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Electroconvulsive therapy (ECT) from the patient's perspective

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ABSTRACT

This is a response to Dr Charlotte Rosalind Blease's paper 'Electroconvulsive Therapy (ECT), the Placebo Effect and Informed Consent', written by Julie K. Hersh who has had ECT. Hersh argues that placebo effect is impossible to prove without endangering the lives of participants in the study. In addition, informing potential ECT patients of unproven placebo effect could discourage patients from using a procedure that from experience has proven highly effective.

Having recently read Dr Charlotte Rosalind Blease's paper *Electroconvulsive Therapy, the Placebo Effect and Informed Consent*, I want to offer my response.¹ I am an electroconvulsive therapy (ECT) patient, and have interacted greatly with the public regarding ECT because of my book *Struck by Living* and hundreds of speaking engagements.² I also testified before the U.S. Food and Drug Administration (FDA) regarding ECT. In my book, I briefly explain my experience with ECT which was terrifying and life saving.

In 2001, with vivid memories of *One Flew Over the Cuckoo's Nest*,³ I approached ECT with low expectations and great fear. Due to the strict consent laws in Texas, the anxiety caused created by the lengthy consent document caused me to leave the building and pace around the parking lot. I anticipated horrible memory loss and alteration of my personality. After several trips up and down the elevator, I finally signed the consent form.

The results of ECT for me were miraculous. I stopped ECT after five bilateral treatments in 2001 due to the disorientation from the procedure. In 2007 when I had ECT again (unilateral), I walked out of the hospital after three treatments. My doctors pleaded for me to continue, but I felt better and feared the negative side effects of ECT. So I abandoned the process. After relapsing a few weeks later, I returned for four more treatments. Since then I have maintained my health by taking 150 mg of Wellbutrin, several years of therapy and attention to sleep, exercise, nutrition and stress management.

My concern about this paper is that forcing a placebo clause into the consent process and repeating the consent process before each treatment throughout the procedure could harm the patient. This dogged approach to consent goes beyond informing the patient of risk for a patient who is already highly negatively predisposed.

A placebo clause inflicts a large degree of doubt and negativity for the patient that can cause him or her to abandon a course of treatment that we know from experience is likely to help. Here is our

dilemma. Depression, like other medical conditions such as chronic pain, is a disease whose symptoms are measured by subjective reports from the patient as well as objective rating scales. However, there is no brain scan that proves a person is less depressed, just as there is no scientific pain metre to measure pain.

An example may further clarify my point. When a patient has a hip replacement, the objective of the surgery is to increase mobility and reduce pain. Normal surgical procedure would require a patient's signature on some version of a consent form. Because we lack a scientific measure for pain, some of the patient's pain relief might be due to his or her perception of pain reduction instead of 'actual' pain reduction. In this situation, the patient is never warned that pain relief might be all 'in his or her head,' or a placebo effect. From experience we know a hip replacement reduces pain. We warn the patient of the possible risks of surgery and try to set reasonable expectations. We do not try to belittle the patient's recovery by pointing out something we can't reasonably prove. In fact, we encourage the patient to have a positive outlook on pain reduction.

Considering this situation, one might argue for ECT testing to prove the placebo effect does not exist. In some ways I wish we could do this. The lack of a study upon which all parties can agree leaves a wide berth for anti-ECT advocates and causes much anxiety among patients contemplating the procedure. Carrying out a study like this, however, creates another medical ethics quandary. Patients who have a level of illness that warrants ECT often have a life-threatening or severely debilitating illness. Is it ethical to administer sham ECT in this case, especially when we have 70 years of experience to indicate the procedure works? Anaesthesia for sham ECT incurs a risk to the patient as well. Further, the need for ECT is infrequent enough that it would be difficult to gather large enough numbers of viable ECT candidates in a similar geographical location for a study to ensure proper controls and to provide a reliable result. A better focus for study would be the continued neuroimaging research that is already beginning to bear fruit to prove ECT's potent impact on brain function.

Depression is a disease of vastly skewed negative thinking. Negative representation of ECT in films like *One Flew Over the Cuckoo's Nest*, *Changeling* and theatrical productions such as *Next to Normal*, as well as strident efforts by anti-ECT advocates stoke the fears of someone considering ECT.³⁻⁵ Even the recent Stephen King novel *11/22/63* features a murderous psychiatric patient who, of



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course, has just had a course of ECT.⁶ The idea of electricity in the brain is good theatre, so ECT gets an exorbitant share of elaborate bad advertising.

The informed consent process and document for ECT in most hospitals is already comprehensive and lists many potential risks and side effects; to add an unproven hint of placebo effect would make a patient more likely to refuse the procedure. Many patients believe that by praying harder or by being more disciplined, they can will away their mental illness. That may be true, however, the patient may also die in the process. People lived through diseases prior to antibiotics, however, far fewer of them survived. An ECT placebo effect clause feeds the already too prevalent notion that mental illness is not a 'real' disease. We should not feed the fears of patients by warning them of risks we can't measure or might not even exist.

After publishing my book, I have had numerous people call me who were considering ECT. Oftentimes I have turned people away from ECT. Those who consider ECT a miraculous quick-fix-solve-all solution, need to be told, as they are in most ECT consent documents, that it is a treatment for their current episode of depression and that they will need additional treatments (medication, psychotherapy or even maintenance ECT) to remain well in the long term. This is not an indictment of ECT, merely the recognition that for most patients, depression is a recurring illness. I often refer to ECT as the 'triple bypass of mental health.' After cardiac surgery, patients must pay attention to exercise and eating habits to stay well. If ECT patients return to an emotional life of burgers and fries after successful ECT, odds of relapse increase.

Many seriously depressed people who call me, however, have tried various medications, life change, and therapy. Nothing seems to work. Their lives are severely disabled, but often their psychiatrists have ruled out ECT because of the fear of side effects. These patients, like I was, are overly informed and unnecessarily frightened about the potential problems of memory loss. In result, they are terrified. I refer these people to psychiatrists I trust for a second opinion to determine if ECT might be a viable option.

Often these people call me periodically during a course of treatment of ECT, seeing improvement, but frightened about memory disturbance. They want some assurance that the temporary memory issues will lessen. I tell them my experience and try to set reasonable expectations. Routinely, people come back and thank me for easing their fears and saving their lives. I don't take any credit for the latter.

If the medical profession is truly trying to come up with the best medical care for a patient who is victim of a disease (depression) that exaggerates negativity, a consent process that increases self-doubt and negativity is not the answer. A physician's conscience might be eased, but the patient's path to health is obstructed. For example, let's assume we follow Blease's lead and we create a consent form that must be signed

before every administration of ECT and contains the suggestion that ECT may work by the placebo effect. With each treatment during a course of treatment, a patient reviews all the possible reasons why the procedure might not work and the possible problems with memory. Telling the patient ECT might work because of placebo denigrates the procedure and it gives this person already plagued with self doubt and negativity more reason to discontinue treatment or, at best, continue the treatment with higher anxiety.

ECT preceded FDA's regulation of medical devices, leaving us with an odd dilemma. While the sham-controlled ECT literature is flawed, we don't have a battery of tests that proves there is no placebo effect. We do, however, have 70 years of remarkably positive experience with the procedure. Further, it would be unethical to conduct new placebo-controlled studies in the very ill population for whom ECT is appropriate. It seems a more ethical solution to give the patient outcome data instead of dwelling on an unlikely theory of placebo effect that can't be proven definitively with the tools we have available today. How do you measure actually feeling better or brain changes due to placebo effect? Ultimately, today, that gauge is always subjective. Data given to the patient should include information on remission and response, as well as information on cognitive effects.

Is it more medically ethical to reinforce negative outcomes to the point of anxiety or provide tools for patients to assess risk and maintain their own mental health? I believe Blease's heart is in the right place, but in practise a placebo effect warning would cause more harm than good. Patients would be better served by a consent form that emphasises three things: information on reasonable outcomes to expect, risks of the procedure and the importance of follow-up care for sustained health after successful ECT.

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- 3 *One Flew Over the Cuckoo's Nest*. Directed by Miloš Forman. USA:United Artists, 1975.
- 4 *Changeling*. Directed by Clint Eastwood. USA:Universal Pictures, 2008.
- 5 *Next to Normal* [musical]. Book by Brian Yorkey, 2008.
- 6 King S. 11/22/63. New York:Scribner, 2011.