

The Cognitive Side Effects of Modern ECT: Patient Experience or Objective Measurement?

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Abstract: This article explores the subjective experience of cognitive deficits of patients who are treated with electroconvulsive therapy, by using actual comments made in clinical situations. The material is divided into 4 themes: the need for clear information, the importance of validation of experience, the impact of daily disruptions, and the issue of self-esteem. It is argued that despite the low correlation which exists between objectively measured cognitive function and the subjectively experienced impairment, the discrepancy creates a need to take both perspectives into consideration rather than to rely on one or the other.

The validity and limitations of using personal narrative as a relevant clinical parameter are discussed.

Key Words: electroconvulsive therapy, patient experience, memory, cognition, personal narrative, stigma

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Electroconvulsive therapy (ECT) continues to be viewed with fear and suspicion. This is not easy to understand, given its undoubted and at times life-saving efficacy.^{1,2} Even recent attempts to normalize and destigmatize depressive illness³ have largely failed to have much impact on this negative view.

At least in part, this can be traced to literature and cinema. Literary accounts from novels and autobiography⁴ and depictions in film⁵ continue to imply that ECT is often ill-advised or frankly dangerous. The much quoted “One flew over the cuckoo’s nest” showed ECT as an archaic, brutal, and useless treatment with the capacity to turn people into zombies. Although side effects are rarely described in any systematic fashion, the images of brain damage or personality change are frequently evoked.

Janet Frame, in her autobiography, gives a good example of this: “After having received over two hundred applications of unmodified ECT, each the equivalent, in degree of fear, to an execution, and in the process having my memory shredded and in some aspects weakened permanently or destroyed...I arrived home, outwardly smiling and calm, but inwardly with all confidence gone.”⁶

Modern anesthesia and more precise techniques of administration have all but abolished the horrors of the procedure she describes, and ECT applied using current criteria has become straightforward and is well tolerated by patients. Most importantly, it remains extremely effective and has the most rapid effect of any treatment in severe depressive illness; superior efficacy compared with either placebo or pharmacotherapy has recently been firmly established by meta-analysis of 24 trials, with a total of 1400 patients.⁷

The question of unwanted neuropsychological effects remains. Here, there is an ongoing tension between the perspective of standardized tests of performance and the subjective complaints of patients.

Even the neuropsychological evidence is confusing, despite the large body of work.^{8–10} There has been a question of the very existence of memory damage,^{11,12} and some studies report paradoxical improvement of memory as depression lifts.¹³ Predictors of the magnitude of cognitive dysfunction after ECT include pre-existing cognitive deficit^{14,15} and technique and frequency of ECT treatment.^{8,16–22} However, considerable disagreement exists on the relative importance of these factors.

Nevertheless, patients continue to report problems with memory^{23–27} and sometimes other cognitive functions such as new verbal learning and retention.⁹ How are we to evaluate this? Memory complaints per se have been shown to be an unreliable predictor of objectively measured cognitive dysfunction.^{28,29} Mood state and neuropathology make self-reporting of cognitive function even less accurate^{30,31}; mental illness in particular has been found to be associated with a tendency to overestimate deficits and underestimate ability.³²

This does not necessarily invalidate the relevance of the personal perception of cognitive function. Cosentino and Stern³³ refer to this personal experience as “metacognition,” the awareness and recognition of cognitive and behavioral deficits. They describe it as a multidimensional construct, affected by disease variables, clinical course, prognosis, and neuropathology.

To achieve a more rounded understanding of the cognitive experience of ECT at the level of personal perception, it may be necessary to explore the phenomenology of this metacognition in finer detail and to recognize it as existing alongside objective, quantitative measures. This article therefore allows patients to “speak” for themselves about their experience, by using quotations taken from spontaneous comments in clinical situations and from first-person written accounts. An attempt has been made to include a wide variety of experience from a heterogeneous group in terms of sex and age. The statements have been grouped in the

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following themes: the need for clear information, the importance of validation of experience, the impact of perceived disruption in daily function, and the issue of self-esteem.

METHODS

Comments made by patients have been used as illustrations of the proposed themes. The subjects include 5 women and 3 men ranging in age from 35 to 70 years. Four of the women were outpatients at the time they made their comments; one was an inpatient. The men were all outpatients. This was a convenience sample, with no attempt at systematic data collection. All patients were treated for depressive illness, and all had undergone voluntary treatment. Details of the number and mode of treatment were not available. Consent to use personal statements was sought and obtained from 4 of the women and 2 of the men; the other 3 patients were no longer in treatment, and their comments have been selected carefully to preserve their anonymity. All names have been changed.

RESULTS

Theme 1: The Need for Clear Information

Exactly what information to give to patients remains difficult, despite general acknowledgment of the clinical imperative to be as balanced and inclusive as possible.^{34,35} This may relate to the uncertainty of clinicians or to the belief that the severity of the mood disorder will impair the ability to comprehend and evaluate information, or may simply reflect the strongly positive view that clinicians quite reasonably hold of ECT as a treatment for depression.

When patients feel inadequately informed by their doctor, the place where they commonly seek information is the Internet. In the Internet, there is a wide variability in what is available; many who consult the Internet have no understanding that what appears on Web sites may be strongly biased toward preconceived prejudice against the treatment, and Web page titles do not always make this clear.

While many postings are positive about ECT, describing it as highly effective in a time of severe mood disorder, other accounts describe near catastrophe.

"I have permanent brain damage from this form of 'therapy.' Shock treatment was the most horrific experience of my life."³⁶

"Other than by causing mental disorientation and memory loss, ECT does not help eliminate the unhappy feeling called depression. This is true even though currently unhappiness or 'depression' is the only 'condition' for which ECT is a recognized 'therapy.' Indeed, rather than eliminating depression, the memory loss and lost mental ability caused by ECT have caused some subjected to ECT so much anguish they have committed suicide after receiving the treatment."³⁷

One particularly alarmist posting quoted an almost 30-year-old reference written by a neurologist which concluded "ECT results in brain disease. [The question is] whether doctors should offer brain damage to their patients."³⁸ No mention was made of the major differences in modern ECT compared with that given 30 years ago.

The fact sheet of the Royal College of Psychiatrists³⁹ is far more even-handed and neutral: "The greater concern is for the long-term side effects, like irreversible memory or personality change. Surveys...usually find a low level of severe side effects...Clearly no one is certain." Fink⁴⁰ goes even further in reassurance: "There is no longer any validity to the fear that electroshock will erase memory." Unfortunately, there is no guarantee that searchers will access these sites rather than those which demonize ECT.

Ann: "Being a psychiatrist myself, I was shocked to find how little I really knew about the way having ECT really felt. I mean, I've been thinking I was giving patients adequate information all this time, and really I was way off the mark. I've never gone into details about waiting for it to be your turn, never discussed the anesthetic procedure. And when it comes to memory disturbance, I've given a vague reassurance, rather than going into some of the details we know, and some of the things we don't. Now, having been through it myself, I'll be recommending it in the same way, but I'll certainly try to be more informative."

Betty: "I didn't know what to expect. I was frightened that I might forget my telephone number, or the password to my bank account. So I made a list of all the important numbers I could think of. But it wasn't like that at all—all the old information was there. In fact, the problems with my memory haven't been nearly as bad as I expected—only some recent things—and mostly I can get around that."

Alan: "I was told that the memory troubles were temporary—that I would completely go back to

normal. That just hasn't been true—I feel like they lied to me.”

Carol: “People told me such horror stories. You didn't know who to believe. Sometimes it seemed like people didn't want to hear anything positive—as if it challenged their ideas. It got to the point where I just didn't tell anyone I was going to have ECT for fear of the reaction.

Theme 2: The Importance of Validation of Experience

The lack of validation by friends or family is often troubling and sometimes hurtful. Depression itself is often felt as a state which creates alienation from friends and family and engenders the feeling that no one can understand the experience or share the suffering. Manning⁴¹ describes this succinctly: “I have lost the language [of friends], their facility with words that convey feelings. I am in new territory and feel like a foreigner in theirs.” Electroconvulsive therapy typically widens this distance even further. Well-meaning attempts to soften the hardships may simply create the feeling of being unheard.

The implication that patients should be grateful for the benefits and not complain about the problems was frequently mentioned.

Ann: “It was really upsetting to discover just how reluctant other psychiatrists were to believe that my memory disturbance was really a problem. One of them—a good friend of mine—said, “It's chicken feed compared to the benefit.” I mean, excuse me, I would always say that it was a great treatment—I think it saved my life—but that doesn't make it chicken feed. This is my brain we're talking about.”

Diane: “I had a friend who was a doctor. She told me that there was absolutely no scientific evidence

of any cognitive dysfunction at all. It made me feel as if she was telling me I was stupid or neurotic.”

Bruce: “My family were so relieved at how much better I was—they just kept telling me that everyone forgets things. I know that, but the way my memory worked after ECT was different. It was like they didn't believe that I could tell the difference.”

Elizabeth: “My children kept saying it was great that I was better as if that made it irrelevant. Of course I was thankful to have recovered, but the way they said it made me feel I had no right to be bothered by the memory problems.”

Theme 3: The Impact of Daily Disruptions

Functional difficulties in day-to-day activities are very commonly described, both in the period immediately after treatment and in the longer term. Early confusion varies widely from relatively mild to being quite profound. Manning⁴¹ describes it poetically: “I have clouds in my head. I'm getting lost on the unit. I'll never admit it out loud, but when I think about going to the kitchen or the solarium, I can't really picture where they are.” This kind of experience may add further disorientation to the already alienating world of the hospital or clinic.

For others, the immediate period after treatment is experienced simply as a nuisance, in that it creates a dependency on others to manage transport and other practical demands. Some even felt that not to have awareness of an unpleasant treatment was a positive effect and that it helped in their recovery and ability to put the episode behind them.

Generally, it is in the medium term that the most troubling difficulties are manifested. They typically become noticeable as the worst symptoms of illness are subsiding and patients are trying to regain their former activities. Problems are described in almost all aspects of life, from work to leisure, and from trivial to burdensome. Often, patients commented that it was the patchiness of the cognitive impairment which made it hard to define and hard to manage. Memory lapses also hindered full enjoyment of recovery signs, such as being able to drive again but losing the way, or opening a book with at last the ability to concentrate, only to have it pointed out that the book had already been read.

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ago are referring to a time when ECT had none of the precision and care with which it is administered today. There are few data measuring long-term impact. One study, using a prospective design, confirmed that cognitive effects could be objectively measured at least 6 months after treatment ended.⁴² This is much-needed evidence for ongoing problems; however, it still covers a very short time frame in the history of a chronic illness.

At the subjective level, the very detailed first-person account by Donahue⁴³ stresses that problems do continue over the long term. In addition, she draws attention to the obvious but often disregarded fact that no memory of past events means no concept of what or how much has been forgotten.

Betty: *"I used to take off my watch and put it away carefully before I went down for treatment.*

And I could never find it when I woke up. It happened every time, and I felt so stupid. Eventually one of the nurses told me to write down where I put it. That worked, but it made me feel like I was an old lady who was going senile."

Carol: *"I don't have any memory at all for the whole course of treatment. I know Mum and my husband took turns driving me there and home again because they've told me, but I have no recollection of that entire time. Mum says it's a good thing. She thinks I was just so overloaded that to have to think about what it was like to be depressed and have treatment would have been too much for me. Why would I want to remember it? What matters is that it worked—being well again was more important than remembering the detail of what got me there."*

Ann: *"It's like whole parts of my life are on the tip of my tongue, but hard to grasp, and sometimes misty and dream-like when they do come back."*

Chris: *"It was when I started driving again that I had problems. I couldn't map the routes I would take properly—it was as if I had lost the way the roads went."*

David: *"I've always been a great reader, and so it was a relief to be able to concentrate on a book again. Not being able to read was one of the worst things about being depressed—I was so glad to get over that. But I find I can't remember books that I've always considered part of me. It's really frustrating."*

Betty: *"I didn't think I was too bad until I went back to work. And then it was like I was in a mine field, and I never knew when a mine would explode at my feet. Someone would refer to something and I would say 'I didn't know that,' and they would look at me as if I were stupid. Sometimes it was whole events that were gone. It really affected me because I was trying to get my confidence back, and this just seemed to set me back to square one again."*

Carol: *"The kids tried to be patient, but they hated it that I forgot things—it made the depression seem to be going on and on instead of being over with when I got out of hospital."*

Theme 4: The Issue of Self-Esteem

In the context of post-illness fragility and the assault that the episode has typically wrought on self-confidence, the

nebulous deficits can be magnified and experienced as profoundly distressing. For those who have tried to keep the nature of their illness secret, memory lapses can become the feared betrayal of their damaged self, the mark of the illness and the treatment. Both remain stigmatized in most contexts. Manning⁴¹ again: "People seem to be more forthright these days about discussing depression...But ECT is in a different class. For months, in my conversations with most people, I have glossed over ECT's contribution to the end of my depression."

The subject of how cognitive deficits were perceived by others came up repeatedly. Embarrassment and shame were words frequently used. Often, well-meaning attempts at reassurance were experienced as inadequate and patronizing.

For some patients, the fear of giveaway forgetfulness hindered their attempts to resume social activities; for others, it made them reluctant to engage in conversations which might include past events.

Ann: "It was such a relief to be back at work, but I worried a lot about what people were thinking of me, whether I seemed like I was not good enough anymore. And one of my colleagues one day remarked that I had asked the same question over and over. He said it was like Groundhog Day. I was so embarrassed."

David: "People said they didn't notice anything, but I never knew whether to believe them or not."

Diane: "Having a good memory used to seem like part of me. So now it's like being a different person, even though everyone else says my memory is fine."

Alan: "I sometimes think my brain has become like Swiss cheese—good quality but full of holes. But I've got used to keeping diaries and lists and things—and anyway, I cope a lot better than I did when I was depressed."

Ann: "I worry about the future a lot—whether this in the end will impact on my work."

DISCUSSION

The fragments of comments included in this article point to the variety of ways in which cognitive side effects are experienced in daily life. They may interfere with communication with others, with self-confidence, self-image, and ability to function at work. There is also an emphasis given to the feeling that others cannot understand or validate the experience. It seems that both mental health workers and friends and family are reluctant to listen to complaints. Patients often said that although they were very aware and relieved by how effective ECT had been, they were unhappy that others were so loath to admit the existence of negative effects or to blame them on ECT. It is worth mentioning that this is not always the case—it may be relatives who are the most upset by cognitive difficulties and the most likely to attribute them to ECT.⁴⁴

For patients, the experience of depression may be severely damaging to self-confidence in and of itself,⁴⁵ and it is not surprising that ECT is sometimes inappropriately blamed for some of the aftereffects. Much of the psychological work in the recovery phase is the rebuilding of a satisfactory self-concept.⁴⁶ Stigma associated with mental illness has been shown to impede recovery and contribute to poor outcome in the social, employment, and treatment domains; this seems to be a function of perception rather than of objective levels of discrimination,⁴⁷ and unfortunately as has been mentioned, ECT remains stigmatized.³

Timely, effective treatment of the depressive episode is the most important first step in recovery. Even patients who complained about a number of perceived unwanted effects were quick to recognize how significant it had been to be returned to health quickly and comprehensively. However, the subjective sense of being cognitively impaired was still a contributor to an enduring negative self-image and to a persistent feeling of being viewed as impaired.

Treating clinicians thus have a delicate role to play. They need to communicate clearly the undoubted efficacy of ECT as a treatment for depression. They must also manage the discussion on cognitive side effects. Patients are saying that they want these to be taken seriously and that their subjective experience is the key issue. They do not want superficial reassurance, although information on the likelihood of recovery is welcome. They also need to be told of the complexity of cognitive function—poor memory is not necessarily linked to global deficit or significant difficulty in day-to-day life. Patients who are still very unwell may not be able to absorb more than an outline of this information; education about cognitive side effects must be discussed on a number of occasions. The most important message should be that the clinician is interested in the patient's experience, is willing to discuss it repeatedly over time, and considers it to be an important issue in the recovery process.

Using the language of patient narrative has both power and weakness. Increasingly, personal stories of illness and treatment as well as fictional narratives have become a legitimate genre in the practice of medicine,⁴⁸ a recognition that “knowledge of life stories helps cultivate attention to patients, an interest in their oddities and their ordinariness—and a tolerance of both.”⁴⁹

The basis of qualitative research methods is the belief that “people are complex and should be studied by watching them, joining in talking, and reading what they write.”⁵⁰ Systematic extraction of themes from focus groups and semistructured interviews would have enhanced the generalizability of the results presented while maintaining the emphasis on individual differences. However, there are limitations and biases inherent even in more rigorous qualitative methods. A completely different set of stories could be collected and presented.

This article makes no claim to containing representative or typical “truths.” Nevertheless, in the arena of brain function, the subjective is significant. Although neuropsychological tests provide important information for comparison and analysis, it cannot capture the daily understandings, misunderstandings, conclusions, and errors which make up the essential cognitive “I.” The patient “voices” presented here may add to the overall picture of this important topic.

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ERRATUM

Rosa MA. Pacheco e Siva and the origins of electroconvulsive therapy in Brazil. *J ECT*. 2007;23:224–228.

The title of the above-referenced article contains a spelling error. The correct title is, "Pacheco e Silva and the origins of electroconvulsive therapy in Brazil."