

12. Do you still have any side-effects?	yes	partly	no
13. Did those caring for you take your side-effects taken seriously?	yes	partly	no
14. Did you have enough time to discuss any concerns you may have had since you had ECT?	yes	partly	no
15. What follow-up care have you had since you had ECT? e.g. in-patient, out-patient, home visits?			
16. Do you feel any stigma as a result of having had ECT?	yes	possibly	no
17. Was this the first time you had ECT?	Yes		no
18. Would you ever have ECT again?	yes	possibly	no