WOMEN DIAGNOSED WITH DEPRESSION: MAKING MEANING AND DECISIONS ABOUT ELECTROCONVULSIVE THERAPY. A FEMINIST ANALYSIS.

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Abstract

This study addresses a significant issue occurring within contemporary societies such as Australia and within the larger international body of literature: the silencing of women’s experiences with electroconvulsive therapy (ECT).

Much of the existing literature in relation to ECT is quantitative in nature, which has produced large amounts of technical knowledge, describing ways in which to either maximise efficacy of the procedure or minimise possible side effects such as memory loss. Yet there remains little in the way of qualitative research to explore the ways in which people experience ECT, and even less work to specifically examine the experience of the procedure from women’s perspectives.

The research uses a feminist narrative approach to explore the ways women with depression make meanings and decisions with regards to receiving ECT. The thesis tells the stories of seven women. Each woman’s story describes her journey with depression, the ways in which she made the decision to receive and consent to ECT and her experiences with post-ECT side effects.

Difficulties related to knowledge, capacity and coercion are highlighted as central to the concept of informed consent. A material-discursive-intrapsychic framework is used to re-frame women’s experiences with emotional distress as the outcome of reciprocal interactions between their physical embodiment and their discursively constructed experiences. The framework is also used to describe how women navigated the difficulties they experienced with post-ECT memory loss, and the identities they held as women.

The thesis argues that women may be left disempowered and isolated in vulnerable states of decision-making by powerful and privileged medical experts, who view women’s emotional responses to life as worthy of medicalisation. Recommendations for change to clinical practice are offered. These include the need to challenge the biomedical understanding and medicalisation of women’s distress, the need for an ongoing critique of the power that lies behind the dominant medical discourse, the need for organisational change that endorses trauma-focused principles and a sustained commitment to the paradigm of women as experts in their own lives.
Publications and Presentations Resulting from the Thesis

Conference – peer reviewed

Journal – Non-peer reviewed
Statement of Original Authorship

The work contained within this thesis has not been previously submitted to meet the requirements for an award at this, or any other institution of higher education. To the best of my knowledge and belief, the thesis contains no material that has been previously published or written by another person, except where due reference has been made.

Signature:

Date: August 11, 2016
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Although I have had many people tell me over the lifetime of this research to “keep it in perspective”, that has been a very difficult task to achieve. The research on these pages feels like my life’s work, one that has changed my clinical work, my relationships and my sense of identity as both a researcher, a clinician and as a woman. Over the lifetime of this journey some amazing people have supported me. Whilst I acknowledge their enormous contribution to my work, there are some who for numerous reasons are deserving of more than a simple thank you, and they need to be mentioned in more detail.

Firstly, this work stands on the shoulders of seven brave and courageous women. They gave up their time and energy, but more importantly they allowed me into their lives and helped me understand the stories of the lives they had constructed. These stories were painful, sometimes exquisitely so. They spoke to me for long periods, they re-lived painful memories as they read their transcripts, and they answered my questions. Then they trusted me to make some sense of it all. To Kate, Anna, Pauline, Elisabeth, Helen, Margaret and Robyn - I hope that I have honoured your stories in a way that allows your voices to come forth. Thank you for sharing with me a wish and a desire to tell your truth.

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Glossary of Terms

**Autobiographical memory loss**: loss of those memories that are highly personal, for example memories of a family holiday.

**Big Pharma**: a colloquial term used to describe the pharmaceutical industry.

**Biopsychiatric model**: a conceptual model of mental illness that includes only biological factors to understand a person’s symptoms. It excludes psychological or social factors that may be contributing to the person’s ill health.

**Bi-frontal ECT**: describes a form of bi-temporal ECT in which the electrodes are placed closer together on the forehead, and the stimulus is passed across both hemispheres of the brain.

**Bi-temporal ECT**: describes a form of ECT in which the electrodes are placed on both sides of a person’s head and the electrical stimulus is passed across both hemispheres of the brain.

**DSM-5**: this refers to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders. It is the contemporary Western classification system of mental disorders and is used in the diagnosis of specific mental illnesses.

**Electroconvulsive therapy (ECT)**: a medical procedure that involves the passing of an electrical current through the brain of someone who is fully anaesthetised and paralysed. This procedure creates a generalised motor and electrical seizure. It is used for a variety of mental health conditions, including the treatment of severe clinical depression.

**Electrodes**: small adhesive circles that are placed on a person’s head, and connected to the ECT machine. They facilitate the transmission of the electrical current during ECT.

**ITO**: an involuntary treatment order (ITO) is a specific section of the Mental Health Act that allows for the provision of involuntary mental health treatment to a person without their informed consent.

**Geographical memory loss**: memory loss that relates to a specific geographical location.

**MAOI**: a group of antidepressant medications, known as Monoamine Oxidase Inhibitors.

**Procedural memory loss**: memory loss for tasks and procedures, such as driving a car or preparing a meal.

**Mental Health Act**: legislation that regulates the provision of mental health care to those individuals affected by mental illness. It directs and governs the provision of involuntary assessment, detention and treatment to those individuals who are unable to provide voluntary consent.
**Right unilateral ECT (RUL):** describes ECT in which electrodes are placed on the right-sided aspects of a person’s temple area and the top of their head. The stimulus passed into the brain is therefore isolated to one side only.

**SSRI:** a group of antidepressant medications, known as Selective Serotonin Re-uptake Inhibitors.

**Thymatron Series IV:** the name of an ECT machine commonly used in Australia, manufactured by Somatics Inc.

**TCA:** a group of antidepressant medications, known as Tricyclic Antidepressants.
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A PRELUDE OF SEVEN WOMEN, LIFE AND ELECTROCONVULSIVE THERAPY

Introduction

You are about to enter the world of seven women. Their words on these pages provide a voice for their experiences with electroconvulsive therapy. Each woman’s unique and remarkable story unfolds to explain their journey with depression, and to provide the context behind their decisions to receive ECT. Each story stands alone. It is necessary to hear from these women first, before any other part of this work is read; they are the reason for this research and their stories are the heart of this thesis. I am merely the feet that carry the thesis to the reader as a final destination.

Yet, I am acutely aware that these stories are my interpretations of their experiences. As both a researcher and as a woman I exist as part of a “Self-Other” relationship with the women in the research, and I have subsequently constructed them as the “Others”. There are difficulties with this positioning, however I am resigned to the understanding that it is only when I construct the women as “Others” that I can experience my own identity as a researcher. Paradoxically this process creates a binary opposite of them and me, which is antithetical for a feminist researcher. Fine (1994) compels researchers to carefully examine this hyphen, the one that exists between the Self-Other. She views the hyphen as a place in which the personal identities of the two are both fused and separated through the invention of the Other within the politics of everyday life by the Self. This relationship between researchers and those who they research is usually concealed, protecting privilege, ensuring distance and shielding possible contradictions. A critical task for qualitative researchers is to carefully examine what lies in “between” the two. So, if I were to write about the women in any other way to the one that I have chosen, I would be ignoring the hyphen, assuming a contradictory stance in which my individual, personal theory is offered to decontextualise their experiences. Therefore, I must consider where I am in relation to the women and the topic under investigation, conscious that we are multiple and unfinished in these relations.
I am fully aware that I am responsible for the “Othering” that occurs on the following pages. I am trying to contain the women’s experiences in compact little packages that allow a flow of language, yet can also facilitate empathy and compassion. I do this whilst I simultaneously hold others responsible for the women’s current situations. It may be likely that I have fallen into the trap of “engaging in intimacy and being seduced into complicity”, where I am “quick to interpret and hesitant to write” as I work this hyphen (Fine, 1994, p. 74). Regardless, it is my aim to uncover that which exists between the two of us. I do so openly throughout this prelude and the chapters to come through my own reflections, to show that I have a voice, a body, and a gender in a specific socio-political context that all influence how I am and how I come to be within the research. In a spirit of authenticity, I openly acknowledge that I bring to my research practice personal politics and perspectives, and a personal history riddled with contradictory ideas. The representations of the women I offer within this prelude then, are personally negotiated and politically situated.

Nevertheless, the positioning of representations of women’s stories to the front of the thesis is done intentionally to interrupt the Othering process. By translating the experiences for the seven women in this research, I hope to achieve a sense of social justice by allowing their oft silent and subjugated voices to be heard first before anything else, rather than to be disregarded only as fragments in service of my research arguments.

The women’s names and those of their family members, their friends, their doctors and their treating hospitals have all been altered to preserve confidentiality.
Margaret: The Walk of Shame

Margaret is 59 years of age, single with grown up children. She has received at least 32 bi-temporal sessions of ECT.

Margaret was employed as a senior sales representative for a large company for over 10 years when she suffered a work-related back injury in 2001. She needed significant time off work, and despite physiotherapy and occupational therapy she did not recover well. She was terminated from her job, and she found herself in a private mental health clinic for the first time. This was a difficult admission, lasting well over five months. Despite many different types of antidepressant medications her experience of distress did not improve. Struggling with past issues of childhood sexual abuse that she felt was not being adequately addressed at the time, Margaret found herself at a point of extreme vulnerability. She was desperate to be well and willing to try almost anything. Her doctors had tried many combinations of medications and although Margaret was resistant to their suggestion to try ECT, she soon reached a point of feeling that she had no other option. It felt like an ultimatum – they had tried all other options, if she did not agree to ECT, then how did she expect to recover? She did not play any active part in making the decision to receive the treatment and described feeling as though the right to make her own decisions was removed. She was frightened and does not recall being given any written or verbal information at the time of the procedure.

She gives a poignant and powerful description of walking to the procedure room, calling it the walk of shame. It was an unpleasant and shameful experience for her, made even more distasteful by being awake in the procedure room whilst having electrodes placed on her head. She felt it was inhumane, lacking in compassion, and merely served to make obvious what was about to happen to her.

Despite a total of 18 ECT treatments during this first admission, Margaret returned home feeling no better than when she had been admitted to hospital. At this point, her relationship with her partner of seven years began to suffer. As a corporate executive, he and Margaret entertained clients regularly, yet her memory loss following ECT made it difficult for her to engage with his clients in a meaningful way. She felt useless, incompetent and a failure as a corporate hostess. He could not cope with her experience and did not like the fact she had received ECT. The relationship irretrievably broke down and he moved out of their shared home. She found herself completely alone.
She continued to struggle with her back injury and required multiple surgeries to try to alleviate her pain. To this day, she has never fully regained her physical health. She feels that the ongoing pain complicated her second mental health admission, which was precipitated by occupational bullying in her new job. Again, after multiple combinations of different medications she found herself agreeing to another 14 sessions of ECT, despite promising herself after her first admission in 2001 that she would never repeat the treatment. She describes the sense of anger at feeling coerced into the treatment against her better judgment, yet acknowledges that she was again at a familiar point of desperation.

She kept a diary of her thoughts whilst she was in hospital and reading it years later, she acknowledges the dark and sad place she was in. The diary describes the significant memory loss she experienced at the time and the difficulty of her entire hospital admission. She coped with the pain of this admission through a newly discovered artistic skill of drawing intricate patterns of geometry, allowing her to escape within. She continues this artwork today and has over 150 drawings in her portfolio. She has no idea what to do with these drawings and is clearly conflicted – although they are beautiful in their detail, looking at them reminds her of a difficult time in her life. She keeps some of them lined up against her lounge room wall, turned inwards so she does not have to look too closely at them.

Her memory loss became obvious during conversation with others. Although previously well versed in talking to large groups of people, Margaret soon found it impossible to be able to engage in a group setting. She attributes this to her fear of not being able to find the right words to express herself. To this day she fears being in a group of people and avoids it at all costs. Memory loss has affected her employment. Although she registered as a marriage celebrant in 2009 she has never acted in this position, feeling that she could not rely on herself to remember how to carry out this role. She cannot commit to a wedding or naming ceremony because she cannot be sure that she would be emotionally well on the day. She no longer works in any employed capacity, attributing her loss of confidence directly to ECT.

She feels unable to participate in family discussions because she cannot recall or contribute to any shared details. These recollections stem back to include personal details of her children, who are now in their twenties and thirties. She feels that it is simply easier to pretend she has not heard the conversation, or to simply disengage when conversation arises. She finds it difficult to make new friends, and is fiercely
adamant that she will no longer consider a new intimate relationship. Memory loss has created a permanent gap where a mutual sharing of memories once resided.

Margaret is very clear – she will never receive ECT again, no matter how unwell she becomes. She feels that she has lost a part of herself that she can never regain, and she will never risk losing more of what still remains. Now under the combined care of a psychiatrist who explores her history of abuse and a pain specialist who monitors and treats her back injury, she feels a little more able to cope. She is somewhat pragmatic about her experiences – she understands that ECT helps many people; it is simply an unfortunate fact that she is not one of them.
Anna: The Memory Game

Anna is 55 years old, married with two teenage boys. She works as a nurse educator in a large tertiary hospital. She has received 18 bi-temporal sessions of ECT.

Although she readily acknowledges that she had been unwell since the births of her two sons, Anna’s official journey with ECT began in 2003 with her first hospital admission. This was a relatively short and uneventful admission, however despite the use of medication the next five years were a time where she barely functioned at all – although she continued to work, there was very little joy in her life. Deciding to take an overseas trip with a friend, she weaned herself from her antidepressants, leading to frequent bouts of panic, anxiety and a second hospital admission. She was given another round of antidepressant medication and discharged home. However, just as she was starting to improve an unexpected and catastrophic storm hit and her family home was completely destroyed. Her emotional state rapidly deteriorated and despite another hospital admission and additional medications she experienced little improvement, if at all.

She was frustrated with her inability to get well, and remembers perceiving similar feelings from her friends, her husband, her mother and her psychiatrist himself. She was horrified and very frightened when he finally offered ECT to her as a treatment option. Although Anna had some general knowledge of the procedure, she was very anxious about the impact of the treatment on her memory. She wondered how others would treat her professionally if they knew she had received it. She spent a week or so contemplating her decision. She was initially resistant, attributing this to her need to be in control yet she readily acknowledges that she would have eventually arrived at the same opinion as her psychiatrist; that ECT was necessary for her to improve. She describes a therapeutic relationship with her psychiatrist – he kept her fully informed at each stage of the ECT, and at no point in her course of treatment did Anna feel that he was making unilateral decisions without her input. She retained some control over the treatment, such as when she was going to start the course of ECT, and believes this was extremely beneficial for her. The little decisions she was able to make made a big difference to how she perceived it. Anna considers that she was given enough information to make her decision, and whilst she recalls her psychiatrist telling her of the slight risks to her memory, she was encouraged by his opinion that it would only be short-term in duration.
Anna remembers making a very active and autonomous decision to receive ECT, yet she was heavily influenced by the distress of her husband, her children, her mother and her friends. She describes feeling that she needed to have ECT for everyone’s benefit, not just her own. Anna also considers that she was not in a position to be making healthy, rational decisions without the support and input of her husband and her friends, emphasising the fact that she felt so unwell at the time.

According to Anna, there was little impact on her memory, despite her previous fears. She attributes this to two things – her own hypervigilance and constant examination of the way in which her memory was operating, and her internal need for control. She used the regular ward routine to ensure that she knew what was happening and where she needed to be, according to a set schedule. She acknowledges her memory was impacted to a slight degree although her friends describe some instances of which she has no recall. She is convinced that they exaggerate the impact of ECT on her memory, and that it is not as impaired as others make out to be.

The full effects of her ECT were not immediately apparent, and Anna was disappointed that she was not suddenly full of happiness and joy as she had anticipated. Regardless, two weeks after she had been discharged from hospital she realised that she was feeling almost happy; feeling very different within herself. It was a turning point for her, and as the positive effects of ECT continued to accumulate over the next few weeks she was able to appreciate exactly how distressed and miserable she had been before the treatment.

Overall, Anna credits ECT for her recovery. She feels better than she has ever felt, only needing a very small amount of medication taken at night. With a wry laugh, she acknowledges that she should have had ECT much earlier in the process. In fact, she is certain that she should have received ECT during her first admission in 2003. With regards to the future, Anna hesitates slightly. She eventually suggests that ECT may be an option that she would consider in the future, however she would still be a little nervous about receiving it, despite already having an experience with the procedure.

She has become somewhat of an advocate for ECT. Initially she did not disclose her treatment to others, fearing that this knowledge would disadvantage her at work. Today, she is happy to talk to anyone and finds herself dropping it into conversations routinely. She describes feeling angry when she watches TV shows that sensationalise ECT as an invasive and dangerous procedure and wants to be able to be a part of a movement that minimises this view of the procedure.
In closing she takes a reflective position on the social perspective, musing that despite being the year 2015, there is still a stigma associated with managing a mental illness. Anna wants this stigma to change, and she is trying very hard to play an active role in the process.
Helen: Enough is Enough

Helen is 60 years old. She is married and the mother of grown up twins. Between 2009 and 2010, she received 47 separate sessions of ECT, a mixture of bi-temporal and bi-frontal placements.

A highly driven senior sales manager with responsibility for over 60 staff, Helen found herself injured through a work-related motor vehicle accident in late 2007. Although initially the whiplash injury appeared mild, it only took a few weeks for the injury to her neck and back to result in bladder dysfunction and the need for regular urinary catheterisation. The pain and disability became so significant that Helen deteriorated to an emotional place where suicide was a realistic option. Every day was spent contemplating how she could take her own life, and she became so obsessed with drowning that she completely stopped showering for fear of carrying through with a plan. She describes herself as completely broken at the time of admission to a private mental health clinic. This was a very difficult admission, and between January and June 2008, Helen spent less than twenty days at home. She had tried multiple combinations of medications, but experienced troublesome side effects of every antidepressant that she was given, and was never able to get to a recommended and therapeutic dose. It was a continual rollercoaster ride of titrating up and titrating down of various medications with no discernible benefit.

Helen found this lack of progress extremely frustrating, and as a corporate trainer, she was used to finding creative solution to problems. Internet research exposed ECT as a possible treatment option. Helen was able to see beyond the websites that promoted ECT as a barbaric tortuous procedure – she knew it was more than portrayed by the movie “One Flew Over the Cuckoo’s Nest”. She gathered her information and gave it to her psychiatrist, wondering whether the treatment would be of any benefit so that she could be weaned from her medication. She described trusting her doctors to have her best interests at heart, and believed that this faith in them was an imperative. She was not given a great deal of information and wonders if it was because the doctors presumed she had enough information from web-based sources.

Helen received three ECT treatments, and improved so much that she was soon discharged – in fact she only spent a further 20 days in hospital for the remainder of 2008. As pointed out by her team, this was indication of an initial success.

She recalls the people who shared her ECT journey in hospital and how they banded together three mornings each week. With some humour in her voice, Helen describes
their camaraderie, how they identified themselves as the Three White Knights by virtue of their white theatre clothes. Having others there made it easier to tolerate, however lying on the table wide awake and having the electrodes placed on her head was a distasteful part of the procedure. Helen remembers always being last on the theatre list, and how the waiting for the procedure was a difficult and anxiety-provoking task. She soon worked out why she was last on the list – the more anaesthetics she received for ECT, the more complicated Helen’s recovery became. She developed a form of neurological weakness after each anaesthetic, her entire left side would become weak and she found it difficult to walk. To this day she suffers from drop foot, and has required physiotherapy and orthotics to enable her to walk correctly. Her speech would be slurred and she would experience urinary incontinence. She eventually developed a plantar fasciitis from the seizure activity and fibromyalgia. Her doctors refuse to acknowledge that this is a result of the frequent anaesthetics or the ECT and will not validate Helen’s disability, much to her disgust.

Helen’s memory loss following ECT was significant. Her son had two separate engagement parties – one at the family home, and was married in 2009. Helen has absolutely no recall of either party, and only minimal recall of the wedding. She feels that this part of her life was stolen. Although ECT stopped her from the intrusive suicidal thoughts, it stripped her of other powerful memories. Although her husband and children are supportive of her memory loss, it has become a family joke. Helen chuckles at this point – frequently her family will laugh and remind her that she has lost a particular memory. She thinks it is ironic; they could fill in the gap in her memory with anything, and she would have no choice but to believe them. She describes losing self-confidence along with her memory.

The loss of memory created some tension between Helen and her husband when she was discharged home. Suddenly, she had no recall of what the dishwasher was for, or how to go about cooking a meal. Concerned, Helen’s husband refused to allow her in the kitchen despite it being Helen’s domain in the house. It took at least six months for them to effectively negotiate when they would take turns to cook. She lost capacity for facial recognition, and even today has to frequently consult her husband to determine if she actually knows the person who has just greeted her by name.

Although Helen was the first to suggest ECT, she failed to maintain any long-term improvement with it. She refused any further ECT although her doctor attempted to persuade her to change her mind. Helen was clear that she was tired of the anaesthetics, the physical complications, the memory loss and the lack of progress.
After 344 days in hospital and 47 separate sessions of ECT she felt that she was no better and for her, it was time to call it quits. She recalls being told that she would be incapacitated by both her physical and mental state, but she refused to see this as an option. Although still unwell she returned home, undertook brain-training exercises to improve her memory, and decided to give up full-time work when her workers' compensation claim was finalised. She now works with the same company in a voluntary training capacity a few times a year.

She is adamant that ECT did not help and that she will never repeat the treatment. With a sense of poignancy and a degree of sadness, she accepts that she would rather be suicidal than to submit to ECT again. This is something that she hopes she never has to make a future decision about.
Pauline: Two Separate Lives, Two Different Lives

Pauline is 44 years old. She has had two separate series of bi-temporal ECT – one administered to her under involuntary mental health legislation in 1995, with a second course received in 2011.

Pauline first became unwell and psychotic when she left senior school and moved away from her home and family in New South Wales. She was admitted to a public hospital and for the next 20 years experienced a never-ending cycle of inpatient admissions and discharges, and of different medications and diagnoses. She soon became institutionalised, her life existing completely within a hospital environment. After one particularly traumatic admission in her early twenties it was suggested that she should agree to a course of ECT. At this time, she was detained in hospital under mental health legislation and was receiving involuntary care. She was too unwell to challenge the decision and went along with what her treating team wanted to do. She felt that she had little part of this decision. She was very frightened, and resigned to the fact that the doctors were going to administer the treatment, regardless of her thoughts or wishes. She did not respond well to the procedure and was traumatised by the entire process, recalling the sound of the machinery in the procedure room. To this day, the sound of cardiac monitors on TV shows sends her into a heightened state of anxiety, and she cannot view any reality shows with medicine as its focus. Despite this original course of ECT Pauline still suffered protracted psychotic and depressive symptoms. For the next few years she trialled a variety of medications that did little for her symptoms other than create havoc with her physical health, inducing a range of metabolic dysfunctions.

She lost significant memories of her earlier life, including memories of her Debutante Ball and those of the close relationship she shared with her brother. She cannot remember being a person under the age of 30 – although she has photos to prove this to herself, she had no emotional attachment to these photos, and no connection with any memories. The anger and sadness in her voice is palpable as she describes feeling that she has lost something that most people have – a long and detailed memory of life.

Pauline experienced significant difficulties with facial recognition, and frequently had to bluff her way through conversations to avoid the embarrassment of not being able to recall a person’s name or their association with her. She also had to rely on her mother to fill in the frequent gaps of memory in order to keep a story consistent. Luckily, her
mother is able to accompany her to ongoing medical appointments, when an accurate longitudinal history needs to be communicated. In relation to other autobiographical memories, Pauline describes how she will often get the impression of some vague and distant memory but not be able to retrieve it.

In 2011, after a particularly difficult time characterised by serious self-harm Pauline was given a second course of ECT. This time it was with her full consent, and she was given the chance to discuss the procedure at great length with a nurse whom she trusted and had developed a therapeutic relationship. She was provided with a full and detailed explanation that incorporated possible risks to her memory, and was given time to contemplate the appropriateness of her decision. Fortunately for Pauline, this course of ECT appeared to help enormously, and she was soon discharged from hospital. She has not returned to hospital since, and for the first time in her life is now living independently and working, using her own experiences to help other mental health consumers both in hospital and the community.

Because of the prolonged periods of illness over her teenage and early adult years, Pauline lost opportunities to develop social and life skills to which most other young people have access. She is convinced that ECT interfered with the way that she processes information and the way in which she can problem solve at both a concrete and abstract level. She still has enormous difficulty in organising her home and housework, and cooking basic meals for herself. She attributes this to the effects of ECT. At the time of our research conversation, Pauline had recently begun working for very short periods of time each week and found the challenges of learning new skills enormously stressful, requiring vast amounts of repetitive practice. For this very reason Pauline did not attempt to obtain her driver’s licence until late 2014.

The second round of ECT took its toll. Having a conversation with someone became mentally draining as she constantly juggled speaking and trying to remember what she wanted to say next. She also found that her speech could be uttered in a backwards style, usually without warning. She had to learn to stop, re-think the sentence, re-order it mentally and then repeat it verbally. As a result of this difficulty in communication she chose to limit her social life to family members. Even now, she prefers to spend most of her free time by herself.

As Pauline reflects, she is not certain that she would ever repeat ECT, even though she responded so well in her final course of treatment. If she did decide to have the
treatment again, she is certain that she would get as much information on the procedure and side effects that she could before she commits to a final decision.
Kate: A Really Insulting Disease

Kate is a 48-year-old married mother. She has two young adult sons. She received a total of four bi-temporal ECT sessions in 2009.

Kate’s story actually started when she was 30 years old, newly married with two young children and extremely busy in her church. Despite what appeared to be a wonderful and satisfying life, she describes being despairing and acutely suicidal. A committed and active Christian, her thoughts of self-harm were at odds with her spiritual beliefs and her first appointment with a doctor who diagnosed her with major depression left her feeling distressed and stigmatised with a the label of mental illness. She was convinced that it did not describe her but given the depth of her despair and her overwhelming belief that doctors know best, she willingly began the first course of antidepressants.

Kate developed a multitude of side effects from the medications – agitation, inner restlessness, insomnia, and sexual difficulties, which she described as being worse than the depression itself. Yet she continued to try to juggle the many roles she occupied – teacher, mother, and coordinator at various ministerial levels within her church. She recalls thinking that the busier she was, the more she could distract herself from her discomfort and unhappiness.

The impact of the label of depression was clear for Kate. The antidepressant side effects made her feel very uncomfortable and her experience confirmed her worst fears – she was on a rollercoaster ride of mental illness that she could not stop. She worried that others would judge her for being in distress and for taking medication – would they think she was a bad person, friend, mother, and Christian? Kate’s life began to be dominated by both self and public stigma of mental illness. She describes experiencing an attack of gallstones late one night after she has been taking a particular medication for some months. The paramedics who attended were initially compassionate and helpful in their assessment until they noted her antidepressant medication. Kate believes they saw her symptoms as being imaginary, ordered her to take Panadol for the pain and call her GP in the morning. They did not transport her to hospital and spent a great deal of time convincing Kate that her pain was not real. She almost began to question her own judgment, until the next morning when Kate saw her GP and underwent an abdominal scan. Gallstones were confirmed and surgery organised immediately.
Kate's distress increased over the next year and following one particularly frightening night full of suicidal thoughts, she found herself in the hospital emergency room. It was at this point in time that she recalls feeling that she had finally crossed the threshold from sanity to true insanity. She was admitted to hospital, and resided in an environment with people who were all behaving in a bizarre manner. It confirmed exactly as she thought – she had entered a world of dangerous and unstable individuals who should have their faces on the front page of the newspaper and she deserved to be there.

Despite many changes in medication her symptoms did not abate over the next few weeks. Her psychiatrist finally suggested ECT. Kate recalls consenting to the procedure, despite feeling that she lacked the capacity to do so. She is adamant that she did not feel that she had much choice because no other options were offered for her to consider at that time. She recalls that the treating team told her there was really no other option if she wanted to get well and go home. She recalls being raised in a family where a doctor’s knowledge and skill were revered and respected, and those like herself – the middle-class and less educated – had no right to be questioning a doctor’s educated decisions.

Kate only required four treatments before her symptoms improved, and given this quick response she was soon discharged from hospital. However, the impact of the ECT on her memory became quickly apparent. Her capacity for facial recognition had all but disappeared. For Kate, this effect was more than devastating. She had worked in the role of the Newcomer’s Coordinator at her church for years, chosen for this role because of her ability to remember names and faces of people she had only met once, and often only briefly at that. She could recall names of extended family members; their children and friends, their interests and hobbies and her skill lay in recalling and appreciating the complexities of relational connections between different members of the congregation. After ECT, Kate could not recall the faces or names of anybody at church, regardless of how long she had known them. Even today, years after ECT the effect is still pronounced. Kate no longer works in this role, nor does she teach. She worries about not being able to remember names and faces of her students, so has elected not to put herself into a classroom situation again. She now undertakes regular missionary work with her husband overseas.

Kate has become a staunch advocate for ways to minimise the impact of stigma. She speaks openly about her experiences in a variety of forums in an attempt to change the personal and public perception of mental illness and ways in which to manage it.
According to Kate, depression was a very insulting disease that robbed her of joy and happiness. It was insulting to her body and to her mind and spirit. She is convinced that if she had suffered a physical illness she would have received far more sympathy and understanding from others, including herself. When it comes to the decision about future ECT though, Kate becomes extremely hesitant in answering the question. The possibility of further cognitive impact is something that she finds difficult to contemplate. Whilst ECT worked for her, she is extremely cautious about recommending it, or antidepressant medication for anyone else. She has now turned her attention to alternative remedies as a future option and recommends that anyone who is considering the procedure be given as much information as possible in order to make a full and informed decision.
Robyn: A Blissful Escape

Robyn is a 59-year-old married mother who has received numerous sessions of ECT both in the public and the private sectors. Although previously employed as a mental health nurse, she is now unemployed and considering her options for a future career.

Robyn finds it hard to discuss her journey with ECT, not because of the emotions associated with the procedure itself, but because of the grave impact on her memory. Her psychiatrist has documented some of the different courses of ECT for her in order to participate in this research, but Robyn has extraordinarily little recall about the finer details of the treatments – number of treatment sessions, position of electrodes, in which hospital she had the treatment, and which year she received the treatment. This makes it difficult for her to have a temporal aspect of the treatment or where it all fits in with the rest of her life. Throughout our research conversation Robyn struggles to recall details to which she simply does not have access. Her capacity to seamlessly connect details, times and memories eludes her and her conversation style remains concrete and disjointed from one detail to the next. Her conversation style when we discuss other aspects of her life is fluid and dynamic. Discussions around her treatment and episodes of inpatient care on the other hand are bereft of detail and associated emotion.

Her first experience with ECT happened in 2006. At a routine appointment with her psychiatrist, Robyn was surprised by her doctor’s recommendation for an urgent inpatient admission. Robyn did not think that she was in any way unwell at the time. She knew that she was sad but she did not see herself at risk, even with the suicidal thoughts she was expressing. She was quickly admitted to a public health setting and the treating team decided that ECT was the most appropriate treatment option. Robyn cannot recall how she consented to the treatment, or whether she was given any information about the procedure itself but she recalls being in hospital for at least four to five months initially. She received a significant number of sessions within this particular ECT course, yet she is quick to point out that she did not get any better. This is an interesting point, as Robyn reminds me that she did not think she was particularly unwell in the first place. She went on to receive further ECT courses in other hospitals, both public and private over the next five years. None of these helped in any way, and Robyn admits that she felt very disappointed by her lack of improvement. She continues to reiterate that she did not ever see herself as being unwell, even though she admits that her doctor and husband would both disagree. She considers the question of capacity, and suggests that as she did not at any point disagree with the
plan of ECT, this could be taken as a sign of how unwell she actually was at the time. She does not feel that she had any part in actively making the decision to receive ECT. She merely agreed with the doctor's decision and went ahead with what her psychiatrist decided was best.

Robyn enjoyed the anaesthetic part of the ECT process, and with a dry laugh recalls the delightful feeling of blissful escape that she was able to experience three times each week. Unfortunately Robyn is the type of person who wakes up from the anaesthetic quickly and with a clear head, and she always felt angry that she was brought back to reality so quickly following each procedure.

Her memory loss became apparent when she was discharged after her first course of ECT. Driving home to the house that she had shared with her husband and children for over 20 years, she experienced no memory of the house, the suburb, or any emotional connection. She remembers being vividly shocked when her husband explained that this was her house, her family home. Geographical landmarks had no meaning to her, and it took many months before she could trust herself not to get lost in her own suburb. Even today, she relies completely on GPS navigation rather than recollection of streets and landmarks.

Her family views her memory loss as somewhat of a family joke. They frequently inform her when they are about to recall something that occurred before she received ECT. This is usually accompanied by the utterance of a code word shared by other members of the family to indicate that she will not remember the memory they are about to share. It used to annoy her – now she is simply resigned to the fact as she realised that she can never regain these lost reminiscences. What does make her angry is her loss of capacity to engage in housework and gardening. Robyn is clear that ECT is to blame for her inability to effortlessly weed, propagate seedlings and add them to her growing garden.

Robyn will never again consider ECT as a treatment option, and nor will her new psychiatrist. It is clear from her story that ECT is not a treatment that has assisted her in any way. She firmly believes that medications, long walks and enjoying time with her dog are the vital ingredients to staying well.
Elisabeth: It Got the Job Done

Elisabeth is 39 years old. She works within mental health services and received 10 bi-temporal ECT sessions in 2009. She identifies herself as a woman of Australian Aboriginal descent.

Elisabeth’s first marriage was not a happy one, and for the entire time she and her husband were together she was on some form of antidepressant medication from her GP. The challenges of infertility and a hysterectomy led to the eventual collapse of their marriage, and she became sad and isolated. At the time she worked within mental health services in an administrative role. Given that she lived in a rural area, she felt uncomfortable about obtaining further help for her distress from anyone within her health district. It was not until she reached the point of feeling suicidal that she realised the cumulative impact of the stress from the previous five years and reached out for help. She was referred to a psychiatrist who organised for an immediate admission to a private hospital and discussed ECT with her for the first time. The rationale presented to Elisabeth for the choice of ECT was her failure at antidepressant medication. Elisabeth recalls that she did not even try to question the decision at the time – the psychiatrist seemed to know what was best. Elisabeth was in a desperate position and was willing to try anything, whatever was needed to get her well. She remembers feeling that she had no idea what she needed, just that she needed to listen to the psychiatrist’s opinion if she was to get well at all.

Once in hospital and receiving ECT, Elisabeth remembers feeling that she had to fend for herself. Consumers who received ECT did not often see their nurses unless they requested so. Given that she now works in the area of Quality Assurance, Elisabeth is aware of the need for close coordinated care for ECT consumers, both in and out of hospital. She expresses her anger loudly, in that she did not experience this at any stage during her admission.

She is clear that she was not given any information at the time with regards to side effects. She is not sure whether her employment within mental health services played a part in this, and that it was expected that she had some knowledge of the treatment, or whether it simply was not standard practice to provide knowledge of the possible impact on memory. She admits that she may have been in a state where she simply does not recall being given information in the first place but given that she had no tangible proof – pieces of paper with information – she doubts that she was given any. She has a great deal of knowledge about the informed consent process and is
adamant that she did not have the capacity necessary to be making the decision to receive ECT. Despite this, she signed over consent for the treatment.

Unfortunately, there was a major impact on her memory, which did not become apparent until she returned home some four or five weeks later. She discovered that she had lost all memory of how to drive a manual car and became effectively housebound for some weeks, requiring the supervision and care of her mother. Even when the procedural memory did return, she found it difficult to break down all the steps necessary to automatically drive a manual vehicle smoothly and without anxiety.

There are still major gaps in her memory of life prior to ECT. Although she did not have the happiest of childhoods, she knows there are some happy memories of her family, however she simply cannot retrieve them. Her brother will ask whether she recalls something from their years growing up, and Elisabeth is unable to recall any details at all. She has limited capacity for facial recognition, and is constantly checking with colleagues and friends for names of people she engages with both at work and socially. The most alarming consequence for Elisabeth is the fact that her memory loss appears to be associated with a lack of sensitivity and tact in her communication with those who she maintains close relationships. Many months after receiving ECT she was mortified to learn that she had been rude and obnoxious to some close friends in the initial weeks after completing the ECT course. She had no recollection of saying anything to them. She now worries constantly about who else she has unintentionally offended, even though she has no recollection of the conversations occurring. The most frightening part of this cognitive loss for Elisabeth is that she felt so well within herself at the stage that this change in tact and diplomacy occurred. If she was capable of insulting people when she was well, she is very concerned about what she could do if she became unwell again and the impact upon her friendships.

Soon after her course of ECT was completed Elisabeth was targeted for a promotion at work, into a senior and strategic role. She credits ECT for being considered at all, and although she was concerned about her memory loss, she informed all her managers who supported and encouraged her to ask for assistance when needed. This was a boost of confidence for Elisabeth and has allowed her to be a voice for the beneficial effects of ECT in her community, especially for those Australian Indigenous people who struggle with maintaining good mental health. She has even spoken to her Aboriginal father about her experiences, despite the general belief by the Aboriginal people in her area that ECT is the domain of white, non-Indigenous Australians.
She remains uncertain whether she would have the treatment again, given the degree of memory loss she has experienced. Regardless, she is glad that she was given ECT. As far as she is concerned, ECT allowed her to reclaim her life. Now in a new relationship, working in a senior role and engaging well with friends and family, she is in a far happier and healthier place.
CHAPTER ONE: INTRODUCTION

The thesis is a story, in two parts. First and most importantly, it is the story of seven women. It is the story of their journey with emotional distress, and the ways in which they and others perceived that distress. It is a story that describes the journey they undertook in order to alleviate that distress, a story that describes how each one of them received a biopsychiatric treatment. Their stories are both powerful and compelling.

There is a second and parallel story to the thesis. This story is my own. It describes my transformation from a clinical mental health nurse to a feminist researcher. My own short reflections are seen in italics at the beginning of relevant chapters and describe ponderings of both clinical practice and research process designed to show how my identity as a clinician, a researcher and a woman have changed and adapted throughout this PhD research.

This chapter offers the reader an outline of the thesis as well as a definition of some of the key terms found throughout. It then provides a background to the study, describing how the research came to be, the questions that were posed, and an overview of how the research was approached.

Structure of the Thesis

The thesis consists of six chapters. The prelude introduces the women at the heart of this research and allows their individual stories to be heard. Chapter two reviews the literature regarding depression, electroconvulsive therapy and memory loss. It also examines some central constructs important to feminist research. Chapter three outlines the research methodology and establishes why a feminist narrative approach is the most appropriate to use for this research. Chapter four describes themes from the women’s stories. It also offers a framework to act as a preliminary to the findings that are discussed in chapter five. The final chapter distils the main insights from the research, offers recommendations for future practice and justifies the need for future research.
Terminology

Language is a powerful force that has the ability to shape our perceptions, and it is important to acknowledge the language that is consistently used throughout this thesis. The word *consumer*¹ has been used to describe someone who uses or who has used a mental health service, or who has the lived experience of a mental illness (Procter, Hamer, McGarry, Wilson, & Froggatt, 2014). This is a term that is well accepted throughout Australian and is widely adopted (Sozomenou, 2000), although it remains a troubling concept. The term *disorder* is also noted throughout certain aspects of this thesis, generally within the context of describing a cluster of symptoms usually associated with clinical depression. As it will become apparent throughout this work, I have attempted to carefully consider my choice of language so as not to fall into the trap of engaging with a dominant medical discourse. This is consistent with my feminist approach, which acknowledges that the use of terminology both describes and creates reality and a sense of subjectivity (McLaren, 2012). The term “emotional distress” has been chosen to highlight the personal suffering that women describe, yet in a way that allows for the inclusion of affective, cognitive and behavioural elements of their experience. However, even whilst using this term I often found myself struggling to find an alternative word or descriptor to describe the experience of depression and the consequential responses that women experienced from medical teams. This is due in no small part to working within an acute care health setting for almost three decades, and the pervasive nature of working with the dominant language of medical diagnosis and treatment. Whilst taking a position of reflexivity allowed me to contemplate the use of alternative terms, I acknowledge that there are some instances when none could be found. Whilst there have been times when I have not been able to step outside the current discourse of writing, I have chosen language intentionally and consciously in a manner that I hope at the very least, is not harmful to either the women within this research, or to the integrity of the methodology.

Language also has the ability to influence the dynamics of power and the word “interview” can be seen to emphasise the imbalance of power between the researcher and participants (DeVault & Gross, 2007). As feminist research challenges the hierarchical nature of empirical research in order to minimise power differences, I have consciously chosen to substitute the word “interview” with “conversation”. This is not an unusual move – the word “conversation” is well regarded within narrative inquiry, and

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¹ Please note that the words “consumer”, “user” and “patient” may be used interchangeably.
conversation is seen to be “the context in which knowledge is understood” (Josselson, 2006, p. 7). Kvale (1992) also writes that the “knowledge produced in an interview comes close to postmodern conceptions of knowledge as conversational…and inter-relational” (p.51). This linguistic substitution therefore creates a context and a situation in which the participating women and I engaged together as co-researchers, participating in a conversation to create negotiated meaning and knowledge. I was aware that despite my best efforts, our relationship was still unequal as a result of the research process. Yet even so, it remained authentic at the time of engaging with the women.

Background to the Research

Depression

The Diagnostic and Statistical Manual of Mental Disorders (Fifth edition) defines a major episode of depression as a clinically significant disturbance of mood that is characterised by the presence of a depressed mood, diminished interest or pleasure in life activities (American Psychiatric Association, 2013). In addition, there are a cluster of associated changes such as alterations in appetite and weight, decreased sleep and energy levels, lowered sexual interest, feelings of diminished self-worth, and poor levels of concentration.

The World Health Organization (WHO) estimates that the ill-health related to depression affects over 350 million people worldwide, making it one of the highest ranked causes of disability as measured by the number of years lost to illness, and the second leading contributor to the global burden of disease (WHO, 2014). The Global Burden of Disease Report (2010), one of the leading publications from a collaboration between the WHO and Harvard University, shows a 37.5% increase in disability related to depression in the last two decades. Previously major depression had been placed as the 15th highest-ranking cause of global burden of disease, yet by 2010 it had moved to occupy the 11th position (WHO, 2014). Currently depression is the second greatest disabler for both men and women aged between 15-44 years combined, and in a less than hopeful forecast the WHO has projected that by the year 2030 depression will outrank any other medical condition as contributing towards the global burden of disease (WHO, 2014). This forecast adds weight to the current research, urging an understanding of the experience of depression and the available treatment options.
In Australia major depressive disorder is positioned as the fourth leading cause of disability behind lower back pain, ischaemic heart disease, and chronic obstructive airways disease (Begg et al., 2007). The National Survey of Mental Health and Wellbeing (Australian Bureau of Statistics, 2007) contains the most up to date national data and captures the state of mental health in the Australian population. In the twelve months prior to the 2007 survey, 20% of the Australian population experienced a mental disorder of some form. Men appeared less likely to develop a lifetime mental disorder than women (males = 17.6% vs females = 22.3%) however a preponderance of women suffering from depression was evident (males = 5.3% vs females = 7.1%). More than a quarter of the sample described more than one co-morbid disorder at the time of the survey, and it appears that the most common combination of mental disorders was that of depression and anxiety (Begg et al. 2007). From these results alone, there is a need to understand depression within a public health context, as well as appreciating the different ways that depression manifests itself according to gender.

While a number of possible causes for the development of depression are proposed and will be developed further within chapter three of the thesis, the treatment for both men and women remains the same. A variety of options are utilised, including the use of antidepressant medications, mood stabilising agents, individual and group psychotherapies, and when appropriate, electroconvulsive therapy.

**Electroconvulsive Therapy**

Electroconvulsive therapy (ECT) is a medical procedure that involves the passing of a small charge of electricity across the brain of a fully anaesthetised and paralysed individual to induce a modified epileptic-type seizure. This seizure creates a series of highly complex effects upon a wide range of hormones and other neurotransmitters within the brain (Kellner, 2012). ECT may be administered across the right side of the brain (right unilateral ECT), across both hemispheres of the brain (bi-temporal ECT) or in a modified position (bi-frontal ECT), all of which are aimed at maximising efficacy and minimising potential side effects. The procedure has been a part of psychiatric treatment for over 70 years, and it has evolved into a highly refined and technical procedure used to treat a variety of mental health conditions (Payne & Prudic, 2009). An estimated 80% of individuals who receive ECT have a diagnosis of major depressive disorder, and previous research claims that a further 90% of these individuals obtain significant remission of symptoms within nine treatments (Kellner, 2012; Loo, Aaronson, & Holtzheimer, 2014). Therapeutic gains may be lost if treatment
is abruptly ceased or discontinued, and relapse rates as high as 84% within the next six months have been observed in clinical trials (Loo et al., 2014).

The current research was undertaken in Queensland, Australia. In Queensland, ECT is provided in both public and privately funded inpatient mental health settings. Informed, voluntary consent is required before the treatment is administered. However, ECT may be administered to an individual who lacks the capacity to provide this consent if the treatment is felt to be urgent or even life-saving. In these cases voluntary consent is waived, and approval is sought under specific sections of the Queensland Mental Health Act 2016.

It has been estimated that as many as two million people worldwide receive ECT as a treatment for their mental health disorders each year (Abrams, 2002). However, variations in clinical practice, guidelines and reporting mechanisms make comparison between and within countries difficult. Each year, approximately 50,000-100,000 Americans receive ECT (Gomez, 2004; Kellner, 2012; Prudic, Olfson, & Sackheim, 2001). In Australia approximately 32,000 Medicare funded ECT sessions were administered during the 2014-2015 financial year, of which almost 10,000 were given in the state of Queensland alone (Medicare, 2015). A comparison of numbers of treatment sessions according to each State or Territory is seen in Table 1.
Table 1: Australian ECT sessions 2014-2015 by region (Medicare, 2015)

<table>
<thead>
<tr>
<th>State/Territory</th>
<th>ECT Sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>7,603</td>
</tr>
<tr>
<td>Victoria</td>
<td>8,319</td>
</tr>
<tr>
<td>Queensland</td>
<td>9,911</td>
</tr>
<tr>
<td>South Australia</td>
<td>2,174</td>
</tr>
<tr>
<td>Western Australia</td>
<td>3,051</td>
</tr>
<tr>
<td>Tasmania</td>
<td>620</td>
</tr>
<tr>
<td>Australian Capital Territory</td>
<td>300</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>37</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>32,015</strong></td>
</tr>
</tbody>
</table>

These figures do not reflect total numbers of ECT sessions accurately as they do not include privately funded ECT. Furthermore, different data collection and reporting requirements often prevent accurate and meaningful comparisons between Medicare and privately funded ECT within and between different States and Territories. As an example, whilst the majority of Australian states and territories do not have such a robust measurement system in place, the Chief Psychiatrist mandates the reporting of all ECT treatments in Victoria, irrespective of the setting in which the procedure occurs (Victoria Health, 2015). The annual report from the Office of the Chief Psychiatrist for the years 2012/13 indicates a total of 21,755 ECT sessions recorded (Victorian Government, 2015). Of these, 12,831 sessions were funded through the Medicare system and a further 8,924 treatment sessions were administered within private health systems (Victorian Government, 2015).

Further analysis of available Medicare data demonstrates that women receive ECT in far greater numbers than men do (Medicare Australia, 2015), and these utilisation rates can be seen in Figure 1. The underlying reasons for this large difference in utilisation rates between men and women are relevant, however they lie outside the scope of this thesis and remain relatively obscure.
The body of literature exploring ECT is extensive and provides information relating to the various technical aspects of the procedure such as electrode placement, dosing regimens and schedules and management of cognitive deficits associated with the treatment. A search of the literature however, simultaneously reveals limited descriptive work that articulates the experiences and lives of those individuals who are treated with ECT, and only a handful of specific studies highlight the experiences of women who receive the treatment (Burstow, 2006; Ejaredar & Hagan, 2013, 2014; Orr & O’Connor, 2005; Tran et al., 2015). This suggests that further investigation of relevant issues that relate to the experience of women with depression and ECT needs to be undertaken.

The Mental Health Consumer Movement and national responses

The Mental Health Consumer Movement emerged from the process of deinstitutionalisation from inpatient to community-based mental health care, the discovery of new medications, increased intellectual critique of the psychiatric paradigm and a growing awareness of consumer’s rights. It was energised by the emancipatory view that those who had the lived experience of a mental illness had the right to speak up and campaign on their own behalf for more appropriate and effective care (Tomes, 2006). Organisations such as the National Mental Health Association (NMHA) in the United States and the Mental Health Alliance (MHA) in the United Kingdom campaigned tirelessly for consumers to be acknowledged and accepted for their unique qualities and state of being, rather than having their differences used as justification for involuntary detention and treatment. This paradigm became influential.
as it encouraged individuals to regain control and purpose within their lives, and helped them to define their identity without the label of psychiatric disability (McLean, 1995).

To situate this within a local Australian context, the last two decades have seen public concerns raised regarding the conditions and care provided to people with a severe mental illness. In response, the Australian government established numerous lines of official inquiry that resulted in a variety of reports and reform. The Burdekin Report (Human Rights and Equal Opportunity Commission, 1993) highlighted clinical and managerial deficiencies in Australian mental health institutions. The Not For Service Report (Mental Health Council of Australia, 2005) reported the experiences of the mental health system by consumers and carers through their own personal narratives. Both documents have contributed towards a critique of the Australian mental health system and raising the public profile of consumers’ experience of care. Since these reports were published, various long term mental health policies and reforms have been developed by States and Territories to encourage the consumer’s voice to be an active part of policy development, service planning and delivery and research within mental health care (Queensland Government, 2008). This has particular relevance for the current study, where the aim was to have the voices of women who have received ECT heard and represented in such a way that women-centred knowledge contributed to our understanding of contemporary mental health practice.

From clinical beginnings: the researcher’s story

The starting point for this study came from my own clinical practice as a qualified Mental Health Nurse. I have worked with individuals suffering from clinical depression for almost 30 years, and have spent just as long working with the procedure of ECT. During that time, I have supported women who have received ECT and I have actively assisted in the administration of the treatment as part of a mental health team. I have observed women who have received the procedure and whose symptoms of clinical depression have remitted, in part as a result of the treatment. I have also born witness to women who did not achieve remission of symptoms, but who were left with debilitating side effects of memory loss. I have seen both sides of the argument that has polarised the treatment as either “life-saving” or “barbaric”.

My initial interest in the current research originated from a clinical issue that I observed within routine practice, that of the difference in the use of ECT according to gender. Irrespective of the Australian state in which I was practising, over the years these observations remained constant. Both men and women could present with the same
diagnoses of depression and they could display the same symptoms of the disorder, yet they were frequently offered different treatment pathways. Men were likely to be prescribed pharmacological options, and women were likely to have ECT prescribed. Although the utilisation rates were higher in women than men nationally and had been so for some years, the situation looked even more extreme in the state of Queensland, where I was practising. There was no robust scientific evidence to back up the disparity in clinical practice I was observing; certainly nothing within the literature to show that ECT was a more efficacious treatment for depression in women. Given the unpredictable risk of adverse cognitive effects associated with the treatment, I found myself in an uncomfortable situation where clinical knowledge of contemporary treatment clashed directly with moral curiosity, and an initial sense of injustice began to emerge. Why was it that women received this treatment more often than men, without compelling support for the clinical practice? How was it that women came to the place where the decision to receive ECT was almost a given? How did women decide that this treatment was appropriate for them, despite the possibility of long-term memory loss? I wondered how women experienced this treatment, and the care that was provided to them before, during and after the procedure. This curiosity drove my decision to find the answers, and I embarked upon my research quest.

It is at this early point in the thesis, that as the researcher of the current study I offer my personal and professional standpoint. Until 2012 I had previously worked as a mental health academic-clinician, teaching the theory and practice of ECT to novice and practising mental health clinicians around Australia. I advocated for a model of care with regard to the administration of ECT that incorporated caring, respect and dignity to those who live with the experience of mental illness, one that I had noticed was often missing from training programs offered throughout health services. ECT has a notorious historical background enshrouded in mystery, myth and misgivings. In its infancy it was administered for a wide range of emotional and behavioural disturbances, more often than not without any scientific basis or reasoning. It was also a procedure that resulted in physical injury and pain due to lack of general anaesthesia and muscular relaxation (Challiner & Griffiths, 2000). Those who received the procedure often felt abused, oppressed and punished (Cyrzyk, 2011), contributing even further to the stigma of mental illness as a whole. Within my contemporary clinical practice this pervasive and powerful image of the procedure translated frequently into caring for women who felt frightened and anxious, uncertain of the treatment and how it would impact them. It concerned me to no end to hear women tell me (often
repeatedly) that they did not understand what was going to happen to them, and did not really understand the procedure.

By the end of this thesis, I will offer an alternative story to describe my personal and professional perceptions of ECT. For now, it is sufficient to say that I identify as a mental health nurse. I am also a woman who is passionate about making a difference to other women who battle the challenges of emotional distress, and the research I have undertaken through this PhD is my attempt to do so.

The Significance, Aim and Focus of the Research

The aim of the research was to explore the experiences of women diagnosed with depression and who had received ECT, and to uncover how and why they arrived at the decision to receive this particular treatment. The research was influenced by clinical practice and research in several key areas. The practice of ECT has evolved over time, and the way in which it is administered as a treatment has become more refined and sophisticated. However it is still a medical procedure that may significantly impact upon women’s quality of life (Smith, Vogler, Sheaves & Jesse, 2009).

Clinicians and caregivers need to think about how the care they provide is received and perceived by consumers. The perspectives of consumers can be used to invoke change within health care delivery, and it is important to consider how their experiences can influence academic and clinical research. Consumer accounts of receiving ECT can be viewed as valid and legitimate knowledge and be seen as equal to the construction of scientific and objective knowledge through dominant medical research (Gillard et al., 2012; Goering & Streiner, 2013). Therefore a clear underpinning aim of this research is to offer an alternative viewpoint through the experience and perspective of the person who has received ECT, with regards to how decisions are made and how care is provided.

Until now, the experiences of women and how they make decisions with regards to receiving mental health treatment has been given little empirical attention. There continues to be a need to understand women’s experiences of receiving ECT, and to understand how social, economic, cultural, political and medical forces influence this decision-making process. The need to further understand the meaning that women attribute to their experience cannot be underestimated if a desired outcome of the research process is to improve the ways that women experience mental health care and service delivery and how actively they participate in determining their own care. This research is unique because it took this specific need and explored the very
experiences of those women whose voices continue to be absent from the scientific literature.

The research design as seen in Figure 2 outlines the research process. The central question when I began this study was: “How do women make meaning and decisions about electro-convulsive therapy?” A feminist ontology guided my questioning as I pondered the way that gender, as a social and relational construct, is infused with notions of power and inequality. Feminist epistemology allowed me to consider the way that women’s knowledge is negotiated, with a focus on the ethics of power. A feminist narrative approach was then used to highlight sub-questions, namely:

- What were women’s experiences of depression?
- What informed their decisions about treatment, specifically ECT?
- What were their experiences of the ECT treatment (and care), specifically would they make the same decision again?

In pondering the main research question however, I soon recognised an over-arching sociological question emerging. The question of “What is the impact of the socio-political context on women’s decision-making and experience in relation to ECT?” is progressed throughout the discussion chapter later in the thesis.
Research Aim
To explore the perspectives of women diagnosed with depression who have received ECT

Research Questions
How do women make meaning and decisions about ECT?
What informed their decision?
What was their experience of ECT?
Would they make the same decision next time?

Feminist Ontology and the Nature of Reality
Gender is a social and relational construction rather than a natural state
Gender is about power inequalities between men and women, which is both the product and the process of this social construction
Social meaning and structures are saturated with gendered power relations

Feminist Epistemology
Knowledge is entwined with power relations; it is socially negotiated and struggled over
Women's ways of knowing include subjective, lived experience as valid knowledge
Ethics is central to knowledge creation and use
Ethics is always about how power is exercised, for whose benefit and at whose cost

Methodology
Feminist narrative research
Stories are the medium for understanding experience
Feminist methodology allows for more reciprocal relationships between researcher and participants
Narrative researchers consider the larger social context in which stories occur

Methods
Face-to-face Interviews with women who have received ECT
Critical reflection of researcher’s field notes

Analysis of Research Material
Thematic analysis of women's stories
Critical analysis of researcher's field notes

Figure 2: Overview of the research design
Conclusion

The chapter has provided an introduction to the current research. Beginning with an overview of the organisation of the thesis for structural clarity and a short description of some key terms, a brief explanation of depressive disorders was provided as a platform to understand the use of electroconvulsive therapy. The recent international movement used to articulate the perspectives of mental health consumers related to scientific research and clinical practice was also discussed. However, as this introduction argues, there remains a lack of robust qualitative research exploring the perspectives of women who have received ECT. Finally, the chapter has described the origins of the current research journey and the approaches that are utilised throughout the study design. The next chapter will explore and review the body of literature that has contributed to an understanding of depression in women and the use of ECT.
CHAPTER TWO: LITERATURE REVIEW

A literature review for a body of work such as this thesis is generally undertaken over many years. It is frequently refined as new or conflicting information is discovered through extensive searching, and it is interesting to reflect on the life of the review itself. In the beginning, this literature review was dominated by studies on the procedure of ECT. Reviewing the body of existing knowledge allowed me to establish and understand what was already known; what methodologies were used; and most importantly what gaps in existing knowledge remained and were yet to be explored. My review of the literature on depression and ECT originated from a dominant biomedical position. This was not surprising, given that as a nurse my views on ECT had traditionally been linked to a disease-orientated model of depression.

By the mid-point of my research journey, I had begun to contemplate an alternative explanation to the nature of depression, women, and the way in which they manifest emotional distress. After interviewing the women of this research, I realised that there were many unanswered questions relating to the nature of women’s mental health. Simultaneously, I was experiencing a significant shift in the way that I viewed and engaged with the research process itself. This led me back to a further refining of the literature, and with a clear vision of my intentions now in place I undertook the literature review using a feminist standpoint epistemology. The central premise here is that all knowledge is socially and historically situated (Heikes, 2012). The logic of standpoint perspective lies in its ability to articulate relations between androcentric social institutions and power and the production of sexist and androcentric claims of knowledge (Harding, 2007). Standpoint epistemology attempts to explore the world from a perspective that identifies, reveals and challenges dominant institutional understandings of women, men and the social relations between the two (Naples, 2007). Therefore, I have undertaken the literature review from the position of exploring the perspectives of women, who have traditionally occupied a position outside of the institutions in which knowledge about social life and health is generated. I have positioned myself to critically evaluate the current biomedical literature that centres on women, depression and ECT, and have also paid close attention to the political protesting and contesting that originates from women’s experiences.
Introduction

The literature review was conducted over the life of the current research, and undertaken in a systematic manner to ensure that all relevant material was located and situated within the review. The major databases used were PubMed, EBSCOhost and CINAHL. Searches were undertaken to identify and review the literature relating to depression and women, initially using key search terms including ECT, electroconvulsive therapy, women, gender, depression, memory loss and quality of life. Additional key terms such as feminism, power, and stigma were subsequently included later in the research process. As sources of literature were obtained, they were systematically organised into groups, and their respective reference lists were examined for further sources. This process was undertaken until no new sources of literature could be sourced. Throughout the life of the research new searches were undertaken, and any new sources that emerged were updated to the review.

This chapter presents the literature review that underpins the research. It begins with a background to set the context for the way that women’s emotional responses to life have been situated from a socio-historical perspective. The understanding of depression as a function of gender and culture is then explored, with a focus on biological, psychological and social factors that present across women’s lifespan. The literature review then presents the perspective of individuals who have received ECT, including their experience of memory loss.

Setting the Socio-historical Context

Before a review of the scientific work around depression, women and ECT can commence it is necessary to offer a brief historical analysis of the nature of community attitudes towards women with psychological distress. This will help to establish the socio-historical and political background with regard to the medicalisation of women’s distress, and the patriarchal nature of psychiatry. These historical and social realities provide an example of the contested as well as gendered context for how emotional and psychological distress has been conceptualised, and what has been regarded as appropriate treatment. This orientation of the literature assists in conveying the feminist theoretical framework underpinning the research that will be discussed in later chapters.

An examination of socio-historical factors throughout history shows a dominant disjunction between women’s own emotional discomfort and how these experiences
have been interpreted and defined by the rest of society, including the medical profession (Appignanesi, 2008). Particular periods in Western history have defined socially appropriate behaviours as either masculine or feminine (Showalter, 1987; Wollstonecraft, 1792). In the early eighteenth century the “Age of Reason” was a time characterised by the freedom to think in intellectual terms and by the emergence of rational and scientific knowledge and rigor. This was mirrored by the gender system of the day, where to be masculine was to think objectively, rationally and linearly; conversely, to be feminine was to think subjectively, relationally and intuitively (Showalter, 1987). Wollstonecraft makes this point in her classic work “A Vindication of the Rights of Women” when she claims “man was made to reason, woman to feel…” (1792, p. 71).

By the beginning of the nineteenth century, emotions were viewed as an inferior and weak quality for a person to possess, and the term hysteria was seen to be a disorder linked to the phenomenon of being feminine (Ussher, 2011). Throughout history, unexplained medical ailments have been linked to the mysteries of women’s reproductive organs and sexuality. Initially described as the result of a “wandering and restless womb” by Plato (Ussher, 2011), the nature of female maladies has been consistently and pathologically situated in the reproductive organs. In an essay that describes the perspective of mid-nineteenth century physicians towards women in puberty and menopause, Smith-Rosenberg (1986) offers the view of one doctor who suggested that the reproductive organs of women:

...exercise a controlling influence upon her entire system, and entail upon her many painful and dangerous diseases. They are the source of her peculiarities, the centre of her sympathies and the seat of her diseases. (Smith-Rosenberg, 1986, p. 183)

Two such diseases were soon labelled as *neurasthenia* and *hysteria*. *Neurasthenia*, or “exhaustion of the nervous system” was a popular term used to describe symptoms of lassitude, fatigue, headaches, bodily pain and irritability (Beard, 1869), and could be compared to a modern-day description of depression (Radden, 2003). Hysteria on the other hand, although initially characterised by a variety of physical symptoms including seizures, paraplegia, or numbness to one side of the body, soon involved interpretations of mood and personality. These symptoms could be compared to a contemporary description of anxiety. The physical symptoms of hysteria were generally abrupt in onset, and were usually preceded by sudden or deeply felt emotion such as fear, shock, a sudden death, physical trauma or marital disappointment. Regardless of
its cause, the symptoms of hysteria usually began with pain in the “uterine area” (Smith-Rosenberg, 1972, p. 661). The link between the womb and distressing female emotions such as hysteria soon became embodied in the belief that all women, by sheer nature of possessing a womb, were perpetually at risk of developing the disorder. As the French philosopher Foucault observed, this served to make medical management of all unacceptable behaviour in women a legitimate process. Doctors tended to uphold the belief that these disturbed emotional states signified a disease state that required medical treatment. Foucault described the process of the female body as being “analysed - qualified and disqualified – as being thoroughly saturated with sexuality, whereby it was integrated into medical practices, by reasons of a pathology intrinsic to it” (Foucault, 1978, p. 104).

The presence of hysterical symptoms resulted in women being described as “narcissistic, egocentric and emotionally labile” (Smith-Rosenberg, 1986, p. 202). Wealthy women with hysteria were described as self-indulgent, and yearning sympathy from others (Smith-Rosenberg, 1986, p. 141). They were independent and needed great amounts of privacy, yet for these characteristics they earned the reputation of being “personally and morally repulsive and manipulative” (Smith-Rosenberg, 1986, p. 133). Women with neurasthenia on the other hand were described in a more positive light. They were perceived as refined and unselfish, and likely to be “the kind of woman one likes to meet” (Showalter, 1987, p. 134). The neurasthenic woman was not overly emotional, and displayed just the right amount of illness whilst still being able to perform her duties, politely and compliantly (Showalter, 1987).

The connection between female hysteria and reproduction had its roots in an understanding of female sexuality, where the prevailing view of the Victorian era was that female desire was morally perilous (Appignanesi, 2008). In an ironic twist, social norms of the day demanded women to suppress any expression of their sexuality. This led upper class women to develop hysteria, although in lower class women the emergence of hysterical symptoms was attributed to their lowly social status (Appignanesi, 2008). Prostitutes were particularly at risk of this malady (Smith-Rosenberg, 1972). Sexual excess and masturbation was viewed as problematic, even within the protective confines of marriage. For women lacking in necessary restraint, radical surgery to remove the clitoris was considered an effective way of quelling the mind (Ussher, 2011, p. 19). Paradoxically, hysteria was simultaneously acknowledged as a functional way of managing the challenges of a rapidly changing Victorian society. The family and marital institutions were changing as were the gender roles – women
were living longer, marrying later in life and often needing to be permanently employed outside of the home. The stresses of life for middle to upper class women were significant, and as Smith-Rosenberg (1972) suggests, hysteria may have served as a functional and adaptive strategy to redefine their domestic and occupational roles.

**Women’s perspectives and a “problem with no name”**

The first wave of feminism in the 1920s enabled women to challenge mandated inequality and freedom (Krolokke & Sorensen, 2006). The second wave of feminism in the 1960s and 1970s created a fertile battleground for many women to argue against the socially prescribed roles of domestic passivity and self-sacrificial child rearing (Silver, 2002). Where earlier efforts of emancipation had earned women the right to vote and to be well-educated, women who rode the second wave of feminism earned the right to clearly articulate how a patriarchal social structure systematically oppressed women via sexism and continued expectations of passive compliance (Krolokke & Sorensen, 2006). This was a time of radical change for many women, not only as they attempted to wrestle back control of their own lives, but also through the manner by which their attempts were judged. As Appignanesi (2008) argues, women’s socio-economic power had been limited for a significant period of time, and many women had internalised compliancy and passivity. Some women found themselves chained to social and domestic roles and tasks that created a state of powerlessness and oppression. Attempting to articulate their dissatisfaction with life created a situation where their problem could best be treated with the use of drugs or electro-convulsive therapy (Appignanesi, 2008). At least, this was the view of those who possessed medical authority.

In Friedan’s “The Feminine Mystique”, the experience of women’s dissatisfaction with their prescribed social roles, and their sense of domestic oppression in the guise of playing “happy families” was defined as the “problem that has no name” (1963, p. 19). Instead of feeling emotionally and physically fulfilled by their domestic, matrimonial and maternal roles, white middle-class women were feeling exceedingly unhappy about sublimating their desires for independence, autonomy and careers for the happiness of their husbands and children. Visits to psychoanalysts proved fruitless, as the “problem with no name” had no definitive diagnosis that could be found in the nomenclature of the Diagnostic and Statistical Manual of Mental Disorders (DSM-II) and psychiatrists were at a loss with regards to treating it (Friedan, 1963).
The focus for psychiatric advancement in the 1960s had only just evolved from the psychodynamic “talking” psychotherapies to a model that emphasised neurological hard-wiring and biochemistry (Rasmussen, 2005). New drugs to treat the symptoms of emotional distress emerged from the pharmaceutical landscape throughout the 1950s and 1960s (Healy, 1997; Horowitz, 2010). Suddenly, a solution to the “problem with no name” became possible. The nameless problem of feminine dissatisfaction could be treated with a drug, one that was designed to treat symptoms of personal unhappiness as a disease (Healy, 1997). This disease was known as depression.

The difficulty here lies in the very definition of the term depression. The scientific literature provides evidence of a variety of positions on the nature of depression although it appears that there is no agreed understanding of the phenomenon. There is confusion that occurs when the term is used to describe an emotion, a symptom and a diagnostic category, and for good reason. Psychiatric literature assumes a biological stance, paying attention to chemical deficiencies of selected neurotransmitters. Psychological knowledge on the other hand attributes priority to certain cognitive states such as faulty negative thinking, to account for the negative view of self and the world (Beck, Rush, Shaw, & Emery, 1979).

To add to the confusion, whilst depression is seen to be a global pandemic (WHO, 2013), in many non-Western cultures there is no emotional description for the term, rendering a universal meaning problematic. As an example, until 1999 there was no equivocal word for mild depression in the Japanese culture (Ussher, 2010). Experiences such as sadness and emotional fragility were seen to be a part of life that were simply endured and accepted. Yet soon after aggressive marketing by pharmaceutical companies and an innovative national campaign, a new “disease” was discovered – “kokoro no kaze” (Ihara, 2011), accompanied by an aggressive pharmaceutical marketing campaign directing individuals to take a pill to cure it. As a result, sales of new generation antidepressant medication in Japan quintupled within the next five years (Currie, 2005; Ihara, 2011).

**The influence of pharmaceuticals**

The evolution of current pharmacological interventions for the management of depression was explored as a response to concerns raised by a Canadian coalition of women’s groups about the rising use of antidepressants in women. Currie (2005) provided an in-depth review of the current literature, which was subsequently used by
the Women and Health Protection Steering Committee to recommend changes to the way in which Health Canada monitored and regulated antidepressant use.

The current Selective Serotonin Reuptake Inhibitor (SSRI) antidepressants had their origins in the 1950s, with the advent of the first muscle relaxant with sedative properties (Currie, 2005). Known as “Miltown”, it became a popular drug specifically targeted towards women (Currie, 2005). It was accompanied by a marketing campaign in which newspapers and magazines promoted the medication as a cure for women’s problems, ranging from a “wife frigidity, to a bride’s uncertainty, to a wife’s infertility” (Metzl, 2003, p. 72). It was a highly popular medication and white, western, middle-class women were prescribed Miltown four times more often than any other demographic group (Metzl & Angel, 2004). By 1961, the pool of potential Miltown prescribers was expanded through the promotion of a small but influential text, “Recognizing the Depressed Patient” (Ayd, 1961). In a strategic move, this book was promoted to general practitioners rather than specialist psychiatrists. Over 50,000 copies were bought by Merck pharmaceuticals and distributed globally (Currie, 2005, p. 9). This led to a veritable explosion of medical “experts” who were now willing and able to diagnose women and prescribe the latest in minor and major tranquillisers, setting the stage for the imminent emergence of new antidepressants.

In an historical twist, when the first potential antidepressants were discovered in the late 1950s, there was little interest shown by the pharmaceutical companies (Currie, 2011). At this point in time they believed that depression was minimally marketable, preferring to focus on the minor tranquillisers such as Valium. The situation was re-evaluated in the 1980s however, when pharmaceutical companies decided to promote depression as a state of neurotransmitter deficiency, leading to the message that depleted serotonin stores needed to elevate in order to recover (Currie, 2011; Healy, 2004). This appeared to be logical reasoning, and as it occurred at a time when concerns about dependency were being raised over benzodiazepines, the situation was ideal for doctors to switch their female patients over from minor tranquillisers to antidepressants to treat their unhappiness and worries. Simultaneously, antidepressants were marketed heavily at a time when women were entering the workforce in large numbers and expanding their financial and occupational independence. Suddenly, the marketing of antidepressants promoted their effects through the images of women as economically and occupationally liberated, working as equal members of society. Indeed, women who took antidepressants were almost guaranteed to develop male-gendered traits described as becoming “optimistic,
decisive and quick of thought, charismatic, energetic and confident... an asset in business" (Kramer, 1994, pp. 16-17). One long-running advertisement campaign for Prozac even depicted its primary effect as restoring and increasing women’s “productive days” (Metzl, 2003, p. 158). A variety of alternative discourses offered antidepressants as a way of improving women’s lot in life when things were not always satisfactory. A large in-depth analysis of pharmaceutical advertisements found in American psychiatric journals published between 1950 and 2002 provided evidence for the ways in which antidepressants were positioned as helpful, and identified categories such as (a) marital status (depression puts a strain on marriage; drugs help the marriage); (b) motherhood (the woman is identified as a “bad mother”; drugs help her to be a good mother); (c) sex (poor libido is unsatisfying to the marriage; drugs help the woman to take care of the marriage); and (d) friends and relationships (depression is socially isolating; drugs enable the woman to be surrounded by friends) (Metzl, 2003).

The concept of depression as either a result of neurotransmitter deficiency or as the result of psychosocial factors remains a contested point. Those who prefer the psychosocial explanation of depression explain the difficulties in conceptualising a phenomenon that is linked to past and present social contexts, that is difficult to visualise or validate, yet is assumed to be biologically determined (Pilgrim, 2007). Conversely, those who defer to a biologic explanation of depression (especially those who maintain relationships between medicine and biopharmaceuticals) have been accused of using a bio-deterministic logic (Pilgrim, 2007). Thus, depression is envisaged as a brain disorder requiring antidepressant medication and pharmaceutical companies continue to promote the view that a serotonin imbalance within the brain can be easily rectified by serotonin-specific medications. Aggressive public and direct individual marketing by these companies has led to an almost uncritical acceptance that these drugs are needed in order to function normally. Yet there is actually very little scientific evidence to support the idea that individuals who experience a sense of depression have a serotonergic dysfunction (Lacasse & Leo, 2005; Murphy et al., 1998). Treatment effects of SSRIs have been found to be modest at best (Attia, Haiman, Walsh, & Flater, 1998; Spielmans & Gerwig, 2014; Thase, 2011), and at worst it has been suggested that 80% of medication response to antidepressants can be observed in placebo controlled groups (Healy, 2004). Furthermore, antidepressant medications are associated with a broad range of side effects such as anxiety and agitation, gastrointestinal disturbance and sexual dysfunction (Bloch, McGuire, Landeros-Weisenberger, Leckman, & Pittenger, 2010; Price, Cole, & Goodwin, 2009).
Regardless of the differing scientific opinions, depression continues to be an ambiguous concept (Russell, 1995). It does seem that a general consensus of depression as a legitimate phenomenon must be accepted, at least for the meantime. This has led to a situation in which the influence of Western psychiatry in creating and maintaining a legitimate view of depression and reinforcing its biomedical standpoint must not be underestimated. The use of SSRIs has become so influential that it has altered and shaped our language, our culture and our assumptions about health and sickness. In 2013 a health “snapshot” of the 33 countries comprising the OECD (Organisation for Economic Cooperation and Development) showed that Australia is currently the second highest prescriber of antidepressant medications (OECD, 2013). This is not an isolated pharmacological occurrence. Increases of medications for mental health disorders in Australia have been rising exponentially over the last decade. Using an analysis of prescribing patterns over the decade spanning 2000-2011, Stephenson, Karanges and McGregor (2013) discovered a 58.2% increase in the prescriptions of psychotropic medications. Alarmingly, this increase was predominantly driven by a 95.3% increase in the use of antidepressants. In the twelve months between 2012 and 2013, the Australian Pharmaceutical Benefits Scheme subsidised approximately 20.5 million prescriptions for antidepressants (Department of Health, 2014). Herein lies the inherent problem with these powerful medications. The majority of prescriptions (approximately 86%) originated from primary healthcare general practitioners (Department of Health, 2014; Hollingworth, Burgess, & Whiteford, 2010), with only 8% prescribed by a specialist psychiatrist. Those who have the least experience and knowledge about the power of these pharmaceuticals are those who are most frequently dispensing them, similar to the situation that followed the release of Ayd’s (1961) revolutionary text on depression.

The use of antidepressant medication is a lucrative business. At a global level, sales continue to grow significantly, and these large organisations remain some of the most profitable companies in the world. It has been projected that sales within Australia will continue to grow at an impressive 10-13% per annum (Lindsley, 2013). No doubt Australia’s share of the antidepressant market, with an estimated annual turnover in excess of twenty billion dollars globally, will help to maintain the vested interests of pharmaceutical companies in the treatment of mental distress (Hyman, 2012).
Culture, Gender and Depression

Although the core feelings of loss, emptiness and helplessness are universal, there is much debate about whether or not other symptoms seen in depression are experienced by people of differing cultural backgrounds (Chentsova-Dutton, Ryder, & Tsai, 2015). In many non-Western cultures, there are no specific words to describe the term “depression” (Kleinman, 1987). For example, in cultures such as Haiti and Asia, symptoms of emotional distress are manifested through somatic complaints such as the discomfort in the head, heart, liver and stomach (Keys, Kaiser, Kohrt, Khoury, & Brewster, 2012; Krause, 1989; Saint Arnault, & Kim, 2008), rather than through the use of words to denote emotional descriptions of sadness. This is an important phenomenon to bear in mind. The argument posed by Western psychiatrists to counter this cross-cultural variance is that the non-Western individual is actually experiencing “depression” (Fenton & Sadiq, 1991), but they are merely somatising the disorder to their head (or chest, or gastrointestinal system). This perspective is problematic. Firstly, a definition of depression is permeated with Western assumptions. Current views of depression are shaped by the Western paradigm of health and “normal” functioning as a state of having positive emotions. Feeling good about one’s self may not always be endorsed by other cultures (Chentsova-Dutton et al., 2015). It has been argued that because there is a Western tendency to view people as independent and autonomous, symptoms of depression are often attributed to internal causes (Stewart et al., 2004). People who belong to cultures that view the individual as enmeshed, interdependent, interconnected and socially contextualised may view the same symptoms as having an interpersonal cause (Chentsova-Dutton et al., 2015; Tafarodi & Smith, 2001).

Relational behaviours such as social withdrawal and failure to maintain daily role functioning may also be more significant in collectivist cultures, rather than the physical symptoms of poor sleep or appetite changes. Subsequently, somatic symptoms that contradict medical explanation may pose a diagnostic dilemma as the dominant paradigm lies in a white, Western psychiatric classification of emotional distress. Furthermore, conclusions drawn from clinical research into depression are often judged against the implicit standards from the researcher’s perspective (Burr & Chapman, 2004).

There is a complex body of research that acknowledges the gender differences in depression, and it is well beyond the scope of the current research to provide an in-depth exploration of the issue. However, it seems women receive a diagnosis of depression more often than men do (Angold, Costello, & Worthman, 1998; Angold & Worthman, 1993; Ferrari et al., 2013; Kessler, 2003; Kessler, McGonagle, Swartz,
Blazer, & Nelson, 1993). While this difference between men and women is one of the most frequently reported psychiatric statistics in the literature, it continues to be one of the least well-understood phenomena. It has been estimated that when compared to men, women have from one and a half to three times a higher lifetime risk of developing depression (Kessler et al., 2005). Yet a wide range of prevalence rates has been reported, with different methodological approaches yielding different results (Kessler, 2003; Parker & Brotchie, 2010), leading to a sense of confusion about the true nature of the issue.

A systematic literature review of 111 relevant studies (published between 1999 and 2010) examined lifespan prevalence rates and correlates of depression in a diverse population of Australian women over the age of 12 years (Rich, Byrne, Curryer, Byles, & Loxton, 2013). The review selected studies that included women from different age ranges, Indigenous and culturally and linguistically diverse backgrounds as well as women who lived in rural areas. Studies were grouped to compare findings across different ages and life stages to compare prevalence of depression in women who were young, women who were pregnant, and women who were middle-aged or elderly. Studies that presented and compared data from both men and women were also included. The findings of the critical review demonstrated that where men and women were compared, women were more likely to experience depression compared to men (Donald, Dower, Lucke, & Raphael, 2001; Goldney, Fisher, Dal Grande, Taylor, & Hawthorne, 2007; Trollor, Anderson, Sachdev, Brodaty, & Andrews, 2007). Rates of depression in women found across studies ranged from as low as 4.3% (Batterham, Christensen, & Mackinnon, 2009) to as high as 43.9% (Donald et al., 2001). Lower rates of depression were found in those studies involving older women (Batterham et al., 2009), whilst higher rates were demonstrated in those studies involving young women of Indigenous (Deemal, 2001) and Asian (Heaven & Goldstein, 2001) background and women with chronic illness such as cardiovascular disease (Jacka et al., 2007). Throughout all ages and stages of life, stressful life events and trauma were associated with higher rates of depression, especially the presence of violent abuse during childhood and/or adulthood (Butterworth, 2004; Hegarty, Gunn, Chondros, & Taft, 2008; Loxton, Schofield, & Hussain, 2006; Trollor et al., 2007). The association between depression and separation, divorce and single motherhood was evident and thought to be attributable to socioeconomic factors such as financial stress and educational status, professional qualifications or lack thereof (Loxton, Mooney, & Young, 2006). In summary, the critical review proposed that the complex associations noted between age, stage of life, life events, demographics, illness and depression
suggested a multitude of pathways that could either precede the onset of depression or could occur as a consequence to its development (Rich et al., 2013).

The development of depression in a person is seen to be a highly complex and multifactorial process, incorporating a complex interplay between genetic predisposition and biological vulnerability (Kessler et al., 1993). Perception of life events (Nolen-Hoeksema, 1990), attributions to psychosocial stressors (Hammen, 2003) and modulation of the neuro-endocrine system via differing reproductive hormones (Steiner, Dunn, & Born, 2003) have all been offered as a plausible justification for the higher rates of depression observed in women. These factors appear reasonable, given the findings of a quantitative meta-analysis, which analysed five family studies and five twin studies to examine the familial aspects of depression (Sullivan, Neale, & Kendler, 2000). The meta-analysis concluded that depression was a complex disorder that resulted from the influences of both genetic and environmental interactions. The likelihood of heritability of depression was estimated to be in the range of 31% - 42%, and it was argued that any environmental influences that were aetiologically important appeared to be individual-specific. For example, there was little evidence to suggest that environmental influences common to all members of the family (such as socio-economic status) increased the likelihood of developing depression. Of the ten studies within the meta-analysis, five failed to reveal any robust or consistent gender differences in heritability (Andrews, Stewart, Allen, & Henderson, 1990; Kendler, Gardner, & Prescott, 2000; Kendler, Pedersen, Johnson, Neale, & Mathé, 1993; Lyons et al., 1998; McGuffin, Katz, Watkins, & Rutherford, 1996), creating a situation in which an alternative and more complex theory to explain the preponderance of depression in women is needed.

Depression in women is a health priority with a high economic and personal cost (WHO, 2009). This is due not only to its high rate of incidence but also to its earlier initial onset, tendency to be recurrent and chronic, and its association with other co-morbid mental health conditions (Blehar & Keita, 2003; Essau, Lewinsohn, Seeley, & Sasagawa, 2010). Women’s responses to medical interventions, both pharmacological and behavioural may differ to the response patterns seen in men and is therefore worthy of continuing research, especially in view of the limited work that includes gendered analyses of clinical drug trials. Effects of traditional pharmacological options for depression such as tricyclic antidepressants (TCAs), monoamine oxidase inhibitors (MAOIs) and selective serotonin re-uptake inhibitors (SSRIs) have noted mixed results. Some of the studies analysed reported more functional outcomes in women (Khan,
Brodhead, Schwartz, Kolts, & Brown, 2005; Quitkin et al., 2002), however many have found no significant differences between the two groups (Hildebrandt, Steyerberg, Stage, Passchier, & Kragh-Soerensen, 2003; Thiels, Linden, Grieger, & Leonard, 2007; Wohlfarth et al., 2004). The results of a large-scale study by Young et al. (2009) suggested that women respond more favourably to the SSRI Citalopram, arguing for the possibility of biological differences between the serotonergic systems of men and women. Furthermore, differences in bioavailability and half-life clearance of SSRI antidepressants in men and women has been identified by Weismann and Olfson (1995), adding further support to the need to understand the effect of medication on both men and women.

Given the mixed results of research investigating gender responses of pharmacological treatments, it seems reasonable to question whether women’s responses to other biological treatments for depression such as ECT may also differ as a function of their unique physiological functioning. A thorough literature search revealed very few studies that attempted to separate data according to gender. One retrospective chart review compared 20 men and 23 women with a diagnosis of depression who were treated with ECT (Bloch et al., 2005). These findings were then compared with those of 11 men and 19 women with schizophrenia who all received ECT in the same treatment setting. The findings demonstrated that depressed women received fewer antidepressants before being referred for ECT when compared to the number of antidepressants that men received. A similar finding occurred with antipsychotic medications. Women with schizophrenia were offered fewer trials of antipsychotic medications before being referred for ECT than their male counterparts (Bloch et al., 2005). Although the treatment outcomes appeared to be more efficacious for the women with schizophrenia who were treated with ECT when compared to men with schizophrenia, no significant difference between the outcomes of men and women with depression was observed. It was proposed that in this particular sample, the women with schizophrenia might have exhibited more depressive symptoms, leading to more favourable outcomes (Bloch et al., 2005). The authors concluded that differences in help-seeking behaviour by women could also have explained the gender differences seen in the rates of ECT, although they could not rule out a gender difference in the prescribing doctor’s attitude towards referring certain individuals for ECT in the first place.
Hormonal Activity Across the Lifespan

Pubertal changes

It has been suggested that the dysregulation of sex hormones is to blame for the gender bias of depression in women, with origins in the fluctuation of hormones in puberty (Angold et al., 1998). It could be argued that this timing coincides with hormonal activity that plays an important role in the onset of depression, or which may be related to some other correlate of adolescence responsible for the rising incidence of depression in girls. Some studies have shown a higher rate of depression in boys prior to adolescence, however by mid-puberty this trend appears to reverse with the prevalence of depression tripling in girls in the post-adolescent period (Angold et al., 1998). Pubertal status, rather than age or the timing of puberty, has been found to be more predictive of rising rates of depression. Mid-pubertal change in rates of depression in girls excludes early hormonal activity as a likely explanation, but there is suggestion that a combination of cognitive effects, the social impact of puberty, life stress and the direct action of hormones throughout the adolescent period could be viewed as likely factors (Angold & Worthman, 1993). In a study of 103 adolescent girls (aged 10-14 years) Brooks-Gunn and Warren (1989) suggested that only 4% of the variance reported was related to the effects of oestrogen, and that 17% of the variance was accounted for by the combination of oestrogen and life events. Nolen-Hoeksema and Girgus (1994) argued for an alternative explanation to that of chaotic hormonal activity in early adolescence. They suggest that rumination, a pervasive pattern of cognition characterised by reflection and worry is apparent in young girls by age 13. Rumination is seen as a coping strategy that involves reflecting to the self or to others. This is very different to the preferred masculine style of coping shown by boys and young men in which direct action is taken to alter the situation. Although there are a variety of competing paradigms, clearly adolescence is a critical marker for ensuing changes in women’s mental health and psychological functioning (Nolen-Hoeksema & Girgus, 1994).

Pre-menstrual changes

The role of hormonal activity in the development of depression has also been examined across the life span of adult women, with attention paid to critical time points such as the pre-menstrual period, pregnancy and menopause when levels of oestrogen, progesterone and testosterone fluctuate markedly (Angold & Worthman, 1993; Steiner et al., 2003). The DSM-5 (APA, 2013) now recognises that some women suffer significantly distressing mood disturbances during the pre-menstrual period and
it has been estimated that the vast majority of women with regular menstrual cycles experience some form of minor mood shift within the pre-menstrual period (Wittchen, Becker, Lieb, & Krause, 2002). The inclusion of Premenstrual Dysphoric Disorder (PDD) as a separate condition within the DSM-5 signifies that in some women, severe pre-menstrual distress may be classified as a mental illness, even when it is accompanied by clear physical evidence of hormonal fluctuation. Within the diagnostic criteria, PDD is characterised by a cluster of symptoms (dysphoria, irritability, and anxiety) that occurs during the premenstrual period, remits completely with the onset of the menses, and which causes significant interpersonal, occupational and/or social distress. According to the DSM-5:

> The intensity and/or expressivity of the accompanying symptoms may be closely related to social and cultural background characteristics of the affected female, family perspectives, and more specific factors such as religious beliefs, social tolerance, and female gender role issues. (2013, p. 172)

The DSM-5 reports a prevalence rate of PDD in the range of 1.3% - 1.8% (APA, 2013). However, a two-year community-based longitudinal study of 1,488 women estimated the prevalence rate of PDD in women to be as high as 5.8% (Wittchen et al., 2002). An additional 18.6% of women in the study reported symptoms severe enough to cause significant monthly impairment, but which fell short of the full diagnostic threshold. It should be acknowledged that these statistics are taken from a population of white, Western women, making generalisation to other cultural and ethnic groups difficult (Jack, Ali, & Dias, 2013). It does seem clear though, that the DSM-5 addendum relating to psychosocial factors within the criteria for PDD adds significant weight to the argument that for some women, responding to a regularly cyclic and biological event creates a situation where symptoms are classified as a mental illness by virtue of the contemporary psychiatric classification system.

**Post-partum changes**

The post-partum period has also been acknowledged as a time within women’s reproductive journey that is highly vulnerable to the influence of rapid hormonal fluctuations (APA, 2013). Both psychotic and non-psychotic mood disorders can be precipitated by pregnancy or childbirth, and given that these mood fluctuations occur simultaneously with chaotic hormonal fluctuation, it seems plausible to offer a causal link between the two (Steiner et al., 2003). Once again though, this explanation does little to account for the impact of the added strains of being a new mother, the quality of
couple relationships (Boyce, Hickie, & Parker, 1991) or the context of women’s lives and the cultural construction of idealised motherhood that is internalised by women. Steiner et al. (2003) are also quick to note that the cascade of biological, psychological and emotional changes in the post-partum period is so profound that it makes it difficult to make any definitive conclusions about the role of hormones in a singular hypothesis.

Menopausal changes

The peri-menopause and menopause have been a focus of intense attention, with research highlighting that these transitions are precipitated by major hormonal disruption and are associated with physical and psychological symptoms (Krishna, 2002; Steiner et al., 2003). The key characteristic of menopause is the gradual depletion of oestrogen and although once thought to require medical intervention, menopause is now seen to be part of a normal ageing process that does not require medical treatment unless for the prevention of osteoporosis or cardiovascular disease (WHO, 2007). The association between menopause and mood disorders is less well understood, however it has been suggested that the use of hormone replacement during the menopause may prevent mood disorders or serve to function as a treatment for those women with a mood disorder via regulation of oestrogen (de Novaes Soares, Almeida, Joffe, & Cohen, 2001; Schmidt et al., 2000; Wharton, Gleason, Olson, Carlsson, & Asthana, 2012). There have been over twenty clinical studies utilising hormone replacement therapy as a treatment for peri-menopausal and menopausal women diagnosed with depression (Wharton et al., 2012), and the majority of these studies have demonstrated that oestrogen replacement can assist with cognitive function, mood and quality of life (Almeida et al., 2006). For example, in a double-blind and randomised placebo-controlled trial, transdermal oestradiol alleviated depressive symptomatology in 68% of women, compared to only 20% of women in the placebo, with the antidepressant effect maintained after a 4-week washout period (de Novaes Soares et al., 2001).

Despite the evidence from these studies to illustrate the importance of hormonal activity in the development and/or maintenance of mood fluctuations during menopause, numerous studies have failed to show support for the proposed association between hormonal depletion and depression (Dennerstein, 1996; Kessler, 2003; Yonkers, Bradshaw, & Halbreich, 2000). The results of Australian research has also argued that not all women experienced depression in their midlife years, and that expectations of menopause are much more negative than the realities of the transition (Perz & Ussher, 2008). As part of a larger study investigating women’s subjective
experiences of midlife, Perz and Ussher (2008) interviewed 21 women from rural and urban regions of Australia to investigate women’s experiences of their bodies, their meanings of life and change during the mid-life years. Women were married or partnered, had an average of two children and all were employed. Themes from the interviews centred around feeling positive, looking forward to the future, having increased confidence, a greater ability to generate time for themselves, and having more self-awareness and self-worth. These findings resonate with earlier research, in which many women in their mid-40s and mid-50s have reported feeling good-natured, clear-headed, confident, loving, useful and satisfied (Dennerstein, 1996), which is at odds with the previously discussed research supporting an association between hormonal depletion and mood. It appears that social and relational context plays a large role in the perception of emotional distress for women and menopause, rather than the hormonal shift in mid-life. Shifts in family dynamics, marital satisfaction and relationship conflicts function as a possible predictor of psychological distress during menopause, just as they would at any other time of the lifespan (Kaufert, Gilbert, & Tate, 1992).

Mood disturbances related to menopause may also be a function of the cultural construction of ageing as well as a function of neuroendocrine moderation. Both Richters (1997) and Krishna (2002) assert that menopause is seen to be a liberating time of flourishing personal and economic power and social status for women in small traditional countries. Large-scale industrial countries on the other hand, often view the menopausal transition as a time of loss and crisis (Richters, 1997). It is therefore essential to recognise that conclusions associating menopausal hormone deficiency and depressed emotional state cannot be generalised to all women.

The Context of Gender Roles and Stress

Contributing factors

It is evident that women’s health is intimately linked to their social status in life, and that gender inequality, discrimination, poverty and violence can impact gravely upon their wellbeing (WHO, 2009). In 1997, the United Nations concluded:

No society treats its women as well as its men. (1997, p. 39)

Social determinants of health such as paid employment, secure and safe accommodation and adequate nutrition have been recognised as pivotal in health and wellbeing, and gendered inequities in these areas have been reported as significant
factors in the development of depression in women (WHO, 2009). Research undertaken in India, China, Zimbabwe and Brazil identified that women who were living in poverty with poor educational backgrounds reported high levels of depression, and that depression was more enduring in those women who experienced chronic and persistent economic deprivation (Patel, Araya, de Lima, Ludermir, & Todd, 1999). Similarly, women who live in societies that afford them higher economic control, autonomy over reproductive rights and greater political participation report greater life satisfaction and lower rates of depression (Kawachi, Kennedy, Gupta, & Prothrow-Stith, 1999). This may lead some to conclude that increasing women’s access to economic resources and employment and facilitating autonomous decision making with regard to reproductive rights could markedly reduce rates of depression in women.

Sexual violence remains a phenomenon that may add to women’s distress. Childhood sexual abuse, or sexual violence experienced later in life has been described as contributing significantly to the gender differences in the experience of depression (Buzi et al., 2003; Haskell et al., 2010). One study has reported that approximately 35% of the variance in the difference between rates of depression by gender can be accounted for by the presence of sexual abuse before the age of 18 years (Cutler & Nolen-Hoeksema, 1991).

**Discrimination**

Systemic discrimination and the experience of stigma remain significant contributors to women’s experiences of emotional distress. Women who perceive higher levels of sexism, racism and personal discrimination report higher levels of distress and depression. In a study of almost 11,000 Spanish women, gender and perceived racial discrimination showed consistent and positive correlations with high rates of depression (Borrell et al., 2010). These patterns of discrimination appeared to be moderated by social class, giving more strength to the role of social determinants in the development of poor mental health outcomes in women. Other forms of discrimination have been offered to explain high rates of depression in women.

There is a growing body of research to indicate significant disparity between the mental health outcomes of heterosexual individuals and those who belong to lesbian and bisexual populations (Balsam, Molina, Beadnell, Simoni, & Walters, 2011; Bostwick, Boyd, Hughes, West, & McCabe, 2014; Cochran, 2001). It has been estimated that lesbian and bisexual women report lifetime mood disorders one and a half to two times more likely than heterosexual women (Bostwick, Boyd, Hughes, & McCabe, 2010).
Health disparities noted among minority groups (including lesbian women) can be understood using the minority stress perspective (Meyer, 2003). This argues that poor mental health outcomes in sexual minority groups arise from a complex interplay of individual factors and socio-environmental contexts that include multiple experiences of institutional and interpersonal discrimination, prejudice and stigma (Bostwick et al., 2014). As an example, Canadian research involving 169 lesbian women demonstrated the linkage between experienced discrimination and psychological health. A positive association with depression was evident in those women who had experienced verbal threats, had experienced objects thrown at them, had their personal property damaged, or who had been sexually assaulted within their lifetime (Morrison, 2012). These findings add further support to the notion that enduring discrimination is detrimental to women’s psychological wellbeing.

**Gendered roles and stressful life events**

The construction of gendered roles is viewed as a significant factor in the persistence of depression in women. In a critical review of gender differences in depression, Piccinelli and Wilkinson (2000) argue that marriage, child-rearing and the gender-specific demands of family life may be detrimental to the mental health of women and may increase the risk of developing depression, due in part to the under-valuing of the traditional nurturing roles of wife and mother. Conversely, entering the workforce may place significant demands upon women and may ultimately create multiple role conflicts between the needs of paid employment and that of the family. Although being in paid employment is seen to be beneficial on numerous economic and psychosocial levels, it may in fact cause role overload and place women at risk of developing depression as a response to role stress (Piccinelli & Wilkinson, 2000).

To add to women’s confusion about their roles, a classic study by Broverman and his colleagues demonstrates the paradox of femininity. Their work demonstrated how women who either conform to or who reject the confines of traditional gender roles are both likely to be labelled as psychiatrically ill by mental health clinicians. This stereotyping is based on internalised stereotypes of femininity and masculinity and the clinicians’ evaluation and subsequent diagnosis of psychopathology (Broverman, Broverman, Clarkson, Rosenkrantz, & Vogel, 1970). It seems somewhat ironic that the act of either maintaining social expectations or forging a new sense of female identity is sufficient for society to view women through the lens of psychopathology and label her as mentally ill. This creates the situation whereby the social reality of her life can be
ignored and the full blame and responsibility for her responses can be located within
the woman herself.

Stressful events often precede or follow episodes of depression (Hammen, 2003; 
Ingram & Luxton, 2005). The stress-diathesis model of vulnerability helps to explain
this by suggesting that a pre-existing biological tendency towards depression (the
diathesis) may be triggered by a specific environmental and/or psychological factor (the
stressor) (Hammen, 2003). It is important to remember that the presence of the
diathesis is not enough to trigger an episode of depression in its own right. A co-
existing stressor however, which is cognitively interpreted as a profound loss or
invalidation within the context of a poorly regulated biofeedback loop of physiological
stress, may be a sufficiently strong antecedent from which depression may follow.

Hammen (2003) reported on the findings of a community study involving 800 Australian
women and their children with a focus on the experience of depression and life
stressors. Four key themes emerged with the experience of depression in these
women - dysfunctional parenting, dysfunctional intimate and romantic relationships, the
generation of stressful life events and the experience of enduring social disability even
when not currently depressed. These themes reflect important dimensions of
interpersonal functioning and important central relationships within women’s lives.
Vulnerability to depression may be enhanced by maladaptive cognitive beliefs about
attachment, intimacy, parenting and stress and these may both cause, and contribute
to, the ongoing experience of depression.

**Cognitive theories**

Other cognitive theories have offered compelling arguments to explain the difference in
rates between men and women. Kelly et al. (2007) have suggested that men see the
cause of depression as stemming from physical illness or work-related stress
depending on their work status, whilst women hold constant a variety of interpersonal
attributions such as family illness, relationship difficulty and role overload. The
response bias hypothesis – the belief that men have a tendency to under-report
symptoms of depression due to the perception that depression is somehow less
masculine and reflecting a weakness of character (Brody & Hall, 2000), has been long
offered as an explanation for the inflated gender differences observed in rates of
depression. In a sample of 622 male and female European-American college students
Sigmon et al. (2005) examined the impact of gender-specific attitudes towards mental
health upon willingness to self-report depressive psychopathology. They measured
symptoms of depression, beliefs about mental health (worry about symptoms,
avoidance of thinking about significance of symptoms, attention paid to presence of symptoms, and fear of hospitalisation) and traits of social desirability. Participant follow-up was manipulated from (a) no further contact; (b) referral to a mental health service was provided to the participant by the research team; (c) participant was contacted by mental health service if significant depressive symptomatology was evident; or (d) participant plus a significant other was contacted by the mental health service if self-harm was suspected. The authors found that as the level of potential follow-up became more intrusive, men reported fewer depressive symptoms than women. In addition, women appeared to be more fearful (and therefore more attentive) to their symptoms of depression, which appeared to lead to a greater expression of help-seeking behaviours. Men became more avoidant of articulating their concerns, and they showed less willingness to seek medical attention. It must be highlighted again that these results may not be universal, and that cultural display rules of emotional expression may confound any findings from this particular study.

The Australian Context of the Consumer Movement, and Public Perceptions of ECT

As briefly outlined in chapter two, the Consumer Movement with the international catch-cry of “Nothing about us without us” reflected both the desire and the need to offer personal narratives from those with the experience of mental illness to inform clinical practice. These stories could be seen as a medium through which to view consumers' unique understanding of the world, and to offer an alternative to the assumption that knowledge originating from scientific experiment was the only true and valid source. Beresford (2000, p. 493) defines these narratives as “hidden users knowledge”, and although they are becoming more prevalent within scientific literature their quality continues to be devalued by dominant scientific discourse, suggesting that they lack true scientific authority and legitimacy (Phillips, 2006). The paternalistic opinion that only those with professional qualifications are able to speak on behalf of those who live with mental health disorders prevails (Beresford, 2000), and this view prevents any disagreement or challenging of dominant assumptions with regard to knowledge and truth. The local Australian experience highlights this well and is deserving of brief discussion.

The Local Australian Response

The way in which Australia has historically provided mental health care has been the centre of numerous high-level governmental Inquiries and Royal Commissions since the early 1990s. The Report of the National Inquiry into the Human Rights of People
with Mental Illness (HREOC, 1993) provided evidence that the fundamental human rights of people with a mental illness were being grossly and systematically violated under the facade of effective transfer of care from the inpatient setting to the community via deinstitutionalisation. Despite numerous recommendations for change, the Not For Service Report: Experiences of Injustice and Despair in Mental Health Care in Australia (Mental Health Council of Australia, 2005) published some twelve years later showed that little had changed, and that consumers and their families were still articulating personal narratives of “injustice and despair” as they sought care from within the public and private mental health sectors (2005, p. 19). This time, consumers and carers found it difficult to access acute inpatient beds and timely care, and stigmatising community attitudes were preventing people with mental distress from experiencing a quality of life. Again, numerous recommendations were offered, yet a recent National Review of Mental Health Services and Programs (National Mental Health Commission, 2014) suggests that the system of mental health care currently operating within Australia remains fragmented, demand-driven, and operating within various silos of isolation. It fails to keep consumers and their loved ones at the centre of care, and in doing so offers up the most vulnerable people in our community to a culture of enduring stigma, discrimination and an environment of inequality and anguish (National Mental Health Commission, 2014).

These significant governmental reports are pivotal in the history of Australian mental health care, in no small part because they provide detailed personal narratives by consumers and carers. In this way, their voices become clearly articulated as sources of true and valid knowledge and expertise, thereby resisting the dominant biomedical regime as it continues to assume legitimate authority over their care (Engel, Zarconi, & Pethetl, 2008). There is a mandate put forth by the Mental Health Consumer Movement to include and articulate the views of consumers when planning, designing, implementing and evaluating services (Phillips, 2006). This very same obligation holds true for social and medical research, yet a search within the literature reveals that this imperative has been more slowly upheld than the directive for service delivery.

The Fourth National Mental Health Plan (Commonwealth of Australia, 2009) and the Queensland Plan for Mental Health 2007 – 2014 (Queensland Health, 2008) are two of the various state and federal policies that articulate principles designed to guide mental health reform, change and improvement. One of these principles refers to the need for consumers to be involved in research activities. Yet the clear lack of research outcomes or published works would suggest that this principle has not yet been fully
translated into action. There is a distinct tension that exists between the ideology of including consumer participation in the delivery of clinical services and research agendas, and the reality in which their participation is (often) directly prevented. As Hunt (1997) asserts, there is significant evidence to suggest that in Australia, a “non-participatory, biomedical research model remains a dominant paradigm” (1997, p. 49) despite a growing acknowledgment for the need for more participatory research in healthcare. This is not simply an isolated experience here in Australia; indeed it mirrors work undertaken internationally, where barriers to consumer participation within research and service delivery are noted repeatedly within the literature (Wallcraft, Amering et al., 2011). It could be suggested that the biopsychiatric model views the experiences and perspectives of consumers through a lens of disease and diagnosis, where the aim of treatment is to cure disease, or at the very least, minimise symptoms (Deacon, 2013). This model can create a situation in which the consumer’s perspective is often discounted or ignored within mainstream research, evident through an absence of literature to incorporate consumer’s experiences. The biomedical view effectively places consumers in a passive role with implications for the way in which they experience care. Firstly, as the consumer’s experiences and emotions are categorically organised according to specific diagnostic classification, this “labelling” creates two possible outcomes: a transfer of ownership of the person’s body to the medical system; and the creation of negative socially and medically constructed meanings of a mind that is diseased (Susko, 1994). These resultant outcomes of labelling with a mental disorder are not a new discovery. Parsons (1975, p. 262) describes four major consequences of being labelled with a mental disorder. These include: (1) being exempted and relieved of daily expectations and tasks; (2) needing to take no responsibility for their current situation; (3) the person must want to try to get well; and (4) they must hand over responsibility and power to whomever society sees fit, responsible or competent to help them get well (that is, mental health services and professionals).

Clinical and research driven practices that directly exclude the participation of consumers contribute to an inequitable situation between those who legitimately “know”, and those who “think” they do, resulting in a silent voice for those who have experienced the challenges of living with emotional health issues (Scheyett, 2006). As Lapsley et al. (2002, p. 4) asserts, it is not by chance alone that consumers have been “stigmatised, regarded as unreliable sources, and denied a voice in the literature of mental health”. This is the direct result of dominant biopsychiatric discourses that deny
the right to those to have their experiences heard loudly enough to make any sort of social, political or interpersonal change.

**Consumers' Experience of ECT**

There is little research exploring either the perspective of the person who is receiving ECT or the lay public’s perceptions of the treatment, although some autobiographical accounts of individuals who have received ECT can be found within the literature (Donahue, 2000; Watkinson, 2007).

Further qualitative research to specifically involve women who have received ECT is significantly absent from the literature, above and beyond a very small handful of clinical case reports that are not specific to women with depression (Burke, Shannon, & Beveridge, 2007; Tran et al., 2015). It was not surprising that throughout the life of this literature review only five studies specific to the experience of women were found. A summary of these studies and their main findings can be found in Table 2, and a more detailed discussion of these studies can be found in a later part of the chapter. Although these studies are lacking in numbers, the authors agree that for the most part, ECT is an experience that carries negative views for women irrespective of the functional outcome of the procedure.
Table 2: Qualitative literature review of studies involving women and ECT

<table>
<thead>
<tr>
<th>Source and methodology</th>
<th>Sample Population</th>
<th>Methods</th>
<th>Main Findings/Claims</th>
</tr>
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<tbody>
<tr>
<td>Burstow, B. (2006). Electroshock as a form of violence against women. <em>Violence Against Women, 12</em>(4), 372-392. Feminist standpoint research Aim: To provide a reframing for ECT as a form of violence against women Testimonial data drawn from archives of public hearings into use of ECT in Toronto (1984) Other testimonies obtained from archived video material, published autobiographical stories and previous literature to facilitate a triangulation of sources No method overtly claimed although appears likely to have used thematic analysis to analyse transcripts of testimonies ECT is a barbaric assault on women’s memories and bodies ECT reframed as a method of social control Themes of helplessness, trauma, punishment and compliance evident in testimonies Memory loss is permanent for most women</td>
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<td>Orr, A., &amp; O’Connor, D. (2005). Dimensions of power: Older women’s experiences with electroconvulsive therapy (ECT). <em>Journal of Women and Ageing, 17</em>(1/2), 19-36. Post-modern feminist and phenomenological research Aim: To explore the subjective experience of older women who receive ECT 6 women aged 71-89 years who had received ECT In-depth face-to-face interviews Powerlessness and feeling out of control in the face of unexpected depression Trust in doctor was equated to getting along with the doctor Most women did not recall signing consent forms; felt they had no choice in the decision. Majority described negative outcomes of memory loss</td>
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<tr>
<td>Study</td>
<td>Participants</td>
<td>Methodology</td>
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<tr>
<td>van Daalen-Smith, C. L. (2011). <em>Waiting for oblivion: Women's experiences with electroshock. Issues in Mental Health Nursing, 32, 457-472.</em></td>
<td>7 women aged 44-65 years (2 currently receiving ECT) who had received ECT up to 30 years previously</td>
<td>Face-to-face focus groups with women</td>
<td>ECT impacted women biopsychosocially, spiritually and financially; often seen as a major trauma</td>
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<td></td>
<td>15 Registered Nurses who participated in the procedure</td>
<td>Focus group with 11 Registered Nurses</td>
<td>Women placed “blind trust” in their doctors to get well, no other option to getting well</td>
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<td></td>
<td>4 Registered Nurses engaged in individual face-to-face interviews</td>
<td>Registered Nurses worked in mental health units, 1 RN worked in peri-operative unit</td>
<td>All women experienced “debilitating” memory loss, for some it was permanent</td>
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<td>All women felt they did not receive enough information before making their decision</td>
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<td>All women experienced the nursing care they received in both positive and negative ways</td>
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<td>RNs focused mainly on the physical care of patients post-procedure</td>
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<td>RNs’ knowledge of the procedure was variable</td>
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<td>RNs’ attitudes to ECT demonstrated deep sense of care and ethics, although some expressed concern at the informed consent aspect</td>
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<td>Ejaredar, M., &amp; Hagan, B. (2013). All I</td>
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<td>have is a void: Women's perceptions of the benefits and side effects of ECT. <em>International Journal of Risk and Safety in Medicine</em>, 25, 145-154</td>
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<td>benefit with ECT, albeit temporary</td>
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<td>Seven out of nine women complained of persistent autobiographical memory loss, cognitive deficits and fear related to the ECT</td>
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<td>Several women associated the procedure with stigma</td>
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<td>Ejaredar, M., &amp; Hagan, B. (2014). I was told it restarts your brain: Knowledge, power and women’s experiences of ECT. <em>Journal of Mental Health</em>, 23(1), 31-37.</td>
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<td>Majority of women found experiences with ECT to be negative</td>
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<td>Experiences were characterised by a lack of knowledge prior to giving consent, especially with regard to memory loss</td>
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<td>Some women were given highly simplistic explanations</td>
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<td>Women described feeling pressured and coerced to consent</td>
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<td>Decisions were made when women felt desperate</td>
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<td>Some women found ECT to be dehumanising and depersonalising</td>
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Although ECT has been identified as a procedure used in the management of clinical depression (Chakrabarti, Grover, & Rajagopal, 2010; Kellner, Tobias, & Wiegand, 2010; Pagnin, de Queiroz, Pini, & Cassano, 2008; Taylor, 2006), it continues to be viewed with stigma and suspicion (Amazon, McNeely, Lehr, & Marquardt, 2008; Cyrzyk, 2011; Dowman, Patel, & Rajput, 2005). Perceptions of the ECT procedure and attitudes held by individuals who have received it have been the subject of interest for the last three decades, led by the pioneering work of Freeman and Kendall (1980). They interviewed 166 individuals who had received ECT in the preceding twelve months and concluded that the vast majority did not find the procedure to be distressing, unpleasant or painful. Although one third of their participant sample complained of “permanent” memory loss, the authors maintained that individuals held positive views about their experience. The magnitude of the reported memory loss in research from 25 years ago is a noteworthy issue, yet Freeman and Kendall’s (1980) conclusion is often quoted in the literature as evidence of consumer satisfaction with ECT. Furthermore, these results often contradict findings from a wide variety of quantitative studies in which a large number of individuals find ECT to be both physically and psychologically distressing (Fox, 2009; Johnstone, 1999; McCall, 2008).

Rose and colleagues (2003) undertook a systematic review of 28 studies that explored satisfaction and perceived benefits of the treatment, rather than simply measuring improvement in clinical outcomes and reduction of depressive symptoms. Their review added clarity to the research methods best used for this type of investigation, by suggesting that length of time between treatment and interview was an important variable to control. They also suggested that discrepancies in levels of satisfaction previously reported across studies were influenced by whether the study was undertaken by clinicians or by consumers-as-researchers and by the level of complexity of the interview questions. It was noted that clinicians conducted those studies that indicated a high positive perception towards ECT. The research interviews for these studies occurred within a hospital setting, were conducted soon after the ECT course had been given, and were comprised of brief and low-complexity questions (Rose et al., 2003). Consumer-led research on the other hand, often occurred outside the clinical setting and in addition to the attitude questionnaires allowed participants to include their own qualitative comments.

It is likely that the perceived benefit might be a significantly more complex phenomenon than simply an improvement in symptoms. In the follow up qualitative analysis using data from Rose et al.’s (2003) systematic review, personal stories
obtained from consumers revealed themes that would not have emerged in quantitative research that was aimed at exploring attitude towards ECT alone. For example, consumers described feeling traumatised, becoming suicidal, and actively lying to doctors about improvement to prevent further treatment (Rose et al., 2004). This review highlighted the complex views that people hold when considering satisfaction with ECT. Those who received the treatment appeared to make complex trade-offs between perceived benefits and the adverse effects (especially memory loss). Considering the concept of satisfaction with ECT as a linear, or a one-dimensional construct is overly simplistic. Viewed this way, it fails to validate the complex way individuals perceive whether ECT has been helpful in their given situation (Rose et al., 2004).

The authors argued that none of the studies they reviewed captured the complex ways in which individuals made their personal evaluations of the treatment, nor did they portray the “trade-offs” made between adverse effects and benefits of treatment in making decisions about whether they would repeat ECT in the future (Rose et al., 2003). To extend on the findings of this previous work, Rose, Fleishman, and Wykes (2004) subsequently obtained 139 qualitative stories from individuals who had received ECT. These personal stories were defined as a person speaking of, or writing of their experience with ECT (Rose et al., 2004). Stories originated from email forum material from a variety of pro- and anti-ECT websites, consumer newsletters and magazines, and the British Library oral history video archive. Using a grounded theory approach and a content analysis, Rose et al. (2004) identified twice as many negative stories as positive stories, with 60% (n=83) of consumers identifying that they would never repeat the treatment again. One third (n=43) of the personal stories showed a positive perception of the treatment, with consumers electing to repeat the ECT if required in the future. Only 10% (n=13) were ambivalent about whether they would repeat the treatment in the future. The content analysis of the testimonies clearly showed that consumers did not hold firm dialectic “pro-” or “anti-” ECT views, but made very complex and multi-faceted accommodations in relation to the perceived benefits of the treatment and adverse effects. This finding is relevant to the current research, as previous quantitative studies had been limited in their attempts to measure concepts of attitude and satisfaction with simple survey tools and questionnaires (Myers, 2007; Rush, McCarron, & Lucey, 2007). Yet it must be noted that Rose et. al.’s (2004) work was also limited by their choice of secondary data sources, a clear operational definition of what constituted either a positive or negative experience to ECT and an absence of any cross cultural analysis.
Consumers’ Experience of Memory Loss

One of the most consistent findings across all studies that explore the consumer’s perspective of ECT is that of memory impairment (Bakewell, Russo, Tanner, Avery, & Neumaier, 2004; Kellner et al., 2010; Sackheim et al., 2008). Persistent memory loss is reported in the range of 29% - 60% of consumers and these findings are consistently replicated across two decades of research. Early studies, systematic reviews, quantitative and qualitative work all show similar results (Fisher, 2012; Fisher, Johnstone, & Williamson, 2011; Freeman & Kendall, 1980; Koopowitz, Chur-Hansen, Reid, & Blashki, 2003; Lisanby, Maddox, Prudic, Devanand, & Sackheim, 2000; Rose, Fleischmann, & Wykes, 2004). These findings occur independently, regardless of whether the research has been led by clinicians or by consumer-researchers with a lived experience of mental health issues.

The difference between these two types of research is important in terms of outcomes that are measured or benefits that are assessed. Clinician-led research often involves measuring a change on symptom rating scales; consumer-led research has a focus on consumers’ perceptions of benefit and adverse effects (Rose, Fleischmann, Wykes, & Bindman, 2002). Rose et al. (2003) argued that the methods used to elicit consumers’ views on ECT influence the research findings, especially perceived benefit, adverse effects and willingness to repeat the treatment in the future. Attitude studies led by clinical researchers frequently suggest that between 70%-90% of those who receive ECT feel that they have benefited from the procedure (Rose et al., 2003; 2004). Yet consumer-led research generally demonstrates much lower levels of perceived benefit and more frequent reports of adverse effects (Donahue, 2000; Peddler, 2000; Rogers & Pilgrim, 1993).

The controversies surrounding memory loss remain, and clinicians and consumers often maintain divergent views with regards to the magnitude of the problem. In Rose et al.’s (2004) work, the effect of ECT on memory was the most commonly reported theme across all sources of personal story. Memory impairment was noted in 99 out of 139 sources. There was little variation noted as a function of time, with people who had received ECT recently describing similar memory difficulties as people who had received ECT almost 50 years earlier (Rose et al., 2002; 2004). Clinicians often judged the problem of memory loss to be a transient and short-term phenomenon, whilst those who were the recipients of ECT often regarded it as significant and persistent. Within the clinical studies, it was noted that a significant problem with evaluating the association between ECT and memory loss lay in being able to differentiate between
the memory loss caused by ECT, and the memory loss caused or maintained by the nature of the depression it was treating. The review acknowledged that although memory problems were commonly associated with clinical depression, there was very little scientific evidence to suggest that traditional treatments such as antidepressant medications were associated with an increase in long-term memory problems in the way that ECT was (Rose et al., 2002).

An assessment of memory loss following ECT usually measures the difficulty in encoding and retrieving information experienced after the ECT period (Robertson & Pryor, 2006), known as anterograde memory loss. Retrograde memory loss on the other hand, is defined as amnesia for memories encoded before the ECT period. Although it has been thought that procedural memory, such as remembering how to drive a car or make a cup of tea, is generally left intact following ECT, it has been noted that this is an area lacking in research (Rami-Gonzalez et al., 2001). Furthermore, limited attention has been paid to the impact of ECT upon autobiographical memory. This specific type of memory is comprised of recollections of past events that are created through personal experience, consisting of specific memory (memory of a specific event) or non-specific memory (memory of a series of events). Specific memory captures events that occur for less than one day (“the birth of my second child”), whilst non-specific memory can be classed as either categorical memory that incorporates a series of events (“every time I have travelled”) or extended memory that occurs for events lasting more than one day (“the entire two weeks of our last holiday”) (Aglan, Williams, Pickles, & Hill, 2010).

Consumer-led qualitative research often pays close attention to the loss of autobiographical memory. Donahue (2000) gives a personal narrative account of how personal and emotional memories were lost following her course of ECT three years earlier. Whilst she believes that ECT saved her life, she describes discovering amnesia for events that she did not realise were missing until layers of information built up from conversations with family, friends and colleagues exposed the gaps in her recollection of daily life. She acknowledges how deeply this discovery altered her self-concept:

To what degree was I a different person, someone I did not even really know, because I had lost so much memory of my past ... the more I heard, the more I realised what I had lost, as one topic led to another. I have experienced more than a “cognitive deficit”. I have lost a part of myself. (Donahue, 2000, p. 134)
Donahue (2000) describes the impact of memory loss upon her relationships with both casual and close friends. Social isolation and withdrawal was needed as she tried to create a sense of meaning to the disconnection between reality and her memory of such. Acceptance was eventually found by creating a new constructivist perspective to her experiences. However, this did not come without a personal cost:

Despite acceptance and a growing comfort in talking openly … despite working through the experience of losing part of my sense of self, I remain bothered by a sense of incompleteness. It is obvious that if there is a serious side effect after heart surgery, there is follow-up intervention. The patient is checked for residual bleeding. I had not been checked for residual bleeding. I felt left hanging. (Donahue, 2000, p.139)

It has been suggested that consumer accounts such as Donahue’s are a rare occurrence and that it is likely the memory loss is an artefact of the underlying depressive illness (Brodaty, Berle, Hickie, & Mason, 2001). This is an argument that is difficult to reconcile methodologically, especially given the issue of measuring autobiographical memory reliably. Yet other qualitative work has echoed similar experiences for some women, suggesting that memory loss following ECT creates an alternative and disconnected sense of self (van Daalen-Smith, 2011).

Van Daalen-Smith (2011) undertook a qualitative study to investigate women’s lived experiences with ECT. The study included focus groups and in-depth interviews with seven women who had received, or who were currently receiving ECT to determine the impact of the procedure on their health and quality of life. The women felt that at the time of consent they were not in a physical or psychological state that allowed for a full comprehension of the procedure. They attributed this to the high doses of medication they were prescribed, and the way in which they perceived their position within the mental health system. They placed “blind trust” in their doctors (van Daalen-Smith, 2011, p. 463), believing there was no other option if they wished to get well. Van Daalen-Smith observed that the memory loss experienced by the women appeared to have impacted upon a fundamental quality for most women – the ability to construct and explain narratives and stories in a way that was coherent, with concepts interwoven in a rich and detailed manner that was layered with thick description and meaning. Post-ECT, the research interviews were noted by van Daalen-Smith to be “choppy, periodically out of order and occasionally repetitive” (2011, p. 465). As a result, the women appeared to have lost their credibility as historians, and also as self-agents of influence and change, acquiescing to the credibility and greater social power
of the dominant medical hierarchy to define their experiences and make medical decisions for them. As van Daalen-Smith succinctly writes: “They have lost credibility ... with themselves. This may be the most devastating side effect of all” (2011, p. 465).

Notwithstanding the effects of memory loss, research has uncovered a variety of additional adverse effects described by consumers. Harrison and Kaarsemaker (2000) found that some particular physical side effects such as intense post-ECT headache can be distressing enough for some individuals to withdraw from treatment prematurely, despite ECT providing remission from the symptoms of the underlying disorder. This highlights the fact that although a treatment may remit symptoms, it does not automatically create the perception of personal satisfaction.

Dowman et al. (2005) assert that fear and anxiety are commonly associated with ECT. Whilst the greatest source of this anxiety is related to waiting for the procedure itself, other distressing aspects of treatment include the use of injections, waiting with other people who are also receiving ECT and the general anaesthetic and recovery process (Dowman et al., 2005). Fox (2009) makes a suggestion that individuals who receive the treatment as an ambulatory, outpatient procedure do not like ECT because of the repeated trips to hospital and the need to burden family and friends with transportation and care issues following the treatment.

Fear as an emotion associated with ECT has been well documented but not well understood (Fox, 1993, 2009; McCall, 2008). It has been suggested that it may have origins in the general apprehension associated with waiting for the procedure or the anaesthetic process, Gallinek (1956) recognised that the fear associated with ECT appeared to be disproportionate, much higher than anxiety associated with any other short surgical procedure. Following interviews with 100 individuals who had received ECT, he offered the observation of a fear that originates in the first treatment, increases throughout the course of the treatments and becomes heightened enough to prevent the individual from recognising the need for future ECT if and when their psychiatric condition warranted it. His hypothesis was that the aetiology of the fear lay with the uncomfortable aspect of regaining consciousness in an amnesic state and finding re-orientation difficult. The study also highlighted that fear of ECT was difficult to explore; individuals rarely disclosed it and it took intense questioning to elicit it. Fox (2009) offers the explanation of aversive conditioning, whereby individuals in a prolonged and heightened state of anxiety over the time course of ECT were thought to develop a heightened sensitivity within the fear centre of the amygdala. This biomedical explanation places fear as an adverse side effect of the procedure, rather
than an individual emotional response to a personally stressful event. Although this may be seen as a more sensitive way of acknowledging and contextualising pre-procedure discomfort, it would seem appropriate to suggest that the use of a dominant medical lens could belie the valid reality of some individuals’ perceptions and lived experiences.

It has been established that the perceptions of ECT held by the general public have been, in the majority, of a negative view and this is certainly not without some justification. The crude beginnings and history of the treatment, the provision of the treatment without anaesthesia or muscle paralysis, indiscriminate use amongst a variety of mental illnesses, and the emergence of alternative pharmacological treatments have all contributed to a poor acceptance of the procedure (Cyrzyk, 2011; Dowman et al., 2005; Hilton, 2007; Payne & Prudic, 2009). It has also been identified that public misconceptions are largely created and maintained through the dissemination of misinformation, originating in lay news reports and articles, media and literary representations, anti-ECT lobbying and the Internet (Payne & Prudic, 2009). The most prevalent themes identified by the lay public are that ECT is painful, that it erases memory, that it is a torturous and barbaric treatment, and that individuals receiving ECT are not actually told what is happening to them (Dowman et al., 2005). There is fair reason for these concerns – ECT is a medical procedure in which individuals who administer it, research it or fund it significantly downplay any risk involved (Andre, 2009). Whilst this argument will form part of a discussion in a later chapter, it must be noted that there is a scientific tendency to minimise side effects, suggesting instead that ECT is a safe and effective treatment. Yet, rather than accepting that ECT is associated with memory loss and openly accepting critique of the procedure, proponents of ECT merely hold the view that the science behind ECT is limited (Andre, 2009). This leads to an untenable situation in which the dominant psychiatric industry continues to maintain control over information that is released into the public domain, effectively silencing any political or sociological criticism.

A Politics About Women, and Depression

As it has been previously highlighted, the fact that women suffer from the effects of emotional distress at rates far higher than that of men is certainly not a random event. There are other contributing mechanisms that operate independently to those circumstances that occur across women’s developmental lifespans. These factors increase women’s risk of responding to life stressors with a variety of psychological sequelae. The experience of emotional distress can be significantly influenced by a
range of socially constructed phenomena such as the diagnostic process itself, activities that originate from mass media activities and strategic marketing by pharmaceutical companies.

The power of the diagnosis

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) is the dominant Western diagnostic classification system used to categorise a plethora of mental ills. Clinicians, patients, insurers, researchers, statisticians and epidemiologists and the pharmaceutical industry all use it routinely within a variety of contexts, settings and populations. The current edition (the DSM-5) is the latest version since its inception in 1952, when a total of 106 disorders were noted (Andreasen, 1988). Today, the DSM-5 contains close to two hundred specific and different mental disorders (APA, 2013).

This current version has been highly criticised. Allen Frances (as Chair of the Taskforce responsible for the revision of the DSM-5) was scathing of the processes behind the revision, especially the initial requirement for Taskforce members to sign non-disclosure agreements. This effectively prevented transparency of the ways in which existing diagnoses are revised and new ones developed (Frances, 2014). Frances also highlighted the process for the inclusion of current diagnoses, explaining that different disorders were not there through any logical or rationally scientific process or merit, rather through “practical necessity, historical accident, gradual accretion, precedent and inertia” (2014, Chapter 1, Section 9, para. 4).

The DSM-5 is constantly in a state of flux and change. Revisions are proposed at least once each decade, giving rise to the notion that the very way in which mental illness is conceptualised and defined is constantly dynamic and shifting. As an example, the initial draft of the DSM-5 attempted to have certain responses to grief labelled as a pathological depressive disorder rather than as a normal human reaction to loss. Given women’s connection to close relational ties with loved ones, it is not hard to envisage the number of women who, following the death of friends and loved ones, would be positioned to meet the criteria for a mental illness. Following an outrage on this draft document by professionals and the lay public alike, the APA included footnotes into the manual to remind experts of the difference between grief and depression (Carey, 2012). The British Psychological Society were also critical of the draft document, complaining that the DSM diagnoses were “neither value-free but rather reflecting current normative social expectations” (2011, p. 2). They aimed their criticism towards
new and existing diagnoses for lacking validity, reliability or prognostic utility, and for
the diagnostic classification all but ignoring social issues such as poverty,
unemployment and trauma as being the roots of many experiences of distress. Clearly,
not everyone was a fan of the new and revised classification model.

A continuing concern regarding the power of the DSM-5 has its origins in the number of
current taskforce members who are responsible for defining these diagnostic
conditions and who simultaneously hold financial relationships with industry partners
such as ECT machine manufacturers and pharmaceutical companies. This creates a
clear conflict of interest for both parties. Seven out of ten taskforce members reportedly
maintain financial ties with the pharmaceutical industry, an increase of 13% from the
previous DSM-IV almost 20 years earlier (Cosgrove & Drimsky, 2012). This conflict of
interest must be questioned, as doctors prescribe medications developed and
marketed by the pharmaceutical companies who pay them, and the pharmaceutical
companies who contribute funds towards the development and publication of the
psychiatric nomenclature that they use to diagnose and label women’s distress as a
clinical depression. Nevertheless, the centrality of the DSM-5 in mental health clinical
practice continues to significantly shape professional decision-making as expert. Thus,
women’s “lay” knowledge can be devalued, and non-medical options to treat emotional
distress can be made invisible, positioned out of sight and “not seen”.

The power of the media

The way in which emotional distress is advertised or promoted also influences the way
in which the experience is understood. Within the last decade, there has been a
significant push by national Australian initiatives to promote and increase mental health
literacy, defined as “the knowledge and beliefs about mental health disorders which
assist in their recognition, management or prevention” (Jorm et al., 1997). Following
the development of multimedia campaigns such as the “beyondblue” initiative
(www.beyondblue.org.au) and SANE (www.sane.org.au) anti-stigma websites, it
became commonplace to see advertisements for the recognition of anxiety and
depression in a multitude of popular women’s magazines and on the walls of public
amenities. These strategies encouraged more people to engage in conversations
about mental health whilst minimising the stigma associated with help-seeking
behaviour (Dunt et al., 2011). Without a doubt the campaigns have been successful,
with people far more willing to engage in conversations about their own, or a loved
one’s, mental health state than ever before (Dunt et al., 2011). Nonetheless there are
risks associated with such endeavours, and there is a possibility that women’s mental
health care may be jeopardised by the content of popular multimedia. Australian research undertaken in 1995 and 2011 attempted to track changes in mental health literacy across a 16-year period (Reavley & Jorm, 2012). Following on from the original data collection in 1995, it was noted that 74% of people were able to recognise symptoms of depression by 2011. There was also a significant change in the number of individuals who believed that antidepressants were an appropriate form of treatment. In 1995, only 28.7% of respondents favoured pharmacological treatment. By 2011, the number of individuals suggesting antidepressant medication as a front line treatment option had risen to almost 60% and almost 45% of those surveyed thought that their GP was the most appropriate person to prescribe them, rather than specialist psychiatrists.

Despite this seemingly positive increase in mental health literacy, these findings are worthy of comment. Reavley and Jorm (2012) suggest that increasing numbers of people endorsing mental health expertise by their GP demonstrates a positive shift of layperson beliefs about effective treatment towards those held by health care professionals. Yet there is a growing body of research that draws attention to the problems inherent in trying to change lay beliefs about depression to those consistent with diagnostic criteria. Gattuso and her colleagues (2005) investigated the impact of lay and professional beliefs about depression as circulated in popular Australian women’s magazines. They highlighted a dominant biomedical discourse of depression frequently seen in celebrity stories, advice columns and resource links. It has been suggested that although depression literacy within the scientific literature privileges medical or psychological expertise to explain depression and promote help-seeking behaviour, discourses within popular women’s magazines emphasise an alternative discourse of depression as predominantly a problem of women’s personal self-management and poor balancing of the demands of gender roles (Gattuso et al., 2005). Further, these alternative discourses suggest extending women’s social support networks or seeking medical pharmacological treatments as solutions to the problem (Gattuso et al., 2005). This view maintains the gendered nature of depression as a biologically determined condition rather than occupying a political position. It therefore encourages women to view their experience of distress as congruent with psychiatric terminology, and it then directs her to medical experts for assistance (generally using pharmacological interventions).

Metzl and Angel (2004) investigated women’s perceptions of depression by examining 81 magazine and 180 newspaper articles published between 1985 and 2000 that
depicted depressive illness. During this period, categories of depressive conditions such as premenstrual dysphoric disorder (PDD), postnatal depression and perimenopausal depression were increasingly treated with antidepressant medication. They found evidence to suggest that previously normative conditions of women’s lives such as marriage, motherhood, menstruation or other reproductive events were now expanded to become popular diagnostic categories of depression that required pharmacological treatment. These gender-specific criteria fell far outside the DSM-5 criteria for depressive disorders, yet over time media depictions have created situations that have shifted perceptions of the “normal/acceptable” and “pathological/treatable with SSRIs” of women’s lives. It must be noted however, that the magazines and newspapers used within this study were from a white Western background. This makes it difficult to compare or contrast them against other forms of written and/or visual representations from other cultures.

There is another powerful way in which media representation can influence the experience of women’s distress. This perception of illness can be observed through the discourse of language. As an example, in the same research Metzl and Angel (2004) established that women’s distress was described in emotive terms, whilst men’s distress was described in medical terms. In the newspaper and magazine articles analysed thematically, the authors found that women who were portrayed as needing antidepressant medication were described in terms that were not specifically related to DSM criteria, such as “feeling down”, “overwhelmed by sadness”, and “never feeling happy” (Metzl & Angel, 2004, p. 580), whilst men exhibited an illness of “depression” or other DSM specific terms, that has its origins in “biochemical roots” (2004, p. 580). Feeling down and overwhelmed, according to popular advertising within the magazines analysed, was enough to persuade women to visit their GP for treatment that was likely to make them happy once again. These antidepressants were depicted as the “Holy Grail” designed to cure the many woes of women’s lives, which appeared to grow greater in number with each passing year due in no small part to a phenomenon known as diagnostic bracket creep.

**Diagnostic bracket creep**

Diagnostic bracket creep describes the way in which new medications become the catalyst for a process in which psychiatric categories and diagnoses became more ambiguous and “fuzzy” as different conditions responded to the same drug (Zita, 1998, p. 68). This is a common occurrence when drugs are discovered to be effective for an expanding set of psychiatric disorders, leading to a surge in prescriptions and a
massive increase in revenue for pharmaceutical companies (Healy, 2004; Currie, 2005). The Selective Serotonin Reuptake Inhibitors (SSRI) are a prime example. Originally designed to treat severe depression, it was found that symptoms of anxiety also responded favourably to their use. Although this may simply relate to similar subjective descriptions of emotional distress, it has rapidly led to more women being prescribed antidepressant medications for their responses to stressful life events.

Hollingsworth, Burgess, and Whiteford (2010) investigated patterns of prescribing antidepressant medication within the context of prevalence rates of anxiety and mood disorders. Prevalence data obtained from the National Survey of Mental Health and Wellbeing (2007) was compared to the antidepressant prescribing data obtained from the Pharmaceutical Benefits Scheme from 2002-2007. It was established that many women were being prescribed long-term antidepressant medications by general practitioners for conditions that did not meet market approval or for episodes of depression and anxiety that did not meet diagnostic threshold. Hollingworth and colleagues acknowledged the lack of evidence supporting any association between increases in prescribing of SSRIs and an increasing prevalence of depression per se. The authors were not able to determine the exact conditions the antidepressants were being prescribed for in their research, however they did note that prescribing for conditions that did not meet approved indications (known as off-label prescribing) was common and occurred in three different scenarios – (a) for women who presented with sub-threshold conditions, despite strong evidence supporting cognitive psychotherapy as first line of treatment; (b) for diagnosable conditions that did not have therapeutic approval for the use of SSRIs (e.g. in women with eating disorders); or (c) prescribed for women with common complaints such as insomnia, or common emotional distress which do not actually constitute a mental disorder. Another alarming finding in this study relates to the high rate of antidepressant medication prescribed to women who are over the age of 90 years. Whilst it could be argued that there is now more public awareness of depression in the elderly leading to an increased number of people presenting for treatment, it seems unlikely that this explanation can account for such a high use in this population. Hollingworth et al. (2010) have considered whether this surge in prescribing patterns is driven by a comorbidity of anxiety and dementia in this age group, acknowledging that it is a situation that requires further research.

**Women and ECT**

Historically, women have been given few options other than those prescribed by the dominant psychiatric system (Appignanesi, 2008). Further, gender has been used to
define the experience and ultimately the treatment of mental illness in women (Ussher, 2011). It is not surprising then to consider ways in which contemporary treatment options may be seen to mirror this earlier struggle for autonomy and self-determination. ECT has been previously reframed as a method of violence against women. In an ethnographic study of women who had received ECT, Burstow (2006) provides a critical feminist reconceptualisation of the procedure. She used information drawn predominantly from official transcripts of public hearings into ECT conducted in North America in the 1980s, women’s verbal and videotaped testimonies, and previous findings of adverse psychological effects of ECT (Johnstone, 1999). Burstow argues that ECT is not only a traumatic procedure designed to socially control behaviour and increase women’s compliance via punishment and fear, but is also a treatment that causes physical damage to the brain. Themes of trauma and powerlessness were identified by women who described ECT as demeaning and humiliating, life-destroying, and an overt sign of contempt towards their gender. The procedure was viewed as a method of punishment in addition to a means of ensuring sex-role compliance, and a comparison to domestic violence was drawn. It was strongly asserted that these themes originated not only from the treatment itself, but also from involvement within a dominant psychiatric system that routinely disempowered women and invoked trauma. A situation was created therefore, where the woman became the passive, fearful and silent child, and the medical team became the omnipotent, all-powerful, all-knowing and authoritative parent claiming to have legitimate authority over the child and the capacity to enforce it (Burstow, 2006, p. 384).

Women’s testimonies within Burstow’s (2006) work described how ECT was given to revoke their homosexual choices, to instil fear of further treatment if compliance with current treatment was not evident, to create socially conforming behaviour as wives and partners and most disturbingly, to utilise cognitive impairment and memory loss to silence and invalidate possible disclosure of sexual and physical abuse, either past or present. Themes of modern day collusion between husbands and male psychiatrists emerged from the women’s recollections, from a landscape that was reminiscent of historical forces of the early nineteenth century (Showalter, 1987). Burstow’s (2006) critique is powerful. She proclaims ECT as an assault upon the memories of women, and that it is a procedure that has grave social and psychological consequences. She asserts that ECT brings “shame, alienation, anxiety and a profound sense of being diminished” (2006, p. 379), a view that is shared by others (Ejaredar & Hagan, 2013).
Ejaredar and Hagan (2013) used a narrative inquiry to explore the perspectives of nine women who had received ECT, focusing on perceived benefits and/or side effects. One participant had received her treatment two days prior to the research interview; others had received their treatment 20 years previously, giving a wide time span from which recollections were drawn. Their study was an attempt to respond to the methodological issue of difficulty in describing autobiographical memory loss, and the use of a qualitative approach was invaluable in eliciting rich and detailed descriptions. The majority of participants found ECT to be a negative experience. Seven out of the nine participants described their persistent autobiographical memory loss as “being left with a complete void” (2013, p. 149). However, for some the loss included the capacity to read smoothly and follow text automatically, or to engage in mutual social conversation. The authors are clear that their purpose with this study was not to generate objective data that could be generalised to a larger population, but to give voice to the experiences of these particular women at this particular time, to give a human face to the experience of receiving ECT.

In their follow up study with the same participants, the authors explored themes of power and knowledge that emerged from women’s narratives about ECT (Ejaredar & Hagan, 2014). Themes that emerged related to (a) participants having little power or knowledge about the procedure; (b) feeling pressured and coerced into agreeing to have the procedure; (c) making decisions about ECT at a time when they felt most vulnerable; and (d) experiencing the procedure as depersonalising. These themes are commonly mirrored by other studies that have explored women’s experiences with ECT (Johnstone, 1999; Orr & O’Connor, 2005; C. van Daalen-Smith, 2011).

ECT has been used more frequently as a treatment option for older adults, particularly with older women (Benbow, 2013; Lima et al., 2015). To gain a better understanding of the ECT experience in this particular group, Orr and O’Connor (2005) used a post-modern feminist approach to interview six women over the age of 65 years who had received ECT for clinical depression. Three central themes relating to issues of power and control emerged as vital for the understanding of the meaning attributed to the ECT experience. The first related to the women’s sense of being powerless over the depression, which was seen to be an all-consuming force that they were not prepared for. The second theme acknowledged the necessity of women creating a strategic alliance with their doctor in order to overcome the depression, which paradoxically required them to surrender further personal control. Orr and O’Connor (2005) described how women ascribed to the “treatment as last resort” explanation, with none
of them giving any indication that they had any other choices available and despite consenting to the procedure. Finally, the process of receiving ECT was another way in which they gave up a sense of personal control to both the procedure, and to the prominent memory loss that accompanied the treatment. Orr and O’Connor (2005) made some interesting observations of their research. Despite encouraging the women to tell their story in an unstructured manner their recollections of personal detail were significantly scant, and the language of a biomedical perspective subjugated their personal stories. It seemed that as more personal power was relinquished, women became increasingly disconnected from their own personal experience. This is a worthy observation, and given the similar embodied disconnections seen among the women in the current research, it will be discussed more deeply later in the thesis.

Similar findings around themes of power have been found, even in research not isolated to the experiences of women. In a study designed to investigate strongly negative views of ECT, twelve women and eight men who had received the treatment within the previous 30 years were interviewed in-depth (Johnstone, 1999). Themes of helplessness, fear, shame and humiliation associated with the procedure were reported. For some of the women in the study who had experienced earlier childhood abuse, the procedure was so distressing that similar feelings of powerlessness and a re-enactment of trauma emerged. The feeling of powerlessness experienced by these participants was compounded by their perceived inability to disclose the magnitude of their negative experience of the procedure to staff. It is well established that women who report childhood sexual abuse and trauma have higher rates of depression than women who do not describe such traumatic childhood events (Goodman, Rosenberg, Muesler, & Drake, 1997; Weiss, Longhurst, & Mazure, 1999). This is an important point that must be kept in mind when considering how women with depression may perceive the ECT treatment, even if it is accepted as a voluntary treatment option.

Summary of the Literature Review

From a socio-historical viewpoint, women’s experiences of unhappiness and discontent have been medicalised as a form of disease that requires medical intervention and treatment. As an illness, depression is a complex disorder that has both familial and environmental influences. There is a large body of evidence that supports the associated biological, psychological, social and economic consequences of depression as an urgent and global health priority. Within the Australian context, more individuals suffer from depression than any other mental health disorder. Significant differences in the rates of the disorder between men and women exist, and a number of factors have
been offered to explain this disparity. Although theories relating to effects of hormonal activity, cognitive processes, life stress, social and cultural roles have all been offered to explain these differences, none appear to be definitive. Both men and women receive similar cognitive and pharmaceutical treatments, however more women than men receive ECT as treatment for their depression.

While ECT can ameliorate some of the symptoms of depression, the procedure is associated with a range of side effects such as fear, anxiety and memory loss. Studies that look to measure functional outcomes such as symptom remission often ignore the complex perspectives and meanings given by those who receive the treatment. Furthermore, there is a significant absence of any qualitative work within the literature that seeks to understand how consumers experience ECT. Less is known about how consumers decide to receive ECT, given the possible side effects of the procedure, and the complex ways in which they accommodate this decision-making process. How ECT is experienced as a function of gender is almost unchartered territory within the literature, although some authors have specifically described the procedure as a form of physical and mental violence towards women.

Despite encouragement by the international Consumer Movement and various Australian government reports to include the perspectives of consumers within mental health service delivery and research, limited attention has been paid to the experiences of individuals who have received ECT. There is a significant lack of any research that explores the perspectives and decision-making of women who receive ECT. This has created a situation where little is known about how women make choices to receive a specific mental health treatment and how they in turn experience that treatment. Therefore, this research explores the perspectives of women who receive ECT. Specifically, the aim of the research is to explore the way in which women decide to receive ECT and the meanings they attribute to that experience.

**Conclusion**

The chapter has presented a literature review that was undertaken and maintained throughout the life of the research process. It has set the foreground for this current research by establishing a socio-historical view of women's mental health, and by examining the gender bias that is seen in the treatment of the phenomenon of depression. An analysis of the limited research that explores consumer's perspectives of ECT was offered, with an emphasis on the differing opinions with regard to memory loss. Finally, the literature review highlighted the inadequate attention that has been
paid to women’s experiences of ECT as pivotal to the need for ongoing discovery. The next chapter will discuss the theoretical and methodological frameworks chosen to answer the questions asked of this research.
CHAPTER THREE: METHODOLOGY

When I began this research, I grappled with working out which methodology would be best suited to answer the questions I was asking. I knew that it was in a feminist direction, however trying to ascertain which type of feminism I was going to use confused and bewildered me. I was born in the mid-1960s, so had effectively missed the second wave of feminism. I grew up in a world where many women had choices of sexuality and identity, and it was not until my early thirties that I deeply understood the subtle nature of gender power relations and struggles for identity and power. It was not surprising then, that the task of being a feminist researcher felt so foreign. It was not until the mid-point of this research journey, after much reading and reflecting that I realised I had been a feminist all along, simply lacking the concrete epistemological understanding of how I had arrived there. Yet this did not come without some discomfort. Actually, it was very uncomfortable to contemplate a new way of thinking, and soon I had a new issue to contemplate – how to move from a comfortable place of knowing, to an uncomfortable place of being. Like all change, this process was challenging and troubling at times, as I needed to re-think previously held binaries, structures of power, and ways of knowing about the world. As unsettling as it was, by the time I had worked my way through this process and reframed my thinking, I found myself profoundly changed – as an academic, as a researcher, and as a woman. Just like Phillips, Harris, Larson, and Higgins (2009), I found myself trying on, being in, and becoming a feminist post-structural thinker. I had found the beginning of a new language, a new way of thinking, a new way of being.

Introduction

The last chapter set the scene for the current research by explaining the need for further inquiry into the perspectives of women who had received ECT as treatment for depression. This chapter explains the theoretical and methodological approaches that have been chosen to answer the main research question and sub-questions. The main research question is “How do women make meaning and decisions about electroconvulsive therapy?” Sub-questions consist of:

(a) What were women’s experiences of depression?
(b) What informed their decisions about treatment, specifically ECT?
(c) What were their experiences of the ECT treatment (and care), specifically would they make the same decision again?
The current work is qualitative research, using a feminist narrative approach. It draws upon two separate and specific methods: (a) a thematic analysis of stories spoken by women who have received ECT; and (b) a critical reflection of my own research practice.

**Feminist Research**

Feminist research relates to practices that affirm the experiences and differences found among women as a social group, and in ways that promote their individual and collective health, safety and welfare (DeVault & Gross, 2007). It is research that focuses on the meanings that women create within an analysis of gender inequality and other power issues. Feminism recognises the gendered nature of struggles of power, conflict and resistance (Elizabeth, 2003; Jacobson, Jacobs, & Marchbank, 2000), and attempts to highlight both the personal and the political contexts of women’s lives (Snyder, 2008).

An underpinning principle of feminist research is the understanding that how the research is undertaken is just as important as the actual content of the research topic (Hesse-Biber, 2007). Given the sensitive topic of depression, ECT and the nature of women’s lives, this principle lay at the heart of the way I engaged with women in the current research. It allowed me the opportunity to critically interpret and challenge assumptions of dominant knowledge that emerged from women’s stories in a way that uncovered constructions of power.

Stanley and Wise (1983) eloquently articulate the unique nature of feminist research. They suggest that it is an opportunity to harness the quintessential nature of feminism, and that:

> It occurs as and when women, individually and together, hesitantly and rampantly, joyously and with deep sorrow, come to see our lives differently and to reject externally imposed frames of reference for understanding these lives, instead beginning the slow process of constructing our own ways of seeing them, understanding them, and living them. For us, the insistence on the deeply political nature of everyday life and on seeing political change as personal change is, quite simply, feminism. (1983, p. 192)

Griffin’s work reflects this view by discussing an earlier historical time when women asserted that:
...our lives, as well as men’s lives, were worthy of contemplation; that what we suffered in our lives was not always natural, but was instead the consequences of a political distribution of power. And finally, by these words, we said that the feelings we had of discomfort, dissatisfaction, grief, anger and rage were not madness, but sanity. (1982, p. 6)

Both Stanley and Wise (1983) and Griffin (1982) continue to have present-day relevance to the current research. The aim here was to explore the social constructs of health and illness in a way that asks the question, who or what determines the nature of this subjective reality? Further, Flyvbjerg suggests that we ask: “who is gaining, who is losing, and by what mechanisms of power?” (2001, p. 131). This question will be progressed in greater detail in a later chapter.

Post-structural feminism

The methodology used in the research is based on a foundation of feminism that has its roots in post-structural theory. Post-structuralism is a way of thinking about the world with a focus on cultural life through the understanding of language and its association with subjective reality and meaning (Gannon & Davies, 2007). Language is linked to social practices, and an analysis of the power of language looks to include the social and historical contexts that surround it (Fairclough, 1992).

Feminism that emerges from a post-structural premise has few clear-cut rules; however epistemologically it provides a set of guidelines and principles that may be adopted. This form of feminism asserts that every account is situated in a certain time, in a certain place by a certain someone (Gannon & Davies, 2007). This means that each account has the power to produce different ways of thinking, and that it should always be open to contestation. As Castor suggests, we are “accountable for what and how we have the power to see” (1991, p. 64). Each woman in the current research has a certain story, set within a certain time, in a certain place, and her voice in this story is boldly articulated within this thesis. Her knowledge is contextual, historically situated and discursively produced, yet I find it necessary to be remind myself that one of the most important qualities of feminist research is the ability to bring the tension of speaking with, rather than on behalf of women to the forefront of the research (Lather, 2004). This is achieved through my use of critical reflection and a willingness to place myself into the research, rather than assuming an objective stance. Thus, the give-and-take reciprocal engagement and social relationship between myself and the women in the current research is seen as a powerful mechanism to negotiate knowledge (Hesse-
Biber & Piatelli, 2007a). It is also achieved by the asking of a new set of questions regarding the social and political construction of life. Indeed, one of the main aims of feminist research is to pursue the emancipation of women – to challenge the status quo of their lives and how meaning of those lives is often created and maintained by external forces (Hesse-Biber, 2007).

The post-structuralist approach pays attention to the ways in which social practices are regulated through discourse (van Leeuwen, 2008), which will be discussed in more detail in the next section of the chapter. Additionally, power, truth, subjectivity, and agency are all important constructs within this paradigm, as they show the ways in which women’s social lives are actively constructed by individuals and groups (Hesse-Biber & Brooks, 2007).

Knowledge, power and discourse

To gain an understanding of the nature of post-structural feminism, knowledge and power as central components must be discussed in some detail. Feminist epistemology examines the way in which gender influences our ideas of knowledge, the knowing subject and the ways in which knowledge is acquired (Anderson, 2015). It also examines the way that gender negotiate with power to claim truth (Butler, 2009). It looks carefully at the way dominant sources of knowledge systematically disadvantage women through (a) their exclusion from scientific inquiry; (b) their denial of legitimate epistemological authority; and (c) a belittling of their unique cognitive styles and modes of knowledge (Anderson, 2015). These dominant regimes of knowledge are also responsible for the production of theories that represent women as inferior, deviant or significant only as they relate to the interests of men; or production of theories of social phenomena that render women’s activities or gendered power relations invisible (Anderson, 2015). In doing so, knowledge is created that reinforces gender and power hierarchies.

A central concept for postmodern forms of feminist epistemology relates to the “situatedness” of knowledge claims in relation to what is known and other knowers. Examining the particular socio-political and historical context of what is known, and the way it is known helps to identify the perspective of the knower. Furthermore, this epistemological approach emphasises that knowledge is often the result of intervention upon the world, rather than the discovery of something completely pre-determined, or a natural order of life (Hawkesworth, 2007). Knowledge is also produced through
embodiment. This is a first-hand perspective in which the world is experienced through
the use of the physical body. It is a valid way of knowing, and yields different
knowledge to that of the person who experiences the world in non-physical ways
(Anderson, 2015). The same can be said for situated knowledge acquired through first-
hand experience, as opposed to knowledge obtained through third-person sources
(Anderson, 2015). Close attention is paid to the impact of the social location of the
knower, and how this affects what and how she knows. These social locations may
consist of social identities (such as gender, race, sexual orientation, kinship status), as
well as social roles and relationships (occupation, and memberships to various
groups).

The use of feminist epistemology helps to frame research questions and identify
knowledge claims. It does this by acknowledging the need to identify the historical
processes that create hierarchically structured relations of inequality, the material
conditions, socio-political structures and psychological mechanisms that maintain them
in the present (Wylie, 2000). Another important concept of knowledge noted by feminist
researchers is the importance of using discourse (relevant to specific socio-historical
structures) as a primary mode of analysis (Scott, 1992). In this way, the understanding
of the complex interplay between knowledge and power is deepened.

There is significant disagreement and debate over the best way to define power.
Multiple points of debate position power either as getting someone else to do what you
want them to do, as an exercise in “power-over” (Connolly, 1993; Weber, 1978), or as
the capacity or ability to act, a “power-to-do” something (Arendt, 1958; Morriss, 2002).
Some writers understand power as an action-theoretical construct and define power in
terms of actions undertaken by particular people (Weber, 1978). There is also a
perception of power that has a focus on relational ways in which individuals and the
social worlds they live in are themselves created and positioned by power relations
(Spinoza, 2002). One of the most influential thinkers ascribing to this viewpoint was
Foucault (1978), who inspired much of the work undertaken by post-structural
feminists.

Post-structural feminism arises from the Foucauldian tradition of examining power
relations and how these relate to knowledge and subjectivity. Foucault (1978)
understood power as an everyday, socialised and embodied experience. He perceived
it not as a discrete entity, but as a mobile and dynamic relation that is produced from
moment to moment in time. He observed that power is found in the everyday spaces of
the social world, “... it is everywhere ... and comes from everywhere” (Foucault, 1978,
He theorised about what constitutes knowledge and the discourses that support such claims to knowledge. What constitutes knowledge at a given point in time is contingent upon the power relations that are present and responsible for shaping such social conditions. This knowledge is then endorsed as authoritative, leaving other potential knowledge as subjugated and inferior (Foucault, 1978). According to his argument, power is not something that is attained, seized, held onto grimly or forcibly removed; it is something that is enacted within the complex interplay of non-egalitarian relations (Foucault, 1978, p. 94). Foucault did not view power as a top-down phenomenon; instead he saw it as a force that operates throughout the entire network of the social body.

What defines a relationship of power is that it enacts indirectly by acting upon another individual's actual or possible actions, either in the present or in the future. Power does not necessarily provoke; it "governs" (Foucault, 1978, p. 341), and in this way it directs individuals and groups to act in a certain way. In fact, the governing effect of social norms may be so firmly embedded that we fail to recognise or acknowledge it, disciplining ourselves and our physical bodies in ways that do not require any deliberate or intentional coercion from others (Foucault, 1975). In Foucault's influential work *Discipline and Punish* (1975), he examined the disciplinary practices that occurred within prisons, schools and factories during the 18th century. He showed how the surveillance techniques at the time, including obsessive time schedules and the regulations of body movements moulded and shaped prisoners, students and factory workers into "docile bodies" that can be "subjected, used, transformed and improved" (1975, p. 136). Foucauldian-tradition feminists have used this concept of docility to explore normative femininity in contemporary society. Bartky (1990) extended Foucault’s work as she critically examined the disciplinary measures that are used to engender female bodies into docile and passive states, such as dietary practices, rules imposed on body positioning and gestures, and body adornment and beautification. She noted that women’s bodies are subjugated and rendered docile more frequently than the bodies of men, and used Foucault's example of the prison, Panopticon, to illustrate her point. Foucault described this ideal prison as one that compelled the prisoner to engage in self-surveillance, becoming “the principle of his [or her] own subjection” (1995, pp. 202-203).

Normative feminine practices such as conforming to feminine expressions of emotion and the ways in which women respond emotionally to challenges and adversity in life may also be self-monitored. A self-silencing effect has been noted to occur with women
experiencing premenstrual syndrome as well as in women experiencing depression (Jack & Ali, 2010; Ussher, 1992). Self-silencing functions as a way of portraying to the world a very specific image of the “good woman”. This “good woman” is an idealised and hegemonic construct of femininity that relates to coping with life, not burdening others with feelings of distress and monitoring other’s reactions to that expression of distress, if and when it is heard. The “good woman” is also considered a template, one against which her accomplishments as a woman are evaluated against by both men and other women (Stoppard, 2000). It has a strong focus on her accomplishment of womanly responsibilities. This is an important point as it relates to the way in which some women may evaluate themselves after experiencing procedures such as ECT and will be progressed in a later chapter.

Finally, it must be noted that Foucault is one of the few writers who has viewed power through a dialectical lens – although it can be repressive and coercive, it can also be a potentially productive force. He asserted, “Where there is power, there is resistance” (1978, p. 94). He recognised the many points of resistance found over time and space, which could at times mobilise groups of individuals to think and behave in certain (and different) ways, challenging the impact of the power on their bodies and minds. He recognised that these bites of resistance did not always create large binary divisions in people’s views of the world. Points of resistance are often only small and transient. Yet they may ultimately lead to a shift in thinking, fracturing binary unities and creating new perceptions of the world (Foucault, 1978). It will be shown that some of the women in this research engaged in their own small acts of resistance, in ways that challenged the power over their bodies and minds to be docile and passive following their experiences with emotional distress and the use of ECT.

Another common thread shared by both Foucault and post-structural feminists is their interest in discourse as a site of maintaining power and resistance within the social body. Discourses are defined as regulated sets of oral, written or visual statements that construct objects (Parker, 1990). Described as “complex, interconnected modes of being, thinking and doing” (Gannon & Davies, 2007, p. 83), discourses are dynamic and fluid, often shifting and contradictory. They are located on temporal and spatial lines, situated specifically within both a historical and cultural context. Medical discourses, which are pertinent to the current research, are discourses that construct ideas about disease, healing, curing, therapy, and expressions of suffering (Wilce, 2009).
Foucault connected power, knowledge and discourse together. He explained that discourses legitimise power relations whilst simultaneously obscuring their constructed qualities (Foucault, 1980). Discourses reinforce power relations that proclaim knowledge as truth, and are vital to the survival of the operation of power. They support power relations by providing them with a legitimate lens through which power relations are viewed as a given, and somehow naturally right (Foucault, 1980, p. 93). It will be shown that medical discourses can be a powerful way of creating and maintaining inequalities between women and individuals in powerful and privileged positions.

Discourses are not static, and they are open to revision. They may change as they become more powerful or more readily accessible (Ravitch & Carl, 2015). They link together “power, knowledge, institutions, intellectuals, the control of populations and the modern state” (Bove, 1990, p. 50). Discourses that relate to femininity, equality, power, sexuality, and reproduction have constructed prevailing views of women’s lives and the conditions in which they find themselves (Davies & Gannon, 2005). Feminists endeavour to contest these dominant regimes of truth by challenging discursive constructs that define qualities of women at specific points in time and place (Gannon & Davies, 2007). They also explore the beginnings and origins of these particular modes of thought in order to understand how they became possible at a particular junction of time and history, and how they became such dominant constructs (Lazar, 2007).

**Oppression, subordination, privilege and patriarchy**

To progress arguments related to power in later chapters of the thesis, three separate yet interwoven definitions of key terms, oppression, subordination and patriarchy, are offered and briefly discussed here. Oppression is used to describe both a process and a state (Prilleltensky & Gonick, 1996). The first definition is seen within a state of domination where the oppressed suffer the outcomes of deprivation, discrimination, exclusion, exploitation, control of culture and violence (Bartky, 1990). A helpful definition for oppression as a process is offered by Mar'i who claims:

> Oppression involves institutionalised collective and individual behavior through which one group attempts to dominate and control another to secure political, economic and/or social-psychological advantage (1988, p. 6)

There are inter-related political and psychological dimensions to oppression, neither of which is mutually exclusive and both maintain a mutually reciprocal relationship (Moane, 1999; Walkerdine, 1997). As Bartky observes:
... what we have in mind most often is an oppression that is economic and political in character. However ... it is possible to be oppressed in ways that need involve neither deprivation, legal inequality, nor economic exploitation; one can be oppressed psychologically ... to be weighed down in your mind ... to have a harsh dominion exercised over your self-esteem... (1990, p. 22)

Prilleltensky integrates state and process with political and psychological elements of oppression to offer a comprehensive definition of oppression. He concludes:

> Oppression entails a state of asymmetric power relations characterised by domination, subordination and resistance, where the dominating persons or groups exercise their power by the process of restricting access to material resources and imparting in the subordinated persons or group self-deprecating views about themselves. (2008, p. 127)

Oppression has both internal and external consequences. The external outcomes (such as deprivation of self-determination and autonomy) can become internalised, leading to the oppressed person acting as their own critic and personal censor. Mechanisms of power such as affective, behavioural, cognitive, cultural, material and linguistic agents of domination act to affirm political and psychological authority over the oppressed individual (Prilleltensky & Gonick, 1996). Actual or potential use of force and violence, a restriction on life opportunities, economic sanctions and an inability to rise up to challenge authority are all key outcomes from oppression (Moane, 1999; Prilleltensky, 2008; Prilleltensky & Gonick, 1996). The eventual psychological consequences are therefore likely to include heightened powerlessness, learned helplessness, fear and obedience to authority and experts (Prilleltensky, 2003).

Subordination is a closely aligned concept to that of oppression. Like oppression, the subordination of women is one of the most important and pressing social issues for feminism (Kelkar, 1995). Subordination of women refers to the way in which women are socially and politically positioned, where they lack access to resources and decision making capacity, and it refers to the patriarchal domination that women experience in many societies (Sultana, 2011). Women’s subordination describes the socially constructed and inferior position compared to that of men within society. Feelings of powerlessness and experiences of discrimination contribute to the phenomenon of subordination, creating a powerful situation where power inequities exist, and where men dominate women at a social group level (Sultana, 2011).
Subordination is not a new concept. In 1949 de Beauvoir argued that men viewed women as profoundly different to themselves, thereby reducing women to the status of “second sex”. It is here that women become subordinate (de Beauvoir, 1974), occupying a dependent sex class under a patriarchal domination (Millet, 1977).

There is a social and political phenomenon that occurs through the conferring of specific advantages via aspects of a person’s status. Known as privilege, this term describes the way in which certain members of society are granted social and political advantage through others’ disadvantage (Mcintosh, 1988). Privilege is neither earned nor justified; yet it acts as a form of oppression by a dominant social group (McIntosh, 1988. White privilege (Dolan-Del Vecchio, 1998), and male privilege (Wildman, 2001) favour those who belong to certain racial groups or to a specific gender, providing them with distinct benefits. As privilege is often an invisible force, it has been suggested that members of the dominant group are taught not to recognise it (McIntosh, 1988). A denial of these unearned assets, or a failure to recognise them in the first instance creates a situation in which little is done to acknowledge, minimise or stop it. When the embedded and institutionalised privilege that accompanies male hegemony is considered, women often suffer harms, which remain invisible and unnamed (McIntosh, 1998). The current research extends this understanding of privilege, by discussing the advantages of those in positions of power. These individuals have privilege by virtue of having the legitimate authority to determine women as suffering from a mental illness, whilst they themselves do not.

Finally, the term patriarchy is one that is generally used to describe the structural and institutionalised power relationship between men and women (Wilson, 2002). It is a concept that is useful to feminist research to help understand the nature of women’s lives. Walby defines patriarchy as “a system of social structures and practices in which men dominate, oppress and exploit women” (1990, p. 20). Patriarchy is conceptualised here as a system in order to reject the explanation of biological determinism or the notion that “every individual man is in a dominant position and every woman is in a subordinate one” (1990, p. 20). In its wider definition, patriarchy refers to the creation and maintenance of male dominance over women and children within the family, and by extension, male dominance over women in society in general (Sultana, 2011). It is a system whereby women are kept subordinate and oppressed in a number of ways through acts of discrimination, disregard, control, exploitation and violence (Sultana, 2011). Lerner argues that this does not necessarily mean that “women are either totally
powerless or totally deprived of rights, influence and resources" (1989, p. 239) and may find ways to resist the effects of the dominance.

Patriarchal ideology exaggerates the biological differences between men and women. It is so powerful even in its insidious and subtle forms that, “men are usually able to secure the apparent consent of the very women they oppress” (Millett, 1977, p. 35). The mechanisms of power through which this ideology is seen are “institutions such as the academy, the church, and the family, each of which reinforces and justifies and reinforces women’s subordination to men” (Millett, 1977, p. 35). I will argue for the inclusion of biopsychiatry as another institutional mechanism for ideological power, and this perspective will be progressed further in chapter five.

**Truth, subjectivity and agency**

There are a variety of arguments to explain the concept of truth within feminism. An underpinning principle of feminist ontology is the rejection of a traditional dualism in which the mind and the body are seen as separate. Feminism challenges these binary modes of thinking by acknowledging the co-existence of the mind and body, reason and emotion, and objectivity and subjectivity (Stanley & Wise, 2002). Yet the medical narrative places the body above the mind to explain experience and perspective and has been given the status of “Master Narrative” (McKenzie-Mohr & Lafrance, 2010). This medical master narrative is viewed as privileged above all others and is often used to judge the truth of other narratives. It is endorsed through social relations, permeating understandings of personal identity and experiences (McKenzie-Mohr & Lafrance, 2010). Feminist research attempts to unsettle this dominant claim to truth.

Further to rejecting binary ways of conceptualising the mind and body, feminist research also rejects binary modes of thinking that relate to the concept of the self and its relationship with the body, the mind and the emotions. The notion of the “self and the Other” is another oppositional construction that is contested with this ontological approach. Yet rejecting the binary concept of the “Other” may be hazardous for the self:

Here, the Other is seen as a threat to the integrity of the self, for, without the Other, the Self would not, could not in this ontology, exist. (Stanley & Wise, 2002, p. 195)

Instead of a binary and oppositional way of understanding truth, the current research utilises a feminist ontology to view the construction of the self as an outcome of the
reciprocal relationships between historical, cultural, social and more specific contexts that are subtly dynamic and frequently changing. The dualisms of traditional masculine ontology (self and Other, individual and collective) are not viewed and treated as oppositions, but are reframed as cooperative endeavours (Stanley & Wise, 2002, p. 195) for constructing both selves collaboratively and collectively.

The concept of the body is also viewed very differently within feminist ontology. Classic Cartesian ontology defines the body in universal terms as a separate physical entity, separate from the mind and its emotions, and biologically determined (Duncan, 2000). Feminist ontology acknowledges a process of embodiment; where the body is inscribed with a variety of culturally recognised and contested experiences, feelings and meanings (Csordas, 2003). Embodiment positions the physical and material body within and often against, cultural discourses of meaning, authority, control and power. It can be emphasised that neither bodies nor minds are inherently gendered; yet they both experience and contribute towards the way that gender is constructed and embodied (Csordas, 2003).

Post-structuralists pay close attention to the process of the self being constructed through the use of discursive strategies, and they replace the term identity with subjectivity (Barrett, 2005). The post-structural feminist paradigm attends to this subjectivity, defined more closely as the “conscious and unconscious thoughts and emotions of the individual, her sense of herself and her ways of understanding her relation to her world” (Weedon, 1997, p. 32). Post-structural feminists look even further, to understand how discursive strategies encourage women to become gendered subjects. The significance of language, social structure and cognition in the construction of subjectivity is highlighted, arguing that subjectivity “is a discursive effect, not a transcendental, ahistoric and unchanging objective status, entity or state” (Flax, 1992, p. 96).

Agency is a concept that has been synonymous with freedom, autonomy, rationality and moral authority (Davies, 1991), and is closely aligned to the process of subjectification. Barrett (2005) discusses the inevitable tension between trying to "speak the self into different subject positions" (p. 86) whilst concurrently “being subjected to the meanings inherent in the discourses through which one becomes subjected” (Davies, 2005, p. 27). This means that women are constantly shifting their sense of who they are, and although they may be able to shift their position within a certain dominant discourse, it is difficult for them to be an active agent outside the particular discourse that is regulating them (Butler, 1993). Post-structural agency
acknowledges however, that some discourses serve to unsettle the hegemonic cultural narratives. Language and practice combine to form dominant structures; therefore words and actions can be used against those very structures they have helped to produce (Davies, 2000).

A central assumption in feminist research is that methodology and methods used are tied to practices of power (Hesse-Biber & Piatelli, 2007a). Feminist research designs are characterised by: (a) being reciprocal, dialogic and interactive; (b) aiming for an egalitarian and participatory relationship between the researcher and participant; (c) working towards a building of knowledge based on a respect for peoples’ experiences and meaning within their own lives; and (d) connecting that meaning to social structures of power, control and history (Lather, 2004, p. 9). Inter-relatedly, post-structural feminist researchers attempt to make visible the historical, social, cultural and discursive practices that maintain current power inequities.

**Feminist narrative**

The current work uses a feminist narrative approach to explore the stories of women who have received ECT. Narrative inquiry, like feminist research, acknowledges experiences through stories as existing at a particular point in time that can be understood through alternative and multiple ways of knowing. There is an acceptance within narrative inquiry of the awareness of the changing relationship between those researching, and those being researched (Pinnegar & Daynes, 2007). Subsequently, I have intentionally chosen to align post-structural feminism with narrative inquiry for the current research. When combined, they possess a synergistic quality for understanding the ways in which women experiencing emotional distress are positioned in their social worlds. Together, these two approaches allow for an exploration of women’s stories whilst simultaneously paying close attention to the nature of the research relationship.

This particular combination of methodologies is not new. Messias and DeJoseph (2004) in work examining the experiences of women’s work during pregnancy used a combination of methodologies that they called feminist narrative interpretations, characterised by co-creation, re-presentation and interpretation of women’s stories. The authors noted the inherent tension with the use of narrative methodology on its own. Traditional narrative researchers differ in the attention they pay to the larger sociocultural context in which stories are embedded (Riessman, 1993), often limiting their exploration and analysis to what people say or do in certain situations. On the other hand, blending narrative inquiry with feminist research allows for an intentional
and conscious focus on how race, class, gender, sexuality, and other various contexts of diversity and inequality surface within and throughout the stories women tell (Messias & DeJoseph, 2004).

Sosulski, Buchanan, and Donnell’s (2010) work is another example of the combined methodological power of narrative and feminist research. They used a combination of life history and narrative analysis with feminist research to explore the experiences of Black women living with severe mental illness. They emphasised that narratives offered by the women did not communicate simple stories of triumph over adversity, nor did they express stories of failure. Instead they offered complex, nuanced stories that were “unexpected, even changing the nature of the research” (2010, p.35). Sosulski et al. (2010) argued for the value of this methodological approach, suggesting that their techniques filled gaps in mainstream research that are created and maintained by the absence of standpoints of marginalised people, such as Black women, and women with mental illness. I agree with their view, that this particular methodology is valuable when considering the reality of women’s lives as a function of the intersection of gender, race, class and mental health status (Collins, 2000). As such, I found it a useful approach as I listened to women’s personal stories and experiences of receiving ECT.

**Narrative Inquiry**

Narrative inquiry is an increasingly popular method of anthropological and sociological research (Huber, Caine, Huber, & Steeves, 2013; Squire, Andrews, & Tamboukou, 2013) and is primarily concerned with making sense of peoples’ narratives. Narratives are stories that tell a series of events in a significant way for the narrator, and are a way of recounting and creating some order within a range of personal experiences (Moen, 2006). Some researchers see narratives as the primary scheme by which human existence is rendered meaningful (Polkinghorne, 1995). For others, narratives are seen as a way of describing “lived time” (Bruner, 2004). They have been described as a particular and specific way of reporting past events (Labov & Waletzky, 1997) and have been deconstructed to show how a connected plot, a problem and a cast of characters can recount a rich and detailed story (Holloway & Freshwater, 2007). Narratives also provide a socio-cultural context that helps to create a rich description of the event (Bruner, 2004; Moen, 2006).
Definition of narrative inquiry

The definition of narrative inquiry has a contested history – it remains unclear and ambiguous and debate continues as to whether narrative inquiry is a research process or a data collection tool (Holloway & Freshwater, 2007). A search of the literature offered a wide array of differing opinions and thoughts about the similarities, differences and complex definitions of research terms (Cathro, 1995; Clandinin & Connelly, 2000; Elliott, 2005; Hardy, Gregory, & Ramjeet, 2009; Holloway & Freshwater, 2007; Kirkman, 2002; Squire et al., 2013) that seemed difficult to reconcile. I finally chose a definition proposed by Clandinin and Connelly, who suggested that:

People shape their daily lives by stories of who they and others are and as they interpret their past in terms of these stories. Story, in the current idiom, is a portal through which a person enters the world and by which their experience of the world is interpreted and made personally meaningful. Narrative inquiry, the study of experience as a story, then, is first and foremost a way of thinking about experience. Narrative inquiry as a methodology entails a view of the phenomenon. (2006, p. 375)

There have been different ways of approaching narrative inquiry. Polkinghorne (1995) suggested two separate and distinct types of narrative inquiry, describing (a) an analysis of narratives and (b) a narrative analysis. In an analysis of narratives, stories are collected by the researcher and become the discrete data for analysis. This results in a description of common themes that hold constant across all stories. In narrative analysis, researchers collect descriptions of events and happenings, and synthesise these into a common plot or story. In an analysis of narratives, the analysis moves from stories to common components, from the specific to the general. A narrative analysis on the other hand, moves from common components to stories, from general to the specific. For the purpose of the current research, an analysis of narratives was a useful way of exploring multiple stories for common themes.

Narration, narratives and concepts of how they contribute to a sense of personal, social and cultural identity have been afforded a great deal of attention within the literature (Gergen & Gergen, 1988; Holloway & Freshwater, 2007). The act of narrating allows for the creation of a sense of self that is dynamic. It is constantly constructing and deconstructing in relation to various contexts, is evidence of personal uniqueness (Bruner, 1991) and is linked to a sense of personal power. Narrating and the
perception of having one’s voice heard is an important concept found in the history of groups and cultures, especially in those (sub) cultures for whom oppression and subordination is a reality. Not being “heard” may equate to a sense of personal helplessness and impotence (Holloway & Freshwater, 2007). This has a particular relevance to the narrative focus in this research. Here, there was a clear aim to articulate the voices of women and to hear stories that have historically been oppressed and silenced (Appignanesi, 2008; Showalter, 1987).

**Narratives, stories and storytelling**

In addition to the ambiguity of narrative inquiry, there is also some confusion with regard to the difference between stories and narratives. The word “narrative” stems from the Latin “gnarus”, which means “knowing”. “Story” on the other hand, is derived from the Greek and Latin word “historia”, which also means “knowing (by inquiry)” (Holloway & Freshwater, 2007, p. 5). The Indo-European root “gna” means to both “know” and to “tell” (Hinchman & Hinchman, 1997) and it has been suggested that the use of narratives is a solution to the problem of how to translate the “knowing” to others (Elliott, 2005). There are some researchers who view the two concepts as very separate entities. In their understandings people do not tell narratives, they tell stories. Therefore for some, the term story relates to the tales that people tell and narrative is a process in which to understand these experiences (Frank, 1995). For the purpose of clarity, I use these terms interchangeably and synonymously, although with a personal preference for the term “story” to describe the events that people reflect on and use to describe a range of human experiences, actions and interpretations.

Stories have been defined as discourses that organise a series of events in such a way that gives them a sense of being whole (Elliott, 2005). Stories usually rely upon chronology to render them meaningful and it is this very temporal characteristic that differentiates stories from mere descriptions. Stories typically have six components as outlined by Labov and Waletsky (1997). This includes an abstract (a summary of the story), orientation (time, place, situation and persons involved), the complicating action (what happened), the evaluation (meaning and significance of the action), the resolution (what finally happened) and then the final coda to return the story to the present perspective. Yet, as other narrative analysts have observed, people do not always tell their stories in a chronological order within research conversations (Lawless, 1993; Poirier & Ayres, 1997). Stories may be clearly bound, but they may also be left unfinished or fragmented (Messias & DeJoseph, 2004).
The context of the storytelling is another important feature of narrative inquiry. Frank (2000) considers the storytelling relation as an important factor with the story developing from within the personal relationship between the storyteller, the listener and the context of the actual telling of the story. He eloquently describes storytelling as an invitation to others to share a view of life by seeing, hearing and feeling life in a different way than they would normally (2000, p. 361). Those who listen not only willingly suspend belief but more importantly accept different beliefs of lives in which those beliefs make complete and utter sense.

Life stories are not simply constructed in isolation. They are greatly influenced by collectively shared norms in a given culture (Berntsen & Bohn, 2009). Each of us lives within a dominant culture. White and Epston (1990) suggest that a person’s individual life story is determined by their cultural story. This cultural story may in turn become a dominant discourse that informs the way their stories are framed and constructed (Jones-Smith, 2015). Dominant discourses may operate at a simple level (stories that families create and tell to each other), or may operate at the highest level – that of a society in which the dominant discourse becomes part of the prevailing culture (White, 1995).

Whilst narratives can function as a platform that people can use to create a coherent and connected description of their life events, these stories can also be seen as vehicles to convey meanings about specific aspects of human experiences. The use of narratives has been shown to be a valuable tool for studying unexpected and disruptive events in life (Kohler Riessman, 2001). For example, experiencing or enduring an episode of ill-health (such as depression) and the impact that this has upon one’s life can be described in rich and colourful detail using a narrative that has illness as a central focus.

Illness narratives

Stories that relate to the experience of chronic illness have received significant attention since Kleinman (1988) first coined the term “illness narratives”. In this description, “illness” denotes a form of human suffering, and how the “sick” person perceives, lives with and responds to symptoms and disability. Illness narratives are used to understand how individuals attempt to deal with their life situation and the problems that chronic illness can bring to the concept of identity (Hyden, 1997). Bury (1982) asserts that as chronic illness disrupts an individual’s world, it has the same impact upon their sense of identity. Therefore, for the person who experiences illness
the use of narrative to reconstruct a life story is vitally important, and allows for a process whereby the life trajectory that has been altered through illness can be given new meaning (Bury, 1991). The storytelling that involves the use of an illness narrative is a dynamic process; new meanings are assumed and old meanings are discarded as the storyteller endures the rollercoaster ride of remittance and relapse.

Illness narratives may be seen as a vehicle for reconstruction of beliefs about the relationship between the body, the self and the social world, especially with regard to resistance to authority and patriarchy. For example, Skultans's (1999) research involved Latvian women to explore narratives of their bodies and illness superimposed upon a macro-narrative of history. In this research women connected state-perpetuated violence with their physical illness. The women however found that their collective and shared sense of political discontent was almost subverted by an overemphasis on diagnoses by medical authorities. This function of narratives as a way of exploring injustice had particular and immediate relevance to the research, as I was interested in understanding how social, political and medical factors influenced women’s decisions with regard to receiving ECT and I wished to open up a critique of power and inequality.

Using her own paradigm of injustice, Skultans (2000) asserts that narratives are a powerful mechanism for a rich and truthful account of the lives of women who live with illness, and attributes this shift in thinking to the impact of feminist theory. Feminist epistemology insists that knowledge is always relative to a certain standpoint, or a set of historical, cultural and biological circumstances. As Haraway succinctly notes, "feminist objectivity means quite simply situated knowledges" (1988, p. 581). The experiences of some groups within society may be more visible than others (Harding, 1992), and being part of a marginalised group can carry epistemic privilege. In a society that is characterised by slavery, the perspective of the slave tells us more than the perspective of the master (Hesse-Biber, 2014). So too, illness narratives told by women experiencing the effects of ill health can give us a deeper understanding of the lives of healthy women. By examining stories with an emphasis on mental and emotional distress, we can learn much about how women’s mental health is conceptualised when they are both well and when they are not.

Exploring the perspective and lived experience of having a severe mental illness has been effectively achieved through the lens of various illness narratives. Roberts (2000) critiques the superiority of quantitative research as the only source of knowledge within mental health and suggests that illness narratives can be used as a collaborative tool
between clinicians and consumers. Specific areas of concern have been explored using illness narratives – parental care-giving of an adult child with a severe mental illness (Pejlert, 2001); the role of cultural stress and suffering in Chinese-Australians with mental illness (Hsiao, Klimidis, Minas, & Tan, 2004); the feelings and experiences of stigma in people with mental illness (Dinos, Stevens, Serfaty, Weich, & King, 2004); insight as a defence against suffering in people with schizophrenia (Lysaker, Clements, Plascak-Hallberg, Knipscheer, & Wright, 2002) and recovery from psychosis (Thornhill, Clare, & May, 2010). Depression has also been explored; for example the aetiology of depression (Kangas, 2001); the relationship between metaphor, culture and the experience of depression in Chinese people (Pritzker, 2007); the experience of women with post-partum depression (Edhborg, Friberg, Lundh, & Widstrom, 2005) and recovery from depression (Ridge & Ziebland, 2006) have all received attention using illness narratives. Although depression as a separate entity was not the focus of the current research, each woman’s story began with the common thread of the development of distress and despair, and these themes will be discussed in more detail in later chapters of the thesis.

The process of reflexivity (captured by critical journaling) allowed me to examine the storytelling relation, the relationship between the women and myself and how the relationship influenced the construction and interpretation of narratives (Frank, 2000; Holloway & Freshwater, 2007). This will be discussed in greater detail within the next section of this chapter, along with a focus on research components and the way in which the research was progressed.

The earlier part of the chapter established the ontological and epistemological framework that feminist research provided to the current research. Greater attention is now given to the research process itself with an emphasis on the epistemological principles that formed the foundation to the research. This next section will discuss the manner in which the women were recruited, and the methods that were used to gather and interpret the stories that women offered and will also highlight the ethics of the current research.

**Sampling and Engagement**

**Participant sampling**

The sampling technique used in the research was purposive. Purposive sampling is a method of non-probability sampling that is commonly used in qualitative research. It is a helpful mechanism when the frequency of a specific characteristic is so low in the
general population that a much more targeted strategy is needed to identify adequate participants for the research (Coyne, 1997; Richardson, 2009). When only certain members of the community have a specific expertise, or hold specific knowledge, purposive sampling allows the researcher to establish inclusion and exclusion criteria to capture those specific qualities. The power of purposive sampling lies in its ability to select information-rich cases for in-depth analysis (Richardson, 2009). The purposive sampling used for the research was homogenous, as all the women had received ECT as treatment for depression.

Inclusion and exclusion criteria

There were specific criteria required for participation in the research. Women needed to be aged 18 years or over to participate in the research. This decision to limit inclusion to women over the age of 18 years was made after carefully considering the challenges that relate to the use of ECT in adolescents. ECT is generally only used in young people who are experiencing disabling, treatment resistant and life-threatening episodes of depression, mania and schizophrenia (Rey & Walter, 1997). There are specific issues that relate to consent, guardianship and the capacity to make autonomous decisions in younger people that could influence the research findings, and for these reasons the research was directed towards adult women.

Women needed to have previously experienced depression, requiring treatment with at least one ECT session. Receiving ECT involuntarily under mental health legislation did not exclude women from participating. They must have received their ECT at least 12 months prior to participating in the research, but no earlier than 2006. The rationale for this time frame was two-fold; firstly, interviews conducted beyond the first 12 months following ECT were less likely to be influenced by associated cognitive impairment (Rose, Fleischmann, Wykes, Leese, & Bindman, 2003). Additionally, the guidelines for the process of obtaining informed consent for ECT have been refined since 2006, and the process for ensuring a fully informed consent is now more extensively regulated (Queensland Health, 2011a). Prior to 2006, an informed consent discussion could occur between the doctor and the woman alone. After 2006, the new statewide guidelines introduced a third party witness signature to the consent form (Queensland Health, 2011a). The guidelines recommended this additional signature to ensure that the informed consent process was coercion-free and followed the Queensland Health guidelines for informed consent and decision making (Queensland Health, 2011a).
Participant recruitment

Recruitment occurred using a three-tiered approach. I was interested in recruiting women who were not currently seeking specialist mental health care. Given that depression is now viewed as a chronic and enduring illness and usually managed through primary healthcare services, general practitioners and other primary healthcare clinics were identified as the most likely health service these women would frequent. A woman who was still receiving specialist mental health care could conceivably still be receiving treatment such as continuation or maintenance ECT. Women in this situation would not fit the inclusion criteria (that is, having received their last ECT at least 12 months earlier). A flyer was sent to the local Focus Area Network, which coordinated activities and communication throughout primary healthcare clinics on the Sunshine Coast and Gympie regions. A copy of the recruitment flyer was uploaded to their website and GP staff and other health services across the Sunshine Coast could view and print the recruitment material.

The second strategy incorporated engagement with local Consumer and Carer groups. These support and advocacy groups meet monthly in various locations across the Sunshine Coast and Gympie. A copy of the GP flyer was made available to the Consumer Participant Facilitators of these groups, who then discussed the research at their next monthly forum with an invitation for interested women to contact me directly.

The third recruitment strategy incorporated the use of a standardised newspaper advertisement placed in the Sunshine Coast Daily, the largest regional newspaper for the Sunshine Coast and Gympie regions. This was aimed at those women who may not be internet-active; who may have missed the recruitment via their primary health care; or who may not be active members of the Consumer & Carer forums.

The most successful recruitment came from the flyers located on the Focus website. Both the newspaper and the consumer/carer group strategy showed minimal recruitment success. Recruitment and interviews with the women took place over a 6-month period.

Methods

Two data collection sources were used in the research. Firstly, a series of face-to-face interviews with the women participating in the research occurred. Secondly, a reflective journal of observations, thoughts and reflections was kept throughout the research process.
In a search for meaning two different, yet inter-related analytic methods were applied, namely:

a) A thematic analysis that examined the narratives offered by women with a focus on their decision-making and experiences of ECT treatment; and

b) A critical analysis that was applied to the reflective journal I maintained throughout the research process. This was examined for the effects of various power dynamics on the women’s involvement in the research and for the impact of my own research practice.

The in-depth conversations

I conducted one single face-to-face conversation with each woman. Face-to-face conversations are advantageous in that they allow synchronous communication (Opdenakker, 2006). The researcher can become aware of social cues such voice intonation, body and hand gestures, facial expression and eye contact (Opdenakker, 2006). These can all add a valuable dimension to the interpretation and understanding of the verbal content of the conversation.

Whilst my original plan was to engage with six women in research conversations, by the end of the recruitment stage I had engaged with seven women in total. There are no clear guidelines for an appropriate or acceptable number of participants within a purposive sample, and the perfect number is driven by the concept of data saturation (Morse, 1995). Previous narrative work that has investigated mental health and illness dimensions has been undertaken with numbers of participants ranging from the single case study (Dysvik, Sommerseth, & Jacobsen, 2010) through to participant groups of 10 or more (Dinos et al., 2004; Hsiao et al., 2004; Kangas, 2001; Pejlert, 2001) in order to reach data saturation. This is the point within the research where it becomes obvious that there are no new themes or information emerging from within the data. The issue of saturation is contested, and while it remains the gold standard for the evaluation of qualitative research within the literature (Guest, Bunce, & Johnson, 2006), there is little consistent information by which it is adequately and reliably operationalised. What is clear however is that data saturation operates according to the law of diminishing return, whereby the inclusion of more participants does not necessarily lead to new information. Although the literature appears confident that purposive samples of between five and sixty participants lead to data saturation (Creswell, 1988; Morse, 1995; Patton, 2002), Kuzel (1993) recommends that only six participants are needed for saturation if the sample is relatively homogenous.
There has been some argument with regard to the in-depth conversation as it relates to differences in power between the researcher and the storyteller. When an in-depth personal narrative is told, it can have powerful and considerable psychological consequences and there are certain risks involved when the stories shared are deeply personal and intimate. Much of this stems from the inherent power imbalance in the researcher-participant relationship in which the researcher holds the dominant position and directs the flow and the direction of the conversation (Sandelowski, 1991). It has already been emphasised that allowing an individual to re-tell their story in their own way may offer them the opportunity to dictate the terms and direction of that story, and in doing so reclaim some of this skewed power. However, whilst some authors view the redefinition of one’s life through the use of a story as beneficial (Corbin & Morse, 2003; Murray, 2003; Rosenthal, 2003), others view the life history telling as being invasive. They propose that re-telling past traumas may open old and painful wounds, especially if it involves sensitive topics in which there are domineering and/or coercive behaviours (Renzetti & Lee, 1993; Shaw, 2003). Yet I did not experience this as a researcher. All the women who participated in my research thanked me for the opportunity to share their story, even the woman who became significantly distressed as she re-told the antecedents to her episode of depression and needed to briefly halt the research conversation in order to contain her emotional distress. This came as a surprise. I thought that I would be the grateful party, given that these women were giving up their time and expending great effort to share their journeys with me. There appeared to be some benefits to both of us, although it would be fair to suggest that the balance of benefits remained unequal. Some of the women had not spoken about their experiences with anyone other than their nearest and closest family members, and as one woman stated, “It’s about time we talked about this.”

The conversations were conducted in a place and at a time of each woman’s choosing and convenience. All participants chose the safety and privacy of their own homes with the exception of one, who chose a local park. Conversation length was somewhat variable, lasting on average 60 minutes. Some were shorter than 50 minutes; some took a much longer 90 minutes. Each story began from the same unstructured place of asking women to describe how it was that they found themselves in the position of needing to receive ECT, described by Spradley (1988) as the “grand tour” question. From this point it became obvious that each woman’s story deviated in a different direction as they described the process of deciding to receive the treatment and consenting to it formally. This deviation seemed to operate as a function of the presence or absence of cognitive impairment associated with the treatment. At this
point, those women who experienced little memory impairment were able to continue to tell their story without any prompting on my part. For others who had experienced significant difficulty in memory, I needed to take a more direct approach to my questioning in order to facilitate and assist their recall. This strategy is supported by the work of De Vault and Gross (2007) who recommend using a more structured approach when interviewing women who experienced cognitive difficulties.

All conversations were recorded using a digital tape recorder, to preserve the accuracy of the woman’s story. I recorded my reflections following each conversation, when my thoughts and perceptions were fresh. This allowed me to maintain a written reflective journal, used to document my thoughts about the conversation, the woman and her story, my perceptions, the way I engaged as a researcher, and any assumptions and biases of which I became aware.

**Research reflective journaling**

A second source of data used to assist in the understanding of the women’s stories was collected throughout the life of the research. A self-reflective journal was maintained (Morrow, 2005), complete with my musings, observations and documented experiences from the beginning to the end of the research process. The journal faithfully recorded my thoughts (and confusions) about the theoretical underpinnings and methodology, my struggle with embracing and understanding my feminist beliefs and paradigms, and my thoughts that followed each face-to-face interview with the women in the research. This journal maintained a record of my reactions to the women’s experiences as well as my thoughts relating to the way that the research process was unfolding. Self-awareness and understandings emerged, sometimes gently unfolding, sometimes emerging abruptly without any warning and causing significant cognitive or emotional discomfort. One of the most important functions of this journal was to help me become aware of my own personal biases that related to the women, women in general, ECT and the concept of emotional distress, as well as the nature of pre-conceived assumptions that I brought into the research space. My process of critical reflection was inspired by Fook (2002). I examined my thoughts for patterns and themes, paying close attention to the development of binary opposites and how they related to aspects of power between the women and myself. I maintained a focus not only on what women were saying, but also what they omitted. Although the women’s perspectives were the ones being voiced, I was also mindful during my critical reflections of the perspectives by others in this story; imagining how they would interpret the same situation.
Documenting my thoughts and taking these to my supervision meetings was invaluable in assisting me to recognise when biases were obstructing my sense of truth and subjectivity or my ability to effectively participate as a co-creator of knowledge with the women in the research. Morrow (2005) encourages researchers to examine these reflective notes and then either set them aside or discuss them critically with supervisors or colleagues. Alternatively, they can be incorporated into the analysis itself (Morrow, 2005). My views and critical ponderings are presented at the beginning of relevant chapters. My thoughts and actions are laid bare as a way of demonstrating their impact upon the relationships I had developed with the women in the research, the process of the research as it unfolded, and on my own professional and personal transformations. The research journal in this case was vital in the way that it allowed me to make sense of these experiences.

Analysis Techniques

Analysis technique of the women’s stories

Data from the in-depth interviews were analysed using a software coding technique and the application of a thematic analysis.

The first layer of analysis required a careful consideration of each woman’s story as it related to her experience with ECT. All conversations were transcribed as soon as was possible after the interviews, and pseudonyms were given to each woman to protect confidentiality. Any references to other people or places were removed during transcription. I began with an initial paradigmatic analysis as set out by Polkinghorne (1995). This type of analysis occurs as themes are inductively identified from the data itself. It is often common to see the development of relationships between themes, and this happened quickly as I delved into a greater understanding of women’s stories and both the similarities and differences between each other. I began by reading each transcription whilst listening to the original recording. This allowed me to ensure accuracy of the written transcription, and to reflect further on my experiences throughout each conversation. I then read over the stories repeatedly, allowing me to become more familiar with each woman’s voice, and the context in which their stories were set.

NVivo software was utilised as an organising tool, allowing me to apply nodes to emerging themes during the analytic process. Nodes were chosen after observing for frequency of occurrence and for intensity and power of emotion underpinning the data. These nodes were designed to attach meaning to chunks of data, and creating
categories allowed me to construct conceptual themes to further understand the rich and detailed information. Seidel and Kelle (1995) consider the role of coding as noticing specific and relevant information; collecting relevant examples and analysing that information in a way that allowed for the identification of commonalities, differences, patterns and structures. Creating categories then triggers the construction of a hierarchical and conceptual scheme that suits the data by asking further questions, comparing across data, changing or dropping categories and making structured order of them. In keeping with feminist tradition, I especially like the understanding of Ely, Anzul, Friedman, Garner, and Steinmetz (1991) who suggest “the process of establishing categories is a very close, intense conversation between a researcher and the data that has implications for ongoing method, descriptive reporting and theory building” (Ely et al. 1991, p. 85).

Flyvbjerg’s (2001) schema for exploring power-drenched situations was contemplated to further understand the context of women’s experiences as they offered their stories. Working my way between the literature and the women’s stories, I pondered the following:

(a) Where are we going with mental health care for women in Australia?
(b) Who gains, and who loses by which mechanisms of power?
(c) Is it desirable?
(d) What should be done? (2001, p. 131)

The results of this critical examination were used to establish an understanding of the nature of power within mental health care, and the results are discussed in chapter five.

As I wove my way through the women’s stories I found myself in the position of having an overwhelming amount of information. I was having difficulty making coherent sense of it all. I needed an additional method that would help me make sense of how to deeply understand the powerful positioning of women’s distress, beyond a dominant biomedical explanation. Going back to the literature led me to a particular feminist framework that had its foundations within a social constructionist paradigm. As women’s realities are shaped by their interactions with the social world, this framework became very useful to the understanding of themes found in the women’s stories. An analysis of the content of the women’s stories will be discussed in greater detail in a following chapter. For now, I will provide a theoretical discussion of the framework to sit within this chapter as a pre-amble to the findings from women’s experiences with ECT.
The material-discursive-intrapsychic (MDI) framework

A search of the literature made it clear to me that there is no consensus definition of women’s emotional distress. Explanations are generally biomedical in nature, and do not routinely include an explanation for the historical or political positioning of women’s emotions and reproduction (Shafter, 1989; Smith-Rosenberg, 1972). The difficulty in understanding women’s experiences lies with phenomena that are invisible and cannot be fully “known”. Psychological symptoms of distress are often inconspicuous, and the only way that they can be reliably collected is through the use of standardised and objective tools. This realist epistemological approach relies upon quantitative methods of data collection, which clearly negate the complexities and paradoxes of women’s lives (Ussher, 1992). Indeed, the use of these standardised quantitative tools assumes that each woman’s “symptoms” can be further categorised in a binary description of either present or not. The only additional factor of complexity to be considered from this perspective is the degree of intensity. This attempt to reduce women’s distress into a neatly packaged diagnostic and psychiatric category is worthy of criticism. It presumes that depression for women is a homogenous clinical experience with a clearly identifiable biological origin, which actually causes the symptoms reported by women and in turn requires medical intervention, often of a highly invasive nature. This completely rejects the socially and discursively constituted experience of women’s lives (Lafrance & Stoppard, 2007). It also emphasises the gendered notion of medical science, which defines how the lives and the bodies of women are examined and understood.

For some time criticism has been levelled at this tendency for positivist epistemology to apply a dialectic, all-or-nothing approach to the understanding of women’s distress (Gilbert, Ussher, & Perz, 2011). Competing biomedical, psychological and sociocultural paradigms of thought assume a discourse of medical naturalism to position depression as a pathological condition occurring within women themselves, caused by biological factors, cognitive patterns or a multitude of life stressors. Feminists would argue that this medicalises women’s distress (Gammell & Stoppard, 1999; Lafrance & Stoppard, 2007; Stoppard, 2000; Ussher, 2010). This approach suggests that women’s distress is biologically determined by reproductive functioning and is therefore considered to be inherently pathological. Positioning women’s experiences solely as a function of the way in which their bodies work (or do not) is problematic and creates a view that overly simplifies the impact of a decidedly complex juxtaposition of biological, social and interpersonal factors.
For this reason, an alternative framework is sorely needed to highlight the complexities of women's lives and to remove the tendency towards biological or psychological reductionism. Whilst there is room to engage in an analysis that identifies the biological or material factors that contribute towards women’s distress, it is just as important to acknowledge how social discourses and women’s own internal perceptions and interpretations of their psychological wellbeing contribute. All of these factors have a profound impact upon the ways in which women’s experiences are shaped by both themselves and others. In this and following chapters, I propose drawing upon elements of a material-discursive-intrapsychic (MDI) framework (Ussher, 2004). This framework (as shown in Figure 3), helps to understand the interconnections of all three domains upon the experience of women’s distress, yet without privileging the dominant analysis of one component over the others.

Figure 3: Material-discursive-intrapsychic framework (Ussher, 2004)

This framework has been previously used to discuss a range of areas pertinent to women’s health, such as postnatal depression, pre-menstrual syndrome, and menopause (Ussher, 2003; 2004; 2011). It can therefore create a space in which a woman’s bodily experiences of depression can be incorporated into an understanding of her distress, and the way in which the treatments she receives are experienced. Although the framework will be discussed in greater detail in chapter five, it deserves an overview at this point in the chapter and can be seen as a prelude to the women's stories.
By focusing purely on the physical components of depression, the social contexts of women’s lives are ignored. Medical interventions indicate that the point of pathology lies within the woman, thereby ignoring the interpersonal, social and political determinants for their distress. In this model the material aspect considers “factors that exist at a corporeal, societal, or institutional level” (Ussher, 2004, p. 102). This includes women’s bodily symptoms of depression, the presence or absence of social support or isolation, gender inequities, inequalities within intimate relationships and the challenges of gaining economic resources, financial independence and freedom. The discursive aspect of the model involves paying attention to the impact of “social and linguistic domains” (Ussher, 2004, p. 103) on a woman's experience. This includes questioning the influence of discursive practices on a woman’s interpretation of her own distress by examining representations of ideology, culture and power and how women are taught to equate success and efficacy with being “good”. Finally, the intra-psychic aspect of the framework involves exploring the factors acting at the "level of the individual and psychological" (Ussher, 2004, p. 103), such as examining conscious or unconscious guilt, shame, fear, self-blame and the impact of previous violence or abuse. Deconstructed in this way, it becomes clear that the MDI framework allows for a deep and thick interpretation of women’s distress and the engendered and embodied impact on their lives, as will become apparent in the analysis contained in chapter five.

There are however, some limitations associated with assuming a wholly social constructionist approach to the understanding of women’s distress, such as this framework would suggest. Social constructionism has been criticised for appearing to ignore the presence and severity, or the impact of depression on women’s lives (Ussher, 2011). There are many women who experience the debilitating effects of depression. An approach that examines women’s psychosocial lives avoids the emphasis on the biological explanation of depression; yet it cannot account for the biological symptoms of clinical depression such as changes in appetite, weight loss and poor sleep and energy. When women are disturbed by these and other physical changes in their bodies that indicate a change in health, a medical approach seems to be the most culturally endorsed pathway to understand and address these symptoms (Lafrance & Stoppard, 2007). I must acknowledge the depth of the despair that the women in this research found themselves experiencing. The embodied nature of their distress had become so burdensome that for them, medical intervention seemed an appropriate next step. I uphold and respect the depth of their experiences and their desperate desire to address the issue.
However, even if the diagnostic validity of the term “depression” is questioned (as it was within the literature review of chapter two), it remains imperative that an understanding of this response by women to the state of their lives is further understood. The goal of applying elements of the MDI framework (Ussher, 2004) to the women’s stories in this current research then, is to be able to reframe their distress as "the outcome of a process involving reciprocal interactions between a woman's physical embodiment and her discursively constructed experiences" (Stoppard, 2000, pp. 108-109). This is the aim of a later chapter.

Ethics

Within feminist research, the concept of ethics is more than simply showing that the process of the research upholds principles of the National and Medical Research Council (Australian Government, 2007). Here, the way that research is considered, designed, carried out and interpreted and disseminated stems from an ethics of care (Noddings, 2003). This concept acknowledges empathy and the ability to both cognitively and affectively understand another's experience. Using a framework that places the commitment to care in its centre, feminist research shifts the focus from ethics based on principles such as justice and rights to one that is based on relationship (Preissle, 2007). This is not to say that feminist researchers ignore these principles. Rather, they challenge the dominance of principles and reformulate them to also be concerned with relationship, constraint and inclusion (Bell, 2014). They consider questions that relate to who will have access to the knowledge produced, who decides this, and how it is decided (Preissle, 2007).

Ethics of research purpose

The ethics of research purpose is considered as feminist researchers question the intrinsic value of conducting research. Research is valuable in uncovering previously invisible knowledge (De Vault, 1999) and may provide alternative views to women’s experiences. Although uncovering new knowledge may be considered beneficial, some knowledge may actually be harmful. Fonow and Cook (1991) note that some women share intimate and personal details in research that produces knowledge they may wish to avoid. As a feminist researcher, I carefully considered the nature of the research process I was embarking upon. I needed to ask, not only who was to benefit from this research, but to consider whether anyone stood to be harmed by my work. I was (and remain) convinced that the interests of women who had received ECT as medical treatment, and those who may contemplate receiving this procedure in the future were at the centre of my purpose for research. The benefits of the research were
carefully considered at the beginning of the process, as were the questions of who would have access to the information and how this would be disseminated.

Sieber and Stanley offer their understanding of a sensitive topic as one that has “potential consequences or implications, either directly for the participants in the research or for the class of individuals represented by the research” (1988, p. 49). They assert in the strongest of terms, that the word “sensitive” is synonymous with “controversial”, and this is a position that rings true for the focus of the current research. The use of ECT and all its associated historical connotations has been a controversial part of psychiatric history for 80 years (Fink & Taylor, 2007). Yet even with a contemporary marketing approach that highlights evidence-based outcomes it remains a procedure that is shrouded in mysticism, misunderstanding and stigma. There is considerable support to suggest that ECT is one of the most controversial medical procedures in use today (Cyrzyk, 2011; Dowman et al., 2005; Hilton, 2007; Kavanagh & McLoughlin, 2009; Payne & Prudic, 2009). It is little wonder then that research into the experiences of receiving ECT remains one that is significantly under-represented.

By its very nature, research into a sensitive topic such as the current one presents problems with regards to the cost to participants. All research bears the cost of inconvenience and time; however when a sensitive topic is the point of focus, the risks to participants can be significantly higher than other forms of research and may include themes of shame, embarrassment or guilt (Renzetti & Lee, 1993). An examination of the historical view of women and emotional distress has highlighted the previous cost to women (Friedan, 1963). The challenge of the current research was to allow the voices of those speaking to be heard in a way that did not create a cost that went beyond the onerous or the incidental.

During the design of the research I had identified that the most likely risk to women was emotional distress related to re-telling their story. To tell their stories of ECT, women were required to recall emotional and powerful memories of their journey and struggles with emotional distress. For one woman this included the recollection of significant childhood trauma and created a state of emotional distress. Clearly, it would have been unethical and unacceptable to leave her in this fragile state. Smith (1992) emphasises that “to interview and then leave someone in emotional distress without adequate support or safeguards is morally wrong” (p. 102). In this situation, I was able to help her regain composure and feel supported; she was offered a referral to an independent mental health service (which she declined) and I made contact with her by
telephone the next day to ensure her emotional safety. While other women also discussed emotionally driven topics, they did so without becoming overwhelmed or distressed, yet I was cognisant of their emotional state throughout the research process and ensured that their mental state was not unduly affected as I completed the research conversations and departed.

**Ethics of research roles and conduct**

Feminist researchers also examine the ethics of research roles and conduct. As a response to historical acts of research “abuse” (Angell, 1997), the role of the researcher is now one of protection, designed to minimise potential harm to participants. For feminist researchers, this description remains problematic in that it assumes that the researcher will remain distant and detached from the research relationship (Edwards & Mauthner, 2002). This position is likely to be challenging for feminist researchers. For example, Oakley (1981) undertook research with pregnant mothers, only to find herself constrained by the expectations of distance and objectivity from the women. This led her to experience an unbalanced and distorted interviewing style, contradictory to her commitment to care for the women as individuals, and to developing a genuine and authentic relationship with them. Self-disclosure by the researcher is but one way in which the power imbalance between those who research and those who are participating may be minimised during the research interaction.

**Self-disclosure**

One of the most unique qualities about feminist research is the use of researcher self-disclosure (Allen & Baber, 1992; Mahalik, Van Ormer, & Simi, 2000). Harding (1987) asserts the best feminist analysis is one in which the researcher is as deeply embedded within the research as the person who is participating. Here, she calls for evidence of race, class and gender and other relevant personal details to be made as visible as that of the participants within the research, boldly challenging the empiricist stance of objectivity, and allowing for an examination of how characteristics of both the researcher and the participants influence the research process of data collection and analysis. Oakley (1981) believes it is both impossible and unethical to maintain a neutral stance with women who reveal highly personal and often intimate details of their lives for the purposes of research.

Researchers must grapple with the dilemma of how to include their own personal details in a meaningful way whilst simultaneously avoiding the criticism that they are merely projecting their own personal experiences onto their research participants (Allen
& Baber, 1992). Self-disclosure leads to various ethical tensions. Allen and Baber (1992) describe the generation of two separate tensions. First, there is the tension that arises in relation to how the researcher is changed during the research process; the second tension concerns the relationship a researcher has with her participants. Feminists often engage in research that is confronting to their own personal experience – for example researching domestic violence may necessitate the researcher not only exploring systems of oppression against women, but also a confronting of her own history with abusive power (Yllo & Bograd, 1988).

I was aware and mindful of these points as I engaged with the women in this research. My use of self-disclosure minimised the difference in power between the women and myself to some extent, as we shared personal information relevant to the research questions and began the process of co-creating knowledge that would eventually emerge from this work. For example, we exchanged personal perspectives of seeking medical assistance for emotional distress. The rationale for this self-disclosure was to not only enhance rapport and trust, but to uphold each of our personal stories as a valid source of expert knowledge. Inserting myself as a researcher into the research process itself also created a situation whereby my own personal feminist views of the world were significantly challenged and altered, and this tension will be made evident in the final chapter of this thesis.

Maintaining an intimate, equitable relationship with participants is not an easy task, and it does not absolve feminist researchers from ethical dilemmas (Duncombe & Jessop, 2002). However, maintaining an ethics of care (Noddings, 2003) can facilitate a process where feminist researchers can evaluate the quality of their researcher role and the balance of power relations. The researcher taking a reflexive stance and examining their conduct and the research process best achieves this goal.

**Researcher subjectivity and reflexivity**

Reflexivity is a holistic process occurring at all stages of the research process, from the formulation of research questions, to working with the fluid and dynamic dimensions of the personalities of both researcher and participants, through to the interpretation and writing stage (Hesse-Biber & Piatelli, 2007b). Researcher self-reflexivity is a way of attending to important aspects of power relations of the research process (Lather, 2007) and the variety of biases and assumptions that are held by the researcher (Finlay, 2002). It questions authority of knowledge, it opens up a critique of knowledge...
claims and it holds researchers accountable to those with whom they are engaged (Finlay, 2002).

One of the main intentions of feminist research has been to provide a less oppressive way of knowing, however this has not always been successful (Varga-Dobai, 2012). Some research practices, such as attempting to interpret and provide a voice for others can quickly become a reification of dominant power relations (Lather, 1991). In order to undertake research that is non-exploitative, Lather (1991) suggested researcher subjectivity and reflexivity, recommending that researchers find a way to write themselves back into their research. She reminded researchers that in order to not become the self-appointed “Master of Truth” (1991, p. 157) they needed to focus on the text and language used to structure and shape their interpretations. Language produces knowledge and truth, therefore researchers must carefully attend to the process of interpretation, the process of constructing findings, and how they come to know what it is they claim to know (Butler, 1993). It is here that the researcher’s own subjectivity is attended to by asking “how does who I am, who I have been, who I think I am, and how I feel affect data collection and analysis?” (Pillow, 2003, p. 176). Paying attention to issues of interpretation also encourages researchers to stay alert for inconsistencies in stories they hear, “the tales not told, the words not written and transcribed, the words thought but not uttered, the unconscious: all that gets lost in the telling and the representing” (Lather, 2007, p. 13).

Exploring the literature around the use of reflexivity it becomes evident that researchers no longer question the need to be self-reflexive. Finlay notes:

As qualitative researchers engaged in contemporary practice, we accept that the researcher is a central figure who influences, if not actively constructs the collection, selection and interpretation of data. We recognise that research is co-constructed, a joint product of the participants, researcher and their relationship. We understand the meanings are negotiated within particular social contexts so that another researcher will unfold a different story. We no longer seek to eradicate the researcher’s presence – instead subjectivity in research is transformed from a problem to an opportunity. The only question to be answered is, how to do it. (2002, p. 212)

The process of reflexivity can at times be messy. Finlay (2002) warns of the danger for researchers who excessively self-disclose and self-analyse at the expense of participants and the development of understanding. She acknowledges it is
problematic, and that confessing to methodological shortfall is difficult for most researchers.

There are two pillars of reflexivity that became useful for me as I navigated my own swamp: (a) introspection; and (b) intersubjective reflection (Finlay, 2002). Introspection occurred through an intense and personal search for meaning. I carefully examined my own personal and professional experience as a researcher and a mental health clinician for new and emerging insights to form the basis of a more generalised understanding of the research process and the social/emotional world itself. This process was at times more than a little difficult as I confronted aspects of my own clinical practice that were completely at odds with a feminist perspective. This was not a value-free experience, and as seen in some of the reflections on my own research practice noted at the beginning of chapter six, reflexivity was often accompanied by feelings of guilt and shame.

Finlay (1998) reminds researchers that the use of reflexivity is not an end in itself. Researchers should move beyond “benign introspection” to a position in which links between knowledge, claims to such knowledge, personal experiences of both researcher and participants and the social context become more precise (Woolgar, 1988, p. 22) which is also relevant to the second pillar of reflexivity that I engaged with, that of intersubjective reflection. This relates to the mutual meanings that transpire from the research relationship itself (Finlay, 2002), focusing on the situated and negotiated relationship at hand to identify complex research dynamics. Throughout the research interviews I continued to view not only the nature of the interview, but also how the complex and often nuanced dynamics between the women and myself were affecting the research relationship.

**Ethics of representation**

The third area of ethics that feminists consider relates to the way in which participants are represented in publications, reports and presentations (Preissle, 2007). Feminist researchers take care in how people are represented within written documentation, and consider how this will impact on the emotional and psychological wellbeing of their participants. They contemplate whether their participants will agree, be surprised or even distressed with how they have been represented. They consider whether individuals or anyone else in the larger public domain will be harmed or placed at risk by the representations offered (Preissle, 2007). It has been suggested that having participants review their verbatim interview transcripts is a useful mechanism to
increase accuracy of representation (Preissle, 2007). Providing participants with copies of transcripts is not without its own biases (Hagans, Dobrow, & Chafe, 2009; Karnieli-Miller, Strier, & Pessach, 2009; Whiting, 2008), and the psychological health of the participants must be kept in mind. Feminist research maintains the participant as an active co-creator of knowledge yet the decision to return the transcripts to participants must be made through an ethics of care. I decided that women needed to see the raw transcript of their interview, and all women were sent an electronic copy for clarification (if required) and verification. Out of seven participants, I received confirmation of receipt and verification from five women. The two women who did not respond to my invitation to confirm the contents of the transcript had pre-warned me that they possibly would not read their transcriptions. Both these women, although happy to participate in the research, found the interviews difficult due to the necessity of discussing previous traumas and did not feel it necessary to read of them as well. This decision was respected, and no further follow up was attempted.

Ethics approval

The Human Research and Ethics Committee of the University of the Sunshine Coast granted ethical approval for this study prior to any data collection. All documentation that relates to this approval can be found in the appendix attached to the thesis (Appendices A – G). Given the vulnerable nature of the women participating in this research, there were additional strategies put into place to ensure the emotional and psychological safety of women participating in the study. One example of such a strategy was having a consultant psychiatrist within the research team. This female doctor was available for any participant who felt that she needed additional support as a result of participating in the study. During the conduct of the research no adverse events occurred that required notification to the Ethics Committee. The values and principles as set out but the National and Medical Research Council (Australian Government, 2007) were adhered to throughout the life of the research.

Conclusion

The chapter positioned feminist research as the most appropriate framework in which to understand the stories that women have told about their experiences with receiving ECT. It discussed the methodology of a feminist narrative approach and described the two methods used to collect and analyse the data from differing sources. The material-discursive-intrapsychic (Ussher, 2004) framework was described as a way of understanding the positioning of women’s distress in a way that does not privilege one
particular dominant explanation over another. Further, the framework was offered as a brief pre-amble to the discussion that will emerge from the analysis of women’s stories in a later chapter. The next chapter however, will pay close attention to the women in the research as they recount their subjective experiences with emotional distress.
CHAPTER FOUR: PRESENTING WOMEN’S STORIES

To suggest that I was excited at the prospect of having a research conversation with the women in this research is an understatement. As a clinical nurse I was adept at engaging in conversations with women post-ECT that consisted of establishing their level of physical comfort, looking for associated post-procedure side effects, pain or headache. These conversations always occurred within the inpatient mental health unit, immediately after ECT, and focused purely on the embodied experience of the procedure. At this point in the research, I had no idea what the women were going to discuss with me. With some trepidation, I realised that whilst I was curious and eager to hear their stories, simultaneously I felt as though I was being given access to a potential Pandora’s Box. I was concerned about what they would tell me and more importantly, what I was going to do with that information. As the research conversations took place, it became very clear to me that the content of the conversations was so deeply personal for the women that it quickly created a sense of shared intimacy between us both. Yet something did not feel right. Regardless of my desire to be “doing feminist research right”, I realised that there was still an unequal relationship between the women and myself, especially at this point of painful recall. There was a sense of trauma associated with some women’s experiences, and I was acutely aware of the need to ensure that the women were not re-traumatised by our conversations yet I could not be certain that this was not occurring. There was a distinct tension between being a researcher interested in “data” and being a woman who was accompanying other women on their emotional journeys. As they re-told their experiences I realised that I had a responsibility to them, a need to protect them from the effects of the research and the process itself. I was treading carefully, trying to maintain their emotional safety at the same time as trying to “hold” various aspects of the research process. So I was surprised when - without exception - each woman thanked me for giving her the opportunity to talk about her experiences, pain and all. I had no idea that they would benefit from this catharsis to such a degree.
Introduction

The chapter pays close attention to the women's stories. Whilst these stories provide a platform for a further analysis that occurs in the following sections of the thesis, this particular chapter has a greater role to play. In order to attend to a fundamental characteristic of feminist research as outlined in chapter three, it provides a space for women's voices to predominate as they describe their journeys with emotional distress and the subsequent healthcare decisions that they made. In an attempt to enhance clarity, all direct quotes from the women have been placed into italics and encased within quotation marks.

The women at the centre of this research deserve personal attention at this point of the chapter. Although each of the women's stories was unique and original, I have chosen to focus on common characteristics found among them by way of introduction. As such it is necessary to provide some demographic details about who these women are, and how they came to experience ECT before progressing through the chapter that presents their specific view of their world.

Although each of the women had received ECT for an experience of emotional distress, their backgrounds and stories were remarkably diverse. They were between 48 and 60 years of age, and four women were currently married. Of the three who were currently single, two had been in long-term relationships before their ECT. Details about intimate relationships were allowed to emerge organically from their stories, rather than being questioned directly. One woman did not provide any past or current information about intimate relationships in her life other than her immediate biological family.

All seven women received bi-temporal ECT, although two women described transitioning to a bi-frontal electrode placement. Another diverse characteristic of these women related to the number of ECT sessions that they received. Women described receiving between four and forty-seven treatments in total as index courses of treatment, designed to place symptoms into remission. No one had received either continuation or maintenance ECT (designed for relapse prevention). Four women reported receiving their ECT in a private hospital admission. One woman received her treatment in a public hospital that provided accredited mental health services, and the final two women described receiving ECT in both private and public health settings.
Eight core themes arose from the women's stories and were identified as (a) the experience of emotional distress; (b) the medication rollercoaster and side effects; (c) making the decision to receive ECT; (d) experiencing the procedure; (e) experiencing memory loss; (f) living with altered social roles, (g) acknowledging and challenging stigma, and (h) making decisions for the future.

Taken in their entirety, the stories demonstrate the process in which women made the decision to receive ECT. First, the women found themselves on a journey with emotional distress, on which they were prescribed a number of different medications and experienced a variety of side effects. After medications had failed to alleviate the emotional distress, they then made the decision to receive ECT in a manner that can be explained as active and autonomous, or passively coercive. Regardless of how that decision was made, once women had received ECT degrees of memory loss were experienced. The loss differed with regards to type of memories affected, severity of loss and the impact on women's lives.

Women experienced a shift in the social roles that they occupied in their lives with friends and loved ones as a result of the memory loss. Memory loss affected their own, and other's perceptions of them as women, as mothers, as wives and as colleagues. Furthermore, some of the women experienced varying degrees of social and internalised stigma that impacted upon the way in which they recovered from their journey with emotional distress. At this point in their experience women adopted a range of strategies to cope with the memory loss and to resist the stigma imposed upon them. Adaptive strategies were useful and allowed women to make up for some, if not all the deficits they perceived. Avoidant strategies on the other hand, were often ineffective and did little to mask the emotional feelings accompanying the loss of personal memories nor the stigma that was associated with the treatment.

The Experience of Emotional Distress

An experience with emotional distress was the first part of the journey towards ECT and one that all the women could readily describe. Each woman's discussion began with the description of a range of life stressors and losses in the lead up to their journey of emotional distress. For some women, the experience of emotional distress was an acute episode following a clear and obvious trigger; whilst for others the origin of the experience began many years earlier. Occupational stressors were also highlighted as playing an important role. A work-related accident was a theme shared by two of the women:
I had an accident at my work, I hurt my back. Over the next year I did a lot of occupational therapy and physiotherapy, but I couldn’t get back to work. I had been there for ten years, but I lost my job and everything just came crashing down. I went into hospital for a long time, but when I came out I was no better. I sold my house, I moved interstate and left all my friends, but my depression never left me. I had a lot of bullying at my new job and that was really hard because they just ignored that ... then I needed lots of surgery on my back, and I ended up with septicaemia, and pneumonia, and I developed meningitis at one point. So it was a problem between my physical health and my back and it affected me quite badly. Actually it almost destroyed me. (Margaret)

I had a car accident at work in the July, suffered severe whiplash. I struggled on with that pain until October when I went on WorkCover leave. I just wasn’t coping; I was in so much pain. Basically I just went downhill. I was useless, totally useless. I couldn’t go to the toilet by myself, couldn’t shower myself. I couldn’t do anything ... I was just broken. (Helen)

For others, the emotional distress had been building for some time, and women like Anna often described it as “years in the making”. For some of the women the daily grind of life and the multiple demands of the different roles they undertook every day laid the platform for a final and triggering event. Anna described how a catastrophic act of Mother Nature caused her to finally succumb to her ongoing distress:

When I think about it, I have probably been unwell since having the children. I probably had post-natal depression that wasn’t properly diagnosed. Then I semi-recovered but I don’t think I actually got really, really well. It just chips away at you and you just manage, cope. Chip, chip, chip, and it just got worse and worse and worse and these funny distorted thoughts, and the knot in the chest. I got back pain and neck pain, all these really physical symptoms. I had been seeing a psychiatrist for some time and I remember stomping into his office and saying “I can’t cope with this anymore”. He put me into hospital for a week or so, he put me on some tranquillisers and I was just starting to come good when we got the massive storm here. The house was just decimated. It was virtually gone. The street was destroyed; it was just gone. I went downhill from that point on. As far as I was concerned everything was finished, over. I was done. I had more drugs and then went home. For all intents and purposes,
people looking at me would think I was completely normal, but I just knew there was something wrong. I thought if I just ignore it, it will go away, but it just got worse and worse and worse until I just cried all the time. It was terrible; I’d just cry. My husband didn’t know what was wrong with me. God, it was just so awful. (Anna)

The remaining women found it hard to put their finger on exactly when their emotional distress peaked to an acute episode, instead describing it as a process of cumulative psychosocial stress, relational difficulties and unrelated health issues. Kate in particular, could find absolutely no reason at all for her downward emotional spiral. She considered herself to “have had everything” – a happy family, satisfying work, great friends and a sense of purpose. Yet even this was not enough to protect her from emotional distress:

I had everything going for me. Great husband. I was a stay at home mum, a vibrant five-year old, a very busy two year-old and we’d just moved to our new home. It looked like life was pretty much perfect. For whatever reason though I wasn’t sleeping. One of my church elders felt that I needed to go and see somebody medical about my condition. I went and saw a doctor who I trusted and he said that I was probably suffering from depression. Well at that, I was pretty taken aback. I knew my life was stressful, but I wasn’t sure it was depression. I really didn’t think it was depression. He made me take this video home because he could see I wasn’t totally convinced. (Kate)

There was no real trigger. I have always had lots of different health issues, had a hysterectomy at any early age, so no kids and stuff but the whole time I was with my second husband I seemed to be on one form of medication or another. I had chronic fatigue syndrome, I was really unwell for a long period of time. Then I finally left him. I left with nothing, so I had to start from scratch and that was hard. And I just kept seeing my GP and trying different drugs, but I was just getting worse. (Elisabeth)

At times there was a significant disjunction between the perspectives of stress by the women and that of their doctors. Robyn in particular felt that although she was stressed, it was not necessarily as bad as the stress of anyone else; that it was simply a matter of moving forward through it. Her doctor disagreed:
I had been seeing this psychiatrist. I didn't think that I was particularly bad, really, but then one day I went up there and she said, "All right, that's it. You're to be admitted to a hospital." I didn't view myself as being that unwell anyway, but she still admitted me. I was there for quite a few months actually. There wasn't anything I could put my finger on as causing it all. I think it was just the stress of life, working within mental health services and such. I mean, it gave me a sense of compassion for the families, knowing what they were going through, but some days it actually made it worse. (Robyn)

Emotional distress dominated differing amounts of time within each of the women's lives. The majority of the women described a minimum of two to three years between the first symptoms of distress emerging and reaching the point where they felt they had recovered to some degree. Pauline, who is now in her 40s, experienced emotional distress for the longest length of time compared to the other women. She described her first episode of distress as occurring when she left home for the first time, away from her family and friends. Her issues began as she was attempting to forge a sense of identity, yet were complicated by a sense of physical and emotional isolation:

I had some issues in high school; nothing that anybody could pinpoint, but I believe a lot of this contributed. I was very badly bullied in high school, physically and emotionally bullied. I was different to the other kids in school, and I think that was why I was ostracized. High school was pretty awful. I met this girl from this church I was involved with, so I moved to Canberra with her and a couple of other girlfriends. Started working in this nursing home, and we're studying at the same time. That's when I noticed that I was having a bit of struggle ... the next thing I'm seeing a psychiatrist and then the diagnoses started happening ... I think I just fell apart eventually and became very unwell and depressed – eventually to the point of being psychotic.

The Medication “Rollercoaster” and Side Effects

Following their initial and often pervasive experiences with emotional distress, all seven women found themselves seeking medical help. None of them were offered psychological input at the time, however their doctors prescribed them a variety of different medications. They described the challenges of dealing with side effects and the search for the perfect medication to settle the physical and psychological symptoms. As Robyn recalled:
I am pretty sure I have been on every drug that they have created. I have this list here that my psychiatrist wrote out for me when I told her I was going to participate in this research. She thought it might help because there is no way I could remember ... you can see I have been on them all. None of them helped, I have tried them all. Except for the one that I am on now and it’s taken years to find this one. Even now I have side effects with it and it just keeps a lid on things, but there is nothing else. I just have to suck it up and get on with it.

Kate too, was prescribed a multitude of different antidepressants. None of them seemed to fix the problem:

My brain had gone from this pill to this pill to this pill to this pill. I was literally a mess. Nothing helped. (Kate)

Anna and Elisabeth’s stories are similar as they describe the medication “rollercoaster”:

I went to my GP; it’s not a good thing to go to your GP first off with when you have a mental illness. Get a referral to a psychiatrist straight off. I went to the GP, and they tried me on this drug and it didn’t work. Then I’d get sick and the dry mouth and try something else … I was just getting worse. My head was just going round and round. Anyway, I eventually got a referral to a psychiatrist. He booked me into hospital the next day. He put me on Avanza, which I’ve never heard of and I slept for twelve hours. Then I came good, dropped down, came good, dropped down, and then we started the merry-go-round of all the drugs and all the drugs, and all the drugs. Actually, it wasn’t so much a merry-go-round as a rollercoaster! Side effects and more side effects. I felt dizzy and sick all the time … I just couldn’t eat. It was just this rollercoaster – up the dose, down the dose, onto the next one. (Anna)

I had been on different antidepressants for over 10 years or so. I had lots of different drugs; I even had antipsychotics at one point although I wasn’t psychotic. The doctor was just trying to find something that would work. They would work for a little while and then they would stop working, or the side effects would get too bad and I wouldn’t do so well, so we had to keep changing and whatever. (Elisabeth)

The side effects of medications impacted on some of the women’s physical health in particularly dramatic ways. Pauline’s experience with medications was especially difficult:
It was like a roller coaster; I would get to a point where I'd be up here, and then I'd drop right down - it wouldn't last for very long. It was ridiculous, and that went on for years and put so much strain on my family. I tried all the old medications, all of the old drugs, all of those sorts of things, right up to the more current ones, the latest ones that are out there. I was on Largactil at one point. I have tried Seroquel and a whole heap of other antipsychotic and antidepressant drugs. The biggest downfall of all those medications, I found was the weight gain. I used to be quite thin, I had quite a good figure in my early twenties, and I just put on the weight. Now I can't lose it. So yeah, it's been really difficult.

Margaret and Kate also found the side effects of their respective medications challenging to cope with, especially if more than one drug was prescribed. Margaret explained that combinations of medications made her “head feel mucked up” and her body “feel like shit”. It was common to hear women complain that they were not aware of the side effects when they were prescribed medication, and the sudden emergence of side effects took them by surprise. Kate remembers the internal agitation she experienced well:

The medication was awful. I think it was Prozac or something. Anyway, the normal SSRIs, whatever they are, they just didn’t seem to do anything. They just seem to exacerbate everything. It was awful. I became suicidal then. The medication was awful and it made me just want to die. Things got worse so I went to another doctor. He decided to put me on Efexor XR. It was the most horrendous drug in the world. For the first six weeks I was beside myself. My husband used to have to hold me in bed because I had this … aggression. I was never really much of a jogger but I was running around the suburb like a crazy person. At three o’clock in the morning I needed to run around the neighbourhood. I was so agitated. And I’ve never had a panic attack before, but Efexor made me have horrendous panic attacks. Every day. I was in this new job and I’m driving to my job every morning just wanting to vomit. I remember sitting in meetings almost feeling like I had to hold the bottom of my chair because I just wanted to run out of the room. Those panic attacks were the scariest things in my whole life because you’re thinking that you’re going to die. Your pulse rate is ridiculous. Your heart rate is ridiculous. You’ve got this desire to escape, whatever. It’s unfounded. What are you trying to escape? But it was horrendous. Then it felt like there were ants under my skin crawling and trying to get out. It was just awful because I’m scratching my skin to try and get rid of
these ants. It was so freaky, freaky. Really freaky and there are other side effects that were just awful … I couldn’t push through the first part of it even if it was going to be much more beneficial because the side effects were just too bad. (Kate)

Helen required numerous different medications, yet each one was accompanied by a variety of different adverse events:

I just couldn’t tolerate any of them, or the side effects. You are on one medication for three or four weeks and they dose, dose, dose up high...and they tell you that one is not working so they dose, dose, dose down; they try another one and they dose, dose, back up ... so it’s up and down, up and down the whole way. I became sick of the medication, sick of the side effects. I ended up on Seroquel at one point, and I was just so drugged out all the time. I would wake up the next day feeling like a zombie, so I started to wean myself off at that point.

In order to cope with the side effects, some of the women attempted to reduce their doses or withdraw from medication completely. This was especially important for the women who experienced sexual difficulties; ones that they attributed to their drug therapies. Weaning from their medication regimes was not a comfortable process for the women, either physically or psychologically:

I started weaning myself off the medications, as you do, even though people tell you not to, because I was actually beginning to feel a little okay. I was tired of feeling sick from the drugs all the time. And sex with my husband was almost out of the question, the way it affected me in that way. So I tried to come off them. Then I just got worse and worse and worse and just got these dreadful, dreadful panic attacks, and just felt absolutely dreadful. The drugs were bad enough. Coming off them was even worse. (Anna)

I actually lost about ten kilos at the beginning of last year when I got off all my anti-psychotics and antidepressants but one. That happened rapidly, but it still took me six months to get off of all of those. I was just violently ill as anything because of the toxins. Even though we did it so slowly, all the toxins were still coming out my body, and I just couldn’t eat anything. I was vomiting; I had the lot for at least six months. Then again, I was on four antipsychotics, two
antidepressants and three anti-anxiety agents, so it was a lot to get off.
(Pauline)

I went on a mission trip overseas with my family. I had actually been talking to my doctor about maybe weaning down, so maybe now would be the time to ditch medication or try something else. There were a few new medications that were coming onto the market. Some of the side effects of the drugs I was taking, I was really, really, really not happy with ... there’s the whole sexual dysfunction and other different things that I knew were changes because of the medication. All I can say is that my husband is a very patient man. So I was thinking maybe now was a good time to try something else since the old drugs weren’t working. Maybe go off this and go on to something else. I decided, in hindsight it was a pretty silly decision, to go cold turkey off the Effexor the second week that I was in Asia. I don’t recommend that to everybody because it was horrendous. If there was a way that you could get sick, I got sick. I got horrendous diarrhoea. I had, I don’t know, brain shakes. I had dizziness. I was still trying to function going at the villages, going out to do projects and stuff. It was just so hard when your body feels so awful. (Kate)

Following on from a journey consisting of a multitude of medications and associated side effects, the women found themselves in a position of having to consider an alternative treatment option – the procedure of ECT.

Making the Decision to Receive ECT

Coercion and consent

For some women, the discussion of ECT as a treatment option was completely unexpected. It had not been previously discussed with them, and for three of the women in particular, it did not follow on from previous conversations in which it was offered as one of many possible treatment options:

I’d never even thought about ECT. It had never, ever been mentioned to me. I’d never even considered it until I went and saw the psychiatrist and she said, “Look, I think this is the only way.” (Elisabeth)

There was no previous discussion about it. Not at all. But suddenly there it was. They just said, “Yeah, we think you need ECT.” (Helen)
Given the lack of therapeutic effect of antidepressant medication for their specific symptoms of emotional distress, ECT was suggested as the next logical step for the women. All seven women were able to clearly recall the conversations with their psychiatrists, in which they were informed that ECT needed to be prescribed due to the lack of efficacy of antidepressant therapy. Kate remembers the doctor suggesting ECT to her husband, stating, “She is not improving with the drugs. I would like to try ECT.”

Other doctors were far more direct in the delivery of their professional opinion:

*The psychiatrist said, “There is nothing more we can do, we have tried everything else, and we have tried all the medications we can. We are frightened you will try to do something to yourself so we need to do something else”* (Pauline)

*I had been seeing my GP who referred me to a psychiatrist, so I went and saw her, that afternoon. She looked at all my history and all the medications, saw that I’d taken just about everything. Basically, she said straight away, “I think ECT would be suitable for you to try. None of your drugs are working. I think this is best.”* (Elisabeth)

*My psychiatrist just looked at me and said, “The drugs aren’t working. I think we need to try something else.”* (Anna)

Robyn was still not convinced that her emotional distress was as significant as her doctor seemed to think it was. She described how it came as a complete surprise to hear her doctor’s thoughts on the matter:

*I didn’t think it was that bad, but clearly my psychiatrist disagreed. She told me that the drugs weren’t working and that ECT was the next treatment available for me. I was pretty shocked at that.* (Robyn)

Some women felt that they had some initial responsibility for making the decision to receive ECT. After months of experiencing minimal improvement using medication, Helen searched the internet extensively and armed with evidence-based research, she took it to her GP, wondering if ECT could help. She felt autonomous in her decision-making at this point in time, and capable of determining her treatment choices. Unfortunately for Helen, the procedure did not help her symptoms and despite the wishes of her psychiatrist to continue with ECT, she had other ideas:
Well I think because I’d already done some research on it, I even said to my GP, “look, is ECT any good? I am at my wits end. It’s not getting any better”. I remember saying, “it’s just not working and I think we need to try something else. My GP agreed. She said, “Well, why not? Nothing else is working” and she then referred me to a psychiatrist. The ECT didn’t work though, so after 47 sessions I said, “This is it, I am over it, and this is the end. I am unwell but I have to go home. I have a family I need to look after”. When you look at it … 344 days … and a lot of ECT. And I was basically told that I would be incapacitated for the rest of my life … that’s why I wanted to go home, and get back to work.

Anna felt that she was given some control over her own health-care decisions, and her psychiatrist gave her some time to think over her decision. Not being forced into rushing the treatment and being able to nominate a start date for ECT gave her a sense of control over her healthcare, which she believes influenced the final outcome:

My psychiatrist, he doesn’t actually dictate to you - he lets you make the decision yourself. He said, “Well, we can try ECT.” He said, “Think about it”. I think I was probably a little bit confronted at first, but I felt I had control over when I started it - I didn’t rush into it. I dictated the terms a little bit. I suppose if I was passive and just said, “Oh yeah, do whatever you like” I might not have had as good an outcome. Because I had a bit more control over it, I had to think about it, and I said, “OK, I’ll do it.”

Another influential factor for some of the women lay in the personal relationships they have developed with doctors, nurses and other people in their lives. Kate explained that the encouragement of one particular nurse was important to help her make her mind up. As she recalls, “She said she’d seen it quite a lot and she’d seen the improvement. She would definitely encourage it.” For others like Anna, it was the closer relationships with spouses, children, friends and other family members who finally swayed their decisions:

I think everyone was getting a bit desperate including my poor psychiatrist. I think he was sick of seeing me every day, looking terrible. All my friends ... they were beside themselves. They were encouraging me to have it because they could see that I wasn’t getting any better. My husband, he was getting a bit desperate because he could see that I wasn’t improving. I had to do it for all of us, for everyone’s benefit. I was thinking, “Hang on, it’s not all about me. It’s
about my children, my husband, my friends, and my mother, her partner, my sister", this whole group of people that were concerned about me, and that probably helped me make the decision. You know, when my psychiatrist first mentioned it to me I was really resistant – I didn't want to have it. But I probably knew deep down that eventually I would come around to the decision myself. I think he did too. (Anna)

It's all really blurry but I do remember my husband saying, “I've read about it. Look, at the moment it looks like the best option. I’m okay with it if you’re okay with it." I trusted my husband. He has always been very much, “If this is what the doctor says, this is what you do." I very much trusted his decision-making because I didn't trust my own decision-making at the time. (Kate)

Pauline discussed the differences between receiving her two courses of ECT, each a decade apart from each other. The first time, the decision to receive ECT was effectively made for her as she was receiving involuntary care. The second course of treatment was significantly different. Pauline described how the impact of knowledge and emotional support from nurses around her became important and influential at this time:

The first time, I think it was done under an involuntary capacity. I was still under an ITO, but it was strongly suggested to me that I have this treatment and agree to have it. I don't remember signing anything, but I know they told me I should have it. I know that from the first time I had it to now, this time, the one a couple of years back, I was more proactive in my decision-making. This time I really thought it through and got as much information, so that it was a real decision that I made myself. Just feeling comfortable with the nurse I was getting the information from was so helpful. Being able to ask as many questions as I could about it, and looking at all the pros and the cons of having it or not having it, and weighing that up, and being supported in that decision as well. They gave me lots of information and we had a great discussion throughout about how it's done, who will be in there, what's the difference between what they used to do to in the past and how it is done now. That's what made it easy to make the decision by myself this time around. Support and information. (Pauline)
Women described the variable amounts of written and verbal information provided to them in the lead up to making their decision. Only two women felt that they were given enough information to inform their choice. Anna remembers “getting the usual patient blurb, which I read. It gave you enough information. I felt I had enough.” For the rest of the women, information was minimal at best, and absent at its worst:

I wasn’t given a lot. Whether it was because they knew I worked in mental health services and would know about it. And I was in the private sector, whether or not that had anything to do with it. I don’t ever remember her giving me a piece of paper and saying, you might lose your memory or there might be this side effect or that side effect. You’re in such a state that you could have been given it and then it’s just ... well I never had it when I went home. It was only when I got home and got on the internet and thought, oh I best be looking at this, and making sure it’s normal and all that sort of thing. I don’t remember getting anything, at the time. I think probably, because at the time, you’re usually so acute, they just think, she’s not going to take it in anyway. We’ll provide it all later or whatever. I don’t know. (Elisabeth)

Women considered reasons for their lack of provided information, which they often attributed to the setting in which ECT was prescribed. Helen recommended her strategy: “When all else fails, go to Dr. Google. I had no information at all, so I had to jump on the Internet. It was a private hospital, so maybe that had something to do with it, why I didn’t have any information given to me in the ward.” Margaret believed that her previous experience with ECT was to blame for being given minimal information:

When they suggested the ECT, I think because I’d had it before they didn’t think I needed any more information, they didn’t need to talk to me about it anymore. That’s how it seemed, because I didn’t get any. (Margaret)

Robyn however, gave the hospital the benefit of the doubt:

I am sure they gave me some information. I just don’t remember it. (Robyn)

Whether or not the women were given information on the procedure became somewhat irrelevant when psychiatrists positioned the procedure as the only viable option to treat the women’s distress. Women talked about being prescribed ECT when it was perceived by doctors that there was no other option. The term “last resort” was used frequently to describe a situation in which they were informed that all other treatment options had been exhausted, and that they had “failed” the medication option.
Women discussed feeling as though the outcome of being prescribed ECT became almost an inevitability, one in which they had little decision-making authority. Margaret believed she was “given no choice in the matter”, whilst Robyn considered that “there was no option. At least no other option. I had no control over the decision”. Pauline recalled feeling that, “I had to be okay with it because there wasn’t any other door open. The decision was made for me, so I just had to go along with it”. The explanation offered to Kate for ECT was an analogy of a computer that had stopped working:

I remember they sold it to us like, “It’s not like the old thing, and you will only have a toe twitch. Your brain’s a computer. It’s like a system; one that just needs rebooting. There was no other way. The crazy thing is that I remember them saying that they really don’t know how it works; they just know that after a person fits they are usually well mentally. So it seemed I had no option either way. I wasn’t given any alternatives. I didn’t think that there were any alternatives anyhow. There wasn’t a choice. Well, if there was nobody told me. Either you stay here in this hospital for the rest of your life or you have ECT. Honestly, to this day I do not see that there was any alternative. That terrified me. (Kate)

The decision whether to accept or refuse ECT was now out of their hands. As doctors determined the next step, the women described the conflict between trusting that doctors knew what they were doing, and yet simultaneously feeling powerless and frightened at the unknown. There was a strong sense of passive coercion to their final decision. Although not overtly coerced, they did not feel that they had a choice, especially if they wanted to get well. Margaret’s doctors drove this point home when they said to her, “Well we can’t help you if you don’t do this. What more do you want from us?” Margaret elaborated:

In my head I wasn’t happy with this idea, but I didn’t know what to feel at this point. So you just go along blindly thinking, “Well hopefully this will work”. If the doctors say that this is what is needed then obviously they know best and I don’t know what I am talking about, so I’ll just go along with it anyway. But it wasn’t a decision that I made readily, it wasn’t a decision that I made at all really. I was just going along with what the doctor said would work. (Margaret)

Many of the women repeated this theme of a passive acceptance of their doctor’s final recommendation and decision. Despite their own judgments or wishes there was a strong sense of being influenced, and the women appeared to hold firm to the belief
that their doctor knew far better about treating their distress than they did. Robyn recalls “simply accepting it, not making a fuss”; because she felt “they knew better than I did”. Pauline agreed:

*I’ve just gone along with it. I didn’t make a decision on what I believed in; more on what they thought needed to be done. I was just, “Okay, I’ll just go along with it.” I think I was pretty resigned to what they were going to do, really. I don’t think, even if I had given my own consent it would have been because I knew what was going on and what needed to be done.* (Pauline)

However some of the women expressed anger at themselves for giving in to the decision to receive ECT. Three of the women who had received ECT before had promised themselves that they would never repeat the procedure. Margaret blamed the level of her emotional distress at the time, saying, “Your head is completely mucked up. It makes it much harder for you to make that decision. Here I was doing something I had promised myself I would never do again.” Pauline expressed similar feelings. Concerned that she may not be able to withstand the pressure of her doctor’s expertise and the effects of memory loss from previous ECT, she made her mother promise to help:

*Mum didn’t want me to have it this time, because apparently I told her from the first one, ”Don’t ever let me have this done again because of all the memory loss and the side effects that I had from the first lot. Make sure I don’t do it.” Apparently I made her promise that she wouldn’t let me do this again. But here I was, making the decision yet again.* (Pauline)

Margaret recalls a particular instance following ECT that highlighted her sense of passive coercion:

*There was one particular time when the nurse came into me and she said “You had a good seizure this time so you will probably be a little bit sore.” And I hated that - I had a good seizure? Really? No seizure is that good is it? I mean, I just thought it was strange terminology to use. At that stage I was doing something I had promised myself I would never do again, the ECT. And so, I really didn’t want to be reminded that it was ECT.* (Margaret)

There was a clear sense of conflict for many of the women, demonstrated by Helen’s internal battle:
Even though I responded to ECT the first time around, I hated the memory loss and swore I wouldn’t do it again. Yet here it was again … in my heart I didn’t want to do it, but my head told me that the doctors knew better. (Helen)

Equally, for one woman in particular, taking a very passive stance could prove to be beneficial and could even be construed as an active element of decision-making. Robyn was one of the two women who described enjoying the anaesthetic process of the procedure. It was a time of escape, however brief. Consenting more to a respite from her thoughts and feelings of distress than to the medical procedure itself, Robyn quickly agreed to another course of ECT. She did not want to give her psychiatrist time to contemplate the appropriateness of the treatment or to change his mind:

I knew the treatment wasn’t working and that it wasn’t helping. But I really liked the escape of the anaesthetic. I feel that I could’ve definitely had a more active part in that discussion but I just chose not to. I didn’t want him to change his mind. (Robyn)

Capacity and desperation

All the women formally agreed to ECT by signing consent documents. Yet all seven women were convinced that they did not have full capacity to be making decisions about ECT, given the degree of distress they were experiencing at the time. Anna remembered how “it was just so difficult to decide to take a simple shower, let alone make a decision like this”. Kate agreed, adding, “I don’t really think I had the capacity to make any decision like this. I was like, “Whatever”. No way should I have been making that decision.”

Pauline brought to mind that by this stage of her emotional distress, the views of her close family members often complicated rather than simplified her decision:

Mum and others that were around me, they didn’t know how unwell I was until they found out that ECT was the recommendation, it was then, they panicked and said, “How do you know?” That’s when it puts the thought into your mind … Have I made the right decision? Have I listened and talked about it? It’s only when other people start getting at you, you think, have I been informed enough? Have I got enough information and whatever else. Can I make this decision at all?
Elisabeth’s job involved developing policies and procedures for health services. She described how the presence of pre-existing knowledge did not guarantee her competency in decision-making:

Knowing what informed consent is and knowing what it’s all about through work, I would probably say, no I did not have the capacity, because I was so acutely unwell and just desperate for anything that would work. Having said that, if you look back and see how unwell you were, I’d probably think, was she in the right mind to be able to be making that decision? I don’t know. (Elisabeth)

Margaret kept a journal for the period of time she was in hospital, mainly to prompt her memory recall which had been significantly impacted by her previous course of ECT. She recalled re-reading her writings only a few months before participating in the current research:

One of the things I had written in it was, ”I went to one of the nurses and said that I hadn’t had my tablets and he turned around and said “You wouldn’t know what day it was”. That was an indicator, it was just sort of told you where my head was at. Makes me wonder about what decisions I was making at all. (Margaret)

The balance between personal autonomy for decision-making and capacity for full and informed understanding for actions was noted to be somewhat tenuous when memory loss is involved. Anna made sense of this when she commented, “You can’t really rely on yourself and your own decisions because you’re just so bloody crook.” With a degree of irony, Helen described the disjunction between the perception of her own desire for personal autonomy and her potential for legal capacity:

Capacity to make these decisions? No, no…not at all! Remember, I’m deeply depressed. I am severely suicidal, deeply depressed, know nothing, can’t remember anything and they want me to sign a consent form. It’s funny isn’t it … I’m not allowed to drive, I can’t cook, can’t even remember how to put the kettle on and they are asking me to make a decision like this. (Helen)

Women had usually been ill for a significant length of time by the time that ECT was suggested. They were frustrated with a lack of improvement and expressed their own sense of desperation. They were willing to try anything to alleviate their distress. All seven women retold a tale illustrated by descriptions of this desperation, and the pain throughout their stories was palpable. Kate perceived herself as “despairing of life, just
wanting relief...any relief at all”. Margaret found herself, “hoping, believing. I was just at that point of complete and utter desperation”.

Pauline felt responsible for her level of enduring distress. As she recalls:

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\text{Nobody seemed to be able to fix the problem and this had been going on for 21 years. They've got to do something. I had been pleading, it was almost like I'd been begging them, "You've got to do something", and no one was being able to do anything. It's like I felt like I wasn't trying hard enough. (Pauline)}
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Helen was very clear on her options at the time. She felt that she had run out of them, and that there was only one other viable alternative:

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\text{I know they were doing the best they could, but it was like I was pleading with them, begging them, they've got to do something. This has been going on too long. I can't cope ... there has to be something else. I was totally desperate. It was either that, or something worse. And what's worse? Suicide. That's worse. So - anything. I will try anything. (Helen)}
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It was this same sense of desperation that led the majority of the women to placing faith and “blind trust” in their doctors in order to make the final decision to receive ECT. Often women lacked trust in their own decision-making, and as the power of their emotional distress overwhelmed their capacity to make some of these choices they needed to trust that doctors would make the right decision on their behalf. Helen commented on this difficult position, “You had to have faith in someone. I mean, your decisions may not be that great at the time. You have your whole trust in your physician and you have to trust them, for right or wrong. You have to. There is no other option.” The belief that their doctor knew what was best dominated this point within their stories:

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\text{You tend to believe what doctors say as gospel, so you tend to go along with whatever, whether you believe it or not because you think that they know best. You take them at their word. (Elisabeth)}
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Kate attributed her attitude towards the expertise of doctors as the result of social learning:

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\text{I remember growing up, that my Mum and Dad always trusted medical people. They were smarter than us. We were taught that we were working class. People who went to university to do medicine and stuff, they were very smart. They}
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were way higher than you. It was the pecking order. So you listen to them. I guess, I did just trust that these people, who're very smart, would know what was best for me. (Kate)

Decisions to receive ECT were not made lightly, nor easily. Some of the women made significant and complex trade-offs and accommodations with regard to decisions about ECT and possible side effects such as memory loss:

I'd been on that many antidepressants, tried so many different things. I didn't even think of...well, not the consequences but the outcomes at the time, the memory loss and all the time off work that I'd need and that sort of thing. I was just willing to try anything to get the job done. Even to this day, the memory loss annoys me, but that still doesn't make me think, "God, I wish I hadn't had the ECT." It still puts me back to thinking, I'm so glad I did because I'm back on meds but I'm still nowhere near what I was years ago. I'm still a lot better than I ever was. I certainly would never say, "I wished I'd never had it." I'm still glad that I did. (Elisabeth)

They describe a process of “weighing up” their options, and finding a balance between possible benefits and the risk of memory loss. Whilst Anna described it as a “balance between good vs bad”, Pauline was convinced that she had more to gain than to lose:

I weighed it up and I sort of felt well, they reckon that there is very little memory loss these days, and that was my biggest fear, was the memory loss, and the fact that I've been so unwell for so long. I had to give it one more go. I simply had to. (Pauline)

Some women like Kate felt that receiving ECT was a forced option, yet simultaneously the available alternatives were difficult for them to contemplate. They created meaning around their decision by looking at the alternative outcomes of not receiving the treatment:

To this day, I still do not see that there was any alternative. I just wanted to be well. It was like weighing up, “Okay what if I lost my short-term memory for good or what if, what if, what if. I actually prefer that than to be suicidal and dead.” Actually, when I think of it, I made pretty huge accommodations, really. But to me there wasn't an alternative. I was not going to get well any other way. (Kate)
Experiencing the Procedure

Women needed a significant amount of prompting to enable them to recall the actual experience of the procedure. Once they did however, their narratives were dominated by recollections of the more negative aspects of the procedure, as well as a clinical commentary of the procedure. Margaret’s memories were highly emotive, as she recalled:

*It was awful! Absolutely awful! I mean, they used to call it the walk of shame. Because that's how you felt. Ashamed. And you didn't want anyone to see where you were going.* (Margaret)

For many of the women, recollections of the procedure were complex and anxiety provoking, often persevering for years after the procedure had been completed. For Pauline, both courses of ECT (even a decade apart) have been a source of intense trauma:

*I actually do not have any memories of the first time I had it, so I reckon it’s because it was too scary, and anyway I lost all those memories the first time. But the second time around I remember I was very nervous, and even to this day there are memories of when I had the last ECT that obviously reminded me of the first time I had it ... I absolutely cannot cope with the sound of the ECG monitor. I've had a couple of procedures under general anaesthetic, I actually think the next time if I have to have any kind of surgery I am going to ask them to turn that monitor off, so I don't hear it while I am awake, because I just can't, it just freaks me out and I start to panic. Even hearing it on like a TV medical show, it just freaks me out. I have to turn the TV off straight away. I do remember the room was very clinical, it smelled of rubber and gas. Just revolting, really. You really, really don't want to go back there.* (Pauline)

A common memory for many of the women was a sense of anxiety associated with lying on the procedure table and electrodes applied to their foreheads. The noise of clinical staff bustling around the room was also common:

*You sit in the waiting room, the dots on your head. I hated that. You get the anaesthetic – it was a tingly feeling. I guess all in all it wasn’t that bad. Just clinical you know? You are lying there; staring at the ceiling, feeling scared but a little removed from the whole thing. I remember there were lots of people. Lots of people, lots of noise.* (Kate)
You are lying there and they put those bloody electrodes on… and you are lying there and I think … I don’t know, I just think it would be far kinder to put somebody to sleep first … than to be lying there and having to put up with that before they put you to sleep, because all of the sudden it was underlined … this is ECT. You know, you’ve been calling it the “walk of shame” any way and you wake up and you’re sort of finished, and then you go back to your bed. It was all pretty distasteful and humiliating in that regard. (Margaret)

Despite the humour apparent in her recollections, Helen remembered the anxiety well:

You normally have other people with you. I can still recall getting dressed up in the white gown. We used to joke about it, because we would look like white ghosts. It became a bit of a joke; you know we were like the “Three Knights”. If you went down there by yourself, you actually got scared. I guess because you knew you were going to get jabbed, and it’s just the thought … not that I was ever awake, but you would gag on the gas. It wasn’t so much that you were going to have your brains fried, but it was just the process. They shove the mask on you and you feel really claustrophobic. You are lying there looking at everything because with ECT you aren’t asleep straight away, so you just lie there until they do the treatment. That bit was pretty awful. (Helen)

Yet not all the women associated the procedure with a complete sense of dread. For three women in particular, ECT gave them blessed relief from their anguish and misery. They soon learned that it provided them with something certain three times each week. Like Robyn who enjoyed the sensation of “floating away”, Pauline and Anna found themselves with brief moments of anticipation in a landscape of emotional distress:

The second time I had ECT, I remember some different things that aren’t too bad - they come and get you and then you go into a theatre. Then they put a cannula in your hand. I love the anaesthetic; I love that feeling of just drifting off, like floating away, that’s what I like best about it just a feeling of floating backwards, just like it’s all over. (Pauline)

I remember everything about the procedure. You actually looked forward to it at the end, the anaesthetic was so lovely and you knew three times a week you were going to just slip away. I can still remember which side I was lying on in recovery and what the inside of the recovery room looked like. Then they would
take you back to the room. They would put you in a wheelchair, tip you onto the bed and you would sit there for a while ... I mean the procedure was pretty good, your psychiatrist would be there every time, the nurses were lovely. (Anna)

Elisabeth was disappointed to learn that in her particular inpatient setting, the period of time following ECT was considered to be business as usual:

I can't remember anything after being in the wheelchair and going down to the Theatre. The next is waking up in your own bed. You had to get straight up because once you're awake, your breakfast was there. They keep your breakfast. None of this laying around business. You'd have to get up, get dressed and go straight around and have your breakfast. Then of course you're expected at group. Yes, sometimes that was a bit of a struggle. (Elisabeth)

**Experiencing Memory Loss**

Memory loss following ECT was the most significant and enduring adverse effect described by the women. There was some variability with regard to how much verbal and written information each woman received prior to ECT that described or prepared them for the possibility of memory loss. Anna’s psychiatrist informed her that memory loss was a possibility, taking the view that “it’s usually short-term and doesn’t really affect you into the future.” Although she cannot recall being provided with information, Robyn gave staff the benefit of the doubt as she considered, “I don’t recall getting any information. I am sure they gave me something though.” Elisabeth however recalled a different scenario:

I don't ever remember her giving me a piece of paper and saying, you might lose your memory. You're in such a state that you could have been given it and then not remember, but I never had it when I went home. I think probably, because at the time, you're usually so acute, they just think, she's not going to take it in anyway. We'll provide it all later or whatever. Whether it was because they knew I worked in mental health and would know about it. Or whether it just wasn't standard practice? (Elisabeth)

There was significant tension for some women, attributing their memory loss to either "not being told" or "maybe I just don't remember being told in the first place", illustrating a lack of trust in the explicit knowledge of how their own memory functioned:
I can’t remember - and I don’t know if that’s a loss of memory - but I cannot remember ANY information given to me about ECT and memory loss. (Margaret)

I wasn’t competely sure whether it was me, or whether it was the ECT that caused that particular memory loss. Maybe they had told me, but I had just forgotten. (Kate)

Some women who experienced the memory loss were very clear with regards to the cause of it. Robyn was adamant in her belief that, “The memory loss is definitely from the treatment.” Margaret agreed:

I would say that losing my confidence was directly associated with losing my memory and stuff like that over the years and so, yes, I would say it was because of the ECT. Sometimes I think, is this just a memory lapse? But I have just lost too much memory for it to be a lapse.” I know a lot of people around my age would turn around and say, “Oh, you lose your train of thought”, but I can be saying stuff and it totally goes out your head and you just don’t get to remember it, if that makes sense. (Margaret)

The loss of memory for some women was more than a subjective experience. Family and friends also observed the physical impact of this apparent memory loss. Margaret recalled her sister’s perception on visiting Margaret in hospital, “She walked past me and she couldn’t believe that it was me. She told me I looked lost and confused.” Elisabeth’s mother had a similar experience:

Mum was very distressed when I came home and I’d lost my memory very badly, for the first few weeks. She said, "We weren’t told, no one knew." I said, “I could have been told. I don’t remember!” Or they might have thought, you don’t need to know all that sort of stuff. It was only when I got home and got on the Internet, and making sure it’s normal and all that sort of thing. I got online and I Googled. I don’t remember getting any information, at the time. I felt like saying to them, “thanks for telling me or if you did tell me I’ve forgotten”. That was the most frightening thing to think about the state of my memory because I felt so well, in myself otherwise. (Elisabeth)

At the same time, many of the women described a distinct disconnect between how women perceived their memory loss, and how it was viewed by other family or friends.
Some of the women questioned this disconnect whilst they struggled with the function of their own meta-memory, not quite sure whether they should believe their own experience or that of friends or family:

*I probably had slight memory loss, but people tell me things, “Oh, Anna, do you remember when I took you out for a walk and then you ran away?” and I say, “No.” Then they say, “We had to run and get you back.” Apparently I ran away from my friends when they took me out. I think they might be exaggerating though. I might have forgotten a few things, but I don’t think my memory loss was as bad as people like to make out.* (Anna)

*I don’t get upset at it, the memory loss. I suppose I am a little matter of fact about it. There is nothing I can do about it, it just is. Mind you, I don’t think my memory is as bad as my husband makes it out to be.* (Robyn)

The women described a wide range of memory losses following their course of ECT. Most described the loss of memories for the time they were in hospital, however for some the memories spanned much further to the past:

*I can’t recall when my kids were in school, things that happened way back when. Rebecca is 30 next year, so yeah, 20? 25 years ago? I have forgotten a lot of those things.* (Margaret)

*I have no recollection of being under 30. I have images, like I know that I was a young person, I know I was a kid, I’ve seen photos and I know that it happened, but there’s no attachment to that person. It’s complete detachment. Even memories from 40 years on, that’s very shaky. Like I did my “Deb”, I have a beautiful photo of me at my debutante ball, and I know I was there. It’s like I have no connection to that person though. I wish I could remember those memories because I would like to be able to remember them.* (Pauline)

Specific types of memory loss were described, including long-term procedural memories. Elisabeth had difficulty remembering how to operate a manual car, despite having driven one for years:

*I needed groceries, but I couldn’t remember how to drive the car. I said, “Mum, I don’t know how to drive the car.” Stupidly, she said, “Are you mad or
something?" I said, "I don't know what's wrong, but I don't know how." If they'd said to me about memory, it still hadn't clicked at this stage. I said, "It must be something to do with the treatment." I said, "It must be something to do with that." Mum panicked. She just absolutely freaked and she rang the psychiatrist who said "That's normal. The memory loss can be from point A to point B." I didn't know then, until I got home, that I couldn't drive for a certain amount of time and couldn't do this, couldn't do that. It took about six months, to have the confidence to get in and drive. I knew that I'd probably be able to get in and drive Mum's automatic, it wasn't so much the road rules that I'd forgotten. It was just the manual, it was, yeah, I've got those pedals and I know that they're for this and that. Then I've got to do the blinkers at the same time. What about if it's raining, so much to think about to try and get it all into place. It was just, I don't think I'd know how to get all those bits together to work, all together. (Elisabeth)

Another common complaint from the women related to losing the capacity for facial recognition. It was more than needing to use a simple "your name is on the tip of my tongue" statement to rectify the issue. It became necessary for some women to routinely check with family to validate their pre-existing knowledge of people who appeared for all intents and purposes to be strangers. As Robyn maintained, "This happens all the time. I certainly don't recognise their faces, but I must know them because they are using my name." Other women described the sense of having absolutely no idea or clear memory of the identity of a large number of people that they met during day-to-day living:

I simply don't remember people anymore – their faces, their names. It's gone, all gone. They said, "You remember him from work." I'm like, "No. No, I don't" I didn't know what job he did, or where he went or where he fitted into anything at all, or how I even knew him. It's like I've NEVER met him. (Elisabeth)

People I've met, I've met on numerous occasions, and they obviously know me really well, and they'd come up to me and give me a big hug and say, "How are you?" I'm thinking, I know this person, but I don't know where or how I know them. This happens to me regularly. It's quite embarrassing sometimes, because they obviously know you but you have no idea of who they are. (Pauline)

Difficulty in recalling faces not only made it difficult for women to remember names, but also to recollect other information pertinent about individuals. Kate's role within her
local church depended partly upon her inordinate skill and awareness of how individuals sat within their social context – who was who, who knew who and how they were all interconnected socially and relationally. She described how this all changed following her treatment and the effects on her memory:

I was the newcomer coordinator at our church. I could virtually remember everybody’s names in the church. There are 800 people in that church, by the way. What they did. What their kid’s names were, who they knew, their hobbies. After ECT I just couldn’t … people would tell me a name. Woosh, straight out. Nothing stuck. Things that used to stick - people’s experiences, what they do, what their life’s like, I could connect them with this person, with that person. I simply couldn’t do that any more. I used to be phenomenal with faces. I would go, “Oh look. I know you from somewhere … Yes. It was in a coffee shop at such and such …” It was freaky scary the way I could do that. A freaky skill, but useful for a Newcomer’s Coordinator. A new person would come to church whereas … I would not even, the next week or the next week after remember that I’ve met them. It disturbed me because I would go, “I don’t remember you.” I don’t have the mental capacity to remember names any more. Not a good look when you are trying to make new people feel welcome. (Kate)

Other geographical memory problems were raised as being problematic following ECT. For Robyn in particular, geographical landmarks held no connection to memory despite living in the same house and the same suburb for over twenty years. This was the home she had shared with her husband, the home in which she had raised her children, yet she had no emotional connection through memory to speak of, or to feel:

Then I remember coming home from hospital and the vivid shock for me was that we were driving along getting closer and closer to our house and me not recognising anything, not recognising my house or anything like that from the memory lapse. I have lived in this house for over 20 years, but there was just no connection to it, I didn’t recognise it at all. I couldn’t drive either, I would get completely lost. Mind you, this was before we had GPS, but it took months to recognise anything around my suburb. (Robyn)

There were difficulties in completing domestic tasks, stemming from problems in knowing where to start the task, or how to break down bigger tasks into their smaller components. It became clear that tasks that were once routine and automatic now took a great deal of time, energy and cognitive flexibility:
Knowing how to go about cleaning or organising your house, or organising yourself. How to cook a meal, like a basic meal. Those sort of skills are all out of whack. Knowing where to begin, where to start. (Pauline)

Housework has become really difficult too. It’s not that I can’t get motivated; it’s just that it’s hard to process exactly what needs to be done. The other thing is gardening, and how it’s affected. I can’t garden at all. I used to be in the garden all day after work, before work. I’d be up at 4:30 in the morning, out there as the sun came up. I would be just gardening all the time. Weekends, people would come to visit me and I’d be out in the garden. That really went downhill as I couldn’t do that. I just stopped. I just could not get out there and that’s how it stands today. I’ve always thought it was from the depression but now that I’m feeling better, I still can’t. I just can’t bring myself to do it. (Robyn)

Difficulties in performing domestic tasks once seen to be routine and automatic became apparent for both some women and their families. This in turn created a shift in the way that women viewed their roles within the home. Helen struggled to reclaim her space and role as the person responsible for the family meals and described how it altered the dynamics between herself and her husband:

I couldn’t remember how to do simple things when I got home, things like being able to use a dishwasher, or cook. Before I lost those memories, he would sit on that side of the kitchen bench talking to me while I did my thing over on this side. Not anymore. Not now. Even now, he just doesn’t trust me. It caused lots of arguments because he just wouldn’t let me do what I usually do. I hated that. I was banished from my own kitchen. Imagine that! I felt so incapable... I lost all confidence in everything that I used to do and it was hard to get it back. (Helen)

Pauline provided a succinct analogy as she described the impact of ECT on both her memory and her cognitive capacity, describing it as, “an itch on the brain that I just couldn’t scratch”. Helen however, gave a more poignant summary of her memory loss, which reflected the depths to which she felt as though she had lost part of the woman she once was:

You don’t understand what memory loss means, or at least not until it happens. I didn’t realise how bad it was, or how bad it was going to get. That you couldn’t really remember anything. You suddenly realise that who you are doesn’t really matter, because you can’t remember that person anyway. (Helen)
Women described many opportunities that they were now unable to participate in fully, especially for those that involved their families. The sense of grief associated with this additional loss was palpable as they described the missing pieces of their lives. Margaret coined it “the added thing”. She described the misery that emotional distress caused, but this was compounded by discovering that, “I had this added thing, this memory loss. I had actually lost my life, and myself”. She added:

   My daughter or my son would say “Oh, remember such-and- such”… I can’t join in on that because I can’t remember it. I feel excluded. I hated that because I’d always been capable. All of a sudden I didn’t feel capable. (Margaret)

Helen’s memory loss was described as a “running family joke”, yet one that she couldn’t join in. She described her family frequently saying:

   “Oh, you won’t remember that Mum”, and then I say, “Well what happened then?”, and they could say anything at all to me. (Helen)

She was not the only woman within the research to use this particular descriptive term. Robyn’s memory loss became “the joke of the family”, accompanied by its own code word:

   It’s always a joke in the family when I forget something which is fairly frequent. My husband says, “Oh, that’s pre-ECT.” It’s a clue to the fact that I am not going to remember something that they are about to discuss. (Robyn)

At this point in the conversations it was clear that many of the women felt angry at their loss of connection with their previous selves. Memory loss had removed very personal memories that they did not expect to be missing. Whilst Pauline expressed a sense of anticipatory anger at the losses she was bound to discover as she grew older, Helen was angry at missing memories of milestones celebrated by her children:

   It does make me angry because I want to be able to recall things that have happened. I remember watching the news recently and this lady, I think she turned 104 and it was a big celebration birthday. She made the comment to the camera man that she can remember every single day of her life, right from when she was a little girl. I can’t say that. I don’t remember anything. (Pauline)

   In 2009 my son got engaged and I don’t remember anything. Apparently we had a party here, at this house, and they had another one somewhere else. I went
to it too, apparently. I only remember tiny little bits about his wedding. That's really awful, not being able to remember your only son's wedding. (Helen)

Helen was adamant about her feelings at this point in her life:

I felt like bits of my life had been stolen. (Helen)

Pauline remained angry at the loss of memories relating to the quality of the relationship she shared with her older brother, something she did not believe would be returned:

I know that I had a great relationship with my brother growing up, but I don't really recall it at all. I'm sort of relying on stories that my family told me and bits and pieces that I can remember, and I try to put it all together. I get really angry when I think about this. I love my brother, so there are obviously memories I used to have that I don't anymore. They probably won't come back. (Pauline)

As women experienced loss of memory recall they often felt incapable of participating in the independent life they had once enjoyed. Strategies were required. They now relied on others to help them remember certain facts, or complete tasks that were once automatic:

And he wouldn't trust me to cook a meal the way I used to do... it was really difficult. You know, that was my space. I used to love getting in there and creating a beautiful meal for everyone. It's only like, in the last 12 months, that we've got to a place of... ok, we are going to take it in turns to cook. Going out in the car to get groceries - no, no. He wouldn't allow me. It's been very very difficult. That was another reason that I went back to work, to prove that I could do it again. I'm okay, I'm a capable person. I can do this. I've got it. I am a capable person, so please stop putting me down and shutting me out. It's not helping me. (Helen)

Pauline and Robyn both struggled with the demands of processing complex cognitive tasks required for maintaining the organisation of the house. Robyn's coping strategy was fairly simple:

I just don't clean anymore. I leave it to my husband. He also does all the gardening. I am no longer the woman of the house, he is. (Robyn)
Pauline on the other hand, required new strategies to help. What she did learn in the process was that she was quite successful at learning a brand new skill:

*I've just worked out how to make spaghetti bolognaise from scratch, and I have discovered I can make something that's actually really delicious. Up until now I would just throw a jar of sauce and pasta together. I just couldn't work out what the steps were that were needed, how to put them together to make it from the beginning. My brain just doesn't work that way. It's like when you are cooking – there might be three or four parts to it, and knowing when to do each section...that's what I have difficulty doing. Trying to work out what to start with, when to add what, will it all be ready at the same time? I can do it now, finally. But it's taken a lot of time, and brain training and practice for me to get there. It's such a basic skill, but I still have great difficulty, so I tend to eat a lot of frozen stuff, which isn't very healthy because I find my brain gets exhausted very easily. (Pauline)*

Strategies that women used ranged from extremely helpful and creative, to those which did little but hide the issue. Some women like Anna and Elisabeth were very open and disclosed relevent information to people at work. They were both relieved and impressed at the level of support that was given to them. Margaret soon discovered that her own personal strategy had significant disadvantages as she noted:

*It's just this big vacant space of nothing. And there comes a time when you just don't want to be confronted with the stuff that you have forgotten. You don't actually say, "Oh I forgotten about that", you get to a point where you just shut up. You just pretend that you know what they're talking about. You stop engaging though. (Margaret)*

Robyn discovered that her strategies were not very helpful either, and that her memory loss overwhelmed her capacity to cope with the gaps in her recollections. With a sense of resignation in her voice, she described how, "nothing really helped. I gave up doing the things I couldn't remember how to do. My husband does them all now." Pauline found that practising a task and repetitively vocalising words assisted her learning and memory consolidation, although she still required the help of her mum to provide information to gaps in memory:

*I rely on Mum a lot like, particularly if I go to a medical appointment or whatever, I can use her to recollect certain things, because sometimes I start to tell bits*
and pieces, but they don't always add up, so I've got to get the accurate story.
(Pauline)

Helen returned to her children’s “Little Golden” books in an effort to re-learn basic mathematics functions. As she noticed, “it’s really hard to keep all the numbers and functions in her brain, going back to basics helped me”. Kate discovered the power of certain memory recall aids:

I found mnemonics work really well for some information. Also the “Door” thing - you know, if you forget something, in your mind you go back through the last door to what you were doing, and then back through the door before that. (Kate)

Although Kate gave up her teacher’s career due to the memory problems she experienced, she soon discovered other areas of her cognitive functioning had escaped ECT’s impact:

It's funny, I found that although I couldn’t remember a lot of words and stuff in English, I found I could learn a brand new language. I mean, it was tiring, and probably took more time for me to learn this language than someone who hasn’t had ECT, but I can speak this new language pretty well, and I am now doing missionary work overseas, where I am now teaching Asian teachers! (Kate)

Margaret set herself some goals for the future, wanting to challenge the impact that memory loss had created for her. This has become a powerfully motivating strategy:

I have actually taken the big step of saying next year I’m going to marry my daughter, and I want to marry my son next year. Also, a friend's daughter. Um, just because I feel like I have to try and move on from where I am, but if I don’t – if I can’t do it, I’ll crash. Because it's the one thing I need to do. You have to never, ever give up. (Margaret)

Managing Alterations in Social Roles

The consequences of memory loss on the women’s capacity to create and maintain social roles and interpersonal relationships were grave for some women. Margaret had previously lost a seven year relationship to the effects of enduring emotional distress and a course of ECT, which has altered how she views future relationships:
It makes you reluctant to actually form any new friendships because you are just so spaced out all the time with your memory. There is just nothing there! The last relationship that I had ended a couple of years after I had the first lot of ECT and it was because we used to have to do a lot of corporate entertaining, and I wasn’t able to do it, so I just wasn’t useful any more. That, and the fact that he couldn’t handle that I had depression. He hated me having ECT, so it’s just easier for me to sit back and just not make any attempts at forming new relationships. You just don’t want to go there again. (Margaret)

Other relationships, such as close friendships were also affected. Following their ECT some women were dismayed to discover, often years down the track, that they had said or done things that they considered hurtful to others. What was even more difficult for them to comprehend was that they seemed to have forgotten that they had done so in the first place. Elisabeth explained that she found this embarrassing and somewhat shameful, because it was just so out of character for her nurturing personality:

Sometimes it took a couple of years to find out things that I’d said or done. People hadn’t said anything to me. I was like, "Why didn’t you say something at the time?" And they, "Oh we knew you weren’t well." But a couple of things were really nasty. I said, “That’s just awful. You should have told me!” Obviously, I just forgot all about it and didn’t want to. Afterwards, that’s really awful. But what can you do? I’d already done it. I mean, I didn’t feel any different, as a person, afterwards. I think that was just the memory loss that was frustrating to me, made me do and say some terrible things. It wasn’t like I killed anybody or anything, but I said things I wouldn’t normally say. And it was hard to make up for them. I felt really embarrassed and ashamed. (Elisabeth)

Pauline also struggles with maintaining social ties, as she discovered that complex cognitive skills are needed for social engagement:

That’s the other thing that I have great difficulty with because I’ve never really had to do it before, other than a small group of people. Social skills, socialisation, I find that extremely hard to hold a conversation and make conversation with someone, over a period of time. I might go over to Mum and Dad’s house for dinner and they might have my brother and his partner there, and after a certain amount of time I’ve had enough, I’ve had enough, I need to go, I need to go. Too much stimulation. Too much going on. I can’t go out at night anymore, not even till 8:00 or 9:00 at night, not that I have anywhere to
go, but if I’m not in a meeting, whatever, because I find when I get home it takes me so long to shut down, to unwind. My brain has just been so scrambled by the ECT and stuff.

Pauline has only regained the use of skills that were either failed to be consolidated or were disrupted by her treatment. She has only just earned her driver’s licence at the age of 42 years. With laughter she described herself as a “late bloomer”, but described her difficulties inherent in the capacity to follow maps and directions, even with the assistance of a GPS system. But she reminded herself that the alternative was not one she wished to think about:

I run the risk of being institutionalised again – this time in my own home.
(Pauline)

ECT is a treatment that has effects on the physical body, due in no small part to the ongoing need for general anaesthesia. Women referred to the profound physical impact of ECT in the recovery phase as they tried to reclaim the social and familial roles they once held. Elisabeth commented, “No one can prepare you for how exhausted you are after ECT. It simply takes everything out of you, physically. I was simply exhausted for months and months.” Anna tried to return to work four months after her ECT, only to discover that she was “so very, very, tired. I had no idea how tired I was going to be.” Helen also struggled, as she tried to prove to herself and those around her that she could return to her previous level of functioning at home and at work. Upon reflection she noted, “I was just too shattered. I had no energy and had to sleep a lot for the first few months. I have no idea how I thought I was going to do it.”

Pauline was grateful for the help of her mother, convinced that she could not have done it without her help:

I am really glad my mum helped me, and looked after me. There was no way I could have done it. I was just physically exhausted all the time, headaches, lethargy, all of that. (Pauline)

Not all the women had this sort of support. Although some had supportive husbands, for the most part they were left alone in the post-ECT period to rest and recuperate. However, many of them described how difficult this was when there were competing demands of children:
I felt that I had neglected the kids for so long, I wanted to get back into being a proper mum. But it was just so hard. Trying to do everything they needed ... it was all a little much to be honest. I simply had no energy to do what was needed. (Kate)

Poor memory functioning impacted upon some women’s capacity for employment and purposeful work. Some women felt “let down” by their brains and found themselves challenged by needing to practise new skills repetitively in order to retain information and skills:

Even going to work, I’m normally at work by 9:00. I mainly get paid from 10:00 to 1:00, but I make it by 9:00 and I don’t leave till about 2:30. I have to, to make sure I have done what I need to, because I usually have to go over everything a hundred times – I forget what I have already checked and then have to repeat it over and over. I waste so much time, but I get anxious that I have forgotten something. (Pauline)

There were reports of observable differences in some women’s employment that occurred after ECT. Some women were offered job promotions after their treatment, which they were certain they would not have been able to do whilst in the grips of their emotional distress. Elisabeth described it as a “real confidence booster”. Others however, like Margaret and Kate, were unable to return to their chosen careers:

I became a marriage celebrant before ECT but I have only done one baby naming since, because I could never actually commit to something because I could never be sure that I wouldn’t be crying all day. So I haven’t done anything. I can’t remember a lot of the stuff that I’m supposed to do with it. I feel I would be unreliable for people to use. So I can’t work now. I get unemployment benefits but that doesn’t pay the mortgage. (Margaret)

Not only could I not remember people’s names at church, but now I couldn’t remember the names and faces of the children I was teaching. I had to give that up, I couldn’t do that anymore. (Kate)

Acknowledging and Challenging Stigma

At times, some of the women experienced the impact of stigma. It was a phenomenon that affected the way they were perceived by others as well as their own self-perception. They now identified as someone with enduring emotional distress who was
navigating the healthcare system. Anna was concerned that stigma was still such a powerful force:

   Yes, but really, when you think about it, it’s 2015. There’s still a stigma with mental illness! We haven’t come that far, really. It took a while though. It took me a few years. Still, if you say that you’ve had a mental illness or you’ve had a mental illness and it’s being managed, people still view you a bit strangely, not everyone, but a lot of people still do. (Anna)

Kate experienced significant self-stigma and this altered her self-concept as a strong and resilient woman. Her story shows the depth of her negative self-evaluations as a person with a mental illness:

   I always had in the back of my mind if anybody knew that you were taking antidepressants, if anybody knew that you have had depression, they wouldn’t want you to be their child’s teacher. They wouldn’t want you to be their friend. They wouldn’t believe your testimony and your faith. The stigma of a person who is suffering from mental illness makes them a lesser person, makes them a weaker person. I believed it. I was always the weak person. I was very, very weak. If I was a stronger person, if I was less anxious, if I was less this, or less that, if I was better at doing health things and stuff, I would be a better person and I wouldn’t have these problems. I didn’t want a label. I’d heard the stigma of depression - people that were lazy or making stupid choices. I reckon I’d get more sympathy and more understanding, if I had cancer... instead I’ve got this stupid disease. I don’t want sympathy from people for this. I don’t want them to know and now everybody knows. All my friends, everybody knows that I am an idiot. Even a psycho! (Kate)

Kate’s experience on admission confirmed her greatest fears:

   They told me in the emergency department that there would be no beds available but they would put me in a surgical ward or somewhere else that would take me in. They tried to find a bed. I can remember thinking, “I’ve started a really freaky journey. I’ve started the psychopathic journey of the people that they would put on a front page of the newspaper as a criminal”. I sat in this little room at the end of the corridor for eight hours, and there was this big security guard who sat outside my room. Eventually I get up into a psycho ward and that just confirmed it because there were all these people doing all sorts of freaky
scary things. I’m just looking all these people going, “I don’t know where I fit here but obviously I do. Clearly I am supposed to be here”. (Kate)

Even when she was discharged, Kate worried about the possibility of ongoing stigma. She had concerns about others knowing of her journey with mental health care, commenting:

It was freaky driving my car to the outpatient clinic though. I really hoped no one recognised that it was my car parked there. (Kate)

The effects of stigma were not lost on some of the other women. Elisabeth received her ECT in a regional hospital, and was concerned about issues to do with confidentiality and privacy, and was “not sure how to keep it (ECT) hidden”. Anna received her treatment in a large tertiary hospital, yet still voiced the same concerns:

I really didn’t want anyone knowing what was going on. I basically hid away from everyone. I must admit, in the first couple of years I told no one except my really, really close friends at work. Initially I thought, oh God, if I tell anyone I’ve had ECT they’ll look at me differently. They’ll think I won’t be able to do the job. They won’t ask me to do a project. (Anna)

Stigma was not simply confined to the thoughts and perceptions of others towards the women. Kate in particular had a difficult time reconciling her own thoughts about her identity as a woman receiving mental health care. Her perception of the difference between needing treatment for a physical illness or a mental illness was stark and contrasting:

I was thinking that if you’re on medication, you’ve got mental illness. But if you’re not on medication, you’re a stronger person and you don’t have mental illness because only weak people take medication. I wouldn’t have said that about a person using insulin. I wouldn’t have said that about my mother having cancer. I wouldn’t have said that about people having blood pressure problems. But for me, a person who has to take an antidepressant was a weak person. If I need medication, I’m weak. If I needed medication for something else … if I need Panadol, that’s alright. But if I need antidepressants that’s not legitimate because to be controlled by your mind means you’re not using self-control. (Kate)
Stigmatising attitudes were also noted to originate from an array of health care clinicians. Helen experienced physical injury post-ECT although her medical team would not validate her concerns:

*My body jerked so much from the seizures. I ended up with plantar fasciitis. The doctors said it was impossible. I have had trouble with both feet, have needed special orthotics and physio, and I didn’t do anything – I had been in hospital the whole time before this happened. They refused to take any responsibility for it, and it cost me a fortune to manage it. It makes me furious, they simply don’t get it, nor do they care about it.* (Helen)

Helen also found her legitimate physical care needs stemming from the original car accident were often minimised. To her it seemed that staff did not perceive these needs as being a domain of mental health care:

*Some of them (the nurses) didn’t care very well, one of them said, “I am not going to catheterise you any more”. She said to me, “I will get a mirror and you can learn how to do it yourself because I am not doing it any more. I am a mental health nurse, not a general nurse.* (Helen)

She experienced similar attitudes from general health care clinicians who falsely attributed an adverse and physical post-anaesthetic event to her diagnosis of post-traumatic stress disorder:

*I started to get really sick with all the anaesthetics from ECT. Forty-seven separate ECTs and the anaesthetics took their toll on me. After each one I would develop a left-sided weakness, couldn’t walk, was incontinent for days afterwards, and I actually developed foot drop. The doctors didn’t want to know. It didn’t stop after ECT though. I was having an anaesthetic for a colonoscopy a couple of years ago and my BP suddenly went through the roof, and my temperature plunged. I was shaking and freezing. And they couldn’t work out what was happening. Eventually this nurse and doctor came into my room and told me they thought my PTSD was causing it and they wanted to transfer me to the pysch ward. They had contacted my previous psychiatrist who I hadn’t seen for ages, for God’s sake. I had not said a word about being diagnosed with PTSD after the car accident years ago. I think when it all went downhill in the recovery room and my BP dropped, they obviously went back into my charts*
and saw all the anaesthetic reports from the ECTs, and made their own minds up about that. (Helen)

Other women experienced similar discrimination whilst attempting to access physical health care. Kate suffered an attack of gallstones, yet a call for the ambulance service resulted in her symptoms being dismissed:

As soon as they found out that I was on a medication for mental illness, they put all my symptoms in a basket and made me feel like I was psychosomatic. They weren’t prepared to transport me to hospital at all. As soon as I said that I was on an antidepressant they asked, “Okay, you’re feeling well now?” They changed their whole demeanour and they talked to me out of having pain and of needing help or transport to the hospital. It was like, “It’s all in your brain. Take some Panadol, have a hot pack and see your GP in the morning”. I was disgusted at their treatment. The next day, we went to the doctor who scanned me. It confirmed the stones. I had surgery less than 8 hours later. (Kate)

Despite numerous episodes of discriminatory attitudes, some of the women described reaching a point where they no longer wanted to keep their ECT a secret. As a result of their experiences they wanted to challenge widely held and dominant assumptions about the treatment. Anna remembered that it took her a period of time to begin to speak openly about it:

Now, if I’m talking to someone at work who is having major issues with a friend, I said, “Oh, well, tell them to try ECT. I’ve tried it and it’s very, very good.” They look at me and think oh, she’s normal and she’s had ECT. I feel like saying, “Ask me, ask me, I will tell what its really like!” (Anna)

Kate found her voice against stigma in a GP clinic on one particular day. She had seen a specific doctor the week before and had complained that she felt “like a crazy woman” as he prescribed yet another course of different antidepressants. She experienced significant agitation with this particular medication and the following week, her exact words were uttered back to her by the GP. She recalls her anger:

Yeah, he used my words back at me. He said, “You’re a crazy woman, then?” I went off! He said, “but that’s what you told me”. I said to him, “don’t you ever call me crazy because I tell you I feel crazy. I feel out of control but it’s absolutely not your right to call me that”. I was incredibly angry because I thought the stigma of depression, of having a mental illness, to me, was so
huge, especially when a person who was a medical professional labelled me, even with the terminology that I used myself. He said, “Well, that’s what you said about yourself,” I let him have it after that. (Kate)

As a way of fighting against misunderstanding and misinformation, Pauline now works with others who have experienced similar journeys:

That's why I decided to work in the industry because there are certain people out there that don't believe in recovery, don't believe in hope. You've got to hold the hope for that person, and that's what made it for me, because a lot of staff had the hope that things would improve for me. They made me believe it was possible, that my life wasn't over and that I was more than my label. (Pauline)

Making Decisions for the Future

Just like making the decision to receive ECT, women’s final attitudes and their feelings towards ECT were multi-factorial, and operated as a function of complex accommodations of benefits and sacrifices. A positive attitude towards the treatment however, was not contingent upon a positive or functional outcome:

As I say, I don’t think I would have done any of that without the ECT. I just wouldn’t have been well enough. I know I have a lot of memory issues, but I think I can work around them. I haven’t gone out and shouted it on the rooftops but anyone close to me knows that I've had it and that I am not sorry that I did. I often think, maybe I was lucky and had a good dose or whatever. I don’t know. There were four or five other people in, at the time, when I was in. They were all the same as me. They all found it a really positive experience and I think that makes it a lot easier. Even if you weren't feeling well or you felt it wasn't working or something, if you have other positive people around you, it makes the outcome better down the track. (Elisabeth)

For others, their appraisal of the treatment was significantly less positive, and they had reached the point where sacrifices to physical health and memory functioning simply did not outweigh the negligible benefits, or it was clear to them that the treatment was not effective. Helen reached this point when the physical effects of ongoing anaesthetics became too demanding for her body:

I reached that point of saying, “I am over this, I just have to go”. I was totally unwell. And unsafe. I was supposed to have more, but I just said, “No, no, no, no”. I just wasn't getting any better. My recovery was getting slower and slower.
And the memory was just gone. And the amount of time I actually felt better was getting shorter and shorter. I was going nowhere. The more I was having, the worse I was getting. (Helen)

For women such as Robyn and Margaret, ECT did not allow symptoms of emotional distress to remit, and it left them feeling just as distressed as before the treatment. Margaret recalls an incident that clearly demonstrated the difference in her perception and others with regards to her response to ECT:

I didn't get any better despite the ECT. I had a doctor come in and see me while I was in the hospital. He wasn't my normal doctor. He said my eyes were really bright, he could see that I've been having it. I thought that was a load of shit, because it seemed that they just wanted people to believe that it was working… no matter what. (Margaret)

Women were asked whether they would consider ECT in the future. Some were adamant about their future decisions, whilst others took a more philosophical stance.

For Margaret, there was only one possible decision that she would consider, vehemently proclaiming, “NEVER, EVER, EVER! I don't care how far down I get, I will never have that again.” Helen had similar thoughts, predicting that “I wouldn’t have it again, and I would probably do something stupid, like kill myself, instead of having to relive the treatment again.” For Robyn, “the decision is obvious. There's no point. It didn't help. I wouldn't do it.”

For other women however, questions about future decisions with ECT were met with hesitancy and a sense of trepidation, even if the outcome with the previous course of ECT had been success in alleviating symptoms. Not one woman was able to commit to saying that she would consent to a future course of ECT if her doctors felt that she required it, or if they prescribed it. It was obvious that making decisions about future treatment options was dependent upon complex accomodations, and involved extreme anxiety around further memory loss:

I'm not sure. I've thought about it and the only thing that scares me, is the memory loss because I think god, if that happened and I can't work, because I'm on my own, I'd be in big trouble. At the moment, I'm pretty good. If I thought I could have maintenance ECT, and just function normally, then sure, I'd be in there like a shot. If I had to go back to being an inpatient, then I'd have to be at that point, I think, that same really sick point, to want to go down that path again.
If you could guarantee that the memory loss could be minimised, compartmentalised or whatever, and that you could make that decision while you were still relatively well, then maybe I would. (Elisabeth)

Apparently I told Mum from the first one, "Don't ever let me have this done again," because of all the memory lost and the side effects that I had from the first lot. I made her promise that she wouldn't let me do this again, so I am really not too sure. I would have to really consider my options. I am really not sure what my decision would be. (Pauline)

Even for someone who perceived that the procedure had been successful, Anna still hesitated as she reflected on the cost. Her final rhetorical question highlighted her inevitable dilemma:

I probably would, yeah, I probably would, because with mental illness it's a funny thing. I'd still be a bit nervous about it, but I probably would go down the ECT path again, I would say. Although ... oh dear, I don't really know, now I think about it. That's a really difficult question to answer. I mean it got me well, that's for sure. But at what price? (Anna)

Conclusion

This chapter has presented findings from the research as a way of identifying prominent themes. The women began their stories by discussing the origins to their emotional distress, the journey of various and multiple medications and the merry-go-round of side effects from these different medications. They described their doctor's justification for ECT as stemming from a failure of medication efficacy. Making the decision to receive ECT was viewed as either an autonomous decision made independently or the result of passive coercion felt from above (via medical experts) or below (via friends, family and loved ones). Placing blind trust and faith in the medical team was a common experience. Some women found personal and therapeutic professional relationships a helpful tool in deciding whether to receive the procedure. The women's complex accommodations as they weighed up both potential efficacy and side effects were highlighted as a prelude to their descriptions of the procedure itself. Their stories then focused on the nature of experiencing memory loss, and the different types of memory affected by the procedure, with a focus on how memory loss disrupted the social roles that women occupied. The experience of receiving ECT was further illuminated through their descriptions of the phenomena of stigma. The women
were able to describe how all these factors came together to allow them to evaluate the procedure from within a benefit-sacrifice ratio. A final discussion regarding how the women perceive themselves making decisions in the future was presented. It is acknowledged at this point that key concepts introduced in the findings of the research have not yet been interrogated, and meanings attributed to these experiences have been for the most part agreed upon by all the women. Using specific elements of the material-discursive-intrapsychic framework (Ussher, 2004) introduced in chapter three, the next chapter will provide a theoretical analysis of the stories that the women have shared to offer a further explanation for the nature of their experiences.
CHAPTER FIVE: THE POLITICS INFLUENCING WOMEN’S EXPERIENCES WITH ECT

Arriving at the place where I began to unpack and understand the experiences of the women in this research was by far the most exciting, yet at the same time the most confronting task throughout this PhD journey. As a researcher, I had been given permission to view very personal aspects of women’s lives that I had never been given access to as a clinician. As a clinical nurse, I was responsible for women’s physical and psychological safety throughout their hospital stay and ECT procedure, and then I said goodbye to them at the door when they were discharged. I had no real understanding of what their lives were like when they went home.

That changed as I began to work my way through this chapter.

I worked my way back and forth between the women’s stories and the literature in an attempt to explain their experiences both personally and politically, and in doing so I became acutely aware of the magnitude of the task and my personal responsibility to these seven individual women. Like many researchers, I had begun this journey with an idea, a preconception of what I might find as I began to work with women and their stories. That journey had begun with an exploration of a considerable body of work that positioned ECT as an intervention used to treat a disorder that is predominantly seen as a bio-chemical brain dysfunction. Yet when I sat with the women and listened to their stories I was aware of my own distinct dis-ease and discomfort. There was a palpable and distinct disjunction and sense of disconnection with what they were telling me. Their stories described far more than I had originally bargained for. Instead of simply portraying stories of illness and the ways in which they decided to receive a treatment, they were articulating stories whose origins could be located in a historical, political, cultural and social space for which I had not been adequately prepared, nor had I thought to even consider in the first place.

Reflecting on my own discomfort, I became acutely aware that when I had immersed myself within the scientific literature at the beginning of my PhD journey I had done so as a clinician, not as the feminist researcher that I had evolved into along the way. My own personal position had shifted significantly after engaging with the women and their experiences, and I needed to return to the literature to ask a new set of questions;
questions that would allow me to translate personal stories into political statements about the nature of women and their mental health. I needed to ask questions of the literature that would allow me to understand the socio-political journey of these particular women, of their journey with distress, diagnoses, medications and eventually ECT. I required knowledge that would allow me to position women’s stories more broadly than simply from the perspective of “How did you come to receive ECT?” Furthermore, I realise that accepting the women’s stories without asking further critical questions would be naïve, on my part. In the spirit of feminist research, I wanted and needed to find a way to uphold and honour their individual experiences by politically re-positioning them into a bigger picture.

As I began to uncover the mechanisms of power, the regimes of truth and the ways in which women as a social group tend to be positioned as pathologically ill and in need of treatment, I experienced a sudden realisation. For the last twenty-five years and through the power of the dominant biopsychiatric model that underpinned my own nursing practice, I had been personally complicit in positioning women as worthy of requiring medical treatment. I had been assuming that the experience of “depression” for women was the same as for men, although understandably confounded and influenced by social factors such as the stress of juggling multiple roles and responsibilities. My nursing training and post-graduate education had not provided me with any alternative to a dominant biomedical discourse through which to view and understand women’s differing perspectives as they responded understandably to life.

As a clinician, I now felt angry. As I woman I now felt guilty, and very sad. I found myself reflecting deeply, not just on my own clinical practice but on my personal values and beliefs about women, men, relationships, health, injustice, power and the ways in which society dictates how they should be defined. I considered my own personal experiences with distress and it became very clear to me – no woman is immune to the effects of the way that society defines how she should experience life. No woman is protected against being defined as pathologically ill. I had a personal testimony that attested to this. My own general practitioner had tried to persuade me that an SSRI would be the best treatment option when I complained of insomnia and stress. The cause of my distress was perfectly understandable; my husband of 20 years had suddenly and unexpectedly died. In my GP’s professional opinion however, my “normal” grief reaction and the stress of working full-time whilst attempting to navigate my nine-year old daughter through her own journey of grief was immediately labelled as a “depressive disorder”. As such and in his opinion, it warranted powerful
antidepressant medication. It took forty minutes of assertive negotiation in order to have a more natural remedy prescribed, and with hindsight I realised how difficult it would be for a less informed woman to withstand the power of a GP’s supposed expertise and powers of persuasion to determine the nature of her experience.

My daughter is now a teenager – an intelligent and empowered young woman. She will never have to fight for the right to vote, to have a voice, to determine her employment status or argue for her reproductive autonomy. The world she is raised in looks very different to the worlds inhabited by the women in this research. Her world tells her that she can (to a large extent), determine her own future. Yet I know she is not immune to the way that society will perceive her by the very nature of her gender. Despite our lives spanning many different decades and despite advances in our social and political worlds, my daughter, the women in this research, and I all share many common factors with each other. Our individual actions, thoughts and identities are variously subjectified, engendered, defined and regulated by others. I suddenly felt an urgency; an imperative to stand up and challenge the nature of this status quo. It was time to be asking new questions, time to be resisting the realities and the identities imposed upon us.

This chapter is my attempt to do so.

Introduction

The aim of the research was to explore the perspectives of women who had received ECT, specifically in relation to their decision-making processes associated with the procedure and their experience. The findings of the research were presented in chapter four. This chapter discusses the findings in more detail, with a focus on the socio-political factors that influence both the way that some women consent to this treatment as well as the meanings that they attribute to their experiences.

This chapter explores the findings further and seeks to provide a theoretical explanation, as well as situating the findings within the literature.

The findings of chapter four highlight how for some women, the decision to receive ECT is one that was made subsequent to a protracted and embodied experience with emotional distress and a variety of medical interventions designed to treat it. The decision-making process was commonly described as one in which little information was provided, and a sense of coercion was felt. Women suggested that the intensity of the emotional distress they experienced impacted upon their capacity to make the
decision to receive ECT. Some women found themselves receiving the treatment against their own better judgment, acquiescing to the perceived expertise of their treating doctors. Decisions to receive ECT were therefore made from positions of relative powerlessness and fear. Memory loss was a common experience following the procedure, and the impact on personal identities and associated social roles was one that the women did not feel well informed about or prepared for.

This chapter will explore the ways in which women’s experiences are medicalised using a variety of socially constructed discourses. These include the language and treatments associated with medical diagnoses, and the powerful social constructs that endorse medical expertise whilst simultaneously perceive women with emotional distress to be ill and worthy of medical intervention. It will be shown that discursive strategies such as the phenomenon of stigma and an implicit acceptance of the imbalances of power that are evident within biopsychiatric systems of care have an impact upon women at pivotal points of their decision making with regards to ECT.

To define the concept of medicalisation Conrad (1992) argued that it required not only a medical definition to describe a social problem, but it also needed medical jurisdiction over the problem. In other words, *(my emphasis has been added in italics and brackets)*:

Medicalisation consists of defining a *(social)* problem in medical terms, using medical language to describe a problem, adopting a medical framework to understand a problem, or using a medical intervention to “treat” it *(and possibly discounting the value of alternative therapies)*. This is a sociocultural process that may or may not involve the medical professional, lead to medical social control or medical treatment, or be the result of intentional expansion by the medical profession. (1992, p. 211)

This meaning has significance for those who may conceptualise depression as existing on a continuum of *normal* behaviour and who wish to describe it as an emotion rather than a dysfunctional syndrome (Pilgrim, 2007). Medicalisation therefore might best be understood as tendency within Western society, directed towards a simplified, somatic, and increasingly disease-orientated explanation of human feelings and behaviours (Rosenberg, 2006). Szasz (2007), as one of the great anti-psychiatry crusaders, describes medicalisation as occurring either from below by choice or from above through coercion. This idea will have significance later in the chapter when I discuss the ways in which decisions about medical care are made.
There is some biological basis to the experience of enduring emotional distress, however regardless of whether emotional states are conceptualised as either a disease or an emotional state, I am mindful of the need to refrain from speaking in a way that detracts and takes away from the lived experience of suffering and distress. There is a complexity of realities in women’s lives, and my aim within the thesis is to unsettle the language that seeks to define these experiences. So although I have on occasion referred to certain diagnostic terms, I have chosen to do so purposefully and with a critical lens, remembering that these terms exist as social constructs. In this way they describe a set of psychological symptoms at a specific point in time, and from within a specific white, Western-centric perspective.

So for some women, the term “depression” communicates their distress in a way that allows them a sense of subjective validation. In reality, there are some women who experience extreme levels of distress, and for whom forms of medical intervention are necessary. I openly acknowledge, respect and accept their experiences without question. Subsequently, I have intentionally chosen to use two alternative terms for the remainder of the thesis. “Emotional distress” (Ussher, 1992) is a term that allows me to signify the level of suffering that women experience, hopefully without adding to the reification of the problem through the use of a diagnostic term and related medicalised language. The word “madness” and the term “maddening practice” (Palmer & Ross, 2014; Ross, 2014) will be used to describe the manner in which those with vested interests are able to legitimately diagnose and label women’s distress as pathological. I have purposefully used this language, as it is my full intention to throw into question how we should view the concept of extreme unhappiness and related socially defined and constructed behaviour.

At this point in the thesis, I again acknowledge that the discussions in this chapter have been heavily influenced by the work of Ussher, who has inspired me to look at the way in which women’s distress has been socially constructed and positioned in new and illuminating ways. Subsequently, I draw from her material-discursive-intrapsychic (MDI) framework (Ussher, 2004; 2010; 2011) in order to view the experiences of the women in this research through much richer and deeper understandings. The material aspects of the framework will be discussed in detail to explain how pharmacological treatments, ECT and their subsequent side effects contribute to and maintain the embodied experience of emotional distress. Socially constructed discursive strategies have already had some discussion within the literature review of the thesis. Close attention has been paid to the power of the diagnostic process, pharmaceutical advertising and
the power of the media used to promote mental health literacy. Given the critical analysis that has been applied to them, they will only be briefly discussed at this point to examine issues of power and patriarchy within the biopsychiatric system at large. Finally, the *intrapsychic components* of the MDI framework (Ussher, 2004) will aid in furthering an understanding of the impact of both the material effects and discursive influences upon the women’s own self-perceptions and those of their roles and responsibilities in life as they make healthcare decisions.

**The Experience of Emotional Distress**

Ussher (2004) uses the material component of her MDI framework to describe factors that exist at a physical, societal or institutional level, and that can be used to understand the nature of emotional distress in women. These are the factors that would generally sit at the heart of a bio-medical understanding of emotional distress. They include the biological and physiological factors associated with psychological distress, such as the experience of illness, injury and pain, and poor sleep resulting from juggling of the demands of life or the experience of various forms of trauma. Previous history of abuse is also partly a material effect in that it affects the reproductive body through gendered and sexual behaviour (Ussher, 2004). From a societal level, economic factors such as loss of employment may cause women to be financially dependent upon men, which may act to legitimise issues of power and control (Ussher, 2004).

This aspect of the framework is evident in the findings of the research, in which each of the women recounted an experience that involved significant stress, distress, loss and grief and explained how it contributed to her experience of distress. It would seem reasonable to assume that most people would perceive the emotional distress experienced by the women in the research as an understandable and a normal response to significant life stressors. Yet it is common for contemporary psychiatry to view a “normal” response to life stressors as pathological (Frances, 2014) and thus requiring some form of medical intervention.

There has been some argument with regards to the way symptoms of emotional distress are interpreted and labelled. The main method for identifying symptoms of clinical depression is through the use of a self-reported checklist (Kjærgaard, Arfwedson Wang, Waterloo, & Jorde, 2014). These tools are readily available online, and are used in a variety of clinical settings. Typically, higher scores on these checklists indicate more severe symptoms of depression. Yet the use of these tools
has received some criticism. Much of the research into depression in women has used such self-report tools, yet it has been proposed that they may in fact identify the presence of *dysphoria* rather than a depressive disorder per se (Dayer, Aubry, Roth, Ducrey, & Bertschy, 2000). A search of the literature fails to identify a consensus definition of the term dysphoria, however Winokur and Clayton (1994) describe it as a state of feeling sad, anxious, irritable, down, fearful, and worried. These words are the very ones used by the women in the research as they described their responses to the stressors in their lives. Their understandable responses to trauma, violence, relationship breakdown, or to loss of employment, health, or personal safety were all perceived by medical experts to be problematic and labelled as such. The consequence for seeking help to deal with emotional distress was for experts to diagnose the women’s responses as a form of *depressive disorder* rather than dysphoria, along with the construction of a formal plan of how to medically treat it. Yet an alternative view of the association between aversive life events and emotional distress can be seen in the literature. In research designed to explore the notion of resilience following life trauma, Bonanno (2004) argues that people who have experienced significant life trauma often experience sub-threshold symptoms of emotional distress for significant periods of time. Arguing for sufficient time and support to moderate the risk for the development of pervasive emotional dysfunction, Bonanno (2004) challenges the assumption that all adults who experience loss or potentially traumatic events experience prolonged distress that requires a diagnosis of psychopathology.

In order to appreciate some of the enduring effects of this diagnostic and treatment process, the following part of this chapter has been divided into sub-sections. They illustrate the various sites where influential discourses and mechanisms of power struggled for dominance and authority over the way in which the women’s emotional distress was positioned.

**The Medication “Rollercoaster” and Side Effects**

Within the context of the current research, the discussion of material effects as described by the MDI framework (Ussher, 2004) is to also talk about the effects of the treatments used to manage emotional distress on women’s physical bodies. The decision to receive ECT began in the same place for all seven women in the research - with the introduction of the first pharmaceutical agent, usually an antidepressant drug. They spoke at great length about the physical and psychological discomfort associated with high doses of antidepressant, antipsychotic and mood-stabilising medication
prescribed by general practitioners and psychiatrists. Women described the medication “rollercoaster” or the “merry-go-round” that they endured in an effort to find the perfect drug therapy. In great detail, they related the numerous and uncomfortable physical and emotional side effects they experienced – skin sensitivity, gastrointestinal disturbance, agitation, anxiety and emergence of panic like symptoms, anxiety, sleep disturbance and frustrating sexual difficulties. These complaints are not isolated to the women in the research. Within the existing literature, headache, nausea and vomiting, insomnia, sedation, and agitation have all been reported (Anderson, Pace, Libby, West, & Valuck, 2012; Ferguson, 2001; Marjoribanks, Brown, O’Brien, & Wyatt, 2013). It was common to hear the women describe the side effects of the drug regimes as worse than the underlying emotional distress that the medications were designed to treat in the first instance. They received three or four separate medications leading up the final decision to receive ECT, often a combination of different antidepressants. The experiences of the women in the current research mirror that found in other work. In a study designed to examine the gendered meanings of depression, Fullagar and O’Brien (2013) interviewed women about their experiences with antidepressant medications. The women in their study described how the side effects of various antidepressant medication could worsen their physical symptoms of emotional distress, create unwanted changes in sexual functioning and how difficulties arose when they attempted to reduce or change their medications (Fullagar & O’Brien, 2013).

Research into pharmacological effects of antidepressants based on gender spans back to the mid-1990s, and these findings have significant implications for women (Hamilton, 1995; Weismann & Olfson, 1995). The clearance of antidepressants from the body is much longer in women than men, creating a greater bioavailability for the female body (Hamilton & Jensvold, 1995; Hildebrandt et al., 2003; Yonkers, Kando, Cole, & Blumental, 1992). Bioavailability of antidepressants is also influenced by hormonal fluctuations. It is increased when women are concomitantly taking oral contraceptives, a situation that is commonly encountered with women in their reproductive years (Damoiseaux, Proost, Jiawan, & Melgert, 2014; Keers & Aitchison, 2010). This means that a lower dose of antidepressant will provide the same effect in women as that of a higher dose taken by men (Grigoriadis & Robinson, 2007), yet prescribing patterns in clinical practice do not seem to suggest a cognisance of this gender disparity. A search of the literature failed to uncover any evidence for this difference in prescribing patterns. Additionally, I reflect upon my own clinical practice throughout 25 years of dispensing antidepressant medication to both male and female consumers. I do not recall any significant differences in doses of SSRI medications prescribed to either
group. Personal correspondence with individuals who work within the pharmaceutical industry confirms my understanding that prescribed medication dosages do remain relatively constant regardless of gender (Grange, October 26, 2015). Further evidence also supports a reduction of the active effect of antidepressants in women who experience “chronic stressors such as poverty and victimisation” (Hamilton & Jensvold, 1995). As previously highlighted, victimisation and poverty are two social conditions more likely to be encountered by women who subsequently experience emotional distress (Mills, 2015).

The risk of medication-induced toxicity and the emergence of a variety of side effects is a significant issue with the use of antidepressant therapy. In a longitudinal study into anxiety, depression and chronic use of SSRI medication in adults from the Netherlands, at least 65% of individuals receiving long-term SSRIs complained of three separate side effects including neurological symptoms (22.4%), gastrointestinal symptoms (18%) and dermatological symptoms (11.4%), with women experiencing more frequent, and more disabling side effects than men (Bet, Hugtenburg, Penninx, Witte, & Hoogendijk, 2013). Sexual dysfunction is another adverse outcome reported with the use of SSRIs in clinical trials. Since women are prescribed SSRIs more frequently than men, they are more frequently subjected to SSRI induced sexual dysfunction that can cause sexual dissatisfaction and marital distress. This is a significant issue, with prevalence rates estimated between 30%-70% (Keks, Hope, & Culhane, 2014; Serretti & Chiesa, 2009; van Rooij et al., 2015). Sexual dysfunction in women is a phenomenon that is not well evaluated through randomised controlled trials, yet it was obvious that for the women in the research who were sexually active, the side effects of various medications created significant levels of distress and interruption to their intimate relationships and self-esteem.

Previous research into sexual dysfunction of women taking SSRIs suggests that managing these side effects is a challenge which may very well maintain the embodied nature of distress (O'Mullan, Doherty, Coates, & Tilley, 2014). O'Mullan et al. (2014) report that at the time of being prescribed antidepressant medication, none of the women in their research were provided with information about the likelihood of sexual dysfunction occurring. They were subsequently left to cope through the use of four main strategies: (a) by searching for information (through online sources) to make sense and validate their experiences, (b) by suffering in silence, (c) by trying to resolve the problems though a biomedical or adjuvant approach, or (d) by accepting the presence of the dysfunction (O'Mullan et al., 2014). It was noted that women’s
experience with sexual dysfunction was influenced by partnership context and the impact of the sociocultural context that influenced their self-concept and identities (O’Mullan et al., 2014).

There have been concerns that the sexual dysfunction stemming from antidepressant medication can persist long after treatment has ceased (Currie, 2005). Whilst some benefits have been obtained through the taking of “drug holidays” or the addition of alternative medications such as bupropion (Safarinejad, 2011) and sildenafil (Nurnberg et al., 2008), to date there is no approved medication for SSRI induced sexual dysfunction. In a strange paradox, women’s emotional states and sexual functioning are again closely linked; reminiscent of the way in which women’s sexuality was closely regulated and monitored throughout the earlier parts of this century.

Making the Decision to Receive ECT

Coercion and consent

Six women described conversations with their doctors in which their experience with side-effects and their failure to respond to antidepressant medication was used by the psychiatrist as a justification for the decision to prescribe the procedure. Clinical guidelines for the treatment of depression suggest the use of ECT when an individual has failed to respond to a therapeutic dose of antidepressant medication (NICE, 2003; 2012). There is though, little guidance in the literature to offer an exact number of medications that should be trialled before a switch to ECT occurs. What is concerning is that some of the most eminent and pro-ECT psychiatrists advocate switching after only one “failed” trial of antidepressant medication (Loo et al., 2014). This occurs despite clear arguments to suggest that medication resistance in individuals is a very poor predictor of successful future remission with ECT, and despite the clinical guidelines recommending ECT be given only after adequate trials of medication have been undertaken (NICE, 2012). There have been significant criticisms of ECT being offered as a “treatment of last resort” (Kellner, Popeo, Pasculli, Briggs, & Gamss, 2012, p. 204) or when it has been administered following failure of medication, suggesting a greater association with poorer functional outcomes and more significant cognitive impairment (Prudic et al., 1996; Rassmussen et al., 2007). Criticism has also been directed towards the procedure being perceived as a last resort at all, suggesting that it creates a resistance to subsequently search for any other treatment modality that lies outside biological parameters (van Daalen-Smith, Adam, Breggin, & LeFrancois, 2014). Furthermore, as seen within the women’s stories there is a tendency for ECT to
be discursively positioned as not only the “treatment of last resort”, but also as the “treatment of no-other-option”. This has profound implications for the conditions required for informed consent.

Like all medical procedures, ECT requires valid and informed consent before it can be administered. Making an informed health care decision is a complex process. As seen in the experiences of the women in the research, a variety of factors can significantly impact upon the outcome of this decision-making process (Queensland Health, 2011b). Consent requires three conditions to be met for it to be deemed as fully informed. Firstly, individuals must be accurately informed of the purpose, methods, risks, benefits of and any alternatives to the proposed treatment. Secondly, they must understand the information provided to them, how it relates to their specific situation and they must be deemed to possess the capacity to make such decisions. The third condition directs that individuals must make a voluntary and coercion-free decision whether to participate in the treatment or not (Queensland Health, 2011b).

Within the mental health or psychiatric literature, coercion is a concept that is poorly defined. Paternalism will be discussed in a later section of the chapter, yet it is important to note that the concepts of coercion and paternalism are often confused. O’Brien and Golding (2003) suggest that coercion involves the use of authority which restrains another person’s autonomy, whilst paternalism is often based on an appeal to beneficence as justification for the coercive action. It is strongly argued that a failure to differentiate between the two concepts has significant consequences for ethical decision-making (O’Brien & Golding, 2003). Coercion though, does not have to be overt to be present and influential. Its strength often lies hidden under the cloak of persuasion, and viewed this way coercion can be seen to be a passive yet powerful process. Passive coercion is present when people sign consent forms based on the belief that they do not have any other option but to do so (Fisher et al., 2011; Orr & O’Connor, 2005; Rose, Wykes, Bindeman, & Fleishmann, 2005). Perceived coercion is defined as a person signing a consent form, yet still feeling that there is pressure to have the procedure (Rose et al., 2005). Previous research asserts that up to one third of individuals are passively coerced or pressured into agreeing to ECT (Rose et al., 2005).

Within the context of the current research all seven women described varying degrees of passive coercion. Although not actively forced to agree to ECT, they agreed to the treatment through verbal persuasion by others and through their belief that doctors were the experts to determine the treatment. Their psychiatrists positioned the
treatment as the last option available. Choices for treatment options became increasingly limited for the women, and it was common to hear them describe their decision-making at this point as a process of submission. Doctors held the greater authority and expertise to determine both the nature of the women’s distress, and what was needed to treat it. None of the women felt that they had the right to refuse or to even question the treatment that was being prescribed by the individuals in positions of power. This hegemonic representation of doctors as the experts and the significant power that they hold can be understood using the discursive lens of the MDI framework (Ussher, 2004). As the findings of the current research demonstrate, a social construction that positions doctors to “know best” became dominant as women described how they came to decide whether or not to receive ECT.

The view that “doctor knows best” has its origins in the days of Plato. He believed that philosophers were rulers over the people; that they had been selected as such for their innate and superior intellect, they had received extensive training and they had served a 15-year practical internship (Ladd, 1980). The rest of the common people were expected to comply with their wishes. Plato extended this thinking to consider physicians as rulers over sick people, with the belief that those seeking medical attention needed to comply with the physicians’ orders (Ladd, 1980). The modern day perception of “doctor knows best” has continued to be a dominant biomedical discourse founded on the notion of paternalism.

Medical paternalism has been defined as “the interference by the physician with the person’s freedom of action, justified on the grounds of the patient’s best interests” (Weiss, 1985, p. 134). This understanding has been extended by Gert and Culver (1979, p. 199) who explain that paternalism by Dr. X against Person Y exists when:

(a) Dr. X’s action is for Person Y’s behalf;

(b) Dr. X’s action violates a moral rule with regard to Person Y;

(c) Person Y’s good justifies Dr. X acting on Person Y’s behalf independently of Person Y’s past, present or immediately forthcoming free, informed consent;

(d) Person Y believes, perhaps falsely, that Dr. X generally knows what is for his/her own good; and

(e) Dr. X must have reasonable expectation of Person Y’s eventual consent
If this line of logic is applied to the experiences of women in this research, it can be suggested that paternalism is a powerful influence in the ways that some women make decisions with regard to ECT. There were women who were raised in environments with parents who deeply respected the intellect and social standing of doctors. With the influence of this social learning some women deferred their personal expertise of their embodied response to life to that of the psychiatrist, believing they knew what was best. Despite not wishing to have ECT, some of the women still maintained the belief that the doctors had their best interests at heart. At this point, paternalistic decision-making had likely superseded the women’s personal autonomy.

The intrapsychic component of the MDI framework (Ussher, 2004) can also be helpful in understanding how the assumption of women as experts in their own lives and their own bodies was contested during the ECT decision-making period. The aspect of the framework pays close attention to psychological factors, which operate at the individual level and are often at the heart of psychological explanations for emotional distress (Ussher, 2004). These factors include the way that women tend to attribute responsibility to themselves for problems in their world, especially within relationships (Ussher, 2004). These factors include feelings of shame, blame, guilt and the fear of loss or separation of relationships. It could be suggested that being told by medical experts that medications had “failed” could result in some women assuming a degree of personal responsibility and self-blame for their enduring experience of distress. It may be possible that some of the women blamed both themselves and their bodies for their experiences to this point. As evident in the women’s stories, there was a significantly lowering of self-esteem, fear and a sense of powerlessness when they were confronted with the doctor’s recommendation for ECT.

Similarly, there was a frequency to their descriptions of passivity in their decision-making. As doctors determined the nature and severity of women’s distress, they found themselves struggling to interpret their own feelings and embodied sensations. This account of personal powerlessness and fear was a common thread among the women’s stories. From their perspective, there was no other choice but to “blindly” trust and accept the outcome as determined by doctors. There were no other options offered; no other alternatives suggested. Previous research supports this finding. In Malcolm’s (1989) work, 45% of the consumers interviewed believed that they would be given ECT regardless of their personal choice or active refusal. Almost 22% of consumers who consented to ECT in the research undertaken by Rajkumar et al.
(2007) believed that it was futile to refuse the treatment. They were convinced that it would be given to them regardless of their wishes (Rajkumar et al., 2007).

Chakrabarti et al. (2010) conducted a review of 75 quantitative and qualitative studies that explored the knowledge and attitudes of over 6000 people from 17 separate countries who had received ECT. The authors highlighted that the majority of people in these studies were women (Chakrabarti et al., 2010). Their review argued that across the studies, rates of perceived coercion consistently ranged from 20%-35% (Chakrabarti et al., 2010). It was suggested that people consent to ECT despite feeling persuaded or coerced because they placed trust in their doctors (Freeman & Kendall, 1980; Malcolm, 1989; Tang, Ungvari, & Chan, 2002). Other studies however offer a contradictory view, arguing that this trust actually stems from a feeling of powerlessness and desperation (Johnstone, 1999; Koopowitz et al., 2003; Rajkumar et al., 2007).

Within the current research, only one woman felt that she played an active role in the decision to receive her very first course of ECT. Her decision making at that time however, appears to be more the exception than the rule and the rest of her story as she consented to subsequent courses of ECT was similar to the experiences of the other women in the research. The stories of the other women demonstrated a significant transfer of power. Each woman uniquely described being in a powerless position, feeling unable to question the necessity or appropriateness of ECT. Personal power was transferred as soon as she engaged with the dominance of experts (usually at the behest of a GP or psychiatrist), who then provided her distress with a different diagnostic name and decided that it needed treating. It was at this point in the women’s conversations that the powerful influence of biopsychiatry and the hospital setting in which ECT was administered emerged. Throughout their story telling, their experiences became obscured by a dominant medical discourse. Their conversations were dominated with details and minutiae of the procedure itself, the procedure room and the people who were in the room and what happened clinically, and it took some time before they were able to turn their attention to and reflect on the feelings and fears they were experiencing at the time of the procedure.

Some of the women maintained an explicit belief that they lacked the ability to influence the outcome of the ECT decision, even if they had wanted to. Others justified their eventual decision to receive a treatment for which they had expressed a previous resistance. This was done in a way that closely aligns to Gert and Culver’s (1979) notion of paternalism. Here, two of the women agreed that their doctor probably did
know best, and they believed that given enough time they would have come to the same conclusion as their doctors, that ECT was the best option. It seems that the expertise of another becomes acceptable for some women when they have been on an extensive journey of having their distress labelled as pathological. It is here where women may turn over personal power to so-called experts, and a normalisation of the dominant group may be observed through acknowledgement of the other’s superior knowledge and expertise. Likewise, there is yet another layer of complexity to the way in which women justify their passive coercion. As the intrapsychic component of the MDI framework (Ussher, 2004) suggests, psychological tendencies of some women can profoundly affect the way that they make important healthcare decisions. Meeting the emotional needs of others such as family, spouses, friends, and even the emotional state of their psychiatrist influenced some of the women’s final decisions, and a sense of personal responsibility and care-taking can be heard loudly within their stories.

Previous research supports the view that the majority of individuals consent to ECT even when they feel that they have not been given enough information about the procedure or the likelihood and nature of side effects (Chakrabarti et al., 2010; Ejaredar & Hagan, 2014; Johnstone, 1999; Malcolm, 1989; Rajkumar, Saravanan, & Jacob, 2007; Rose et al., 2005). The process of receiving information from doctors and nurses that relates to possible side effects such as memory loss is at times highly unpredictable (Blease, 2014), and the perceptions from the women varied in relation to the amount of information they received from their treating doctors. Although two women believed they had been given sufficient information, these experiences seemed to be more the exception than the rule. The majority of the women were given either too little information that related to the possibility of side effects and memory loss, or none at all. Similar experiences have been found in the literature (Johnstone, 1999; Malcolm, 1989; Rose et al., 2005; Smith et al., 2009), where the very act of withholding or omitting information (intentionally or not) can disempower women from being able to make full and informed decisions about their own health care and their bodies. Moreover, given that informed consent requires that an individual has full knowledge of the benefits and risks to a proposed treatment, the findings here raise concerns about how adequate the informed consent procedure is between doctors and those whose care they plan.

The provision of simplistic explanations is another way in which some of the women were deprived of the power to make choices for themselves. The workings of ECT have remained unclear for many years, and books written by so-called ECT “gurus”
suggest that it remains “a major puzzle” (Fink, 2009, p. 94). It is difficult to know exactly how the treatment works to improve the symptoms of severe clinical depression when there are no biological markers to be measured, and when the delivery of the treatment is for all intents and purposes “invisible”. However, much has been theorised about the workings of ECT and its effects on the brain (a comprehensive overview of such theories is offered in Swartz, 2009) in which to inform clinicians working with the procedure. In a powerful argument, Blease (2014) asserts that doctors have a duty to be well-informed about the treatment options they prescribe, contending that ethical problems and associated health risks occur when doctors fail to disclose the depth of knowledge – or the lack thereof – that relates to a particular treatment. She suggests that providing crude over-simplistic explanations for depression and its treatments (such as endorsing the biochemical explanation for depression and the computer analogy for ECT) renders all other explanations redundant and could be viewed as a “medical deception” (Blease, 2014, p. 226). Moreover, she argues that being provided with inadequate information about treatment options threatens the autonomy of an individual’s decision-making, and may even threaten an individual’s recovery. The often-quoted analogy of the brain envisaged as a computer that requires a hard reboot (Swartz, 2009) provided to some of the women is unacceptable in current mental health care. Furthermore, it has been argued that simplistic understandings can create difficulties in a person’s recovery process (Deacon & Baird, 2009). People who endorse a narrow medical explanation for symptoms of their own depressive experience are more likely to hold negative views of their prognosis and are subsequently less likely to address the need for other psychosocial modifications (Deacon & Baird, 2009; France, Lysaker, & Robinson, 2007).

In order for women who are receiving care to be actively and fully involved in making decisions for their own health and wellbeing, they must be given adequate information in order to make informed decisions. Yet there was little information provided to them about technical aspects of the procedure, such as electrode placement, the introduction of intravenous medications, a discussion of staff who would be present in the procedure room, or possible side effects, beyond a brief mention of the possibility of transient short-term memory loss. Again, this situation is mirrored within earlier work by Rose et al. (2005), who undertook a descriptive systematic review of studies investigating the perceptions of those receiving ECT in the United Kingdom. Rose et al. (2005) found that a deficiency in technical knowledge related to ECT was commonly reported. A lack of information however does not necessarily mean that the information was not provided in the first place. This erosion could be an artefact of time, or it could
be the manifestation of ECT-related cognitive impairment, or it may even be the result of poor concentration that results from overwhelming distress at the time of the procedure. Regardless, the replication of this earlier finding within the current research remains a cause for alarm. Healthcare policies and guidelines remind clinicians of the importance of providing a full and detailed explanation of a particular procedure, including any technical aspect (Queensland Health, 2011b). The discovery that there are some women consenting to an invasive procedure such as ECT, yet who are being denied a full and detailed explanation of that procedure remains unacceptable and in need of considerable attention.

A lack of information about the procedure or a simplistic version of these same facts creates an oppressive situation where women lose power to make informed decisions for themselves. Women’s personal and embodied expertise can erode to a helpless, dependent and desperate state. They rely upon others to make decisions for them - decisions that are often based on a paternalistic and patriarchal view of their distress as pathological and dysfunctional. It is this state of dependent decision-making that is implicated in the third requirement of informed consent, namely capacity. I will argue that it is here that the material, discursive and intrapsychic elements of the MDI framework (Ussher, 2004) intersect and influence the way in which women make decisions to receive ECT. Here, material effects of both the physiological symptoms of distress and the experience of antidepressant treatments on women’s bodies combine with various discursive strategies in which society endorses medical expertise whilst simultaneously positioning women with emotional distress as ill and in need of medical intervention. The combined effects of the material and discursive elements of the framework may create a situation in which some women may feel overwhelmed. As a result, the intrapsychic component of the framework suggests that they begin to take personal responsibility for their ongoing emotional distress and they may lose the ability to interpret and define their own experiences. Feeling powerless and fearful, the capacity of some women to make decisions is significantly compromised at this point, as they try to make decisions from a place of emotional desperation.

**Capacity and desperation**

Repeatedly, the women described making their decision to receive ECT from a place of anguish and despair. They were willing to try anything to alleviate their misery. Without exception, all the women who contributed their experiences to the research agreed – at the time of providing consent for ECT they did not believe that they actually possessed the capacity to be making such an important healthcare decision. This finding is
significant and unique to this research. Previous research has explored the concept of capacity in relation to decision-making by people with the diagnosis of a mental illness (Appelbaum, 2007; Appelbaum & Grisso, 1995; Davies, 2005; Grisso & Appelbaum, 1998). However, to date there has been no research undertaken that has explored the concept of capacity as it relates to consent and decision-making in women who receive ECT.

Capacity is a term that is difficult to define (Owen, Okai, & Hotopf, 2007). It can be understood in two different ways, and in combination they describe a psychological construct that refers to a person’s ability to make a decision (Owen et al., 2007). In the first instance, capacity relates to the legal status of a decision. In the second instance, this legal status can be contested by assessing the psychological “soundness” of a person’s decision-making processes (Owen et al., 2007).

In the broadest sense, capacity is defined by four elements: (a) understanding; (b) appreciation; (c) reasoning; and (d) communicating (Grisso & Appelbaum, 1998). Understanding relates to a basic level of knowledge about a procedure or a treatment proposed. To be deemed fully competent to make such a decision however, a person must also show appreciation for the nature and significance of the decision they are faced with. Grisso and Appelbaum conclude that individuals with capacity must realise that it is their decision to make, that it is their life, values and future that are at stake (Grisso & Appelbaum, 1998). Yet consent is not a fixed entity, and it is seen to be situation specific. For example, a woman may have the capacity to decide to contact her family by phone, or to refuse treatment for a physical health condition such as high blood pressure, yet simultaneously she may not have the capacity to decide to discharge herself from hospital. Consent therefore is a black and white term, and described as a “threshold” construct (O’Brien, 2010). In other words, a person either has or does not have capacity in relation to making a certain decision at a certain time.

It is suggested that capacity should be assumed to exist unless proven otherwise (Appelbaum, 2007; Queensland Health, 2011b). Previous work demonstrates that clinicians tend to view lack of consent as being symptomatic of mental illness (Lauder, Ludwick, Zeller, & Winchell, 2006). The notion of capacity is somewhat difficult to understand when it relates to legal mental health status. On one hand it has been suggested that those receiving involuntary mental health care should be presumed to maintain the capacity to determine their own healthcare decisions (O’Brien, 2010; Queensland Government, 2016). On the other hand, it is also recommended that those
who appear to lack such capacity should be afforded legal protection via mental health legislation (Queensland Government, 2016).

As this research was located in Queensland, Australia, the Queensland Health Guidelines for the Administration of ECT outline the requirements for the informed consent process (Queensland Health, 2012), and directs the psychiatrist, psychiatric registrar or appropriate medical practitioner who is involved in the individual’s care to undertake an assessment of capacity. The difficulty here is that consent may be transient and may change over time (Owen et al., 2007). Nurses, as a function of their 24-hour care, are more effectively positioned to see the fluctuating nature of this consent capacity (Davies, 2005) than medical professionals who may only see the individual for short periods of time.

Typically in contemporary practice, doctors as well as other clinicians assess a person’s decision-making capacity prior to a procedure or treatment occurring. There are few recommendations however, to guide clinical practice when the person who is making the healthcare decision does not subjectively feel they have capacity to do so, despite the doctor’s differing perception of that very same capacity. A search of the literature establishes this as an area that has yet to receive attention. A lack of capacity to make mental health care decisions is generally responded to with mental health legislation, such as the Queensland Mental Health Act (2016). This is both a powerful and a highly contentious law that is designed to protect the rights of people when the effects of severe mental illness impair reasoning and decision-making capacities. As discussed in the introduction to the thesis, mental health legislation can be used to provide treatment (such as ECT) to individuals who are unable to provide informed consent, and in doing so it aims to protect their health and their human rights (Queensland Government, 2016). In the case of a person who is assessed to be severely unwell, and for whom psychiatrists believe ECT is the most appropriate treatment, the Mental Health Act substitutes medical authority to act in the place of the person’s decision-making capacity until they are well enough to make their own autonomous decisions (Queensland Health, 2011b, 2012). Yet it is this very substitution of professional authority that creates both an ethical and a legal conundrum. It will subsequently be shown that the current Mental Health Act fails to protect women in their most vulnerable of decision-making.

In general, a person who lacks capacity to consent or who refuses to consent to mental health treatment will be usually given involuntary status under the Mental Health Act (Queensland Government, 2016). This allows clinicians to administer the mental health
treatment irrespective of the person’s wishes. Despite this involuntary mental health status however, they still maintain the right to refuse any treatment for a condition that is not related to their mental health (Queensland Government, 2016). For example, a person receiving involuntary mental health treatment such as antipsychotic medication can refuse to be given antibiotics for a chest infection. This demonstrates the way in which consent and capacity to consent are viewed as situation-specific attributes. When a person who is receiving involuntary treatment requires ECT, the psychiatrist will make an application to the Mental Health Review Tribunal (MHRT), an independent advocacy committee that ensures the appropriateness of involuntary care (Queensland Government, 2016). Once the MHRT have approved the course of ECT, it can then commence, without that person’s informed consent.

It is at this point that a significant issue with mental health legislation becomes apparent. The Queensland Mental Health Act (2016) becomes less clear in its explanations of the legal options available to clinicians to provide care for a person who is receiving voluntary mental health care, who is able to make autonomous decisions with regard to all other aspects of their physical and mental health, yet who states that they do not believe they have capacity to make decisions related to ECT. There is no ambiguity with regard to the position of the Queensland MHRT – they will not approve ECT for a person who is not under an involuntary treatment order or a forensic order, nor will they approve ECT if the doctor knows that the person receiving voluntary care is unwilling to receive the procedure (Mental Health Review Tribunal, n.d.). Email correspondence from senior advisors from within the Queensland Office of the Chief Psychiatrist acknowledges that this very scenario that I have posed is not one that they have recently needed to determine. Under their interpretation of the legislation however, if a woman were to articulate that she felt unsure of her own capacity to consent to ECT then the psychiatrist or doctor should apply to the MHRT for ECT-specific involuntary authority (Madden, personal communication, December 14, 2015). This is an interesting position. At no point in my 28-year mental health career have I seen an involuntary application for ECT made on behalf of an individual who is deemed to be capable of receiving all other mental health care voluntarily. There is significant ambiguity around the way in which the Act is both interpreted and enacted which must be rectified.

To add to the confusion, there is also a problem in which acceptance of treatment is routinely equated with consent underpinned by capacity, and where refusal of treatment is associated with a lack thereof (Appelbaum, 2007). This is a concerning
point, as although the literature points out that being diagnosed with a mental illness does not presume lack of capacity (Fistein, Holland, Clare, & Gunn, 2009), the women in the current research would strongly argue otherwise. They subsequently felt powerless and helpless under the influence of the dominant biopsychiatric healthcare system. For the majority, they did not trust their own embodied or psychological perceptions and decision-making abilities. They placed blind trust in their doctors to know how to interpret their distress and how best to treat it. Viewed from such a vulnerable position, the motivation of those persuading women to undergo such an invasive procedure must be contested. Whilst there is no question that the majority of clinicians maintain a deep desire to help women alleviate their distress, many women are desperate and willing enough (although one could suggest not capable enough) to agree to a procedure that has the capacity to impair the very centre of their sense of self and identity, as will be seen in the next section of this chapter.

Ironically, for some women the motivation to receive ECT was made not just in the hopes of getting well, but also from the desire to physically and legitimately escape the pain of their reality under the influence of an anaesthetic. Three women continued to receive ECT (or consented to receive a further series of treatments), after they had experienced the procedure as giving them some form of escape from the relentless misery they were experiencing. Describing the anaesthetic part of the procedure as “blissful”, Robyn and Anna made their decisions after realising that ECT allowed them to emotionally and physically withdraw into an anaesthetic coma, albeit temporarily. The motivation for Kate was slightly different and certainly more sombre; she wanted and hoped that she would to die whilst under the anaesthetic. This situation would thereby prevent her from having to make the decision to take her own life, which was contrary to her faith. Other studies have replicated these very same views (Ejaredar & Hagan, 2014; Fisher et al., 2011) with some women perceiving ECT as a form of fatal escape, with the anaesthetic providing either a “brief offering of peace” (Ejaredar & Hagan, 2014, p. 34), or a method of passive suicide. This has to raise alarm bells, as the personal and the political of women’s lives collide. It is here that women’s misery is made up of their individual sufferings being privatised, whilst simultaneously the privileged stakeholders gain from maintaining the status quo vis-à-vis mental health treatment such as ECT. It should not be assumed however that the women in this particular scenario were passive. It could be legitimately offered that their thoughts, decisions and actions were a resistant stance against the power struggles being played out against the medical experts.
As a final note to the discussion on capacity and consent, the informed consent process impacts upon the way in which ownership of a physical body is negotiated. Katz (1994) argues that physicians “take too much license with patient’s bodies and that the common law doctrine of informed consent has insufficiently addressed the question of who owns our bodies” (1994, p. 70). He asserts that the “caring custody” between doctors and patients can mislead physicians into believing that ownership of a body must be temporarily “transferred” to that of the doctor (1994, p. 71). This statement can also hold true for other members of the healthcare team involved in the care of women with emotional distress, such as nurses and other allied health professionals. Nonetheless, there are feminist implications for this idea, especially in light of the long history of women striving to reclaim personal and political ownership of both their bodies and their minds (Rowland, 2004).

**Experiencing the Procedure**

Although the women in the research were given free reign and space in which to elaborate on their experience of the procedure, there was a sense of hesitancy during their reflections as they pondered the clinical aspects of the procedure. It was clear that there was a mixture of emotions and perceptions occurring for them, yet they chose to focus on the clinical aspects of the procedure, rather than their embodied response to it. Similar to the responses of participants in research undertaken by Koopowitz et al. (2003), the women in the current research were quick to suggest similar ways in which the procedure could be improved. It was important for them to recommend that all machinery be quiet. They suggested this could be done by turning down the volume of monitors, or simply turning it off until they were under the anaesthetic. They preferred electrodes to be left off the head until they were asleep and to have some form of communication with staff in the procedure room, rather than simply lying on the table staring at the ceiling and waiting for the inevitable.

Whilst there was certainly a sense that women were consumed by the dominant medical discourse and clinical language they used during reflection of their experience, it seems likely that their suggestions were less about reducing fear (as seen in Koopowitz et al.’s (2003) work) and more about enabling resistance and a sense of subjective empowerment. The women in the research who were the most vocal and emotional with their suggestions for future change of the procedure were the ones who expressed the most anger that they were repeating the treatment again. Akin to Foucault’s (1978) assertion of power as a productive force, these small sites of
resistance became the women’s weapon to challenge the power over their bodies to be docile during the procedure.

**Experiencing Memory Loss**

The material aspect of the MDI framework (Ussher, 2004) is also helpful in critically exploring the embodied nature of memory loss that results from ECT and how for some women, it can maintain the experience of emotional distress long after the procedure has been completed. There is a large body of knowledge that demonstrates the significant memory loss that can result from ECT (Donahue, 2000; Ejaredar & Hagan, 2013, 2014; Fraser, O’Carroll, & Ebmeier, 2008; Freeman, 2013; Rose et al., 2003; Rose et al., 2005; Sackheim, 2014; Tirmizi, Raza, Trevino, & Hussain, 2012). What is less well understood however, is the variance between short and long-term memory loss, and between transient and permanent loss of memories. Objective testing of anterograde and retrograde memory suggests that memory loss is transient and confined to autobiographical memories (Lawson, 2009; Sienaert, 2011; Singhal, 2011). Unfortunately there is very little within the literature to discriminate between different types of memory that may be impacted such as autobiographical, geographical or procedural memories, leaving a significant gap in knowledge. Personal accounts by those people who have received the ECT often reveal more substantial and widespread loss of personal and task-related memories that they attribute to the treatment itself (Donahue, 2000; McDiarmid, 2005; Watkinson, 2007; Webber, 2009). The findings of the current research relating to memory loss are unique. They provide robust and detailed descriptions of the difficulties with geographical and procedural memory that may be experienced in the post-ECT period that are often absent in the quantitative literature.

It is common to see these consumer reports criticised for having little measurable objective and scientific validity and a common argument offered for their findings is to suggest that the memory impairment is either an artefact or a residual effect of the underlying disorder that ECT is used to treat (Porter, Douglas, & Knight, 2008). It would seem that the difference between the memory loss that accompanies ECT and that of depression are both quantitatively and qualitatively different (Robertson & Pryor, 2006). It has also been suggested that individuals who find ECT beneficial are unlikely to complain of memory loss based on the relief they experience (Ottosson & Odeberg, 2012). Yet a careful examination of the stories offered by women in the current research show that irrespective of a positive functional outcome, all seven women experienced the cognitive effects of the treatment.
The memories of the women in this research were significantly impaired after ECT. Each one of them described varying degrees of loss of those memories that were highly valued and intensely personal, spanning months for some and decades for others. These findings are not unexpected with previous work supporting the vulnerability of short-term memory to problems with long-term consolidation (Lawson, 2009). Far more concerning was the impact on the women’s long-term memories, and the persistent extinction of these memories for many years after ECT. This created a significant issue for the women, as this memory loss desensitised them to the political nature of their suffering, and the ways in which this experience was individualised, hidden, isolated, and silenced.

The descriptions of long-term memory loss and the profound impact on women’s lives provided in this research mirror those found in previous works (Donahue, 2000; Ejaredar & Hagan, 2013; Johnstone, 1999; Orr & O’Connor, 2005). Using powerful words such as feeling humiliated, and ashamed, women described losing their independence. They recounted stories in which their “old” selves were described as competent and capable. Many of the women had previously occupied senior management roles and other high functioning jobs. Following treatment with ECT they described the difficulties they experienced in making everyday decisions and maintaining a sense of self-efficacy. This is replicated frequently throughout the existing literature (Ejaredar & Hagan, 2014; Smith et. al., 2009; van Daalen-Smith, 2011) as women describe their difficulties in “navigating the world” (Burstow, 2006, p. 379) following treatment with ECT as wives, mothers and as women.

Managing Alterations in Social Roles

Practices of femininity

As disturbing as the memory losses were for the women in the research, the loss of a sense of their personal and social selves subsequent to the ECT memory loss was equally difficult for them to comprehend. There was a continued expression of grief as they recounted their stories. Women are social beings, defined to some extent by the roles and relationships that connect them to others. These roles are not fixed categories as such. Rather, as suggested by Davies and Harré (1990), they are the end result of a process of subjectivity, in which women define themselves through their subjective experiences. Women often engage in certain “practices of femininity” (Stoppard, 2000), rituals and practices that determine the ways of “being” a woman. Gender is far more than a biological assignment, and it has been suggested that
individuals are able to “do” as well as “be” a certain gender (Stoppard, 2000). In this sense, being a woman consists not only of dressing and behaving like a woman, but also encompasses ways of being a woman throughout daily life.

In this way, conceptualising gender as more than an embodied identity allows a socially and culturally constructed meaning to be shared by women. This consists of knowledge of what it is to live life as a woman. Within a specific socio-cultural context, the lives of many adult women can share a reassuring symmetry about them and there is a familiar shape and direction to them across the lifespan involving nurturing practices such as child rearing and involvement with families (Stoppard, 2000). These discourses of femininity tend to be motivated by love and concern for others. They can be intrinsically rewarding and for many women represent a highly important aspect of their identity as women, wives and mothers, providing them with fulfilment, satisfaction and a deep sense of connection. This is not to assume that being a woman equates to engaging in practices of domesticity, rather through various social constructs, discourses and social behaviours, practices of femininity allow some women to identify as being a “good” woman (Stoppard, 2000; Ussher, 2011).

Through an understanding of the combined effects of the material and discursive components of the MDI framework (Ussher), it would appear that the effect of ECT on memory might create a situation in which a woman’s ability to construct a coherent and well-defined sense of personal identity and her ability to “be” a woman is profoundly affected. For some of the women, practices of femininity such as creating a meal for the family were affected, transforming the kitchen from a place of warmth and security into a strange and foreign landscape. Some women within the research described how devastating this was to their sense of being a “good” mother and wife. A woman’s identity is often moulded by the socially constructed ideals of feeling “good” enough in the subjective sense of providing an adequate level of care for her family (Stoppard, 2007; Ussher, 1992). There is an emphasis on the link between food and love, and the nurturing element of food (Bordo, 1993), where the preparation of food is socially constructed as a visible expression of a woman’s care and love for her family. It became clear that for some of the women, her personal and subjective evaluation of her identity and role within the home was at odds with the socially constructed ideal of what it meant to be a “good” woman. Her dissatisfaction and feelings of lowered esteem were a direct result of her perceived failure to care for her family in a way that was deemed socially acceptable. This is yet another example of the ways in which
discourses of femininity are embedded within activities of women and are regulated and governed by the ideals of others (Lafrance & Stoppard, 2007).

It is suggested that for some women, personal identities are often based on activities and nurturing practices that incorporate their families (LaFrance & Stoppard, 2007). Helen described her distress at being “banished” from the kitchen, a place where she had previously derived significant satisfaction through her identity as a wife and mother. The memory loss that she experienced subsequent to the ECT meant that she could no longer create a meal smoothly and automatically. Likewise, Robyn had previously been a woman who was able to maintain a beautiful home and garden. The effects of the ECT memory loss left her in a situation where she no longer identified as the “woman of the house” as her husband took over these duties. Lafrance and Stoppard’s (2007) research with depressed women indicated that the lives of some women may be “consumed by domestic practices and by the needs of others” (p. 27). Their sense of self is oriented towards relationships with loved ones, and caring for others. It would seem that deficiencies caused by ECT memory loss in these specific areas are not only affected by the embodied experiences of ECT, but also serve to maintain enduring feelings of emotional distress. Women’s distress can thus be understood as the result of experiences that arise within the place where both “discourses of femininity” and “practices of femininity” meet (Lafrance & Stoppard, 2007, p. 28). It is here where women’s sense of identity and self are regulated discursively by the socially constructed notion of the “good woman” (Stoppard, 2000) whilst simultaneously enacted upon physically, by the finite resources of a body that has recently undergone a profound physical intervention. Living the discursive life of the “good woman” is physically taxing, especially when she has undergone numerous anaesthetics and ECT procedures each week. The women in this research described the profound exhaustion as they tried to return to work, cope with the demands of families and throw off the cloaks of their pervasive distress. They soon discovered how physically demanding it was to live the “good” woman life, or at least the one that was socially constructed and expected of them (Stoppard, 2000). It could be suggested that their pervasive exhaustion and ongoing distress was an embodied response to the discursive and material paradoxes inherent in a life that is dictated, determined and often de-valued by a patriarchal and sociocultural context (Lafrance & Stoppard, 2007; Stoppard, 2000) that dictated how they should “be” women.

For some of the women in the research, their embodied experience of ECT was more than costly. They described a variety of physical injuries resulting from the procedure
as either minimised or completely ignored by medical staff. The denial of accountability by those administering the procedure left women positioned as personally accountable for their injuries, and they were consequently left with the ongoing expense to manage these physical effects. There is a state of unfairness about these experiences, and I would suggest that this unfairness is another form of oppression towards women in highly vulnerable positions. As Burstow (2011) notes, physical injury from ECT is often hidden within the medical discourse surrounding the effects of the procedure. Previous research with women in the post-ECT period has argued that injury arising from the procedure does exist (Burstow, 2006; Funk, 1998), with women describing significant bodily injury ranging from permanent knee damage resulting from seizure activity to generalised right-sided body weakness (Burstow, 2011, p. 381). Given that the practices of femininity needed to be a “good woman” are a physical demand on a body that is often undervalued in a contemporary Western society (Wolf, 1991), women’s experiences post-ECT can soon become significantly physically and financially burdensome.

Bodies are the material and physical means by which some women accomplish the care of their families. The cultural ideal of the “useful” body (Bordo, 1993) offers another view of the ways in which the physical and cultural aspects of life are connected. The concept of the “good woman” can be extended, and a contemporary discourse of femininity has been offered to explain the “new woman” (Stoppard, 2000, p. 106). This is a woman who expends physical energy caring for her family, as well as juggling the demands of a career. It would appear that at the point of transitioning back to their previous lives following ECT, women may become trapped between two contradictory points – that which is needed by the construct of the “good woman” or the “new woman” and the limits of capacity of their physical embodiment (Stoppard, 2007). This can be a significant disempowerment of women that is derived from an expert-driven system of care and justifies itself at women’s expense.

Returning to the workforce occurred for some, but not all the women in this research. Returning to work was contingent upon the impact and significance of each woman’s level of memory loss and whether or not their symptoms of distress had remitted. For those women with the least amount of continuing memory loss, a return to their previous careers was not surprising. Yet some women experienced profound autobiographical and procedural memory loss, resulting in a loss of previous career and ambivalence towards their future career choices. For Margaret, her memory loss and continued emotional distress created a financially detrimental situation. She was
unable to work and found herself living close to the poverty line, supported only by government benefits. The embodied effects of ECT had now created a situation in which her financial security and emotional wellbeing were both at risk to a greater extent than prior to ECT.

Difficulty in recognising faces (prosopagnosia) and names (nominal aphasia) was a frequent complaint for most of the women. Previous work has indicated a female-gendered strength for facial and name recognition relative to that of males (Herlitz, Nilsson, & Backman, 1997; Lewin & Herlitz, 2002; Voelkle, Ebner, Lindenberger, & Riediger, 2012). From an evolutionary perspective this would seem logical, as it is assumed that women were responsible for maintaining knowledge of who belonged to each social group in order to facilitate bonding and socialising (Dahlberg, 1981). It was common to hear women in the research complain of the difficulty they experienced whilst trying to remember people’s faces and their names. This was especially difficult for those individuals who the women were aware they should have known. Memories of people’s names and their faces often became so vague and difficult to consolidate that women minimised their social engagement for fear of future discomfort and ridicule. This finding is not an isolated or random experience for the women in this research. Both Johnstone (1999) and Donohue (2000) have described the significant embarrassment and frustration associated with loss of facial recognition. Given the importance that women place upon creating and sustaining supportive and nurturing interpersonal relationships (Dwyer, 2000), an inability to remember another person’s identity could be seen as beyond mere social inconvenience.

Communication styles also suffered as a result of memory loss for some of the women. Although polite, diplomatic and tactful communication styles are not just the domain of women, these communication styles do serve to facilitate affiliation and bonding among both genders (Tannen, 1990), and they help contribute to the maintenance of mutually reciprocal relationships (Meadow & Weiss, 2012). The concept of communication styles in women is simply too extensive to cover in this thesis. It is sufficient to say that maintaining harmonious relationships through sensitive, tactful and diplomatic communication is another way in which socialised and regulated feminine behaviour complies with the image of the “good woman” (Stoppard, 2000). For some women however, the memory loss following ECT appeared to work in a way that circumvented these highly regulated and socialised communication styles, leading to shame and embarrassment when women discovered (some years later) that they had made rude and hurtful comments to friends. Additionally, the lack of ability to communicate
effectively within a social context cost some women long-term intimate relationships. They subsequently lost their perceived “good woman” (Stoppard, 2000) standing and began to feel “useless” in their female social roles.

Acknowledging and Challenging Stigma

Throughout the stories offered by women, the effects of both public and self-stigma were apparent. Stigmatising words and practices were felt at many points along their journey of emotional distress and in the post-ECT period. Returning to the MDI framework (Ussher, 2004), stigma can be positioned and understood as a discursive strategy that may be used to silence women’s experiences, both before and after their experience with ECT. It continues as a hegemonic socially constructed phenomenon, communicating the message that women’s responses to the challenges in their lives are worthy of a psychiatric label. Deconstructing it as a “mark of difference” (Goffman, 1963, p. 4) felt by the women, stigma can help to identify ways in which social, interpersonal and cultural perceptions of emotional distress may interfere with the way women access help through systems of health care.

Stigma is a mechanism that delivers unfair and oppressive care to someone experiencing emotional distress. It is a phenomenon that exhibits its effects through behaviours that discriminate against those with both acute and enduring mental illness. This same behaviour is acknowledged as an illegal offence under a variety of national and state-driven legal statutes such as the Australian Human Rights Commission Act (1986), the Australian Disability Discrimination Act (1992) and the Queensland Anti-Discrimination Act (1991), yet still serves to function as a method of social control. Despite the capacity for legal sanction, the women in the research described actions and behaviours by healthcare clinicians that were unrecognised, not acknowledged and at times left unchallenged. Consequently, these actions had the power to operate at the intrapsychic level, leaving women to question whether they were emotionally distressed, or truly mentally ill.

It is equally important to discuss the ways that stigma may operate and be present within the micro-practices of clinical work undertaken by clinicians within a variety of practice contexts. These practices are often imbued with stigma, providing powerful labels to people who are experiencing emotional distress. It is, as Foucault (1978) argues, these everyday clinical micro-practices in which power sits to effectively distinguish the difference between a state of not mentally ill to one that is. Furthermore, these practices of power function to normalise the dominant (not mentally ill) and
privileged group, and to legitimise their power at the expense of those who are vulnerable. Women within the research readily described specific interactions with clinicians both inside and outside of the hospital environment in which they felt “othered” and separated; labelled as a person with a mental illness rather than as a woman experiencing emotional distress originating from a psychosocial crisis.

Despite a great deal of work to improve mental health literacy, the label of mental illness has been described as one of the most powerful forms of stigma in existence (Bathje & Pryor, 2011). It can significantly influence an individual's quality of life, and it is suggested that possessing a psychiatric diagnosis and the very act of seeking help for it is highly stigmatising to the larger community (Bathje & Pryor, 2011; Corrigan, 2004). Mental illness is a cultural construct, and therefore any cultural definition of stigma will depend upon the cultural meanings attributed to the nature of mental illness itself, as well as beliefs about the cause and treatments available and the effects of the negative attribute on the larger society (Walker, 2006). Stigma operates as a universal concept at an individual level, yet there are also sociocultural factors that influence the way that stigma is interpreted by the person against whom it is directed, as well as affecting the dynamics of the social group's response to a stigmatised status (Becker & Arnold, 1986). These in turn determine what constitutes a particular stigma, the specific attitudes that people hold towards the stigma and the responses of a stigmatised group (Becker & Arnold, 1986).

The experience of stigma for a person emerges from social attitudes that are at times elusive yet pervasive. Regardless, those people who are stigmatised quickly feel the effects of the phenomenon by others through the body language of face-to-face encounters, and the power of the media (Walker, 2006). Feelings of personal responsibility for stigma is common, and those who feel the impact of stigmatising attitudes find themselves in a constant struggle to overcome the negative status they have been granted, and the devalued status they occupy as they seek out strategies to deal with the stigma (Becker & Arnold, 1986). Bloom and Farragher (2013) acknowledge the pervasive danger of the biomedical approach in viewing people's responses to traumatic situations. Here, people are positioned as “sick” and labelled with a psychiatric diagnosis that “shames clients from the moment they enter care” (2013, p. 30), often within primary healthcare settings. Although it has been suggested that the attitudes and behaviours of clinicians in primary health care are less stigmatising than other health care providers (Wrigley, Jackson, Judd, & Komiti, 2005), the findings of the research demonstrate that this is not always the case. The everyday
micro-practices of power (Foucault, 1978) enacted by a variety of health care professionals continue to add to the experience of stigma.

**Diagnostic overshadowing**

Evidence suggests that people with mental health conditions are often provided with less than optimal physical health care compared to those who do not have a mental health concern (Nash, 2013; Wahlbeck, Westman, Nordentoft, Gissler, & Laursen, 2011). Discrimination by healthcare clinicians can occur following the misattribution of a person's physical symptoms of ill-health to their pre-existing mental health condition in a phenomenon known as *diagnostic overshadowing* (Jones, Howard, & Thornicroft, 2008). A psychiatric label can influence and determine the treatment (or lack therefore) afforded to a person in need of physical health care in ways that do not occur to individuals without a psychiatric diagnosis. The phenomenon of diagnostic overshadowing involves micro-practices of power by those in privileged positions within the health care setting and this was made evident by the experiences of some of the women.

Emergency departments and primary health care settings are obvious places for individuals with emotional distress to present for assistance, especially if the situation has reached crisis-level. The attitude of staff working within these areas plays a vital role in determining how an individual’s identity and self-esteem is impacted by this experience of seeking help. In a study designed to examine the perspectives of emergency department clinicians, in-depth interviews of 25 clinicians were undertaken to explore the barriers and facilitators to making a correct physical diagnosis in people who also had a current or past psychiatric history (van Nieuwenhuizen et al., 2013). Thematic analysis of the interviews showed that diagnostic overshadowing was acknowledged as a significant phenomenon within emergency settings by staff within emergency settings, with senior clinicians displaying more awareness of the issue than more junior staff members. Lack of knowledge of mental illness appeared to a major contributor to the problem, with clinicians acknowledging that this knowledge deficit caused discomfort when working with individuals with mental health issues.

Other studies have echoed reports by individuals of the difficulties they experience when attempting to access physical care. In focus groups conducted by Clarke, Dusome, and Hughes, participants reported feeling labelled and triaged as “psychiatric” regardless of their medical complaint (2007, p. 129). Others felt their medical concerns were minimised, or completely dismissed, with one participant commenting: “I had a
gallbladder attack and they shipped me off to psych” (Clarke, Dusome, & Hughes, 2007, p.128). This example was similar to some of the experiences of women in the current research. They commented on the ease with which surgeons, nurses and paramedic officers became confused between the presence of physical pain or unexpected responses to anaesthetic agents and a history of a psychiatric diagnosis. Some women were denied urgent physical care that they required and had a legitimate right to receive. A literature search failed to uncover any significant body of work to explore the issue of diagnostic overshadowing by those employed within paramedic services, although the term was noted to be very briefly and superficially defined within one academic text on paramedicine practice written by Australian and British authors (Willis & Dalrymple, 2015). Regardless, as the findings of the research demonstrate, misattribution of physical distress to a previous psychiatric history can prevent appropriate treatment for acute medical conditions that required immediate intervention, leading some women’s health to be placed further at risk.

It has been argued that gender is one of the most predictive factors associated with help-seeking behaviour for emotional distress, with women seeking help more than men (Mackenzie, Gekoski, & Knox, 2006). Yet the quality of that help-seeking experience also determines whether or not the experience is perceived as helpful in the long-run (Corrigan, Druss, & Perlick, 2014). The experience of perceived stigma within help-seeking episodes was a powerful force for some women in this research and their stories described two dominant forms of stigma. Public stigma refers to the common social reaction to individuals who seek help for emotional distress, whilst self-stigma refers to the internalised psychological impact of that public stigma (Ben-Zeev, Young, & Corrigan, 2010; Corrigan, 2004). The effect of public stigma on seeking help has been redefined as treatment stigma, in which stigmatising attributes are bestowed upon an individual receiving mental health care (Vogel, Wade, & Hackler, 2007). This in turn may lead them to avoid treatment. According to Bathje and Pryor (2011) stigma is associated with treatment avoidance in at least two separate ways: firstly, individuals will go out of their way to avoid being identified publically and will conceal their engagement with the services that provide mental health care. Secondly, the very fact that individuals are seeking care means they are implicitly accepting the label as “someone who needs psychological help”, which may threaten a person’s self-esteem and self-efficacy significantly (Bathje & Pryor, 2011; Corrigan, 2004). Women in the research discussed the lengths they went to in order to protect their privacy, and the fears they harboured about the effect on their professional, social and personal reputations.
Self-stigma may be seen as the outcome associated with the seeking of help for emotional distress in systems of care. Self-stigma may be confirmed by a tacit acceptance by women, as they identify with “someone who needs mental health treatment”, and the potential this has to damage a person’s self-esteem. Corrigan’s (2014) social-cognitive theory of stigma development underpins this argument and explains how public stigma can influence the development of self-stigma. According to Corrigan (2014) this model of public stigma suggests that people with mental illness are “violent, incompetent and unpredictable”, and can co-exist with a self-stigma that can influence individuals to perceive themselves as dangerous and incompetent.

**Sites of resistance**

It could be suggested that mental health systems imposed their decisions upon the women, who consequently found themselves occupying a passive state. Yet their stories demonstrated ways in which the women were simultaneously finding ways to re-author themselves, to discover ways of creating an alternative meaning to their stories outside that of a psychiatric diagnosis (Becker & Arnold, 1986). This re-authoring was a highly sophisticated mechanism to resist the ways in which they were identified as depressed women in need of medical intervention (McKenzie-Mohr & Lafrance, 2011).

Foucault (1975) was concerned with the nature of the social world according to the binaries found within it (such as good/evil and normal/pathological), and he spoke of the need to resist these divisions. This is precisely what some of the women in the research did, as they challenged the labels of mental illness and the accompanying stigma and oppressive care. The manner in which they did this can therefore be re-framed as a strong and courageous move against a dominant system that views emotional distress as a pathological state, where women’s responses to life are viewed as either pathological or not.

The agency of the women, even in moments of extreme distress requires acknowledgement. Although it would appear that some of the women acquiesced to the powers of the medical authorities who determined that they needed ECT, the women made brave choices, even when they felt that they had none. These acts of resistance shown by the women may be small, yet they are highly political and in themselves very powerful. Power is diffuse, and ubiquitous yet resistance both eludes and threatens power (Foucault, 1975). In doing so, an act of resistance can become a source of its own power, becoming creative, productive and affirmative (Pickett, 1996).
The women showed courage as they made difficult choices. Some of the women who were left with physical disabilities at the end of the ECT refused to continue with the procedure. Even as their doctors recommended further treatment, the women resisted attempts to have their bodies rendered “docile” (Foucault, 1975). Other women demonstrated resistance and power by literally finding their voices and speaking to others about their experiences. Becker and Arnold (1986) describe how the development of a group identity may assist in resisting the effects of stigma. As people become aware that stigma affects others as well, they begin to articulate their experiences. In doing so, a personal change begins, and what begins as a personal problem soon becomes a social issue (Becker & Arnold, 1986).

This is an important point. Foucault viewed certain practices (such as the power of hospitals and prisons) as intolerable in the way that they silenced those marginalised groups within them (Foucault, 1975). He also viewed resistance as a way of changing these practices. In a critical analysis of Foucault’s writing, Pickett elaborated further:

> Once the asylum inmate ... is enabled to speak, and his memory of struggles and subjugated knowledge is allowed its insurrection, those who are subjected to power can force change. (1996, p. 462)

Nowhere was this more evident than in the stories of some women, who have now chosen to work within mental health services, where they hope to have some influence on the experiences of other women. They do this by speaking with legitimate authority on their own experiences with ECT. Indeed, the very act of participating in the current research can also be viewed as a powerful method of resistance. By allowing the experiences of their emotional distress and the use of medical interventions such as ECT to be head, the voices of the women may be instrumental in creating change for others in the future.

**Making Decisions for the Future**

In a similar vein to the various sites of resistance that the women found to challenge their identities as sick and passive individuals, the way in which they thought of future decisions relating to their mental health care are also strong and powerful proclamations of an unwillingness to accept the labels and constructions by others. Whilst it has been suggested that the rates of people who are willing to receive further courses of ECT in the future range from 23% (Rajkumar et al., 2007) to 85% (Rush et al., 2007), these studies are not without methodological flaws. Quantitative methods often fail to capture the depth of complex decision-making in which people engage.
Similar to previous research (Rose et. al., 2002), each of the women made complex adjustments and accommodations in her own evaluation of the ECT and her willingness to repeat the procedure in the future. This evaluation and future decision-making was made independently of whether or not her embodied symptoms of emotional distress had been alleviated by the procedure. Of the seven women in the research, four women were able to say that ECT had reduced most of their symptoms of enduring emotional distress and that they considered themselves to be “cured”. The remaining three women were not able to do so. They were left with residual embodied suffering as well as the addition of significant memory loss. They were adamant in their decisions. None would risk ever having the procedure again. Helen in particular was unshakeable in her decision. Resolved to taking her own life through suicide if she ever found herself in the position of receiving ECT again, the power of her resolute decision-making is frightening. To realise that some women would rather face death than endure the effects of ECT is testimony to the degree of suffering this treatment can cause.

For the remaining women however, decisions for the future were less clear. Despite now feeling better within themselves, and experiencing minimal residual emotional distress, none of them could say for certain they would repeat the procedure. For the most part, ECT had been a procedure that had left them feeling oppressed, disempowered and devalued. Even Anna, who felt that she had been given some control over the treatment, was very hesitant to commit an answer. Refusing, or remaining non-committal was the most reasonable way for the women to resist the power and maddening effects of dominant medical discourses.

How well these decisions will stand the test of time remains unclear at this point. Enduring and embodied emotional distress and a sense of desperation wears down physical resistance, as Margaret’s story in particular demonstrated. This dilemma was soon made apparent. On further reflection, two of the women acknowledged that although currently their first choice would be to never repeat the treatment, this was a decision that they would need to re-visit should they find themselves in a place of emotional distress again.

In addition to the factors that have been critically analysed in this chapter, there are other socio-political factors that can and often do contribute to the experiences such as those described by the women in the research, and an analysis using Flyvbjerg’s (2001) schema is useful to understand. Flyvbjerg’s line of sociological questioning allows for a consideration of women’s mental health care in Australia, especially as it
relates to the women in the research who received ECT. Of particular importance are his questions of: (a) who gains and who loses through the positioning of women as *pathologically ill* (my emphasis added) within systems of mental health care, and (b) through which mechanisms of power do these gains and losses operate? (Flyvbjerg, 2001, p. 131).

There is an indication of who is gaining at the expense of women’s embodied experience of emotional distress. Privileged stakeholders such as psychiatrists, general practitioners, psychologists, nurses, other professionals who provide allied health care and pharmaceutical companies all continue to profit from the positioning of women’s lives as problematic, pathological and in need of treatment. Through the routine everyday practices of professional and clinical work that includes diagnosing and prescribing, Big Pharma companies and the medical professionals who hold financial ties to them continue to gain financially. The marketing and sales of a variety of antidepressant and antipsychotic medications contributes to and maintains the situation where those with a vested interest in maintaining this status quo financially benefit from women’s emotional responses to life being individualised, politicised, and pathologised. Yet the privileged position of the experts does more than provide them with financial gains. It gives them an unfair advantage at women’s expense through the oppressive management of their distress. Whilst the people in powerful positions benefit through privilege, women can be left marginalised and disempowered through certain maddening practices. Within the context of the current research, the term “maddening practices” is used to describe the hidden and dominant discourses of abuses of power by people in dominant positions of authority and social privilege, against women with emotional distress (Ross, 2014).

There is a certain type of maddening practice that can be observed in the way that women’s experiences are perceived in contemporary Western society. This mechanism of power occurs through the application of stigmatising labels, medical discourses and interventions by those with professional power as they define what is and what is not normal (Ross, 2014). Subsequently, these practices can create significant harm as they construct “others” (i.e. women) to be the problem. This practice requires a significant and open critique, as well as the answer to the question of who is best served by this practice. For as long as this practice is left unchallenged and unsettled, no one is required to be accountable or to take responsibility for the outcomes for women. It has been suggested that the people in the middle of this practice thereby become “containers” for the failures of others to question or challenge the status quo.
This situation continues to function as the norm, and the problem is seen to belong to “others”. As a result, a highly stigmatised social group continues to wear labels that tend to serve the vested interest of professionals within the mental health systems of care. This power functions to normalise the dominant group and legitimise their maddening power.

Furthermore, there needs to be a questioning of whom exactly is wielding this power that exists through the language of a medical discourse. It is not difficult to identify the people and organisations – general practitioners, psychiatrists, psychologists - the industry comprised of pharmaceutical companies (known as Big Pharma) and nurses all play pivotal roles through the use of a medicalised language. Whilst those who have the power to enforce particular versions of the truth are left unchallenged, a political power struggle ensues within a playing field that is not equal.

The two leading companies who manufacture ECT machines also gain, as they profit financially from the global sales of their equipment and associated products. In an email to the author, a national sales representative for the Thymatron Series IV ECT machine estimated the current cost of the machine at almost $30,000 (Elkjoje, personal communication, November 11, 2015). Ongoing costs related to ancillary equipment increase this price significantly. There is evidence of the close relationship between renowned psychiatrists who research and promote ECT and the two international companies responsible for the manufacture of these machines - Somatics Inc. and MECTA Corporation. Two American Psychiatric Association members, Richards Abrams and Conrad Swartz, both belonged to the American Psychiatric Association (APA) Task Force on ECT. They went on to develop Somatics Inc., the international company responsible for selling more than half of all ECT machines, earning the company in excess of one million dollars by the end of the 1990s (Kneeland & Warren, 2002). Swartz and Abrams also collaborated with other Task Force members on the development of promotional videos for the company, with the machines, books and brochures all appearing within the appendix of the Task Force report. These ancillary materials are still used widely in circulation within mental health services in many countries. Abrams also holds the patents to these ancillary devices as well as the patents to an assortment of mouth guards, conductive gel and disposable electrodes, earning a significant profit from their sales (Andre, 2009). In 2002, the Journal of ECT ran an advertisement from Somatics Inc., boasting of their success with sales of over one million electrodes (Andre, 2009). At the price listed in the advertisement, this equates to almost $3 million. The APA Task Force Report on ECT has since been
unofficially renamed as the “Manufacturers’ Task Force Report on ECT” (Cameron, 1994). The procedure of ECT is a financially lucrative procedure for those with vested interests in both the manufacturing and promotion of the equipment.

This is not the only vested interest relationship however. ECT “experts”, including directors of the companies who manufacture the ECT equipment have written and published significant numbers of articles and books based on the technical aspects of the administration of ECT (Abrams, 2002; Swartz, 2009; Swartz & Manly, 2000; Swartz & Shen, 2007). The book written by Abrams (2002) is currently the only ECT text on the market, meaning that anyone who wishes to learn more about the procedure from an academic source is actually taught by him. These individuals stand to gain power, academic and clinical prestige and influence. These researchers often hold powerful positions on a variety of editorial boards where they wield the power to decide who and what is published in influential journals (Andre, 2009). The same individuals also serve on committees that evaluate research applications. As Andre (2009) concludes, if these experts do not like a particular research question with regards to ECT, they could have the legitimate power to reject the application and silence the scientific exploration. They also wield a powerful influence over what other doctors hold to be true about ECT, using their teaching positions in universities, teaching hospitals and through the provision of continuing professional development conferences. It is here that the power to silence any scientific or sociological criticism becomes apparent.

I am asserting that these mechanisms of power are created by the combined forces of pharmaceutical companies and their prescribers, and by the manufacturers of ECT equipment and those who promote and administer their services. These financially reciprocal relationships can operate to the detriment of women’s health and wellbeing. As such, some women may continue to lose their physical health, and their capacity for sexual intimacy and expression. They may continue to lose their connections to personal memories and ownership to their sense of self.

Yet it must not be forgotten that women can and are active and resistive in the way that they make sense of their experiences. As the women in the research demonstrated, their personal suffering did not automatically position them as helpless, or powerless. Sites of resistance are often identified and similarly to Foucault’s (1978) perception of power accompanying resistance, the women in the research found small ways to assert their own authority over their bodies and decisions. In this way, they were able to challenge the impact of power from the medical system and the privileged medical professionals who operate within it.
Conclusion

The chapter has discussed the experiences of women with emotional distress and the way in which they made meanings and decisions about receiving ECT, using aspects of a material-discursive-intrapsychic framework (Ussher, 2004). The material aspect of the framework demonstrated how the women experienced their physically embodied responses to both emotional distress and the treatments used by medical experts, including how they negotiated the medication rollercoaster and the associated side effects. The discursive aspect of the framework identified ways in which social, interpersonal and cultural perceptions of emotional distress may interfere with the way women access help and systems of health care. The intrapsychic aspect of the framework provided a foundation to explore how the experience of the distress and the treatments received altered the self-concepts of women at pivotal points of decision-making. Furthermore, a situation occurred in which all three (material, discursive and intrapsychic) components of the framework combined. It was at this junction that women often made decisions in moments of desperation and relative powerlessness when they felt, to some extent, incapable of making these important healthcare decisions. The chapter has also highlighted the impact of ECT on women's memories. Memory loss can affect the perceptions that women hold of themselves, and can impact upon their ability to navigate their world.

Stigma was identified as a discursive mechanism that can maintain women's emotional distress. The various ways that the women challenged this notion were highlighted as moments of powerful resistance against labels and constructions of mental illness.

Finally, selected socio-political elements of the current state of mental health care for women in Australia were identified. Key stakeholders within healthcare were highlighted, and the various mechanisms of power that are responsible for these potential abuses of positions of power and privilege were also acknowledged. Flyvbjerg's (2001) questions enable me to ask whether this situation as it relates to the state of mental health care for women in Australia is desirable or acceptable. Specific ways in which this situation can be approached to change the experiences of women will be the focus of the next, and final chapter.
CHAPTER SIX: IMPLICATIONS FOR PRACTICE AND RECOMMENDATIONS

As I approached the three-quarter mark of this PhD journey one of my Supervisors reminded me that as an advocate of ECT, I would usually proclaim (quite passionately) that the procedure “saved lives”. I had not only participated as a senior team member administering the treatment for almost three decades, but I had travelled the country training other clinicians in how to administer the treatment in ways that were safe, effective and ethical. Dare I say, I was considered to be somewhat of an “expert” in the field, or at least that was the perspective of my colleagues.

At the time of this comment by my supervisor I still agreed with this statement - yet only to a point. I did believe that it could save the lives of some women who were deeply depressed and in danger of losing their battle with emotional distress to suicide, women who were absolutely and desperately miserable. For some women, ECT might very well place those symptoms into remission. My experience within the clinical setting demonstrated that. However, at the same time something just did not feel right within me. I sat with a continued sense of emotional and intellectual dis-ease, working my way through my readings and interpretations of the stories women offered me, and I tried to make sense of the social and discursive construction of their experiences.

Not long after this, I was having a discussion with my other supervisor. I was reflecting about the findings, and my feelings of them. It was at this point that I suddenly had an epiphany – the sort that was to change the very nature of the way in which I perceived the world and my place within it.

I suddenly realised that whilst ECT may save lives, it also creates a certain kind of “death” for some women. It creates a death of memories, a death of identity, and a death of being, as Stoppard (2000) describes a “good enough” woman. This was a significant revelation, and one that was certain to have implications for my personal and professional practice. As a result of this insight, I realised that changes would need to be made to the way in which I worked, changes which would simultaneously have repercussions for both my academic and personal identity.

It became clear that women’s emotional and physical responses to the stress of life were frequently defined as an illness using multiple layers of socially constructed and hegemonic discourses. What was less obvious within existing work was how this occurred as the result of maddening practices, in which psychiatric labels are applied
routinely by so-called medical experts. I was now faced with an imperative. In concluding the research, I wanted to make a powerful statement in a way that did not simply pay lip service to feminist thought, but actually made those who are responsible for participating in the care of women – psychiatrists, nurses, doctors and other clinicians contemplate the nature of the way in which women and their mental health is perceived. This was a significant challenge. I contemplated my own personal meaning and I pondered the overarching political landscape that needed to shift to enable the voices of women to be heard. I needed to get this right. More importantly, I needed to get this right in a way that altered the manner in which women are portrayed, and perceived.

Introduction

The thesis presents a study that explored the perspectives of women who had received ECT. It presents seven women’s individual stories - stories of their journey with emotional distress, the ways in which they made meaning about their experiences and the ways in which they reached the decision to receive ECT. The thesis also presents my own personal researcher’s story and it describes the broader social context in which all these stories occurred. Elements of the material-discursive-intrapsychic framework (Ussher, 2004) helped to describe the themes that emerged from the women’s stories. Flyvbjerg’s (2001) schema gave their stories a socio-political framing in order to gain a deeper understanding of their context.

Initially, the research set out to question how women make the decision to receive ECT and the meanings they construct around this experience. The answer to this question was extremely complex. In order to understand the experiences of the seven women in this study, it was also important to examine the manner in which the women's often-understandable responses to the nature of their lives was deemed to need medical intervention. This required a much deeper understanding of the way in which discursively constructed practices position the women’s emotions as worthy of medicalisation.

The study asked each woman a series of questions: (a) what informed her decision to receive ECT, (b) what was her experience of depression and ECT; and (c) would she make the same decision next time? The findings from the women’s stories indicated that decisions to receive ECT were made at the end of a very long biomedical journey. Multiple pharmaceutical interventions and debilitating side effects dominated the women’s embodied response to stressful life experiences, and ECT was subsequently
positioned as the only treatment option available. Two women claim they will refuse outright to ever repeat the procedure due to the trauma associated with the procedure and the poor functional outcomes attained. The other five women remain highly ambivalent about repeating the treatment at any stage in the future, despite experiencing some remittance of the physiological and psychological aspects of their enduring emotional distress.

The research offers the view that the women made the decision to receive ECT from within an expert-driven, medicalised socio-political context that made it appear the only alternative to them. Decisions relating to ECT were made from a personal position in which they felt desperate and coerced, lacking in both knowledge and the capacity to make a fully informed decision. Some women in the research subsequently began to consider themselves as powerless, and felt frightened and helpless. It is suggested that ECT treatment may create a situation in which some women lose memories and a sense of their identity whereby they are often left struggling to navigate their own realities. Yet at the same time, the women’s stories embed resistive efforts and resilience in their re-authoring. It is my hope that the exploration of the women’s stories within the thesis may contribute to an alternative discourse around how women make meaning of the experiences of emotional distress, and that of the help they seek from contemporary systems of mental health care.

**Implications for Clinical Practice**

There is a need to consider the implications of the research findings for the mental health clinicians who are responsible for providing care to women in emotional distress. Clinical practice within mental health care is the work undertaken by individuals from a multidisciplinary background, for example doctors, nurses, social workers, psychologists and occupational therapists. These clinicians, whilst heterogeneous in professional discipline, belong to a multidisciplinary team that should operate to promote a common goal – high standard care and treatment of a person with specific mental health needs (Mental Health Commission, 2006). Yet these professions are either a part of the medical dominance, or at least highly influenced by its effects upon clinical practice.

The three main implications arising from the research of the women’s experiences with ECT are the need to:
(a) Understand women’s experiences with distress from a larger sociological perspective;

(b) Limit the power of the medical discourse; and

(c) Review the way in which informed consent for procedures such as ECT is navigated by women and clinicians.

It will be shown that addressing these issues will require:

(a) A challenging of the specific diagnostic signatures of biopsychiatry that label and position women as pathologically ill as they respond to the nuances of life;

(b) Some resistance to an over-reliance on medicalised treatment options; as well as:

(c) A need for clinicians to listen to and be influenced by women’s experiences.

A beginning point is the recognition that labels describing mental illness are powerful social constructs that do not always serve the people seeking mental health care. Medical diagnoses in the mental health system do not describe an underlying disease process that ultimately causes the difficulties that women experience. Rather the constructs perhaps describe a set of particular behaviours that are socially and culturally normalised and accepted at a particular point in time in order to regulate women’s behaviour and bodies (Fredrickson & Roberts, 1997; Ussher, 2011).

It is crucial to understand women’s experiences of life from a deeper socio-political and cultural context to ensure they do not bear the costs of an over-reliance on medicalised discourses and treatments for socio-political bases to their personal experiences of emotional distress. For example, the ways in which social learning influences the cultural perception of medical experts requires a more critical examination. Unconditionally upholding doctors as experts prevents their actions, behaviours and motives from being questioned or examined by others (Ross, 2014). Openly challenging this dominant perception of their expertise (Thompson, 2011) could extend the range of treatment and care responses for women experiencing emotional distress.

Additionally, an alternative and socially just discourse is required regarding the political nature of women’s gendered socialisation, ruminating cognitive patterns, and the tendency to self-silence, to self-objectify and internalise the problems of life (Ussher, 2011). These characteristics are often seen as female attributes that can cause
symptoms of severe emotional distress. Yet in reality they reflect socially constructed discourses of femininity and embodied constructions of what it is to be a woman in Western, capitalist societies. In fact, they leave little space for women to challenge or resist these constructions. Whilst it has been suggested that these feminine qualities are ineffective ways of coping, it has also been argued that these reflect forms of resistance that operate according to some women’s access to financial and practical resources (Stoppard, 2000). For instance, mainstream conceptions of active coping presume that women have access to sufficient money, power and status to enable active coping. If women tend to cope with life problems through the use of ruminating strategies, this may occur because alternative and/or costly strategies are unavailable to her (Stoppard, 2000). So rather than envisaging rumination as a poor method of coping, an alternative view that this reflective type of coping is used to search for meaning and is a means for re-authoring is significantly more helpful to understand the power and agency that women can and do possess, even in moments of emotional distress and despair.

The experience of emotional distress is both real and authentic. There are some women who are emotionally beyond despair, for whom life is such an existence of misery and agony that they harm themselves or take their own lives (Ussher, 2011; Stoppard, 2000). Acknowledging some women’s pain and legitimising the need for medical treatment may be vital to their survival. Acknowledging a woman’s pain however does not mean that her experience needs to be reified or reconstructed as a mental illness. An alternative view can be chosen. Her experience and distress can be reframed as an understandable response to the material nature of her life; her gendered and discursively constructed roles and her intrapsychic and subjected responses to these constraints.

Nonetheless, at the completion of the research and thesis I now find myself agreeing with Burstow (2006) - ECT is and will continue to be a form of socially and State-endorsed violence against women, disguised under the cloak of evidence-based best practice and duty of care using mental health legislation. Some of the women’s accounts read at the beginning of the thesis illustrate how ECT can physically assault their bodies. Their stories also show how ECT can be a form of assault on their memories, and that in doing so it can threaten the very core of their identities. For some women ECT was reminiscent of earlier childhood trauma and abuse. For other women ECT assaulted not just their bodies but their spirits and sexuality, making them
feel powerless and helpless. Yet the medical experts continue to suggest, prescribe and direct the treatment.

**Recommendations Arising From the Research**

There are three significant areas in which recommendations arise from the research, namely recommendations for (a) social and clinical practice; (b) organisational change; and (c) future research.

**Recommendations for social and clinical practice**

As noted in the previous chapter, there are numerous groups of people who must be held accountable for the ways in which women’s lives are pathologised and medicalised. Psychiatrists, general practitioners and psychologists all carry the weight and responsibility of proffering diagnoses, and prescribing medication. Nurses and other allied health professionals, although not qualified to prescribe medications, still contribute significantly to the diagnostic process of labelling women’s distress using a dominant biomedical approach.

One of the most pivotal and fundamental recommendations emerging from the research is the need for an alternative and viable way to view the problems within women’s lives that is not necessarily dominated by the biomedical model. A social model of distress has been offered as an alternative to the biomedical model of mental illness (Beresford, Nettle, & Perring, 2010). This social model highlights the links between people’s distress and broader social oppression and discrimination. Further to this understanding, some countries within the European Union have invested viable primary healthcare options that link complementary and alternative non-medicalised therapies within a stepped care model (Bundes Psychotherapeuten Kammer, 2011). Although Australian healthcare systems are not yet embracing this holistic and non-medicalised model of care, it would seem to be an effective paradigm to aim for.

An alternative discourse which is socially just and personally affirming, and which acts to legitimise women’s responses to their lives without the use of an over-reliance of, or exclusive use of, medications and ECT is highly recommended. The current research suggests that there are problematic consequences to the way in which women’s emotional responses continued to be individualised, pathologised and medicalised. Labelling women’s behaviours with a psychiatric diagnosis and prescribing powerful medication or ECT does little to improve the nature of their circumstances. A shifting of the boundaries of clinical language to denote a continuum of emotions is needed.
Substituting the term “depressive disorder” or “clinical depression” with words such as “extreme or severe distress”, or “persistent or prolonged misery”, may better communicate the message that experiences such as depression are not universal and binary, but are experienced on a continuum and may become a useful way of creating meaning about the experience (Ussher, 2011). The term “broken-hearted” is another expressive term that could be a legitimate and alternative discourse insomuch that it describes the very nature of depression (Eisenberger & Lieberman, 2004). People can and do feel “broken” in the depths of their despair (Eisenberger, 2015). A variety of mental ills stem from a position of being broken-hearted, and people often behave in a range of ways that externalises their emotional hurt (Wernik, 2011). The term is therefore easily understood by a layperson as well as clinicians, and is less likely to be associated with stigma than a psychiatric diagnosis. Encouraging a culture that is accepting of a multiplicity of terms to describe emotional distress is one way that society’s discourse can expand beyond that which uses psychiatric terms to describe divergent responses to life. A society that embraces a more caring attitude towards the emotional responses of its people is a more compassionate society indeed, and one that should be aimed for.

An ongoing awareness and critique of the power that lies behind the dominant medical discourse is required and strongly recommended for clinical practice. As most of the women in the research attested, ECT was positioned for them as the treatment of last resort, and the treatment of “no other option”. None of the women were offered psychological therapy before medication and ECT. This is not necessarily surprising. Within the Australian healthcare system, some alternative non-pharmacological therapies may prove to be financially burdensome unless a person has adequate private health insurance. For some women, primary health care may be the only viable option of obtaining assistance for their distress. Nonetheless, the decision-making of medical experts in the field must be challenged. These experts often speak with certainty, with authority, and with a legitimate sense of their own medical knowledge, possibly without taking into account or acknowledging other options available to treat women’s emotional distress (Stoppard, 2000). It is here that the dominant medical discourse can collapse any other options for women at a critical point of making decisions. When women’s own knowledge and personal power is not acknowledged as either legitimate or valid, it can leave a significant gap in the opportunities available to treat their emotional states. This could potentially leave women experiencing a sense of isolation within an individualised experience, as they are left alone to make highly complex decisions about their mental health care.
The use of medication as the dominant mode of treatment must be openly contested if the persistent cycle of medical intervention for women with emotional distress is to be minimised. National and international clinical guidelines advocate for non-pharmacological treatment as a first line and step-wise model of treatment for emotional distress ( beyondblue, 2009; National Institute for Health and Clinical Excellence, 2012). A recent review of treatment options has highlighted that psychotherapeutic interventions, marital/couples/family counselling and therapy, inclusion of family members, psycho-education, exercise, nutrition, problem-solving therapy and guided self-help are all useful options in the management of mild to moderate depressive experiences (National Institute for Health and Clinical Excellence, 2012). This opens up an additional line of inquiry, one that examines these as strategies to prevent (or at least minimise) some women embarking on a rollercoaster of interventions and treatments that leads them from seeking help for emotional distress to ultimately receiving ECT. Primary health care should respond to women with emotional distress in a way that highlights the importance of providing comprehensive cognitive and other non-pharmacological approaches as a first step in managing problematic symptoms of emotional distress.

Changing the way in which the process of informed consent is understood within mental health care remains an ethical imperative. The findings of the current research mirror those of previous work (Deacon & Baird, 2009; Ejaredar & Hagan, 2013, 2014; Orr & O’Connor, 2005; Rose et al., 2005; Smith et al., 2009; van Daalen-Smith, 2011), in which it was found that women consented to receiving ECT without being provided with adequate information on which to base their decision. This is also about a failure of procedural justice in their care and treatment (Swain, 2009), and it is more than concerning that recommendations from previous work relating to the provision of information as part of the consent process remain unheard. There has been consideration of whether the problems with ECT consent are similar to other non-mental health treatments, yet my literature searches have failed to reveal any other comparable bodies of work. It would seem that there are unique characteristics of providing informed consent for particular mental health treatments that need to be more clearly understood if women are to be assured of the best option for them, not simply the last option according to a dominant medical discourse. Whilst the recommendation for clinicians to ensure that women are provided with sufficient information in order to make an informed decision continues, it is also necessary for women to be engaged with at the point of consent in a way that allows them freedom to
express any concerns they may have about their own subjective capacity to provide consent to ECT.

There remains a need to understand women’s experiences, created by listening to their own voices, and their unique and particular perspectives. The legitimacy of women’s accounts of their own experiences with ECT and the effects of the procedure upon their bodies, memories and identities must be acknowledged as a valid source of knowledge. This can only happen if the voices of the experts are minimised, so that the voices of women can be heard. It is concerning that the perspectives of clinicians and policy-makers continue to be seen as separate from that of women. These privileged individuals need to ask themselves how women’s voices can be heard in the midst of those most critical, most complex, and most professional moments of decision-making and discussions of which women are typically not a part. Clinicians need to listen deeply to women’s stories and perspectives at every point of the ECT journey from decision making to recovery from anaesthesia and beyond. This active and conscious listening becomes a crucial mechanism as clinicians begin to perceive themselves as working and learning beside women as partners, and as valuing their knowledge at every point.

It is not enough to simply encourage clinicians to listen to women in the clinical health care settings. Recommendations for the educational context are also needed. Women’s influential voices should also be heard within the curricula of both undergraduate and postgraduate programs to influence the ways in which emerging doctors, nurses and allied health clinicians hear and understand the experiences and perspectives of the women for which they will ultimately provide care. The recommendation to embed women’s voices of experience within educational content cannot be underestimated as a powerful mechanism for change in clinical practice.

Within the clinical context, it is in the very partnerships between women and clinicians where points of power and negotiation sit. Although it is recommended that clinicians continue to perform the therapeutic work that they undertake with women in their care, they also need to be willing to commit to a conscious engagement with women in this partnership. The commitment to receiving ongoing professional development delivered by both educators and by women who have received mental health care themselves will assist clinicians to see women they work with as having equal authority in their own experience (Burbank, 2014). This recommendation also has the potential to fundamentally change clinical practice for the better.
Certainly there is a need to change the way that emotional distress, maddening practices and the nature of mental illness from a dominant biomedical perspective is understood. From the perspective of a cultural positioning of emotional distress, I am aware that listening deeply to the experiences of women across the continuum of their journey is unlikely to change the clinical landscape of power and privilege on its own. An alternative paradigm is therefore recommended, which may prove useful as it reconstitutes the problems of emotional distress and mental illness as politico-cultural issues. Viewed in this light, it becomes possible to address them through the implementation of major strategies at both organisational and educational levels.

Recommendations for organisational change

As the experiences of the women in the research demonstrate, one of the most difficult points of decision-making occurred whilst they were receiving care within mental health organisations, such as acute inpatient facilities. As they wrestled with the decision of whether to receive ECT, they experienced a variety of overt and subtle actions by those in powerful positions that were to some extent coercive and stigmatising. In a place in which the women expected healing, those in privileged positions were perhaps abusing the women’s most basic rights to self-determination, autonomy, dignity and respect. The women’s experiences highlight the nature of many mental health systems of care, which are characterised by injustice and acts of violence of all kinds (Bloom & Farragher, 2013). In this context, violence refers to and describes any act that makes a person feel physically or psychologically unsafe, and one which is often the result of power imbalances between consumers and clinicians (Ross, Campbell, & Dyer, 2014).

Everyday practices by clinicians can be felt as coercive, and are often left unchallenged. This in turn creates a situation in which options are collapsed, leaving the dominant option (such as the biomedical approach) as the only possible choice for women receiving care. There is limited discursive room for questioning or challenging of authority, as the women in the research discovered in their decision-making of ECT.

Unfortunately, facilitating change from a local and individual perspective is unlikely to alter this issue of injustice and violence. All levels within systems of mental health care need to change. In order to do so, beneficial and supportive political contexts, liberal and enlightened policies, high levels of support from managers and collaborative engagement by mental health community leaders are needed (Ross et al., 2014). A further recommendation at this point endorses the need for mental health systems of care to endorse principles of non-violence, equality, democratic and collaborative relationships and trauma-informed clinical practice. This approach is aligned to
principles of recovery-oriented care, where people’s dignity, autonomy and self-determination is upheld and they are recognised as experts within their own lives (Queensland Health, 2005). This will require significant work, as sustained change requires a whole-of-organisation approach (Holman, Devane, & Cady, 2007). To this end, mental health systems will need to embed principles of recovery and simultaneously be trauma-informed. Trauma-informed organisations are those in which there is a deeply held commitment to eradicating practices and policies that subsequently harm consumers or the staff who care for them (Bloom & Farragher, 2013).

There is a significant body of work that links violence to traumatised organisations, and it has been argued that authoritarian practices are the dominant underpinning force that contributes to this violence (Bloom & Farragher, 2013; Bloom & Sreedar, 2008). Whether direct, indirect, actively or passively coercive, it is these practices that create interpersonal and organisational injustice that is felt by both consumers and staff (Ross, 2014). An unjust organisation can become socially irresponsible, and ethically compromised (Bloom & Farrager, 2013) with a tendency for bystanders to watch the unjust behaviour and do nothing. As described by Ross (2014), this leaves vulnerable people at risk of becoming the scapegoat for the failure of others to question, challenge or act upon the situation. Furthermore, environments with hidden acts of injustice and violence do not create environments of safety for either consumers or clinicians.

To prevent the perpetuation of this cycle of violence, and to prevent the coercive and stigmatising experiences of the women in the research from recurring, a major shift in the paradigm held by mental health organisations is recommended. As a useful example, Ross (2014) describes a template for mapping organisational change. Actions are implemented at the personal (interpersonal), the cultural (organisational) and the structural (social) level and these will be briefly discussed here as they relate to the care of women with emotional distress within mental health systems of care. This recommendation alone has the capacity to change the experiences of women who find themselves seeking care from inpatient mental health facilities.

At the personal level, a commitment by all staff to the development and maintenance of relationships with women that are non-violent, egalitarian, mutually respectful, inclusive, and collaborative can, and should be sought. In this way, women and clinicians are viewed as equal partners in care. Clinicians can draw on models of
health and illness that embrace alternatives to the biomedical model and which are informed by humanist ideas and trauma-based knowledge. Care provided to women by clinicians can be built on trauma-informed principles and can involve deep listening, inclusion, group based therapies and non-violent strategies. In order to provide this care, it is recommended that all clinicians receive education and training in trauma-informed principles of care. Additionally, they will need regular reflective supervision, debriefing and rest from the high demands of inpatient work. These recommendations would all significantly influence the ways that clinicians engage with women in the long-term.

In order to effect change at the organisational level, Ross (2014) argues for a shift in power dynamics. To this end, multidisciplinary teams will then be able to communicate in non-violent ways without fear of shame or blame. Clinicians will feel free and able to challenge a culture of silence that endorses inequalities and injustices without fear of retribution or powerful “Tit-for-Tat” repercussions (Bloom & Farragher, 2013) within the micro-power dynamics of the team. An eradication of binary “us” and “them” processes will help to minimise stigmatising attitudes towards women with emotional distress (Burr, 2002; Duvnjak & Fraser, 2013). Sustained change at this level however, requires recovery and trauma-based education for the whole organisation. Furthermore, it requires an environment where the expertise of women and their autonomous choices are upheld to prevent forms of active or passive coercion within their decision-making.

The last part of Ross’s (2014) template for organisational change is directed towards facilitating change at a macro level. It is here where wide-sweeping social changes are required to address actions of violence and marginalisation of women on all levels. Ongoing conversations and dialogue will need to occur at the community level to address issues of fear, ignorance and stigma towards emotional distress and mental illness. This recommendation requires a sustained commitment by all people who have a connection to mental health systems of care to value the expertise held by women as fundamentally central to and required, to inform interventions and decisions about their care. To begin with, it is recommended that the organisational norm to have women with the lived experience of emotional distress sitting as members on management boards within mental health organisations is endorsed. As a final note, these social reforms will require education, training, innovative clinical practice and consumer controlled research to occur in which women, clinicians, managers and policy makers all work beside each other with equality and mutual respect for each other’s wisdom.
Issues relating to the expert use of authoritarian power can then begin to be addressed by the people involved in the system of mental health care.

Recommendations for future research

It has already been highlighted that there is a lack of research into the experience of emotional distress in women. A determined effort by researchers is required to further explore the nature of women's lives and the way in which they navigate emotional distress and make health care decisions, using a variety of theoretical approaches that distinctly challenge a dominant biomedical hypothesis. The ways in which women make sense of their experiences can be subsequently used to better inform models of care that promote emotional wellbeing. Furthermore, rather than continuing to study down (Palmer, 2014), with the focus of research being women with emotional distress, an approach that considers studying up (Palmer, 2014) may be useful. The actions of privileged and powerful medical parties are often aimed at protecting themselves from close scrutiny (Gusterson, 1997), however research to explore these mechanisms of power and influence may function to increase accountability and transparency.

Additionally, there are areas pertinent to the issue of the informed consent process that require further understanding. Currently, there are almost no recommendations to guide clinical practice when the woman who is making the healthcare decision does not subjectively feel that she has capacity to do so, despite the doctor’s differing perception of that very same capacity. A search of the literature establishes this as an area that has yet to receive attention, and the findings of the current research would suggest that deeper inquiry is needed to understand this important legal and ethical issue.

Study Limitations

Like all research, I am aware that the current research is not without its limitations. It may be that the experiences of the women in the current research do not represent the usual experiences of consenting to, and receiving ECT. These women were of Australian background, and it is possible that women from a different culture of origin may in fact experience both the procedure, and the outcomes differently. This would be certainly worthy of further research. All the women in this research had received their ECT in a privately funded health care setting, although two of the women had received earlier courses in a public hospital. From my own professional practice, I am aware that there are many differences in the models of service delivery, and the policies, procedures and clinical guidelines governing the provision of ECT in these very
different health care settings. It could be argued that the experience of women who receive ECT in the private healthcare system differs from that of a woman in the public system. The methodology of a feminist narrative approach facilitated an in-depth exploration of the stories of seven particular women who had received ECT. A different sample of women taken at a different time and place may have yielded different results. Given the heterogeneity of the women in this sample, the results found here may guide future research.

The way in which the research conversations were gathered may also influence some aspects of the findings. Feminist research often brings women together within group spaces (Lather & Smithies, 1997). The face-to-face group setting often helps to invoke a sense of politicism, as women (and the researcher) listen to each other's stories over a period of time. In this way, a social dimension of understanding is created for individual women. The current research however, consisted of individual settings and individual meetings. This did not allow for the development of a social discourse between the women or myself (as either a woman or a researcher), and it therefore prevented the facilitation of a more politicising sense of their individualised positions. It could be reasonably expected that a group setting would have allowed women to take a more resistant stance. Furthermore, their ability to be more resistive to the effects of their stories would have become more obvious throughout the face-to-face conversations within a group space (Lather & Smithies, 1997).

It may also be reasonable to question the implications of possible selection bias (Collier & Mahoney, 1996). Some of the women in this research have been employed (or still are) within the health sector, and are cognisant of the importance of research into the area of mental health. Their experiences may differ from other women who do not work within the health sector. There is also the issue of reproducibility (Cavanagh, 1997) – I cannot guarantee that a different researcher would have interpreted the data in exactly the same manner that I have, nor would I expect this to be so given that I am part of the story of the research.

A final limitation refers to the use of a particular model to further understand the nature of women’s experiences with emotional distress and ECT, namely the MDI framework. I am aware that this model is based on social constructionism, and as such it could be argued that this choice limits the validity of subjective knowledge, namely because it is not recognised as a dominant mode of research. On the other hand, whilst a theory based upon social constructionism may not be seen as an empirical form of research, for the purposes of this work it was a logical choice to launch from. Future research
could overcome this limitation by the designing of research that uses a mixed methods approach.

**Summary and Concluding Comments**

The research contained within the thesis is significant, important and unique. It has argued that the ways in which some women make decisions to receive ECT is influenced by a consent process that includes elements of both active and passive coercion and a lack of available information, both of which can disempower women in vulnerable moments of important decision-making. A unique finding from this research is that some women may make decisions in moments of desperation and relative powerlessness when they feel, to some extent, incapable of making these important healthcare decisions. There is a clear disjunction that can exist between women’s subjective evaluation of their capacity to make personal decisions relating to ECT, and that of their treating teams who may perceive otherwise. To the best of my knowledge, this is also the first work to demonstrate a significant association between various types of short and long-term memory loss following ECT and the profound impact that this memory loss can have on the ways in which women navigate their worlds, as they construct personal and social identities as women, wives and mothers.

Women’s responses to life and the myriad of ways in which their emotional distress is individualised, politicised and medicalised has been critically deconstructed to examine social and institutional issues of power, control and privilege. The various mechanisms that can function to leave some women disempowered and isolated in their most vulnerable states of decision-making have been identified and it is my hope that an open critique of these mechanisms of power will progress from the research.

Until significant social and institutional change occurs, privileged experts will continue to medicalise women’s experiences. Their professional perspective of the ways that women respond emotionally to life needs be openly challenged. A sustained commitment to the paradigm of women as experts in their own lives can help to facilitate this change.

Implications for future social and clinical practice and recommendations for the application of the findings are proposed within the context of the informed consent process. Further research is suggested to explore the experiences of women as they make meaning and decisions about their mental health as well as the need to explore and examine the actions of those in powerful and privileged positions. A final recommendation to work with and learn from women across all stages of emotional
care is suggested, and the need for change at individual, organisational and social
levels is strongly encouraged.

Although this thesis is now complete I am aware that the research has raised far more
questions than it has answered in the process. It is not enough to let this research sit
as an isolated body of work. More must be done to answer these points of inquiry. Yet
for now, the thesis will form part of a larger personal research journey, where I am
determined and committed to understanding the medicalisation of women’s emotional
distress and the positioning of their mental health.
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APPENDICES
Appendix A: Ethics Approval

13 August 2014

Michelle Searle
Director, Office of Research
Tel: +61 7 5459 4574
Email: humanethics@usc.edu.au

Ms Karen-Ann Clarke
Ass Prof Margaret Barnes
Dr Dyann Ross
University of the Sunshine Coast

Dear Karen-Ann, Margaret and Dyann

Human Research Ethics Committee ethics approval for research project: Women with depression: making meaning and decisions about electroconvulsive therapy. A Feminist Perspective (S/14/606)

This letter is to confirm that on 21 July 2014 following review of the revised application for ethics approval of the above research project, the Human Research Ethics Committee of the University of the Sunshine Coast granted conditional ethics approval for the project. The condition of approval has now been satisfied.

The period of ethics approval is from 5 August 2014 to 1 March 2017.

Could you please note that the ethics approval number for the project is HREC: S/14/606. This number should be quoted in your Research Project Information Sheet and in any written communication when you are recruiting participants.

The standard conditions of ethics approval are listed overleaf.

If you have any queries in relation to this ethics approval or if you require further information please contact a Research Ethics Officer by email at humanethics@usc.edu.au or by telephone on +61 7 5459 4574 or 5430 2823.

I wish you well with the success of your project.

Yours sincerely

Michelle Searle
Director, Office of Research

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Appendix B: Invitation to Participate

Invitation to Participate in Research

Project: Women and depression: making meaning and decisions about electroconvulsive therapy.
A Feminist Perspective

USC Ethics Approval No: S/14/606

I am conducting research that explores the experiences of women who have received electroconvulsive therapy (ECT) as treatment for depression, and how they make decisions with regard to the treatment. There is a great deal of technical information known about ECT, however there is very little research that explores women’s perspectives of the treatment. It is important for health care workers to understand the viewpoints of women and ways in which they make decisions about ECT in order to have the best evidence for women’s centred care within mental health services. For this reason, this project requires the assistance of women who have experienced depression and who have received ECT.

Involvement in this project is completely voluntary. It will involve being interviewed about your experience of receiving ECT, and about how you came to make the decision to receive the treatment. I anticipate that the initial interview will take up to two hours to complete and will be held at a venue and time that is convenient to you that is safe, secure, private and confidential. There may be a need for a follow up interview to clarify any points of understanding and this will be negotiated with you. The interviews will be audio recorded with your permission so that I can accurately recall what we have discussed, but you are free to ask to have this turned off at any time. Information that is provided will be used for academic purposes and will be used in professional publications, conferences and presentations that are part of the requirements of a PhD. The information that you provide for this study will be collected and coded in such a way that you will not be able to be identified and all information will be treated as confidential.
The University of the Sunshine Coast Human Research and Ethics Committee has approved this research and the findings from this project may help mental health clinicians better understand the way in which consumers make decisions about mental health treatments.

To be eligible to participate in this project you would:

- Have had at least one experience with depression; and
- Have required at least one ECT treatment that was administered at least 12 months ago but no earlier than 2006

I would be very keen to include you in this research project. If you are interested in participating, and would like any further information, please do not hesitate to contact:

Karen-Ann Clarke
Phone: (07) 5459 4834 or 0401615621
Email: KClarke@usc.edu.au
Appendix C: Participant Information Sheet

Research Project Information Sheet

Project: Women and depression: making meaning and decisions about electroconvulsive therapy.
A Feminist Perspective

USC Ethics Approval No. S/14/606

Principal Researcher: Karen-Ann Clarke PhD Candidate
Phone: (07) 5459 4834
Email: KClarke@usc.edu.au

Dear Participant,

Thank you for your consideration of this research project. It is important that you take the time to carefully think about whether you wish to be involved. When you have done so, please contact Karen-Ann Clarke either by telephone or through email.

About the research project:
As part of a PhD undertaken at the University of the Sunshine Coast, I am conducting research that explores the experiences of women who have received electroconvulsive therapy (ECT) as treatment for depression, and how they make decisions with regard to the treatment. There is a great deal of technical information about ECT; however there is very little research that explores women’s perspectives of the treatment. It is important for health care workers to understand the viewpoints of women and ways in which they make decisions about ECT in order to have the best evidence for women’s centred care within mental health services. For this important reason, this project requires the assistance of women who have experienced depression and received ECT.

What your participation in the project will involve:
Involvement in this project is completely voluntary. It will involve being interviewed about your experiences with receiving ECT, and about how you came to make the decision to receive the treatment. I anticipate that the initial interview will take up to one hour to complete and
will be held at a venue and time that is convenient to you. There may be need for a follow up interview to clarify any points of understanding and this will be negotiated with you. The interviews will be audio recorded with your permission so that I can accurately recall what we have discussed, but you are free to ask to have this turned off at any time. You may also withdraw your participation in this project at any time without needing to provide a reason. If you would like a summary of the key findings at the completion of the project, these will be made available to you when the project has finished.

The University of the Sunshine Coast Human Research Ethics Committee has approved this research. The findings of this project may help mental health clinicians to understand the complex nature of decision-making with regard to ECT and the experiences of women who undergo specific treatments such as this.

To be eligible to participate in this project you would:

- Be aged 18 – 85 years
- Have been diagnosed with depression; and
- Have required at least one ECT treatment that was administered at least 12 months ago, but no earlier than 2006

**Benefits and Risks**

The findings from this project may benefit mental health clinicians by providing a better understanding of the ways in which consumers make decisions regarding ECT. It may also help them to better understand the perspective of women who receive that care. This will ultimately help other women who receive ECT in the future.

You may benefit from the opportunity to discuss your experiences of ECT, and how you made the decision to receive it as a treatment. If at any stage throughout the project you feel that you need to speak with an independent mental health specialist, you can contact the Mental Health Access team, who are located at 100, 6th Avenue Maroochydore (Telephone: 1300 767 155).

All information collected during the project will remain completely confidential and secure. Information will be coded in such a way that you will not be able to be identified, and all recordings, tapes and transcripts will be securely stored at the University of the Sunshine Coast.
Coast. The information collected will only be used for the sole purpose of this project. If you decide to discontinue your participation with the project, your information will not be used. Results from this project will be disseminated through a PhD thesis, conference papers and published journal articles. Although there may be some extracts of your taped interview within these publications, no names or identifying information will be used.

The research team consists of Karen-Ann Clarke, who is a mental health nurse and a PhD student supported by senior academics (see next page) who possess experience in the particular research method being used for this project.

If you have any concerns or complaints about the manner in which this research is being conducted you may contact either the Principal Researcher (Karen-Ann Clarke) or alternatively you may contact the Chairperson of the Human Research Ethics Committee at the University: (c/- the Research Ethics Officer, Office of Research, University of the Sunshine Coast, Maroochydore DC 4558; telephone (07) 5459 4574; email humanethics@usc.edu.au).

Thank you again for your consideration and assistance in this project. If there are any other questions that you would like to raise, or concerns you would like to discuss, please do not hesitate to contact the Principal Researcher (Karen-Ann Clarke) on (07) 5459 – 4834 or email KClarke@usc.edu.au
Research Team:
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Appendix D: Participant Consent Form

Consent to Participate in Research
Project: Women and depression: making meaning and decisions about electroconvulsive therapy. A Feminist Perspective

USC Ethics Approval No. S/14/606

**Principle Researcher:** Karen-Ann Clarke PhD Candidate
Phone: (07) 5459 4834
Email: KClarke@usc.edu.au

**Project Overview**
There is very little research looking at women’s experiences with electroconvulsive therapy (ECT) and how women make decisions regarding this treatment. This project aims to talk to women about their experiences with regard to how they made the decision to receive ECT. The findings of this study may help mental health clinicians better understand how women make treatment decisions to improve practices within mental health care in the future.

I understand that:
- I do not have to participate in this research study if I do not want to; and
- I understand the contents of the Research Project Information Sheet for the research study “Women and depression: making meaning and decisions about ECT” and this Consent to Participate in Research form. I agree to participate in the project and give my consent freely. I understand that the project will be carried out as described on the Research Project Information Sheet, a copy of which I have kept. I realize that whether or not I decide to participate is my decision. I am aware that I can withdraw from the study at any time and that I do not have to give any reasons for withdrawing. Any questions I had about this research project and my participation in it have been answered to my satisfaction.

- I understand that if I have any concerns about the ethical conduct of the project I can contact the Chairperson of the Human Research Ethics Committee at the University of the Sunshine Coast: telephone (07) 5459 4574; facsimile (07) 5430 1177 or email humanethics@usc.edu.au

Participant's Name (please print)
.................................................................................................................

Signature
.................................................................................................................Date:
.................................................................................................

Note: All parties signing the form must date their own signatures.
INVITATION TO PARTICIPATE IN RESEARCH

Project: Women and depression: making meaning and decisions about electroconvulsive therapy

USC Ethics Approval No: S/14/606

Are you a woman who has experienced depression?

Have you received electroconvulsive therapy (ECT) since 2006?

If so, this project may interest you!

This research, based at the University of the Sunshine Coast, wishes to explore the perspectives of women who have received ECT as a treatment for their depression. This may help increase our knowledge of how women make decisions about specific mental health treatments. Participation would involve a face-to-face conversation about your experiences with the procedure.

If you would like to participate, or have any questions about the project, please contact the Principal Researcher (Karen-Ann Clarke) on (07) 5459-4834, Mob: 0401615621 or email KClarke@usc.edu.au
Appendix F: Newspaper Advertisement

RESEARCH VOLUNTEERS NEEDED

Are you a woman who has previously experienced depression? Have you received electroconvulsive therapy (ECT) since 2006?

If so, this research study may interest you! Based at the University of the Sunshine Coast, this study wishes to explore the perspectives of women who have been treated with ECT. Results of this study may help mental health clinicians understand the complex nature of decision-making with regard to ECT and the experiences of women who undergo specific mental health care. Participation would involve a face-to-face conversation about your experiences with the procedure.

If you would like to participate, or have any questions, please contact the Principal Researcher (Karen-Ann Clarke) on (07) 5459-4834, Mob: 0401615621 or email KClarke@usc.edu.au
Appendix G: Focus Area Network Website Advertisement for GPs

USC Research - Women, depression and ECT

Public Health Alerts
Primary Health News
Newsletters
Events Calendar

Women, Depression and ECT - USC Research Project
A University of Sunshine Coast researcher is seeking participants for a research project entitled Women and depression: making meaning and decisions about electroconvulsive therapy.

Karen-Ann Clarke, a Registered Mental Health Nurse and university academic, hopes to gain the assistance of women over the age of 18 who have experienced depression and who have received ECT at least 12 months ago (if not longer). Involvement for women in this study will require an audiotaped face-to-face interview of up to two hours duration, at a time and place that is deemed to be safe, private and confidential, and convenient.

There is a great deal of technical information known about ECT, however there is very little research that explores women’s perspectives of the procedure. It is important for health care workers to understand the viewpoints of women and ways in which they make decisions about ECT in order to have the best evidence for women’s centered care within mental health services.

The findings of this project may help mental health clinicians to understand the complex nature of decision-making with regard to ECT.
Karen-Ann has produced a one-page flyer (click here to download) for general practitioners, mental health clinicians and other health professionals to provide to women who may wish to participate.
Karen-Ann is aiming to complete interviews by December 2014, but may consider extending if women wish to participate after that time. Practitioners or potential participants who want to find out more are encouraged to contact Karen-Ann directly via the details on the flyer.