



Patient Reported Experience of Electroconvulsive Therapy (ECT)

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ABSTRACT

Objective

Negative attitudes towards Electro Convulsive Therapy (ECT) persist, despite the evidence of its clinical efficacy and benefits. This is partially due to negative media portrayals, inaccurate information and prohibitive consent processes. The aim of this study is to review patient ECT experience literature and report patients' perspective of their ECT experience.

Methods

A patient data and insight platform was employed to gain patient satisfaction and patient feedback statements of their experiences of ECT in an UK National Health Service (NHS) provider.

Results

Patients feel well informed, involved in decisions made about them, treated with dignity and respect, and treated well by the staff; and almost all patients would recommend the hospital delivering ECT. Findings show that interactions with staff have a positive effect on patient satisfaction and experience. Patients describe how ECT gave them their lives back again and prevented suicide attempts.

Conclusion

The study highlights the importance to patient's satisfaction and experience of staff's engagement, relaying information, friendliness, support, and compassion. The results provide information to both patients and prescribers regarding patient's experience of ECT. It is important to acknowledge that the patient experience of ECT literature identifies that patients frequently report memory loss.

Keywords

Electro Convulsive Therapy ECT, Service Delivery; Media, Patient Perspective, Qualitative, Feedback

Introduction

In the UK, National Institute for Clinical Excellence (NICE) recommend the use of electroconvulsive therapy (ECT) for people with severe depression, catatonia or a prolonged or severe manic episode [1]. There is a lack of

collated ECT delivery data, but it is estimated that over 11,000 patients receive ECT annually in the UK [2].

Studies continue to prove the efficacy of ECT for treating severe depression [3,4] with many showing ECT to be superior to pharmacotherapy

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[3]. ECT is still the most effective treatment for severe depression [4]. In addition, patient's perceptions of benefits are based on broader considerations than relief from symptoms alone [2]. They include an improved sense of self, feelings of calm, increased optimism, and resumption of normality [5]. ECT is associated with improvement in quality of life as assessed by both physicians and patients [6].

Despite this, controversy surrounding the use of ECT persists in both popular culture and the medical profession [7]. Negative attitudes towards ECT might be attributed to a combination of inconsistent standards surrounding patient information and consent processes [8,9], misinformation [10] and negative media portrayals [11-13], rather than the experience of treatment itself [3,4,14]. In the majority of cases, patients who have undergone ECT report positive attitudes towards the treatment [8,14-17]. Indeed, it has been found that despite side effects, the majority of patients find it to be beneficial, would recommend ECT and have it again [18,19].

Negative portrayal of ECT, such as the books and films: 'One Flew Over the Cuckoo's Nest' and 'Any Angel at my Table', remain influential on people's opinions. A review of all films featuring ECT reported that films have become progressively more negative about ECT, portraying it as cruel, brutal, harmful, and abusive with little therapeutic benefit [10]. There are also many internet sites falsely proclaiming negative aspects related to ECT [10]. It is not therefore easy for people to discern the truth. This can create stigma for individuals undergoing ECT, possibly leading to discrimination [10]. Misrepresentation of ECT is potentially harmful on a number of levels: dissuading healthcare professionals from prescribing ECT to patients who might benefit and preventing patients from considering ECT as an option to discuss with their physician. There is little to counter the negative portrayal of ECT in the media [10]. It is important to counter ill placed public perception that it is anarchic, barbaric and severely damages those who undergo it [10] and this can be achieved by qualitative research sharing the experiences of those who experience ECT [10].

Recent surveys of patients who have undergone ECT treatment have revealed positive attitudes to its effectiveness [20-22]. In one study, less than a fifth of respondents rated ECT as slightly as or much worse than going to the dentist [21]

and most (97%) did not report the experience to be very stressful. Support for further sessions of ECT remains high [22]. However, an extensive review of patient experience revealed high rates of unsatisfactory pre-treatment information, feelings of treatment coercion, and un-allayed fears; identifying the need to enhance patient engagement with knowledge about ECT and empower involvement in treatment choice [8].

In 1947, one patient reported that they were given scientific papers to read on the various physical treatments for depression, including leucotomy, cardiazol and ECT [23]. Their psychiatrist explained the process of ECT and answered questions to describe benefits and allay fears; therefore they were able to form their own opinion of treatment choice and knew what to expect during the treatment. The patient reported positive experiences of ECT in terms of the process and effectiveness. This sets a good standard for patient information and communication, but a recent review revealed that this is often not the standard that some patients experience [8].

However, there have been improvements since a 1976 review in which only 21% of patients reported that they were given adequate information prior to treatment [14]. For example, in a 2004 study around 80% stated that the treatment had been fairly or very well explained [21], with 85% in a 2007 study stating that written information was helpful [22]. Fears about ECT treatment can be alleviated if a patient has the process and treatment fully explained to them by medical staff [24].

A negative side effect of ECT is memory loss, but there are differing views on the extent of this [2], and it is a complex issue due to the association between depression and memory impairment [25]. Neurological tests used in ECT studies have shown little evidence of persistent memory loss, however these tests tend to measure ability to form new memories, whereas patients report erasing of autobiographical memories or retrograde amnesia [2]. In one study 80% [19], and in another 60% [22], of patients reported memory impairment, and in a further study 45% reported persistent memory loss [9]. The more courses of ECT someone undergoes, the more it is likely to affect their memory [25]. There are also short term side effects that may occur immediately after treatment including drowsiness, confusion, headache, sickness and aching muscles.

Qualitative research reveals that patient's views and experience of ECT is complex, emphasising the value of gaining qualitative feedback [2]. In this paper, results from a feedback survey are analysed to gain patient satisfaction and patient feedback statements of their experiences of ECT in a NHS provider. Most previous studies reporting patient views have used questionnaires or interviews constructed by researchers [9] rather than the free response approach reported in this paper.

Methods

■ ECT treatment

Service delivery protocol is based on: 'The ECT handbook: the third report of the Royal College of Psychiatrists' Special Committee of ECT' [26] 'Guidance on the use of electroconvulsive therapy' [1], and 'ECT Accreditation Service (ECTAS) Standards for the administration of ECT' (Fourteenth edition) [27], The equipment used is Thymatron System IV ECT machine.

■ Procedure and Measure

Patient receiving ECT is invited to fill in a short feedback questionnaire either during or after their treatment. The feedback questionnaire collects qualitative and quantitative data regarding the experience that the patient has of their ECT treatment.

There are five statements, which are scored on a scale from one to five, with one being lowest and five being highest. In addition to this, there is one question that gives patients the opportunity to leave free-text responses.

Statements are as follows:

1. Would you recommend this hospital to friends and family if they needed similar care or treatment?
2. Were you treated with dignity and respect?
3. Did you feel involved enough in decisions made about you?
4. Did you receive timely information about your care and treatment?
5. Were you treated well by the staff looking after you?

The survey can be filled out on paper or electronically via an app or online. Paper forms are left in clinic and patients are encouraged to leave feedback. These responses appear online

and can be viewed by anyone. Patient responses were anonymous. The data was collected and analysed by an independent patient data and insight platform: iWantGreatCare. A researcher independent to the healthcare provider carried out a thematic analysis of the free text comments.

Results

■ Patients

Approximately 55 patients had ECT treatment during the period. A course of treatment is normally considered to be 12 sessions of ECT. Many patients have more than one course of treatment and therefore some completed more than one feedback survey. Of the 128 responses 73 (57%) were from females and 51 (40%) from males, with 4 (3%) unknown. There was a broad range of age group responses.

■ Quantitative Data

128 sets of feedback were received between January 2015 and February 2017 inclusive.

■ Qualitative analysis

The qualitative data collected was in response to the request: "Please help others get great care by sharing your views and experience." There were 116 free text comments. None of the comments received were negative. Thematic analysis undertaken grouped comments into four broad themes:

1. Operational processes: 54 comments
2. ECT treatment: 24 comments
3. Staff attitudes and behaviour: 97 comments
4. Outcomes of ECT: 47 comments

Representative statements were extracted from two areas that were focus of this paper: 'staff attitudes and behaviour' and 'outcomes of ECT'.

Below are statements made by patients, who illustrate and are representative of the 97 'staff attitudes and behaviour' statements made:

- "My son was anxious but everyone I met made us feel welcome and relaxed"
- "The nurse who looked after me was interested in how I felt and about me, not what I should be feeling but was asking about me, she was the first person who listened"
- "To all the staff at ECT thank you for all the help and support you've given us"

tremendously amazing.”

- “The nurse here treated me like I was a normal person and that it mattered that I was comfortable.”

Below are statements made by patients, who illustrate and are representative of the 47 ‘outcomes of ECT’ statements made:

- “I want you to know that I am feeling much better. I am still on my medication but life worth living again.”
- “I really like talking to the [staff] here they make me feel that I have something to live for.”
- “The wonderful treatment of ECT has been so helpful to me; depression is such a dangerous sad illness it has brought me near death so many times. ECT and all the nurses that go with the treatment have saved my life so many times, myself and my family will always be grateful to the actual treatment [and] doctors and nurses always.”
- “To all the team I cannot thank you enough

for bringing me back to me.”

- “You have no idea the difference you have made to me and my whole family. The house is a different place to be.”
- “I am now looking forward to twelve days holiday with my family for the first time in years.”
- “I now have a job and have a place at university. Thanks to everyone who helped me.”

Discussion

Qualitative research tends to focus on the negative aspects of ECT [29,30]. What this paper finds is that when you allow people to choose what to report, they report positive aspects. This supports the findings of another qualitative investigation of patient experience, where positive aspects were frequently mentioned [5]. The experiences reported in this paper identify and demonstrate key aspects of best practice in administering ECT.

The results showing that patients feel ‘treated with dignity and respect’ and ‘treated well by the staff’, and that a majority of comments related to the positive impact of contact with staff align with those of a recent ECT qualitative study carried out at another UK NHS provider [19]. The attitudes of clinical staff play a pivotal role in delivering a positive patient experience of ECT [5], and these positive attitudes can also affect the patient reported outcomes for the treatment. The results of this paper align with other surveys carried out where 91% of patient’s rated ECT staff as pleasant [21], and 100% of staff were friendly and reassuring [22].

There were statements by participants that ECT gave them their lives back again and, for some, this meant that they did not commit suicide; this aligns with accounts reported in other studies [5]. The exclusively positive experiences relayed by participants provide evidence opposing the negative view portrayed in the media [11-13,20] and on some internet sites [10]. It is important that the public have a chance to understand the experience of people who undergo ECT in the NHS today, and that the media provides a balanced and accurate portrayal of ECT [31].

In this paper patients report high levels of agreement to the statement of ‘receiving timely information about your care and treatment’. Most ECT patients today receive adequate

Table 1: Age of respondents.

Age (years)	Number of responses	Percentage
18-20	2	2%
21-30	12	9%
31-40	14	11%
41-50	28	22%
51-60	35	27%
61-70	20	16%
71-80	10	8%
80+	1	1%
Unknown	6	5%
Total	128	100%

Table 2: Data Cleansing.

Number	Description
128	Reviews in the data extract
-4	Blank quantitative responses
-6	No comment/blank qualitative responses
-2	Responses for TMS not ECT
116	Valid responses for thematic analysis

Table 3: Scoring of five statements.

	Score out of 5
Recommend	4.9
Dignity	4.97
Involved	4.9
Information	4.95
Staff	4.97
Average across all questions	4.94

information but some do not [21,22]. It is important to ensure that they do to support informed consent, prevent coercion, and comply with guidance [26].

Linked to ‘timely information’, patients reported high levels of agreement to the statement of ‘feeling involved enough in decisions made about you’. Involving patients in ECT treatment decision and gaining consent is a requirement [26]. Only in rare cases is ECT given without consent, in the UK there is provision to do this under the Mental Health Act and the Mental Capacity Act. Services should ensure that patients are effectively involved in decisions about treatment to ensure that ECT is a treatment of patient choice [8].

Implications

Patient views are important indicators of quality of care and should be used to improve ECT practice. I Want Great Care is a useful tool to understand patient experience and the reasons why patients feel that they are getting a good or bad experience. Feedback gained allows services to understand what they are doing right and what they are doing wrong, and enact changes to address patient concerns and make improvements. Publicly sharing patients’ first-hand experience of ECT may help reduce negative perceptions, enabling more patients to benefit from potentially life-saving treatment.

Limitations

Data was from single site in the UK limiting generalizability. There were more females than males responding, limiting the generalizability to males.

Conclusion

There are negative side effects of ECT; patients frequently report memory loss [9]. This paper acknowledges the significance of memory loss due to ECT, but it highlights that when you allow patients to choose to leave feedback on their experience, this feedback is positive.

To deliver good outcomes, it is not enough alone for the treatment itself to be clinically effective. ECTAs standards – specifically sections three and four – should ensure that all ECT centres provide adequate information and guidance for patients and their careers. Adhering to guidelines set, providing patients with information about procedures and evidence based information about risks and benefits and having staff provide informative, responsive, compassionate and person centred care ensures that the best possible patient experience and outcomes.

It is important that inaccurate negative views of ECT do not prevent ECT treatment when it is in the patient’s best interest to do so. Patients and those who support them need have access to accurate and unbiased information to be able to consider ECT as a treatment of choice [10].

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