

The subjective experience of patients who received electroconvulsive therapy

Leslie Frank Koopowitz, Anna Chur-Hansen, Sally Reid, Miriam Blashki

Objective: Despite the vast amount of scientific literature available on electroconvulsive therapy (ECT), there is little qualitative focus upon the patients' subjective experience of this procedure. Using an exploratory descriptive methodology, this study aims to provide a more unique insight into what certain patients actually think of ECT.

Method: Semistructured interviews were conducted to explore eight patients' opinions and experiences of ECT. Interviews were subjected to analysis by a five-step framework approach that identified prominent themes in relation to five broad questions and in conjunction with issues raised by the subjects themselves.

Results: Eleven major themes were identified. Four of these were chosen for discussion, not only as the most prevalent themes (in terms of how frequently they were mentioned by the subjects), but also as the most striking (in regards to the intensity of emotions evoked, or their influence on their perception of ECT as a future treatment option). The four themes are fear of ECT, attribution of cognitive decline and memory loss to ECT, positive ECT experiences, and patients' suggestions.

Conclusions: Using such a qualitative approach, the depth of the information obtained has revealed new perspectives on how patients perceive the experience of ECT. Fears reported by patients present an opportunity to address specific areas of the procedure that generate the most angst. These were closely associated with recommendations that many patients proposed throughout the interviews. Patients' perceptions of the cognitive effects of ECT do not necessarily correspond with those commonly reported in the literature on ECT. Positive experiences with ECT were more complex than simply its efficacy. There is a need for future research in order to explore and address patients' experiences of ECT.

Key words: cognition, electroconvulsive therapy, fear, memory, patients' experiences, qualitative research.

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Although regarded in the scientific literature as a safe, effective and potentially life saving procedure, electroconvulsive therapy (ECT) is still one of the most

Leslie Frank Koopowitz, Senior Lecturer in Psychiatry (Correspondence);
Anna Chur-Hansen, Senior Lecturer

Department of Psychiatry, University of Adelaide, Adelaide, South
Australia 5005, Australia.
Email: leslie.koopowitz@adelaide.edu.au

Sally Reid, Fifth Year Medical Student; Miriam Blashki, Fifth Year Medical
Student

University of Adelaide, Adelaide, Australia

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controversial and misunderstood treatments used in psychiatry [1].

Despite extensive studies into the use of ECT, relatively few have explored the subjective experiences of patients who have received ECT. The majority of these studies were quantitative in nature, in that they categorized experiences and attitudes, and compared relative numbers of negative with positive answers [2–14]. Although some of these studies had the potential to analyse data qualitatively, in that they used open-ended questions and/or semistructured interviews, the results were presented quantitatively [2–4,8,10,11,13,14].

Several papers have used either single (some autobiographical) or multiple case studies to describe patients' experiences with ECT [15–18]. Relatively few papers could be described as primarily qualitative in nature [19–23].

Reid [19] described personal or family experiences of ECT, as communicated to him by psychiatrists or their families. Squire and colleagues [21] used a novel self-rating scale to examine both quantitative and qualitative aspects of memory prior to and following ECT. Crompton *et al.* [22] interviewed and performed projective tests on 96 male psychiatric patients given either simulated or genuine ECT. Some degree of fear of ECT was found to be universal. No association was found between the degree of fear, feelings of guilt or punishment, or death-rebirth fantasies and clinical improvement. Plaut [23] interviewed seven patients who had failed to improve on ECT. Initial resistance against the passive role of receiving ECT, followed by a fear of leaving the hospital following failed treatment, emerged as the predominant themes.

Of most relevance to the present work, was a study conducted by Johnstone, a clinical psychologist [20]. She conducted interviews with 20 people who had reported unhappiness regarding their ECT. Themes that emerged included feelings of fear, shame and humiliation, worthlessness and helplessness, and a sense of having been abused and assaulted. Very few of these patients had felt they were able to tell their treating health professionals about the strength of these feelings.

Quantitative research, due to its emphasis on the testing of formulated hypotheses, can be limited by the expectations of the researcher, and important information may be missed. Qualitative approaches can similarly be influenced by the researchers' position on an issue, but any biases are explicitly stated. Qualitative approaches are valuable for exploring patients' perceptions of an experience [24], and interviews are powerful research tools in health care [25]. As the patients' subjective perceptions of ECT have received relatively little attention, an exploratory, qualitative approach in which patients are able to freely describe their experiences and emotions is likely to be most informative. Furthermore, interviewers who do not have any authority regarding the patient's condition or treatment may elicit more valid data than a current or past treating clinician.

This study aimed to assess patients' recollections of the practical aspects and procedures of their ECT, the emotions experienced at the time they received ECT, whether they felt they were given adequate informed consent, their perceived side-effects, and their attitudes towards ECT, before and after the procedure. We also

hoped to uncover and explore any relevant issues the patients themselves may have raised.

Methods

Sample

Eight patients who underwent a course of ECT at a South Australian public hospital between 1 July 1997 and 30 June 1999 were interviewed. All patients were over 18 years. Prior to ECT, patients (and their families, if appropriate) had been shown an educational video on the principles and administration of ECT. Patients could withdraw consent at any time during the course of ECT. On the rare occasion, when a patient was too unwell to give informed consent, permission to perform the course of ECT was sought from the Guardianship Board, in terms of the Mental Health Act of South Australia [26].

This was not a random sample; it was a sample of convenience. The senior author (LFK) chose 10 patients from a population of 55 on the basis of their contactability by telephone and letter, their willingness to communicate with the researchers, and capacity to present for interview. Subjects were also chosen to ensure a range of psychopathology and indications for ECT, and variable clinical responses to ECT.

The interviewers (SR and MB) were, at the time of the study, undergraduate Fourth Year medical students. As such, they had not previously been involved in the prescription and administration of ECT at any level. They were not informed of the above selection criteria, and were blind to the psychiatric history of the patients. They had no previous contact with any of the patients.

Initially, 10 patients were contacted by mail. The letter explained the nature and purpose of the study, and contained a consent form. As per the content of the letter, if patients did not contact the interviewers declining the interview, they were telephoned. All 10 patients were contacted by telephone. One refused to be interviewed, and one agreed but did not arrive for the appointment.

Interviews

Following a further explanation of the study, written consent was again obtained. The interviews ranged from 40 to 90 min. The interview process followed a semistructured format. Non-identifying demographic information was elicited. Patients were then encouraged to talk spontaneously about their views and experiences of ECT. Following this, they were asked about the number and timing of their treatments, their psychiatric symptoms at the time, why the treatment was stopped, their experience of the treatment sessions themselves, any side-effects, if they felt the treatment helped them, whether they would undergo ECT again, and whether they felt they gave true informed consent. Patients were asked a series of knowledge-based questions about ECT, and about their attitudes toward the procedure. Each interviewer conducted four interviews.

Analysis

The interviews were audiotaped and transcribed by the interviewers. Each interview was subject to qualitative analysis, the aim of which was to determine important themes that arose from patients' experiences. As per Pope *et al.* [24], a five-step framework approach was

utilized, involving in-depth discussion and revision at each step. Each interview was initially analysed by the investigator who performed the interview (SR or MB). Once all the interviews were individually analysed, a list of themes was drawn up by each investigator. There was intense discussion in identifying the themes. This debate was a crucial part of the analysis. Even if the reasoning differed between the interviewers, the conclusions were usually similar. Documentation of the entire interview and analysis process (audit trail) was kept. In addition to keeping a meticulous record of how the findings were achieved, the audit trail helped identify personal values or assumptions. At every point there was a search for disconfirming evidence. In this manner, insights were obtained not by eliminating bias but by comprehending it.

Results

Eight patients were interviewed. The age range was 25–50 years with a mean of 35.4 years. Five patients were female. Four had been diagnosed with Bipolar Mood Disorder, and four with Major Depression. The indication for ECT in each patient was a severe depression that had not responded to pharmacological treatment. Three of the patients were clinically assessed as psychotic at the time of ECT. The number of courses of ECT that each patient underwent ranged from one to four, with the number of actual treatments ranging from 9 to 35. Response to ECT varied from no response to complete recovery from depression.

Eleven major themes were identified Table 1. While important insight may be gained from each theme, it is clearly not possible to discuss all. Four major themes have thus been identified for discussion: fear of ECT, attribution of cognitive decline and memory loss to ECT, positive ECT experiences, and patients' future suggestions. These four themes have been chosen, not only as the most prevalent (in terms of how frequently they were mentioned by the subjects), but also as the most striking (with regard to the intensity of emotions they provoked).

Discussion

Negative experiences – fear of ECT

Due to its powerful impact, as well as frequent mention throughout the interviews, fear of ECT emerged as a dominant theme. Although the word 'scary' was mentioned frequently in the description of the actual

procedure, fear was experienced differently between patients.

Most experienced fear at the time of the ECT, but felt they were less affected by it at present. Some described anticipatory fear, akin to any surgical procedure: 'It's just like any operation thing you know . . . so you still get the same nerves'. Some described the whole experience as overwhelmingly frightening. One patient still experiences nightmares three years post ECT: 'To this day I still dream about it. Bolt upright, sweating in bed. They've actually zapped me before I went to sleep'.

Reasons for fear of ECT ranged from fear of not waking up from the procedure, to fear that it would induce personality change. There was a strong fear of brain damage: 'I wasn't scared of what was going to go on, I was scared of what it would do to my brain'.

A number of articles have focused on fear of ECT as an important theme [8,12,13,17,20,22]. The studies that used the most open-ended format [20,22] identified fear of ECT as its most predominant theme. There is a clear need to investigate this fear in more depth. Research is needed to identify and address those specific areas of the procedure that generate the most fear. Qualitative methods are the most appropriate for this, since what health care practitioners assume to be the basis of fear may not concur with patients' perceptions.

Attribution of cognitive decline and memory loss to ECT

Only one patient did not feel memory or cognition was affected: 'To me nothing was different'. All the other patients interviewed spontaneously complained of some form of memory impairment. This was universally attributed to ECT: 'I do think ECT was the one that did my memory, one zap too many'. This sentiment was often coupled with the perception that ECT had affected overall cognitive function: 'I think the ECT had an effect

Table 1. Themes developed through the framework approach of analysis (not in any order)

Side-effects of ECT, including short-term and current side-effects and the distress these caused Cognitive functioning and memory, including global impressions of functioning pre- and post-ECT Informed consent, including reasons for consenting and the educational video Knowledge of ECT, including lack of knowledge Social supports and family concern about ECT, including supports and isolation Experiences prior to ECT, including symptoms and treatments Negative experiences, including fear, anxiety, anger, secrecy, stigma, embarrassment Positive ECT experiences, including trust, efficacy Hospital experiences, including positive and negative, discrepancy between different sites Recommendations for the future, for other patients and for self Suicidal ideation, including pre- and post-ECT, reasons to live
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on my brain, I feel stupider'. This decrease in cognitive abilities was described as an overall feeling of diminished intelligence, or as a decrease in ability to be articulate. It was very frustrating: 'Basic little things like that become frustrating you know. Because before you wouldn't have had that problem and then suddenly you do'.

Short-term memory impairment was particularly distressing: 'I turned into a vegetable . . . I couldn't look after myself. I turned into a zombie between ECTs'. And: 'Waking up and not knowing who I was, or where I was, or even how to contact people'.

Although attribution of memory loss and cognitive decline to ECT was expressed strongly, patients would often display an element of uncertainty later on in the interview: 'I don't know whether it is through the ECT . . . maybe you just lose things as you get older'. Or: 'What do you blame for that? I don't know whether it is my condition or the ECT'. Or: 'But then do you blame the ECT? Do you blame the depression, you know? What do you blame for that?'.

Some patients complained of large gaps in memory about the actual procedure, yet they were able to describe the procedure in detail.

Memory and cognitive impairment were frequently perceived as being permanent: 'I feel like there are blank spots in my brain where I used to have information'.

Interestingly, attribution of memory loss to ECT did not necessarily result in a negative global impression. Some patients actually felt that memory loss was ECT's mechanism of action: 'You lose your memory so you don't know what you're unhappy about'. Or: 'I still don't know whether the treatments just made me forget how much I wanted to die'.

The literature on memory and cognitive impairment associated with ECT is extensive, controversial and contradictory [2,13–15,21,27–42]. Memory and awareness of cognitive abilities are such subjective concepts that it is difficult for the individual to pinpoint exact losses and be certain of their attribution. A common and still unresolved theme is whether depression or ECT is to blame for cognitive impairment [27,35,37,38,40,41]. Indeed, Prudic *et al.* concluded that this controversy is likely to persist as current objective tests of memory may not include components that are most affected in reports of subjective memory [30]. No studies explore in-depth what this subjective experience of memory and cognitive decline means to the patient's sense of self. Perhaps qualitative research could contribute to understanding this important effect from the patients' perspectives.

Related to memory and cognition is the question of informed consent. If patients do not recall having had the procedure explained to them ('I don't remember seeing

the video'), and in some instances do not recall having given informed consent, does their consent remain valid? Indeed, does the very nature of psychiatric illness acutely severe enough to warrant ECT compromise the ability to be legally competent to sign informed consent? For example, one patient gave consent in the belief (hope?) that the procedure may be fatal: 'I also felt there's a good chance that maybe I'll die'. Again, the literature on this topic is extensive and controversial [2–4,6,7,11,16,17,32,43–47].

Positive experiences of ECT

Despite much discussion regarding the negative effects of ECT, positive experiences were frequently mentioned.

Patients reported feeling pleasant emotions soon after they regained awareness; for example, a feeling of calm or empowering euphoria: 'I felt so good and I thought, "If this can happen, it's really terrific, I can work this world out".'

As they improved, many patients felt a global positive impact on their sense of self: 'I started feeling like my old self again'. It was apparent that it was as if their perception of reality had become clearer: 'Must have done some good for me . . . because I'm not as paranoid as I was . . . I'm a bit more normal . . . it really brought me back to reality'.

A frequent recognition throughout the interview was that of ECT having been a life saving procedure: 'I basically believe it saved my life – without ECT I would not be here, sitting talking to you today'. One patient was less effusive: 'Well, I'm not dead'.

For others, ECT became a positive experience because it was a proactive procedure: 'In one way it was nice to think that people cared about me'.

Reasons for positive experiences with ECT are more complex than simply its efficacy. Quantitative research, while overwhelmingly acknowledging the benefits of ECT, does not explore the perceived benefits in much depth [2–5,7–13]. Johnstone, in her important qualitative study, focused on the negative aspects of the ECT experience [20].

Patients' suggestions

Throughout the interviews many patients reflected on the changes they believed were required to provide a better experience of ECT. The weight of these suggestions as a theme was also due to the passion that some exhibited as they spoke. This was clearly an area of great importance to them: 'Don't start any machines, don't

strap peoples' heads – just get the person off to sleep, then string 'em up, hook 'em up, turn on the machines, zap 'em, put 'em in Recovery!'

Four principle suggestions emerged:

1. The waiting time prior to the procedure should be decreased: 'Waiting, when you've got to wait, you know. If you just go straight in, it's not so bad'.

2. Staff communication with patients both before and throughout the procedure, as well as the awareness of staff about the discomfort of the procedure should be addressed: 'But put one of them in a bed one day and put them through the same thing, they'd realize it's not such a pleasant experience'. Thus: 'I do believe the way it's orchestrated or whatever could be done better. A lot more of the patient in mind'.

3. Prevent patients being exposed to the discomfort of other patients. Because ECT at this hospital was performed in the General Theatre, patients, while they were being wheeled to theatre, or while in the Recovery area post-ECT would be exposed to varying degrees of patient distress. Some of the patients clearly thought that the pre- and postoperative distress of patients subject to other procedures was related to ECT. The Royal Australian and New Zealand College of Psychiatry (RANZCP) Guidelines for ECT [48] advocate the construction of purpose-built ECT suites, away from General Theatre.

4. All the patients who were interviewed felt that more research into what patients actually experience was needed.

One patient refused to give recommendations: 'I wouldn't comment. No, because my advice is so strongly against it, that's not fair if it might help somebody'.

In the scientific literature reviewed, no articles focused on what patients themselves would recommend about making ECT a less unpleasant experience.

Methodological considerations

This study has several limitations. Ideally, data collection should have continued until no new themes were identified. Time constraint, however, prevented the re-interviewing of patients, or interviewing other relevant parties such as relatives or treating doctors. There was a concern that the fact that the interviews were conducted in the Department of Psychiatry may have intimidated some patients into being less forthright about their views or willingness to criticize those who had participated in their treatment. The fact that the interviewers themselves were medical students and not qualified doctors may have mitigated against this concern. It should be noted that our findings were in no way devoid of negative opinion. Those who had strong views spoke

out with little inhibition. What was less certain was whether there were people in the mid-ground who felt more upset by aspects of ECT than they were prepared to divulge.

Our sample size was small. However, this is characteristic of qualitative research, which does not aim for generalizability of results to a population. We wanted to conduct an exploratory, qualitative study of patients' perceptions of their experiences with ECT. In this context, the small number should not be considered a methodological weakness. This study serves as the basis for more comprehensive qualitative and quantitative research. Along the same lines, the lack of a random, representative sample should not be considered a methodological flaw.

Conclusions

Through the use of qualitative methodology, information was discovered that has revealed new perspectives on how patients themselves perceive the experience of ECT. In addressing the patients' views of the actual procedure, their suggestions as to minimizing the longer-term psychological impact of ECT have been acknowledged. To address the psychological consequences caused by fear, as well as the perception of memory and cognitive decline, and what this does to sense of self, an increased focus on these areas in the months following the ECT could be considered. This may not only improve individual outcomes, but also contribute to a greater knowledge and understanding of the side-effects of ECT.

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