

# Papers

## Patients' perspectives on electroconvulsive therapy: systematic review

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### Abstract

**Objective** To ascertain patients' views on the benefits of and possible memory loss from electroconvulsive therapy.

**Design** Descriptive systematic review.

**Data sources** Psychinfo, Medline, Web of Science, and Social Science Citation Index databases, and bibliographies.

**Study selection** Articles with patients' views after treatment with electroconvulsive therapy.

**Data extraction** 26 studies carried out by clinicians and nine reports of work undertaken by patients or with the collaboration of patients were identified; 16 studies investigated the perceived benefit of electroconvulsive therapy and seven met criteria for investigating memory loss.

**Data synthesis** The studies showed heterogeneity. The methods used were associated with levels of perceived benefit. At least one third of patients reported persistent memory loss.

**Conclusions** The current statement for patients from the Royal College of Psychiatrists that over 80% of patients are satisfied with electroconvulsive therapy and that memory loss is not clinically important is unfounded.

### Introduction

Electroconvulsive therapy is generally indicated for depression that is resistant to treatment. The procedure, which involves the application of electrodes to the head to induce a convulsion, is carried out under general anaesthetic. Although electroconvulsive therapy is less commonly used today than in the past, over 11 000 patients receive it in England annually.<sup>1</sup> Nearly one fifth of patients receive treatment under a special section of the Mental Health Act 1983.

The Royal College of Psychiatrists' fact sheet states that more than eight out of 10 depressed patients who receive electroconvulsive therapy respond well.<sup>2</sup> "Electroconvulsive therapy is the most effective treatment for severe depression and people ... report that it makes them feel 'like themselves again' or that 'life is worth living.'"<sup>2</sup> Although reviews on attitudes to electroconvulsive therapy in the 1980s concluded that patients found treatment beneficial and that they were satisfied with it, this is currently opposed by individual patients and groups.<sup>3,4</sup> We aimed to examine the

sources of this controversy and to assess the debated distinctions between efficacy, effectiveness, and satisfaction.<sup>5</sup> Efficacy is restricted to what can be measured in a controlled clinical trial, often over a short period. It will not necessarily predict the effectiveness of a treatment in a real life situation, still less will it predict satisfaction. For instance, a systematic review of randomised controlled trials investigated evidence of the efficacy of electroconvulsive therapy as measured by symptom scales completed by a mental health professional.<sup>6</sup> But these ratings may not be the same as perceptions of relief of symptoms by patients themselves. For example, in one study similar numbers of patients were regarded as improved by themselves and by health professionals, but in 20% (n=13) of cases these were different individuals.<sup>7</sup>

Patients' perceptions of benefit are likely to be based on broader considerations than just the relief of symptoms. They may take into account the amount and length of time symptoms are relieved (clinical benefit) as well as any side effects. One side effect is memory loss. The Royal College of Psychiatrists' fact sheet states that while memory of recent events may be affected by electroconvulsive therapy, "in most cases this memory loss goes away within a few days or weeks although some patients continue to experience memory problems for several months. As far as we know, electroconvulsive therapy does not have any long term effects on your memory or intelligence."<sup>2</sup> Some patients, however, report severe and longlasting memory losses after electroconvulsive therapy, and these will influence decisions on the risks and benefits of treatment.

Despite these disagreements there has been little systematic study of patients' views about the effectiveness and safety of electroconvulsive therapy. We aimed to ascertain patients' attitudes on the perceived benefit of treatment, as distinct from clinically rated outcome, and reported memory loss after treatment.

### Methods

We searched the databases Psychinfo, Medline, Web of Science, and the Social Science Citation Index for papers and reports of patients' views on treatment with electroconvulsive therapy (see [bmj.com](http://bmj.com) for search terms). Bibliographies were also hand searched. Articles were excluded that concerned lay or

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professional opinion, children or adolescents, or where not all the patients had received treatment.

Of the 27 papers identified, 26 were authored by academics or researchers and conducted in psychiatric facilities. A reference group enabled us to identify nine reports written either by patients or in collaboration with them. The work of Communicate, the user group at the Maudsley hospital, is awaiting publication, but we had access to its raw data. Although our searches included global sources, articles written by patients were confined to the United Kingdom in all but one case.

### Analysis

We calculated the proportion of patients with positive responses to questions on effectiveness of treatment and the 95% confidence intervals. Positive responses were defined as an affirmative response to the statements "electroconvulsive therapy is helpful" or "I would have electroconvulsive therapy again." A Forrest plot was produced on the raw (proportion) scale as to whether electroconvulsive therapy was considered helpful, with normal approximation standard errors.

The research studies were rated on four methodological variables. These were selected from either previous research (setting and interviewer), preliminary analysis of the data (interval between treatment and interview), or the social science literature.<sup>8</sup>

#### Interval between treatment and interview

We considered the interval between treatment and interview because the benefits of treatment may be short lived and side effects only apparent later. The scores were: 0 for during course of treatment or maintenance treatment; 1 for within four weeks or predischage; 2 for 1-6 months; and 3 for more than six months.

#### Number of questions

As a few brief questions are likely to produce less engagement than a more exploratory list of questions, we scored: 1 for five or less questions; 2 for 6-14 questions; and 3 for 15 or more questions.

#### Complexity of interview

With simple response options there was less scope for patients to express their opinions whereas multiple choice questions or semistructured interviews allowed more complex opinions to be recorded. The scoring system was: 1 for dichotomous responses; 2 for simple Likert scales; 3 for complex Likert scales or multiple choice; and 4 for a semistructured interview.

#### Setting of interview and status of interviewer

Conducting an interview has been shown to influence the willingness of patients to be critical about services.<sup>9</sup> They are more likely to be critical when interviewed by a fellow patient in a neutral setting. Because the setting and status are always highly correlated, we amalgamated them into one category. The scoring system was: 1 for inpatients; 2 for same hospital or treating doctor; 3 for non-treating doctor or at home; 4 for day care or voluntary sector; and 5 for source independent of health services, and choice of setting.

Logit models were fitted to assess associations between positive responses and methodological characteristics and the distinction between clinical and patient studies. SPSS version 10 and Stata version 7 were used for the analyses.

## Results

In 16 studies patients were asked if they found electroconvulsive therapy helpful and in 12 studies they were

**Table 1** Details of perceived benefit of electroconvulsive therapy, date, sample size, and four scored methodological variables of studies eliciting patients' views on treatment. Values are numbers (percentages; 95% confidence intervals) of patients unless stated otherwise

Study	Country	Sample size	Perceived benefit of treatment		Methodological variables			
			Helpful	Would have again	Interval since treatment*	No of questions†	Complexity of interview‡	Setting or interviewer§
Freeman and Kendell 1980 <sup>10</sup>	United Kingdom	166	129 (78; 71 to 84)	98 (59; 51 to 67)	3	3	4	2
Hughes et al 1981 <sup>7</sup>	United Kingdom	72	59 (83; 73 to 91)	52 (72; 60 to 82)	2	3	2	2
Kerr et al 1982 <sup>11</sup>	Australia	88	64 (73; 62 to 82)	Not available	2	3	1	3
Aperia 1986 <sup>12</sup>	Norway	30	21 (70; 51 to 85)	19 (63; 44 to 80)	3	2	3	2
Benbow 1988 <sup>13</sup>	United Kingdom	54	39 (73; 58 to 84)	37 (69; 54 to 80)	1	3	2	1
Szuba et al 1991 <sup>14</sup>	United States	25	19 (76; 55 to 91)	18 (72; 51 to 88)	1	1	2	1
Rogers and Pilgrim 1993 <sup>15¶</sup>	United Kingdom	231	99 (43; 36 to 50)	Not available	3	3	3	4
Riordan et al 1993 <sup>16</sup>	United Kingdom	37	21 (56; 39 to 73)	25 (67; 50 to 82)	2	3	4	3
Pettinati et al 1994 <sup>17</sup>	United States	78	Not available	76 (98; 91 to 100)	1	1	1	1
United Kingdom Advocacy Network 1995 <sup>18¶</sup>	United Kingdom	308	92 (30; 25 to 36)	55 (18; 14 to 23)	3	3	2	5
Mental Health Foundation 1997 <sup>19¶</sup>	United Kingdom	107	32 (30; 21 to 40)	Not available	3	2	3	5
Bernstein et al 1998 <sup>20</sup>	United States	52	43 (83; 70 to 92)	41 (79; 65 to 89)	0	2	1	1
ECT Anon 1998 <sup>21¶</sup>	United Kingdom	200	58 (29; 23 to 36)	Not available	3	Not given	Not given	5
Wheeldon et al 1999 <sup>22</sup>	United Kingdom	150	121 (81; 74 to 87)	115 (77; 70 to 84)	1	1	1	1
Goodman et al 1999 <sup>23</sup>	United States	24	Not available	20 (82; 63 to 95)	0	3	1	2
Pedler (MIND) 2000 <sup>24¶</sup>	United Kingdom	418	150 (36; 31 to 41)	Not available	3	3	3	4
Manic Depression Fellowship 2002 <sup>25¶</sup>	United Kingdom	97	29 (30; 21 to 40)	Not available	3	3	3	5
Communicate¶	Pending	45	20 (44; 30 to 60)	18 (41; 26 to 56)	2	3	1	4

\*0=During course or maintenance electroconvulsive therapy; 1=within four weeks or predischage; 2=1-6 months; 3=more than six months.

†1=Five questions or less; 2=6-14 questions; 3=15 or more questions.

‡1=Dichotomous; 2=simple Likert scale; 3=complex Likert scale or multiple choice; 4=semistructured interview.

§1=Inpatient; 2=same hospital or same treating doctor; 3=non-treating doctor or at home; 4=voluntary or collaborative, day care or choice; 5=source independent of health services, choice of setting.

¶Patient study.

asked if they would have the treatment again (table 1). The level of positive responses varied widely between studies (tests for heterogeneity:  $\chi^2=370$ ,  $P<0.001$ , for treatment helpful,  $\chi^2=256$ ,  $P<0.001$  for would have treatment again). The Forrest plot for “helpful” shows that the patient led and collaborative studies report the lowest levels of positive responses; there was, however, an overlap in the confidence intervals (figure and table 1).

A funnel plot showed no evidence of publication bias among the clinical studies. No systematic relation was found between perceived benefit and the country, or region of the United Kingdom, where the research was undertaken.

**Methodological variables**

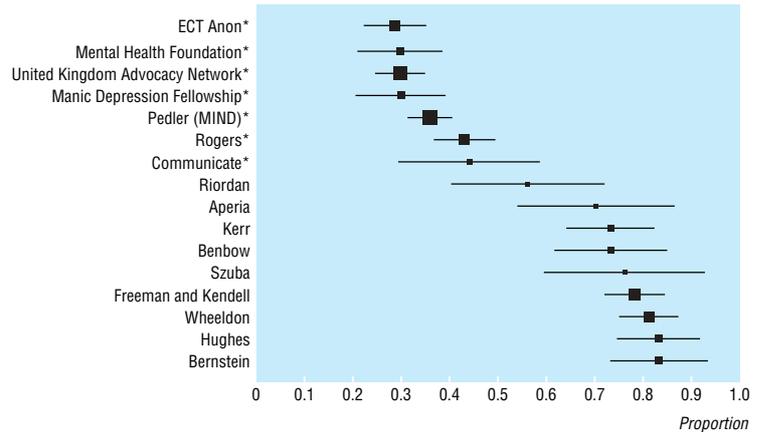
The number of questions, complexity of the interviews, and the interval before interview were intercorrelated (between number of questions and both the other two variables  $r=0.54$ , between interval and complexity  $r=0.75$ ). The clinical studies tended to use fewer questions, less complex schedules, and a shorter interval, although the difference in complexity was not significant (see table 1).

Studies where the interviews were conducted soon after treatment, in hospital settings, by the treating doctor, were more likely to report positive views of electroconvulsive therapy (table 2). Studies with low complexity schedules, few questions, and a short interval were also associated with high perceived benefit. In the case of treatment considered helpful there was a clear hierarchy in setting, as coded from studies of inpatients (coded 1) to studies based in the community (coded 5).

When the analyses were repeated for the clinical studies alone, the effects were in the same direction and of a similar magnitude. Because of reduced sample sizes, fewer associations were significant. Within clinical studies, the number of questions remained significantly associated with treatment considered helpful, and complexity and interval were associated with whether the patient would have treatment again. In multivariate models, only setting remained significant.

**Persistent memory loss**

Of the 35 studies, 20 considered memory loss as a consequence of electroconvulsive therapy. Thirteen were excluded because data were not given or the interval between treatment and questions about memory loss was less than six months. In four of the remaining studies, respondents were asked specifically whether they had experienced persistent or permanent memory



Proportions of patients who would find electroconvulsive therapy helpful, by study. Lines indicate approximate 95% confidence intervals; size of box indicates precision. \*Patient study

**Table 3** Numbers (percentages) of patients reporting memory loss, by study

Study	Memory loss	
	Strict definition*	Loose definition†
Freeman and Kendell 1980 <sup>10</sup>	48/166 (29)	131/166 (79)
Kerr et al 1982 <sup>11</sup>	26/88 (30)	—
Pedler (MIND) 2000 <sup>24‡</sup>	176/418 (42)	—
Squire and Slater 1983 <sup>26</sup>	17/31 (55)	—
Pettinati et al 1994 <sup>17</sup>	—	40/78 (51)
Communicate‡	—	23/45 (52)
United Kingdom Advocacy Group 1995 <sup>18‡</sup>	—	225/308 (73)

\*Persistent or permanent memory loss.  
 †Any memory loss reported.  
 ‡Patient study.

loss, and in four studies any reported memory problem was sought (one study reported on both; table 3).

The rate of reported persistent memory loss varied between 29% and 55%, but, unlike levels of perceived benefit, the rate did not seem to depend on whether studies were clinical or patient based, with relatively high levels being reported by both types of study.

**Discussion**

The methods used to elicit patients’ views on electroconvulsive therapy influence the reporting of perceived benefit and willingness to repeat treatment. Variation in levels of perceived benefit was also related to the source of the research. Patient led studies reported lower rates of perceived benefit than clinical studies. This might be attributed to a selection bias,

**Table 2** Associations between positive responses and methodological variables of patients’ responses to electroconvulsive therapy. Values are odds ratios (95% confidence intervals) unless stated otherwise

Study characteristic	Treatment helpful (n=16)	P value	Would have treatment again (n=12)	P value
Schedule*:				
Interval between treatment and interview (scale 0-3)	0.542 (0.491 to 0.597)	<0.001	0.482 (0.422 to 0.551)	<0.001
Complexity of interview (scale 1-4)	0.804 (0.733 to 0.880)	<0.001	0.918 (0.815 to 1.035)	0.161
No of questions (scale 1-3)	0.353 (0.288 to 0.433)	<0.001	0.508 (0.432 to 0.597)	<0.001
Setting†:				
Same hospital or treating doctor	0.861 (0.592 to 1.253)	0.435	0.727 (0.529 to 1.017)	0.063
Non-treating doctor or some at home	0.311 (0.154 to 0.629)	<0.001	0.863 (0.419 to 1.773)	0.688
Collaborative	0.198 (0.137 to 0.285)	<0.001	0.276 (0.146 to 0.530)	<0.001
Patient led	0.124 (0.092 to 0.169)	<0.001	0.090 (0.063 to 0.129)	<0.001

\*Per unit increase in scale.  
 †Compared with inpatient.

with patient studies only selecting people who were antagonistic to treatment. The study by Communicate, the user group at the Maudsley Hospital, is, however, a prospective one, where the interview schedule was clearly stated to come from a patient group. This study still reports lower rates of satisfaction than any of the clinical studies, indicating that even with a prospective design, patient led or collaborative research finds lower rates of satisfaction with treatment. Our findings suggest the difference may be attributed to a tendency for clinical studies to take place soon after treatment, to use medical assessors in clinical settings, and to use brief questionnaires with low complexity for responses.

Qualitative data collected as part of a wider review supports the above conclusions but show, in addition, how patients' views on electroconvulsive therapy are often complex. These data illuminate the way in which patients make decisions about electroconvulsive therapy by weighing the risks and benefits of treatment. Most of the studies we reviewed used simple response categories that did not allow this complex trade-off and other attitudes to be described. One hypothesis is that many patients are not simply for or against the treatment or even are neutral about it. The concept of satisfaction and its measurement are also subject to these criticisms of oversimplification. Future research should include qualitative measures with representative samples of patients who have received electroconvulsive therapy.

Electroconvulsive therapy is a complex intervention comprising many stages and the involvement of many staff. Patients may have varying views about these different stages. As the literature we reviewed relied on global ratings, however, it was not possible to investigate each stage independently. The exception was the information and consent stage, which will be reported later.

### Memory loss

Although the studies did not use consistent definitions or standardised ratings for memory loss, levels were between 29% and 79%. The levels were not determined by whether studies were clinician led or patient led, but the two types of study did differ in their analyses and interpretation of findings. Patient led research typically presents numerical results and illustrates these with quotations to show what the data mean in terms of patients' lives, whereas clinical researchers tend to undertake further statistical analysis of the data, sometimes ignoring the original data. For example, one study asked participants to assess the statement that "electroconvulsive therapy permanently wipes out large parts of memory."<sup>11</sup> The study then reported that people who had never received treatment were more likely to endorse this statement than those who had received it. It did not, however, comment on the finding that one third of those who had received treatment agreed with the strongly worded statement.

Another study controlled for depression in the analyses and found that memory loss continued to be significant.<sup>27</sup> Nonetheless, the authors concluded that long term memory loss was an important problem for only a small group of people and were doubtful about the causative role of electroconvulsive therapy.

The findings relate to the experience of persistent memory loss. Routine neuropsychological tests have

### What is already known on this topic

Around 11 000 people receive electroconvulsive therapy in England annually

Controversy exists as to whether treatment is beneficial and whether patients are satisfied with it

Patients' views have never been systematically reviewed

### What this study adds

At least one third of patients report significant memory loss after treatment

Routine neuropsychological tests to assess memory do not address the types of memory loss reported by patients

Reported patient satisfaction with electroconvulsive therapy depends on the methods used to elicit a response

been used in studies of electroconvulsive therapy to establish objective measures of memory loss and concluded that there was no evidence of persistent memory loss. It would seem that these are the studies on which the Royal College of Psychiatrists based its findings. The studies, however, typically measure the ability to form new memories after treatment (anterograde memory). Reports by patients of memory loss are of the erasing of autobiographical memories or retrograde amnesia. Thus the risks reported by patients do not appear in clinical assessments.

### Controversy between medical opinion and patient organisations

We found possible sources of controversy between professional bodies and some patients and patient organisations. The levels of perceived benefit differed between patient led and clinician led studies because different methods were used and because in many cases these methods did not allow an adequate description of the complexity of subjective experience. Even where findings, such as persistent memory loss, did not differ between patient led and clinician led studies, the interpretations may have differed radically. It is therefore not surprising that disputes can arise between professionals and patients and that organisations should emerge that provide support and a forum for those who feel their treatment has not been beneficial.

### Conclusion

Although clinical trials concluded that electroconvulsive therapy is an effective treatment,<sup>5</sup> measures of efficacy did not take into account all the factors that may lead patients to perceive it as beneficial or otherwise. Studies of treatment are needed that are able to investigate a range of outcomes valued by patients. Important among these are factors that impact on effectiveness and satisfaction. Also important is loss of autobiographical memory, which is widely described but insufficiently systematically investigated.

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