

Adverse psychological effects of ECT

LUCY JOHNSTONE

University of the West of England, St Matthias Campus, Oldbury Court Road, Fishponds, Bristol, UK

Abstract:

Although it is known that a proportion of people find ECT distressing to receive, these adverse psychological reactions are little understood. Twenty people who reported having found ECT upsetting were interviewed about their experiences in detail. A variety of themes emerged, including feelings of fear, shame and humiliation, worthlessness and helplessness, and a sense of having been abused and assaulted. This had reinforced existing problems and led to distrust of psychiatric staff. Few had felt able to tell professionals of the strength of their reactions, implying a possible hidden pool of trauma. Implications for the practice of ECT are discussed.

Introduction

Although ECT (electroconvulsive therapy) is widely used in depression and some other conditions, it continues to attract controversy. Disagreement mainly centres around the possibility of memory loss and intellectual impairment, with the generally accepted official view being that 'As far as we know, ECT does not have any long-term effects on your memory or your intelligence' (Royal College of Psychiatrists, 1997). Although the debate about cognitive impairment has received much attention (Breggin, 1991; Frank, 1990; Friedberg, 1976), the question of possible unwanted psychological effects has, until recently, been almost totally neglected. No mention is made of them in most summaries of adverse effects, such as that in Weiner & Krystal (1994). The ECT handbook contains a single paragraph referring briefly to pre-

treatment anxiety (Royal College of Psychiatrists, 1995). This omission has been commented on both by psychiatrists: 'Doctors who give ECT have shown remarkably little interest in their patients' views of the procedure and its effects on them and only recently has this topic received any consideration in the literature' (Abrams, 1997) and by service users: 'What is never discussed in the literature is the profoundly damaging psychological effects ECT can have' (Lindow, 1992).

This is in contrast to earlier, mainly psychoanalytic, theorising about the psychological impact of ECT. Psychogenic theories of ECT's action were summarised in a review article by Cook (1944). Earlier belief in the therapeutic effects of fear had been largely replaced by theories about the healing nature of this symbolic death and re-birth. There was speculation along Freudian lines that the fit 'by its severe motor manifestations "dis-

Address for Correspondence: Lucy Johnstone, Senior Lecturer in Clinical Psychology and Counselling, University of the West of England, St Matthias Campus, Oldbury Court Road, Fishponds, Bristol BS16 2JP, UK. Tel: 0117 965 5384; Fax: 0117 976 2340; E-mail: Lucy.Johnstone@uwe.ac.uk

charges” large amounts of energy inherent in the destructive and death drives and unloads them in a...harmless manner’. Gordon (1948) listed 23 possible psychological explanations of ECT’s effects, such as the destruction of narcissistic protective patterns and the eroticising of the body. Some clinicians believed that these and other hypothesised reactions, such as the relief from guilt and self-punishment following the experience of ‘a sadistic, real attack’, made the conjunction of ECT with psychoanalysis a particularly fruitful one (Weigart, 1940 in Boyer, 1952). Boyer includes a lengthy case history in which the young female client equates ECT in fantasy not only with death and re-birth, but also with intercourse, castration and impregnation, with ultimately favourable results in her therapy.

On a less positive note, Abse & Ewing (1956) noted that conscious attitudes towards ECT are ‘time and again’, in long-term therapy, succeeded by feelings that it was cruel and destructive. There is ‘a revival of threatening and punitive parental figures’ who are often, like the physician, initially credited with good intentions. The ECT appears to arouse anxiety and fear, while at the same time holding out hope of forgiveness and a fresh start. Wayne (1955) noted that certain aspects of the procedure may evoke unconscious meanings in both doctor and patient; for example, ‘It has all the characteristics of an overwhelming assault...and this can be documented by the reactions of some patients who have had this treatment’. Fisher *et al.* (1953) investigated the conscious and unconscious attitudes towards ECT in 30 psychotic patients, and concluded that ‘the majority of patients found electric shock to be a traumatic experience’. D.W. Winnicott (1947) argued that psychological reactions to ECT often compounded patients’ difficulties and defences; for example, obsessional people might need to become even more controlled.

An exception to these analytically-orientated accounts is Warren’s (1988) description of the implications of ECT for the self and for family relationships. In her interviews with ten women admitted to a state hospital in California between 1957 and 1961 and their relatives, there was uniform confusion and bewilderment at the loss of memory in everyday life. Sometimes this forgetfulness, for example of previous hostile outbursts, was welcome to their husbands. Fear of future ECT stopped some women from confiding emotional upsets, and family relationships were subtly altered all round.

With the general decline of psychoanalytic influences on psychiatry, theorising and research in this area appears to have been abandoned until Gomez’s survey (1975) of side-effects in 96 ECT patients. Findings from this and other attitude studies (for example, Freeman & Kendall, 1980; Hughes *et al.*, 1981; Kerr *et al.*, 1982) were reviewed in Freeman & Cheshire (1986). Subsequent studies by Malcolm (1989), Szuba *et al.* (1991), Riordan *et al.* (1993) and Pettinati *et al.* (1994) used essentially the same format of asking patients to respond to questions or complete checklists about their attitudes to and experience of ECT. The conclusions from this series of investigations can be summarised as follows:

- Most people appear to find ECT helpful (varying from 83% in Hughes *et al.* to 56% in Riordan *et al.*).
- Most people also report side-effects, (around 80% in all studies), with memory impairment complained of most frequently, and headaches and confusion mentioned less frequently.
- Most people do not seem to find ECT particularly frightening to receive (Freeman & Kendall); 50% less so than a visit to the dentist. However, a majority does experience some level of anxiety (74% in

Gomez, 69% in Riordan *et al.*), and a significant minority reports much stronger reactions; (13.1% said it was so upsetting that they would not want it again, Freeman & Kendall; 14.3% say it was more upsetting than surgery, Pettinati *et al.*; 23.7% agreed with the statement that ECT is a barbaric, inhumane treatment, Kerr *et al.*).

- Most people do not report other anxieties about ECT, although a minority does mention worries about brain damage. Death, personality change and being anaesthetised are also feared by some.
- Most people who have had ECT are profoundly ignorant about the whole procedure, and say that they were given no or inadequate explanations. (Sixty-nine per cent did not know that ECT involved a convulsion, Hughes *et al.* Only 21% said they were given a good explanation of the procedure, Freeman & Kendall.) It is not clear how much these findings were influenced by memory loss.

(Two other studies produced broadly similar results, but are not directly comparable to those described above because scores for each item were averaged across all responses. See Caley *et al.*, 1991; Baxter *et al.*, 1986.)

In summary, these studies would seem to justify Freeman & Kendall's (1980) often-quoted conclusion that patients find ECT 'a helpful treatment and not particularly frightening.' However, there are reasons for believing that the picture may be more complicated than this.

First, there are the limitations acknowledged by Freeman & Kendall, which may apply to some extent to all these psychiatrist-led investigations: 'It is obviously going to be difficult to come back to a hospital where you have been treated and criticise the treatment that you were given in a face-to-face meeting with a doctor.' Earlier researchers certainly

found such factors to be relevant: 'The majority of the patients seemed to be motivated by the idea that any criticism that they might make of shock would in an indirect sense be a criticism of the psychiatric staff... patients expressed themselves sincerely only after the interviewers spent considerable time in establishing a relationship'. (Fisher *et al.*, 1953.)

Secondly, there is the unusual degree of compliance noted by several investigators, who were puzzled by patients' willingness to agree to ECT despite being anxious and ill-informed: 'We were left with the clear impression that patients would agree to almost anything a doctor suggested' (Freeman & Kendall, 1980). Referring to the same phenomenon, Riordan *et al.* (1993) suggested, 'This may reflect a high level of trust, or a resigned lethargy, in part reflecting mental state, but also a feeling of lack of involvement in their own management'. Freeman & Kendall (1980) quote a particularly striking example: 'Two patients who misunderstood the initial appointment letter ... came fully prepared to have a course of ECT. Neither had been near the hospital for nine months and both were quite symptom-free.' Little attempt was made to explore the meaning of this kind of behaviour, but it does raise the question of whether the absence of criticism reflects satisfaction, or merely learned helplessness and passivity.

Thirdly, there is the fact that a minority of people in all the studies did express very strong negative feelings about ECT, although this has been obscured by focusing on the majority view. In the only paper that acknowledges this as a problem, Fox (1993) describes how a 'difficult-to-elicited, etiologically obscure and currently under-recognised "pathological" fear of treatment develops in some proportion of patients undergoing ECT... Fear of ECT merits further study'.

Fourthly, there are several recent surveys carried out by investigators from outside the hospital setting which paint a much less reassuring picture. In the first one, UKAN (United Kingdom Advocacy Network) received 306 replies to a questionnaire distributed through UKAN-affiliated groups, Mindlink and Survivors Speak Out (both the last being service-user run organisations). Overall, 35.1% described ECT as ‘damaging’ with another 16.5% saying it was ‘not helpful.’ Although 30.1% found that it was helpful or very helpful, those who did not were likely to express very strong views against it, using words like ‘brutal’, ‘barbaric’ and ‘degrading’. Psychological after-effects included loss of confidence, dignity and self-esteem; fear of hospitals and psychiatry; anger and aggression; loss of self; and nightmares (Ukan, 1996). Similar themes emerged from a series of semi-structured interviews with 516 psychiatric patients contacted through MIND (Rogers *et al.*, 1993). While 43% found ECT helpful or very helpful, a large minority (37.1%) said it was unhelpful or very unhelpful, with a high proportion of the latter group strongly condemning it. Psychological effects included fear, flashbacks and nightmares. The same themes emerged from two smaller surveys by two researchers who had had ECT themselves, (Wallcraft, 1987; Lawrence, 1997) and from MIND’s (1995) survey on ‘Older Women and ECT’. In addition, the recently formed organisation ECT Anonymous has collected several hundred reports from people who say that ECT has had a variety of disabling physical and psychological effects on them. However, respondents from all these sources were self-selected and might show a bias towards greater dissatisfaction.

In summary, all of the more recent research acknowledges that a proportion of people have very strong reactions against ECT, although very little is known about the nature

of, and reasons for, these adverse psychological effects. The differences between the reported rates of adverse reactions (varying from 13.1% in the hospital-based surveys to 35.1% in the others) also remain puzzling.

While some of the earlier accounts may seem far-fetched, they do make an important point that has been over-looked in most subsequent surveys, that ‘there are crucial psychodynamic events involved in...organic therapy’ (Abse & Ewing, 1956) and that attitudes can influence the outcome of the treatment. (Fisher *et al.*, 1953; Hillard & Folger, 1977). Clearly, we need to know more about the meanings that ECT carries for a certain number of recipients, and which make it such a traumatic event for them. This may also throw some light on issues such as compliance and its possible effects on participants’ responses. In order to investigate these areas, the existing questionnaires and pre-structured checklists of possible reactions need to be complemented by an approach that allows a detailed, in-depth exploration of the experiences of those people who find ECT a distressing event, entirely separate from the hospital setting. For these reasons a qualitative design was used in the present study.

Participants

The study targeted people who had had negative reactions to ECT. They were recruited by posters and flyers asking, ‘Have you been given ECT? Did you find it upsetting or distressing in any way?’ which were distributed through local mental health voluntary organisations. Twenty-two people contacted the researcher, and 20 were eventually found to fit the criteria. There were 12 women and eight men, with an age range of 27–63 years. One of the men was a female-to-male transgender. Ten were unemployed, and ten were involved in voluntary or paid

work. Two described themselves as mixed race and the rest described themselves as white.

Participants were not always able to be precise about the details of their treatment, but nine of them reported that they had had more than one course of ECT, and six had had at least one course under section. The most recent course of ECT was 2–5 years ago for five participants; 5–10 years ago for five participants; 10–20 years ago for six participants; and 20–30 years ago for four participants.

It can be seen that within the overall category of adverse reactions to ECT, participants represented a wide range of backgrounds and treatment circumstances.

Method

The aims of the investigation were explained to the participants, and confidentiality was assured. The researcher emphasised that she had no current connections with psychiatric teams. Participants were invited to take part in a semi-structured interview at a place and time convenient to them, concerning all aspects of their experiences of ECT. Interviews were tape-recorded and transcribed, and a thematic analysis was performed on the results.

Results

Themes can be organised under the following main questions.

What were the circumstances in which you came to have ECT?

Participants described their mental states at the time mainly in standard psychiatric terms, for example:

'I'm diagnosed as manic-depressive, and in those years I did suffer from some form of depression rather than mania, and I suppose

I went into such deep depression that they thought ECT would help to get me out of it'.

'I was just really depressed and I was getting a bit manic as well, and I didn't seem to be responding to the medication, and they said I should have a course of ECT'.

However, as the interviews progressed, more complex background situations emerged:

'I always knew I had problems that were emotionally-based, to do with my life. And although I'd gone in partly under the influence of drugs, LSD, I also knew when I was growing up that I had some problems'.

'I was a very mixed-up and distressed person, and then my closest friend was killed six weeks after I got married...and my world fell apart'.

'I was in nursing...One day I was a student, the next day I was qualified and in charge of a ward, which I wasn't trained to do. I was just too young for the job'.

'If I look back on what caused the depression and what caused me to try to take my life, it was quite normal, average things...a divorce, I had two children, I was three months pregnant when I left...holding three jobs down, mundane jobs, trying to keep it going really. I was worn out, absolutely worn out'.

What kind of explanation of ECT were you given?

A problem here, as with other questions that asked for specific details about events, was that many participants had uncertain recall due to the effects of ECT itself. As in other surveys, nearly everyone felt that explanations had been completely inadequate or lacking altogether, and that there had been minimal opportunity for discussion.

'I don't remember anything being explained. I think they just said they were going to attach these things. I don't remember any discussion beforehand'.

'She said, "I don't think the Valium's doing you any good, so I'll put you on ECT".'

Why did you agree to have ECT?

Six of the participants had had ECT under section on at least one occasion. The answer to the puzzling question raised by other researchers, of why the others consented despite inadequate explanations and the fact that many of them already had doubts based on the experiences of relatives or other patients, lies in their feelings of extreme desperation and powerlessness.

'I was so ill, I felt so desperate, I didn't know which way to turn. I was just looking for answers as to why I was so strange, so peculiar'.

'I wasn't in a fit state to make any of those decisions. We were just grasping at straws, trying to find an answer'.

'If you're at your wits' end and they've drugged you up to the eyes you don't question...you're not thinking straight anyway'.

This desperate desire to get better was often coupled with a tendency towards compliance and a strong assumption that 'doctor knows best'. Moreover, participants felt they could not risk alienating these powerful people who seemed to hold the key to their cure:

'I was a very compliant young woman, I was very frightened of everybody and that was part of the problem...I wouldn't have known how to object, it wasn't on the horizon. You didn't disagree with doctors, you did what they said'.

'You believed that whatever they were going to do was going to work, you believed what you were told really'.

'He is the one with the power, he is the one ultimately that has the answer...if that's the only help you're getting you've got to hang on to it'.

A man who ended up completing his course of ECT despite his own reluctance and encouragement from the nursing staff to refuse it, put it like this:

'It was like, the consultants and the psychiatrists have such a powerful influence over you. In one sense your life is in their hands and it's wanting to please them, I suppose, because...part of depression is losing your sense of self really, and you're so easily influenced and so easily willing to accept authority'.

One woman found that her refusal to have further courses of ECT was, in fact, respected. Others who were able to be assertive were not so fortunate:

'They asked me if I would agree to it, but they did say if I refused they'd go ahead with it anyway...being forced to stay there is bad enough but being forced to have something that you don't want is ten times worse, so I did agree, yes'.

'Now what so often happens in psychiatric hospitals is, it's not the psychiatrist that forces you to have it. Long before that happens you get confronted by staff nurses who are very anxious to stop hassle...so what they do, they see that you're weak and vulnerable and they say, 'You'd better sign', just like that'.

'I said immediately that I didn't want it, and I pointed out that the previous consultant ... had said to me that she didn't think I was an appropriate case for ECT...and he (the consultant) got into a real huff basically and got up and walked out of the room...I felt absolutely devastated. I just burst out crying and didn't know what was going to happen to me, or whether they were going to section me, or what'.

In summary, nearly all participants wanted to emphasise how far their apparent agreement was from being fully informed consent:

'I wasn't physically taken to the suite or

anything, I walked there on my own, but I felt it was forced on me'.

What was the actual experience of ECT like?

Six people said that ECT was not particularly frightening to receive, although one woman attributed this to the numbing effects of her medication. All the other participants reported a very high level of fear, with a lack of accurate information sometimes supplemented by observation of other patients who had had ECT and by their own imaginations:

'I really didn't know what to expect, so I was absolutely terrified...I imagined great big metal things being put each side of my head and, like, sparks coming out, thunder and lightning, and my whole body shaking'.

'When you'd been on the ward there were certain people who had had ECT and all the other people were very scared by this...you would see them afterwards when they couldn't remember who they were and were very confused and had terrible headaches and weren't themselves at all'.

All this generally produced a high level of anticipatory anxiety:

'I remember the very first time I had it, walking down to the ECT (suite) from the ward and I remember feeling very agitated, sick and scared. And when I got into the waiting room there, I came to a standstill. I couldn't go through with it, I didn't want it. They talked to me and said I'd signed the consent form and I was under section'.

'As they wheeled you in you'd see what they used, they'd put some gel on it, they didn't even hide it from you...You were scared, yes'.

'I can remember sitting in the room waiting for treatment and looking at some of the other people who were there as well and I suppose it was almost like a pre-execution room really...We were all sitting there in complete silence. I remember reading in some-

thing, I think a hospital pamphlet, (that) it was just like going to the dentist, which is completely absurd...It's not like going to the dentist'.

One participant reported that the reality was not quite as terrifying. However, the terror of the other participants remained or even increased as the course continued, and many found the immediate after-effects equally devastating:

'I thought maybe second time around it'll be much easier and I won't feel so scared and terrified, but it was just the same, if not a bit more'.

'You dread it, your heart starts pumping, here we go again. Horrible, absolutely terrifying...It's like going to your death, your doom, isn't it'.

'I was absolutely convinced they were trying to kill me...you know, I was so bad and evil, all they could do was get rid of me'. (A woman who was psychotic at the time.)

'They could be doing anything, you don't know what they are doing...you get paranoid and think they are trying to poison you, or do weird experiments or something like that'. (A woman with a diagnosis of paranoia.)

'Afterwards I felt as if I'd been battered...I was just incapacitated, body and mind, like a heap of scrunched-up bones'.

'...Pains in your head and the memory loss, and sometimes I used to have a bruise. I'd be dribbling, I looked insane...I felt terrible, I was only 22 and I must have looked 82. I just couldn't do anything'.

When asked what was the most frightening aspect of receiving ECT, participants most commonly mentioned feelings of being helpless and out of control, and worries about long-term damage.

'It's a horrible sensation. You feel like a zombie, they could do what they want with you when you've had that and you would do it, because you don't know no different'.

'It was the whole treatment, being carted off. I felt like a slave, taken away to this little room and put on a bed. No control, it was awful'.

'You can't get it out of your head, how would you end up?...you'd be so brain dead you wouldn't know what you were doing'.

'What I was most concerned about wasn't the fact that it was unpleasant at the time, it was how it was going to affect me for the rest of my life...I remember feeling very disorientated and feeling that I'd been damaged for life'.

For several, ECT was a confirmation that they were truly mad, and had reached the last option:

'It seemed to reflect how ill I was, the fact that he was saying I had to have ECT this time...this was the last desperate thing that they do'.

'It was because this was the last resort...so what is there left, annihilation or what?'

'I knew I wasn't crazy. I knew what had happened. (After ECT) I was beginning to think maybe I am mad...I must be mad to have ECT'.

What other emotional or psychological effects has ECT had on you?

Fear is the only psychological reaction to ECT that has been investigated to any extent. However, these participants described a complex range of emotional responses including feelings of humiliation, increased compliance, failure, worthlessness, betrayal, lack of confidence and degradation, and a sense of having been abused and assaulted:

'It made me feel like a cabbage, like I wasn't worth anything at all. All I could do was sit around all day'.

'It was like I was a non-person and it didn't matter what anybody did to me'.

'I suppose I saw myself as worthless for a long time...almost being an empty person

and having to start again, having to build up a personality, having to build yourself up'.

'It's horrible to think that these people, doctors and nursing staff, are going to see you having a fit. It's degrading'.

'I knew that the only way I could get out would be by being insignificant...by being a very good patient, and it worked. I wasn't any better, I felt quite terrible'.

'I suppose as a woman, I feel...a lot of stuff was reinforced. You know, being the gender I am, it feels like you have to comply even more'.

'It made me feel like a freak, and it's only since I've talked about that with a therapist about two years ago that I've got over that feeling'.

'This psychiatrist had built this relationship with me, so I trusted him and then he did that (prescribed ECT)...This chap had been clued up enough to realise he needed to build my trust, but didn't appear to be clued up enough to know that giving somebody electric shocks to their head might actually damage that trust...ECT I feel is just such a betrayal, this frightened young woman and they do that. Terrible'.

'It's a really horrible feeling...a sense of failure, and what's wrong with me that I'm not getting better'.

'It felt like I had been got at, yes, bashed, abused, as if my brain had been abused. It did feel like an assault'.

Most people said that they did not mind others knowing that they had had ECT. For some, though, the perception by them and others that ECT is an intervention reserved for the extremes of madness, produced a strong sense of shame and stigma:

'I was deeply, deeply ashamed of having ECT...this was real serious stuff, this was a mad person'.

'People can't imagine what on earth situation you need to be in, that you need to be

electrically shocked. So they imagine that you must have been some kind of absolute raging animal or something to need that.'

'I have told a couple of people in the past and they think for you to have ECT you must really be off your rocker'.

ECT was experienced by several participants not just as a sign of madness, but also as a punishment for and confirmation of badness.

'At that time I was completely convinced I was being punished for something...I thought, well, I must have done something wrong to be treated like this'.

'Maybe if I had been good or if I hadn't done this or that, I wouldn't be punished. Yes, I thought it's a form of abuse, a punishment'.

Three of the women identified themselves as survivors of child sexual abuse. Of these, two drew explicit parallels between these early experiences and the experience of being given ECT, in terms of the emotions experienced at the time, confusingly mixed feelings towards both psychiatrists and original abusers, and inability to deal with their own powerful feelings of helplessness and rage afterwards:

'It certainly felt, "Do what you like", and that's something I felt as a child, that I had no power, there was no way I could stop anyone doing whatever they wanted to me, so rather than get hurt I'll let them do it and maybe they'll like me...especially because it was men doing it, the men actually operating the machinery or whatever, and I can remember it was men putting the needle in. Yes, again there would have been no way I would have said I don't want this...And then just sort of lying there, feeling really frightened and yet completely passive. So it was like all trapped, all my emotions were trapped anyway and my feelings were trapped, so it was all trapped inside. And on the other hand not caring what happened to me'.

'I've had physical abuse as a child and I've had sexual abuse as a child and mental abuse as a child. I suppose I did think about it a couple of times going through the ECT, that this was some form of abuse, being put on you when you don't want it, or being more or less said that you've got to have it...I sometimes feel very angry to the people involved, that I can't get back at them or take revenge at them. So that I don't do that, I self-harm, I cut myself'.

(LJ) *'Who do you want to get back at?'*

'Sometimes it's the doctors, the professionals, sometimes it's the abusers that have abused me...I always tend to turn it in on myself. I've been told many times by doctors and counsellors, "You've got to stop turning it on yourself", but I don't...It's like I feel I need to punish myself, maybe all the abuse is all my fault'.

Although this investigation did not specifically seek to investigate the effects of ECT on memory, nearly all participants spontaneously reported some degree of loss. While acknowledging that medication and depression itself can affect the memory, they nevertheless believed that ECT had also been an important factor, and this caused much concern:

'Sometimes it really affects me, I break out in a cold sweat. Have I really got brain damage?'

'It's not the thought disorder that's disturbing me now, it's the damage done by the ECT...I've probably got another 50 years to go, and I thought, well, I'm going to be damaged for the rest of my life'.

Some participants had lost large pieces of their lives, which was particularly upsetting where the memories involved young children:

'My memory is terrible, absolutely terrible. I can't even remember Sarah's first steps,

and that's really hurtful...losing the memory of the kids growing up was awful'.

'I can't remember when they started junior school, I can't remember when they left infant school. Now those are things you remember, they're highlights...and I'm quite resentful really to think that my ex-husband has got more memories of my children and did pretty well nothing to help'.

The commonest complaints were inability to follow films, books or TV programmes, and problems with facial recognition. These disabilities were both frustrating and embarrassing. Less tangible was the general loss of sense of self described by a few participants:

'I can be reading a magazine and I get halfway through or nearly to the end and I can't remember what it's about, so I've got to read it all over again. Same with a film or a programme on the telly'.

'I can understand the individual sentences but when it comes to taking in the whole story, you don't know what the hell's going on really...I like reading and I find it very irritating'.

'People would come up to me in the street that knew me and would tell me how they knew me and I had no recollection of them at all...very frightening'.

'It happens all the time. It's tiny little things, which on their own don't really matter, but it's this permanent sense of something that you've lost.'

'It's a void, I can't describe it, and there's also a feeling of something fundamental that I don't even know what it is missing...just like an intrinsic part of me that I feel isn't there and it was once...Part of it feels like there was a real death of something, something died during that time'.

Did ECT have any beneficial effects?

Nine people said that ECT had given them at least some temporary relief from depres-

sion, or in one case from hearing voices, although all but two of these felt that the costs had far outweighed the benefits. Two other participants reported a paradoxical effect:

'I felt I'd reached the absolute rock bottom and I couldn't go any further. Everything had been tried...Perhaps I felt the ECT gave me permission to get better'.

'In a very bizarre sort of way, because the treatment and the abuse was so terrible, it made me come to my senses. I've got to get my act together, I've got to help myself'.

Two of the nine believed that ECT had 'worked' by triggering a high mood. A man with a diagnosis of manic-depression described how ECT had several times precipitated a change from suicidal depression to elation:

'I felt fantastic...Basically it puts you high, so you need the help then, that's when you need the help. Not, "aren't you doing well, how are you feeling on a scale of one to ten," "oh about eight or nine, good I can get a job", "are you, oh fantastic, go out and do it then". Because you're sick, still sick'.

A woman who also responded dramatically described it like this:

'I felt as though I had become a completely different person...I felt as if I had just totally gone off my head. I was totally dependent on the ward and everything and all of a sudden I think ECT had blasted me into this other reality. And some positive things did come out of it because I went out and I worked for a year and I was discharged from hospital...It was at a very high cost, obviously. You feel you've got to adapt to this new person that you are...For a year or two afterwards I felt very mad...I felt I'd lost the person I used to be...Too happy, really, too sort of split off from the side that was there before I had ECT, that all disappeared completely'.

Nine years later, this woman felt that she had still not entirely reclaimed her real self.

Did you tell anyone how you felt about ECT?

Most participants had felt unable to tell psychiatrists or other professionals of the strength of their feelings about ECT, for the same reasons that prevented them refusing to have it in the first place. The few who tried to hint at their reluctance and terror felt they had been met with little response:

(LJ) 'Did you explain to anyone how traumatic it had been for you?'

'No, I didn't dare. They had complete control over you, they could lock you up. You can't be angry with them. People who are, get a really bad time'.

'Once or twice I've been able to say that I think it's a waste of time... and they say you've got to complete the course now, you've got to go through to the end and it's best for you and you're not in any fit state at the moment to know what you want. It's like the power's taken away from you all the time'.

'I can remember asking him (the consultant) about what happened about me coming round (from the ECT) crying, and telling him I felt really frightened having it. And he certainly didn't acknowledge the fact it was frightening'.

'I always said I wasn't feeling any better, but they started saying towards the end they thought I was feeling better, and I discovered a lot later that on my notes they invented that the ECT had been a successful treatment, and there was no way I was any better... At the end of the treatment I had a meeting with the consultant who said he thought I was biologically cured of depression... The implication was, I suppose, that all the other things were just personal things I'd got to sort out'.

It is perhaps not surprising that the experience of ECT had left some participants with a lasting distrust of mental health professionals and hospitals:

'When I was in hospital last time I was terrified that they were going to give it to me again. They promised they wouldn't, but can I trust them, can I trust them? I was terrified, I hated walking across the room where they did it'.

'It was a useful lesson really. It's not sensible in this world to tell psychiatrists of your, what they call "delusional systems", and in fact I never told them another one'.

(This woman was feeling suicidal around the time of the interview, but had deliberately not told her community psychiatric nurse. She had previously had ECT under section.) *'They've only got to mention the word hospital to me and I freak out... when I go into hospital, I won't trust nobody in there, because my mind runs away with me. Are they going to force me to have ECT?... I know the staff on the ward, I've been there so many times, but each time I've been and come away, when I have to go back again I try and build that trust up all over again'.*

Many participants were very unhappy with other aspects of their psychiatric care, such as the use of medication. However, a number of them made the point that there is something qualitatively different about ECT: the idea of putting electricity through someone's head carries powerful symbolic meanings which still apply no matter how caringly the intervention is delivered. It can be experienced as a brutal assault on your very self:

'I think to tie somebody up and zap them with electricity... it goes back to the days of Frankenstein, doesn't it?'

'Well, it's an assault on your head, isn't it? It's an assault on who you are, you are in your head. And yet you've gone to them expecting them to heal you'.

'I would have thought anyone would be apprehensive about something like that, especially when they are messing about with your brain. That's the centre of your being, isn't it?'

'They make it all nice, they're nice to you when you go into the room, they pamper you a bit...talking to you very personably (sic) and all they want to do is jolt you with a thousand volts...It goes back to the Jews, doesn't it, who went into this room and had a nice shower'.

What other forms of help would have been more appropriate instead of ECT?

Nearly all participants were convinced, looking back, that ECT and all its disadvantages could have been avoided had the right kind of counselling and support been available instead:

'It was so obvious that one of the things I needed help with was grieving for this friend. I needed to be given some way of knowing that I belonged to the human race'.

'You used to say what you thought your troubles was, and she was nice, this doctor I had, and she would talk back and explain everything to me...If I could have carried on with her, on Valium, I would never have had ECT'.

'There was one nurse who was actually a trained counsellor and about three or four years ago I was quite ill and there were things I wasn't disclosing to anybody, not even friends or whatever, and when I was in hospital I managed to talk to her and it all came out, and that was like a step forward'.

'Although at that particular time I was very very psychotic, I needed to be allowed to be mad, but be somewhere with human decency and not be so restricted...I needed someone to talk to more than anything'.

'Somebody sitting down with me in a room on your own, talking to you when you needed it...There were so many people on the ward and only three nurses, so you didn't get a lot of attention'.

Ten of the 20 participants had ultimately been able to take up a variety of occupations

including student, caretaker and voluntary or paid worker in the mental health field. Two of the ten felt that they had recovered largely by their own efforts. The other eight had finally found the help they needed through a mixture of counselling/therapy, self-help groups and support from other service users:

'I've had private therapy on and off for about 4 or 5 years which I pay for, so that's helped a lot'.

'I ultimately found the answer at a tranquilliser withdrawal group. I work for them and we all help and encourage each other, support each other and it's brilliant. And you have to build back your self-esteem, your self-worth, it doesn't just happen...and it's fantastic'.

'I had so much inspiration from other people who were further on (at a support group), and I really just got involved and started helping out there and becoming a bit more empowered...I just knew that's what I wanted to do, try and help other people in the way that that helped me'.

A common theme in this group was how anger at their treatment had turned their earlier compliance and conformity into assertiveness and a determination never to let others take control over them again:

'It taught me a lesson...always to question, never ever believe professionals, never assume because the doctor is a professional that he knows better than I do about my pain. I'm dreadful in a doctor's surgery. I do honestly make sure I get my time, I need to know what's going on. Never let them control me again like they did'.

'It's really starting to come through now...angry at the way you've been treated by people over the years, doormat, really put upon. I'm really starting to realise how badly at times I've been treated and now I'm changing that and putting my foot down and speaking out about things I'm not very popular, but that's too bad.'

'I just feel...very angry, and basically I know my rights so much now, I'm in charge'.

But most people still had unresolved feelings about ECT, in some cases many years later:

'Certainly if I do talk or read about ECT it does bring back all these horrible memories of the actual treatment. I always get the same symptoms, headaches, nausea and things'. (23 years on.)

'I had absolutely terrifying lucid dreams. I couldn't explain to you how terrifying they are, it's just beyond words. I started telling this therapist about them to try and make sense (of them) and I always described this feeling as if I was having electricity...Terrible sensations, feeling like I was just about to die, and very, very lucid dreams, not like ordinary ones, where I wasn't sure if I was awake or asleep'.

'This is one of the problems, when I feel I'm bitter towards this person, perhaps I'm not on Jesus's side...perhaps he hasn't accepted me because I hold this grudge'. (A man with strong religious beliefs who was angry with the nurse who had put pressure on him to have ECT.)

'I do feel very angry, and sometimes I just have to stop myself dwelling on it because if I do I just get very angry. It's difficult to know what to do with that anger'.

What are your overall views about ECT?

All the participants except one were very clear that they themselves would refuse ECT if they were ever offered it again. The exception was a man who said that he would consent as a 'very, very last resort' if he ever became ill again.

One person thought that there was a place for ECT for some people, and 13 others thought that people should be able to make their own informed decision on the matter.

This was a conclusion generally put forward with some reluctance, with two participants adding that in their personal opinion it should be banned. The six remaining participants had no hesitation in calling for a universal ban even if some individuals wanted to have it.

'I think it's up to the individual really. I wouldn't touch it ever, even if I was really ill...I think if people gave you full information, a lot of people wouldn't have it'.

'Personally I think there should be a ban, but until that happens I suppose if users feel it might benefit them, then go ahead, but I'd like to see in the next few years a total ban worldwide'.

'It is not justifiable to give people something that harms their brains and gives them an epileptic fit on the NHS. It's just not, in my view, an ethical way to proceed'.

Most participants expressed their overall views on ECT in strong terms. They saw it as a blunt instrument that produced brain damage without dealing with the person's real problems:

'It's like being hit on the head by a hammer, that's the way I would describe it...How do I know they're getting the right area and don't kill cells in a different area? It's a crude tool'.

'Well, it deadens your brain, doesn't it? That's what it does'.

'They didn't have the time and they didn't have the staff and so I think ECT is just a quick way, a quick job, less expensive'.

'It's short-term relief...obviously until you find a solution to the problem it's just going to recur and you're going to keep on having ECT'.

'I think it is barbaric giving it to people on the scale that it is. And I've never actually met anyone who said it had done them any good, so...I don't know where this eight out of ten figure comes from'. (The proportion of peo-

ple benefiting from ECT, according to this man's consultant.)

'Quite barbaric, really, barbaric to put electric shocks through people's heads'.

'I think it works by causing brain damage...It knocks out the memory...so being unable to remember the unpleasant feelings, you are less able to feel depressed'.

'When you think that shock treatment is a form of torture, then you can see the relationship...It's very extreme and it's abusive. Well, it's not a treatment really, is it, it's just a violation of a person's body'.

'To be treated physically for something that isn't a physical complaint...I do object to that for emotional, psychic, spiritual problems'.

'It is inhuman and inhumane.'

Discussion

Since this study specifically targeted those with a negative experience of ECT, the results cannot be taken as representative of all ECT recipients. However, the study does confirm that for a certain proportion of patients, ECT is a deeply and lastingly traumatic experience. Few participants doubted the good intentions of the professionals; as one of them put it, 'I don't think the psychiatric system is made up of bad people wanting to harm people'. Unfortunately, the fact that professionals genuinely believe that they are acting in the patient's best interests by prescribing ECT does not guarantee that the patient will experience the intervention as beneficial. This investigation provides ample evidence that organic therapies do carry meanings, and that these meanings, filtered through the individual's own background/context and interpretations, influence how such therapies are experienced. Having said this, we must be careful not to discount the possibility that some of their concerns also have a factual

basis; for example, that ECT does cause definite cognitive impairment, and anxiety about brain damage is not just a psychological phenomenon but an understandable response to a real danger.

Although participants represented a wide range of treatment circumstances, the themes that emerged from their accounts were remarkably similar. There are a number of areas of particular concern to mental health professionals. First, there is the fact that ECT may be undermining therapeutic work in ways that professionals are unaware of. One woman appreciated her psychiatrist's sensitive attempts to build a relationship with her, but lost all trust in him when he subsequently prescribed ECT. Another was encouraged to direct her anger outwards, while simultaneously being forced to undergo a treatment that increased her anger and self-blame to the point of self-harm.

Secondly, ECT may actually exacerbate existing psychological problems. Some participants who already believed themselves to be bad, saw ECT as confirming this. Several women who saw unassertiveness as having been part of their problems, received the message that they must comply and keep quiet. A man whose religious beliefs had caused him great conflict was deeply worried about his unresolved anger about ECT. In addition, ECT seemed to feed into two women's delusional beliefs; one was convinced that she was being killed, while another thought that 'weird experiments' were being carried out on her. Feelings of shame, failure, badness, unworthiness, self-punishment and helplessness are common features of depression, and in so far as ECT reinforces them, it will obviously be unhelpful. Perhaps most worrying were the cases of the two women survivors of sexual abuse who clearly experienced ECT as a re-abuse. Given that an estimated 50% of women in psychiatric hos-

pitals have suffered sexual and/or physical abuse in childhood (Williams & Watson, 1994) and that ECT is most commonly used on women, this raises the disturbing possibility that a number of patients are, in effect, being re-abused in the name of treatment.

Thirdly, ECT may be leaving some people with a distrust of psychiatric services that undermines any future attempts to form therapeutic relationships. They may be both unhelped – perhaps even in a worse state – and at the same time harder to reach.

It is important to appreciate how powerless and vulnerable psychiatric patients perceive themselves to be in relation to the professionals. The apparent willingness to consent to ECT remarked upon by other researchers may merely be a case of desperation and compliance temporarily overcoming terror and reluctance. Similarly, what seems like a successful outcome may simply be conformity and a fear of confiding one's true feelings to professionals.

Powerlessness, control and conformity were themes that constantly recurred in the participants' responses. They came for help feeling confused, helpless and desperate. The help they were offered was experienced as a further loss of power and control which left them even less able to protest and assert themselves than before. None of them had felt able to convey the strength of their feelings about ECT to mental health professionals, implying a possible hidden pool of distress that is unlikely to be picked up by hospital-based surveys; hence, perhaps, the disparity in reported rates of psychological trauma after ECT.

The most optimistic outcomes were for those who were ultimately able to direct their anger outwards, reverse their previous pattern of compliance and take control of their lives again. That they were able to do this

despite rather than because of their treatment, and mainly with help from outside the psychiatric services, is a matter for profound concern.

What lessons can be learned about the use of ECT from this survey?

Standards for the administration of ECT are still very variable, as the most recent audit (Duffett & Lelliott, 1998) indicates. The participants in this study particularly objected to lack of discussion beforehand, seeing trolleys and equipment as they waited, overhearing people being given ECT, and distant or offhand staff attitudes. All this could be remedied relatively easily, in line with measures already suggested by other researchers, but at the risk of being seen as hypocrisy or window-dressing; it is the central fact of having electricity passed through your head that was so unacceptable to these participants. Not only did this carry powerful symbolic meanings, it was also seen as irrelevant and damaging. The superficial adoption of psychiatric terminology ('manic-depression', 'psychotic' and so on) disguises the fact that participants believed they had broken down for *reasons* which a physical intervention obviously could not address. This mismatch of models, with the professionals offering biomedical explanations and treatments while the patients tend to prefer psychosocial ones, has been noted by other researchers (Rogers *et al.*, 1993.)

Also problematic is the call for fuller information on both positive and negative effects. The issue of what counts as accurate information about ECT is still controversial, although these participants are in line with some critics in believing that it can cause long-term brain damage (Breggin, 1991; Frank, 1990). Whether or not they were correct in reporting that no one had discussed ECT adequately

with them, it seems clear that they would consider many current factsheets (for example that produced by the Royal College of Psychiatrists 1997) a highly misleading portrayal of possible cognitive and psychological consequences.

Whatever the true figures about adverse reactions to ECT, professionals obviously need to be very alert to the expression of fear or distress and to take such feelings very seriously, since such patients are likely to find ECT not only unhelpful, but actually damaging. It should be emphasised that consent can be withdrawn at any time, even after signing the form. The most constructive overall response may be to heed the call for much more access to counselling and general emotional support as an alternative to ECT. This is consistent with other recent surveys of service user views on treatment, for example those by MIND (1993), and the Mental Health Foundation (1997).

For some, the present findings will raise the question of whether there is a place for ECT at all. If up to a third of people will suffer psychological trauma after ECT, and if there is no way of identifying these individuals in advance, the ratio of costs to benefits may begin to seem unacceptably high. As always, more research is needed. However, this should not be an excuse for complacency about the experiences of those for whom the description of ECT as 'a helpful treatment and not particularly frightening' is profoundly untrue.

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