ELECTROCONVULSIVE THERAPY;

CLIENT-CENTERED

EVALUATIONS

OF ITS EFFECTS

By

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This work is dedicated to our daughter-on-the-way, Olivia Catherine Murphy-Major. May your life be rich beyond the telling, little one.

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CHAPTER ONE

INTRODUCTION

Electroconvulsive therapy (ECT, also known as Electro-shock Therapy) has generated an enormous amount of controversy in its sixty-year history of use as a psychiatric intervention. While the public has grappled with its use in such films as One Flew Over the Cuckoo's Nest (adapted from a Ken Kesey novel of the same name), and the courts have enacted guidelines for its use (Finch, 1999), the psychiatric and psychological communities have sustained a wide-ranging discourse on ECT's efficacy, mode of action, adverse effects, and ethical underpinnings. However, in spite of more than 1,000 studies done on ECT in the 1990's alone, very little attention has been paid to the subjective experience of those clients who have undergone electroconvulsive therapy. Thus, while enormous energy and resources are expended to understand ECT within a concerted scientific context, a crucial piece of the treatment is almost wholly unreported: what do the people who have experienced ECT have to say about it?

Perhaps the most important aspect of ECT to appreciate in contextualizing the under-representation of client experiences is ECT's alleged history of misuse and abuse. As stated in the National Institutes of Health Consensus Statement on ECT:

As often occurs with new therapies, ECT was used for a variety of disorders, frequently in high doses and for long periods. Many of these efforts proved ineffective, and some even harmful. Moreover, its use as a means of managing unruly patients, for whom other treatments were not then available, contributed to the perception of ECT as an abusive instrument of behavioral control for patients in mental institutions for the chronically ill (NIG Consnsus Statement 1985).

Adding to this history is the long-standing controversy surrounding ECT's possible side effects. A great deal of concern has existed throughout ECT's history of use about its potential to cause temporary and permanent memory loss (Fink, 1999). Additionally, some medical professionals contend that ECT's primary therapeutic mechanism is brain damage (Breggin, 1986). It is also unclear whether or not ECT is effective. In some cases, the numbers are extremely favorable, citing 80 percent improvement in severely depressed patients after ECT (Fink, 1999). However, other studies have found similar improvement rates with a placebo (Greenblatt, Grosser & Wechsler, 1964). Further, other studies (Bourgon & Kellner, 2000) indicate that the relapse rate is as high as 90% within 6 months, without maintenance ECT or psychopharmaceutical prescription(s) as follow-up. Some researchers insist that no study proves that ECT is effective for more than four weeks (Breggin, 1986). Another problematic aspect of studies attempting to assess ECT's efficacy is that

they typically measure outcome solely in terms of symptom reduction, and fail to address more global functioning such as quality of life and social/familial reintegration.

A recent study done in the United Kingdom by Johnstone (1999), begins with the thesis that "although it is known that a proportion of people find ECT distressing to receive, these adverse psychological reactions are little understood." The study involved interviews of twenty individuals who self-reported having found ECT upsetting. Interviews revealed a variety of themes including "feelings of fear, shame and humiliation, worthlessness and helplessness, and a sense of having been abused and assaulted." In summary, Johnstone points to the commonality of the suppression of those feelings, indicating a "possible hidden pool of trauma."

Lastly, a number of organizations such as "The Committee for Truth in Psychiatry" (http://www.ect.org/ctip_about.shtml), and web sites such as "ect.org" (www.ect.org), have formed over the last few decades as a means to augment the current practice of ECT, including the attempts to standardize treatment, informed consent, and record keeping of the practice, the latter of which is currently only done in four states in the U.S. Especially of interest to this study, in addition to activism these organizations have created on-line communities via discussion forums, which serve as repositories for information on ECT and as communities

sympathetic to those who feel they have been disabled by their ECT treatments.

Statement of Problem

Given the variety of scientific and personal responses to ECT, the lack of client-centered research on the subject, the existence of a multitude of web-based resources and national organizations dedicated to the reform of ECT, and the traumatic experiences elucidated by the little research on client experiences which has been done, the need to include new client-centered approaches in ECT-related research is clear.

Purpose of the Study

The purpose of this phenomenological study is to gain a qualitative understanding of the client experience of ECT by looking for common themes in and among client stories as they have been posted, anonymously, on a discussion forum on the World Wide Web. The site, "Let's Talk", is part of an ECT-related website by the name of "ect.org" (www.ect.org) and offers three discussion forums. Its "General ECT Discussion" forum is the one from which this study gathered its data. This particular forum concerns itself almost exclusively with ECT-related issues. The "Let's Talk" forum's address is:

http://www.ect.org/cgi-ect/ubb/Ultimate.cgi?action=intro

This method of data collection was chosen because it allows conversations about ECT and its impact on the lives of its consumers, past

and present, to be witnessed directly. This forum itself was chosen because it is the only medium of its kind currently available to specifically address the experiences of ECT and its clientele, as opposed to other mental health issues. It is hoped this approach will yield a greater appreciation for the shared themes occurring across the subjective experiences of ECT clients, and that this appreciation might point to specific aspects of the entire ECT experience that have value in assessing, understanding, and predicting positive and negative client experiences with this therapy.

Research Questions

1. What themes emerge in analyzing client narrations of negative experiences related to undergoing ECT?
2. What themes emerge in analyzing client narrations of positive experiences related to undergoing ECT?
3. What implications do these themes have for the practice of ECT?

Significance of the Study

As noted previously, the literature reflects a great need for client-centered research on the experience and effects of ECT. Despite what a great deal of research posits is a benign and quite effective practice, the discrepancies between research data and the reports of many individuals whose experiences have run quite counter to the proposed trajectory of

treatment suggests that ECT research needs to turn its focus on the subjective experience of those who have received it.

Important elements to this study which are lacking in prior research are:

- The inclusion of a more general sample rather than one self-selected on the criteria of negative ECT experiences.
- The use of client-initiated report unguided by researcher presence and questions

CHAPTER TWO

REVIEW OF THE LITERATURE

Introduction

ECT has been called "the most controversial treatment in psychiatry" (NIMH, 1985). The purpose of this literature review is to familiarize the reader with the history, current practice, proposed mechanisms of effect, and problems associated with electroconvulsive therapy, or ECT. With a history of more than 60 years, and studies that span a continuum of sentiments and data as to its efficacy, its ethicality, and the desirability of its continued incorporation as a valued treatment modality in modern psychiatry, ECT is a practice that continues to garner, and perhaps require, great scrutiny. Importantly, a review of the literature about ECT reveals that despite the great controversy surrounding it, there is a fundamental paucity of client-centered research on the subjective effects of ECT. The existing body of client-centered research strongly suggests that a constellation of unsettling effects may affect a significant portion of those treated with ECT.

History of Shock Therapies

The use of electric shock as a means to therapeutically address psychiatric problems has its earliest documented history in a 16th century

Jesuit missionary account of Ethiopia. Referring to a ritualized practice of applying electric catfish as a means of exorcism, the missionary writes: "The superstitious Abassines (Ethiopians) believe that it (the electric catfish) is good to expel Devils out of the human body, and it did torment Spirits no less than men." (Torrey, 1972)

The use of electricity in treating mental disorder appears again in mid 18th century France, where Desbois de Rochefort's medical text recommends its application on various parts of the human body as a means to assuage "organic nervous diseases and...patients suffering from grief reactions." (Atlshule, 1954).

Over the course of the next 100 years, the use of both convulsive and non-convulsive electric shock applied as a therapeutic modality for both physical and mental ailments took greater prevalence shape. It was not until 1870 and 1872 however, that the first scientifically rigorous examinations of the effects of electric shock on "insanity" were done by Arndt and Allbutt, respectively. Their findings, which reported good results in treating the conditions of apathy, dementia, and melancholia, were well received by the medical and psychiatric communities and were in common use for the next two decades (Berkwitz, 1939).

The basis for the modern incarnation of electric therapy used within a psychiatric context is actually found in the therapies of Insulin-induced Coma and Metrazol Convulsive Treatment, both of which were conceived

of in the early 20th century. Beginning in 1927 with Austrian psychiatrist Manfred Sakel, hypoglycemic shock induced through insulin injection was utilized as a treatment for individuals with schizophrenia. Inspired by the seeming beneficial effect of epilepsy on schizophrenia, seven years later Ladislaus von Meduna, a Hungarian psychiatrist, induced epileptic-like convulsions through the injection of camphorated oil as a means to treat the same population. (Mowbray, 1959)

The heritage of association between effective treatments of marked mental disorder and the instigation of convulsion or coma (stemming from the theoretical incompatibility of schizophrenia and epilepsy) laid a solid groundwork for the introduction of modern electroconvulsive therapy by Italian psychiatrist Ugo Cerletti in 1938. Cerletti was attracted to electricity as a potential method of causing therapeutic seizure. Although initially wary of "the danger of electric applications to man" (Cerletti, 1943 in Sackler et al, 1956), Cerletti was emboldened as his research on canines suggested that severe harm or even death was actually quite difficult to achieve once the application of current was modified to exclude the heart from the circuit of electricity by placing electrodes on either side of the head:

> The animals that received the severest treatment remained rigid during the flow of the electric current, then after a violent convulsive seizure they would lie on their sides for a while

> sometimes for several minutes, and finally they would attempt to rise. After many attempts of increasing efficiency, they would succeed in standing up and making a few hesitant steps until they were able to run away. These observations gave me convincing evidence of the harmlessness of a few tenths of a second of application through the head of a 125-vold electric current, which was more than sufficient to insure a complete convulsive seizure. At this point I felt we could venture to the experiment on man, and I instructed my assistants to be on the alert for the selection of a suitable subject.

Cerletti found his subject, and thus was born electro-shock treatment, now known most commonly as electroconvulsive therapy or ECT.

While ECT was very popular from its beginning, as early as 1947 the concern over ECT was apparent even in mainstream psychiatry. That year, the well-respected Group for the Advancement of Psychiatry (GAP) released a report that stated the following:

> In view of the reported promiscuous and indiscriminate use of electro-shock therapy, your Committee on Therapy decided to devote its first meeting to an evaluation of the role of this type of therapy in psychiatry. Both the extravagant claims as to its efficacy made by its proponents and the uninformed condemnation of its

use at all by its opponents indicate the emotional aura which surrounds this whole topic (GAP, 1947).

In conclusion, the Group recommended that:

> Abuses in the use of electro-shock therapy are sufficiently widespread and dangerous to justify consideration of a campaign of professional education in the limitations of this technique, and perhaps even to justify instituting certain measures of control.

The next 25 years saw ECT become incorporated into the psychiatric establishment of the United States as a widespread treatment. It became especially popular as a technique with severely disordered patients in the then popular mental institutions. During this period extensive research lead to refinements in the procedure (discussed later in the chapter) but not before ECT was abused. As stated in a recapitulation of ECT's history by the National Institutes of Health Consensus Statement on ECT:

> As often occurs with new therapies, ECT was used for a variety of disorders, frequently in high doses and for long periods. Many of these efforts proved ineffective, and some even harmful. Moreover, its use as a means of managing unruly patients, for whom other treatments were not then available, contributed to the perception of ECT as an abusive instrument of behavioral control for patients in mental institutions for the chronically ill. (NIG Consensus Statement, 1985)

In the following decades, these issues led to demonstrations, legal actions, and a number of books by psychiatrists, physicians, and clients of ECT who were of the opinion that ECT should be at the very least heavily regulated if not banned altogether.

The issues raised about ECT during that period have yet to be resolved. Research is still being done to define this therapy's method of action (Bergland, 1985) and possible damaging effects (Zachrisson, 2000), books are still being written which decry ECT as state-supported torture and mind control (Breggin, 1999), and laws are still being passed which regulate the practice of the therapy (Finch et al, 1999). Though the intensity of the controversy surrounding ECT seems to have stayed the same, the volume of such controversy *has* waned (at least until ECT's recently renewed popularity, discussed in the next section), due mainly to the introduction and subsequent widespread adoption of effective psychopharmacological medications that have dramatically reduced the perceived need and number of ECT treatments each year.

Current Status

After ECT's peak prior to the introduction of psychopharmaceuticals in the 50's, use of ECT declined until the early 1990s. In analyses of national hospital survey data, Thopmson et al. (1995) found that the use of ECT decreased by 46% between 1975 and 1980, stabilized between 1980 and 1986, and began to rise again from 1986 until now. Increases

in use of ECT have occurred among women, whites, the Medicare-eligible disabled, and the elderly. (Rosenbach et al., 1997)

The most currently available data show that electroconvulsive therapy is practiced almost exclusively in for-profit venues, such as general hospital psychiatric units and in psychiatric hospitals (Grosser, 1974). In the U.S., it is estimated that between 50,000 and 200,000 patients undergo ECT every year. Estimates are cited because only four states (Colorado, California, Texas, Massachusetts) require reporting on ECT statistics. These estimate figures place the percentage of people receiving ECT each year at 0.002-0.013% of the estimated 15 million Americans receiving psychiatric treatment. The National Institue of Mental Health, in a study of ECT in the year 1975, found that women received ECT more often than men at a ratio of 2:1 (NIMH, 1976). Use of ECT varies widely across the United States (Hermann et al, 1995), despite the consistency of distribution of diagnosed major depression (ECT's primary disorder of treatment) across the nation (Robins et al., 1991). In fact, the variation in use of ECT among cities is so great that while one-third of cities do not use it, among the cities where its use is reported, "the rate in the city with the greatest use (is) more than fivefold higher than the rate in the city with the least use." (Hermann, et al., 1998).

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Hermann et al. (1999), found in their study on the characteristics of psychiatrists who perform ECT that only 8% of all U.S. psychiatrists

provide the treatment. Data from the 1988-89 Professional Activities Survey conducted by the AMA show that of those psychiatrists who do perform ECT, the majority are male and earned their degrees abroad. Significantly, while women are almost equally represented in the psychiatric workforce, female psychiatrists are one-third as likely to administer ECT as are male psychiatrists.

Method of Practice and Treatment Populations

As it is practiced today, electroconvulsive therapy involves the application of a brief electric current passed through the brain by two electrodes in order to instigate a generalized seizure. Classic, or unmodified ECT, was administered without anesthesia, or muscle relaxants. As a consequence broken bones and tissue damage was common. Patients of the treatment today are given a general anesthetic for pain and an anti-spasmodic to prevent bodily injury during convulsion. Assisted breathing is necessary due to the pulmonary-paralyzing nature of the anti-spasmodic. The electric shock given is typically between 140 and 170 volts, and lasts between 0.5 and 1 seconds. A course of treatment typically consists of 4-12 shocks, given over a period of 2-3 weeks with at least one day between treatments.

Although in the past a wide variety of mental disorders were considered within the scope of ECT's treatment efficacy, its current indication is limited almost exclusively to major depression (delusional and

endogenous), but ECT is also used to treat acute mania and certain schizophrenic conditions.

Postulated Mechanisms of Effect

Psychodynamic/psychoanalytic

Early theories of ECT's action were most often based in psychodynamic models of personality rather than physiological science, as they typically are today. As quoted in Johnstone (1999):

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 hypothesized 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 favorable results in her therapy. As psychodynamic/analytic models were steadily abandoned for biological and behavior-based psychology from the late 50's on, research into the symbolic action and meaning of ECT declined.

Neurophysiological

By far the most popular current model, and the mechanism of action purported by the majority of the medical and psychiatric community, is the neurophysiological. This explanation, which is based on the biological view of depression, suggests a number of alternative theories. Fink (1999) posits that disordered regulation of hormones in the "hypothalamic-pituitary-adrenal axis" (p. 83) in depressed persons results in high cortisol production by the adrenal glands, which causes the prominent behavioral features (especially disrputed rhythm functions such as loss of appetite and sleeplessness) associated with depression. He goes on to explain that ECT-induced seizures "stimulate the hypothalamus to discharge its hormones" (p. 82), which in turn restabilize pituitary and adrenal gland function, thereby ending depression. Other studies (Mann & Kapur, 1994) suggest that ECT's antidepressant action may be due to the finding that ECT enhances the transmission of a number of key neurotransmitter systems in the brain.

Brain Damage

The hypothesis at the other end of the continuum, which seems to be ascribed to by most critics of ECT, holds that brain damage (documented in the form of damage to blood vessel walls and nerve cells, as well as the breakdown of glial cells) and the memory loss stemming from these brain changes, are the primary effect of ECT on the psychological condition of its recipients. Breggin (1990) maintains that

ECT is essentially a type of acute organic brain syndrome, which follows a typical course of unconsciousness and memory loss common to blunt-force trauma, electrocution, and severe seizure. Sackiem (1986) defines it in this way:

> The ECT-induced seizure, like spontaneous generalized seizures in epileptics and most acute brain injury and head trauma, results in a variable period of disorientation. Patients may not know their names, their ages, etc. When the disorientation is prolonged, it is generally referred to as an organic brain syndrome (Sackeim, 1986).

It should be noted that recent research (Zachrisson, 2000) measuring different biochemical signs of cerebral trauma has found no evidence to support the theory that ECT causes brain damage.

Efficacy of ECT

Controlled studies of ECT point to its short-term efficacy in treating severe major depressions (delusional and endogenous), in acute manic conditions, and in certain types of schizophrenia. Unfortunately, controlled clinical trials examining ECT's efficacy do not extend beyond the treatment of the acute episode, which lasts approximately 4 weeks (National Institutes of Health Consensus Development Conference, 1985). Another problematic aspect of most studies attempting to assess ECT's efficacy is that they typically measure outcome solely in terms of symptom

reduction, and fail to address more global functioning characteristics such as quality of life, self esteem, and issues associated with post-ECT social and familial reintegration.

Depression

Fink (1999) cites figures of improvement in approximately 80% of endogenous depressions treated with ECT. Studies done on the effects of ECT on depression typically use psychopharmaceuticals such as tricyclic antidepressants (TCA), monoamine oxidase inhibitors (MAOI) and selective seratonin reuptake inhibitors (SSRI). Most studies find ECT to be of at least equal efficacy to medication treatments. However, while no controlled study has yet found a treatment to be superior to ECT in the short-term management of severe depressions, these studies do not typically address the long-term persistence of these benefits. Current data suggests that relapse rates are quite high in the year following ECT if no antidepressant medications are prescribed as a follow up to ECT treatment.

Importantly, two older studies by Greenblatt, Grosser & Wechsler (1964) and Lowinger & Dobie (1969) give convincing data to suggest that ECT's therapeutic effect on depression might not exist outside of its placebo effect. In the study done by Greenblatt et al., 32 recipients of ECT were selected from three hospitals. In hospitals 1 and 3, ECT was as effective as imipramine. In hospitals 2 and 3, ECT's efficacy was equal to

that of a placebo. While this study found ECT to produce improvement in 70-80% of depressed patients, a 69% improvement rate after 8 weeks of placebo was also noted. Lowinger and Dobie (1969) reported that improvement rates as high as 70% to 80% can be expected with placebo alone.

Acute Manic Episode

In a review of 50 years of data on ECT's effect on acute manic episodes, Mukherjee, Sackeim and Schnur (1994) found that ECT is associated with remission or marked clinical improvement in 80% of manic patients. Generally, ECT is an effective treatment for patients whose manic episodes have responded poorly to pharmacotherapy.

Schizophrenia

ECT's efficacy in treating schizophrenic populations is highest for those individuals with "a shorter duration of illness, a more acute onset, and more intense affective symptoms" (NIMH, 1985). Neuroleptics are cited as the first line of treatment for schizophrenia.

Negative Features of ECT

Memory loss

Perhaps the most consistent negative feature associated with ECT treatment is memory loss. An excerpt from Neurobiologist Dr. Peter Sterling's 1978 Testimony Prepared for the Standing Committee on Mental

Health of the Assembly of the State of New York provides a helpful reference to this subject:

> Losses of memory for past events commonly occur following insult to the brain...it should not be surprising that memory loss also accompanies the damage done to the brain by ECT. Such losses have been documented in numerous case reports dating back to the 1940s (Levy, et al., 1942). In some cases the loss is catastrophically complete: memory is erased for professional skills as well as orientation to places and friends (e.g., Roueche, 1974). More commonly, the loss is "patchy": some events are lost while others are remembered; recent events are more likely to be lost than those in the distant past, but amnesia can extend backward for several years and can include events of early childhood that date back 20 to 40 years; some memories return while others do not (Janis, l948; A Practicing Psychiatrist, 1965; Brody, 1944; Valentine, et al, 1968; Medlicott, R.W., 1948; Squire, et al, 1975).

Modern ECT treatments have evolved in large part to diminish its possible memory disabling effects. Electrodes are now most often placed on one side of the head (to limit exposure to the non-dominant hemisphere, typically determined by handedness), in a technique known as unilateral ECT. Additionally, the electrical currents used in ECT have changed in duration and intensity (Fink, 1999).

Brain Damage

In what is perhaps the most extensive study of ECT's possible damaging effect on the brain (Breggin, 1979), Hartelius (1952), exposed a group of forty-one cats to ECT at varying rates (from 4-16 treatments), while 16 others cats went unshocked as a control. After the clinical trials, a double blind scenario was created in which a pathologist was able to discriminate between the shocked and nonshocked animals by studying only their brains (Hartelius, 1952). The study itself claimed that the probability of such correct classification in a random distribution would be less than 0.0001. The experimental animals showed changes in their blood vessel walls and nerve cells, and displayed a glial reaction (indicating the breakdown of glial cells). This damage was more pronounced in those animals who had been subjected to the greater number of ECT treatments. These findings have in large part been demonstrated by human autopsy studies after ECT (Breggin, 1979).

In spite of the abundance of evidence that ECT sometimes causes brain damage, the Report of The Task Force on Electroconvulsive Therapy of the American Psychiatric Association (1978) makes a legitimate point in stating that the preponderance of human and animal autopsy studies were carried out prior to the modern era of ECT administration that included anesthesia, muscle relaxants, and hyperoxygenation.

Zachrisson (2000), in the most recently released research on ECT's possible brain-damaging effects, found no evidence of cerebral damage as reflected by different biochemical measures. In their limited study of nine patients with major depression, cerebrospinal fluid (CSF) was collected before and after ECT treatment. Upon examination, 3 established markers of brain damage found in CSF showed insignificant if any changes post treatment exposure, while all patients showed "significant decline of depressive symptoms" as assessed by the Montgomery-Asberg Rating Scale for Depression (Zachrisson et al., 2000).

In a literature review of 159 articles, Devanand et al., (1995) evaluated whether ECT causes structural brain damage. Their findings point to transient cognitive deficits during the period of time immediately following ECT treatment, but no ECT-induced structural changes are evidenced in repeated computerized tomography and magnetic resonance imaging studies. The final conclusion of the study: "There is no credible evidence that ECT causes structural brain damage" (p. 64).

Other Issues and Adverse Effects

Death

In ECT's infancy, mortality was a noted problem. Data from 1940-60 suggest an overall mortality rate of 1 per 1,000, or 0.1 percent (Frank, 1978). Modifications to the treatment, including the administration of anesthesia, muscle relaxants, and the provision of oxygen (to counteract

apnea) have reduced the mortality rate significantly. Current figures cite a mortality rate of 1 per 10,000. (Fink, 1999).

Other Complications

A variety of complications were associated with historical ECT treatments, including but not limited to tissue damage, broken bones (typically in the form of compression fractures of the vertebrae), and cardiac arrest. These complications were reported in up to 40 percent of treatment recipients (NIMH, 1985). Current data suggest that with the present methods of ECT administration (which includes muscle relaxants, general anesthesia, and assisted breathing) these risks have been dramatically reduced. Large modern studies such as the California Dept. of Mental Health's Report to the California State Legislature on ECT use from 1989-1994 consistently find a complication rate of 1 per 1,300 treatments.

Table 1 shows total complications from the years 1989 through 1994, excluding 1993, for which no data was available. Of 12,310 patients treated, 2,589 or 21% of all patients suffered complications.

As the data in Table 1. shows, memory loss is by far (93.6%) the most prevalent complication of those clients treated with ECT. Other complications not considered in the California statistics include laryngospasm, circulator insufficiency, tooth damage, status epilepticus, peripheral nerve palsy, and skin burns (NIMH, 1985).

TABLE 1.

Complication	Number	% of all patients	% of all complications
Cardiac Arrest	6	0.04	0.23
Memory Loss	2,424	19.7	93.6
Fractures	5	0.04	0.2
Apnea	154	1.25	5.9
Deaths	0	0	0

Efficacy and relapse

Although many studies cite reduction of depressive characteristics in up to 80% of treatment populations (Fink, 1999), there is convincing evidence to suggest that ECT is no more effective than a placebo (Greenblatt, et. al, 1964 and Lowinger et. al, 1969). These findings give convincing data to suggest that ECT's therapeutic effect on depression might not exist outside of its placebo effect.

Most studies (NIMH, 1985) suggest that long-term ECT efficacy is quite low in the year following ECT if no antidepressant medications are prescribed as a follow up to ECT treatment. Current data provided by Bourgon & Kellner (2000) suggests a relapse rate of 50% without follow-up treatment (defined as either maintenance ECT, antidepressant medication, or both), the majority of which occurs in the first 6 months after treatment.

Gender Distribution

One of the more consistent features through ECT's evolution has been its predominant usage with female populations. In the National Institute of Mental Health's "Facts about Electroshock" (1972), a ratio of 2:1 is cited. Studies as recent as California Dept. of Mental Health's Report to the California State Legislature (1995) on ECT report a breakdown of application across gender that shares this ratio. In the case of that particular report, of 12,310 total recipients of ECT between 1989 and 1994, 8,373 or (68%) are women. Breggin (1979) mentions in his book "Electroshock; its Brain Disabling Effects" that "advocates of ECT have explained this (gender specificity) by claiming that more women develop severe or psychotic depressions. I do not know of any evidence to support this view" (p. 187). Recent data from the National Institute of Mental Health shows that although men and women are equally likely to develop bipolar disorder (Narrow, 1998), nearly twice as many women

(6.5 percent of the adult population in the U.S.) as men (3.3 percent) are diagnosed with major depressive disorder.

Age Distribution

A similar inequality of application exists when ECT treatment populations are categorized by age. The California Dept. of Mental Health's Report to the California State Legislature on ECT reports the from the period 1989-1994, 6,038 of 12,310 recipients of ECT (49%) were over sixty-five. Other nationally surveyed data by Rosenbach et al. (1997), supports this figure.

Profitability

Other common criticisms leveled at the proponents of ECT are its profitability and the promotional ties prominent researchers and practitioners in the field have to manufacturers of ECT equipment. In "Managed Care: How Are Psychiatrists Surviving?" an article by Dr. Michael Wise which appeared in 1996, ECT is promoted as a profitable way of diversifying a psychiatric practice in times marked by dealings with HMOs:

> The old adage, "Don't put all your eggs into one basket" seems to apply. If most of your patients are long-term psychotherapy cases, this is unlikely to continue. For example, learn brief, focused therapies or specialized treatments, such as electroconvulsive therapy (ECT). One psychiatrist whose practice was self-described

(6.5 percent of the adult population in the U.S.) as men (3.3 percent) are diagnosed with major depressive disorder.

Age Distribution

A similar inequality of application exists when ECT treatment populations are categorized by age. The California Dept. of Mental Health's Report to the California State Legislature on ECT reports the from the period 1989-1994, 6,038 of 12,310 recipients of ECT (49%) were over sixty-five. Other nationally surveyed data by Rosenbach et al. (1997), supports this figure.

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> as "strictly inpatient" took a week-long practicum in ECT and has since developed an inpatient and outpatient ECT service (Wise, 1996. p 54).

Many of the vocal proponents of and prodigious researchers on ECT have vested financial interests in the therapy. Emeritus professor of psychiatry Max Fink, M.D., author of 3 books and nearly 40 articles on ECT, has admitted to compensation (including royalties) from videos created and marketed by Somatics (Aubrey vs. Johns Hopkins Hospital, 1991), one of the four companies in the U.S. that manufactures ECT machines. Somatics is owned by psychiatrist Richard Abrams, himself the author of more than a dozen articles on the subject. In 1990, the APA formed an "ECT Task Force" with the intent to set recommendations for the "standard of care" for the nation's practice of ECT (APA Task Force, 1990). Three of the six members of the Task Force (Fink, Richard Weiner of Duke University, and Harold Sackeim of New York State Psychiatric Institute) can be seen on various informational and commercial videos produced by the manufacturers of ECT machines (Cameron, 1994).

Inadequate Training

Currently, there is no standardized procedure for training or licensure for physicians utilizing ECT; even a minimal standard for education does not exist. Due to the paucity of training programs available in postgraduate psychiatric residency (Fink, 1999), ECT training

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is almost exclusively done in "continuing-medical-education programs" (p. 102). And as a consequence of the abbreviated nature of these courses, "practitioners are left to develop their experience while treating their first patients" (p. 103).

Parallels to Sexual Abuse

One possible negative impact of ECT is that it has the potential to recapitulate traumatic sexual events for clients who have experienced such abuse. In a discussion of her findings in a qualitative study done with ECT patients who had experienced dramatic negative reactions to the treatment, Johnstone (1999) finds that:

> 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 hospitals 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. (p. 79)

This is a startling and wholly unresearched topic within the already scarce literature on client experiences of ECT.

Client Experience of ECT

Very few studies exist which examine the treatment population's subjective experience of ECT to any degree. Of more than 2000 search results on ECT research done since 1990, fewer than 1 out of every 500 records are based on subjective measures of ECT (from search results on the PsychINFO database, keyword "ECT"). Of those few studies that do address this facet of ECT research, many focus on the experience of adolescents and parents of adolescents who experienced ECT. Of those studies, approximately 60% of adolescents and their parents found the treatment effective, while "all patients complained of memory impairment, and worries and fears about ECT were often expressed" (Taieb, Cohen, Mazet & Flament, 2000 p. 143).

A foundational study done in the United Kingdom by Johnstone (1999), begins by noting that "although it is known that a proportion of people find ECT distressing to receive, these adverse psychological reactions are little understood." The study goes on to interview twenty individuals who self-reported having found ECT upsetting. Johnstone's research illuminates a variety of themes shared by ECT recipients, including "feelings of fear, shame and humiliation, worthlessness and helplessness, and a sense of having been abused and assaulted" (p. 69). In summary, Johnstone notes:

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> 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. (p. 74)

Other studies that utilized self-selecting populations have found similar results. Of more than 300 replies to a survey constructed by the United Kingdom Advocacy Network, 30.1% of respondents described ECT as "helpful" or "very helpful", while 35.1% found ECT to be "damaging". A constellation of negative effects were elucidated through the narrative responses allowed by the questionnaire. Among them were: "fear of hospitals and psychiatry; anger and aggression; nightmares; and loss of confidence, dignity and self-esteem (Ukan, 1996).

Summary

A recent study by Reid (1995) attempts to dispel the whole contentious history of ECT:

> Although temporary confusion and amnesia are expected immediately after treatment, no reliable data suggest that permanent memory loss or cognitive deficit is caused by modern ECT. Indeed, because severe depression itself often causes both memory and cognitive deficit, ECT's remarkable therapeutic effectiveness is associated with long-term improvement in cognition, learning ability, and memory in many patients. Controversy over safety and effect on memory is fueled largely by public misinformation.

While ECT is seen by the medical community on the whole as a safe and effective treatment (NIMH, 1985), the wide variety of opinions about it and the amount of research validating a continuum of effects from damaging to healing make ECT "the most controversial treatment in psychiatry" (NIMH, 1985). Despite enormous amounts of research done on ECT, there exists an unsettling under-representation in the research of subjective reports of those people who have undergone ECT as a treatment. In the scarce research which validates the existence of negative client experiences of ECT, both the reasons for and consequences of ECT's negative effects are poorly understood.

With the wide variety of opinions and research regarding ECT, and given the devastating trends pointed to by recent qualitative research (as well as the presence of grassroots and cyber-based movements to reform

or abolish ECT) the need to listen to client accounts of their own ECT experience is vital, if not ethically mandated.

CHAPTER THREE

METHODOLOGY

Biases

The way in which ECT is and has been practiced, its nefarious history in institutions, the ties to ECT industry had by many of its most vocal researchers and proponents, and the composition of the populations who receive it today (the majority being white women over 65) all point to ECT being a psychiatric technique that perhaps more than any other modern treatment is *implicated* as being performed against a backdrop of inequality, profitability, sexism, and abuse of power.

Simply as a student in this field I believe that the spectrum of data ready to support every manner of stance regarding ECT's impact on people points only to one thing: What does the client say about ECT? The Hippocratic oath is the foundation of the helping professions. It states, "Do No Harm". In the case of ECT, we must stop looking at statistics and start looking at clients. We must ask them, "Are we doing harm?" These beliefs have guided my interests into this research, and will undoubtedly inflect my analysis of the data.

Participants

Participants were not directly used. ECT client stories were taken from "General ECT Discussion" section of the "Let's Talk!" discussion

forum, created and maintained by the website "ect.org" (www.ect.org). Posts used as the data for this study were gathered from current contributions and archives up to approximately one year ago. Contributors are identifiable by an anonymous user name, which has been stripped (along with any other identifying information) from the records for the purposes of this research. Subjects have been labeled 1-24, and their individual posts separated. A true random sample of subjects will not be available due to the lack of other discussion forums of this nature, as well as the stated intent of this forum, which is decidedly anti-ect.

In the U.S., between 50,000 and 200,000 patients undergo ECT every year. Studies consistently find that women receive ECT more often than men at a ratio of 2:1 (NIMH, 1976). This is statistic is consistent with the prominence of major depression, which is also diagnosed on a 2:1 ration of women to men (Narrow, 1998). Although in the past a wide variety of mental disorders were considered within the scope of ECT's treatment efficacy, its current indication is limited almost exclusively to major depression (delusional and endogenous), but ECT is also used to treat acute mania and certain schizophrenic conditions.

No informed consent form will be needed, due to the anonymous nature of the material posted on this discussion forum. Topics deemed relevant to the research based on the criteria stated in the preceding paragraph will be copied directly from the forum and pasted into a word

file, where it will then be stripped of all usernames and any identifying references to persons or places.

Subjects will have undergone or will be undergoing ECT, which in its modern incarnation involves the application of a brief electric current passed through the brain by two electrodes in order to instigate a generalized seizure. Almost exclusively, the client's psychiatrist performs the technique. Patients of the treatment today are given a general anesthetic or a short-acting barbituate (by an anesthesiologist). The drug succinycholine is administered to temporarily paralyze the muscles and to prevent bodily injury during convulsion. The therapy session is typically attended to by at least one additional nursing staff. Assisted breathing is necessary due to the pulmonary-paralyzing nature of the anti-spasmodic. During the procedure, an electroencephalogram (EEG) monitors the seizure activity while an electrocardiogram (EKG) monitors the heart rhythm The electric shock given is typically between 140 and 170 volts, and lasts between 0.5 and 1 seconds. The patient wakes up between 10 and 15 minutes later. Upon awakening, patients typically experience a brief period of confusion, headache or muscle stiffness, but these symptoms usually subside within 20 to 60 minutes. A course of treatment typically consists of 4-12 shocks, given over a period of 2-4 weeks with at least one day between treatments. This study will include stories from a variety of ECT recipients, and will utilize data from past and present

clients of ECT. Due to the open nature of the forum, some former clients might have undergone treatment prior to many of the modern techniques currently used in the practice of ECT. Differences such as these will be accounted for in the data analysis.

Research Design and Procedure

This research is designed to gather ECT client stories and perform a qualitative, phenomenological analysis of them. The purpose of the research was to discover common themes in and among the posted narratives of those individuals who have received ECT treatment. Twenty-four unique contributors to the forum posted more than 50 messages. These posts were taken from the "Let's Talk!" discussion forum, created and maintained by the website "www.ect.org". Data was gathered from a discussion forum rather than through a qualitative interview protocol in the hope that the unrestricted environment of the forum might produce clearer insight into the client experience.

A true random sample of subjects was not available due to the lack of other discussion forums of this nature, as well as the stated intent of this forum, which is decidedly anti-ect. Only those materials directly relating to forum contributors own thoughts, feelings, and behaviors relating to their experience with ECT, or a loved one's experience with ECT have been included in the analysis stage of this project.

Topics deemed relevant to the research based on the criteria stated in the preceding paragraph were copied directly from the forum and pasted into a word file, where they where then stripped of all usernames and any identifying references to persons or places. They were then numbered in ascending order from 1 to 24. Quotations from these posts included in the text have not been altered from their original content or spelling and therefore appear with grammatical and spelling errors.

Phenomenology and Qualitative Research

Phenomenology seeks to give language to basic human experiences. In its application to qualitative research methods, it can be helpful in construing fundamental themes across multiple experiences: "The essence of phenomenon is universal which can be described through a study of the structure that governs the instances or particular manifestations of the essence of that phenomenon" (van Manen, 1990, p.10). Research using phenomenology seeks to uncover the meanings in our everyday existence.

This project follows an inductive, phenomenological process of analysis combining processes outlined by van Moustakas (1994) and van Manen (1990). The steps include:

- The researcher outlining a description of his or her personal experience and biases relating to the phenomenon to be studied

- The devlopment of "meaning units" of the experience which can be categorized
- The devlopment of themes based on the insights yielded by the discovery of meaning units across multiple data sources or subjects.

Van Manen (1990) extrapolates on the construct of the theme in this way: "A theme is placed, laid down. It is tied to a position, a value, meaning. Phenomenological themes may be understood as the structures of experience" (p. 79).

The theme is essentially "the experience of focus, of meaning, of point...the form of capturing the phenomenon one tries to understand" (p. 87). These theoretical frames allow an excellent point from which to construct meaningful categories and themes from the subjective experiences of ECT clients.

CHAPTER FOUR

RESULTS

Research findings were based on more than 50 separate posts by 24 unique contributors. Using the phenomenological analysis procedure discussed previously, 6 distinct categories and 2 distinct themes emerged from the data. The categories are: general negative responses, general positive responses, family member responses, memory loss, brain damage, and distrust of psychiatric professionals. Two themes were distilled from these six categories, addressing the respective overarching patterns of the negative and positive client experiences. The themes directly address the stated research questions of this project.

Categories

General Negative Responses

This category includes non-specific negative impressions and experiences with ECT therapy. Negative experiences of a specific nature, typically that of memory loss, brain damage, or distrust of psychiatric professionals, are included in their own respective categories. As the following segment of a post reveals, these general negative responses needn't be precise to impart the depth and breadth of the authors' feelings regarding their treatment:

> I pray for all the people that have been adversely affected from ECT. I, too, am one of these people. My experience is like ---- mentioned in the above post, the "positive" effects are very short-term, but, for me, the negative effects are so bad that I pray I never get ECT, again. But, strangely enough, since the depression is coming back so fast and so furious, I told my husband that I felt like getting a lot of ECTs, so my brain would be totally fried and I wouldn't have to feel the pain of depression anymore. Now, to me, that's pretty bad, and it scares the poop out of me to even be thinking this way! God help us all. (Subject 5)

These generalized responses help clarify the boundaries of negative ECT experiences. Another narrative gives insight into a fundamental sense of dislocation that some ECT clients feel after their treatment, usually as a result of memory loss:

> I fought for a year to re-learn my job and keep it, but in the end my employer though it best I move on. Carreer counselors have recommend I reassess myself and choose perhaps another type of job other than management.
>
> My wife and I are still married. I have moved away to another city and have a place of my own...I live in a small studio apartment by the beach in a diffrent city and she and the kids live in a 3,000 square foot two story home. I'm happy about where I live and she

> and the children are in a safe neighborhood. However, my wife is persistant and wants her former husband she was in love with for 17 years back. Many marrage counselor said she needs to go on with her life... alone... that I have changed since ect. and my memories of her and my children are gone. She finds this unacceptable. I admit I feel guilty sometimes that maybe I haven't tried long enough to be who I once was to my wife, my family and friends. I've had my amnesia for 22 months.
>
> Other than that, my new life seems fine. I'm making new friends and recently have a new girlfriend who is very loving and caring. However, this new life is in conflict with the new (Subject 8).

Another ECT recipient vocalizes a similar sense of loss in the following segment from a larger post: "I have lost 2 1/2 years of life because of them (ECT treatments). I am getting my life back but it is a different one than I had. I say I was raped of the wonderful life I had" (Subject 13). This sense of dislocation, of having lost, or been stripped of, a sense of self, plays a significant role in one of the themes that develop in later analysis of this data.

General Positive Responses

This category includes distinctly positive client experiences with ECT. Of the 24 original contributors, 6 had overall positive experiences with the therapy. Their posts offer interesting insight into an area lacking

from previous qualitative research regarding ECT, in that those studies have been geared exclusively towards elucidating the experiences of those who had adverse reactions to ECT (Johnstone, 1999). Figuring heavily into the second of two themes to be explored later in this chapter, elements of this category include the remission, if not reversal, of depressive symptoms and the sense of having a renewed sense of freedom; in the words of one person: "It was like being released from jail" (Subject 6). The following ECT client narrative offers clear insight into a fairly representative positive response to treatment.

> Shortly after three attempts at suicide over a ten-day period I was literally RESCUED by a series of seven ECT treatments spread over a period of a little over two weeks. Although I had never been suicidal before, I had, for many years, been the victim of recurrent severe depressions in spite of long-term treatment with antidepressant drugs.
>
> I was completely amazed at how effective the ECT was in totally reversing my suicidal depression! ...Since my ECT treatment in 1997 I have been free of any significant depression and have been happier, wiser, and more effective than I had ever been before. It is true that ECT is not a permanent cure for depression, but it can be a life-saving treatment for severe depression. Just as is usually prescribed, I have been on low maintenance doses of Prozac and

Wellbutrin since 1997 and expect to continue these for the rest of my life, just as a diabetic stays on insulin (Subject 9)

Another person (subject 6) shares a similar experience of liberation from their depression, but also notes the existence of side effects. After struggling with depression for eight years, this person was treated with ECT only after he "had reached the point where (he) could no longer summon up the energy to get out of bed". His account follows as such:

Within a month I felt like I used to when I was a young. It was like being released from jail, I was able to mix and I had the energy to follow through my ideas. This new energy allowed me to study and graduate, it enabled me to get a job and to subsequently express myself in work.

The ECT treatment worked however there has been downsides. I have lost nearly a month of memories. During this month I did almost nothing, so what's the big deal? It is a very disconcerting experience to have words that you don't remember saying thrown back at you. It is a bit dehumanising to grasp at a memory that floats by and not catch it.

How much do these things matter? That is almost certainly a subjective matter. I can understand someone who thought this was too large a price to pay. For me, I am glad I paid it and I feel I will never have topay it again.

This person's narrative, while advancing a more complex relationship to the treatment, including a sense of trade-off or having "paid a price", nonetheless points to an extraordinary relief of disabling depression. These experiences, while not commonly reported on the "Let's Talk" forum, are nonetheless an important piece in appreciating client perspectives on ECT treatment.

Family Members

Another largely unreported aspect of client treatment is the reaction of family and/or friends to their response to ECT. Of the 24 individual contributors, only 2 had not received ECT themselves and cared for someone who had or was having the treatments. Subject 4, in caring for her mother, states the following:

> I believe that by allowing ECT over the years, as my mother continued to spiral ever more downward in her world of unspeakable terror, I caused her to become this zombie. Perhaps if I had never allowed any ECT she would not be in this condition today. All her psychiatrists have called her an enigma. She has never responded to drug therapy or any alternative treatments I have sought.

While that person struggled with their past decision and its possible negative ramifications on a loved one, the mother of a 19 year-old

undergoing treatment had this to say regarding her experience as a bystander:

> I watched my son, who has always been in gifted programs in school, and who was talent searched by duke university when he was in 7th grade...because his psat scores were high enough to get him into any university in the country, descend into hell. through this treatment i am witnessing his climb out of the abyss. the chance of his being able to have a happy, functional life instead of being warehoused in a mental health facility or living in a refrigerater box under some overpass somewhere is the issue (Subject 15).

This post displays a significant possible feature of those whose experience with ECT was positive; the relief and joy on behalf of family and friends in seeing their loved one remit from serious mental illness.

Memory Loss

The subject of memory loss had by far the greatest occurrence of any category across posts. This is due to the fact that this category includes stories of memory-related issues to ECT imbedded in posts that have also been designated to other categories. For instance, even positive experiences with ECT, such as the post by subject 6, sometimes mention negative effects on memory, and for that reason those sections have been included in this category.

The severity and longevity of memory deficits appears to have a wide range across subjects. Subject 1 says in one post: "I got a fried brain with no memories". Subject 6 reports an overall good experience with the treatment, but adds, "I have lost nearly a month of memories...it is a very disconcerting experience to have words that you don't remember saying thrown back at you."

Others had far more profound losses of memory. Subject 8 claims to be a "blank slate" who in addition to losing 17 years of memory of a marriage his wife describes as "wonderful", had to move on from a job he no longer knew how to perform, and become alienated from friends and a family. In a clear and compelling narration of his or her life subsequent to ECT treatment, Subject 11 gives the reader a sense of the initial excitement following the remission of depressive symptoms directly after the first weeks of ECT, and then the long-term consequences of their memory impairment as time went on:

> First few weeks after my ECT treatments, I felt really good. Yes I was aware of some memory loss. I listened a lot and others filled in the gaps for me. People were glad to talk about their experiences with me (ex. I had a good time when we....) Often they did not know they were filling me in because I did not share that I had amnesia. The few I did share about my memory loss did not take it well. So I keep this information to myself. Besides, the doctor said

> it was normal to have some memory loss and it would return. In fact, he said ECT cured my depression. I was glad at the time I went through with the ECT. Damn I felt good...while I was struggling to keep my job, my personal life started to fall apart. I became gradually aware that the shock treatment had caused lasting substantial amnesia in all area's of my life. This included the loss of most knowledge and memories of my wife and our years of marriage with teenage children and our life together. I couldn't remember melodies of songs that friends and family expected and even wanted to hear me sing. I did not know how to run my personal music studio equipment. It was not enough any longer for me to just listen to others fill me in about who I was. It was time for me to participate like I knew what I was doing. Friends and family began to take personal offense to my non-participation as my old self.

While this person goes on to describe an increasingly harrowing ordeal with the fall-out from his memory deficits, the passage included here lends a startling human face to the smooth phrase: "memory loss". The nuances of this and other posted narratives regarding memory loss figure heavily into a central theme of negative client experiences with ECT.

Brain Damage

This category contains far less numerous, and less developed, stories than does the category of memory loss. Three contributions within this arena are notable. Interestingly, each reference to brain damage is tied to separate subject lines, yet each are designed to ward off potential clients of ECT from the treatment. Subject 21 says, "Usually it is for 10 - 15 treatments, not one or two, and by that time your brain is fried. Be careful." Subject (22), in a terse reply to a person seriously considering the treatment, "Remember, if you opt for ect that will be the day you murdered your brain." Another contributor, Subject 1, offers a more comprehensive picture:

> In spite of what our beloved psychiatric community preaches ECT produces enough voltage to traumatize the brain every time it is used.Why the hell do you think you have such a terrible and painful headache after this procedure.I had nausea enough to keep me in bed for the day.I imagine they hit me pretty hard.It is not just Hollywood who shows people in a fetal position following this procedure.I have seen it all to many times.Why do you suppose this is?I guarantee you it is not because something positive is happening inside this unconscious human being.

Like the other categories containing aspects of negative client experiences, the subject of brain damage and the posts containing

Still another former client, Subject 1, received his ECT as an adolescent in the early 60's. As stated in the following post, his experience conveys a sense of having been left out of the loop, at the cost of his memory and for the benefit, in his eyes, of his physician:

> No one ever asked me what I wanted for my life or how I felt about what was happening to me.And a totally broken family was the result.the doc got his new Cad paid for and then some.I got a fried brain with no memories.and a broken home that never will be repaired.

Even more graphic is the same subject's contribution later on in that subject thread, wherein he seems to wish to eclipse perhaps diluted language of previous posts with this dramatic account of his year-long ECT experience as a teenager:

> By the way, my ordeal was a horror.I was sixteen.I am a male.It was like being raped three times a week for a year.It was the most horrible,humiliating and degrading experience of my life.I hate the people who did this to me.

Although it is important to note that this is the only experience mentioned which likens ECT to sexual abuse, previous literature points to this as a more common finding.

These categorized posts provide an extraordinary window into the experience of ECT. Some good, some bad, representing extremes of both

certainly, these forum contributions allow a much deeper felt experience of the personal struggles (and sometimes successes) of ECT clientele. It is important however to turn towards a utilization of these categories as tools with which to construct a larger sense of the themes at play throughout the body of client narratives on this site.

Themes

Two distinct themes emerge from the six categories recognized above. Each answers one of the research questions of the study, with one positive and one negative theme. This study identifies the negative theme as the "oppression and the destruction of self-determination". This involves a constellation of adverse effects, typically including memory loss and a distrust of the profession/professionals involved with ECT. The second theme, in representing the deeper commonalities across positive client reports, is the "relief of suffering". This theme expresses itself through the remission of depressive symptomology, and the feelings of having been "saved", "set free" or the like.

Oppression and the Destruction of Self-Determination

This theme expresses a central current of nearly every negative ECT story; in having ECT these men and women express a basic violation of their rights as humans and patients. Whether through a lack of truly informed consent (or in some cases involuntary treatment) or as a result of debilitating side effects (typically memory loss), these clients feel that

ECT not only failed to treat their depression, but actively damaged their minds, spirits, and livelihoods. Subject 23 states, "I wouldn't wish this on anyone yet, that is how angry I am for what was done to me without my consent". The following narrative by subject 20 gives voice to a common story; crushing memory loss accompanies the loss of employment, and these losses are amplified in the face of the helping professional who places blame on the client:

> My memory is full of holes, I can't do my job and the depression has returned. And now they want to do this to me again. My husband agrees and said they'll have to shoot him before he would allow this again, so at least I don't hae to worry about that. But the worst part is that my doctor is now treating me like I'm a big liar or something. He says my memory is fine and that I was just lazy and didn't want to go to work anymore.

This story is, unfortunately, not unique. Subject 19 states something similar, "Well, my husband is very upset now because he feels lied to and I do too. I've been fired from my job now because I can't concentrate any more. I was an accountant and numbers just don't make any sense." Having been told by their psychiatrist that ECT "would cure the depression", this woman now finds that not only has she lost her primary skill for gainful employment, her doctor disregards her claims, "my doctor told me I was wrong and that I'm confused because I'm depressed."

Others have lost relationships, such as subject 11, whose memory of his 17-year marriage was obliterated without a trace. Still others recount a tale of voicelessness during the process itself, aside from the memory impairment that would come later. Subject 1, who received more than 100 ECT treatments as a teenager in the early 60's, states, "my ordeal was a horror.I was sixteen.I am a male.It was like being raped three times a week for a year.It was the most horrible,humiliating and degrading experience of my life.I hate the people who did this to me." He goes on to say, "For me ECT shattered my spirit, broke my will, which is what was intended to be done" and in an earlier post, "no one ever asked me what I wanted for my life or how I felt about what was happening to me." While this narrative must be understood as occurring within the context of an earlier, and by all accounts less humane, period of ECT administration, it still addresses basic issues of the treatment which have not, if the other stories on this board are to be taken as true, been adequately addressed by the medical community.

Relief of Suffering

As extreme as the previous examples are in terms of damaging experiences, many narratives register on the opposite side of the spectrum. These clients feel, with only occasional mitigating factors to their stories, that they have been given a new life.

After the extraordinary suffering involved with depression that is nearly universal in these stories, these men and women report a type of salvation, a release from an unwanted and painful existence. Subject 9 expresses his shock at seeing so many negative experiences posted, and then goes on to write, "Four years ago I was suicidally depressed, and my life was literally saved by a brief course of ECT treatments." Another longer contribution from an ECT client (subject 24) asserts an experience that is radically different from the majority posted at this site:

> I have nothing but good words to say about ECT. The first time I had it (it involved a course of 6 'zaps') I actually desparately requested it from my psychiatrist. He was most cautious about this and gave me a very comprehensive and informative book to read on the subject before I actually signed on the dotted line. And so, when I had managed to convince HIM that this was what I wanted (needed - because drug therapy simply was not working) he sanctioned the therapy of ECT. As I say, the first time I volunteered for ECT it did most definitely work wonders! I was absolutely clinically depressed at the time - after the birth of my first child, and having already spent 6 weeks in a psychiatric hospital. I had the prescribed minium of six zaps and was out of hospital and back to normal life (looking after my baby)within 3 weeks. And the second time I had this treatment was when my second child was

about 18 months old. I was again suffering with clinical depression and quickly realised that drug therapy was no good so sought the agreement of my psychiartist for me to have ECT once again. And yes, you've guessed it, it did indeed work wonders. I was out of hospital as soon as the treatment ended. In both instances, after just the one zap I was HUGELY improved and my husband actually remarked on the massive positive change in me.

Another positive experience is mitigated by memory deficits, but the client uses a language of liberation that speaks directly to this theme. Subject 6 writes:

> I got seven shocks in February this year. Within a month I felt like I used to when I was a young. It was like being released from jail, I was able to mix and I had the energy to follow through my ideas. This new energy allowed me to study and graduate, it enabled me to get a job and to subsequently express myself in work.

These experiences are not typically voiced on this web site, and have not been sought out in prior qualitative research. They represent a crucial experience of ECT recipients and round out the larger picture of this therapy, giving clear insight into one reason why the treatment is as popular as it is.

CHAPTER FIVE

CONCLUSION

Summary and Discussion of Findings

The issue of the side effects of memory loss and brain damage, if appreciated from recent mainstream research, is moot. Reid (1995) summarizes the body of this research by saying that,

> ...although temporary confusion and amnesia are expected immediately after treatment, no reliable data suggest that permanent memory loss or cognitive deficit is caused by modern ECT. Indeed, because severe depression itself often causes both memory and cognitive deficit, ECT's remarkable therapeutic effectiveness is associated with long-term improvement in cognition, learning ability, and memory in many patients. Controversy over safety and effect on memory is fueled largely by public misinformation.

A literature review by Devenand states the following after studying more than 100 prior research projects on ECT's possible brain-damaging effects: "There is no credible evidence that ECT causes structural brain damage" (p. 64).

These studies are in sharp contrast to client-generated reports of the subjective experience of ECT treatment. The limited prior research

done by Johnstone (1999) and the United Kingdom Advocacy Network (1996) which sought-out greater insight into the experiences of clients who self-identified as having adverse experiences with ECT treatment finds striking commonalities across those individuals, including the "loss of confidence, dignity and self-esteem" (Ukan, 1996). Johnstone iterates themes of "powerlessness, control and conformity" (p. 74) which she hypothesizes might actually skew quantitative research done during or immediately following treatment.

In the face of such extraordinarily complex and diverse findings in the literature concerned with ECT, this study attempted to further explore client-centered accounts of ECT. Using an inductive analysis on the qualitative data, six categories and two distinct themes emerged from more than 40 posts by 23 individual subjects posting on the "Let's Talk!" general ECT discussion forum of the "ect.org" website. The results of this study confirm the limited prior research (Johnstone, 1999; Ukan, 1996) on negative client experiences with ECT and in addition propose two new thematic undercurrents with regards to respective negative and positive experiences. Research findings also indicate important patterns within positive ECT client stories, an area lacking from previous studies of both qualitative and quantitative methodologies. Finally, the addition of qualitative data from family members of ECT clients yields important

insight into the process of those intimately involved with the clients themselves.

The essential findings of this study are two themes, addressing the respective questions of what constitutes positive and negative ECT experiences. On the positive side of the experience, clients vocalized a theme of "relief of suffering" which was constituted by patterns of symptom reduction or remission, whole personality changes for the better, and feelings of having been set free or released. The theme that emerged from negative stories was of "oppression and the destruction of self-determination." This theme encompasses a constellation of adverse side effects of the treatment (such as debilitating memory loss and its subsequent consequences) as well as the senses of having received dishonest informed consent and having the report of negative experiences utterly dismissed by the performing physician.

While the themes found by this research are represented as polar opposites, it is important to appreciate these findings within the larger picture of ECT. Rather than interpret the two themes of negative and positive experiences as a bad/good dichotomy, a more productive interpretation of these results might be to see them as simply enriching the conversation about ECT, making it more complex. While some clients had negative experiences and some had positive experiences, only on rare occasions did their stories not contain elements of both. Subject 6 sums it

up well by saying, "I can understand someone who thought this was too large a price to pay. For me, I am glad I paid it and I feel I will never have topay (sic) it again." Essentially, the findings of this research and the themes which were distilled from those findings suggest not that ECT is completely good or completely bad as an experience for clients or as a form of therapy, but rather that it is complex in nature, with much more about it yet to be understood.

Limitations

As a qualitative, phenomenological study, the purpose of this project was descriptive and insight oriented in nature. The study does not attempt to provide a strict analysis of a particular feature of the ECT experience, but rather to amplify the possible categories and themes operating across multiple client narratives of this therapy. For this reason, these findings are not immediately generalizable to the population of ECT recipients as a whole, but instead identify and expand upon possible underlying issues facing at least a portion of that population. However, the following aspects of this study's design might limit that intention.

Subject Bias

This study lacks a random sample, utilizes a small sample population, and collects its data from a site more likely to viewed by someone with a negative experience with, or perception of, ECT.

Trustworthiness of Data

A number of factors confound the trustworthiness of this project's data. The emotionally muted format of the data (being in typed form), and the inability of the researcher to dialogue with the subjects, act as limitations to the study. Although the unrestricted voice of the subjects was important to the design of this research, the lack of opportunity for the researcher to follow up on important experiences, ask clarifying questions, witness the nonverbal behavior of the subjects, or have a subjective response process (such as a journal) places all responsibility for meaning, clarity, and genuineness on the subject.

Directly related to the aforementioned limitation, and what is perhaps the most profound limitation of this study, is the fact that the posts used as data for this project are considered without the full context and history of the lives of the subjects. Without a clear psychosocial history on each subject, the effect of ECT cannot be understood as thoroughly and objectively as if that information were available. The impact of family, prior experiences with psychological/psychiatric care, other pretreatment interventions, and the effects of psychotropic medication are just a few of the profoundly influential possible arenas of experience which cannot be fully considered in a study of this design.

Implications For Future Research

The findings of this study, despite their wide-ranging nature and limitations, express a negative theme that warrants an investigation of client narratives on a much larger scale. Although the themes discovered by this research are somewhat polarized in nature, when added to the corpus of literature about ECT, these findings simply point to the complex nature of ECT as a psychiatric technique. This complexity begs for a greater understanding.

The use of random sampling techniques, a direct interview format, and a long-term follow up data collection plan might all contribute to a more comprehensive and accurate sense of the true ramifications of this therapy might be ascertained. It is important the as further research is done on this subject, the voice of the client maintain center stage. Even as qualitative approaches seek to represent this experience in causal rather than descriptive language, the stories included in this work argue that the inclusion ECT client-voices in such work is nevertheless imperative.

Conclusions

The data available from the "Let's Talk!" discussion forum on general ECT issues suggests that for those who report negative experiences with the therapy, memory loss and/or other side effects of the treatment, in not being adequately addressed by the psychiatrist in

the informed consent process and/or respectfully considered after the end of treatment constitute an infringement on their rights as human beings and patients of the medical establishment. Thematically what emerges is the sense of exploitation at having received the treatment with promises of excellent results, but in the absence of those results, which as the positive narratives testify do exist, and in the face of serious lifestyle problems arising as a consequence of the therapy's side effects, client stories seem to be simply ignored by the performing physician.

The power of choice, the right to fully informed consent, and the client's entitlement to a voice throughout treatment are all features of medical care which arguably play a powerful role in honoring the Hippocratic Oath: to your patients "do no harm." These issues, as suggested by the data collected by this study, are crucial to someone facing torment from their own mind/existence and choosing ECT to help solve those difficulties. This study has examined data that points to an experience of at least some patients of this therapy wherein those rights were challenged. With that knowledge, professionals in this field are ethically mandated to consider the client as the most important, most powerful, voice when it comes to the use of electroconvulsive therapy.

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APPENDICES

Appendix A
Table I

TABLE I

California Dept. of Mental Health's Report to the California State Legislature on ECT use from 1989-1994

TABLE 1.

Complication	Number	% of all patients	% of all complications
Cardiac Arrest	6	0.04	0.23
Memory Loss	2,424	19.7	93.6
Fractures	5	0.04	0.2
Apnea	154	1.25	5.9
Deaths	0	0	0

Appendix B

IRB Approval

Oklahoma State University
Institutional Review Board

Protocol Expires: 7/24/02

Date: Wednesday, July 25, 2001

IRB Application No ED01135

Proposal Title: ELECTROCONVULSIVE THERAPY: CLIENT-CENTERED EVALUATIONS OF ITS EFFECTS.

Principal Investigator(s):

Kenneth Major
916 E. Moore Ave
Stillwater, OK 74075

Marie L. Miville
401 Willard Hall
Stillwater, OK 74078

Reviewed and Processed as: Expedited

Approval Status Recommended by Reviewer(s): Approved

Dear PI :

Your IRB application referenced above has been approved for one calendar year. Please make note of the expiration date indicated above. It is the judgment of the reviewers that the rights and welfare of individuals who may be asked to participate in this study will be respected, and that the research will be conducted in a manner consistent with the IRB requirements as outlined in section 46 CFR 46.

As Principal Investigator, it is your responsibility to do the following:

1. Conduct this study exactly as it has been approved. Any modifications to the research protocol must be submitted with the appropriate signatures for IRB approval.
2. Submit a request for continuation if the study extends beyond the approval period of one calendar year. This continuation must receive IRB review and approval before the research can continue.
3. Report any adverse events to the IRB Chair promptly. Adverse events are those which are unanticipated and impact the subjects during the course of this research; and
4. Notify the IRB office in writing when your research project is complete.

Please note that approved projects are subject to monitoring by the IRB. If you have questions about the IRB procedures or need any assistance from the Board, please contact Sharon Bacher, the Executive Secretary to the IRB, in 203 Whitenurst (phone: 405-744-5700, sbacher@okstate.edu).

Sincerely,

Carol Olson

Carol Olson, Chair
Institutional Review Board

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VITA

Kenneth Eric Major

Candidate for the Degree of

Master of Science

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Professional Memberships: Student Member, APA. Doctoral program representative, Psychology Graduate Student Association, Our Lady of the Lake University