Patients’ experiences of and attitudes towards ECT

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Since its introduction electroconvulsive therapy (ECT) has received varied responses from the public and the media. Even though it is an effective treatment, its use has been restricted to very few serious psychiatric disorders. In this paper, Dr Guruvaiah and colleagues capture patients’ and their carers’ positive experience and attitude towards ECT following their treatment, which can act as reassurance for patients undergoing this efficacious therapy.

ECT is a recommended treatment option for various psychiatric disorders, including severe depressive illness, catatonia and a prolonged or severe manic episode. Even though it has been in use since the 1930s, over the years its use has been restricted to fewer and more serious conditions. That may be due to the availability of various psychotropic medications, effective psychological treatment and, to some extent, the media’s negative coverage. Although ECT is a safe and effective treatment, it remains controversial due to misconceptions and negative attitudes amongst patients and their relatives and due to the ambivalence amongst professionals. However, a study conducted in Scotland in the 1970s revealed that the majority of patients did not find the treatment unduly upsetting or frightening, nor was it a painful or unpleasant experience. In that study, most of the sample felt ECT helped them and hardly any felt it made them worse. In general, most patients had a very positive view about ECT. However, it was clear that patients wish to be told more about the treatment. Since its publication in 1980, we could not find any similar published literature in the UK highlighting the experience and the attitudes of patients and carers towards ECT. In 2003, the Royal College of Psychiatrists introduced practice guidelines and standards for administering ECT to assure patients that they will be provided a quality service, with due concern for their dignity and consent.

The aim of the study was to look at:
1. Current attitudes of patients and their carers towards ECT.
2. Patients’ and carers’ current experience of receiving ECT treatment, especially after the implementation of ECT Accreditation Service (ECTAS) standards.

Methodology

Sample
Patients who had had ECT at Worcestershire Health and Care NHS Trust between January 2013 and December 2014 were included in the study. A list of patients who underwent therapy was generated using the Trust’s patient data, including their demographics and current clinical contacts. The clinical governance department for the Trust gave approval for the study.

Interviewers then contacted patients and their care coordinators, if necessary, to arrange an interview schedule. Patients were offered the choice to take part in the study and those who agreed were given the written and verbal information. Informed consent (written / verbal) was obtained.
from those who agreed to take part in the study.

**Questionnaire**
A questionnaire was designed to capture patients’ experiences and attitudes, along with carer’s views about ECT. The design was based on a previous study⁶ and current ECTAS⁷ standards.

The questionnaire included:

- Patients’ demographic details
- Type of ECT
- Previous experience of ECT
- Mental Health Act status
- Diagnosis
- Information provided on ECT
- Consent process
- Experience before, during and after ECT
- Quality of care received
- Side effects
- Attitudes and experience regarding the outcome
- Carers’ experience of ECT.

**Interview schedule**
A group of interviewers (psychiatrists and psychiatric trainees) contacted patients individually to arrange an appointment for either a face-to-face or over the telephone interview. The timing of the interview was decided according to patients’ choice and convenience. The interview was arranged either at patients’ homes or at their clinic appointments. At interview, information about the study was given in a written or verbal format before obtaining patients’ consent. Interviewers used the questionnaire to elicit patients’ experience and attitudes. Carers were interviewed at the end, to include their views on ECT. Each interview lasted approximately 20–30 minutes. The interviews were conducted between January 2015 and April 2015.

Sixty patients, who had completed at least one course of ECT during the study period, were identified, of which eight people were deceased (not related to ECT; either due to old age or physical ailments), 11 refused to take part, six could not be traced and five could not take part due to significant cognitive impairment. At the end, our final study sample constituted 30 patients.

**Results**

**Demographic details**
The age of patients who participated in the study ranged between 20 and 81 years. The average age of the sample was 62 years. Forty four percent of the sample population were under the age of 65 years and the remaining 56% were over 65 years old. The majority of the sample was females (93%).

**Details of ECT and consent process**
All of the study population had bilateral ECT and more than half of them had ECT in the past. Eighty percent received ECT as inpatients, 10% as outpatients and the remaining 10% as both inpatients and outpatients.

Three quarters of the sample had ECT voluntarily (informally) and the remaining had it formally under the Mental Health Act.

Of those who had ECT under the Mental Health Act, nearly half had given consent to ECT treatment, a quarter did not have capacity to consent and the remaining could not remember whether they had given consent or not.

**Consent**
Three patients lacked capacity to consent for ECT treatment and hence 27 patients participated in the consent process.

The majority of the sample population agreed to have ECT, 45% of the sample could not remember whether they had signed a consent form or not and 15% felt pressurised to have ECT (Table 1 section A).

**Information about ECT treatment**
Around half of the sample confirmed that they had received some (either written or verbal) form of information about ECT.

The majority of the patients who received written information said that they had a good understanding of why they were having ECT, 58% had a better understanding of the problems and side effects of the treatment (Table 1 section B).

**Experience and feelings**
Figure 2 depicts the feelings and experience of our study sample before having ECT.

Most patients described their experience with clinical staff as pleasant. Some of the unpleasant experiences reported were during the recovery period, anaesthetic injection and waiting for treatment (see Table 2).

**Side-effects**
One patient could not remember whether she had experienced any side-effects from ECT; hence we included information obtained from the remaining the 29 patients (see Figure 3).

**Quality of care**
Nearly two thirds of the patients responded positively to the overall quality of care that they had received (Table 1 section C).

**Waiting time before treatment**
When we looked at the waiting time for patients before receiving treatment, 43% of the patients waited for 15–30 minutes and only a small number (6%) of the sample waited for more than 30 minutes (figure 4).

**Patients’ comments**
- Was a positive experience; worked well for me; ECT staff were kind and friendly; able to go home
after five months of inpatient stay as a result of ECT
- Treatment delayed on one occasion as case notes were not received in time
- Always looked after well
- Very impressed with quality of care
- Staff were very relaxed and friendly; scary imagination reduced by staff; atmosphere was very nice and caring
- Waiting time could be minimised, as it makes one nervous
- Felt respected
- Staff were really professional and friendly and explain things at your pace
- Oxygen mask was not comfortable; overall it was a pleasant experience

Table 1. Patients’ responses to questionnaire: consent; information; quality of care; outpatient treatment, and carers’ experience

<table>
<thead>
<tr>
<th>A. Questions regarding consent (n=27)</th>
<th>Yes</th>
<th>No</th>
<th>Cannot remember</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you say to your doctor that you agreed to have ECT?</td>
<td>22 (81.5%)</td>
<td>0</td>
<td>5 (18.5%)</td>
</tr>
<tr>
<td>Did you sign a form to show that you agreed to ECT?</td>
<td>15 (55.6%)</td>
<td>0</td>
<td>12 (44.4%)</td>
</tr>
<tr>
<td>Did you have enough time to think about ECT and discuss with doctors before making a decision?</td>
<td>16 (59.3%)</td>
<td>2 (7.4%)</td>
<td>9 (33.3%)</td>
</tr>
<tr>
<td>Did you have enough time to discuss with the care co-ordinator / Nurse before making decisions?</td>
<td>16 (59.3%)</td>
<td>2 (7.4%)</td>
<td>9 (33.3%)</td>
</tr>
<tr>
<td>Did you have enough time to discuss with your family?</td>
<td>17 (63%)</td>
<td>4 (14.8%)</td>
<td>6 (22.2%)</td>
</tr>
<tr>
<td>Did you feel forced or pressurised to have ECT?</td>
<td>4 (14.8%)</td>
<td>19 (70.4%)</td>
<td>4 (14.8%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>B. Questions relevant to written information given (n=17)</th>
<th>Yes</th>
<th>No</th>
<th>Cannot remember</th>
</tr>
</thead>
<tbody>
<tr>
<td>Why were you having ECT treatment?</td>
<td>14 (82.4%)</td>
<td>1 (5.8%)</td>
<td>2 (11.8%)</td>
</tr>
<tr>
<td>What ECT was likely to do for you?</td>
<td>11 (64.8%)</td>
<td>2 (11.8%)</td>
<td>4 (23.4%)</td>
</tr>
<tr>
<td>What would happen to you during ECT treatment?</td>
<td>10 (58.8%)</td>
<td>2 (11.8%)</td>
<td>5 (29.5%)</td>
</tr>
<tr>
<td>The problems and side effects of ECT treatment</td>
<td>11 (64.8%)</td>
<td>1 (5.8%)</td>
<td>5 (29.5%)</td>
</tr>
<tr>
<td>What other treatments you could have had?</td>
<td>8 (47%)</td>
<td>4 (23.4%)</td>
<td>5 (29.5%)</td>
</tr>
<tr>
<td>What would happen if you did not have ECT?</td>
<td>6 (35.5%)</td>
<td>3 (17.5%)</td>
<td>8 (47%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C. Questions regarding quality of care (n=30)</th>
<th>Yes</th>
<th>No</th>
<th>Cannot remember</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did a member of staff accompany you to the ECT clinic?</td>
<td>22 (74%)</td>
<td>2 (6%)</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>Did you know the member of staff who accompanied you?</td>
<td>20 (67%)</td>
<td>0</td>
<td>10 (33%)</td>
</tr>
<tr>
<td>Was the member of staff who accompanied you to the ECT still there when you woke up?</td>
<td>17 (57%)</td>
<td>2 (6%)</td>
<td>11 (37%)</td>
</tr>
<tr>
<td>Did ECT team members introduce themselves prior to treatment?</td>
<td>24 (80%)</td>
<td>0 (0%)</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>Did the doctor check that you still agreed to have ECT before your treatment?</td>
<td>14 (47%)</td>
<td>0 (0%)</td>
<td>16 (53)</td>
</tr>
<tr>
<td>Was ECT clinic staff friendly and reassuring?</td>
<td>29 (97%)</td>
<td>0 (0%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Was the clinic clean and comfortable?</td>
<td>28 (94%)</td>
<td>0 (0%)</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>Do you feel you were properly cared for immediately after treatment?</td>
<td>28 (94%)</td>
<td>0 (0%)</td>
<td>2 (6%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>D. Questions regarding outpatient treatment (n=6)</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know / cannot remember</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the clinic staff confirm that you should be accompanied home by an appropriate responsible adult?</td>
<td>6 (100%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Did the clinic staff confirm that you should be under supervision of an appropriate responsible adult for 24 hours following ECT treatment?</td>
<td>6 (100%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Did the clinic staff confirm that you should not drive a vehicle or operate a machinery during the ECT course?</td>
<td>6 (100%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Did the clinic staff advise you that you should not sign any legal documents during ECT course?</td>
<td>6 (100%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Did the clinic staff advise you that you should not drink alcohol for 24 hours following ECT treatment?</td>
<td>5 (83%)</td>
<td>1 (17%)</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E. Questions regarding carers’ experience (n=27)</th>
<th>Yes</th>
<th>No</th>
<th>Don’t know / cannot remember</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did the doctor speak to you about ECT treatment before starting the treatment?</td>
<td>18 (67%)</td>
<td>5 (18%)</td>
<td>4 (15%)</td>
</tr>
<tr>
<td>Were you offered written information on ECT treatment?</td>
<td>14 (52%)</td>
<td>7 (26%)</td>
<td>6 (22%)</td>
</tr>
<tr>
<td>Did ECT benefit your relative?</td>
<td>23 (85%)</td>
<td>0</td>
<td>4 (15%)</td>
</tr>
<tr>
<td>Would you support your family member to have another ECT course, should the need arise?</td>
<td>24 (89%)</td>
<td>1 (3.5%)</td>
<td>2 (7.5%)</td>
</tr>
<tr>
<td>Were you happy with the help and support provided during ECT treatment?</td>
<td>23 (85%)</td>
<td>2 (7.5%)</td>
<td>2 (7.5%)</td>
</tr>
</tbody>
</table>
• More explanation on ECT treatment would be better
• Staff and doctors were very attentive; anything to prevent tongue biting would be good
• Make this treatment more available

Response to treatment
The majority of the sample felt that ECT was a useful procedure; it worked faster than medications and they would be happy to have it again if indicated. Less than half felt that it works for a short while and that the effects do not last longer (Table 3).

All of the patients who had ECT as outpatients were happy with the ECTAS standards followed for outpatient ECT treatment (Table 1 section D).

Carers’ views
Three patients had no carers and hence only 27 were included.

Nearly three-quarters of the carers said that the doctor consulted them before starting the treatment. The majority of them felt that ECT was beneficial and would support the family member to have ECT again. Most of them were happy with the overall support and help provided during ECT treatment. However, only half of the carers reported having received written information on ECT treatment (Table 1 section E).

Carers’ comments
• Always felt better after ECT treatment
• Wasn’t given enough information, wasn’t counted at all, need to be explained in layman’s term
• Having somewhere to park
• Very good treatment but comes with obvious side effects, no other alternative treatment worked
• Worried more about anaesthesia than ECT
• Had very good support and happy for my wife to have ECT again if she became unwell again

• Wished it had been started sooner
• Would have to be last resort, needed a lot of support afterwards due to memory impairment
• It was the best thing that my wife could have had at that time, a good decision by the doctors
• Would have preferred better communication from the ward staff and doctors between ECT treatment
• Whole team has been amazing, ECT was incredible, we were quite worried at first but the team assurances proved to correct, well done
• Information received was fine
• Felt like I wasn’t told anything, no one asked my opinion, more explanation about the risks and benefits needed
• Felt pressurised to agree with the treatment, as said she would be treated legally under MHA anyway.
• Had power of attorney for health matters, no one discussed with me before treatment

Figure 2. Feelings and experience of the study sample before having ECT

Table 2. Patients’ rating of treatment experience

<table>
<thead>
<tr>
<th>Rating of treatment experience (n=30)</th>
<th>Pleasant</th>
<th>Neutral</th>
<th>Unpleasant</th>
<th>Do not know</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aspect of treatment</td>
<td>8 (27%)</td>
<td>14 (47%)</td>
<td>2 (6%)</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>Premedication</td>
<td>8 (27%)</td>
<td>13 (43%)</td>
<td>1 (3%)</td>
<td>8 (27%)</td>
</tr>
<tr>
<td>Waiting for treatment</td>
<td>12 (40%)</td>
<td>10 (33%)</td>
<td>3 (10%)</td>
<td>5 (17%)</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>23 (77%)</td>
<td>1 (3%)</td>
<td>1 (3%)</td>
<td>5 (17%)</td>
</tr>
<tr>
<td>Anaesthetist</td>
<td>26 (87%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>4 (13%)</td>
</tr>
<tr>
<td>ECT staff</td>
<td>29 (97%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Anaesthetic injection</td>
<td>9 (30%)</td>
<td>12 (40%)</td>
<td>3 (10%)</td>
<td>6 (20%)</td>
</tr>
<tr>
<td>Falling asleep</td>
<td>16 (53%)</td>
<td>5 (17%)</td>
<td>1 (3%)</td>
<td>8 (27%)</td>
</tr>
<tr>
<td>Waking up</td>
<td>16 (53%)</td>
<td>8 (27%)</td>
<td>1 (3%)</td>
<td>5 (17%)</td>
</tr>
<tr>
<td>Recovery period for few hours after treatment</td>
<td>17 (57%)</td>
<td>5 (17%)</td>
<td>4 (13%)</td>
<td>4 (13%)</td>
</tr>
</tbody>
</table>
More than half of our sample population were over 65 years, which reflects the current trend that ECT is more frequently prescribed for older patients. Most of the patients in our study group were females: depression is more common in women, which may explain the predominance of females in our study.

Although ECT is indicated in various psychiatric disorders, it is commonly considered in severe depression. Memory impairment was experienced as the most common side effect; some of the carers’ views were that they would consider ECT only as a last resort due to memory impairment. All the patients in our study sample had bilateral ECT and that could explain the predominance of memory impairment as a side effect.

Even though headache is a common non-cognitive side effect, our study sample rated it as the third most common after memory and confusion. Most of the patients had given consent to ECT; however, more than half of them could not remember whether they had signed a consent form or received any information. This could be due to patients being quite unwell and lacking capacity to consent before the treatment. Therefore, we emphasise the importance of providing information before each treatment session. One of the unpleasant experiences of the treatment was the long waiting time before each treatment session, which increased patients’ anxiety and nervousness. However, we could not corroborate the findings with our records. It is important to mention that the time needed to complete the required paperwork and the practicalities before each treatment should be balanced against the actual waiting time.

Overall quality of care was rated as high and this could be attributed to the adherence to ECTAS standards.

### Discussion

More than half of our sample population were over 65 years, which reflects the current trend that ECT is more frequently prescribed for older patients. Most of the patients in our study group were females: depression is more common in women, which may explain the predominance of females in our study. Although ECT is indicated in various psychiatric disorders, it is commonly considered in severe depression.

Memory impairment was experienced as the most common side effect; some of the carers’ views were that they would consider ECT only as a last resort due to memory impairment. All the patients in our study sample had bilateral ECT and that could explain the predominance of memory impairment as a side effect.

Even though headache is a common non-cognitive side effect, our study sample rated it as the third most common after memory and confusion. Most of the patients had given consent to ECT; however, more than half of them could not remember whether they had signed a consent form or received any information. This could be due to patients being quite unwell and lacking capacity to consent before the treatment. Therefore, we emphasise the importance of providing information before each treatment session. One of the unpleasant experiences of the treatment was the long waiting time before each treatment session, which increased patients’ anxiety and nervousness. However, we could not corroborate the findings with our records. It is important to mention that the time needed to complete the required paperwork and the practicalities before each treatment should be balanced against the actual waiting time.

Overall quality of care was rated as high and this could be attributed to the adherence to ECTAS standards.
The response rate for ECT treatment in our study was similar to the evidence in the literature.6

Carers felt happy with the overall quality of the treatment. However, they were not fully satisfied with the information provided prior to treatment. In order to improve carers’ experience, staff should allocate more time to address carers’ questions and concerns and also provide them with a separate ECT information leaflet.

**Limitations**

We acknowledge that the sample size was small and the study could have been carried out in a larger population. We experienced great difficulty in locating patients who had treatment many months ago, especially when they were not under secondary care. This had an impact on the size of the study population. Patients who refused to take part in the study might be the ones who had very bad experiences. It would have been helpful to have their views, as we could have used that information to improve the experiences in a positive way.

**Conclusion**

It is clear from this study that the overall experience and attitude of patients and carers were positive. Although ECT was considered as a barbaric treatment in the past, we cannot ignore the fact that it was the only effective treatment due to the limited availability of alternate pharmacological and psychological interventions.

In the past, ECT was also used as a placebo,13,14 which had probably led to the controversy and the negative attitude in the media. However, it is important to emphasise that it was a potential lifesaver in many cases15. More treatment options are available now for psychiatric disorders but ECT is still considered as an effective treatment. The improvement and sophistication in ECT administration and the ECTAS7 standards help validating ECT as a less frightening experience for patients and carers.

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**Conflicts of interest**

No conflicts of interest were declared.

**References**


