A large exploratory survey of electroconvulsive therapy recipients, family members and friends: what information do they recall being given?

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ABSTRACT

The right to informed consent is a core ethical principle. Recent audits of patient information leaflets about electroconvulsive therapy (ECT), in Australia, England, Northern Ireland, Scotland and Wales, suggest that this principle is often not implemented, with efficacy being exaggerated and risks minimised. In the current study a convenience sample of 858 ECT recipients and 286 family members and friends, from 44 countries, responded to an online survey about their experiences of ECT, including the information they recall being given to them before ECT. Most (59%) of the ECT recipients reported that they had not been given 'adequate information' and a further 17% were 'not sure'. For example, 63% of recipients recall being told that 'ECT can cause temporary memory problems', but only 17% that 'ECT can cause long-term or permanent memory problems, 12% that 'ECT can cause heart problems' and 28% that there are 'Risks from repeated general anaesthesia'. There were higher levels of recalling being told about definite benefits, even though some of these benefits are disputed. When asked to consider a list of items of misinformation, many recipients and relatives reported being told 'Depression is caused by a chemical imbalance in the brain' (58% and 53%, respectively) and 'ECT corrects chemical imbalance or other brain abnormality' (42% and 41%). Study limitations include potential sampling issues (eg, self-selection bias, snowball sampling bias, or other barriers to representativeness due to convenience sampling or network-based recruitment), as well as potential recall bias among survey respondents (last ECT treatment was between 1958 and 2024; average=2012.5). Nevertheless, these findings, in conjunction with previous studies, suggest an urgent need for greater efforts to ensure that patients and families are provided with comprehensive, balanced, evidence-based information when deciding whether to have ECT.

INTRODUCTION

Informed consent

The World Psychiatric Association's Code of Ethics[1] states:

> In pursuing informed consent, psychiatrists should offer patients accurate information about their diagnoses, proposed treatments, risks, potential benefits and alternatives (p. 4)

The Code of Ethics of the UK's Royal College of Psychiatrists[2] elaborates:

> All treatments and procedures have potential detrimental as well as beneficial effects, and so it is important that the patient, and their family if appropriate, is involved in partnership with the treating psychiatrist in the decision-making process. Valid consent must be obtained before embarking on a treatment course or procedure. [This involves…] the sharing of sufficient and understandable information to enable the patient to make an informed decision regarding the accepting or rejecting of treatment (p.11)

This paper summarises the self-reports of 738 electroconvulsive therapy (ECT) recipients and 217 family/friends about the information they recall being given prior to ECT.

Electroconvulsive therapy

ECT involves 6–12 administrations of electricity to the brain, under general anaesthesia, over several weeks, to produce tonic-clonic seizures. Since its invention in 1938, it has remained a controversial procedure.[3 4] More than 80 years after ECT was introduced, there is no consensus about risks, benefits, mode of action or dosing protocols. One meta-analysis reported that 'Views on ECT vary from researchers who consider that it is probably ineffective but certainly causes brain damage, through to those who think it is the most effective treatment available in psychiatry and is completely safe'.[4] Presumably, this lack of consensus about efficacy and safety contributes to what one international review described as 'large variation between continent, countries and regions in utilization, rates and clinical practice'.[5] A recent audit[6] found a 47-fold difference in rates of ECT usage between the highest and lowest using areas of England.

ECT and depression

Some of the disagreements about effectiveness and, therefore, about what information patients should receive, stem from the lack of consensus on the extent to which mood improvement following ECT is attributable to placebo effects.[3 7–11] A review of studies of placebo responses to ECT for depression found 'an unexpectedly high rate of response in the sham [SECT] groups'.[7] There have only been 11 placebo-controlled depression studies comparing ECT with 'sham'/'simulated' ECT (SECT),[8] in which the general anaesthetic is administered but the electricity and convulsion are withheld. The most recent was forty years ago, in 1985. A review,[8] coauthored by Dr Irving Kirsch, Associate Director

of Harvard Medical School's Programme in Placebo Studies, found that all 11 studies failed to comply with today's methodological standards. The review concluded:

> Four of the 11 found ECT significantly superior to SECT at the end of treatment, five found no difference and two found that psychiatrists reported a difference and patients did not. Neither of the only two high Quality studies reporting data at one or six months post-treatment produced a significant difference between ECT and SECT and, when combined, they produced a very small pooled effect (0.017) in favour of SECT.

ECT and schizophrenia

An analysis of Cochrane reviews[12] concluded that 'What is common in all versions of these Cochrane reviews is that in spite of seven decades of clinical use of ECT for people with schizophrenia, there still is a lack of strong and adequate evidence regarding its effectiveness'. The UK's National Institute for Health and Care Excellence (NICE) current guidelines state that ECT 'is not recommended for general use in managing schizophrenia'.[13] The most recent placebo-controlled study found no difference between ECT and SECT.[14]

ECT and suicide

A meta-analysis by the UK Government's ECT Review Group[4] concluded: 'Although ECT is sometimes thought to be a life-saving treatment, there is no direct evidence that ECT prevents suicide'.[8 15 16]

ECT and memory loss

While most authorities agree that memory disturbance can be caused by ECT,[2 4 17–19] there is no consensus on how common, long-lasting or severe the disturbance is.

The first large prospective study[20] found that retrograde (autobiographical) memory was significantly impaired ($p<0.0001$) compared with pre-ECT levels, 6 months later. Twelve per cent had 'marked and persistent retrograde amnesia'. Impairment was greater among women and those receiving bilateral rather than unilateral ECT.

A 2003 review[21] identified four studies (n=703) that had asked the patients themselves about 'persistent or permanent memory loss', producing a range of 29%–55%, and an average of 38%. A recent meta-synthesis of 16 studies reporting pateints' experieinces[22] found that:

> … in 15 papers, participants described complete erasure of their memory of events and experiences that occurred prior to, and sometimes immediately after, having ECT. Some participants described not remembering specific important life events, like a son's birth or their mother's death. For others memory loss was extensive: "the past 25 years are missing". This memory loss was usually considered permanent.

The American Psychiatric Association[17] recently acknowledged that 'some individuals may report having memory problems that remain for months or years, or even permanently'.

ECT and heart attacks

A 2019 review reported that 'approximately one in 50 patients develop major adverse cardiac events after ECT'.[23] A subsequent review[24] concluded:

> Having corrected and updated the 2019 review with five subsequent studies, it is calculated that the probability of ECT causing one or more of six cardiac events (myocardial infarction, life-threatening arrhythmia, acute pulmonary edema, pulmonary embolism, acute heart failure and cardiac arrest) is between one in 15 and one in 30 patients, and that these cardiac events are a major cause of ECT-related deaths.

In summary, there remains considerable dispute about the benefits and risks of ECT. The discussion above covers only the most claimed and reported benefits and adverse effects. It is not exhaustive.[21 22 25 26]

ECT and informed consent

An audit of patient information leaflets at 36 ECT clinics in England found that 'Patients are being misled about the risks they are taking and the limited nature of ECT's benefits'.[27] Specifically:

> The most common inaccurate statements included: ECT corrects biological deficits; misleading claims of very low mortality risk; minimization of memory loss; claims that ECT saves lives; and claims of very high improvement rates. The current (2020) RCPsych leaflet contained seven inaccurate statements.

A subsequent audit, in Northern Ireland, Scotland and Wales,[28] concluded:

> Electroconvulsive therapy information leaflets in these three nations are barely more accurate than those in England and do not comply with the ethical principle of informed consent. Patients and families across the UK are systematically being misled about the risks they are taking and the limited nature of ECT's benefits.

(The key sources of research evidence supporting the definition of statements as accurate or inaccurate for the purposes of the two audits, and supporting the choice of questions for the current paper, are provided in the second audit[28]).

An audit in Australia[29] found that ECT information sheets, including that of the Royal Australian and New Zealand College of Psychiatry, 'lacked accuracy and balance' and that 'Linguistic tools were used to exaggerate positive outcomes and minimise negative effects'.

In 2013, Blease[9] argued:

> In the case of procedures such as ECT which carries potentially very serious side effects, the need for improvement in patient information can be regarded as timely. Given the prevailing variety of claims made about the effectiveness of ECT (from straightforward endorsement for severe depression, to qualified concerns, to outright repudiation of its use as a therapeutic tool), it seems only appropriate that patients are informed of these serious controversies.

Other commentators critiqued Blease's interpretations of the research and argued that too much information may dissuade patients from accepting treatment.[11 30] Blease's response[10] included:

> Advocating a paternalistic policy of not providing full or relevant information is risky: it is one that assumes that patients cannot handle information or are not equipped to make their own medical decisions

In the UK NICE[18] has long noted the absence of clear, evidence-based information for patients, and recommended:

> National information leaflets should be developed through consultation with appropriate professional and user organisations

> to enable individuals and their carers/advocates to make an informed decision regarding the appropriateness of ECT for their circumstances. The leaflets should be evidence based, and include information about the risks of ECT and availability of alternative treatments.

In 2008, the United Nations[31] declared:

> It is of vital importance that ECT be administered only with the free and informed consent of the person concerned, including on the basis of information on the secondary effects and related risks such as heart complications, confusion, loss of memory and even death.

In 2023, a joint report by the WHO and the United Nations[19] confirmed that:

> People being offered ECT should be made aware of all its risks and potential short- and long-term harmful effects, such as memory loss and brain damage.

The current paper reports the information provided to ECT recipients, as recalled by them. Relatives and friends were also included because: (1) they are seldom asked about their experiences of the process or outcomes of ECT, (2) the outcomes can impact them and their relationships with the recipient, and (3) it might be informative to compare their account of information received with that of recipients, especially given the memory problems encountered by many people after having ECT (see Limitations).

METHODS

The methodology employed, described below, is the same as that used by multiple previous online surveys about other psychiatric treatments, using large convenience samples of people with experience of the treatments.[32–35]

Instrument

The anonymous, cross-sectional survey consists of questions based on previous research, briefly summarised above, and the personal experiences of the three members of the research team who have received ECT. *Mind*, the UK's largest mental health charity, commented on a draft. The feedback was provided by a member of *Mind*'s information team which oversees its own surveys and outputs, and which, in conjunction with *Mind*'s lawyers and ECT recipients, had recently been involved in their own work on ECT.

There are quantitative questions, with yes/no/don't know, multiple choice, or Likert Scale responses, and qualitative questions inviting written responses. The survey (see online supplemental file for complete survey) includes questions about the year, country, type and number of ECTs; reasons ECT was given; positive and adverse effects; monitoring of cognitive problems; self-reported causes of the problems for which ECT was given, and whether those were addressed by psychiatric services, whether they would recommend ECT, and information given before ECT. The survey was designed to take 25–30 min to complete. There was a maximum possible total of 84 questions, depending on how many follow-up questions were triggered. Questions were not mandatory (other than the informed consent questions).

At the start of the survey, potential participants were provided with a participant information sheet (see online supplemental material). Participants had to be over 18 years old and either have had ECT (not in the past 4 weeks) or be 'a friend or relative with an understanding of the impact of ECT' on the person concerned. To avoid people feeling pressured to participate, and preclude possible bias from ECT staff, the Introduction states 'Mental health professionals must neither invite their patients/clients to complete the survey nor complete it on behalf of their patients/clients'. The Participant Information Sheet listed sources of support in case participants were distressed by the content.

The survey, and the administration and reporting thereof, met all applicable criteria of the Consensus-Based Checklist for Reporting of Survey Studies.[36]

Information questions

Family members and friends were asked 'Were you involved, with X, in the process of being given information about ECT?' Those who replied 'yes', and all ECT recipients, were asked 'Did any of the doctors or nurses involved tell you about the following [seven] potential adverse effects?' (see table 1), followed by 'Did any of the doctors or nurses tell you any of the following' six statements (see table 2). Finally, everyone was invited to 'Please add up to two other things the doctors/nurses told you about ECT, if any.'

The data relating to these questions are available on request from the corresponding author (JR).

Responses to other questions

Responses to the other questions are being published elsewhere, specifically: Self-reported positive and negative effects (from open questions);[37] Efficacy;[38] Incidence, severity and duration of memory deficits;[39] Adverse effects beyond memory loss;[26]

Table 1 'Did any of the doctors or nurses tell you about the following potential adverse effects?'

	Recipients*			Family/friends†		
	Informed	Not informed	Not sure	Informed	Not informed	Not sure
ECT can cause temporary memory problems	468 (63.4%)	175 (23.7%)	95 (12.9%)	54 (74.0%)	14 (19.2%)	5 (6.8%)
ECT can cause long-term or permanent memory problems	126 (17.2%)	504 (68.9%)	102 (13.9%)	36 (49.3%)	32 (43.8%)	5 (6.8%)
Women are more likely to have memory problems	39 (5.3%)	598 (81.9%)	93 (12.7%)	13 (17.8%)	40 (54.8%)	20 (27.4%)
Older people are more likely to have memory problems	67 (9.2%)	532 (72.9%)	131 (17.9%)	21 (28.8%)	34 (46.6%)	18 (24.7%)
Bilateral ECT is more likely to cause memory problems	156 (21.4%)	471 (64.6%)	102 (14.0%)	33 (45.2%)	27 (37.0%)	13 (17.8%)
ECT can cause heart problems	85 (11.6%)	532 (72.8%)	114 (15.6%)	24 (32.9%)	34 (46.6%)	15 (20.5%)
Risks from repeated general anaesthesia	204 (27.9%)	410 (56.1%)	117 (16.0%)	41 (56.2%)	22 (30.1%)	10 (13.7%)

*n=729–738
†n=73
ECT, electroconvulsive therapy.

Table 2 'Did any of the doctors or nurses tell you any of the following?'

	Recipients*			Family/friends†		
	Told	Not told	Not sure	Told	Not told	Not sure
Depression caused by chemical imbalance in the brain	428 (58.3%)	142 (19.3%)	164 (22.3%)	38 (52.8%)	22 (30.6%)	12 (16.7%)
ECT corrects chemical imbalance or other brain abnormality	311 (42.3%)	215 (29.3%)	209 (28.4%)	29 (40.8%)	30 (42.3%)	12 (16.9%)
ECT can be life-saving/prevents suicide	500 (68.2%)	128 (17.5%)	105 (14.3%)	56 (77.8%)	7 (9.7%)	9 (12.5%)
ECT is the most effective treatment for severe depression	465 (63.3%)	143 (19.5%)	127 (17.3%)	45 (62.5%)	11 (15.3%)	16 (22.2%)
No evidence ECT has any long-term benefits	86 (11.9%)	503 (69.4%)	136 (18.8%)	7 (10.1%)	47 (68.1%)	15 (21.7%)
Legal rights in relation to ECT	156 (21.5%)	381 (52.6%)	188 (25.9%)	37 (53.6%)	23 (33.3%)	9 (13.0%)

*n=725–735
†n=69–72
ECT, electroconvulsive therapy.

Problems for which ECT was prescribed and whether those had been addressed;[40] Impact of ECT on families;[41] ECT and women.[42]

Procedure

The questionnaire was disseminated, via Qualtrics, from 16 January to 30 September 2024. The researchers contacted a large range of mental health organisations in all continents except Antarctica. For example, all 44 national group members of Mental Health Europe (www.mentalhealtheurope.org), an independent non-governmental network organisation, were emailed and asked to disseminate the survey to their members and other mental health groups in their countries (see online supplemental file section 2, for an example of emails). The survey was also disseminated on social media, including Instagram, Facebook, Twitter/X and YouTube (see online supplemental file section 3, for the study advertisement to which social media posts were linked).

Data analysis

1211 respondents answered at least some questions. There were 63 repeat responses (identified by IP address), 55 of which were deleted because the demographics and/or responses were similar. Twelve responses were deleted because of grossly discrepant responses (eg, last ECT at age 16 years, first at 100 years), 'straight-lining' on at least three questions (selecting same option for lists of multiple items, eg, 'severe' for all 27 side effects), being a recipient's nurse, or because more than one relative of the same patient had responded. Removing these 67 (5.5%) left 1144 for analysis. Most of these (837, 73.2%) completed all questions; the other 307 left one or more questions unanswered. The responses are presented as frequencies and percentages.

Table 3 Responses based on the 682 ECT recipients who recalled at least one piece of information

ECT can be life-saving/prevents suicide	500	(73.3%)
ECT can cause temporary memory problems	468	(68.6%)
ECT is the most effective treatment for severe depression	465	(68.2%)
Depression is caused by chemical imbalance in brain	428	(62.8%)
ECT corrects chemical imbalance or other brain abnormality	311	(45.6%)
Risks from repeated general anaesthesia	204	(29.9%)
Bilateral ECT is more likely to cause memory problems	156	(22.9%)
Legal rights in relation to ECT	156	(22.9%)
ECT can cause long-term or permanent memory problems	126	(18.5%)
No evidence ECT has any long-term benefits	86	(12.6%)
ECT can cause heart problems	85	(12.5%)
Older people more likely to have memory problems	67	(9.8%)
Women more likely to have memory problems	39	(5.7%)

ECT, electroconvulsive therapy.

RESULTS

Sample characteristics

Demographics

The 1144 respondents comprised 858 ECT recipients and 286 family members (216) or friends (70). Respondents were from 44 countries, most frequently USA (46% of ECT recipients, 37% of relatives/friends), UK (14%, 28%), Australia (11%, 6%), Canada (8%, 4%), Spain (2%, 5%), New Zealand (2%, 2%) and Ireland (2%, 2%). Other countries, providing up to 15 respondents in total, were: Austria, Belgium, Brazil, Bulgaria, Chad, Colombia, the Czech Republic, Denmark, Egypt, El Salvador, Finland, France, Germany, Greece, Guatemala, Hungary, Iceland, India, Iran, Iraq, Israel, Italy, Lithuania, Mexico, Netherlands, Norway, Pakistan, Poland, Saudi Arabia, Slovakia, South Africa, South Korea, Sweden, Turkey, Turkmenistan, Uruguay and Venezuela.

Most respondents were white (87% of recipients, 89% of recipients reported by family/friends). Most were female (73% of recipients, 68% family/friends). The average age at the time of last ECT was 41.9 years (recipients) and 41.7 years (family/friends), ranging from 12 years to 87 years. Most ECT recipients (73.0%) had their last ECT between 2010 and 2024, and 1.7% between 1950 and 1969. The respective figures for family/friends were 58.6% and 9.9%.

Reasons for ECT

When the ECT recipients were asked to select one or more reasons why ECT had been given, 74.3% chose 'Depression', 17.2% 'Psychosis/schizophrenia', 15.3% 'Bipolar disorder/mania', 7.8% 'Catatonia', 12.8% 'Other' and 5.7% 'Don't know'.

Information

Of the 735 ECT recipients who answered 'Were you given adequate information about ECT before having it', 178 (24.2%) said 'yes', 431 (58.6%) 'no' and 126 (17.1%) were 'not sure'.

Of the 217 relatives/friends who answered 'Were you involved, with X, in the process of being given information about ECT?', 74 (34.1%) said that they were involved. Of the 73 who answered 'Were you and X given adequate information about ECT?', 44 (60.3%) said 'yes', 20 (27.4%) 'no' and 9 (12.3%) were 'not sure'.

Table 1 summarises the responses of 729–738 recipients, and 73 family/friends, to the seven questions about being told about adverse effects. Table 2 presents the responses of 725–735 and 69–72 family/friends to the questions about being told the six other pieces of information.

Table 4 'Please add up to two other things the doctors/nurses told you about ECT, if any'

Minimising memory loss and/or other adverse effects	154	*See table 5 for subcategories and examples*
Last resort/no other options left	51	They had run out of options…meds did not work. It was the only thing that could help me. No other choices. It is the last solution. They meant well. Last opportunity to get better. A last ditch effort for people who are treatment resistant. The only choice for treatment resistant depression.
Fast acting	15	Provides fast improvements regarding suicidality. Fastest way to treat depression, would essentially "snap you out of your depression immediately". Most fast-acting treatment for suicidal ideation. Faster than medication. Quicker than antidepressants.
ECT 'resets'/'reboots' the brain	12	ECT would reboot my brain like a computer. You are rebooting your damaged brain. It will reset your brain chemistry. ECT will reset the brain electrically and allow it to function normally.
Don't know how ECT works	10	Professionals didn't understand why/how ECT works. We don't know how it works, we just know it does.
'Miracle'	5	A miracle cure. They've witnessed it perform miracles.

ECT, electroconvulsive therapy.

Because not remembering being told something, or being 'not sure', does not mean one was not told it, especially for information imparted just before ECT (see Limitations), percentages were calculated for the 682 who *did* remember being told at least one piece of information. These are presented in table 3.

Comparisons *between* items are more reliable than the raw data in tables 1–3. For example, one can calculate that recipients were about 3.7 times more likely to have been told about temporary memory problems as they were about long-term/permanent memory problems. They were about 5.4 times more likely to be told ECT is the most effective treatment for severe depression than they were to be told there is no evidence it has any long-term benefits. They were about 5.9 times more likely to be told ECT can be 'life saving/prevents suicide' than to be told that it can cause heart problems.

Other information

363 recipients, and 37 family/friends, provided up to two 'other' pieces of information that they recalled being told. Responses given by five or more people are presented in table 4. The most common information reported (154 recipients and 11 family/friends) involved minimising memory loss or other adverse effects in various ways. Table 5 shows that the most common ways that adverse effects were minimised were to deny any long-term effects (51) or simply state that ECT is 'safe' (34). 51 respondents recall being told ECT was the only option, mostly because psychiatric drugs were ineffective. (One person was told 'The only memories that would be erased would be those negative memories causing depression'.)

Table 5 'Other' things doctors or nurses said about ECT: Ways that memory loss and other adverse effects are minimised

No long-term adverse effects; short-term only	52	No long-term side effects. No long-term negative impacts. Memory problems would go away after 6 weeks. No permanent effects. No side effects are permanent. No permanent side effect. Only temporary memory loss. All side effects are temporary.
'Safe'	34	Safe. Extremely safe. Incredibly safe. I'm completely safe with ECT, even though I asked about long term memory effects. Safe & harmless. Safer than medication. "Safe & effective." I heard this over and over, like a catchphrase, from everyone involved.
Focus on headaches	13	Worst thing you would feel afterwards was a little headache. Might have a headache on the day.
No side effects	12	I was told that there is no negative effects of ECT. There were no risks. Harmless. He told me that he had never had a patient who experienced memory loss as a result of ECT… And he'd been the main ECT doctor at Yale psychiatric ward for several decades. A nurse told me it's funny that I'm the only person experiencing a bad reaction, everyone else is fine.
Memory loss only around time of treatment	10	Memory loss would only be during the time of ECT. Any memory loss would be very short lived and only impact memories of immediately before the ECT.
Memory loss caused by depression, not ECT	8	That memory problems were most likely caused by depression. The memory loss was caused by depression. Any long term effects were from the mental illness and not ECT. His memory issues are not caused by ECT.
No brain damage	7	Doesn't cause brain damage. Said it doesn't cause brain damage, but rather is good for the brain. Won't cause brain damage or heart damage. "Dont google ECT" because the common opinion that it caused brain damage is false.
Memory loss in the past, not now	7	Did cause memory problems in the past but had been improved and was now safe. It was new and improved from 30 years ago. Said it's improved, no longer like in the movie One Flew Over the Cuckoo's Nest
'Rare'/'unlikely'	6	Memory issues were extremely rare. Complications were rare.
'Minimal'/ 'mild'	5	Side effects generally mild. The risks were minimal because I was young and healthy. It's mild, no big deal.

ECT, electroconvulsive therapy.

DISCUSSION

These findings are broadly consistent with the recent audits of information leaflets in Australia,[29] England[27] and the rest of the UK,[28] all of which found exaggeration of effectiveness and minimisation of risks. The minimisation of risks, particularly long-term adverse effects, was pronounced, in both our quantitative and qualitative data.

The findings are also consistent with findings that most users of antidepressants[32–34] and antipsychotics[43] are not fully informed about most of their adverse effects.

The finding that about half of respondents (58.3% recipients; 50.0% family/friends) reported being told that depression is caused by a chemical imbalance should be considered in the context of there being no robust evidence for that long-standing hypothesis.[9 44] There is also no evidence that 'ECT corrects a chemical imbalance or other brain abnormality', and yet 42.3% of recipients and 37.9% of family/friends report being told this.

Family and friends

Families and friends reported being told about adverse effects more often than recipients; for example, about three times as often regarding long-term adverse effects and about heart complications. This would seem to be an artefact of the fact that these findings are based only on the third (34.1%) that were involved in information sharing, thereby ignoring the two-thirds who were given no information. It could also indicate, however, that some ECT recipients had forgotten what they were told. See 'Limitations'.

The American Psychiatric Association

The 2025 edition of the American Psychiatric Association's Task Force Report on 'The Practice of Electroconvulsive Therapy'[17] recommends patients be told that 'there is no guarantee that ECT will be effective', that there is a 'substantial risk of relapse after an acute course of ECT', that 'major risks' include 'mortality, adverse effects on cardiovascular and central nervous systems (including both transient and persistent cognitive adverse effects)' (p. 128), that 'some individuals may report having memory problems that remain for months or years, or even permanently' and that 'bilateral ECT is more likely than right unilateral to lead to memory difficulty' (p 315). There is no mention, in the 470-page report, however, of any research about how often patients are actually told any of those things.

Limitations

The results are, of course, dependent on memory, in some instances for events many years previously. (Although 73.0% of recipients had their last ECT in the last 15 years, 6.7% had it before 1990). Events in the period just before ECT are particularly vulnerable to being lost because of the ECT. Therefore, recipients reporting that they did not recall being told something, or who were 'unsure', does not definitely mean they were not told it. Tables 1 and 2 show that between 12.7% and 28.4% of recipients were 'not sure' about whether they were told various things. Figures in table 3, based only on percentages of those who did recall at least one piece of information, are therefore probably more reliable than the figures in tables 1 and 2. Furthermore, the *relative* frequencies, comparing the probabilities of being told various pieces of information with each other, are probably even more informative.

Sample bias towards those for whom ECT had a *negative* outcome may have occurred. The survey was disseminated on social media by the researchers, some of whom have critiqued ECT in research papers and online. This could have meant either that people dissatisfied with the information they received were more likely to participate in the study, or that those who did participate exaggerated the inadequacy of the information received. To minimise this potential sample bias, social media posts and emails to NGOs (see online supplemental file 1) included phrases like 'This is your opportunity to share your experiences of this treatment, positive, negative or mixed'.

Sample bias in favour of people who had a *positive* outcome was also potentially present, in four forms. Those for whom ECT had failed to alleviate the severe depression for which it is often prescribed might be uninterested in, or unable to complete, a survey. Second, those whose suicidality was not alleviated by ECT, and who have killed themselves, could not respond. Third, patients who died during or soon after treatment due to cerebral or cardiovascular events[23 24] did not participate. Fourth, some people in whom ECT caused severe cognitive damage may have been unable to participate.

It is impossible to know whether either of these two types of bias, towards people with a generally positive or negative view of ECT, was operating. The same two types of bias potentially influenced similar surveys of other psychiatric treatments.[32–35] All these studies produced a wide range of views, as did the current study. For example, when asked 'what effect did ECT have on your mood', 41% of ECT recipients endorsed 'better' or 'much better', 30% selected 'no difference' and 29% chose 'worse' or 'much worse'.[38]

Affective biases could also have influenced responses. Adverse effects might be particularly likely to be attributed to an unusual and, for some, frightening intervention which is negatively portrayed in the media.

We did not recruit adequately from countries beyond North America, Europe and Australasia. Providing the survey in multiple languages is recommended for future surveys.

Although 5.5% of responses were considered problematic and discarded (see Data analysis), it is possible that some people who were neither ECT recipients, nor relatives/friends thereof, completed the survey. Mental health professionals were requested 'not to complete the survey nor complete it on behalf of their patients/clients'. It is conceivable that some completions by professionals went undetected. There may have been other motivations for fake completions. We did not take steps to prevent 'research bots'.[45] The absence of financial incentive for participation may have reduced the probability of fake completions.

The methodology, including exclusion criteria and analysis plan, was not preregistered.

CONCLUSIONS

Despite the subjectivity involved, patient-reported outcome measures are increasingly being used.[46] A study of internet-based surveys in the English National Health Service found that 'patients' website ratings of hospitals and more conventional measures of patient experience from large random surveys are significantly correlated'.[47] It concluded, 'Our findings add to the increasingly persuasive literature promoting the notion that one needs to view safety, quality and service delivery through a number of lenses to get an accurate picture'.

Our international survey, the largest ever conducted, seems to confirm audits of ECT leaflets, in Australia[29] and the UK,[27 28] which found that the principle of informed consent is being consistently breached.

The legal implications of not ensuring informed consent are substantial. In 2023, after 7 days of trial proceedings in Florida, the jury in Thelen v. Somatics (a manufacturer of ECT machines) 'found that Somatics failed to warn about the risks associated with its ECT devices'.[48]

In a rebuttal of a critique of their 2023 Guidance on mental health and human rights, by prominent ECT proponents,[49] the WHO recently wrote (along with ECT recipients and researchers, including JR and SH) the following:[50]

> Informed consent requires the provision of accurate information about a treatment's efficacy - for example, people should be

informed that controlled trials have found outcomes from ECT to be comparable to those from placebo, or sham ECT, where individuals receive general anesthesia but no electrical stimulation (Read *et al*, 2019). It also requires information on potential side effects and risks of harm, enabling individuals to make autonomous, informed decisions.

If efforts to persuade hospitals and clinics to comply with the ethical principle of informed consent by providing balanced, comprehensive, evidence-based information are unsuccessful,[51] professional, regulatory and government organisations should intervene.

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