

**WOMEN'S EXPERIENCES OF ELECTRO-CONVULSIVE THERAPY:
A QUALITATIVE STUDY**

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“Human beings are members of a whole,
In creation of one essence and soul.

If one member is afflicted with pain,
Other members uneasy will remain.

If you have no sympathy for human pain,
The name of human you cannot retain”

Sheikh Saadi,

Persian poet of the medieval period

To all the individuals who have undergone ECT.

Abstract

This study explored women's experiences of electro-convulsive therapy. This is a commonly used treatment for major depression, yet it remains one of the most controversial psychiatric interventions. Questions abound regarding both its benefits and its harms. As well, the literature on its safety and efficacy is incomplete focusing mostly on the opinions and knowledge of healthcare professionals rather than the patients who have undergone the treatment. Since the majority of patients who receive ECT are female, the female perspective of this treatment is significant.

In-depth person-centered interviews were conducted with nine women who experienced electro-convulsive therapy. The primary researcher chose narrative inquiry design and used thematic content analysis to extract emergent themes from the verbatim textual data. By exploring women's narratives of electro-convulsive therapy, this study gave voice to these women, extended formal understanding of women's electro-convulsive therapy experiences, and encouraged improved electro-convulsive therapy practices for this population.

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Table 2. Identified themes from Chapter 4.

List of Abbreviations

APA	American Psychiatric Association
CIHI	Canadian Health Institute for Health Information
CPA	Canadian Psychiatric Association
ECT	Electro-Convulsive Therapy
EEG	Electro-Encephalographic
ERB	Ethics Review Board
HDRS	Hamilton Depression Rating Scale
NICE	National Institute for Clinical Evidence
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
MRI	Magnetic Resonance Imaging
UK	United Kingdom
UKAN	United Kingdom Advocacy Network
US	United States

Chapter 1: Introduction

Electro-convulsive therapy (ECT), commonly known as shock therapy, was first established in 1934 as a therapeutic intervention for the treatment of schizophrenia (Faedda et al., 2009). Electro-convulsive therapy was, and continues to be, used as a therapeutic intervention for depression and other mental health conditions such as bipolar affective disorder and suicidal ideation. Electro-convulsive therapy involves induction of seizure activity in the brain. Seizures—from the Latin root *saicre*, “to take possession of” (Lowenstein, 2005)—are abnormal, excessive, and synchronous neuronal activity observed using an electro-encephalographic (EEG) recording. They may be accompanied by convulsions, which are involuntary movements (Engel, 1996; 2001).

The use of ECT is on the rise worldwide (Breggin, 1998; Masters, 2006; Rosenbach, Hermann, & Dorwart, 1997) and in Canada (Hoag, 2008). According to Canadian Psychiatric Association guidelines, ECT is a safe and effective intervention, primarily for the treatment of depression (Enns, Reiss, & Chan, 2009). Even though the Canadian Health Institute for Health Information (CIHI) conservatively estimates that the administration of the procedure in Canada is approximately 15,000 procedures per year (Hoag, 2008), this number may be much greater, as it does not include outpatient numbers for all provinces (Hoag, 2008).

Despite its widespread use, ECT continues to be controversial. Controversies focus on the neurological, cognitive, and psychological effects of ECT. While some researchers and ECT practitioners believe there is no neurobiological damage associated with the treatment – or that any potential problems are short term (Abrams, 2002; De-Vand et al., 1994; Fink, 2004; Kusumakar, 2000; Weiner, 1984), others have argued ECT

is associated with permanent brain damage, particularly memory loss (Ferraro, Roizen, & Helfand, 1946; Meldrum et al., 1973; Zarubenko, Yakovlev, Stepanichev, & Gulyaeva, 2005). Moreover, some researchers have argued that ECT recipients have experienced psychological distress and emotional disturbances associated with the procedure (Johnstone, 1999; Koopowitz, Chur-Hansen, Reid, & Blashki, 2003); while other researchers have reported that ECT has helped to reduce depression and improve patient quality of life (Rayner et al., 2009). However, research exploring patient experiences of this intervention is underrepresented, and thus a gap exists in the literature (Johnstone, 1999; Koopowitz et al., 2003; Orr & O’connor, 2005).

In addition to neurobiological, cognitive, and psychological controversies, significant ethical considerations exist. For instance, data collected by the Professional Activities Survey in the United States (US) suggests that only 8% of psychiatrists prescribed ECT (Hermann, Ettner, Dorwart, Hoover, & Yeung, 1998). Unfortunately, to the knowledge of the researcher, more recent trends are not available. Since only a small percentage of psychiatrists used this intervention in the 1990s, its acceptance within the profession is questionable in the 1990s and today. None of the research located for this thesis offered any reason for its infrequent use: whether practitioners disapprove of ECT, whether they prefer to refer patients to other colleagues who perform ECT, or whether they possibly avoid using this controversial procedure. Moreover, some male psychiatrists—especially those trained outside the US during the 1960s and 1980s rather than the 1970s (Hermann, Ettner, Dorwart, Hoover, & Yeung, 1998)—were more likely to prescribe ECT as a treatment intervention than their female counterparts. The power dynamics that exist between doctors and patients (Sutherland, 2007) may be further

intensified when patients feel vulnerable about their condition and an invasive procedure such as ECT is recommended (Johnstone, 1999; Orr & O'Connor, 2005). As reported by Johnstone (1999), patients were not able to share their feelings about ECT with their psychiatrists out of anticipated reprisal.

Problem

Missing from discussion of these controversies is the patient perspective. Literature has suggested that while ECT may effectively counter some depressive symptoms (Kelly & Zisselman, 2000; Koenig 1999; Weiner & Krystal, 1994), the impact of this treatment on each patient as a whole is not well understood. Only a few studies have focused on developing a holistic understanding of patient experiences of this treatment (Johnstone, 1999; Koopowitz et al., 2003; Orr & O'Connor, 2005; Rose, Fleischmann, & Wykes, 2004). Patients have reported both positive and negative feelings about their experience with ECT treatments. Positive experiences were reported and gathered from qualitative testimonies (Rose, Fleischmann, & Wykes, 2004). These testimonies indicated that 30% of the patients would submit to ECT in the future (Rose, Fleischmann, & Wykes, 2004). Furthermore, the positive outcomes included immediate improvement in mood and relief from depressive symptoms (Rose, Fleischmann, & Wykes, 2004; Dukakis & Tye, 2006). Such patients described the negative side-effects of an ECT treatment, such as memory loss, as less significant and more manageable than the debilitating symptoms of the depression (Dukakis & Tye, 2006). In contrast, two other qualitative studies with eight (Koopowitz, et al., 2003) and twenty (Johnstone, 1999) participants reported that the most common negative experiences involved fear, shame, powerlessness, and trauma. Some patients experienced a short-term feeling of fear,

attributed to the medical nature of the procedure and the use of anesthesia (Koopowitz et al., 2003), while one participant from the group reported long-term feelings of fear that presented as reoccurring nightmares (Koopowitz et al., 2003). The rationale for long-term term fear, as reported by Koopowitz and colleagues (2003), varied among patients yet included apprehension regarding brain damage, personality change, and the chance of not surviving the procedure. Thus, patients – in various research studies - have reported positive, neutral, and negative outcomes of the treatment.

Patient perspectives have indicated a perceived imbalance of power existed for women. Researchers supporting the feminist perspective have argued that medicine has exploited women in areas such as reproductive technologies and psychiatry, medicalising and pathologising women (Chesler 1989; Klein, 1993; Raymond, 1993; Woodlock, 2005). Since 72% of ECT interventions have been reported in women (McCall & Dickerson, 2001), it is important to explore women's experiences of ECT from a feminist perspective. This study, therefore, employed a feminist philosophical approach. This philosophical approach is discussed later in the thesis. The study offered women a platform to share their experiences, addressing existing gaps within the literature. Therefore, the voices of women who have undergone ECT are essential to understanding the nature of this treatment as well as the narratives surrounding it.

Purpose and Outline

The aim of this study was to achieve a better understanding of women's subjective experiences of ECT. Overall, this thesis consists of five chapters: Chapter One is a brief introduction to the research problem and the methodology used, Chapter Two summarizes relevant literature and identifies areas that had been underrepresented or

would benefit from additional study, Chapters Three and Four report on the results from the thematic analysis of the interviews in two standalone (and potentially publishable) papers, and Chapter Five summarizes the overall findings, draws some conclusions, discusses the strengths and weaknesses of the study, and provides possible implications for future research.

Method

The researcher used person-centered interviews to elicit women's stories that were then thematically analyzed. The following sections describe the research procedures and include details of the recruitment process, the sampling process, data collection, data analysis, and trustworthiness criteria. Finally, the issues related to compliance with ethical standards are addressed.

Research design. This study relied on narrative inquiry to explore the experiences of women who have undergone ECT. Clandinin and Connelly (2000) defined narrative inquiry as a method relying on various data sources including stories, autobiographies, journals, field notes, and interviews. The basic component of narrative inquiry is a personal account, a story. Stories are a common way of communicating and are a natural form of expression because humans are storytellers (Hesse-Biber & Leavy, 2006). Barthes (1977) postulated, “[N]arrative is present in every age, every place, in every society” (p. 79). Further, Bruner (1987) asserted, “[We] seem to have no other way of describing ‘lived time’ save in the form of narrative” (p. 12). Whether it is documenting the oral traditions of the Blackfoot people, gathering the life histories of women who participated in the Feminist Movement (Belenky, Clinchy, Goldberger, &

Tarule, 1986), or situating Black Americans in the time of American Slavery (Botkin, 1945), stories have been used to communicate a wide variety of human experiences.

One benefit of narrative accounts is that stories are so prevalent; therefore, they are a readily available form of potential data. An individual's story contains the usual elements of context, characters, plot, setting, a conflict, and a turning point as well as a resolution that has personal meaning for the teller (Polakoff & Gregory, 2002). How and why individuals share their stories and how they frame themselves in the text is "not merely a way of telling someone (or oneself) about one's life; they are the means by which identities may be fashioned" (Rosenwald & Ochberg, 1992, p. 1). Narratives can also provide meanings, which in turn can provoke actions (Riley & Hawe, 2005). Thus, stories reveal motive, emotional or volitional responses, and other non-tangible elements of an experience.

Another benefit of narratives to researchers is that they can garner a broader spectrum of data than quantitative measurement alone. Narrative inquiry encompasses personal and human aspects of experience over time while considering the relationship between individual experience and cultural context (Bleakley, 2005). Narratives allow researchers to view life through the eyes of others and to endeavour to understand the thoughts and values of humans (Riley & Hawe, 2005). In narrative inquiry, the individual is the main character, who makes sense of experiences and constructs identity (Blumer, 1969; Giddens, 1984, 1991; Schwandt, 1998).

The narrative methodology offers another advantage to the researchers. Since it focuses on human responses, narrative inquiry can sometimes yield data that dispute the traditional, scientific contentions about objective reality (Bleakley, 2005), yielding more

complex understandings of the subject. Stories focus on order events and include some kind of problem or disturbance in the normal pattern of daily life, some kind of unanticipated event that provokes a reaction and warrants adjustment (Riessman, 2008), data that are sometimes overlooked in a quantitative approach. Thus, narratives enrich research with an analysis of subjective human experience.

In addition, narrative inquiry allows the researcher to better understand an individual's socially constructed nature of reality (Denzin & Lincoln, 1994), which is relative and uses subjective epistemology (Guba & Lincoln, 2004). Lincoln and Guba (1985) stated, "If you want people to understand better than they otherwise might, provide them information in the form in which they usually experience it" (p. 120); one form is the vernacular that women in this study use to recount personal experience. In this study, in-depth, person-centered interviews (Hollan, 2005; Levy & Hollan, 1998; Polakoff & Gregory, 2002; Tarrant & Gregory, 2003) were used to collect data on the socially constructed realities of several women who have experienced ECT. The interviews were analyzed through the paradigms of constructivism and feminism (Harvey, 1990; Patton, 2002; Letterby, 2003) to help discover new themes and meanings of women's experiences of ECT.

Person-centered interviews. In this study, personal narrative was collected using interviews. Person-centered interviewing is a combination of informant and respondent approaches in which interviewees are experts of their own stories; this approach provides the researcher with information about participants' culture, perceptions, and particular experiences (Levy & Hollan, 1998).

The interviews were initiated by inviting participants to tell their ECT story, starting at whatever point in time they desired or believed was important. Freedom to structure and recount the story allowed interviewees to oscillate between their role as informants and respondents, and, by doing so, “illuminate spaces, conflicts, coherence, and transformations” (Levy & Hollan, 1998, p. 336). While the response to various probes and questions provided the researcher with a rich source of data, the behaviour (such as the pauses and silences) of the participants was of special interest. Hollan (2005) stated, “There are things we can learn about people by actively engaging with them, talking to them, and listening to them that we can learn in no other way” (p. 465). Thus, person-centered interviewing was deemed the most appropriate method of collecting personal narrative for this study as it promoted a better understanding of the feelings, perspectives, and thoughts of the participants on the specified phenomenon.

Philosophical underpinnings. Research paradigms are the philosophical, theoretical and methodological foundations of the research process (Morgan, 1983). Moreover, a study’s specific paradigms will determine its ontological and epistemological stances (Guba & Lincoln, 2004). Kalischuk (1999) stated, “The way in which knowledge is gained is directly related to the paradigm perspective adapted by the researcher and the corresponding ontological and epistemological claims” (p. 36). The ontological stance is concerned with establishing the nature of reality and questions the existence of a reality that exists independently from our knowledge (Guba & Lincoln, 2004), while epistemology, also known as the theory of knowledge, is embedded in the theoretical perspective (Creswell, 2003) and informs all aspects of the research process. Research methodology allows the merging of philosophical perspectives and method,

which allows the researcher to pursue the answer to a specific question through the use of a specific method, while acknowledging the assumptions, identifying personal biases, guiding ethical principles, and social context (Neuman, 2006).

Constructivism. Constructivism, one philosophical stance of this study, asserts that knowledge cannot be constructed from a single objective reality, and thus requires multiple truths. Constructivism also suggests multiple implications in interacting with others (Patton, 2002), and holds that truth is subjective to each individual and that individuals “may in fact understand social reality differently, producing different meanings and analyses” (Hesse-Biber & Leavy, 2006, p. 15). From a constructivist perspective, understanding of the world and reality is dynamic, changes continuously, and is shaped by our experiences (Patton, 2002). A constructivist reality insists that an individual’s experiences can be altered and reframed (Patton, 2002).

In constructivist research, knowledge is co-created through a collaborative process between the researcher and the research participants (Guba & Lincoln, 2004); that is, multiple perspectives are considered, not just that of the researcher’s. Participants are considered co-researchers (Colazzi, 1978) and the experts of their own stories (Hesse-Biber & Leavy, 2006, p. 128). The researcher working from a constructivist framework actively participates in the research and does not claim objectivity but instead acknowledges personal biases (Hesse-Biber and Leavy, 2006). This method of inquiry is most successful when all participants feel secure in sharing their knowledge, and the researcher creates an atmosphere of trust (Polit & Hungler, 1996).

Feminism. Voicing the concerns of women and exploring their perspectives is the main thrust of feminist research (Harvey, 1990; Letterby, 2003). Feminism is rooted

in the belief that “women are oppressed or disadvantaged by comparison with men, and that their oppression is in some way illegitimate or unjustified” (James, 2000, p. 576). Feminist research endeavours to end oppression, empower women, and raise consciousness of women’s issues by providing women with a platform from which they may share their voices and instigate change. In extension, feminist research strives to equalize power between the researcher and the research participants by acknowledging that the participants are experts of their own narratives (Brayton, 1997). Feminist research assumes that society is socially constructed (Crotty, 2003) and that individuals have different perspectives of the world based on their position and status within a society (Hesse-Biber & Leavy, 2006). While acknowledging the importance of situatedness, feminists further recognize that factors of age, ethnicity, culture, education, race, and sexual orientation influence the female experience (McCormick & Bunting, 2002).

McCall and Dickerson (2001) stated that 72% of ECT recipients, in the US, are women. Furthermore, using logistic regression, Hermann et al. (1998) noted that 93% of the psychiatrists who prescribed this treatment were males. Unfortunately, this information is dated and to the knowledge of the researcher more current data were not available. Hence, applying the feminist lens (Burstow, 2006) to personal accounts of ECT may add beneficial understanding and perspective of this therapy. Thus, the feminist philosophy, specifically Hughes’ (2002), theory on the nature of gender inequality, will guide the analysis of the stories, perspectives, and themes collected in this study.

Sample and setting. This study targeted nine adult women who had undergone ECT. The researcher used the following criteria to select participants:

- At least one ECT experience in their lifetime
- Women
- At least 18 years of age.
- Ability to verbalize in English their thoughts and memories related to their ECT experiences.

Location of interviews. Interviews were conducted either by telephone or in-person by either the researcher with a supervisor or the researcher alone. The researcher arranged to phone participants who lived outside the city of Lethbridge at a mutually convenient time. During these telephone conversations the researcher and the supervisor remained at their offices at the University of Lethbridge. The in-person interviews were held at a mutually convenient location (e.g., at the participant's home) and at a time that ensured privacy, confidentiality, and the comfort of the participant.

Sampling methods and recruitment. The purposeful convenient sampling method was used (Hesse-Biber & Leavy, 2006). In addition, the researcher used the snowballing sampling technique in order to achieve sufficient number of participants (Hesse-Biber & Leavy, 2006). Saturation allows a researcher to collect a substantive amount of data and to identify repetitive patterns (Morse, 1994). Previous qualitative research suggests that saturation can yield a range of six (Orr & O'Connor, 2005) to eight (Koopowitz et al., 2003). Participants were assured of confidentiality and reassured that their decision to participate in the study would not be shared. Moreover, all identifying information in the transcripts was excluded, protecting the identity of each participant.

Recruiting participants who had undergone ECT was done through an advertisement poster posted in several places within Lethbridge, including the Lethbridge

Public Library, the Lethbridge Women's Shelter, Southern Alberta Self Help Association, the Canadian Mental Health Association office in Lethbridge, the Schizophrenia Society Of Alberta office in Lethbridge, the University of Lethbridge campus bulletin boards (both physical and computer-based). The advertisement consisted of a general description of the study and an invitation to contact the researcher directly by phone or email (see Appendix A).

Data collection procedures. Although a narrative, person-centered approach was primarily used during the interviews, probing questions were also used as necessary during data collection (see Appendix B). The first few interviews were conducted by the research supervisor, Dr. Bradley Hagen, while the principal investigator, Maede Ejaredar, observed and took notes on the interviewing techniques. Once the principal investigator had acquired sufficient interviewing skills, she conducted the remaining interviews under the supervision of Dr. Bradley Hagen. At the end of each interview, the researcher collected demographic information, such as age, marital status, the number of ECT sessions, and reasons for ECT (see Appendix C).

Interviews were digitally recorded and lasted between 60 and 90 minutes. A transcriptionist then transcribed the interviews verbatim. To protect the identities of the study participants, the transcriptionist signed an oath of confidentiality prior to the transcription (see Appendix D).

As per narrative inquiry (Hollan, 2005; Levy & Hollan, 1998; Polakoff & Gregory, 2002; Tarrant & Gregory, 2003), the interviews were initiated by inviting the participant to start recounting their ECT experiences at whichever point in the story they believed was an important starting place. The researcher used probing questions to help

participants gradually progress from narrating the “outer layers” of the experience to narrating the “core layers” of the experience, thereby gradually allowing an atmosphere of trust, equality, and respect to develop (Hesse-Biber & Leavy, 2006) within each interview. Monitoring the essential components of interviews in this way placed the interview participants in positions of authority, that is, as the experts (Hesse-Biber & Leavy, 2006) over their own stories. After the interview each participant was informed that upon the completion of the thesis, each could request a summary of the study’s findings from the researcher.

Data analysis. Thematic content analysis (Braun & Clarke, 2006) was applied to the data obtained from the interviews and completed manually. Thematic content analysis was a strategy that allowed the researcher to identify categories, form common themes, and identify patterns within the textual data (Braun & Clarke, 2006).

Several phases occurred during thematic data analysis (Braun & Clarke, 2006). First in this study, the transcripts were printed on pages, leaving with generous, one-quarter page margins along one side of the page. The researcher familiarized herself with the content of the data by reading the transcripts multiple times. During this phase, initial notes were taken from the transcripts. Second, the researcher began to form codes and to organize the data into meaningful categories. Third, different categories were combined to form more prevalent themes. These larger ideas, categories, and themes were identified and color-coded. The emergent themes were then printed beside the transcripts on the remaining one-quarter width of the page. Fourth, the themes were reviewed and refined in such a way that thematic maps of the data could be formulated. During the next stage, the themes were named (based on previous literature findings as well as the philosophical

approaches of this study). Finally, these emergent themes were applied to generate, describe, and explore women's experiences of ECT. The researcher worked closely with the research supervisor, Dr. Bradley Hagen, during the processes of data collection and analysis.

Trustworthiness. Data trustworthiness is dependent on how well the findings are supported by the collected data. Trustworthiness entails multiple components including credibility, transferability, dependability, and conformability (Lincoln & Guba, 1985). Within this study, the researcher used the member-checking process to enhance the credibility and conformability of the results. The researcher provided each participant with a copy of the transcript of the interview, either by email, by registered mail, or during a second meeting. During the member-checking process, each participant was asked to add, delete, change or confirm the information recorded in the transcript. Also, each participant was given an opportunity to remove any information they felt compromised their anonymity. This process allowed participants and the researcher to jointly interpret some of the preliminary themes.

The thick description technique (Geertz, 1973) was applied to enhance transferability. During the thick description process a close and sensitive reading of the textual data is performed to ensure that sufficient information about the context is provided and the interpretations will resonate with the experience of others who have encountered similar phenomenon (Geertz, 1973; Shapiro, 1986). The researcher completed this phase of the analysis with each participant.

Finally, triangulation of the data was applied to enhance trustworthiness. Triangulation involves using multiple data sources to achieve an understanding (Denzin,

1978). In this study, triangulation was achieved by comparing transcript and thematic data with the researcher's field notes, which offered an additional source of data beyond the transcriptions. Field notes were written documents, which included personal feelings and observations made by the researcher (Connelly & Clandinin, 1990; Morrow, 2005). Moreover, joint interpretations of the data by the researcher and the research supervisor were completed and facilitated this study's trustworthiness.

Ethical considerations. A research proposal along with a sample of the consent form (Appendix E) was submitted for ethical review to the Ethical Review Committee for Human Subjects at the University of Lethbridge. This study was reviewed using criteria outlined in the University of Lethbridge's Tri-council Policy paper and received approval from its Ethical Review Committee for Human Subjects.

Processes of obtaining consent. Following recruitment, participants were informed of the potential risks, such as potential psychological distress as a result of recollecting unpleasant memories, and benefits associated with the study, such as giving voice to women. Furthermore, participants were informed that their participation in the study was completely voluntary and that they had the right to withdraw from the study at any time and for any reason without any consequence. Also, they were informed that if they wished to withdraw at any point during the study, any information contributed prior to the point of withdrawal would be completely removed and destroyed. Upon agreement, the participants were asked to voluntarily sign a consent form (see Appendix E). In the case of telephone interviews, their consent to voluntarily participate was recorded. Once each consent form was signed, one copy was stored in a locked filing cabinet at the University of Lethbridge, and one copy was given to the participant. Once the participant

had the opportunity to ask questions and sign the informed consent, the interview (and digital audio-recording) began.

Confidentiality and anonymity. The primary ethical consideration of this study was to ensure confidentiality and anonymity, partially achieved by having each participant assume a self-selected pseudonym. Upon transcription, any identifying information was deleted or modified as appropriate. In addition, only the principal investigator (Maede Ejaredar) and the research supervisor (Dr. Bradley Hagen) had access to the original digital audio-recordings and transcripts. The transcripts and consent forms were stored in a locked filing cabinet at the University of Lethbridge, but in separate locations, so it would not be possible to associate one particular name with any given response. Then, if the participants felt any identifying information remained in the transcripts, they were able to change or delete this information during the member-checking process. After transcription was completed, the digital recordings from the interviews were deleted.

A password-protected folder was created for the electronic copies of the transcribed interviews and was kept on only two computers belonging to the researcher and the supervisor. File passwords were known only to the principal investigator and the research supervisor. Finally, participants were told that electronic copies of the interviews would be deleted from any hard-drive after five years. Hard and electronic copies of the transcripts will be kept for five years after the completion of the study in a locked filing cabinet and secure, password-protected computers at the University of Lethbridge and only the principal investigator and research supervisor will have access to them. Thus, after five years, all data-related files will be destroyed or deleted.

Managing psychological distress or discomfort. Since the purpose of this study was to explore women's experiences of ECT, the researcher recognized that the interviews might cause emotional distress, recollection of painful memories, and/or psychological discomfort. To address this concern, the research supervisor, Dr. Bradley Hagen, also a registered psychologist, agreed to be present as either the principal interviewer or as a monitor during all interviews. Thus, if participants expressed any discomfort, they were invited to take a break, to switch topics, or to discontinue the interview. Also, after the interview, participants were provided (if they desired) with a list of community resources and a list of affordable counsellors with contact information (e.g., phone numbers and addresses). Furthermore, in order to ensure the mental/psychological wellbeing of each participant, the researcher contacted each participant the day after each interview as a courteous follow-up. If any sign of discomfort or distress was voiced or seemed apparent, participants were once again encouraged to pursue a community resource or counsellor.

Challenges for researchers. Narrative research requires awareness of several potential issues. Challenges may include establishing rapport (Liamputtong & Ezzy, 2005), developing friendship (Ceglowski, 2000; Higgins, 1998), maintaining boundaries (Dickson-Swift, James, Kippen, & Liamputtong, 2006), dealing with emotions (Payne, 1994; Rager, 2005), or ending the study (Hubbard, Backett-Milburn, & Kemmer, 2001). These may be compounded when the research phenomenon is of a personal and sensitive nature (Lee-Treweek & Linkogle, 2000; McCarroll, Blank, & Hill, 1995; McCosker, Barnard, & Gerber, 2001). Thus, considerable thought and planning must be invested to overcome these challenges.

This study involved a vulnerable group who elected to share personal stories; thus, the researcher experienced some of these challenges. Before the study began, the researcher identified potential challenges, including the need to instigate clear and honest communication, to share and negotiate a plan with each co-researcher/participant, to debrief herself with the research supervisor after the interviews, and to access student counselling services at the University of Lethbridge if needed. At the time of the research, the primary researcher was a graduate student at the University of Lethbridge. Thus, accessing student counselling services at the University of Lethbridge was free of charge and convenient for her.

Researcher's professional biases. The researcher had associations to this study's subject matter through previous graduate-level research in neuroscience during which the researcher studied the impact of convulsions and stress on the brain in animal models during her work on epilepsy. In her previous studies and observations, the researcher developed convictions that epileptic convulsions were devastating and traumatic for the patients, resulting in a bias that ECT experiences may be similar. Acknowledging this bias prior to the interviews as well as engaging in the process of mutually interpreting the preliminary themes with the help of the participants allowed the researcher to gain a better understanding of ECT from the eyes of the patients who have actually experienced it, thereby potentially minimizing the effects of some of her biases. Moreover, the interview questions and follow up probes were formulated in such a way that kept the researcher's stance as neutral as possible.

Chapter 2: Literature Review

This chapter reviews the history, prevalence, modulating factors, and efficacy of ECT. In addition, ethical considerations and controversies are discussed. Finally, some of the existing qualitative research is reviewed.

History of Electro-Convulsive Therapy

Like many other medical interventions, convulsive therapy was discovered by serendipity. Dr. von Meduna introduced convulsive therapy in 1934 (Faedda et al., 2009) as a therapeutic intervention for schizophrenia. He observed that none of his schizophrenic patients were epileptic and that none of his epileptic patients were schizophrenic. Thus, he mistakenly concluded that convulsions protected the brain from developing schizophrenia. This observation led him to pharmacologically induce convulsions, first using camphor and then with pentylenetetrazol (also known as metrazol or cardiazol) in schizophrenic patients. Von Meduna subsequently treated more than 100 patients with schizophrenia during the mid-1930s (Fink, 1984).

Soon after, in 1937, Ugo Cerletti and Lucio Bini, an Italian neurologist and an Italian psychiatrist respectively, who had been using electric shock to induce seizures in animal experiments, decided to substitute metrazol with electricity to induce convulsions in human subjects. Thus, ECT was first used on a 39-year-old man with catatonic schizophrenia (Faedda et al., 2009). This patient, who prior to the treatment was wandering the streets and could not speak comprehensible language, started talking, although agitated, after the first treatment (Faedda et al., 2009). As described by Dr. Nuland, a medical historian who himself experienced dramatic help from shock therapy,

They thought, “Well, we'll try 55 volts, two-tenths of a second. That's not going to do anything terrible to him.” So they did that....This fellow— remember, he

wasn't even put to sleep—after this major grand mal convulsion, sat right up, looked at these three fellows and said, “What the fuck are you assholes trying to do?” Well, they were happy as could be because he hadn't said a rational word in the weeks of observation (TED Talk, 2001).

Subsequent reports of the patient's stabilized health status garnered much attention from mental health professionals in around the world. By 1940, the procedure had been introduced in both Britain and the US (Lebensohn, 1999). Soon after, in an attempt to minimize the complications associated with the treatment, such as fractures or dislocated bones, muscle relaxants were administered to the patients (Read, 2004). By the 1950s, a short acting anesthetic was also administered prior to the procedure to prevent the feeling of suffocation associated with the use of a muscle relaxant (Read, 2004). Thus, ECT procedures evolved into their present form.

With the steady growth of antidepressants, ECT use declined between the late 1950s and the 1980s (Fink, 1984; Rudorfer & Goodwin, 1993). However, in 1985 the National Institute of Mental Health (NIMH) and the National Institutes of Health (NIH) organized a conference to develop a consensus around the use of ECT. Although ECT was considered the most controversial psychiatric treatment at the time and was associated with significant side-effects, the treatment was generally considered effective for a narrow range of severe psychiatric disorders (Blaine & Clark, 1986). Sixteen years later, in 2001, the American Psychiatric Association (APA) released a report on ECT emphasizing the importance of informed consent and the expanded role that the procedure has in modern medicine (APA, 2001).

Prevalence of Electro-Convulsive Therapy

After a period of decline, ECT use in the world continued to vary yet has steadily increased during the past three decades. In the United States, NIMH documented a 46% decline in ECT use within hospitals between 1975 and 1980 (Thompson & Blaine, 1987) indicating only 2.4% of psychiatric admissions in 1980 were for ECT treatment. This downward trend in the United States did not continue long, as 36,558 inpatients received ECT interventions in 1986, some 5,000 more individuals than at the start of the decade (Thompson et al., 1994). Among Medicare recipients, the number of patients treated with ECT continued to rise into the next decade. During the five years between 1987 and 1992, the number of United States patients treated with ECT rose from 12,000 to 15,560 (Rosenbach et al., 1997), an increase of 13%. A more recent study estimated that between 50,000 and 100,000 patients underwent ECT annually in the United States (Sadock et al., 2007).

In Canada, although ECT use has oscillated during the last 70 years, ECT is now well established (Hoag, 2008). The Canadian Health Institute for Health Information (CIHI) conservatively estimated administration of ECT at approximately 15,000 procedures per year (Hoag, 2008). Recent data indicated that ECT was being administered as an outpatient procedure (Hoag, 2008). Data also confirmed that inpatient ECT accounted for half the treatments provided in Canada in 2002, but only 36% in 2005 (see Figure 1). In Ontario, the number of treatments has risen moderately, from 7,800 to 10,800 between 1999 and 2005 (Hoag, 2008). Although the numbers on current ECT use in Canada were incomplete and although outpatient numbers from Alberta and Quebec were not reported (Hoag, 2008), data suggested that ECT use had plateaued in Canada since 2002.

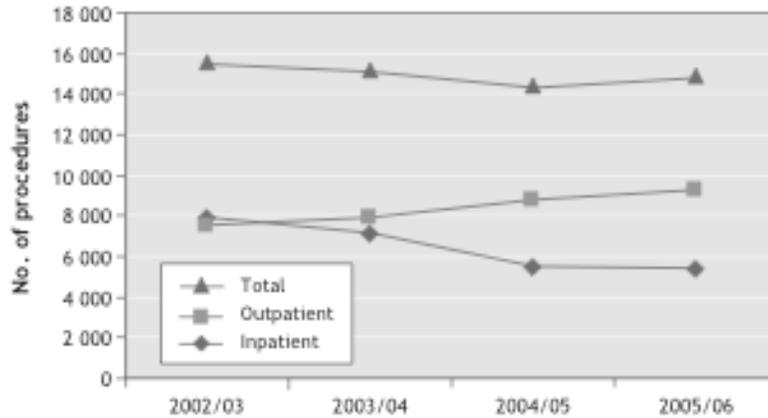


Figure 1. Total number of ECT procedures administered in Canada by inpatient and outpatient basis (adapted from Hoag, 2008).

In Europe and other continents, ECT use has increased since the 1990s (Breggin, 1998; Rosenbach, Hermann, & Dorwart, 1997). For example this trend is evident in the Netherlands that reported an increase in ECT use of over 400% between 1992 and 2008 (Shock, 2009). Similarly, ECT use in Australia and Germany has almost doubled during the past decade (Masters, 2006).

The literature indicated that specific populations were more likely to receive ECT. Interestingly, the population undergoing ECT for depression is comprised largely of females and the elderly (Prudic et al., 2001). For instance, 76% of the ECT recipients in Finland (Huuhka et al., 2000), 72% in the US (McCall & Dickerson, 2001) and 68% in England (Department of health, 1999) were females. Patients over the age of 70 received 30% of all ECT procedures in 2005 compared with only 23% in 2002 (Figure 2). Moreover, ECT was used less prominently in ethnic minorities (Euba & Saiz, 2006).

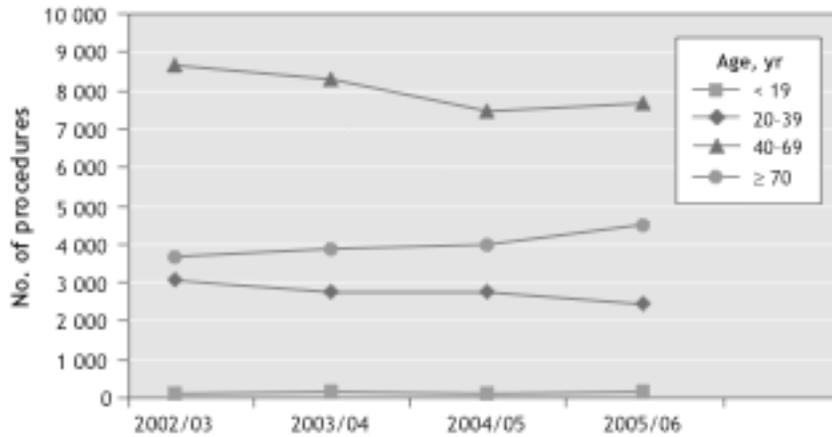


Figure 2. Frequency of electroconvulsive therapy procedures by age group (adapted from Hoag, 2008).

Current Electro-Convulsive Therapy Practices

The literature suggests standardized practices as well as variations in the administration of ECT. In general, patients should be informed about the risks and benefits of the procedure through an informed consent (APA, 2001). In a modified version of ECT, patients are primarily anesthetized using short acting anesthetics such as methohexial or propofol (APA, 2001). This is followed by an administration of a muscle relaxant such as suxamethonium also known as succinylcholine (Minneman, 1995).

Electrodes are then located on either side of the skull (a unilateral procedure) or on both sides (a bilateral procedure) (Rudorfer, Henry & Sackeim, 2003). Bilateral placements are more commonly suggested in both the United States and the United Kingdom (Duffett & Lelliott, 1998; Prudic et al., 2001). The electrodes release a brief-pulse electrical current of about 800 milliamps (Prudic et al., 2001). The intensity of the current is equivalent to one and half times of the seizure threshold in bilateral ECT and up to twelve times in unilateral ECT (Prudic et al., 2001). The seizure threshold is identified through dose titration, a fixed dose, or based on a patient's age and sex (Prudic

et al., 2001; Rudorfer et al., 2003). Usually a course of 6 to 12 treatments are administered during a period of 2 to 6 weeks (Prudic et al., 2001).

Modulating Factors of Electro-Convulsive Therapy

Literature has also documented variations in ECT procedure as necessitated by multiple patient factors. First, a patient's weight, age, and sex are associated with seizure threshold (Coffey, Lucke, Weiner, Krystal & Aque, 1995a, Coffey, Lucke, Weiner, Krystal & Aque, 1995b; Dawkins, Ekstrom, Hill, Isaacs & Golden, 2000; Sackeim, Dencina, Prohovnik & Malitz, 1987). Seizure threshold is the minimum dosage of electricity needed to induce a seizure (Lowenstein, 2005). Research has demonstrated that seizure threshold is increased in older patients relative to younger ones, in males relative to females, and in African Americans relative to other ethnic groups (Coffey, Lucke, Weiner, Krystal & Aque, 1995a, Coffey, Lucke, Weiner, Krystal & Aque, 1995b; Dawkins, Ekstrom, Hill, Isaacs & Golden, 2000; Sackeim, Dencina, Prohovnik & Malitz, 1987).

Second, the location of electrode placement on the skull results in different outcomes. Research has indicated that unilateral stimulation compared to bilateral stimulation leads to less severe side-effects (Lisanby, Maddox, Prudic, Devanand & Sackeim, 2000; Sackeim et al., 2000). Moreover, Bailine and colleagues (2000) concluded that bi-frontal electrode placement was as effective as bi-temporal electrode placement yet was associated with fewer and less severe side-effects.

Third, the duration of the electrical stimulation as well as the number of stimulations had an impact on the outcome such that longer stimulation is positively associated with manifestation of side-effects (Bailine et al., 2000; Sackeim et al., 2000).

Finally, different types of electrical currents have resulted in varying levels of side-effects. For example, application of sine wave currents resulted in more severe side-effects relative to brief, pulse currents (Bailine et al., 2000). That is, varying individual responses to ECT may result in varying treatment outcomes. Thus, biological characteristics of the patients, electrode placement and the type of current used during the procedure were some of the treatment-related variables that could influence the outcome.

Efficacy of Electro-Convulsive Therapy

According to CPA guidelines, ECT is an effective intervention, primarily for the treatment of depression (Enns, Reiss, & Chan, 2009). Despite its wide use however, considerable controversy exists surrounding the efficacy of ECT, as measuring the effectiveness of interventions used to treat mental illnesses is difficult. The literature has highlighted three areas of consideration: (a) the extent of symptomatic relief experienced by patients receiving ECT versus those experiencing simulated ECT, (b) the perceived long-term effectiveness of the ECT treatment, and (c) the suicide rates of patients who received ECT treatment compared with those who did not.

When evaluating the effectiveness of ECT, it is necessary to compare the results of patients treated with those not treated. Simulated electro-convulsive therapy (SECT) has served as the intervention used with the control groups. However, ensuring a double blind experiment in which neither the psychiatric team members nor the patients were aware of the treatment received is difficult. Concealing the identity of patients who received the “real” ECT treatment was particularly difficult since 25-50% of patients experienced headache (Datto, 2000; Devanand, Fitzsimons, Prudic, et al., 1995), approximately 30% reported muscle soreness (Devanand, 1995; Maletzky, 1981), and

many reported confusion (Perera, Luber, Nobler, et al., 2004; Price, 1982a; Price, 1982b); these symptoms were not present with SECT. Furthermore, studies involving SECT have been plagued by design issues and ethical challenges (Ross, 2006). As stated by Kendell (1981), these ethical challenges included both withholding an effective treatment and enforcing a treatment that involved losing consciousness. As a result, ECT researchers have dismissed the need for control groups (Brodarty et al., 2000; O'Connor et al., 2001).

Although comparing real ECT and SECT treatment continues to be the best way to determine whether or not ECT has actually benefited patients, the possibility of a placebo effect cannot be disregarded. Since a large placebo effect was evident in less dramatic interventions, it was logical to question if more invasive treatments would yield a similar if not more profound effect. Kirsch (2009) argued that there was a large placebo effect associated with antidepressants to the point that in one situation red colored pills were viewed as more effective than beige colored ones, larger pills were perceived as more effective than smaller pills, and an IV dose of the medication was considered more effective than an oral one. Thus, it could be deduced that a complex procedure such as ECT may be associated with a large placebo effect.

Interestingly, multiple older studies comparing the effectiveness of ECT and SECT were conducted with inconclusive results. While some have argued that ECT and SECT showed no significant difference in their effectiveness (Lambourn & Gill, 1978; Miller et al., 1953; Sarita et al., 1998; Ukpong, Makanjuola, & Morakinyo, 2002), others have claimed ECT is an effective intervention (Abraham & Kulhara, 1987; Brandon et al., 1984; Brandon et al., 1985; Freeman, Basson, & Crighton, 1978; Gregory, Shawcross, Gill, 1985; Johnstone et al., 1980; Ulett, Smith, & Gleser, 1956; West, 1981). However, it

is noteworthy that improvements in patients' health were not perceived uniformly nor was the effectiveness of ECT noted across all patient types. In one study, the determination of a positive outcome was only perceived by the patients' psychiatrists and not by other medical staff or by the patients themselves (Taylor & Fleminger, 1980). Few studies compare ECT and SECT; unfortunately, the results of one longitudinal study comparing these groups were questionable as the SECT patients were given ECT only 3 weeks after the initial SECT treatment (Gregory et al., 1985). Since replicating identifying side-effects, such as headache, is ethically questionable, and since it is difficult to conceal which participants are receiving the true treatment, the efficacy of ECT has yet to be confirmed using a control group.

Even if it could be determined that ECT is effective in the short-term, the long-term benefits remain questionable. For instance, two literature reviews indicated no significant difference in the effectiveness of ECT and SECT on depressed patients one month after treatment (Brill et al., 1959; Gregory et al., 1985; Johnstone et al., 1980), two months after treatment (Brandon et al., 1984; Gregory et al., 1985), and six months after treatment (Johnstone et al., 1980). Additionally, Abraham and Kulhara (1987) indicated that benefits of ECT treatment on patients with schizophrenia were negligible after an eight-week period, suggesting ECT had no long-term benefits. More recent studies appeared to confirm these findings (Greenhalgh, Knight, Hind, Beverley, & Walter, 2005; Painuly & Chakrabarti, 2006; Tharyan & Adams, 2005; Ukpong et al., 2002).

ECT should perhaps be considered a short-term intervention associated with a high relapse rate after discontinuation (Sackeim et al., 2001). A relapse rate higher than 50% with the majority of the patients experiencing remission within 6 months after the

treatment had been documented (Kellner et al., 2006; Lisanby et al., 2008; Tew et al., 2007). As a result, anticipated relapse has warranted a continuation of therapy in the form of medication or monthly ECT sessions and has been recommended by healthcare professionals (Prudic, Olfson, Marcus, Fuller & Sackeim, 2004; Sackeim et al., 2001). Since the efficacy and the long-term effectiveness of the intervention have not been identified, long-term use of ECT is questionable.

ECT is often recommended as a first choice treatment for depressed patients with high or serious suicide risk (APA, 2001). Compared with other treatments, such as antidepressants, ECT provided faster relief of symptoms and thus was considered preferable for treating severe cases (Sackeim, Davanand, & Nobler 1995). In a study of 148 patients, Prudic and Sackeim (1999) reported that ECT treatment decreased suicidality. Furthermore, more recent studies asserted that ECT was an effective treatment for preventing suicidal ideation (Kellner et al., 2006). For instance, using Hamilton Depression Rating Scale (HDRS), Kellner et al. (2006) measured suicidal intent before, during, and after ECT treatments. Suicidal intent was greatly reduced with ECT, such that 38.2% of patients expressed relief after three treatments, 61.1% expressed lessening of symptoms after six treatments, and 80.9% benefited by the end of the treatments.

Conversely, other literature suggested that ECT did not decrease the risk of suicide in the long-term (Gazdag et al., 2009; Milstein, Small, Small, & Green, 1986; Prudic & Sackeim, 1999). A Canadian study that compared the records of 45 inpatients who committed suicide with 45 patients matched for gender, age and diagnosis upon admission, reported no benefits of ECT (Sharma, 1999). In fact, one study asserted that

the number of suicide attempts was less for individuals treated with antidepressants than for those treated with ECT (Bradvik, & Berglund, 2006). Evidently, no studies of suicidal patients compared those treated with ECT and those treated with SECT; thus, the efficacy of ECT requires further evaluation.

Although widely used for the treatment of depression and other mental health conditions such as bipolar disorder, suicidal ideation, and schizophrenia, ECT continues to be surrounded by controversy and ethical debates (Reisner, 2003). Ethical considerations involve patient knowledge, patient perception, and the informed consent process while controversy stems from the neurobiological, cognitive, and psychological impact of ECT.

Ethical Considerations of Electro-Convulsive Therapy

It appears that patients who have undergone ECT had limited understanding and knowledge of the nature of the treatment. In a review of nine studies, only 50% of ECT recipients believed they had sufficient information prior to giving consent (Rose et al., 2005). In an older study, Hughes et al. (1981) suggested that 69% of the patients who had undergone ECT did not know it involved inducing convulsions. Moreover, other survey studies reported that only 15% of ECT patients appeared to have a full understanding of the procedure based on survey measure, 43% had partial understanding of the treatment, and 30% had no understanding whatsoever of ECT (Freeman & Kendall, 1986; 1980). Furthermore, qualitative research has indicated that some patients has expressed that they did not recall being provided with adequate information on ECT (Fisher et al., 2011; Johnstone, 1999). Even though it was not clear how much patient recall was influenced by memory loss, patient reports suggested individuals undergoing

ECT treatment received inadequate information (Fisher et al., 2011). Evidence of limited patient understanding of the ECT procedure has raised major ethical concerns regarding the decision-making process and the informed consent procedure.

In response, ECT advocates have argued that patients agreed to undergo the ECT treatment because they trust the recommendations of their medical caregivers. As Riordan et al., (1993) suggested, “This may reflect a high level of trust, or a resigned lethargy, in part reflecting mental state, but also a feeling of lack of involvement in their own management”. As one patient stated, “He [the psychiatrist] is the one with the power, [so] he is the one ultimately that has the answer...if that's the only help you're getting you've got to hang on to it” (Johnstone, 1999, p. 74). Another patient articulated her fear and expressed her belief that no other options were available to her,

I was a very compliant young woman, I was very frightened of everybody and that was part of the problem... wouldn't have known how to object, it wasn't on the horizon. You didn't disagree with doctors, you did what they said (Johnstone, 1999, p. 74). One patient even expressed that she could not refuse the treatment: “They asked me if I would agree to it, but they did say if I refused they'd go ahead with it anyway...being forced to stay there is bad enough but being forced to have something that you don't want is ten times worse, so I did agree, yes”. (Johnstone, 1999, p. 74)

More recently, a qualitative study by Fisher et al. (2011) suggested that only one third of the participants believed that they were given enough information about the treatment. In addition, half of the participants stated that they were not provided with enough information about the potential side-effects of ECT. For instance as one patient stated, “They didn't give me no information on it, like what you're going to feel or what they're going to do” (Fisher et al., 2011, p. 349). Similarly another participant confirmed, “Went in with my eyes closed. . . I was going into it not knowing what was really going to happen.”

Further, the lack of information could lead to a sense of betrayal and loss of trust in many individuals who have undergone ECT. For example, one ECT patient stated,

They've only got to mention the word hospital to me and I freak out...when I go into hospital, I won't trust nobody in there, because my mind runs away with me. Are they going to force me to have ECT?...I know the staff on the ward, I've been there so many times, but each time I've been and come away, when I have to go back again I try and build that trust up all over again. (Johnstone, 1999, p. 74)

The literature has suggested the need for increased information in the decision-making process. Several factors point to the increased need for full disclosure to the patient: studies indicating up to 30% of individuals receiving ECT felt they have not consented freely to the treatment (Rose, Wykes, Bindman, Fleischmann, 2005), the dangers inherent in ECT, and the possibility that the treatment may be ineffective.

Moreover, providing accurate information assisted individuals with the decision-making process (Teh et al., 2007). This is of specific importance as lack of proper explanation surrounding the procedure may cause patients to make an uneducated decision (Smith, Vogler, Zarrouf, Sheaves, & Jesse, 2009), possibly leading to feelings of powerlessness and betrayal (Johnstone, 1999). In such situations, significant concerns about power and compliance are inherent when dealing with a vulnerable population. Concerns about the issues of power and compliance are also evident in statements from members of mental health teams. In one situation a health care worker reported, "Two patients who misunderstood the initial appointment letter...came fully prepared to have a course of ECT. Neither had been near the hospital for nine months and both were quite symptom-free" (Freeman & Kendall, 1980, p. 16). Furthermore, in another study, the feeling of powerlessness during the decision-making process had been expressed by one patient as follows:

It was like, the consultants and the psychiatrists have such a powerful influence over you. In one sense your life is in their hands and it's wanting to please them, I suppose, because...part of depression is losing your sense of self really, and you're so easily influenced and so easily willing to accept authority. (Johnstone, 1999, p. 74)

In another case a patient stated,

Now what so often happens in psychiatric hospitals is, it's not the psychiatrist that forces you to have it. Long before that happens you get confronted by staff nurses who are very anxious to stop hassle....so what they do, they see that you're weak and vulnerable and they said, "You'd better sign," just like that. (Johnstone, 1999, p. 74)

The literature clearly revealed power dynamic in the decision-making process. Even when patients consented, it is uncertain that they are "truly informed" and their right to decline the treatment remains limited.

A discrepancy exists among studies gathering the perceptions of patients who have received the treatment. Some surveys from the 80s and 90s suggested that most of the recipients did not find ECT particularly frightening (Freeman & Kendall, 1985; Riordan et al., 1993); in fact, 50% of patients in Freeman & Kendall (1985) reported less fright than a visit to the dentist. Also, in another study, more than 58% of the patients who experienced ECT perceived the treatment no more bothersome than a counselling session (Bustin et al., 2008). In one study conducted with a group of 516 patients, 43% found ECT "helpful" or "very helpful" (MIND, 1993; Rogers, Pilgrim, & Lacey, 1993). However, in the same study, 37.1 % believed it was "unhelpful" or "very unhelpful," with a high proportion of the latter group strongly condemning it (MIND's, 1995).

Others reported negative perceptions of the treatment (Teh, Helmes, & Drake, 2007; Santa Maria, Baumeister, & Gouvier, 1998). Interestingly, the negative attitude among patients corresponds with the almost 60% of individuals who stated that if given

the option, they would decline the procedure in the future (Rose et al., 2004). Moreover, when studying the levels of fear and anxiety towards the treatment, a range of 69% (Riordan, Barron, & Bowden, 1993) to 74% (Gomez, 1975) of patients reported some level of anxiety. In fact, 14.3% of patients found ECT to be more upsetting than surgery (Pettinati, Tamburello, Ruetsch, & Kaplan, 1994) and 23.7% agreed with the statement “ECT is a barbaric, inhumane treatment” (Kerr, McGrath, O’Kearney, & Price, 1982).

Negative responses to ECT have been confirmed in qualitative studies. For instance, one patient described her/his feelings as follows:

As they wheeled you in you'd see what they used, they'd put some gel on it, they didn't even hide it from you...You were scared, yes. I can remember sitting in the room waiting for treatment and looking at some of the other people who were there as well and I suppose it was almost like a pre-execution room really....We were all sitting there in complete silence. I remember reading in something, I think a hospital pamphlet, (that) it was just like going to the dentist, which is completely absurd.. It's not like going to the dentist. (Johnstone, 1999, p. 75)

Another patient expressed the terror he/she experienced, comparing ECT to death: “You dread it, your heart starts pumping, here we go again. Horrible, absolutely terrifying...It's like going to your death, your doom, isn't it” (Johnstone, 1999, p.75). Although some patients perceived only minor discomfort, others experienced acute negative consequences.

Neurobiological Effects of Electro-Convulsive Therapy

The neurobiology of ECT has not been well described in the literature. ECT proponents have asserted there has been no evidence for ECT-induced brain damage. In one study, researchers used Magnetic Resonance Imaging (MRI) to measure structural brain damage associated with ECT (Coffey, Weiner, Djang, et al., 1991). Evidence of structural damage was investigated using MRI before ECT treatment, 2 days following

ECT treatment, and 6 months after receiving ECT treatment, yet no abnormalities were identified (Coffey, Weiner, Djang, et al., 1991). More recently, potential hippocampal atrophy was investigated using proton magnetic resonance spectroscopic imaging. Fourteen depressed patients participated in the study and were examined before and after right unilateral ECT (Ende, Braus, Walter, et al., 2000). The results revealed no change in N-acetylaspartate signals, suggesting there was no evidence for hippocampal atrophy (Ende, Braus, Walter, et al., 2000).

Conversely, neurologists have generally agreed that the experience of multiple seizures have been harmful for the central nervous system and results in morphological changes (Solviter, 1999; Tasch et al., 1999). Post-mortem histological analysis of the brain tissue in both humans and animal models suggested that ECT has been associated with widespread pinpoint hemorrhages and scattered cell death (Ferraro, Roizen, & Helfand, 1946; Meldrum et al., 1973). Furthermore, other researchers have found reductions in the number of cells in specific regions of the brain such as the entorhinal cortex (Cardoso et al., 2008) and the hilus of the dentate gyrus of the hippocampus (Zarubenko, Yakovlev, Stepanichev, & Gulyaeva, 2005). Thus, it could be concluded that these regions were more vulnerable to ECT.

The morphological damage induced by convulsions resulted from prolonged seizure activity, a condition known as status epilepticus, and the anoxia associated with it (Bernasconi et al., 2000; Bernasconi et al., 2003; Bernasconi, Natsume, & Bernasconi, 2005; Du et al., 1993; Pitkänen & Sutula, 2002). Therefore, ECT advocates believe that a modified version of ECT, in which oxygen is provided during anesthesia, is considered relatively harmless (Kusumakar, 2000).

Cognitive Effects of Electro-Convulsive Therapy

Beyond these morphological changes, seizures have been associated with cognitive impairments. The nature of these impairments were dependent on the structure most affected. Damage to hippocampal cells may be associated with decreased hippocampal function in patients who have undergone ECT. Thus, seizure-induced damage is associated with the loss of cognitive function.

When ECT is being considered, memory loss is a primary concern. While, some studies have suggested that ECT does not impact memory loss (Abrams, 2002; Fink, 2004) most research has indicated that some degree of cognitive impairment is certain (Ikeji et al., 1999; MacQueen et al., 2007; Sackeim et al., 2007). Within the literature, the nature of memory loss, the duration of memory loss, and the factors influencing memory loss after ECT treatment are discussed.

Much of the literature is concerned with the type of memory loss that ECT patients experience. Specifically, the literature examines the influence of ECT treatment on retrograde memories (memories made before treatment), anterograde memories (memories acquired after the treatment), and autobiographical memories (memories of events from an individual's own history). Electroconvulsive therapy has been associated with acute and chronic memory impairments (Ikeji, Ohaeri, Osahon, & Agidee, 1999; MacQueen, Parkin, Marriott, Bégin, & Hasey, 2007; Sackeim et al., 2007) including retrograde and anterograde memory (Durr & Golden, 1995).

However, retrograde amnesia has been experienced to some degree by all ECT patients (Read & Bentall, 2010) with the newest memories being the most affected. Anterograde memory loss is also experienced by the majority of patients who undergo

ECT and involves an inability to preserve new memories and recall them when desired. These memory impairments were mainly related to public events rather than personal information (Lisanby et al., 2000). It is noted that patients may be most concerned about deficits in their autobiographical memory as this information connects them socially with others and is unique to them (Johnstone, 1999). However, Fraser et al. (2008) noted that despite the importance of autobiographical memory, few studies have been conducted on the topic.

In a review of the literature, Ross (2003) reported that 29-55% of patients believed they have experienced long-lasting or permanent memory impairments as a result of ECT (Rose, Fleischmann, Wykes, Leese, & Bindman, 2003). These memory impairments were mainly related to public events rather than personal information (Lisanby et al., 2000). Moreover, Feliu and colleagues conducted neuropsychological analysis on 46 patients prior and after ECT treatment. Their results suggested significantly lower recognition and delayed recall in verbal and visual memory (Feliu et al., 2008). The degree of the impairment has been partially dependent on a method of electrical current stimulation as well as the location of the electrodes. Most literature asserted that unilateral brief-pulse stimulation is less harmful (Bailine et al., 2000).

The literature also has reported varied perceptions by patients regarding the effects of the treatment on their cognitive abilities. For instance, 35 to 42% of patients believed that ECT results in the loss of intelligence (Philpot et al., 2004). Moreover, 45% to 72% of individuals receiving this treatment reported moderate to severe memory loss (Philpot et al., 2004; Rose, Fleischmann, & Wykes, 2004). Other studies suggested that only 53% of the individuals receiving this treatment reported beneficial outcomes on their

cognitive abilities (Riordan, Barron, & Bowden, 1993). However, in one study, 35.1% described ECT as “damaging,” while another 16.5% said it was “not helpful” (UKAN, 1996). And although 30.1% found it “helpful” or “very helpful,” those who did not were likely to express strong views against it, using intense word choices such as “brutal,” “barbaric,” or “degrading” (MIND, 1993; Rogers, Pilgrim, & Lacey, 1993).

Patients have reported distress about losing life memories as well as the ability to process chronological events in media. Qualitative studies have documented that some patients have lost memories of episodes of their life: For instance, Johnstone (1999) reported, “My memory is terrible, absolutely terrible. I can't even remember Sarah's first steps, and that's really hurtful...losing the memory of the kids growing up was awful” (p.77). A different patient in the same study asserted,

I can't remember when they started junior school; I can't remember when they left infant school. Now those are things you remember, they're highlights...and I'm quite resentful really to think that my ex-husband has got more memories of my children and did pretty well nothing to help. (Johnstone, 1999, p. 78)

Others reported the inability to follow films, books, or TV programs as well as problems with facial recognition, as follows: “I can be reading a magazine and I get halfway through or nearly to the end and I can't remember what it's about, so I've got to read it all over again. Same with a film or a programme on the telly” (Johnstone, 1999, p. 78). The experience of undergoing ECT and the potential of debilitating memory loss may exacerbate existing psychological problems for patients who already view themselves negatively. For these individuals the procedure of ECT may act to confirm this perspective.

Psychological Effects of Electro-Convulsive Therapy

The psychological effects of ECT vary among patients. Some have reported strongly positive experiences with a complete sense of satisfaction in their recovery (Rayner, Kershaw, Hanna, & Chaplin, 2009), yet others have exhibited feelings of fear, shame, and betrayal (Johnstone, 1999; Koopowitz et al., 2003). Others have reported psychological after-effects including loss of confidence, dignity, and self-esteem, fear of hospitals and psychiatry, anger and aggression, loss of self, as well as nightmares (UKAN, 1996). In some individuals, the negative experiences have been so intense they have been compared to very traumatic events such as rape (Johnstone, 1999). As one patient in Johnstone's study explained:

It certainly felt [like I was pressured to say], "Do what you like," and that's something I felt as a child [referring to sexual abuse incidents as a child], that I had no power, there was no way I could stop anyone doing whatever they wanted to me, so rather than get hurt I'll let them do it and maybe they'll like me...especially because it was men doing it, the men actually operating the machinery or whatever, and I can remember it was men putting the needle in. Yes, again there would have been no way I would have said, "I don't want this..." And then just sort of lying there, feeling really frightened and yet completely passive. So it was like all trapped, all my emotions were trapped anyway and my feelings were trapped, so it was all trapped inside. And on the other hand not caring what happened to me. (Johnstone, 1999, p. 77)

One patient described the feeling of an ECT as an assault to the brain: "It felt like I had been got at, yes, bashed, abused, as if my brain had been abused. It did feel like an assault" (Johnstone, 1999, p. 76). Thus, some patients equate ECT to various types of assault.

Moreover, patients also have reported other negative psychological effects such as reoccurring nightmares (Johnstone, 1999; Koopowitz et al., 2003), as expressed by one individual:

I had absolutely terrifying lucid dreams. I couldn't explain to you how terrifying they are, it's just beyond words. I started telling this therapist about them to try and make sense (of them) and I always described this feeling as if I was having electricity....Terrible sensations, feeling like I was just about to die, and very, very lucid dreams, not like ordinary ones, where I wasn't sure if I was awake or asleep. (Johnstone, 1999, p. 81)

Some patients have expressed that the negative feelings persist long after the treatment. For instance, one woman expressed her feelings 23 years after treatment: “Certainly if I do talk or read about ECT, it does bring back all these horrible memories of the actual treatment. I always get the same symptoms, headaches, nausea and things” (Johnstone, 1999, p. 81). Thus, ECT carries the possibility of a variety of debilitating negative neurobiological, cognitive, and psychological effects.

Summary

A review revealed a gap in the research literature on the experiences of women who have undergone ECT and the meaning they assign to the experience. To generate a better understanding and further investigate the phenomena of women's experiences of ECT and to hear their voices, a qualitative study was implemented. Inviting women to speak their truth while acknowledging that they are “experts of their stories” enabled them to speak to any aspect of the experience that resonated. Data from existing quantitative studies complemented the detailed, in-depth exploration of the experiences of women who had undergone ECT.

Chapter 3: Power and Women's Experience of ECT

Introduction

Since more than half of mental health clients reported low satisfaction and/or negative experiences while receiving care (Allen, Carpenter, Sheets, Miccio, & Ross, 2003; Baker, Lovell, Easton, & Harris, 2006; Burstow & Weitz, 1988; Everett, 2000; Jennings, 1994; Kumar, Guite, & Thornicroft, 2001), it is essential to identify the sources of these concerns. Primary source of concern involves a power disparity between patients and mental health practitioners (Burstow & Weitz, 1988; Everett, 2000; Kumar, 2000; Kumar et al., 2001; Laugharne & Priebe, 2006; Lowry, 1998; McCubbin & Cohen, 1996). This discrepancy in power has been recognized among patients who have received ECT (Johnstone, 1999; Koopowitz et al., 2003).

Power inequalities have been rooted in a patient's inability to maintain autonomy and exert personal choice (Barnes & Wistow, 1994; Bassman, 2005; Burstow & Weitz, 1988; Howard, El-Mallakh, Rayens, & Clark, 2003; Johansson & Lundman, 2002; Kumar, 2000; Linhorst & Eckert, 2003; Lowry, 1998; Olofsson & Jacobsson, 2001). One area that patients perceived limited choice has been regarding the amount of information that mental health professionals share with them (Allen et al., 2003; Baker et al., 2006; Howard et al., 2003; Olofsson & Jacobsson, 2001; Olofsson & Norberg, 2001). It has been assumed that when informed consent is obtained patients have received sufficient information about the procedure and its potential side-effects (NICE, 2003; 2010). However, some studies indicated that almost one third of ECT patients felt they did not authorize full consent for the treatment (Rose et al., 2005). These patients believed they lacked sufficient knowledge about the process, the potential side-effects, and the

possibility that the treatment may be ineffective (Rose et al., 2005). Previous research investigated patient satisfaction with information received when consenting to ECT (Fisher et al., 2011; Malcolm, 1989; Rayner et al., 2009; Rose et al., 2005). One review (Rose et al., 2005) found that across nine studies, approximately half the participants felt they had enough information about ECT prior to consenting. The authors concluded that not being given enough information, combined with memory loss, contributed to participants later reporting that they had not been fully informed. Some older studies suggested a range of 15% (Freeman & Kendall, 1980; 1986; Malcolm, 1989) to 69% (Hughes et al., 1981) of individuals who had undergone an ECT treatment either misunderstood or did not understand the process and indicated they did not realize the treatment involved convulsions. Lack of knowledge deprived patients of the ability to intelligently negotiate this procedure and raises ethical concerns about the validity of the informed consent.

Mis-understanding and under-informing have been commonly reported in the ECT experience. For instance, one health care professional reported that two people misinterpreted an appointment letter and, despite being symptom free, came to the hospital fully ready to receive ECT (Freeman & Kendall, 1980). Rather than giving patients the time to become informed about ECT and ask questions, health care professionals have reportedly intruded and forced patients to sign consent forms (Johnstone, 1999). The perception of being forced to consent contributed to a sense of being betrayed by the health care professional (Johnstone, 1999). Regardless of the process by which patients are under- or mis-informed, a lack of information rendered

them unable to actively negotiate the ECT journey and they remained in a disempowered position.

Since accurate information is critical (Teh et al., 2007), insufficient knowledge about the ECT procedure may cause patients to make an uneducated or naïve decision (Smith, Vogler, Zarrouf, Sheaves, & Jesse, 2009), that may have resulted in feelings of powerlessness and betrayal (Johnstone, 1999). Both Johnstone (1999) and, more recently, Koopowitz et al. (2003) listed the feeling of powerlessness as one of the more common yet most traumatizing negative emotional results of ECT.

While analyzing the nature of the power imbalance, an area of profound concern involved the perception of coercion by psychiatrists, the suspension of individual rights, and treatments received involuntary (Allen et al., 2003; Baker et al., 2006; Bassman, 2001; Breeding, 2008; Haglund, Von Knorring, & Von Essen, 2003; Jarrett et al., 2008; Lind, Kaltiala-Heino, Suominen, Leino-Kilpi, & Välimäki, 2004; Olofsson, Gilje, Jacobsson, & Norberg, 1998; Olofsson & Jacobsson, 2001; Rogers, 1993). Mental health professionals rationalized their actions by stating that ECT is primarily used in “life-threatening” situations where no alternatives existed (Angell, 2006; Fink, 2001; Haglund et al., 2003; Jarrett et al., 2008; Laugharne & Priebe, 2006; Lind et al., 2004; Olofsson & Norberg, 2001). Individuals, who have undergone ECT, commonly asserted they lacked voice—or power—in the decision, that it was made for them by others, such as a family member or psychiatrist (Rose et al., 2005). Rose et al. (2005) found that approximately one third of patients felt coerced or pressured into consenting to ECT. Coercion does not need to be explicit or deliberate; it can be as simple as patients being unaware of their right to refuse ECT.

Previous research supported the patients' perception of lack of power in decision-making. For instance, a survey conducted by Freeman and Kendell (1980) found that 23% of their sample believed that they could not refuse ECT and another 40% were unaware that they could decline treatment. Qualitative interviews confirmed that patients were often told that ECT was their "last chance," and other choices were not offered (Johnstone, 1999). Individuals who had ECT also recalled that other people implied that they needed the treatment (Johnstone, 1999). Some patients received warnings that their lives would be ruined or jeopardized by continued depressive symptoms or that they may commit suicide if they refused the intervention (Johnstone, 1999). At the extreme, some respondents recall giving consent against their will. As reported by Johnstone (1999), claiming to have more expertise allowed those in power to, directly or indirectly, persuade people to have ECT, thus reinforcing powerlessness. In addition, Morrison (2009) suggested that the presentation of ECT as a "last resort" negatively impacted her experience of consenting to the treatment. Believing that no options exist, patients may assume the role of "good patient" (Bassman, 2005; Burstow & Weitz, 1988; Everett, 2000). However, this may have a negative impact on patient's level of trust (Johnstone, 1999), which may limit the benefit of treatment (Allen et al., 2003; Baker et al., 2006; Bassman, 2001; Everett, 2000; Johansson & Lundman, 2002; Laugharne & Priebe, 2006; Olofsson & Jacobsson, 2001; Olofsson & Norberg, 2001).

Perceiving a link between ECT treatment and expert authority, some patients relinquished their power. Individuals contemplating ECT are often involved with a myriad of professional caregivers, may begin to view themselves as less knowledgeable and, "accept [the] authority [around them] (Johnstone, 1999, p. 74). Ranking themselves

as the least knowledgeable in the medical hierarchy, patients placed themselves in a disempowered position. This attitude of “the doctors knows best” or “they are the experts” can produce the response, “He [the psychiatrist] is the one with the power, [so] he is the one ultimately that has the answer...if that's the only help you're getting you've got to hang on to it” (Johnstone, 1999, p. 74). Given the importance of the patient/ doctor relationship and power dynamics, it is surprising that research in this area is not more available (Rose, Wykes, Bindman, & Fleischmann, 2005).

Sutherland (2007) suggested that the balance of power between doctors and patients may become skewed when patients are vulnerable about their condition or unsure about an invasive procedure such as ECT (Johnstone, 1999; Orr & O'Connor, 2005). Feelings of victimization and anticipated reprisal prevented patients from sharing their feelings about ECT with their psychiatrists (Johnstone, 1999), indicating a disempowered position. Additionally, Riordan et al., (1993) interpreted the patients' yielding of decision-making to others, such as health care workers or family members, as a possible form of giving up, withdrawing, or surrendering control of their health care plan. A lack of knowledge about an unknown process may cause people to willingly and, even happily, relinquish their power, effectively transferring it to others. Deliberately surrendering power may indicate an intentional desire to renounce personal power due to suicidal ideation. For example, Fisher et al., (2011) reported that two participants consented to ECT believing that it might kill them. The desire to abdicate power could reflect victimization, frustration with negotiating the mental health system, or the desperation of struggling with mental illness (Hagen & Nixon, 2011).

The most extreme form of powerlessness, which may result from a lack of knowledge, is perceived as traumatic. In some individuals, negative experiences of ECT are so intense that they have been compared to very traumatic events such as rape (Johnstone, 1999). Other patients have described ECT as so deeply traumatizing that the experience is perceived as death: “Horrible, absolutely terrifying...It's like going to your death, your doom, isn't it” (Johnstone, 1999, p.75).

Trauma occurs when patients' ability to choose is discounted (Johnstone, 1999). Lammers and Stapel (2011) labeled this process dehumanization and argued that increased power of the psychiatrist increases dehumanization in patients. Women were particularly vulnerable to this type of dehumanization in the ECT process (Burstow, 2009).

Identifying dehumanization as a type of disempowerment is especially important from the feminist perspective. Feminist research explores the belief in the “illegitimate or unjustified” oppression of women (James, 2000, p. 576) and examines why feminine traits such as sensitivity can be reinterpreted as impulsiveness in the dehumanization process. Burstow (2009) states that ECT “mutually constitutes the woman shock recipient as a powerless child who knows that she will not be heard and the presiding male as all powerful parent who knows what is best and will enforce it” (p. 28). Researchers further argued that medicine has exploited women in areas such as reproductive technologies and psychiatry (Chesler, 1989; Klein, 1993; and Raymond, 1993) that medicalize and pathologize women (Woodlock, 2005). Since women are diagnosed with mental illness more often than men (Chesler, 1989; Graham, 1994; McLellan, 1995) and are more likely

to receive ECT intervention (Thompson, Weiner, & Myers, 1994), exploring women's experiences of ECT from a feminist perspective is a worthy endeavor.

Moreover, the patients view the mental health professionals as being detached and impersonal (Baker et al., 2006; Barnes & Wistow, 1994; Bassman, 2000; Everett, 2000; Jarrett, Bowers, & Simpson, 2008; Johansson & Lundman, 2002; Olofsson & Jacobsson, 2001). Finally, given the prevalence of the medical model, patients often felt they were not viewed holistically and that contextual and/or environmental factors that may impact mental health were disregarded, and alternative interventions, such as counselling were dismissed (Bassman, 2000, 2005; Breeding, 2008; Everett, 2000; Kumar, 2000; Laugharne & Priebe, 2006; McCubbin & Cohen, 1996; Modrow, 2003).

Although the theme of powerlessness permeates patient narratives of ECT experience, some respondents reported acts of reclaiming power in their ECT journey. For example, by obtaining a personal directive, some participants regained power and ensured that they would not be subjected to ECT treatment in the future (New Zealand, Morrison, 2009, p. 165). Others involved themselves actively in alternate therapies such as counselling as a form of regaining power in their healing process.

While ECT may effectively counter some depressive symptoms (Kelly & Zisselman, 2000; Koenig 1999; Weiner & Krystal, 1994), the impact of this treatment on patients is not well documented in the literature. Only a few studies have focused on developing a holistic understanding of patient experiences of this treatment (Johnstone, 1999; Koopowitz et al., 2003; Orr & O'connor, 2005; Rose, Fleischmann, & Wykes, 2004). A woman's ability to nurture wholeness and overcome the challenges for which the ECT had been prescribed will ultimately depend on the participant's ability to enter

the ECT process as an empowered participant. The literature suggested that this empowered position is essential for many ECT participants as they journey towards healing (Hagen & Nixon, 2011). Limited research may contribute to lack of knowledge and powerlessness in patients. Additional research may also inform mental health professionals about the way ECT patients perceive them and thus empower all members of the therapeutic team.

Most of the existing data regarding satisfaction and power dynamics in women's experiences with ECT was gathered using quantitative surveys (Rose et al., 2003, 2004). Previously data was gathered by survey or questionnaire format by a hospital representative while the patient was still in the hospital (Freeman & Kendall, 1985). The presented study addressed the weaknesses of previous studies that relied on quantitative evidence alone. This study used in-depth qualitative interviews to explore the phenomenon of women's experience of ECT and perceived power dynamic.

Methods

Design. Using narrative inquiry, the personal accounts of women who had experienced ECT were collected in this study. The technique of person-centered interviewing was chosen as it privileges each informant as the authority on her particular experience (Hollan, 2005; Levy & Hollan, 1998; Polakoff & Gregory, 2002; Tarrant & Gregory, 2003). The data shared by the informant reflected her particular reality and supplied information on her background, viewpoint, and particular experiences as understood in that time and place (Levy & Hollan, 1998).

Informants were encouraged to tell the story of their experience with ECT in any manner that felt comfortable for them. They did not need to follow a chronological order

and were invited to begin with a particular scene or feeling that resonated with them or encapsulated their experience. Sharing information in this manner allowed the informants to freely assume both role of expert informant while fulfilling the role of respondent. All aspects of the storytelling were important including body language and audible features such as tone, volume, pauses, and silences (Hollan, 2005). The familiar format of a story assisted the informant in comfortably talking with, listening to, and engaging with the researcher (Hollan, 2005).

Participants. Recruitment posters advertising the study were placed at several locations in the City of Lethbridge. Through this recruitment strategy and word of mouth, nine individuals volunteered to participate in the study. Each of these persons were eligible to participate in the study as they met the following requirements: were female, spoke English, were at least 18 years of age, and self-identified as receiving at least one ECT treatment. The participants' ages ranged from 22 to 63 and each participant reported their ECT experience in detail.

Ethical considerations. The University of Lethbridge's Research Ethics Board (REB) granted ethical approval for this study. Participant anonymity has been protected as pseudonyms were assigned and identifying information has been excluded from the report.

Data collection. Interviews were conducted in person or by telephone, and were digitally-recorded. Although a narrative, person-centered approach was used during the interviews, statements and probing questions were introduced as a means of encouraging participants, eliciting further details, and confirming or clarifying aspects of the data

when necessary. One of the benefits of this design method was that it allowed rapport to build between the interviewer and the participant resulting in rich data collection.

Data analysis. The data analysis technique chosen was thematic content analysis. This strategy allows the researcher to identify categories, form common themes, and recognize patterns within the textual data (Braun & Clarke, 2006). Due to the small number of participants and the researcher's desire to work closely with the data, the interviews were coded manually.

As suggested by Braun and Clarke (2006), seven steps for thematic data analysis were followed. First, the researcher transcribed the digital recordings of the interviews. Second, the researcher became familiar with the text by reading the transcripts multiple times and making notes. Third, the researcher began to form codes, identify patterns, and organize the data into meaningful categories. Fourth, the different categories were combined to form themes. Fifth, the themes were reviewed and refined in such a way that thematic maps of the data could be formulated. Sixth, based on previous literature findings the themes were assigned names provided in the interview text. Finally, these emergent themes described and explored women's experiences of ECT and issues of power. It is noteworthy, that the preliminary analysis of the data was initiated following the first interview. This allowed the researcher to adjust the interview probes by adding or deleting the questions based on the information that emerged during the interviews.

Results

Using thematic analysis the experiences of women who have undergone ECT were identified. These themes were then explored in relation to perceived power dynamics. The themes included: "I was kinda going into [it] blindsided", "It is not really

your decision”, “It was kind of like we’re cattle or something”, “I was desperate”, and “Trying to control my own life”.

“I was kinda going into [it] blindsided”. Participants were asked to explain the information that they were given prior to the ECT treatment. This theme entailed the lack of information or mis-information provided by health care professionals. This theme was divided into two subthemes: “He did not say much” and “I was told it restarts your brain”.

“He did not say much”. This subtheme described the amount of information provided to the participants prior to the ECT treatment. None of the participants believed they received enough information. For instance, Sally Ann stated that: “I wasn’t explained very much. I just went through it on a day. They just stick an IV in you and knock you out and then you wake up and you’re very tired.” In addition, Bonnie explained her experience as follows: “He [the psychiatrist] didn’t really explain it; he just says I have to get it done. He didn’t tell me nothing just that I have to go for ECT.” Katherine confirmed it by stating, “He didn’t really say much. He just said that uh, it would be probably the best benefit.”

Only three participants stated that they were given some information about the possible short-term memory loss. All of the participants wished that they had been given more information about the treatment. As Maggie stated, “I think that there is a possibility of memory loss and it’s sometimes a bit longer term than people, you know, say. It is possible that it would be longer term for you. But of course anything like that, then you’re gonna refuse it.”

The lack of knowledge resulted in disappointment and anger directed at the health care providers. Natalie explained her feelings toward her psychiatrist: “[I am] angry at the psychiatrist for not explaining it to me, giving me all the information. Mostly that, cause if I was explained to why, I probably wouldn’t have had it done.... In some ways I feel like he made the decision because he really didn’t give me all the, like, all the answers. He just basically said, “You know, I think this will help, you should do it.” To me that wasn’t really my decision when he, when you say it in that context. So I said “Okay”.... [I feel] a little disappointed, angry, little frustrated about it. Why? Cause I wasn’t told the truth. If I was told the truth I probably wouldn’t have had it done.”

“I was told it restarts your brain”. Limited information resulted in naïve and/or limited understanding of how the ECT procedure worked. Maggie stated, “What they said was they didn’t know how it worked.” Further, participants demonstrated naïve understanding of the procedure. As Carla explained, “It’s, I know it’s a minimal like it’s not.... A full blown [seizure].... It’s [ECT] to trigger the body to have the seizure but then yeah I, I it’s just [that] ECT is actually simulating something [a seizure] that occurs naturally in some people.” In addition, only two participants understood that convulsions caused chemical changes in the brain. As Sally Ann explained: “Just that it kind of shocks your brain. And changes the chemicals and stuff like that.” Paula expanded on the concept: “So, all I know is, is that it, it shocks your brain in some areas into producing the more happy chemicals that other people produce....Um, on their own.” Rachel stated “I was told it restarts your brain.... yeah it’s just it’s supposed to restart your brain to make you more, so you can function better.” Maggie explained that prior to the treatment she was told, “It’s been getting harder to treat you and we think this is the answer. It

[ECT] is only a very short convulsion and you'll be fine, you'll be fine".... Of course they say, that it's not gonna hurt me." Right? And that it [memory loss] was going to be short-term and everybody's gonna live happily ever after."

"It is not really your decision". This theme explained how the participants expressed lacking power during the decision-making process. As Natalie stated, "He really, it really screwed me over because you know, he never really, he, he didn't give me the, he just, you know, he just said, "Here", you know, "If you do this, this is what's gonna happen." He didn't give me the negative sides until it was too late.... So I was kinda going into [it] blindsided.... No [information was provided], none at all, he didn't really give me any, no, pros or cons. He just said that this could help and I thought, "Oh, okay, well let's see if it could help."

Maggie explained her lack of power and involvement in the decision-making process and informed consent as follows, "I don't really think I decided to get ECT.... [There] was, 120 day permission given to my inpatient psychiatrist so he signed it and I obviously signed it...It was just a piece of paper that I signed, and obviously, I did sign it, but I would have said that I [didn't] have a clue what I was signing."

Rachel confirmed Maggie's feelings and stated, "I'm frustrated that, you know, he [the psychiatrist] kinda, he kinda pushed me into it.... I think it was other people making the decision for me cause I had my aunts saying, "Oh go for it." I had my doctor you know saying, "You gotta do it." You know really pushing me in that direction". In addition to not being involved in the decision-making some participants mentioned that they felt pressure from the psychiatrist. In Sally Ann's words, "I think my doctor put a lot of pressure on me though, to do it."

Furthermore, some participants were made to feel guilty about refusing the treatment, as Natalie explained, “He was like, you know, “You should have them, you know, their successful rate is like 98% and, you know, if you don’t have them then, you know, I’m gonna be very upset with you” and just saying things like that.” Others stated that the imbalance in the level of knowledge placed the health care providers in the position to make the treatment decision. For instance, Maggie stated, “But uh, just, you know, we [psychiatrists] know what’s best for you, just quiet down now, my dear” Katherine expanded on this concept and explained, “Because all it’s based on his [psychiatrist] decision and he decided so, it’s not really your decision. It’s his decision. Because he’s your doctor, I mean.... I believe that he being, since he was the head of the whole, of the whole, of the whole psychiatry, he knew what was best.”

“It was kind of like we’re cattle or something”. Some participants described the process of ECT treatment as barbaric and dehumanizing. Sally Ann, for example, described her feelings as she was wheeled into the surgery suit, “I remember, umm, well, there’s like the bunch of us that did it at the same time. And we woke up it was kinda like a train, like they took turns knocking us all out, while we were waiting. Like a, they just moved us on, one after another, one after another, and then you wake up in the recovery room and there’s of bunch of you laying there.... It was kind of like we’re cattle or something.” She further explained being anesthetized as follows, “They just like shove a needle in you and knock you out and that’s all they do”. Katherine described what she was told about the shocking procedure as, “I would get a little jolt and that was all.”

Rachel expressed her negative feeling towards the procedure as, “It’s, I think it’s kind of barbaric in some ways; you’re shocking someone’s brain.” Katherine confirmed

this feeling by posing the following question, “How would you like someone to take you, put you to sleep, put electrodes on your brain, and then shock your head up or your brain, just because you’re having problems?”

“I was desperate”. This theme described how some participants were willing to give up their power. This theme was further divided into two subthemes: “last chance” and “If it doesn’t work it’ll kill me”.

“Last chance”. Many participants were told that it was their “last chance” and no other alternatives were offered to them. Some mentioned that they did not respond to medications and so they decided to try ECT. As Carla explained, “I went through different medications, it’s just like nothing was, was helping. So they suggested ECT. And that was pretty much, I was just desperate.” Paula confirmed the feeling of desperation, “Well I just, I just felt so awful. I was suicidal and I just felt so absolutely horrible and withdrawn from the world that I was willing to try anything.” Rachel however, was told that she needed fast relief from her symptoms, “And by Monday, my doctor’s like, hey we need to do something drastic, cause we can’t have you hurting yourself Well I thought it couldn’t get any worse.”

“If it doesn’t work it’ll kill me”. Some of the participants seemed to want to lose power. For example, Carla stated, “And yeah the other part too that I remember with just the, the recent one [the recent ECT treatment] is that when I think about it, it is kind of a sad, well, it’s kinda like I, when I think about it it’s kind of sad that I actually was there. But when they put you under I always looked forward to that, because it was so peaceful. Like I, cause you’re just uh so relaxed and there’s nothing. And I remember looking forward to being put out.” Others mentioned that they passively agreed to ECT and have

even used the treatment as a form of self-harm. For example Sally Ann stated, “I agreed to it, umm, the problem was that I kind of, was hoping I was gonna be the one in one thousand that died from it. I didn’t want it to help me I wanted it to kill me.... And, I kind of liked the feeling of, the sensation of losing control cause I thought, I thought that I wasn’t gonna wake up from it.” Rachel confirmed this, “Because I thought, you know, if, at least if it doesn’t work it’ll kill me.”

“Trying to control my own life”. Some participants strove to get their power back and relinquish the passive patient role. In some cases, someone advocated on their behalf. For example, Natalie explained an interaction between her husband and the psychiatrist as follows, “My husband and him had a good falling out. And uh, to put it in easy terms, he [psychiatrist] just, he, he was a real prick. He uh, tried to get me to, he, he put words into my mouth. He tried to get me to believe that my, my father molested me, which wasn’t true. My father never touched me. When, just before I was diagnosed with schizophrenia, my husband went to him and said she doesn’t have multiple personalities, she’s schizophrenic and uh, he’s, he was like, “No she’s not” you know, “She’s got this”, and my husband pulled out a bunch of, cause my husband worked with ----- up at the university at this time. And he pulled out a bunch of papers you know, saying, “No, this is what she is” and he’s like, “No, you know, where do you get these findings from” and blah, blah, blah, and my husband’s like, “I took them out of you know these books” he’s like, “Well you, you can’t take them out of these books” you know, blah, blah, blah. My husband’s like, “You’ve got those books sitting right behind you, you know.” So they had a big falling out and that was the end of it you know. I got a new psychiatrist because he was a real jackass.”

Moreover, Rachel explained a need for an advocate as follows, “Well, I’ve never had a therapist up until, till like two years ago and I do, I find it helps a lot more. You can talk to your doc, to your therapist and you have someone on your side.” Bonnie, a woman who suffered from epilepsy and whose ECT treatment triggered an episode of status epilepticus explained how she stopped ECT “He [her brother], I think he came down and spoke with Dr. ----- and said no more ECT on my baby sister.... I felt like, I felt good when they stopped it, especially my brother...And my therapist said, “Let’s not [let ECT] happen [again]” because she knows I have epilepsy.”

However, perhaps the most striking of all was when Maggie called the researchers of this study. She informed them that as part of her active role in healing she decided to make a legal document. In Maggie’s words, “I thought, no way! I’m gonna go to a lawyer and I’m gonna say, Is there any way to have this written that would have any kind of impact. I have a, a part of my living will where, the lawyer just happened to put it. I have, and uh a statement that says that under no circumstances am I to be given uh, convulsive, electroconvulsive treatment and I think some more, I think it’s a little bit longer maybe another line in it. But basically my lawyer assured me that uh, that will stop them.... And of course my daughter, now being the oldest and she’s my next of kin, she has a copy of it. So if [in the] future, you know what I mean, nobody might look in the chart for it, but she has it and I’m assured by the lawyer, but for me it was you know, it was just trying to control my own life.”

Discussion

Themes identified through thematic data analysis indicated that women who underwent ECT treatment shared similar experiences related to power. The imbalance of

power experienced by the women was associated with the information provided and the decision-making process. Additionally, some women reported feeling dehumanized and desired to give up control of their medical care. Interestingly, others who reflected on the process expressed a strong desire to reclaim their power.

Most of this study's participants possessed a naive understanding of the ECT process. Previous research indicated that just over two-thirds (69%) of ECT patients did not comprehend that ECT involved convulsions (Hughes et al., 1981). In this study, most of the participants did understand that the intervention involved convulsions although it was unclear if they knew what a convulsion actually entailed. Most did not understand the repercussions of having convulsions or the possible risks associated with ECT.

Concurrent with previous findings (Fisher et al., 2011), a majority of this study's participants (six) felt that their ability to comprehend information about ECT was limited by a lack of knowledge. This partially compromised their ability to give fully informed consent. The results indicated a flaw in the consent process—including verbal explanation and the consent form itself—that must be addressed and remediated. Attention must be given to augmenting the amount of information given to patients, perhaps simplifying the language, expanding content, and checking to ensure that information transfer has occurred prior to seeking informed consent. Additionally, patients should be given the opportunity to think about and pose questions at any time without fear of being ignored or belittled. Furthermore, an increase the awareness about the procedure, its potential side-effects and the patient's right to refuse the ECT treatment, at any time, would allow the patients to take an active role during their healing.

Participants demonstrated a variety of mis- and under-informed states. The patients were mis-informed about their right to refuse treatment and to discontinue treatments at any time once they had been initiated. Previously reported by Fisher et al. (2011), some participants felt anxious about their decision yet did not withdraw from the treatment suggesting that they may not have realized their right to suspend treatment. A majority of participants (six) in this study thought that they were compelled to complete the entire course of six or 12 treatments once they were initiated.

Seven participants stated that the psychiatrist made the decision for them. They felt obligated to consent to the procedure because it was presented to them as a “last resort,” with no other alternatives given. This illustrated under-information about other types of treatment still available to them, only one of which was ECT. These participants were misled about the extent of their condition as requiring a “last resort” treatment.

Lacking knowledge, some women experienced dehumanization. The term “barbaric” was used by four respondents in this study and this sentiment was also reported in previous literature (Johnstone, 1999). A few perceived the health care professionals as uncaring or cold, using the words “nasty” and “nose up” to characterize those involved in the procedure. Treated disrespectfully, participants felt disempowered and angered that they did not have the same opportunity to choose as their caregivers did.

All participants were unaware of feminist issues in ECT. When asked how they felt towards ECT from a woman’s perspective, most were surprised. None knew that more male psychiatrists give ECT and more women patients are treated with ECT. Their reactions included: “I didn’t know” as well as gasps of surprise. Since the concept was new, all participants responded as if they could not comprehend this reality. This, too, is

an example of how participants lacked knowledge and became disempowered. However, some participants expressed their belief that ECT had little to do with gender and power than it did with being ill, vulnerable, and desperate for relief from symptoms.

In agreement with a previous report (Fisher et al., 2011), two of the nine participants in this study mentioned they had hoped the ECT would kill them and consented to receive ECT as a form of deliberate self-harm. Moreover, confirming previous findings, all of our participants agreed that they would benefit from greater use of counselling (Allen et al., 2003; Baker et al., 2006; Everett, 2000; Johansson & Lundman, 2002) as well as more caring and supportive relationships with staff (Bassman, 2005; Everett, 2000; Olofsson & Jacobsson, 2001; Olofsson & Norberg, 2001). However, it is noteworthy that counselling services may not be viable for all patients. Not fully covered by public health care systems, such as Alberta health care, counselling services may be quite expensive if unsubsidized. In Fall 2011, the website for the Psychologist Association of Alberta reported an average fee of \$170 for a 50 minute session (Psychologist Association of Alberta, 2011).

Since their ECT treatments all participants have implemented other means to regain control over their lives. For instance, all the women have tried some counselling; three have asked another health care professional to advocate for them; and one has taken legal steps to ensure she is not treated with ECT in the future. Patients should be given full information about alternative treatments and ways to empower themselves.

All participants experienced a pronounced loss of power that permeated all facets of their lives. Regardless of type of employment previously held, most participants were unable to return to their previous workplaces. None of the participants had realized how

profoundly ECT would impact their health and other areas of their lives. Exploring additional repercussions of ECT would be beneficial for individuals considering the procedure and is an area that warrants additional research.

In summary, ECT was articulated as a distressing psychological experience for all participants. Lacking sufficient knowledge to discern all their options, the phrase “giving up power” inadequately depicts the extent of their victimization. The trauma they experienced was deeper than mere victimization since the process damaged their self-identity and self-confidence, limited their voice, and their ability to articulate their losses. Concurrent with previous findings (Barnes & Wistow, 1994; Bassman, 2005; Burstow & Weitz, 1988; Hagen & Nixon, 2011; Howard et al., 2003; Johansson & Lundman, 2002), a few of our participants suggested that they were “seen but not heard”.

Participants revealed three types of loss: (a) They became victims of the procedure; ECT had profoundly damaged and altered their lives, (b) ECT silenced their voices; many participants had lost some of their ability to communicate about the experience (their memory of the trauma, their ability to express thoughts about the process, and their desire to talk about the process) and resultant damage; and, perhaps most unsettling, (c) in some cases, ECT erased their knowledge so that they could not acknowledge and articulate their experience. Interviewers in this study became aware that some participants had no knowledge that they had lost their ability to recount the experience. This third type of loss can be characterized as an abrupt slide into profound muteness.

The losses associated with ECT were overwhelmingly painful as the participants were aware of their losses. As a result, some participants in this study apologized

repeatedly for their inability to track the conversation or remember details, while others responded with shame about their inability to think well. Thus, by informing the patients about the procedure and its potential side-effects they could be involved in the decision-making process. This would empower them and perhaps improve the therapeutic outcomes.

Chapter 4: Perceived Benefits and Risks of ECT from Women's Perspectives

Introduction

According to the Canadian Psychiatric Association (CPA) guidelines as well as the American Psychiatric Association (APA) ECT is a safe, effective intervention for the treatment of depression (Enns, Reiss, & Chan, 2009). Despite endorsements from these associations ECT remains a controversial treatment (Challiner & Griffiths, 2000; Hilton, 2007), as conflicting perspectives exist regarding its effectiveness (Reisner, 2003; United Kingdom Advocacy Network, 1996), mechanism of action (Breggin, 1991; Fink, 2001) and possible side-effects (Breggin, 1991; Fink, 2001). NICE (2003) identified the discrepancies in the opinions of health professionals (Culas et al., 2003) and patients (Dowman et al., 2005).

ECT advocates argued that the procedure might have a positive effect on mood and provided depressed patients at risk for suicide with some relief from their symptoms (APA, 2001; Fink 2001). Previous literature suggested that ECT decreases the risk of suicide (Kellner et al., 2005). In addition, recent research found that ECT could reduce depression and improve patient quality of life (Rayner et al., 2009). Furthermore, patients had reported positive experiences including immediate improvement in mood and relief from depressive symptoms (Rose, Fleischmann, & Wykes, 2004). Patients who experienced benefits from ECT reported that the negative side-effects of ECT treatment, such as memory loss, were less significant and more manageable than the debilitating symptoms of depression (Dukakis & Tye, 2006).

Conversely, ECT opponents argued that it had no long-term beneficial effect on suicidality (Sharma, 2001) and that suicide risk was higher with ECT than with

antidepressants (Bradvik, & Berglund, 2006) and thus the perceived benefits may be associated with a placebo effect. Furthermore, the risks associated with ECT included adverse psychological effects, cognitive impairments, and social consequences (including disempowerment, see Chapter 3).

One of the most commonly reported psychological effects of ECT is fear. Quantitative survey studies indicated that 69% (Riordan, Barron, & Bowden, 1993) to 74% (Gomez, 1975) of patients experienced varying degrees of anxiety about the procedure. Fears associated with ECT may be related to short-term apprehension about the initial treatment, such as the patient's fear about receiving anesthesia (Koopowitz et al., 2003), or longer-term anxieties that may contribute to nightmares (Koopowitz et al., 2003). Long-term anxieties included fear of brain damage, personality change, and chance of not surviving the procedure (Koopowitz et al., 2003). Fears ranged in intensity. Approximately 14.3% stated ECT was more distressing than surgery (Pettinati, Tamburello, Ruetsch, & Kaplan, 1994) while almost one in four (23.7%) labelled ECT "barbaric" and "inhumane" (Kerr, McGrath, O'Kearney, & Price, 1982). Extreme terror, equated by participants with the terror of facing death, can also occur (Johnstone, 1999).

In addition, although headaches could be considered a physical side effect of ECT, they may be also a psychological consequence. Long-term headaches may be associated with the high levels of anxiety experienced by ECT patients. A quarter to one-half of ECT patients have reported experiencing headaches (Datto, 2000; Devanand, Fitzsimons, Prudic, et al., 1995).

Supporting quantitative research findings, some qualitative research has identified adverse psychological effects of ECT. Johnstone (1999), initially offered

adverse psychological experiences of ECT patients, and Koopowitz et al. (2003) more recently, agreed that the feelings of fear, shame, and betrayal were common. Other common negative psychological outcomes included lowered levels of confidence, dignity, esteem, and empowerment (UKAN, 1996). Some ECT patients have compared ECT to the trauma of rape (Johnstone, 1999), brain assault (Johnstone, 1999), or even the threat of death (Johnstone, 1999). Furthermore, long-term psychological trauma from ECT could include reoccurring nightmares (Johnstone, 1999; Koopowitz et al., 2003), distressing memories (Johnstone, 1999), as well as resultant headaches, nausea, and other physiological symptoms (Johnstone, 1999).

The potential of neurobiological damage of ECT treatment contributes to the controversy of the procedure. Some argued ECT caused no neurobiological damage (DeVand et al., 1994; Kusumakar, 2000; Weiner, 1984), while others disagreed (Ferraro, Roizen, & Helfand, 1946; Meldrum et al., 1973; Zarubenko, Yakovlev, Stepanichev, & Gulyaeva, 2005). Furthermore, some associated the neurobiological damage from ECT treatments with permanent cognitive impairments such as memory loss (Ikeji et al., 1999; MacQueen et al., 2007; Sackeim et al., 2007), while others argued that the memory loss was short-term and transient (Abrams, 2002; Fink, 2004).

While studying the nature of the memory loss, the literature discussed how ECT affects retrograde memory, memories made before treatment, anterograde memory, memories made after treatment, and autobiographical memory, memories of events from patients' personal lives. Although patients can incur acute retrograde and anterograde memory loss (Durr & Golden, 1995), all ECT patients experience retrograde amnesia to some extent (Read & Bentall, 2010), especially the loss of recent memories. Rose et al.

(2003) asserted that a quarter to one half (29-55%) of ECT patients experienced long-term memory loss. Long-term memory loss was more likely to be of public rather than personal events (Lisanby et al, 2000) and verbal or visual information than other sensory information (Feliu et al., 2008). In addition, qualitative study by Johnstone (1999) confirmed that most ECT patients have reported experiencing autobiographical memory loss. Although Sackeim et al. (2007) argued that cognitive damage is not related to the type of shock administered; Bailine et al. (2000) disagreed and stated that the type of electrical current affects the severity of the impairment. In addition Chanpattana et al. (2000) suggested that the seizure threshold increased by an average of 269% within one course of treatment, implying that more frequent ECT treatments may expose the patients to a dangerously high dose of electricity.

Patients have varied opinions about how ECT has affected their cognitive function. Almost half to three quarters (45% to 72%) of patients reported moderate to severe memory loss (Philpot et al., 2004; Rose, Fleischmann, & Wykes, 2004), and over a third (35% to 42%) asserted ECT had damaged their intelligence (Philpot et al., 2004). A United Kingdom study reported that 35% of ECT patients reported negative cognitive function (UKAN, 1996). However, Riordan et al. (1993) suggested that 53% of ECT recipients experienced positive cognitive results. Two 1993 studies merged these viewpoints by asserting that about a third (30%) found ECT helpful to their cognitive functioning, but those who did not expressed their dislike with strong language such as “brutal,” “barbaric,” or “degrading” (MIND, 1993; Rogers, Pilgrim, & Lacey, 1993). Other types of cognitive losses included the inability to follow movies, books, and conversations (Perera, Luber, Nobler, et al., 2004; Price, 1982a; Price, 1982b).

Arguments against ECT are gaining momentum and professional recognition. Literature questions the feasibility of ECT as a long-term solution (Greenhalgh, Knight, Hind, Beverley, & Walter, 2005; Painuly & Chakrabarti, 2006; Tharyan & Adams, 2005; Ukpong et al., 2002), and recommends ECT as a short-term and very limited intervention (Sackeim et al., 2001). Evidence affirmed high relapse rates of greater than 50% within six months (Kellner et al., 2006; Lisanby et al., 2008; Tew et al., 2007). Therefore, medications, counselling, and possible monthly ECTs have been recommended (Prudic, Olfson, Marcus, Fuller & Sackeim, 2004; Sackeim et al., 2001).

Considerable ethical debate exists about ECT. Some research linked the treatment with severe psychological distress (Johnstone, 1999; Koopowitz et al., 2003). Strong opponents are increasingly advocating its complete discontinuation (Bartow, 2009; 2006). Bonnie Burstow, a Canadian academic who is noted for her strong advocacy on behalf of women psychiatric patients, including ECT patients, defined ECT as violence against woman that is protected by medical hegemony (Burstow, 2009, p. 17; Burstow, 2006; Burstow & Weitz, 1998). She further interpreted ECT as a form of battery against women (Burstow, 2009) and discounted all benefits, both perceived and real, from the scope of this treatment. While outlining harms, literature points to some benefits of ECT (Fink, 2001). Only further research will reveal the full scope of women's experiences with ECT and illuminate a fuller understanding of ECT's efficacy.

Despite its wide use, patients' subjective perceptions of ECT are not very well understood. Through the use of narrative inquiry, this study aimed to examine women's recollections of perceived benefits and risks associated with ECT. Furthermore, overall attitudes towards ECT were investigated.

Methods

Design. Using narrative inquiry, the personal accounts of women who had experienced ECT were collected in this study. The technique of person-centered interviewing was chosen as it privileges each informant as the authority on her particular experience (Hollan, 2005; Levy & Hollan, 1998; Polakoff & Gregory, 2002; Tarrant & Gregory, 2003). The data shared by the informant reflected her particular reality and supplied information on her background, viewpoint, and particular experiences as understood in that time and place (Levy & Hollan, 1998).

Informants were encouraged to tell the story of their experience with ECT in any manner that felt comfortable for them. They did not need to follow a chronological order and were invited to begin with a particular scene or feeling that resonated with them or encapsulated their experience. Sharing information in this manner allowed the informants to freely assume both role of expert informant while fulfilling the role of respondent. All aspects of the storytelling were important including body language and audible features such as tone, volume, pauses, and silences (Hollan, 2005). The familiar format of a story assisted the informant in comfortably talking with, listening to, and engaging with the researcher (Hollan, 2005).

Participants. Recruitment posters advertising the study were placed at several locations in the City of Lethbridge. Through this recruitment strategy and word of mouth, nine individuals volunteered to participate in the study. Each of these persons were eligible to participate in the study as they met the following requirements: were female, spoke English, were at least 18 years of age, and self-identified as receiving at least one

ECT treatment. The participants' ages ranged from 22 to 63 and each participant reported their ECT experience in detail.

Ethical Considerations. The University of Lethbridge's Research Ethics Board (REB) granted ethical approval for this study. Participant anonymity has been protected as pseudonyms were assigned and identifying information has been excluded from the report.

Data Collection. Interviews were conducted in person or by telephone, and were digitally-recorded. Although a narrative, person-centered approach was used during the interviews, statements and probing questions were introduced as a means of encouraging participants, eliciting further details, and confirming or clarifying aspects of the data when necessary. One of the benefits of this design method was that it allowed rapport to build between the interviewer and the participant resulting in rich data collection.

Data Analysis. The data analysis technique chosen was thematic content analysis. This strategy allows the researcher to identify categories, form common themes, and recognize patterns within the textual data (Braun & Clarke, 2006). Due to the small number of participants and the researcher's desire to work closely with the data, the interviews were coded manually.

As suggested by Braun and Clarke (2006), seven steps for thematic data analysis were followed. First, the researcher transcribed the digital recordings of the interviews. Second, the researcher became familiar with the text by reading the transcripts multiple times and making notes. Third, the researcher began to form codes, identify patterns, and organize the data into meaningful categories. Fourth, the different categories were combined to form themes. Fifth, the themes were reviewed and refined in such a way that

thematic maps of the data could be formulated. Sixth, based on previous literature findings the themes were assigned names provided in the interview text. Finally, these emergent themes described and explored women's experiences of ECT and its perceived risks and benefits. It is noteworthy, that the preliminary analysis of the data was initiated following the first interview. This allowed the researcher to adjust the interview probes by adding or deleting the questions based on the information that emerged during the interviews.

Results

Using thematic analysis the interviews of women who have undergone ECT were analyzed and three themes emerged. These included the perceived benefits, perceived risks, and overall stance towards ECT.

Perceived benefits. Out of the nine interviews that were conducted only three women had relatively positive emotions towards ECT and perceived it somewhat beneficial. For example, Carla explained the way she found ECT beneficial as, "I think because of the ECT it just gets you um into a different space.... Well, it kind of feels like it lifts you out of that, that darkness, that heaviness.... I think part of it, it's just that I felt lighter, like, like better.... It's kind of like it's like yeah it's uh you just feel light, like lighter like that." She further explained her feeling after ECT, "I'd say more like after probably like after a run, or exercise.... maybe if you're running on caffeine."

However, the minority who believed ECT was beneficial, concurred that ECT had limited effect on improving their mood as Carla explained, "I was able to go back home but, I'm still, it [ECT] helped me to get out but I, it [ECT] still didn't make me like a hundred percent." Furthermore, the positive effect lasted for a limited time such that

there was a need for maintenance ECT. As Paula explained, “But, like I said having, being in the hospital here for three months when I got out instead of stopping the ECT they continued with maintenance ECT and that’s been successful for me and that’s kept me out of deep depression.” Anna confirms the need for maintenance ECT in order to have a relief from her symptoms “[the positive effect lasts] for weeks. To be honest I wish I was getting ECTs every month instead of every six weeks.”

Perceived risks. Out of the nine interviews that were conducted all women expressed some risks associated with ECT. Four sub-themes emerged with the perceived risks. These included: “Putting them in a cage with a bear.”, “I felt pressure.”, “Learn to live it all over again.”, and “[ECT] fried my brain up”.

“Putting them in a cage with a bear”. While explaining the procedure seven of the nine women expressed feelings of fear and/or embarrassment associated with the procedure. Maggie, whose mother also received ECT treatments, expressed her feelings as, “She [her mother] had ECT after I was born. So of course it was always when, when your mother was sick after Maggie was born.... You know, you uh, you are to do with this illness so I was linked to the illness from day one.... Just fear that I was gonna lose my mind and I was never gonna, you know, that was the fear...The ECT would, would destroy my, you know, my brain the way it had my mother’s.... I never know, I never saw anything about her except what was left over was uh, quite an acute amount of memory loss.”

She expanded on the nature of her fear “I had two very faithful visitors who tell me they have never seen anybody as frightened in their life before. My cousin said, he would say to me, But Maggie what are you frightened about? And I couldn’t even tell

him right?.... I went home but I do still have memory loss and I'm a bit anxious as I talk to you about it because I'm remembering. I mean what I had to tell myself after a while is that nobody tried to do me any ill you know?...With no, no harm meant, but my gosh! They couldn't have done better! I think what it was, was not particularly at the end of when I look back it wasn't just the ECT, I was terrorized you know it's like taking somebody who's afraid of a bear and putting them in a cage with a bear...The only thing that I would say here that was much different was the ECT and for me the terror around it because it is perhaps the most terrifying thing in the world." However, not only was Maggie worried about reliving her mother's life she was worried about her children. In her own words, "I was really frightened and upset, I used to insist that my son come in and be with me, I never believe children should do, you know, I'm the mother, I'm not the child right?.... My son told me this and he said, "Mom you'd be so upset." And then he's like 22 when this happened and I would never do that to him.... I know I wrote notes to ----- and ----- [her children]. To say you know, "If I die", and so on and so forth. And but, I can think of it now as a total terror of something like you say you were always afraid of." In another interview Bonnie, a woman who had seen one of her friends receiving ECT, stated, "I was scared. That I might not wake up....I lost my memory, like a gap."

Other participants expressed feelings of embarrassment. For example, turning her gaze to the ground, Rachel stated "It was pretty messed up, I mean, it's kinda embarrassing, but I lost my bladder every time I had it ... just it was like, they injected me, and I don't like being like that outta control." This feeling extended from shame to social embarrassment. As Rachel expressed, "I was pretty embarrassed and ashamed... I

felt embarrassed about having to do it. In my family, my family always told me that it's just for crazy people and my dad even looked down on me. Because of the umm, the ECT he thought it was for like crazy people." Sally Ann confirmed the existence of the same kind of social stigma.

"I felt pressure". All of the women expressed that they had experienced headaches after ECT. For example, Carla explained her headache as, "Like after I remember just having really bad headaches ... So yeah the jaw was really tight and the head." Paula confirmed a similar side-effect, "I'm finding that that anaesthetic leaves me wiped out for two days ... Like, like it's like I feel totally hung over ... Just that it's like having a really, really, really, really, really bad hangover ... It's like you have this intense tiredness.... The headaches are like no other headache that I've experiencedThey're like um just terrible pain in your whole skull."

However, perhaps the most striking of all was when Katherine expressed that she still experiences the same kind of headache after twenty years. While placing her hands on two sides of her skull and trying to indicate the location of the electrodes she explained, "I felt pressure in my head.... Pressure and that, that it down, sometimes it really bothers you.... It still goes on today. It's been about 20 years [after ECT].... It just my head hurt and that's about all I mean."

"Learn to live it all over again". All women expressed that they had experienced some degree of memory loss. More specifically they expressed autobiographical memory loss to the extent that they felt large portions of their life stories were gone. For example, Paula explained, "Well, for example my mom will talk about something that happened

two years ago. And um, it involved me and that I was actively a part of, and I have a void. I don't even remember bits and pieces of it it's, it's just like a complete void."

These stories included memory of their hospitalizations. As Paula stated, "I would have trouble remembering things that had recently happened.... Well my stays in the hospital. [I stayed] for three months here in [name of the hospital] I have very little recollection of my stay in the hospital." Anna and Maggie express similar experiences. Maggie stated, "I had three ECTs at which I have no memory, I have no memory of any of the hospitalization and I have a lot of other lost memory."

However, the memory loss was not just around the hospitalization. Eight of the participants have lost portions of their childhood memories. For example, Natalie explained, "Oh yeah tons of childhood memories are gone. Like I can't remember half of what like, half the stuff that happened when I was a kid I, don't remember.... It's sad. It makes me sad because I, I, I can't remember things that happened, when I was a kid you know? Well, I wish I could remember things that happened when I was a kid, you know? Cause most people do remember you know childhood memories and you know, places they've been and you know places that they've travelled when they were a kid. I don't." Rachel expressed similar experience, "I totally like I totally forget things, mainly, umm, things like from my childhood.... [The memory loss is] insane! All the bad memories are still there but all the good memories [are gone]"

As participants expressed their experiences with autobiographical memory loss there seemed to be a corresponding sense of losing oneself. For example, Katherine expressed how she needs to retrace her past memories, "It [ECT] did erase a lot of my past memories and stuff like that and my siblings will come up to me and go, Don't you

remember this or that? And I'll go, no. And I have no recollection of any of it. Even now, some of it's in my youth and so, I just have to go on from now cause I don't remember.... After ECT I haven't been able to remember anything about my sisters um and my grandmother or any of that stuff.... And that you would end up having to come back...Retrace your thoughts and then have to learn to live it all over again. Like most people [who have undergone ECT] do they have to retrace their memory again? And it hurts, hurts more than ever. To retrace back into their memory. And it's harder to do that when you try go back, somehow, and figure out what you've already forgotten."

Unfortunately, the memory loss was not limited to hospitalizations or childhood but expanded into important life events. For example, Maggie stated, "It's just like there's a whole block of time gone My daughter is um a voice major and she did her master's in [name of the city] ---- so in 2007 which is the year before I was treated in hospital, the year before that I went to see her at her graduation concert. I went to see her at her first opera thing that she was paid in complete, complete gone." Maggie further explained how she did not remember another event, "Well my nephew was married in [name of the city] ----- and I didn't remember it. He came to visit last year and he said, he said, Maggie, you didn't stay around very long at the wedding. And I, you know, and you can't, you run out of lies to cover up. But I didn't remember his wedding either." Natalie expressed how she felt about losing those personal memories as, "It's sad for, you know, people to have to go through ECT and you know lose things that are dear to them."

"[ECT] fried my brain up". The participants expressed other memory and cognitive problems. This included inability to perform daily activities efficiently, problems with focus and reading, and finally loss of conversational and social skills,

which could potentially result in friendship losses. Perhaps most importantly was the inability to recognize some of the previously encountered people.

When the participants were asked about the effects of ECT, Bonnie expressed, “[ECT] fried my brain up.” Perhaps less negative, but still speaking to ECT’s ineffectiveness, Sally Ann explained, “I didn’t think it was working because I still wanted to die every time. And, umm, I feel like, it kinda made me stupider, in some ways. Like I was a university student and I then had to drop out and then umm, I just feel like I woke up and I couldn’t comprehend things. So the knowledge from schooling is lost.”

Inability to read efficiently was one of the main concerns of the participants in this study. For example, Rachel explained, “I’ll read the same book three or four times just to absorb it.” Further Natalie expanded on the same complaint and stated, “Reading, I can’t read, because I’ll read like the first paragraph, don’t even remember what I watched.... It’s horrible, like I can’t, I can’t read a book anymore because, like I’ll get through the first paragraph and I can’t even remember what I just read. It’s horrible, like, how would you like it if you, if you can’t read a book? Cause I, I could read books like you wouldn’t believe. I could sit down and read 4, 5, 6 hours a day. Read a book, no problem. As soon as I had the ECT, forget it, couldn’t do it. I’d, I’d sit down, I’d start reading, I’m like, Wait a minute, where am I? Did I, oh, I think I just read that paragraph. Go back up. Did I read that paragraph? Dang it! I think I read that paragraph, oh I’ll read it again just to make sure.” Like who in their right mind would read a book like that?”

Sally Ann expressed similar problems with not being able to focus while reading or talking, “I would read something and I wouldn’t even know what I read or I talk to my mom on the phone after I hang up and umm, I don’t remember what we talked about and

things like that.” The inability to keep track of the thoughts during the conversations was also evident during the interviews. Carla confirmed this, “I do have, like right now [referring to not remembering to what she is trying to say during the interview], I can’t sometimes I can’t always keep my thoughts together.... it’s, there’s times where I really had a hard time piecing it all together...And also sometimes reading I can’t really grasp what I’m reading sometimes.” Natalie expressed a similar phenomenon and expressed frustration associated with it. In her words, “[You] can’t remember telling your husband something and then not even ten minutes later “Oh by the way Hon”, and him turn around and say, “Yeah you just told me that”. How’d you feel?” While expressing a similar experience Anna stated how the loss of effective communication skills impacts a person’s social skills “ It messes with, messes with my social skills and my, and my conversation.... But, like it, I hate it I can’t remember what I’m trying to say.... And, and I remember something I wanna say to some person but if I try and wait for them to finish talking, I forget what I’m gonna say. And it gets frustrating with the other people because um I’m interrupting them because I can’t remember what I was going to say And it might affect my social skills.”

Another major complaint was inability to remember TV programs. For example Natalie stated, “ I can watch a TV show and the next day can’t remember watching it and then I’ll watch it again and it’s like, Oh did I watch this? And my husband will say, Yes, you watched it, Hon [says my husband], Oh okay [I say], like you know I don’t remember watching a TV show for crying out loud.”

Moreover, Natalie expressed difficulty remaining focused in completing daily activities. For example, she stated, “Well, even in daily activities. I forget like, I’ll be

doing something and then, sometimes like I'll have to go to the bathroom so I'll go to the bathroom and then I'll come out and I'll start doing something else, and I'm like, Wasn't I just doing that? Oh yeah! I was just; I was over here doing this. So I'll go back doing that and then I'll get distracted and I'll go do something else and I'm like, Wasn't I just doing that? Oh yeah right, I was over here doing this. So it's like my brain doesn't, you know, I'll, I'll be doing something and then I'll get distracted and I'll go do something else and I'm like, Oh yeah I was over here doing this."

In another example she raised the difficulty of being focused while driving "Even when I'm driving like I'll, I'll be driving and I'll get to a stop sign or something and I'm stopped and I'll look to see if any other cars are coming and I'll start to go and then all of a sudden oh there's a car there! Oops! So I have to stop because it's like my brain doesn't, I don't know what it is but it's like I, I don't focus or something or it's like my brain doesn't register that there's another car there or something? So I have to stop really quick cause there's another car there it's like almost like my brain's not registering properly. I don't know what it is."

In addition, participants complained about not being able to remember the location of the places as well as items. As Natalie explained, "I'll be going somewhere it's like, Okay I gotta go here and then I'll go to turn. I'm like, Where am I going? Oh right! I'm going here." Bonnie expressed a similar experience "Ever since then [after ECT], sometimes I can't remember nothing.... Like sometimes I'll put something somewhere and I forget where I put it, or sometimes I pour myself a cup of coffee and let it sit and I forget about it...And sometimes I forget what like, like if I go to the store and I forget what I want to get and I just, come home." Another complaint was remembering

the names of the people. For example in Natalie's words "It just like with, with, with that I just have a hard time remembering people's names. You know, like somebody will say their name and within two minutes I don't remember their name."

Some participant had problems recognizing people whom they have encountered previously. For example, Maggie explained, "It's funny I ran into some of them [the people she knew] one day and cause I don't have the memory of it and I looked at them and I said I know her and she's a really nice person and I went up to her and I said, "This is a really strange thing but do I know you?" She said, "Well yes" She said, "Maggie, I was one of the nurses in hospital." Can you believe that?" Bonnie had encountered similar experience "She [her therapist] knows, like I can't remember her, I can't remember anybody after the shock treatment." However, perhaps one the most striking moments during the interview was when Bonnie stated that her brother had to remind her that he is her brother every time he calls.

Overall stance towards ECT. Four sub-themes emerged with the overall stance towards ECT. These included: "It takes you to a much more contented place", "I think it's archaic" "Do not do it", and "You can talk your issues out and not shock it away"

"It takes you to a much more contented place". Three participants expressed relatively positive experiences of ECT. For example, Anna stated, "I wanna shock, you know I need, some, to shock some sense into me when I get my treatments.... It's just like house cleaning I call it...ECT it cleans my, my stuff out.... I guess that after the ECT my mind is clear.... It's like you said I kinda look forward to it a little bit. I mean because it, it'd like it's called house cleaning to me." Paula expressed her positive stance with a different language, "It just, it takes you to a much more contented place.... I can notice

the effects sometime the same day.... The day of ECT and other times it takes me about two days to know the others, there is a, a difference in the treatment, like not every treatment is successful.... So, like my mom will ask me did you have a good treatment and that usually, I know that the day of the treatment, if I've had a good seizure like I can tell just by the mood that I'm in." She further expressed that she would recommend it to others, "Because when you're, I mean depending upon the level of your depression. But when you're in the depth, the depths of a deep depression, I think it's one of the only ways to um be brought out of that [darkness]. Despite the relatively positive experience, Carla stated that ECT did not cure her depression but rather it helped her to move on, "It's not like it's, it's a cure-all or anything but it just kinda gives you that boost to be able to, to I don't know I was gonna say move on but that's not, I don't think it made me like a hundred percent better.... But it helped me to I guess move on. It had to have been months. Because I was able to come back home.... But then I mean I'm still dealing with um depression.." Paula confirmed Carla's stance and stated that the benefits of ECT were greater than the costs. In her words, "Now I just, gotten to the point of acceptance and I just uh simply listened to her [mother] tell me about what she's [mother] talking about and I, I accept the fact that it's [memory loss] from the ECT and the ECT is more of a benefit than a hindrance."

Of the three participants who had relatively positive experiences, none would recommend ECT except in very specific circumstances. For example, Paula stated, "It's a lot of work and um it also takes two, sometimes three, days out of your week where you're just absolutely more or less incapacitated by the side-effects of ECT and the anesthetic. I would say that a person should be debilitated by their depression quite

deeply before they proceed with the ECT. Just because of the, um, the, uh, complexity of the treatment like the after effects that you experience. Like it really does take a chunk out of your week. You know where you, you basically do nothing for two sometimes three days like um the, the amount of Side-effects can outweigh the benefits if like let's say somebody's experiencing depression but it's, it's not to a real, real serious level.” Carla was even more hesitant and stated, “I would say probably this is my experience but it's not that I would recommend it for someone else. It's like everyone's experience is different and I mean it, it helped me to get [better].”

In addition, of the three participants who had relatively positive experience, all agreed that the positive effects of ECT were short-term and as Paula stated, “I found that it lasts for about two weeks. And I'm going to inquire about getting it weekly if I continue to feel the way that I've been feeling.” Therefore, patients are faced with maintenance long-term ECT, with unknown risks and/or long-term consequences. As Paula expressed, “To keep on some sort of uh sustainable level where you're not going back into depression and um in terms of how long maintenance ECT has to last I really have no idea like I think about that sometimes like, like that if I make it to be an old lady am I still gonna have to be going to the hospital every two weeks and getting maintenance ECT?”

“I think it's archaic”. The majority of the participants (six of the nine) had a very negative experience with ECT. As Maggie stated, “Oh no, I think it's archaic, I really thinks it's, if you can't, if there are so many doctors who won't do it and can find solutions for their patients, it's the quick and easy answer. And I think you know, how many people will say, no, I don't give it. But somehow or other the patients get well on

whatever combination of medications there is. And um, so no if you can't do it, you'll find something else to do." In addition, most found it ineffective, as it did not give them relief from their symptoms. For example Rachel stated, "I found that they're not working because it's like I'd wake up and my voices would be like, "Oh look, it didn't work!" It didn't really help any... Cause I still wanted to commit suicide and I still wanted, I still wanted to just kill myself."

"Do not do it". The majority of the participants (six of the nine) would not recommend it to anyone else. For example, Natalie stated, "I would say don't do it, DO NOT DO IT. I, from all the people that I have heard that have had ECTs it's been nothing but bad because I know probably about six people now that have had ECTs and they've all had negative effects. Like with memory, memory seems to be the worst. Everybody seems to have problems with their memory. So it's like, you know, don't do it, it's not worth it. It just, it's just not worth it."

In addition, the majority of the participants (six of the nine) believed that ECT should be banned. For example, Bonnie stated, "I think it should be banned. Cause, a lot of people, they're, they're losing their memory." Katherine confirmed Bonnie's statement "I think it should be banned, because it's dehumanizing." Natalie confirmed and expanded on the same stance, "I think it should be banned. Too many people have problems from it. Too, too many bad side-effects you know it's, so many people that I've known to come out with bad side-effects. Like you know, I don't know. I would like to know how many people it's actually helped. Like really truly helped you know I would like to see, cause the people I've talked to it hasn't helped. So I, I would like to see how many people it has actually helped, without, without the cons." However, perhaps the

most interesting of all was Carla's stance. Despite her relatively positive experience she still believed that it should be used with specific populations. In her words, "I could see it being banned...I yeah, I just couldn't see it being, doing it on a young person like."

"You can talk your issues out and not shock it away". All of the participants believed that they would benefit from a form of alternative medicine. For example, Carla stated, "I think the combination of alternative and prescribed.... I am taking medication. I've um also found out that I was anemic so that's been treated which helped a lot.... and just uh by exercising and trying to um I'm not working yet but uh I just started volunteering.... I do yoga I know that, dealing with like emotions like doing like emotional therapy like, like just, I don't, it's like dealing with your issues.... Well something I figured out with myself is uh I have done a lot of like emotional like release or just dealing with that part."

In addition, all of the participants believed that they found counselling helpful. As Paula stated, "By going to counselling it provides an interaction to address and um release some of these thought patterns." Natalie confirmed a similar stance, "I think counselling is good.... Well [it] lets people release you know, lets them get everything that they need to, just have somebody to listen to." Sally Ann shared the same perspective and emphasized the importance of human contact, "Someone who's in a lot of pain needs comforting and things like that... Come and talk to me more.... Talk to a therapist. It's more human contact.... And, understanding, and care and stuff like that." When comparing ECT and counselling, the majority (six of the nine) preferred counselling. For example Bonnie stated, "Talk to them [the patients] better than giving them [the patients]

the ECT.” While sharing the same stance Rachel stated, “Well you, you can talk your issues out and not shock it away.”

Discussion

Participants in this study did indicate some minimal net benefit from ECT. Only three of the nine participants interviewed had somewhat positive responses to ECT. Still their responses could not be classified as overtly positive but rather as relatively positive. These participants enjoyed the high feelings they gained from the treatments as well as the relief of allowing another person, their psychiatrist, to make a difficult decision for them.

However, confirming previous findings (Kellner et al., 2006; Lisanby et al., 2008; Sackeim et al., 2001; Tew et al., 2007) the elevated mood that these three participants experienced lasted only a short time, all stating they felt the need for maintenance ECT once the euphoria had disappeared (Prudic et al., 2004; Sackeim et al., 2001). One participant even stated she wanted to continue having ECT every week because it knocked her out, helping distract her from the challenges and struggles in her life. She stated a desire for more ECT despite the fact that she would be severely debilitated for three days afterwards. However, she admitted that she was not sure if she would want to continue receiving ECT in her old age, indicating that time and fatigue was of concern. Furthermore, two participants feared the long-term effects of maintenance ECT, especially its effects on their memory.

Supporting previous findings (Gomez, 1975; Koopowitz et al., 2003; Johnstone, 1999; Riordan, Barron, & Bowden, 1993), the majority of the participants reported negative emotional responses, including fear and embarrassment towards the procedure.

Participants expressed fear of possible negative results such as memory loss, brain damage, or even death; that is, they were worried they would not wake up. In addition, as previously reported by Johnstone (1999) another negative emotional response towards ECT was embarrassment. Two participants stated they became embarrassed because of the social stigma associated with the procedure, the resultant ostracism from their normal social circles, and perceived rejection from family members. Further, this embarrassment caused increased anxiety or even hopelessness about restoring relationships that had been lost as well as a sense of alienation from loved ones. As stated by two of the participants their relationship with their dad worsened after ECT. Another source of shame was caused by loss of bladder control during the treatment. Two participants felt embarrassment because the procedure caused them to lose bladder control. Both mentioned that if they had a choice, they would prefer a female psychiatrist.

Confirming previous findings (Datto, 2000; Devanand, Fitzsimons, Prudic, et al., 1995), all participants suffered from extremely painful headaches after the procedure. Unfortunately, one participant mentioned she still experiences headaches 20 years after cessation of ECT treatments, confirming the adverse psychological effects previously described by Johnstone, 1999. Furthermore, all participants experienced high levels of tiredness after the procedure and stated that the extreme exhaustion prevented them from resuming daily routines for at least a couple of days. This outcome is of special importance as most participants had been treated as outpatients.

In agreement with previous findings (Ikeji et al., 1999; Johnstone, 1999; MacQueen et al., 2007; Sackeim et al., 2007), all participants reported some degree of memory loss. Furthermore, confirming the previous findings (Rose et al., 2003) patients'

perceived the memory loss to be long lasting or permanent. As previously described by Johnstone, 1999, eight of the participants of this study stated they had lost childhood memories as well as other important memories such as family events, weddings, and times with loved ones. All participants indicated their greatest regret was losing autobiographical information as these memories linked them to others in their social and family networks. They often equated autobiographical memories of family events and other important personal events as intrinsic parts of their personhood; thus, some participants who have lost these memories stated they feel they have lost themselves. One participant had determined to retrace and recreate her lost memories. Despite the importance of this type of cognitive loss to ECT patients, little research has been conducted in this area.

Other cognitive impairments such as inability to focus were previously reported by Johnstone (1999). In agreement with previous findings, seven participants acknowledged cognitive impairments with the most common being the inability to maintain focus while reading or participating in a conversation. Importantly, two participants mentioned that this inability had affected their social network, since they could not keep up when talking with friends. This loss became apparent during the interviews when participants would lose track of the gist of their thoughts and had to be reminded what they had talked about, even if it were a concept mentioned only a few minutes earlier. Unfortunately, most were cognizant of their inability to maintain a conversation and expressed how discouraged and embarrassed they felt; during the interviews they apologized for this repeatedly. Moreover, the debilitating effects of memory loss from ECT became apparent when the researchers had to remind participants

of the meeting time one hour before the interview time. Despite being reminded, and writing the appointment down on their calendar, two participants forgot to attend the interview as they forgot to consult their calendar. In other words, they had forgotten that they might forget.

Asked about their overall impression of ECT treatment, the majority (six of the nine) expressed very negative perceptions towards ECT and felt it did not benefit them. In addition, as also reported by Fisher et al., (2011) two participants stated that ECT failed to prevent suicidal ideations and was actually used as a form of self-harm.

Moreover, six of the nine participants felt that the risks of ECT outweighed the benefits and that the procedure should be banned. Conversely, even the three participants who had relatively positive perceptions of ECT would only suggest ECT under extreme circumstances. For instance, one participant felt children should not receive ECT and vehemently stated, “No one should recommend it for any other person.”

All participants believed they had received ECT for a long-term, sustained problem. One participant, however, reasoned, that long-term problems should not be addressed with short-term, “quick fix” treatments such as ECT: “You cannot just shock it [her long-term condition] away.” In agreement with previous literature, (Hagen & Nixon 2011; Johnson, 1999), all participants felt that counselling helped them to resolve personal problems at a deeper level and in a more sustainable manner.

Chapter 5: Discussion

Summary of Findings

The purpose of this study was to explore women's experiences of ECT. Using narrative inquiry nine women who self-identified as having undergone ECT at least one time during their lifetime described their experience. Thematic content analysis of the qualitative interviews isolated two main themes: first, chapter 3 reported the perceived absence of power in women's experiences of ECT, (see Table 1) and secondly, chapter 4 documented the perceived benefits and risks associated ECT as expressed by the women (see Table 2).

Table 1. Identified themes from Chapter 3.

1. "I was kinda going into [it] blindsided"
 - a. "He did not say much"
 - b. "I was told it restarts your brain"
2. "It is not really your decision"
3. "It was kind of like we're cattle or something "
4. "I was desperate"
 - a. "Last chance"
 - b. "If it doesn't work it'll kill me"
5. "Trying to control my own life "

Table 2. Identified themes from Chapter 4.

1. Perceived benefits.
2. Perceived risks.
a. “Putting them in a cage with a bear”
b. “I felt pressure”
c. “Learn to live it all over again”
d. “[ECT] fried my brain up”
3. Overall stance towards ECT.
a. “It takes you to a much more contented place”
b. “I think it’s archaic”
c. “Do not do it”
d. “You can talk your issues out and not shock it away”

While analyzing the first theme of perceived power (Chapter 3), three subthemes emerged. First, the information provided impacted women’ decision-making power: the contention that the participants weren’t given enough information to develop adequate knowledge about ECT, which resulted in two things: (i) Women who were not able to understand the procedure and its ramifications and exercise their power, (ii) Women expressing having naïve and/or limited understanding about how ECT works. For instance, one participant stated that doctors just give patients a “little seizure”, something she believed occurred naturally in other people.

Second, a theme of lack of power and involvement in decision-making process emerged. Although patients may have signed an informed consent, the consent’s validity was questionable, as the women were not truly informed. Some participants stated that

they did not make the decision for their treatment but rather the healthcare providers coerced them.

Third, some of the participants were told that it was their “last chance” for recovery and it was implied they needed ECT or their lives would be ruined by the symptoms of depression or by a suicide attempt. Thus, no other treatment options (such as counselling) were offered to the participants and thus they agreed to have the treatment out of fear or desperation.

Fourth, the feeling of desperation was apparent to the extent that some participants willingly or even happily relinquished their power. For example, some participants discussed “wanting to go to sleep” and “not wanting to wake up”. This may be an indication of the system failing to promote independence and healing

Fifth, some participants (six of the nine) perceived ECT as a dehumanizing treatment. For instance, some participants described the process as “being lined up” or “being given jolts”. This aspect of the findings is of particular interest as feeling dehumanized may have an impact on the level of trust between health care professionals and the patient.

Finally, after reflecting on their ECT experiences some participants actively engaged in the act of “getting power back”. This was where participants strove to regain their power and relinquish dependence and the passive patient role. For example, one participant stated that she acquired a legal document stating that under no circumstance is she to be given ECT treatment.

While analyzing the second theme (Chapter 4) several subthemes emerged. First, a minority of participants (three of the nine) described perceived benefits of ECT. These

participants perceived ECT as relatively beneficial, providing short-term improvements in their mood. Due to the limited, short lasting effects, the participants stated a need for maintenance ECT.

Second, a majority of participants described perceived risks and negative outcomes of ECT. Several subthemes could be identified in this category. First, women expressed fear of the procedure itself. Several participants identified that they disliked “loss of control” and that they were fearful of “not waking up” and/or “being harmed during procedure”. Second, women reported experiencing debilitating Side-effects such as headaches and tiredness. Third, autobiographical memory loss was reported; where women felt large portions of their lives/stories were gone to them. Several participants stated that they have no recollection of pivotal family events and/or their childhood memories. These participants expressed a loss of self through loss of autobiographical memory. Fourth, some participants described other cognitive impairments, such as problems with focus during reading and conversation. The inability of conducting a coherent conversation was very frustrating, as it had impacted their ability to communicate and socially network.

Third, overall views and stances towards ECT were examined. A small minority had relatively positive experiences. They stated that they would only recommend ECT as a last resort and that they would warn people about memory loss. Furthermore, women described their ECT experience as not as beneficial as they expected. They expressed that the positive effects only last for 2-6 weeks, and therefore they were faced with maintenance long-term ECT. Two women raised their concerns about the unknown risks and/or long-term consequences of ECT.

Conversely, most participants expressed very negative experiences and stated that ECT did not help their mood or suicidal ideation at all, and that they are still plagued with Side-effects years later. Due to the debilitating consequences most of the participants felt it should be banned.

Limitations

This study presented three possible limitations: first, it included a small sample size of nine participants. And a larger sample size would increase reliability of the results. Second, the information collecting process was limited; researchers interviewed participants only once. The process of developing trust with each participant could have improved if the interviewers had conducted multiple interviews with each participant. Multiple interviews could have given participants greater opportunity to share their stories in fuller detail.

Third, the study was limited by gender: only women were interviewed. It would be interesting to see if the same perceptions existed among men. Fourth, this study was not ethnically diverse. Participants were derived from only a Caucasian population. Fifth, results of this study may have been limited by the distortions that each participant experienced. Some were unsure about details of the procedure, the timing of other details, and about the effects of ECT itself. However, memory loss after ECT is so commonly reported that it should be accepted as a given side effect during research in this field.

Sixth, despite the researchers' efforts to recruit participants randomly from the pool of people willing to participate, the nature of the research meant participants with a negative view of ECT were more likely to volunteer, possibly skewing the results. This meant that the views of patients with negative view of ECT may have been over

represented and the views of those with positive views of ECT might have been under-represented.

Implications

This study yielded several implications. First and most importantly, ECT patients require better information prior to the procedure. The information needs to be more understandable, more complete, and better communicated. The methods of imparting the knowledge also require improvement. Also, more sensitive feedback systems must be implemented to ascertain whether knowledge has been received and whether it can be retained and used by patients in an empowered manner. Second, implementing a more comprehensive information transfer process would guarantee a better process of obtaining informed consent (Fisher et al., 2011). The process of giving informed consent should be in such a way that the patients are aware about the side-effects prior of the treatment. Additionally, they should be assured that they could refuse the treatment at any time. Third, counselling must be incorporated within the ECT process to identify and acknowledge underlining causes of the symptoms. For example, four of the participants had experienced hardships during their lifetime: one had lost her husband to cancer after caring for him for one year, but none of her ECT charts mentioned this factor as part of her case. Another participant had lost her mother and seen her dead; again no mention of this trauma had been listed in her case report. Two had lived in foster care and one had alcoholic parents, but mention of these difficult circumstances had not been acknowledged. Perhaps more focus should be placed on the underlying causes of depression and greater attention be given to grief and losses. These examples confirm the psycho-social component of depression (Hagen & Nixon, 2011). In addition, as indicated

in the results (see chapter 4) and confirmed by previous research (Johnstone, 1999) the ECT treatment may result in autobiographical memory loss. A corresponding loss of self may occur and thus patients may benefit from counselling during and after ECT treatment.

Future Research Direction

Since all the participants had incurred memory loss, it would be interesting to conduct neuropsychological studies that would explore the malfunctions of memory and memory loss as well as the extent and types of memory loss. Another interesting endeavor would be to conduct qualitative research with the family member of patients, to investigate the perceptions of family members, not only of their loved-one's experience, but also of their own response to the member's ECT journey. This would no doubt reveal some of the problems of memory loss that this study outlined. A third study would probe interactions of the health care professionals involved with ECT patients and look at the same power dynamics explored in this paper, but from their perspectives.

Appendix A: Poster



ECT Study Participants Needed

Are you a woman who has had electroconvulsive therapy (ECT)?

Would you like to share your story?

Research participants are needed for a University of Lethbridge study on women's experience of ECT (electroconvulsive shock therapy). Participants will be asked to take part in an interview of approximately one hour, to find out how women perceive the experience of ECT. Your confidentiality and anonymity will be completely protected. A \$10 gift card to Tim Horton's will be given in appreciation of your time.

If you are interested in sharing your experiences of ECT, please contact Dr. Brad Hagen (University of Lethbridge Health Sciences Professor) or Ms. Maede Ejaredar (U of L Health Sciences Graduate Student).

CALL: (403) 329-2299 (Dr. Hagen) or (403) 394-3863 (Ms. Ejaredar)

EMAIL: brad.hagen@uleth.ca or maede.ejaredar@uleth.ca

Appendix B: Possible Probing Questions

- Please begin by telling us a bit about when you first started getting ECT.
- What was your decision-making process around having ECT? In addition, how much did you make the decision versus other people make decisions for you?
- What were you told before you had ECT?
- What were you told around how ECT actually works? (Specifically, how would shocking your brain help your depression/anxiety/etc.)
- What information weren't you told about ECT that you would've liked to have known about before having it or making the decision?
- What was the actual experience of ECT like?
- How did you feel after the ECT treatment? What benefits and/or damage/side effects do you associate with having ECT?
- Please elaborate on any memory difficulties you had that you believe might be associated with ECT?
- Some people are skeptical that ECT causes memory problems. If you do have memory problems, how do you know that they are likely due to the ECT you had?
- If someone asked you for your opinion about ECT and/or wanted your advice, what would you tell them? (For example would you recommend it -- why or why not?)
- How do you feel about the people who gave you the ECT?

- Do you think that ECT should be allowed? Why or why not
- As a woman, how do you feel about ECT?
- Do you have any other women he you know who have ECT who might be willing to speak to us? If so could you please talk with them, and see if we could contact them?

Appendix C: Demographic Information

<p>What was the age when you first received ECT and what is your approximate age now?</p>	
<p>Overall what was the approximately number of ECT treatments you received in total, and for approximately how many years?</p>	
<p>How long has it been approximately since your last ECT treatment?</p>	
<p>What was the reason you were given for needing ECT (for example, depression)?</p>	
<p>Do you happen to remember if they told you if you were receiving unilateral (electrodes only on one side) or bilateral (electrodes both sides) ECT?</p>	
<p>Could you please list any other treatment you tried for your problems or concerns (for example medications, counselling, etc.)?</p>	
<p>What was your current (and/or past) occupation? (For example homemaker, service industry, etc.)</p>	
<p>Please get the participants address -- so we can mail them the transcript (and gift card if need be)</p>	

Appendix D: Oath of Confidentiality For the Transcriber

I, _____, do affirm that I will not, directly or indirectly, disclose to any person any information or other matter that may come to me regarding the participants who are referenced in a student’s research study titled: “Women’s experiences of electro-convulsive therapy: A qualitative study.”

_____ (Printed Name)

_____ (Signature)

_____ (Date)

_____ (Name of Witness)

_____ (Signature)

_____ (Date)

Appendix E: Informed Consent Form

March 17, 2011

Dear Participant,

You are invited to participate in a research project entitled “Women’s experiences of electro-convulsive therapy: A qualitative study.” The principal researcher is Maede Ejaredar, a graduate student who is working under academic supervision of Dr. Bradley Hagen, Faculty of Health Sciences, University of Lethbridge. This research project is in partial fulfillment of the requirements for the Master of Science degree in Health Sciences at the University of Lethbridge. The intent of the study is to acquire a better understanding of women’s experiences encountering electro-convulsive therapy.

Participation will involve an interview conducted by Dr. Bradley Hagen and/or Maede Ejaredar. During the interview, you will be asked to describe your experiences with electro-convulsive therapy. The interview will last 60 to 90 minutes. You will be provided with a copy of the transcript of your interview (either through email and/or registered mail or during a second meeting). You will be asked to add, delete, change or confirm information about your experience. Also, this will be an opportunity for you to remove any information that you may feel compromises your anonymity. The in-person interviews will be held in a comfortable and quiet setting that will be mutually agreed upon. The location of the interview will ensure your privacy and confidentiality. The telephone interviews will be conducted at the telephone number provided by you. The researcher will be located the University of Lethbridge during the interview. With your

consent the researcher will digitally record and transcribe the interview that will allow for a more in-depth reading of your experience.

You are asked to freely and voluntarily consent to participate in this study. Upon agreement to participate in the interview a \$10 gift card will be given in appreciation of your time. It is your right to withdraw from the study at any time, without reason. If you feel uncomfortable sharing your personal experiences, you may choose to discontinue the interview at any time. A list of community resources and affordable counsellors will be provided to you at the end of your participation, should you feel any discomfort or distress after the interview, and you are welcome to seek support from these individuals.

Your participation will be an invaluable to this study, as you will contribute to better understanding of the experience with electro-convulsive therapy. Findings may help persons in the future by improving the quality of health care provided. Also, the findings of the study will be available to you (through email or registered) upon request.

Participation in this study will be kept confidential and your identity will remain completely anonymous. To maintain anonymity, a self-selected pseudonym will be used in place of your name. Under no circumstances will identifying information be disclosed in either the verbal or written findings of this study. The interview transcripts as well as identifying documents will be kept in a locked filing cabinet that will only be accessible to the researcher, Maede Ejaredar, and the academic supervisor, Dr. Bradley Hagen. The transcripts will be retained for five-year period after the completion of the study, at which time they will be shredded.

The results of this study will be written as a Master's Thesis and will be presented to the researcher's Committee members, colleagues, and the public. Also, the results may be published in academic journals, presented at conferences, and/or to university classes. The information provided will be kept anonymous and confidential at all times and your selected pseudonyms will be used to refer to the information.

If you have any questions with regards to this study, you may contact Maede Ejaredar, the principle researcher, at (403) 394-3863 or maede.ejaredar@uleth.ca. The inquiries may also be directed to the academic supervisor, Dr. Bradley Hagen at (403) 329-2299 or brad.hagen@uleth.ca. If you have any concerns about your treatment or rights as a research participant, you may contact the Office of Research Services at the University of Lethbridge at (403) 329-2747 or Email: research.services@uleth.ca.

Sincerely,

Maede Ejaredar, M.Sc.

M.Sc. Candidate (Health Sciences)

University of Lethbridge

Email: maede.ejaredar@uleth.ca

Phone: (403) 394-3863

Based on the information provided in the consent form (the previous three pages), I freely consent to participate in the study entitled "Women's experiences of electro-convulsive therapy: A qualitative study."

_____ (Printed Name)

_____ (Signature)

_____ (Date)

I freely consent to have my interviews digitally recorded by the interviewer.

_____ (Printed Name)

_____ (Signature)

_____ (Date)

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