

# Waiting for Oblivion: Women's Experiences with Electroshock

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**This article presents findings and analysis stemming from a two-year qualitative study that explored, in their own voices, women's lived experience of electroshock. Feminist standpoint theory frames and provides the moorings for both the validity and methodology of this woman-centered inquiry. In addition, nurses' experiences with and views of ECT are explored and compared to the experiences reported by the women recipients themselves. Vulnerability and disconnection as emergent themes are presented for the nursing profession's sober consideration. The nurses interviewed believed electroshock culminated in a net gain for patients, but for the majority of the women interviewed, electroshock resulted in damage and devastating loss. This article closes with pressing questions for nurses to ask ourselves as we enter the second decade of this new and promising millennium.**

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Oblivion: (noun) From the Latin *oblivisci*: to forget. The condition of forgetting or the state of being forgotten (Merriam Webster Online Dictionary, 2011)

Dear Cheryl,

Since our interview, I've been writing more about my "lived experience of electroshock." You asked me what I remember about that experience. I remember nothing, absolutely nothing, associated with ECT from the time I was an in-patient, but I have my charts now, after a long battle. I remember a few things

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from the time I was an outpatient getting maintenance ECT. My memories: the gurneys lined up in the hallway; a young man who had to remove his artificial arm; the same young man who had paid for someone to accompany him; the words, "They're calling for you" (that may even be from in-patient times); getting up on the gurney; my red clogs being placed under the mattress; being terrified, being terrified, being terrified, being terrified; the matter-of-fact assembly line workers; the smell of the mask; the prick and the pain of the IV needle; oblivion; . . . I feel sick. Not sure if I can write anymore about this. . .

A few days ago I accompanied an elderly (90) gentleman to (hospital X) for cataract surgery. He is bright and energetic, and several fact-takers were surprised that he was not on any pharmaceuticals. The gurneys lined up in the hallways freaked me out. Ordinarily I would have done Therapeutic Touch. Not anymore. A door was open to what appeared to be a recovery room. I saw a row of beds and people with oxygen masks. The masks frightened me. I was "back" in the torture room at (hospital Y) with a mask over my face . . . waiting for oblivion.

"Lee"

Dear Lee,

I can't even begin to thank you for all the work that went into your writings that you've sent to me over the past year or so. Just this morning, I've been trying to write my article about the women's experiences with shock that I've compiled across the province. And, there again, I found one of your many gifts. First it was your observation that post-ECT, women compensate, compensate, compensate, compensate . . . stunning revelation. But I've been struggling with a title. My working title of, "That's Not What I Needed," has never really landed strong enough for me. But there, this morning, just minutes before the 6am hour, I found it.

The description of your recent experience of taking a man to the hospital and finding yourself in the recovery room, which triggered memories back to your ordeal, there, dear Lee, fast became a way to best represent what I have been feeling and hearing from women's stories. And so, I've re-named the paper. Your observation, this visceral punch in the stomach rendered visible only through that trauma you re-experienced by being

“back in the torture room” is why I want to say a big thank you this morning.

And also a huge apology for bringing you back to this, by asking you to recount, to remember, and to tell. I’m sorry for the trauma that this has caused you. Again.

Cheryl

## HOW I BECAME INTERESTED

I remember hearing rumblings of an upcoming series of panel hearings, where individuals involved in the psychiatric system could give testimony about their experiences. And when I heard there would specifically be panels about electroshock, like many, I was surprised to hear of its currency. Upon invitation, I attended, as an RN, and bore witness to stirring first person accounts, where people, often for the first time, spoke without fear of retribution. Hands shook, voices broke, and many of the testifiers needed help to begin. Some spoke from notes, others spoke from their gut calling up images and instances which brought observers and other testifiers to tears. Some spoke with pain, others with emancipatory anger, and all of them, all of them, found community.

These hearings were historic, not because they were in Toronto or because the organizers booked City Hall as the weekend venue, but because those to whom the efforts of the psychiatric system were directed were asked to describe their experiences without any chance of judgment, interruption, devaluation, pathologization, or reprisal. Aside from preambles of self-deprecation—“I’m not a public speaker,” or “You’ll have to excuse me, I’m not very good at these sorts of things”—the testimonies of men and women who had received electroshock or were prescribed upwards of 20 to 30 medications, simultaneously or cumulatively, were un-apologetic.

While so many issues stood out for me, what most occupied my consciousness was the clear call to action for nursing. Every person who testified during those four days had many nurses with them throughout their journeys. And when it came to electroshock, it was the nurse who prepped, assessed, accompanied, monitored, and readied for discharge each and every person. Those nurses bore witness then and, by virtue of that privileged invitation to attend those hearings, so now had I.

It was this experience that compelled me to initiate this study. Aside from nursing school when I was assigned accompaniment and tongue depressor duties for an individual receiving shock in the 1980s, and another similar experience at a pediatric facility in early 2001, I have neither direct shock experience as a practitioner nor as a patient. I am an outsider. But maybe that’s a good thing, for my intent is to re-start the vibrant discourse that was once present in nursing literature.

The path is the goal. If there’s any possibility for enlightenment, it’s right now, not at some future time. Now is the time. This very moment is the perfect teacher. —Pema Chodron (2000)

The intent of this paper is to present findings stemming from a 2-year pilot study that explored, in their own voices, women’s

lived experience of electroshock. In addition, nurses’ experiences with and views of ECT are illuminated and discussed. Feminist standpoint theory frames and provides the moorings for both the validity and methodology of this inquiry. Emergent themes are identified and discussed, and this article closes with pressing questions for all of us to ask ourselves as we enter the second decade of this new millennium.

## ELECTROSHOCK

Electroshock, also known as Electroconvulsive Therapy or ECT is a psychiatric procedure that involves the passing of 100 to 190 volts of electricity through a patient’s head in order to cause a convulsion or grand mal seizure (Breggin, 1997). Electroconvulsive therapy is usually prescribed for psychiatric diagnoses of major depression, bipolar disorder, mania, and some forms of schizophrenia (Gomez, 2004). The treatment can be performed either bilaterally or unilaterally, and a debate exists among psychiatrists as to which method is preferable (Fink & Taylor, 2007; Sackeim, 2007). The voltage used to induce a seizure varies with the age and sex of the patient. Unilateral ECT requires more current than bilateral. According to Breggin (1997), for the past four decades, people receiving shock have usually been given a general anesthetic, a very powerful muscle relaxant to prevent fractures, and oxygen because the muscle relaxant renders natural breathing impossible. According to Breggin (1997) these improvements, as argued by shock proponents, raises the seizure threshold, which then requires the voltage to increase in order to cause a sufficient seizure. A typical course of ECT is 6–12 treatments, administered 2–3 times a week (Gomez, 2004). Maintenance ECT is often prescribed after the initial course of treatment to prevent a relapse of depression. While the most commonly published side effect of ECT is memory loss, many shock recipients report other debilitating effects and are calling for a full and complete ban on its use (see for example, [www.mindfreedom.org](http://www.mindfreedom.org); Breggin, 1998; Service User Research Enterprise [SURE], 2002). Of additional concern is the fact that women and the elderly, particularly elder women have been the prime recipients of electroshock. In Canada and the US, approximately 70% of shock survivors are women, 45–50% are over 60 years old, and several are 80 years and older. In fact women receive electroshock two to three more times than men. Seventy-one percent of the patients given ECT in provincial psychiatric institutions are women, and regardless of setting 75% of the total electroshock procedures was administered to women (Ministry of Health, Ontario, 2002). Many theories about how ECT works have been proposed over the years; to date, none has been conclusively proven (Challiner & Griffiths, 2000).

## GAPS IN THE NURSING LITERATURE

Which side of the ECT debate an author or a nurse finds him- or herself on is the product of many factors, including which

side of the story of ECT he or she believes; whose perspective he or she trusts; and what one has witnessed in practice. However, a significant gap exists in what information and which perspectives are being given to nurses. Very often, only the pro-ECT arguments are given, only the pro-ECT research is cited, only the pro-ECT perspectives, themes, and ethics are given a voice. Negative accounts of ECT are rarely to be found, and the official reports of survivor groups and the anti-ECT lobby are not to be found at all. Obviously, this fact has implications for any nurse who is required to participate in the use of ECT.

There are other worrisome gaps and issues in the nursing literature on electroshock worth mentioning. I recently performed a review of the nursing literature regarding electroshock (van Daalen & Gallagher, 2011), which shed light on two important gaps. First, there was a dearth of research conducted by nursing that explored the lived experience of those who have undergone electroshock. Second, a pro-ECT bias emerged in the overall analysis of the literature, with most of the sources that nurse-authors quoted being from physicians who are shock proponents or from journals dedicated to promoting ECT.

The lack of first-person survivor testimony is particularly troubling for nursing practice, since nursing is best driven by patient choice and perspective and also since patients typically disagree with psychiatrists over the benefits of shock (Rose et al., 2003). When survivor testimony has been included in nursing journals, it paints a troubling picture. In a phenomenological study that asked patients to describe in their own words how ECT impacted the quality of their life, Smith et al. (2009) found that the decision to have electroshock was the product of severe mental anguish, the belief that ECT was a last resort, and blind trust in their doctor. After receiving electroshock, the study participants experienced side effects that were more severe than they had been led to expect. Electroshock caused a loss of independence, feelings of disheartenment, and the belief that these patients had not been clearly informed of the risks before being given shock. These findings are typical of survivor testimony (van Daalen-Smith & Gallagher, 2011).

Of course, these gaps are significant for nurses. Recent literature has addressed knowledge deficits among nurses (Uko-Ekpoyong, 2007; Munday, Deans, & Little, 2003), but this has focused on the how-to role nurses play during ECT, and the elimination of prejudice against ECT. As Gass (2008) found, nurses must adopt the role of "information giver," "persuader," and "supporter" before and during ECT. "Persuasion" means both giving (approved) information about electroshock and "backing up" offers of ECT from the psychiatrist (Gass, 2008, p. 194); nurses are instrumental in "selling ECT" (Gass, 2008, p. 194). He found nurses have three strategies available to them when dealing with patients; being "engaged," (actively empathizing with the patient); being "present" (focused on the treatment process as opposed to the patient's own experience); or being

"detached" (i.e., disengaged, inert, and unresponsive to the verbal and nonverbal cues coming from the patient) (p. 199). Gass concludes that being present best allows nurses to perform their duties during ECT (being engaged makes it stressful for nurses when they are expected to coerce the patient into accepting treatment); however, his focus is on how well these relational models serve nurses, and how well they serve the electroshock process; he does not investigate the consequences for the patients themselves. Such an oversight is all too common in nursing literature.

Outside of survivor testimony, there has been little scholarly nursing attention paid to the lived experiences of survivors, both before and after their association within the psychiatric system. Few authors seem to regard the question of why patients are in distress as significant for nurses (Burke, 2003b, is a notable exception). This raises troubling implications when we consider that many patients (particularly women and the elderly) have social reasons for depression that have nothing to do with mental illness (Burke, 2003b). Most ECT studies fail to adequately track the progress of their patients once they have completed ECT (Tielkes, Comijs, Verwijk, & Stek, 2008). Taken together, these gaps may be limiting nurses' full understanding of the role electroshock will play in the lives of their patients, and in the role they will have as proponents (and purveyors) of shock.

In a recent and promising study, Smith, Vogler, Zarrouf, Sheaves, and Jesse (2009) explored and documented the struggles and ethics involved in patients' lived experience of the decision-making process and what they term the "aftermath" of this procedure. Smith et al.'s interest was in the quality of life of individuals after receiving ECT. And so an opportunity exists for all of us. Smith et al. (2009) has led the way and opened the door for further phenomenological research in nursing regarding the lived experience of those receiving electroshock. Further, a more balanced representation of electroshock's controversial nature, impact, and outcome is crucial if nursing and nurses are to be the patient advocates we are called to be.

## OVERVIEW OF THE STUDY

This article reports on a two-year study that explored seven women's lived experiences of electroshock, with an emphasis on its impact on their present health status and quality of life. Additionally, the women reflect upon the role that nursing played within their experience of receiving electroshock. Finally, the practice reflections of 15 nurses involved with ECT are explored. An in-depth review of nursing literature regarding ECT provides further evidence of the need for a study specifically exploring women's experiences. The goals of the research project included:

1. To initiate research that will empower participants to voice their experiences in a climate of safety, respect, and affirmation
2. To explore women's lived experience of ECT

3. To highlight and articulate common themes across their experiences
  4. To explore the experiences of Registered Nurses who participate in the administration of ECT
  5. To explore the perceptions of Registered Nurses regarding the use, value, and impact of ECT
  6. To promote awareness within nursing regarding women's lived experience of ECT
  7. To disseminate these findings in a peer reviewed nursing journal and in a professional nursing conference
5. What was your experience with ECT? What are your thoughts about it?
  6. What roles, if any, did nurses play in your experience with ECT?
  7. What do you want nursing to know regarding women's experiences with ECT?

## Methodology

This study was qualitative in nature: Its triangulated structure of literature review; focus groups; interviews with nurses and with seven women on a one-to-one basis, is well substantiated. The study's epistemology and methodology stem from Feminist Standpoint Theory, as outlined by Smith (1997). The standpoint in question is of women who have experienced electroshock. Feminist Standpoint Theory begins with the individuals who are living the life or phenomenon in question: In this case, women who have received electroshock. "Women's standpoint as a method commits us to beginning in the local historical actualities of one's experience, and as such makes ruling relations visible from a standpoint located in an embodied subject situated in the everyday/every night actualities of her own life" (Smith, 1997, pp. 128–129). Standpoint theory highly values lived experience and validates it as a legitimate source of knowledge. As Burstow (2006a) and Smith (1987) remind us, a researcher involved in such a style of research is not neutral but, instead, is directed by the standpoint. The testimony of the women who agreed to sit with me and tell me their story is viewed as truthful, valid, and valuable.

The constant-comparison method of qualitative data analysis was employed, whereby codes, themes, and proposed relationships between data are proposed (Lincoln & Guba, 1985). The data were divided into manageable portions called bibbits and were then coded to identify themes (Chenitz & Swanson, 1986). Periodic check-ins with the participants occurred during the process of data analysis. Rooted in the principles of feminist emancipatory research, semi-structured interviews were conducted, all of which were recorded on digital voice recorder. The women were asked to talk about their experiences with ECT, discuss what the health impact of electroshock has been on their lives, and to reflect on the role of nursing. The women were free to add anything else they wished to share. Specifically, the main question and follow up probes included:

Tell me about your experience with ECT?

1. What is life like for you now?
2. What was life like for you prior to ECT?
3. What do you know about ECT? What were you told?
4. Through what series of events did you find yourself experiencing ECT?

## Participants

The study included 7 English-speaking women and 15 registered nurses. Their lived experiences of receiving or caring for individuals receiving electroshock formed the basis for the findings, discussion, and recommendations in this qualitative study. The seven participants ranged in age from 44–65 and all but one were white. Participants were recruited through posters hung at ECT clinics, and then through word of mouth of practitioners or confirmed participants. The distributed posters were first cleared by the respective managers of ECT clinics in Ontario, Canada. News of the study spread, and participants came from two other provinces (Alberta and Saskatchewan) as well. All potential participants received a letter of information and a consent letter. Further, verbal consent was sought in addition to written consent. After informed consent was obtained, a mutually agreeable time and location was chosen for individual interviews. Focus groups with nurses were arranged by managers overseeing psychiatric nursing units, and were granted after interviewing the researcher and reviewing all letters of information and letters of consent. Many women contacted the researcher, but were worried about confidentiality. Despite having completed their electroshock, some still feared reprisal, and declined to participate. Approval for the study was obtained from the York University Research Ethics Review Panel.

## FINDINGS

### ECT Patients in this Study

It's often been said that everyone has a story. This holds true regarding the pathways that the seven women in this study took to their electroshock treatments. While two of the women interviewed for this study were in the middle of their experience with electroshock, the five remaining self-defined as "shock survivors." Five of the seven women received unilateral electroshock; one received both types, and one was the recipient of bilateral electroshock. Their stories follow.

#### Ruth

Ruth is a 47-year-old white woman living in Northern Ontario. When I met her, she was in the middle of a series of shock treatments but was unsure if she'd had four or six. Her mouth was very dry and she was quite weak. She explained that despite significant opposition by friends and family to her having electroshock, she herself agreed to it. In addition, Ruth explained that she'd had shock in the past for long-standing depression

but “became very manic” and signed herself out after five treatments. Ruth asked if I would observe her treatment the next day.

#### *Sandra*

Sandra is a 44-year-old French Canadian and Metis woman living in Northern Ontario. Like Ruth, Sandra had experienced depression since childhood and because a myriad of medication combinations didn't work, shock was suggested and agreed to “as a last resort.” She had received six treatments and stated her mood seemed to be better. She explained that she felt like she was taking a risk doing shock “because nobody knows what the end result will be. But I have suffered from depression for probably close to 30 years, so I'll try anything to feel better.”

#### *Linda*

Linda, is a 52-year-old white woman living in Southern Ontario who, as a young 28-year old mother, working two jobs at the time, was overwhelmed. She went to her family doctor explaining how she was feeling and what life was like for her. Her marriage was rocky, she was tired, and she wanted support. The doctor said she needed to be admitted “for a rest,” and within 48 hours Linda was prescribed more than eight strong drugs and within two weeks was prescribed electroshock. She was given ECT 18 times in six weeks as an inpatient. Linda explained that she was not depressed or suicidal. She was overwhelmed with a 3- and a 6-year-old and an uncertain future. She asked for help and told me “ECT? That's not what I needed.”

#### *Celeste*

Celeste is a 54-year-old white woman living in Eastern Ontario. She describes herself as disabled. Celeste described having a history of sexual abuse at the age of four and physical and mental abuse at home until she was 17. When she disclosed to a school psychologist that she was being abused at home, it was suggested that she go to the local emergency department “to be assessed.” “That started my psychiatric career,” Celeste explained. She eventually left home and was homeless, but still managed to make some of her Grade 12 classes. Celeste was prescribed countless drugs, but was promptly put in a locked psychiatric unit and was told if she didn't take the shock, she'd “never get out.” Despite refusing countless times, including in the OR, Celeste's parents consented to her receiving ECT. She called it forced torture, saying, “I had already been abused. Now one of my abusers got the right to consent to more of it.”

#### *Fran*

Fran is a 53-year-old white woman living in rural Canada, who upon consulting her family doctor for a throat infection expecting antibiotics, was prescribed Prozac. She had a fever and pain and she recalls “two tears” falling down her face. As a result of those two tears she wasn't prescribed antibiotics, but a “new drug.” For the next ten days she didn't eat or sleep and felt “just awful.” She was promptly diagnosed with bipolar

depression and was admitted for what ended up being a 14-month stay on a psychiatric unit, acquiring over 30 different DSM diagnoses and receiving 43 shock treatments. She knows this, as she obtained her chart after a lengthy battle with the hospital regarding her right to review her own medical records.

#### *Lee*

For as long as Lee, 65 years old, could remember, she had difficulty sleeping and had been prescribed Ativan. After the devastating death of her mother, her insomnia worsened and she was prescribed a myriad of “Benzos” upon which the grip of debilitating anxiety took hold. The insomnia worsened due to the anxiety caused by the medications and the starting and abrupt stopping of many of them. First diagnosed with depression and then Bipolar disorder, Lee was eventually diagnosed with a litany of other psychiatric disorders—all of which were accompanied with new medication cocktails. Lee, too, knows this from having reviewed her medical charts. She told me she “was medicated to insanity,” and was “so frenzied, I could no longer function.” Despite refusing ECT, doctors convinced her husband it was her last resort. She received 25 treatments.

#### *Cathy*

Shortly after her fortieth birthday, Cathy told her family doctor that she experienced severe depression the day before her period every month, and asked if that was normal. She was diagnosed with premenstrual dysphoric disorder. Several meds were prescribed. Her mood worsened significantly, and she was told that meds “no longer would help [her] condition.” She received 13 outpatient electroshock treatments. Subsequently, EEGs revealed and led to diagnoses of organic brain syndrome and dementia. Cathy was no longer able to work, and reported losing most of a 15–20 year period of her life.

### **First-Person Accounts from the Women in the Study**

I was 17 years old when I ran away from my middle-class home after many years of physical and psychological abuse. During an 18-year period, I was hospitalized 20 times in five different hospitals and given seven different psychiatric diagnoses. At [XXX] Psychiatric Hospital, I was forcibly electroshocked five times and tried to resist. My heart stopped on the fifth shock, and I now suffer from “permanent memory loss.”

At first, I was prescribed the antidepressant [medication X]. The drug triggered a manic episode, which lasted six to eight months, and eviction. I “crashed dramatically” and attempted suicide. I was never the same after that drug. As an outpatient at [an] Institute of Psychiatry, I was talked into and underwent 38 bilateral shock treatments in two months. The shocks caused severe memory loss and intellectual disabilities. And now, I can't recall any experiences before that time. My life as I knew it has been wiped out for me by ECT. . . . I don't know who I am.

After 14 months of being inside the psychiatric unit, I returned home to a family I had no memory of. I didn't know how to be a

mother to my young sons or a wife for my husband. I had to learn my name, how to speak, do up buttons, brush my teeth, and so on. I didn't even recognize my own parents, sisters, and brothers. My social work career and law aspirations vanished.

Psychiatric treatment has taken a tremendous toll on my life. I would very much like to put the entire experience of being locked up and drugged and shocked behind me and move forward with my life, but it's been 14 years, and so far I haven't been able to. ECT destroyed brain cells filled with memory. During my first ECT seizure my kneecap dislocated. The needle which held the muscle relaxant drug "slipped" out of my arm. The kneecap was surgically removed. One of my heart valves was permanently damaged and a recent head CT scan revealed irregularities.

### Life Now for Women in the Study

I don't know whether it's worse not to have had a life because you had ECT, or to have had a life and not remember it because you had ECT. (Cathy)

Whether the women were currently receiving shock or had it in the past dictated how they were doing. In the present, two of the women were in the midst of their ECT series and described life as "on hold" and "hopeful." One woman spoke of the anxiety and discomfort on the day of her treatments and mentioned the judgment she was enduring from her family members, friends, and family doctor. Both of these women explained being desperate and deciding to put their trust in their doctor, their nurses, and the system. One of the women (Sandra) explained that she gets flashbacks following the ECT.

After I go home after the ECT, I'm wiped out. Through the days to follow I have weird flashbacks of memory things: memories from the morning of my ECT to my childhood. It's very strange. It's very real like it's happening right then. But, it's disturbing because I can't hold on to the memory. It kind of floats by.

Ruth explained feeling lighter for a while: "For a few weeks I feel lighter. I feel like I have nothing to worry about."

The remaining women interviewed were post-ECT and were all experiencing what they described as debilitating side effects. Celeste explained that severe memory problems prevent her from holding down a job. She's been diagnosed as learning disabled and has not been able to complete any attempts at schooling.

I am poor and I live on a disability pension. ECT and all the drugs have cheated me of a life. You can't get a good job without a good education. You can't learn [or work] if you can't remember. I might live in sheer poverty but that doesn't stop me from being honest and vocal about ECT.

Linda explains that she feels as though a part of her has been taken away. She doesn't really know who she is, but keeps trying to put one foot in front of another. Her daughter reminds her of who she is, and helps her to press on.

The deep emotions that were a part of me have disappeared. Lost somewhere. My life is as if I'm looking through a window watching the activity going on inside and trying to be a part of that, but never being able to truly connect. My life now? I'm going through the motions.

Lee echoes Linda, stating that her "life is that of joyless striving. . . . I compensate. I compensate. I compensate. I compensate. I compensate." Lee goes on to say:

What is life like for me right now? Right now I'm sitting at my desk and both legs are trembling. My big toe is twitching. It's been twitching ever since. I have a low-grade headache most of the time. I sleep 4 1/2 to 5 hours a night. It is not enough. I have had several dental problems, cracked fillings, chips off tooth corners. Coincidental? Most of my old friends are gone. I feel betrayed. They disappeared when they saw me trembling and spasming and muttering after 25 shock treatments. I am overwhelmed. I work non-stop. I don't want to think. I am not living. I am enduring. I have a life of joyless striving.

Other common descriptions of what these women's lives are like now included complaints of constant headaches, body complaints, memory problems, problems with coordination, difficulty thinking and processing information, weight gain, sleep disturbance, unemployment, loss of family, loss of friends, and loss of self. Fran's response to this question put a different spin on things. Although stating that she "lost everything," she also says ECT gave her a unique opportunity. She tells me she's an optimist.

In the process of ECT, I lost everything. I was therefore forced to create/invent a new life. It still boggles my mind some days to know that this memory loss occurred as a result of brain damage purposely done by doctors in the name of helping me. I lost my memory of my family, lost my career, and lost a kneecap. But I got to decide on my values, morals, rather than inherit them.

### Life Before ECT for Women in the Study

After all I've read, after all I've heard, and after all my careful preparations, that I, a highly reflective nurse and researcher still asked these women to remember what their life was like before shock treatment is incomprehensible. How could I ask this question, knowing that memory loss is the key adverse effect of shock? Even though I wanted to know what led up to their experience of electroshock, I knew better than that. And reading and listening to their answers drove home this key learning moment.

I can't speak a whole bunch about this since I don't remember. My life sounds, by all accounts, to have been going quite well. I was a social worker. I had good health and a really good brain. (Fran)

I don't remember much. ECT erased 20 years or more of my life. I do have journals though. I have a box of cards and thank you notes. I try, but I just can't recreate who I am. I just don't know. I was and am married. I have photographs. (Lee)

### **“Don’t Worry”: What the Women were Told about ECT**

They told me it would cure my depression. No one cared why I was depressed. (Celeste)

Every health care professional associated with psychiatry with whom the women were involved either believed that ECT was a good thing, a necessary thing, or didn’t acknowledge if they didn’t. All agreed, except for some of the ward nurses. Lee recalls some of the psych unit nurses “being horrified at what I was having to endure.” Some of the women explained that they became so incapacitated by the drugs given to them upon admission and throughout their hospitalization, that they were no longer able to adequately comprehend anything explained to them. Lee’s husband was told that ECT was the “only solution.” Most of the women asked no questions when told they needed ECT; they “put their trust in the doctor.” Most also explained being in no state to be able to ask questions or argue. The common thing all the women were told about ECT was that their individual situation was what warranted it, that they needed it if they ever hoped to be better, and that medications “don’t seem to work for them.” They all were convinced that if the medications had worked on them, then they’d not need ECT. Some internalized this as a further signal that something was wrong with them.

The two women who were in the middle of their ECT series at the time of their interviews, explained being shown a patient information video on electroshock. It was produced, funded, and distributed by the manufacturer of the shock machines being used in that particular hospital. As well, they remember being told that people with a similar diagnosis and similar system responded well to ECT. One woman stated that she was told, “I was a good candidate and that it would only augment the antidepressants that I was on.” Some participants were told the “theories about it and that there might be some short-term memory loss which would come back.” Two other women, when asked what they were told about ECT, couldn’t remember. I asked Ruth if she was aware of any risks associated with ECT and she replied, “I really don’t know.”

I reluctantly agreed to this procedure being ignorant about the risks and it is something that I have consciously chosen to do. To not think about what I don’t know. (Ruth)

Celeste was told that she had to have ECT, and was told: “Celeste, you are getting depressed and the pills aren’t working so I am going to give you ECT.” She remembers asking her psychiatrist what it was and was told what would happen procedurally:

I was distraught to hear what Dr. [X] had just told me. To put electricity through my brain, I thought would be like frying an egg, and that would damage my brain. I was only 17 years old, but somehow I was bright enough to know that you don’t fool around with Mother Nature, especially a complicated organ like the brain.

Celeste explained that she was told it was safe and was told that any memory loss would be only short-term. “Don’t worry,” she

was told. All seven women recall their families also being told not to worry.

My husband believed what they told him—that ECT was the last resort, that there would only be some minimal and temporary memory loss. Nothing else. It was a soft sell. But they lied. They lied by omission. (Lee)

### **The Women’s Experience with ECT**

These treatments were handled like an assembly line, with a row of gurneys ready in the hallway. I shook from terror as I looked at the matter-of-fact faces above me. I thought I was going to die. Then, as the anesthetic hit—merciful oblivion. (Lee)

By far, asking the women about their actual experience with ECT, was the most difficult question. Some knew they had forgotten pieces of this time period and that this (in certain eyes) diminished their validity as historians. But what they were able to recount was difficult to tell and difficult to hear. Three of the women successfully fought to get access to their full medical records. I’ll never forget the day one of the women read to me from her chart and sobbed at the barrage of negative notations branding her as “non-compliant,” “hysterical,” or “attention seeking,” among other, more harsh, notations.

One woman described how she experienced a dislocation of her kneecap during one of her ECT seizures and that she was told that the needle that held the muscle relaxant “slipped out of my arm.” She explained that as a result of the kneecap injury and lack of repair, she continues to have debilitating pain and mobility problems to this day. One of the women who was in the middle of her ECT series described being hopeful. She wasn’t, however, able to tell me how many treatments she’d had.

I’m becoming very aware of how ignorant I am on the whole subject. I know it works. I feel more positive for a few weeks. Then I come and get “topped up.” (Ruth)

For the women in the midst of treatment, their experience was one of hopeful desperation—of blind, yet powerful, trust and faith in systems that promised to help. Their nurses were their supports and their doctors their partners in health. But for the women whose experiences were in the not-so-distant past, their reflections were peppered with distrust, dissatisfaction, coercion, denial of voice, and of un-met needs. They felt damaged by the experience and said they were worse off for having had shock.

They man-handled me, grabbed me, and forced me into the ECT room. The room was small, white, and there was a metal box with wires hanging out of it. There was a rubber head strap and a needle. I yelled, fought, and pleaded for help. No one came to my rescue. (Celeste)

One woman likened the experience to that of “an assembly line” where things would go more smoothly if she was quiet, didn’t resist, and just “surrendered.” The women felt that if they wanted to get better or get out of a given psychiatric facility, then they were to accept the ECT. Fran pleaded with her physician

to stop because the “shock was making me forget everything and everybody I was supposed to know.” According to Fran, her doctor responded, “What difference does it make?”

I remember being in that room. They put me on my back, put a rubber thing around my head. In the hall and in the room, I told everyone: “I don’t want this.” The machine was on my left. And then straps on my arms and then a needle. I remember the look of the electrodes. They zapped my brain without my consent. And on my fifth time my heart stopped. My dad was told and that is the only reason I didn’t have to undergo any more. (Celeste)

The gurneys lined up in the hallway; a young man who had to remove his artificial arm but had no one to give it to. I remember the words, “They’re calling for you,” . . . getting up on the gurney; my red clogs being placed under the mattress; being terrified, being terrified, being terrified; the matter-of-fact assembly line workers; the smell of the mask; the prick of the needle; . . . waking up with blood in my mouth unable to care for myself for a full day, at least. (Lee)

### Far Away Eyes: The Role of Nursing as Seen by the Women in the Study

In recognition of nursing’s consistent presence in all aspects of the ECT experience, it was important to invite the women to reflect upon the role nursing played. I met several nurses during the two years I spent researching women’s lived experiences of electroshock. And while those findings are discussed a bit later in this article, I will say that, in general, their dedication to the well-being and recovery of patients in their care was palpable. Although some nurses were not able to explain how ECT worked, “just that it did,” others were more closely affiliated with ECT through community-based outpatient clinics and were pleased to discuss their training and knowledge in the area. When I left those nurses, so moved by their exemplary professionalism and deep dedication to quality of life for their patients, I knew what I’ve always known: No nurse wants to participate in any procedure that is harmful in any way. I knew that what was central to their practice was congruent with what the women themselves had been telling me: safety, efficacy, dignity, quality of life, wholeness. And so I asked the women in the study about the role nurses played in their experience of ECT.

The two women currently receiving ECT as outpatients, experienced their nurses as key supports and educators: “They answer my questions, reassure me, and explain what will happen on the day of my treatment.” Both women stated that the nurses in the hospital monitored their physical status, and their outpatient nurses were there as well.

Fran’s experience with nurses was different and quite negative. She didn’t feel any degree of support from them and explained circumstances where she asked for Tylenol after ECT and was yelled at for “asking for attention” and “focusing on yourself and your symptoms.” She remembers that it was nurses who would “punish” her, and “take away privileges” like cigarettes, using the phone, walking outside, or getting out of

her hospital gown. Celeste remembers the nurses “threatening” her that if she didn’t take her medicine or take her shock treatment, that they’d “have to tell the psychiatrist” and she’d “never get out of here.” She added, “They’d say, ‘If you don’t take your medications, Celeste, we’ll have to give you a needle.’”

Celeste, Fran, and Lee recalled many of the hospital nurses as being detached, cold, distant, and almost, at times, seemingly less than apathetic. Lee remembers looking at her nurses, whose faces were “matter of fact,” and noticing that they would look away from the gurney “with far away eyes.” In Fran’s words, “The nurses were there, but not really. Very cold, cold stares, just doing their job and listening to the psychiatrist’s instructions.”

Many of the women commented on being treated with little respect by nurses on the inpatient unit:

I didn’t like the nurses talking to me like I was an idiot . . . as if I was below them, or that I was mentally retarded. And even if I was, I’m sure I wouldn’t have liked it still. They were disrespectful always. (Celeste)

Some of the women commented on the little power nursing seemed to have in the hospital and wondered if nursing could really change the way things were. One example of this is Fran, who said, “To the psychiatrists, they were just women, just like me. What could they do, really?” Celeste, likewise made this point:

Some of them would listen to me but in that oppressive system, there wasn’t much that they could do. They had to give me the pills that the doctor prescribed. They had to tell me to take them. I bet they had to force me into the shock room, too. It was their job, you know?

Fran remembers some of her nurses, during her long hospitalization, being concerned about the impact of the medication she was taking, the hospitalization, and the electroshock.

There were nurses who were horrified at what was happening to me. . . . the deterioration of my health, personality, life. I’ve been told that two nurses quit during or shortly after my experience because they could no longer stand by. (Fran)

### Loss: The Impact of ECT on the Women in the Study

I miss the person that got away from me. (Linda)

The two women, Ruth and Sandra, currently receiving ECT remained hopeful that their years of depression where “medication didn’t help,” or “made me feel far worse,” would be lifted. Indeed they both felt different for a few weeks after their procedure: “lighter,” and “more like me,” although “numb” and “forgetful” were also included as descriptors. Ruth and Sandra couldn’t describe anything more than this, considering where they were in their particular journey.

The women who were post-ECT unanimously felt that the impact of ECT on their cognitive abilities was devastating. This



TABLE 1  
Reported Impacts of Electroshock

Diffuse encephalopathy	Forgetfulness (safety risk)
Dementia	Erased education
Limbic involvement	Loss of friends
Confusion	Unemployed/unemployable
Disorientation	Unable to complete tasks
Decreased emotion	Unable to complete schooling/courses
Changed personality	Low attention span
Don't recognize people who know them	Get lost in house/neighborhood/plaza
Significant short-term memory loss	Apathy
Weight gain	Flashbacks
Poor coordination	Embarrassment
Unable to manage household tasks	Labeled
Unable to schedule things	Stigmatized
Unable to remember or keep appointments	Learning disability
Disorganization in life and surroundings	Poverty/living on disability
Living in fear it will happen again	Loss of imagination
Stunted creativity	Numbing of emotions
Back problems	Shyness
Joint problems	Forgets things from one day to the next
Forced to re-learn how to dress, brush teeth	Amnesia
Barely know children/husband/family	Memory disability
Not believed/seen as credible	Can't think the way I used to
Written off/categorized/demoralized	Forget what read almost immediately
Feeling paranoid	Headaches
Cracked teeth/dental problems	Tremors
Constantly shaky	Nightmares
Not feeling grounded	Hands/feet tingle
Arrhythmias	Leg tremors/twitches
Guilt for impact on family	Constantly lose track of what I'm doing
Embittered	Loss of self-confidence
Anxious	Loss of self
In a stupor/fog	

was true regardless of whether their ECT was bilateral, unilateral, or in the 1970s, 1980s, 1990s or in the 2000s. The impact was physical, emotional, mental, spiritual, social, and financial. To date, the women reported that the changes have been permanent. The effects they report are listed in Table 1.

While thinking about the women's narratives, I began to wonder if there was a flaw in my research. I had been asking women to recall a story—to tell or talk about context that has, in part, been erased. The women struggled to piece together a cohesive memory, and, at times, had to start over, or ask me if they had told me about situation X or Y. Because of this struggle, many would (re)label the women as inconsistent, unreliable, or poor historians. And truth be told, it is this that actually illuminates the most glaring finding. For the post-treatment women, ECT eroded their previous ability to describe, recount, or explain situations or stories in a tightly woven fashion. Instead their

descriptions were choppy, periodically out of order, and occasionally repetitive. Because of this, they have lost their ability to be heard, believed, and trusted. They have lost credibility, not only with doctors and others with greater social power, but also with themselves. This may be the most devastating side effect of all.

### The Nurses in this Study

As mentioned earlier, at every step, a nurse is involved and present in the experience of any person receiving electroshock. And while this isn't specific to ECT, given the controversy surrounding ECT's efficacy and ethics, it's important to understand nursing's roles and lens. A total of 15 nurses were interviewed, four on a one-on-one basis, and the remaining nurses participated in focus groups consisting of five to six psychiatric unit

nurses. One nurse interviewed was a perioperative nurse, admitting and overseeing the care of persons receiving ECT, two were outpatient ECT clinic nurses, and one was a general psychiatric unit nurse. All were practicing in Canada. I invited the nurses to explain and articulate their role in the delivery of ECT, to discuss their experiences with that role(s), reflect upon and discuss women's experiences with ECT, and discuss their views regarding ECT as a treatment modality. All nurses were given a letter of information regarding the study, and all signed an informed consent letter. Names, when used, have been changed to ensure anonymity.

### Roles of the Nurses in this Study

A big part of a nurse's role when it comes to ECT is education: Education of the general public, the patient, her family, her GP, students—pretty much everybody not directly involved with it on a daily basis. (Nurse Sidney)

In general, the nurses concerned themselves with the physical monitoring of women receiving electroshock, be that just before, during, or upon returning to the ward, “completing the checklists as we would any surgical patient.” Comfort measures were mentioned as well as ensuring patients understood “what they were here for,” or “what had just happened to them.”

Participating in the administration of ECT to women for me meant more hand-holding, more client tears. I always found myself double-checking the consent forms and eliciting verbal acknowledgement from the client about what was about to happen to them. (Nurse Paula)

The nurses described multiple scenarios, each involving nursing's presence, including “we accompanied the patient,” or “we received them from the OR.” As well, all of the nurses in the two focus groups commented on their role in supporting “the plan of care,” and if that included ECT, then their role was to “support the psychiatrist's decision” and make sure the patient was “up and ready” on treatment morning. They agreed that there were many times that patients didn't want to go to ECT, but explained this as a “part of the patient's depression.”

Upon invitation to expand, the nurses began to discuss their role in advocacy, consent, and quality of life. Nurse Sonia indicated that a nurse's role was to “comfort the patient with medication for their headache and supporting their anxieties and fears.” Some of the nurses commented on their need to advocate for the dignified treatment of “their” patients. Other nurses focused on their role in education, and for some, participating in the informed consent process. Nurse Sidney stated that their “health teaching” was done so that the patient could decide if ECT was for them, stating “we don't try to push it on them,” and that after the health-teaching, patients could either consent or refuse. Nurse Eva also stressed that her role was as an educator, focusing on GPs/physicians not associated with the ECT program.

I have had a huge struggle in this community. When I was first doing my job to educate the GPs here, even though there's a huge psychiatric institute in our own backyard. (Nurse Eva)

### Nurses' Reflections on Women Receiving ECT

There was no difference between the service for men or women that I was aware of, but mostly women, in my experience, were offered ECT. (Nurse Sonia)

When I asked about women's experience of ECT, most of the nurses interviewed couldn't decipher or discuss any specifics. Nurse Paula noticed her female patients said thank you more often and remembered there being “many women.” She remembers her women patients “seeming more vulnerable than male patients” and that she spent more time reassuring them that all of her pre- and post-assessments were routine and not because there was anything individually wrong with the patient or her situation.

I remember a few clients stating that “they would try anything,” and that “the doctor thinks this is best.” I just remember the women always seeming so very vulnerable. (Nurse Paula)

Nurse Sonia explained that she couldn't contrast her experiences between women and men, their experiences, or the care provided. She, like others, noticed that mostly women were given ECT. Nurse Eva reflected on her experience, noting that women who are depressed “have huge anger issues,” and that they often come to ECT “out of desperation. Very desperate. It's a very very sad thing. We're their ray of hope so it's very challenging.” She also discussed peri-menopause, postpartum, and many issues of transition for young women. She stated “some of mental illness is driven by situations as far as I'm concerned, or biological/hormonal changes. Many of the women are usually carrying a lot of baggage.” One of the nurses commented on the prevalence of elder women, stating their depression often has to do with multiple losses.

### Nurses' Knowledge of ECT

Findings in this area ranged from nurses with just cursory knowledge to nurses who had specific knowledge and could quote medical studies. For the ward nurses, their knowledge was “that it works. We've seen it. They come on depressed and unable to care for themselves, and leave up, dressed, and sometimes thanking us for giving their life back.” Most stated that ECT was for patients with severe depression for whom medications don't work. Nurse Sonia stated “I understand ECT as a last-resort measure. The concept behind ECT, only a theory, is that the electrical stimulation from the introduction of electrical current to the brain changes the brain chemistry and sort of gets the brain from spinning its wheels to get out of the rut of depression, or whatever the treatment is being administered for.” While the ward nurses were not familiar with any literature regarding

ECT, the ECT clinic nurses were. One of them produced a box of articles she'd collected from leading psychiatrists all over the world. She told me there weren't any nursing articles in that box, nor articles from ex-patients "that she was aware of." Only two of the nurses interviewed were aware of the case being made regarding ECT's potential devastating side effects or the presence of a growing global movement aimed to end electroshock.

### Nurses' Experiences and Views Regarding Electroshock

I think for me, the jury is still out regarding the use, value, and impact of ECT as a treatment. (Nurse Sonia)

Some of the nurses interviewed shared reservations they've had regarding the efficacy or the ethics of the ECT experience. Issues around informed consent, unintended coercion, and un-proven theories regarding the neuro-mechanisms of electroshock underpinned much of the discussion in one-to-one interviews or in subsequent e-mail correspondence initiated by the nurses themselves. This did not occur in the two focus groups. Some nurses discussed how many of their colleagues didn't want ECT duties on a given shift, and that switching shifts frequently occurred with others who "didn't mind." There was discussion, particularly in the focus groups, regarding the strong views of some nurses regarding ECT, and some of the nurses expressed frustration with peers who "were against it." Despite seeing patients become "more animated and interactive," some of the nurses expressed lingering doubts about ECT and wondered if there was another way. When asked if ECT was risky, one nurse in a focus group answered, "These days, crash carts are always available with a defibrillator and oxygen ready." In one-to-one interviews, discussion occurred regarding humiliation and shame.

What I do believe I understand is the humiliation of having to have the treatment. I really wonder why people consent to such a severe procedure. But then again, I believe consent is made in a place of shame. Even after they are given all (?) the information, it's still a place of shame—shame and desperation. (Nurse Sonia)

I'm aware of controversies surrounding ECT such as irreparable memory loss, long-term value and, still, questions about how it really works. I was always concerned about the consent issues. Although the clients had written consents on their charts (by themselves or a substitute decision-maker), I always wondered about unintended coercion. Clients in such a disadvantaged position, i.e., "You won't be able to go home unless you get better." I always wondered, is that really full consent? (Nurse Paula)

When discussions ensued regarding consent and patient dignity, advocacy was mentioned. But some of the nurses, like Nurse Gail, wondered what, if anything, nurses could really do if they did had concerns.

What can you do about it as a staff nurse, when all the paperwork lines up and clients verbally agree? (Nurse Gail)

### Nurses' Perceptions of Patients' Changed Lives

I see results. We've picked them up. They're broken, and we can fix them. We can put them back in the community—back into their lives and they can continue. We give them their life back. (Nurse Eva)

All the nurses interviewed stated seeing improvements in mood and ability to perform Activities of Daily Living shortly after electroshock. The ECT clinic nurses stated and described scenarios where they felt "they had changed lives," and "gave people their lives back." It was evident that these nurses were deeply impassioned about the work they were doing, and took pride and comfort in their ongoing training to ensure the procedure was safe and given to only the right people in the right situations. I was truly humbled to spend time with them, to listen to their stories and to hear how important the quality of life was for their patients. They were sure that the work they were doing was beneficent, and for the most part believed strongly in ECT's efficacy and ethics.

I don't find it stressful at all going to work. When I go to work I don't have these deep-seated feelings that I'm doing anyone any harm. I know there is the possibility of the short-term memory loss and the muscle pain and the other stuff. I feel it's a safe treatment. (Nurse Sidney)

We are going to make them better. They're going to improve. Their quality of life, these gals, is going to improve hugely. It's not the be all and end all. It's not a cure. Meds are going to have to be put into place afterwards. Interventions are going to have to be put into place, like psychotherapy, because once they get better they often want to deal with all that they have been carrying. It's been sucking them dry. (Nurse Eva)

None of the 15 nurses interviewed had any knowledge regarding the status of any individuals after discharge, unless they were re-hospitalized or returned for "maintenance" ECT.

## DISCUSSION

Three themes emerged from the results of this study: vulnerability of the women recipients of electroshock, a sentiment of "That's not what I needed," and a disconnect between the women participants' experiences and nursing's general viewpoint and lens regarding electroshock.

### A Spectrum of Vulnerability: Desperation, Shame, Powerlessness, Misinformation, Fear

Vulnerability is, for some, a human trait and, for others, a state of being created by persons in positions of power. It is derived from the Latin words "vulnus" meaning "wound" and "vulnerare," meaning "to wound." Daniel (1998) argues that vulnerability is inherent and sees it as an opportunity to engage in what she calls authentic nursing. Watson (1988) tells us, "We learn from one another how to be human by identifying ourselves with others or finding their dilemmas in ourselves" (p. 59).

Vulnerability is also about susceptibility, about inequity in agency and, by default, about denied or dismissed voice. The women who experienced electroshock were vulnerable in numerous ways. The inherent power imbalance between patient and provider has a long history of scholarly commentary (as does the relationship between nursing and medicine). The same can be said about the vulnerability of patients labeled psychiatric (Reaume, 2006). As Burstow (2006a, b) astutely points out, the fact that approximately seventy percent of people who are prescribed and receive electroshock, with over half of all people administered ECT being over sixty years of age, and given the disproportionate damage being done to the brains of women and the elderly. In fact, Sackeims et al.'s study (2007) confirms that women and the elderly are more damaged by shock. And so, vulnerability becomes all the more urgent. But does the uncertainty stemming from the presence of unproven theories to explain how electroshock works place women's brains and lives at risk (Challiner & Griffiths, 2000)? Is the practice of "maintenance ECT" perhaps a symptom of its inadequacy or failure as a beneficent treatment?

For the women whose stories provide the backdrop to this discussion, their journey involved an acceptance of their own pathology and this, in turn, they say, contributed to their belief that a "last resort treatment" was needed. Desperation was key for the women and all put their faith and trust (sometimes blindly) in their doctors, hoping that they'd be helped. Smith et al. (2009) also discovered this finding in her team's research. The finding that all of the women interviewed were told "for them, medications just don't work" is salient. The underlying presumed truth is that it is "them" that is different, atypical, and so it is "them" that is creating the need for the last resort procedure. There wasn't any investigation into the psychiatric medications themselves, of their potency or of their possible role in contributing to the diagnosis of ECT-warranting mental illness.

Background vulnerabilities, such as contributing factors to their depression were not attended to by any of the health care providers, according to the women's reports. None of the women discussed any interest or attention on the part of their health care providers as to why the woman was depressed. Their depression was viewed as a syndrome, and one that needed to be chemically or electrically ameliorated, leaving the possible source of their sadness or insomnia unattended, and those vulnerabilities unchecked. The women felt vulnerable before, in the midst of and after seeking and/or receiving ECT. This coincides with a recent study out of Vancouver. Alison Orr (2005), a social worker in Vancouver, Canada interviewed older women who had received electroshock. Her key finding, underpinning all of the women's stories, was a loss of all forms of power as a direct outcome of having had shock. Orr called for a complete revisit of the process of informed consent and invited further study into the lived experience of electroshock recipients, particularly women, citing their particular vulnerability both to and during this treatment.

Also contributing to the women's vulnerability was fear. The women described having a fear of their illness; the procedure; their new life; the mental health system; of not getting out; of losing privileges; of upsetting family members or the medical team; of speaking up; of getting worse; and a fear of what others would think of them. These fears further contributed to and reinforced these women's vulnerable state. But the most critical component related to vulnerability that demands our attention stems from the women's lived experience of the process of consent. None of the women interviewed were aware of any of the side effects listed in Table 1, and the women in mid-therapy were told only of short-term cognitive impacts that would subside. Two of the women admitted to "ignorance" about ECT, yet were scheduled to receive the treatment the next day. They hoped it would help and they trusted the team to help them. All of the women described being prescribed powerful psychiatric drugs and it was these drugs, in fact, that most of the women believed had rendered them incapacitated. To be found incapable has serious implications, and to dispense medications that contribute to it is of the utmost importance to nursing. Misinformation creates further vulnerability and erodes the informed consent process. Further, that some of the women refused ECT but were overruled exemplifies further flaws in the consent process associated with electroshock. Smith et al. (2009) found that the participants interviewed in her study felt that they were given incomplete information regarding ECT. She argues for revisions in the informed consent process for both patients and family members, demanding that they receive all the information about the associated risks.

The fact that the majority of the women interviewed for this study did not freely consent is alarming. Often, their health care team pursued and relied upon third-party consent by husbands, children, or parents. Many a bewildered husband or family member were convinced of the "last-chanceness" of their loved one's situation that would necessitate ECT, leaving some, like Lee's husband and Linda's daughter with devastating guilt. Any consent process rooted in disorientation, dismissal of voiced concerns, misinformation, or desperation requires rigorous review. Additionally, if an encounter with the psychiatric process exacerbates a patient's guilt, internalized pathologization, or vulnerability, this also demands evaluation and reflection.

### **That's Not What I Needed: The Women's Perspective**

The last time I looked, I was 40. Now I'm 65, and the past 25 years are missing. (Lee)

I was an abused girl who just needed to be heard. To be believed. To be validated. I just needed a good meal, love, caring friends, somewhere to go where they knew my name, like a supportive drop-in and someone to wrap their arms around me and listen. But all those drugs and then lectroshock? That's not what I needed. (Celeste)

The women interviewed for this study had hope, faith, and trust in the promise of being helped. Their lives were figuratively and literally placed in our collective hands. But upon inquiry,

for the women who were post-ECT, their conclusion was that electroshock was not what they needed. Fear, humiliation, and trauma were a part of their experience. Linda wept while describing the procedure as, “an assault on [my] mind, body, spirit.” Lee wished for merciful oblivion to have at least a temporary reprieve from what was happening to her on the psychiatric ward, with ECT three times a week and the medications she was constantly required to take. Smith et al. (2009) also reported that her participants felt ECT was not what they needed: “Disheartened feelings emerged when people felt their lives were made worse or ruined by ECT. Many of the participants felt that their quality of life was significantly reduced” (Smith et al., 2009, p. 558).

The women described their experience as fraught with powerlessness and one where they had no control. Their experience resulted in loss and damage with the underlying issues (if there were any) being ignored. Linda asked for help to deal with multiple stressors; Lee came for help with chronic insomnia; Fran had a sore throat and a fever; Celeste was an abuse survivor struggling to create a new life away from a hurtful past. The women explained that being given more and more medications and being hospitalized resulted in physical, spiritual, and emotional upheaval. They now had great difficulty navigating the world. Smith et al.'s (2009) participants also experienced upheaval. Smith explained how her participants named “loss of an ability to independently attend to their activities of daily living (ADLs)” and despite being told they’d experience ‘some’ short-term memory loss, “they actually experienced significant memory loss and a decrease in executive functioning” (p. 558).

When describing their experience with electroshock and the process leading up to it, all post ECT women recounted situations of not being heard or believed, of being judged and labeled, and of having their concerns dismissed. Three of the women had their charts from when they were hospitalized and described numerous entries supporting these statements. And in reviewing their charts, Cathy, Fran, and Lee experienced further trauma and re-victimization from reading how they were viewed. Burstow's (1994) video interviewing shock survivors supports and reinforces these findings.

Damage to the brain, impairment of memory and other cognitive functions, and the dismal effects on the women's lives is a common theme in women survivors' testimony. Many women spoke at length about their difficulty navigating the world because of electroshock-induced damage. Women testified that the damage was extensive, that much of it was permanent, and that it had wreaked enormous havoc in their lives. Problems typically listed by women include: not being able to remember family, friends, or conversations; no longer being able to hold down meaningful jobs and a sense of diminishment. (Burstow, 1994)

You become a permanently diminished human being. (Cathy)

Perhaps most concerning of all, more concerning than even the list of effects outlined in Table 1, was the loss of a life once known. Smith et al.'s (2009) research highlighted the impact of the loss of cherished memories including “not remember-

ing their children growing up, their educational history, family member's deaths, or special trips” (p. 558). Lee continues to have to compensate and Linda still grieves the person that got away. Fran lost a career and Celeste lost any dream of living a disability-free life above the poverty line. Be it cognition, memory, or credibility, ECT resulted in losses so significant that five of the women believe it is not only non-beneficent, but also maleficent.

What is the sense of ruining my memory, which is my capital, and putting me out of business? It was a brilliant cure but we lost the patient. —Ernest Hemingway (Hotchner, 1966)

### A Disconnect between Nurses and The Patients in this Study

It was a traumatizing experience for me that still haunts me to this day. (Fran)

We give people their lives back. (Nurse Eva)

Nursing prides itself for being client-driven and for having our collective ear to the ground regarding how our patients are doing and what they need. Indeed the nurses interviewed for the purpose of this study were deeply concerned for the well-being and quality of life of their patients. Interestingly, some similarities exist between the two groups.

It could be argued that nurses themselves appear to experience the same power imbalance their patients perceive: nurses, too, must rely on incomplete information regarding ECT, they are expected to defer to the judgment of others, and there is the same lived experience of powerlessness when they feel ECT is not needed. Yet, this imbalance has different consequences for the nurses and their patients. However, even a cursory glance at the women's reflections and the nurse's impressions about ECT will expose a substantive disconnect.

One area of disconnection is the apparent lack of knowledge held by the nurses interviewed about the presence and basis of psych-survivor testimony regarding electroshock. The same holds true for what can be found in published nursing literature. My evaluation of the literature from the past several decades uncovered a dearth of information regarding the lived experience of ECT, or of critiques of it as a treatment modality (van Daalen-Smith & Gallagher, 2011). As well, there is a clear disconnect between the impact of electroshock as understood by nursing, and the impacts reported by the post-ECT women in this study. Nurses continue to state that ECT causes short-term memory loss that self-resolves, yet this study and many others demonstrate that this is simply not the case. What became evident is that often the assessment of how ECT patients are doing is based, in general, on how they are at discharge. That they are more animated, verbal, and functional is deeply meaningful to nursing. But those same nurses explained that they had no idea how patients who had received electroshock were post-discharge unless the patients returned for subsequent care or treatment.

Other areas of disconnect deserve comment. While much of the nursing literature states that patients are offered ECT, many of the women feel it was pushed or forced on them. They were asked to understand it as a last resort—a last ditch effort to correct their illness. Where some of the nurses viewed women's depression as about cumulative loss, they didn't verbalize an appreciation that ECT resulted in additional, and sometimes devastating, losses. While the nurses understood electroshock as providing a fresh start, a renewed life, and a return in health and quality of life for patients, the women in this study understand and live electroshock as wholly associated with loss. For the nurses, ECT is understood to result in a net gain, but for the women, the result was absolute loss.

Perhaps the most compelling disconnect is the observation made by some of the women regarding some nurses' "cold stares, blank faces, and detachment" on the way to, from, or during the ECT procedure. Gass (2008) and his team in Aberdeen, Scotland studied the work of mental health nurses involved in ECT. Included in the methodology was non-participant observation. He described nurses as either present or detached, and when detached, focusing solely on the treatment process. He suggests "being detached may be seen as a means to prevent one from confronting not only the patient's but also his own experience in the ECT drama" (p. 199). Gass wonders if it is the anxieties associated with witnessing patient turmoil that creates the disconnect. He also wonders whether this disconnect might be associated with role conflict experienced by nurses who want to be engaged and present, yet realize their expected role in persuading or forcing a patient in order to get the job done is antithetical to their wishes? (Gass, 2008, p. 201). Could this be the reason for nursing's "far away eyes" aptly observed and named by Lee?

## IMPLICATIONS FOR NURSING

Compassion is not a relationship between the healer and the wounded. It's a relationship between equals. Only when we know our own darkness well, can we be present with the darkness of others. Compassion becomes real when we recognize our shared humanity.  
—Pema Chödrön (2005, p. 36)

It is important for nurses working in mental health to know the perceptions of women who have received electroshock. As well, inviting nurses to describe and reflect upon their experience in ECT delivery, is of equal importance. I asked the women what they wanted nurses to know and most asked me to, "Please tell them. Tell them what our lives are like. Tell them it wasn't what we needed." They wanted to make sure that nursing heard and believed their stories. While some wondered if we could do anything about their experiences, others implored us to try. The analysis of the interviews and focus groups highlighted many important concerns relating to the needs of women and the role nursing can play in meeting them. But, most assuredly, the overarching finding is that this issue is huge, at times murky,

and begs further exploration. I wish to honor its complexity and bring into the light the many tough questions that have emerged from this two-year study, and I know that the findings have implications for nursing that we may wish to consider.

According to the American Nurses Association (ANA; 2010), nurses have specific and explicit responsibilities associated with patient advocacy, arguing that persons in psychiatric units may have diminished capacity for asserting their rights. It is therefore incumbent upon the nurse to protect, speak up and collaborate to solve ethical issues (ANA, 2010) According to the Canadian Nurses Association (CAN; 2008) nurses are expected to "provide safe, compassionate, competent and ethical care, [and] to question and intervene to address unsafe, non-compassionate, unethical or incompetent practice or conditions that interfere with their ability to provide safe, compassionate, competent and ethical care to those to whom they are providing care, and they support those who do the same" (pp. 8–9). The glaring finding of the women's vulnerability and that this lived state was exacerbated by their involvement with mental health systems within which nurses work, now becomes an ethical issue for nursing. Many of the nurses interviewed commented about their patient's vulnerabilities during consent processes and/or associated with the treatment itself. What exactly is our role regarding patient vulnerability?

Nursing has rigorous responsibilities related to ensuring informed consent, yet the women told us that either they received inadequate or bad information or had their refusal of ECT overruled. Indeed, some of the women explained that whether they were viewed as supportive or oppositional to the proposed treatment plan determined whether they were viewed as competent (or not) to participate in the consent process itself. And further, that when they went along with ECT, they were told that they were doing better, and making progress. The 2010–2015 CNA's Registration Examination Core Competencies include the nurse's role in consent and refusal of treatment:

The nurse ensures that the client's informed consent has been obtained prior to providing care, and supports the informed choice of the client in making decisions about care (e.g., right to refuse, right to request care, right to choose, right to participate in research. (CNA, 2010, NCP-8/9)

Nurses are expected to be team players and to promote and support the treatment plan. A review of the literature exposed this, and this study and the Gass (2008) study reinforces this finding. In fact, Gass (2008) found that nurses played the role of ECT educator, which he demonstrates, included persuasion. He found that a nurse's role is clearly to sell ECT or fear reprimand for insubordination. What implication does that have for nursing? If there are patients in or previously in our care who are telling us that the treatment resulted in damage, it wasn't what they needed, that they received inadequate information, that they did not consent but had a family member consent on their behalf against their wishes, what are we to do?

Nursing's knowledge regarding ECT is not sufficiently based on first person accounts regarding its' impact or efficacy months after discharge. And nursing is not doing enough research regarding ECT, relying instead on psychiatry's research imperatives, analyses, and underlying assumptions about health, illness, and quality of life. Our literature is peppered with pro-ECT psychiatric literature and research, with little, if any first-person accounts. As well, we are basing our evaluation of its efficacy on client status at discharge when long after the "positive" or "desired" effects of ECT have worn off, patients, like many of the women in this and other reports, are left to re-build their lives.

There is a dearth of adequate follow up, as evidenced by the nurses interviewed reporting not having knowledge about how any patients were doing unless they were readmitted for maintenance ECT. Might nursing initiate and implement programs involving long-term follow up and build these findings into its own set of recommendations regarding electroshock? Is this too unrealistic and far too expensive, or is this too little, too late?

The consistent presence of powerful medications in the lived experience of all seven women also has implications for nursing, for it is our discipline that dispenses and administers their medications. All of the women told of being prescribed powerful psychiatric drugs and subsequently being told that the drugs didn't work for them and that ECT was, therefore, necessary. It was their last resort. There was no critique of the medications' side effects, efficacy, or adversity. Further, the cocktail approach (Breggin, 1997; Inquiry into Psychiatry, 2005), common in psychiatric pharmacotherapy, was never called into question nor explored. Nursing dispenses medications, and nursing is also responsible for informing patients of the clinical indications and side effects of medications and to chart having done this appropriately. Perhaps it's the drugs that are the problem in the first place? In what way might the medications being prescribed and their related side effects contribute to conclusions being drawn about the need for a last resort treatment? Perhaps when doing the five checks of medication administration (i.e., right person, right time, right drug, right route, and right dose), when it comes to the check of right drug, we pause?

Electroshock has consequences that nursing needs to be aware of. Indeed, I'm convinced more than ever that our profession wants to know the whole story. Nursing understands the false binary (pro vs. con) found in most ECT discussions is simplistic and narrow. Critical ECT discourse within the nursing community surged primarily in the 1980s but has dwindled except the most recent reflections by Smith et al. (2009) and Gass (2008). Nursing must create its own knowledge by drawing on the major tenets of our discipline. Beholden to no one but the individual, families, and communities we partner with, nursing research is truthful, ethical, and brave. It's time for the critical discourse to return. It's time to render our glances at ECT's dilemmas and controversies conscious. We have to shed a bright light on our role, because if there is a disconnect between what our patients are saying long after they leave us, and what we

are seeing at discharge, that matters. If there is a disconnect between what our patients have lived and what either we've been told about the impact of ECT, or what we ourselves have been saying about impact, then our job as nurses is to somehow mend that disconnect. How can we be nurses if we're not connected to our patients? We are called forth to care for patients and to assist them to reach a place of health and wellness as they define it, and to these women—memory matters. We cannot remain unaware. We cannot rely on non-nursing research or limited and limiting definitions of what "better" looks like for psychiatric patients. We cannot remain oblivious. It's incomplete. It's inadequate. It's not nursing.

### Out of Oblivion: Eight Questions Nursing Now Asks

Oblivious : (adj.) A state of unaware. Lacking conscious knowledge, awareness or mindful attention (Merriam Webster Online Dictionary, 2011).

While traveling home from those historic first-person hearings in Toronto, Canada, I realized something profound. And this realization struck even more forcefully as I listened to these 7 women and 15 nurses cautiously reveal their journey, experiences, and their recommendations regarding electroshock. We are with our patients at every step. At every stage and for every person receiving ECT, there is a nurse standing beside and bearing witness (perhaps, reluctantly). And now, by virtue of journeying through the raw narratives here in this un-obstructed account, you, dear colleague, now also bear witness. Perhaps it's not the first time, but maybe, just maybe, the critical questions I close with regarding this controversy-laden treatment will compel us to re-institute the critical discourse surrounding electroshock in nursing. Our patients deserve it. The women and the nurses in this study deserve it. And so do we.

1. Why has mental health care settled for a treatment that has never been proven?
2. In the psychiatric system, what is believed about patients that the input of family members is sought and relied upon more than that of the person living the life him- or herself?
3. Why are so many women (vs. men) selected for ECT?
4. Should persuasion be part of a nurse's repertoire?
5. Regarding "maintenance ECT," what is it that is being maintained?
6. What is it that makes us look away, have blank faces, disengage, during the ECT process?
7. What obstacles does nursing need to overcome in order to fully enact our role as advocates?
8. If nursing can't hear these narratives and critiques, who can?

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