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Family Experiences of Caring for Relatives Who Have Received Electroconvulsive Therapy (ECT)

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Abstract

The research literature on family members' experiences of the use of electroconvulsive therapy (ECT) is limited. This article explores the perspectives of family members whose relatives had received ECT. Drawing on a social constructionist perspective, this qualitative study collected data using in-depth interviews with nine families in South Australia (SA), to examine how family members constructed the supports and challenges they experienced. The research found that families experienced a range of social and service system barriers, including social stigma and isolation and limited support from health professionals. They had to negotiate caring expectations within a social context that stigmatised both mental illness and ECT. A need for ECT-specific mental health support groups was identified.

Implications:

- Social workers' roles in Australian hospitals could be further expanded to accommodate supporting families whose relatives have received ECT, referring families to community support and advocating for specialist support post ECT treatment.

- Social workers can further articulate their unique contribution to community care post ECT treatment and advocate for supporting families.
- Increased focus on ongoing and preventative care for supporting families is a potential growth area for social workers in mental health.

Keywords: Social Stigma; Social Work; Mental Health; Family; ECT

Background

Social work practice in mental health requires specific skills and knowledge to support individuals, families and communities, within a social justice and human rights framework (Bland et al., 2009). The rights of people affected by mental illness are highlighted in the United Nations (UN) principles for the protection of persons with mental illness and the improvement of mental health care (UN, 2001). However, very little is known about the individual, social and service barriers families face when a family member has received ECT. While there are studies that focus on families and mental health (Bland & Foster, 2012), few investigate family experiences of ECT. Previous biomedical research has focused on the experience of ECT recipients after treatment, including their quality of life and memory loss (McCall et al., 2004; Smith et al., 2009). One hospital-based nursing study from the USA interviewed eight family members in an acute setting to explore their carer experiences, relationships, fears and hopes for the future (Sethi &Williams, 2003). This study found that, given the ineffectiveness of medication for their relative, they were hopeful that ECT would help. Families felt that they needed more supports, particularly emotional support and information about ECT. Little research in a community setting could be located that gathered the perspectives of families in the context of a relative receiving ECT.

ECT is a medical treatment used by psychiatrists to treat severe depression as well as schizophrenia and mania, when other treatments have been unsuccessful. ECT is administered by an approved psychiatrist in a hospital and is usually a day procedure. After receiving a general anaesthetic and muscle relaxant (Royal Australian and New Zealand College of Psychiatrists (RANZCP) 2016), ECT is administered as a short electrical pulse through two electrodes placed on the individual's scalp, evoking a seizure like response. On average, a person may receive 8-12 sessions of ECT over the course of 3-4 weeks (RANZCP 2016). Legal consent is obtained prior to the treatment being administered. However, should an individual not be well enough or their condition be life threatening, the psychiatrist may consult with the family and present an argument to the Guardianship Board to obtain consent (RANZCP 2016).

ECT continues to be widely used across Australia. Around 7,500 Australians receive ECT each year (RANZCP 2016). The present research was undertaken in South Australia (SA) where the most recent statistics indicate that 480 people (305 female and 175 male) received ECT between 2013 and 2014 (SA Health 2014). ECT was often prescribed to people aged 45-54 years (25.1%) in the public health system, and to people aged 50-69 years (42.6%) in a private hospital setting (SA Health 2014). Western Australia (WA) reports lower rates compared to Victoria and New South Wales (Teh et al., 2005). In Victoria, 1,025 people received ECT between 2014 and 2015 in the public health system, and of these, 60% were women, mostly aged 70-79 years, compared to men who were mostly aged 40-49 years (Victorian Government, 2016). In WA, only 611 people received ECT between 2014 and 2015 (Teh et al., 2005), and of these, 70% were 19 to 64 years and 27% over 64 years old (Teh et al., 2005). Despite these statistics, there is a dearth of Australian research on family experiences of relatives who have received ECT which specifically explores the voices of families when ECT is being prescribed.

Broadening the Focus: Family Experiences of ECT

Previous social work literature has focused on families and mental illness more broadly. Social workers Bland and Foster (2012, p. 517) argued that there is an "ambiguity" about the family in clinical, family focused and policy oriented mental health literature, which can be a "barrier to developing positive and constructive policy and practice approaches" (Bland & Foster, 2012, p.518). The clinical literature tends to highlight family pathology, the impact of caring on the health and wellbeing of family members, including increased risk of depression and physical health problems, as well as social impacts such as higher unemployment, limited social support, and financial stress (Bland & Foster, 2012, p.521). This also includes literature about hospital discharge planning processes, which has often found that families were provided with limited information about support services (Barber, 1985; Cleary et al., 2005; Ewertzon et al., 2011; Ewertzon et al., 2010; Kokanovic et al., 2006; Lawn & McMahon, 2014; Marshall et al., 2013; McCann et al., 2011; Slade et al., 2007; Strand et al., 2015).

The assumption that families are burdened by relatives with a mental illness is widespread, with family advocacy literature in particular constructing "the burdened family" (Bland & Foster, 2012, p. 517). Clinical studies conducted in the UK (Rowe, 2012), Sweden (Erlingsson et al., 2012), Germany (Jungbauer et al., 2004), Canada (Ricard et al., 1999) and Australia (Goodwin & Happell, 2007) have focussed on subjective and objective family burdens, although it is conceded that these concepts are difficult to define, operationalise and measure (Ricard et al., 1999, p. 74). Objective burdens relate to practical challenges such as financial hardship, social life and family disturbances, whilst subjective burdens relate to

culturally bound emotions, which include worries about a relative's care and behaviour and their readiness to live in the community, often with limited assistance (Ricard et al., 1999).

In contrast to the literature focussing on family burdens and barriers, some studies have found that family members experienced their support roles as rewarding, providing them with personal satisfaction (Dunne & Rogers, 2013; Lawn & McMahon, 2014). In Australia, Lawn and McMahon (2014) researched the "intimate labour" of 28 spouses and found that they did not see their caring as a "burden" but rather part of their "responsibilities" in the spousal relationship (Lawn & McMahon, 2014 p. 263). It is unknown how families of people who have received ECT perceive their relationships with professionals, their caring, and their experiences of service provision. However, it is known that when family members felt stigmatised, the burdens they perceived were compounded (Chang & Horrocks, 2006; Dunne & Rogers, 2013; Ricard et al., 1999; Rowe, 2012). Social stigma can bring shame and embarrassment to the family, which may in turn affect their help-seeking behaviours (Link et al., 2001; Strand et al., 2015). These studies relate to families in the context of broader mental health concerns. More research is needed to explore the experiences of families with relatives who have been treated with ECT.

Deinstitutionalisation and associated mental health policy changes have created "the obligated caregiver" or the "family as carer" (Bland and Foster, 2012, p. 517, 523). In the context of the declining number of acute beds, the changing role of hospitals and increased staff workloads, social expectations and responsibility to provide care has shifted from institutions to individuals and families (Barber, 1985; Cleary et al., 2005; Cochrane et al., 1997; Goodwin & Happell, 2007; Janardhana et al., 2011; Kokanovic et al., 2006). There are complexities and multiple impacts of mental illness and treatment on families (Kokanovic et al., 2006) who often lack the skills, knowledge, training and support, which paradoxically, can increase the risk of readmission into mental health units (Cleary et al., 2005; Jones et al.,

2009). Families have differing perceptions to health professionals, which can cause some confusion about their role in the context of mental illness and ECT treatment. It is unknown if families whose relatives are treated with ECT feel burdened, expect to care for their relatives or feel stigmatised. This paper contributes to this literature by reporting on research that specifically explored family experiences of ECT in the Australian context.

Method

This research was a small, time limited, exploratory study of the experiences of families of ECT recipients. The study was framed within a social constructionist perspective that acknowledges reality is socially constructed through social interactions, and that the beliefs and meanings people create exist within a social context (Berger & Luckmann, 1991; Burr, 2015; Crotty, 1998; Germov & Poole 2011; Neuman 2011; Rubin & Babbie 2014; Sarantakos 2013; Walter 2013). Social constructionism provided a theoretical lens for positioning and exploring family experiences within a wider social context, in contrast to the predominant individualist and biomedical perspectives in this field (Gallagher, 1980; Germov, 2009). This lens allows for a broader focus on social attitudes and expectations that shape their meanings and lived experiences of families in the context of their relative being treated with ECT. Social constructionism supports an interpretive approach (Germov & Poole, 2011; Neuman, 2011; Sarantakos, 2013; Walter, 2013), which makes visible the perspectives of family members of ECT recipients.

A combination of purposive, convenience and snowball sampling was used to recruit the research participants. Family members were recruited through a multipronged strategy which included academic, professional and personal networks and circulating flyers and invitation emails to a range of mental health services across South Australia. The family members in this study self-selected by contacting the first author directly. Semi-structured

interviews were used to obtain in-depth information from participants about their subjective experiences and the challenges they faced to accessing support services. Each participant was interviewed separately and in a confidential space. The interviews lasted for 30 to 60 minutes and were audio recorded and transcribed verbatim. The findings are retrospective as most of the recipients had not received ECT in over 18 months. This limited the ability to gather data on current mental health systems and reforms. As detailed in Table 1 below, nine people participated in the study, six females and three males, with differing relationships to the ECT recipient, and with ages ranging from the late 30s to early 80s (see Table 1).

INSERT TABLE 1 HERE

Thematic analysis was conducted to inductively identify and report patterns within the data (Braun & Clarke 2006; Morse 2008; Walter 2013; Neuman, 2006). The first author conducted the interviews and all three authors analysed the data separately and together, a process which involved reading the interview transcripts several times to become familiar with the data, assigning initial codes, organising the codes into emerging themes, refining and finalising the themes, and analysing the themes to determine those most important to the research questions. After several team meetings, agreement was reached on the five key themes. The University of South Australia Human Research Ethics Committee approved this study.

Findings and Discussion

Family members were asked about their perspectives on ECT and the social and service system supports and barriers they experienced. The data was analysed and grouped under five core themes: the effectiveness of ECT; the stigma of ECT and mental illness; caring for a family member is expected but socially isolating; the family as “a strong unit” despite

subjective burdens, and limited professional support. A key finding unique to this study related to the stigma associated with ECT, which was compounded by the stigma of mental illness. See Table 2 illustrates the contested ways that each participant perceived the effectiveness of ECT and stigma, which was associated with the informal and formal supports they received.

INSERT TABLE 2 HERE

The Perceived Effectiveness of ECT Treatment

As illustrated in the table above, family perceptions about the effectiveness of ECT were mixed. Four participants (Sally, Sarah, Simon and Susan) felt positive about ECT treatment and noticed "good results", with additional treatments perceived to be necessary for some. One participant (Scott) felt his relative "recovered" but not enough; two participants (Sabrina and Salena) felt that ECT had damaging effects on their relative's personality, and two participants (Sophie and Stephen) did not notice any effects. These perceptions of effectiveness did not seem to be related to when the ECT treatment occurred. For example, Sally's relative was treated 6 months ago, while Susan's relative was treated 24 years ago, but they both provided positive accounts. However, while previous research has found that ECT provided relatives with hope that their caring responsibilities would decrease and social and family relationships would improve (Sethi & Williams, 2003), this was not the case for our participants. Their caring responsibilities either remained the same or increased. As well, all participants recounted experiencing social isolation and stigma.

The Stigma of Mental Illness and ECT

The family members reported feeling shamed and socially isolated from their family and friends because of the social stigma associated with ECT, which was strongly related to the stigma of mental illness. Simon and Scott stated that having a family member with a mental illness could be a reason why "people" (such as friends) "drift away" (Simon) because they are "frightened of" mental illness (Scott). Consequently, Simon had experienced barriers to accessing formal and informal supports: "we didn't get much help", which is "still there today, but much less" (Simon), indicating a reduction in social stigma over time.

The stigma associated with ECT was evident when Sally said: "If I mentioned that he [husband] had ECT, they'd look at me strangely and say 'ohh I didn't think they still did that" (Sally). This stigma also contributed to a lack of knowledge and access to information about ECT. As Salena said: "Information about ECT, yeah nothing I could get from my sources ... nobody could help me there. I hadn't heard anyone that had had ECT". This in turn affected how supported and valued families felt: "The stigma is still alive, out there and it shouldn't be" (Sabrina). The shame and stigma associated with mental illness and ECT meant that some families were selective about who they would talk to about the treatment: "A lot of people wouldn't know what I've been dealing with at home because I wouldn't really talk about it" (Salena).

ECT is poorly understood in the community, in part due to its stigmatised representation in the public domain. Participants reported that their knowledge of ECT was gleaned from movies which also stigmatised ECT:

> ...everybody thinks of *'One Flew Over the Cuckoo's Nest'*... that's the version people have of it, not that they're anaesthetised, that they're given muscle relaxants, until you're told that, there still is this stigma, taboo, fear around what it is (Sarah).

These public representations of ECT influenced family members and the recipients' experiences and fears about ECT when they received it for the first time: "When patients are

about to have ECT for the first time, and the first time is really scary because you can be told all sorts of things" (Sophie).

To alleviate feelings of fear, shame and stigma, Sabrina suggested people "speak up" about mental illness and ECT: "I was open enough to talk to people at work about it. I'm not at all ashamed about the stigma of mental health or treatment". Sabrina advocated for normalising mental illness and ECT to address this historically constructed stigma:

Normalise it, you have stigma of mental health, but you have this fear and horrific history of ECT (Sabrina). Sophie added that community education about mental illness was important: You need to try and get rid of the stigma and educate people, psychiatric problems cause a hell of a lot of isolation.

Participants also reported that ECT-perpetuated stigma stems from other sources such as medical professionals who provide treatment in hospitals, service providers who provide support post-treatment, and support groups for carers. For example, Sarah's request for a referral to support services was met with a response that reflected the social silencing of mental illness: "I asked the psychiatrist if I could access supports and he said, 'why get another person involved if we don't need to?'" (Sarah). Furthermore, Susan said that when families did access support groups, even support groups for carers: "no-one really talked about having ECT". Such responses were unexpected by participants as they anticipated support which was more professional: "We received negative reactions from the most unexpected places. Some of the treating professionals at first had treated us harshly" (Sophie). This stigma contributed to the socially isolating experience of family members.

Caring as Expected and a Socially Isolating Experience

Consistent with previous research, this study found that the family is socially expected to care for their relatives with a mental illness (Bland and Foster, 2012; Goodwin & Happell, 2007).

The families in this study all felt that it was their responsibility to care for their relative:

We'll just basically looking after him I suppose, because he would not have looked after himself (Susan). Despite this expectation, a repeated finding was that there "wasn't much help around for carers" (Susan). Families' experienced social isolation which intensified concerns about loss of relationships and social stigma. As Salena said: "It's true what they say, you become so isolated in this situation". Families put their own lives "on hold" because they were constantly worried about their relative and stayed home to care for them: "We really stopped doing it [socialising], we literally devoted ourselves entirely to it [caring]" (Simon). Without additional supports, families put their own needs aside and withdrew socially: "We were in auto pilot, we were just in it and we didn't think about ourselves really" (Sabrina). Families described how they withdrew from their social networks, as friends and extended family asked too many questions, such as why their relative had not met social expectations:

> The odd family barbeque... was more of a problem than anything else, because people would ask what he was doing, and what job did he have, all that sort of stuff, and of course he didn't have any, so he felt like a failure (Simon).

They felt as though they had lost friends and family and even when their relative's mental health improved, rekindling relationships was difficult: "Trying to re-engage with my life, I had cut off from... I'd become really isolated" (Salena).

These findings mirror those from other studies in the general caring and mental health literature (Chang & Horrocks, 2006; Clearly et al., 2005; Dunne & Rogers, 2013; Janardhana et al., 2011; Lawn & McMahon, 2014). However, receiving ECT treatment and the severity of mental illness intensified family isolation due to the social stigma of ECT. Thus, being a family member of a person who had received ECT presented additional challenges.

Family as a 'Strong Unit' Despite Subjective Burdens

Social stigma also affected the family's decision about whether to support ECT treatment or not. If the individuals prescribed ECT themselves stigmatised the treatment, this subjectively burdened the family in their decision-making about ECT. For example, Sabrina explains:

> ...it didn't sit right for mum who had sworn, who asked me to swear that I would never let that happen to her. So, that would be the only emotional part of the whole thing [cries], I made a promise, couldn't come through for her [cries] (Sabrina).

These findings are consistent with previous research (Erlingsson et al., 2012) which has also found that having to go against a family member's wishes increased their perceived burden of care.

Similar to the findings of previous research (Sethi &Williams, 2003), our participants also wanted to be more involved in decisions about their relative's medical care: "For professionals to include you, the carer, in the deal, and you're pretty important, that they do" (Simon). However, in some instances, where a relative was unwell and/or detained under the *South Australian Mental Health Act 2009*, the decision was removed from them and made by the Guardianship Board:

> That's where we went, went down to [the treating hospital] and we sat there and we were dressed beautifully and we were a strong unit... I think he [father] was probably always going to go with what they [medical professionals] suggested, however my oldest sister and me really had our concerns and voiced them, but at the end of the day, the Guardianship Board took the decision away from all of us (Sabrina).

This comment about the family being a "strong unit" resonates with Lawn and McMahon's (2014) findings of families presenting a "united front" to the mental illness and the treating professionals (Lawn & McMahon, 2014). However, given dominant negative representations of ECT treatment and the lack of available information, having the decision removed from

the family or the person affected by mental illness is confronting. Families experienced subjective burdens in the context of contested decisions about ECT treatment. Nevertheless, when family members received informal assistance and support from friends, extended family and neighbours, they reported feeling more socially engaged and less isolated. As Sarah said: “I could leave the house, so life just sort of started to go back to normal”.

Professional Support

Consistent with recent literature highlighting family concerns about the support and responses of mental health systems (Sawyer et al., 2016), the families in this study also expressed disappointment about a lack of support post-discharge from the treating hospitals, as well as a lack of follow up from community mental health services:

> The only follow up from [treating hospital] is they rang her and asked her if she had anymore thoughts of harming herself... so that was it, not even a visit (Stephen).

Families therefore had to find the services themselves or rely on informal supports from family and friendship groups. Thus, families were expected to assist their relatives prior to, during and post-ECT treatment, with limited professional support. For example, when Sarah asked her doctor for a referral to services, after receiving little support from her extended family, she was refused and encouraged to rely on her own “strengths”: “I asked the doctor if I could access supports for me, like all doctors at the time [12 years ago] they’d say, ‘you’re strong, you can cope with this’”.

The most common services accessed by participants were generic mental health support groups, facilitated by counsellors. However, they did not access self-help groups when their relatives were receiving ECT and found it difficult to locate relevant support groups. The family members who later attended these groups felt excluded due to the stigma associated with ECT. Some also felt these groups were not the ‘right fit’ for their situation.

Most felt uncomfortable discussing ECT, with some identifying a need for ECT-specific support groups. Although, as Simon notes, these groups are very difficult to locate: "Somebody caring for someone treated with ECT is to find a support group, an appropriate support group, not a generic one, and that is very hard to do". The lack of ECT specific information, social and professional support increases the social isolation and stigma experienced by families. This key finding is important for social work and is an area of advocacy for social workers who are employed in mental health services and facilitate mental health support groups.

Implications for Social Work

Given social work's emphasis on client rights, person-centred practice, human rights and social justice, supporting families is an important area of practice (Bland, Renouf, & Tullgren, 2009; Renouf & Bland, 2005; Courtney & Moulding, 2014). In the field of mental health, Renouf and Bland (2005, p.419) particularly emphasised "the importance of working collaboratively with consumers and families in a way that values their human rights and the lived experience of mental illness". While families are perceived to be an "important part of the care system" due to their potential to be a "cost effective" resource (Strand et al., 2015, p. 147), further research is needed to explore the complex challenges experienced by families supporting a relative who has received ECT treatment. This is consistent with the social justice aims of social work to recognise and respect the voices of families who are supporting relatives with mental health problems.

Social workers participate in conducting family assessments in the hospital discharge process and it is often assumed that families will care for their relative post ECT treatment. Furthermore, contested legal consent issues surrounding ECT often require families to be involved in decision-making processes (Australian Human Rights Commission Act 1986

(AHRC1986). Therefore, the perspectives of families of ECT recipients can contribute to improving policies, practices and service responses, in the context of discharge planning after ECT treatment. Early work by Katz (1992) has posited that social workers should be trained to support families during ECT. However, this research was limited to highlighting the perspectives of family members and the current social work role regarding ECT is an area of research that needs further consideration.

Conclusion

This study contributes to social work research knowledge about the rights of families to access supportive mental health services from the perspective of family members of ECT recipients. It describes the experiences of a small group of families in South Australia, which although cannot be generalised to all families, provides important insights that may have broader relevance and applicability. Within the current context of deinstitutionalisation and limited acute and community mental health support services, there is increasing pressure on families to provide high levels of informal care to their relatives. The findings of this research build on previous mental health and social work studies that highlight the challenges and rewards of caring for family members, as well as systematic barriers to accessing support services (Bland, Renouf, & Tullgren, 2009; Renouf & Bland, 2005; Courtney & Moulding, 2014). This research found that a specific issue for families when supporting a relative who has received ECT include the double stigma associated with mental illness and ECT treatment. This stigma is deeply entrenched in our society and has important human rights and social justice implications for social workers who are committed to providing effective support to families, especially in the context of ECT treatment. As this study was small, time limited and exploratory, further research is needed to examine the complex and diverse

experiences of families and to gather the perspectives of social workers about their practice and perceived role in this context.

Table 1: Sample characteristics

Name	Age	Gender	Caring Role	Length of caring	How long ago was ECT given	How many courses of ECT	Employment status while caring
Sabrina	36	Female	Daughter	26 yrs current	5yrs ago	12 courses	Full time
Salena	46	Female	Daughter	8 yrs current	5yrs ago	12 courses	Part time
Sally	70	Female	Wife	18mths current	6mths ago	17 courses	Retired
Sarah	52	Female	Wife	13yrs not current	12yrs ago	16 courses	Fulltime
Scott	82	Male	Husband	19 yrs current	10yrs ago	12 courses	Full time
Simon	78	Male	Father	21 yrs current	24yrs ago	8 courses	Full time
Sophie	63	Female	Wife	10 yrs not current	15yrs ago	12 courses	Full time
Stephen	48	Male	Son	21 yrs not current	9yrs ago	8 courses	Full time
Susan	75	Female	Mother	21 yrs current	24yrs ago	8 courses	Part-time

Table 2: Participant's Perspectives about ECT

Name	Effectiveness of ECT	Supports and Stigma due to ECT
Sabrina	Felt her "mum was not the same" post ECT, her personality had changed.	Experienced shame speaking about ECT, but could talk about it with friends.

Salena	Felt as though they had “lost their mother”, questions if it [ECT] was effective.	Family experienced shaming from people post-treatment, mostly towards her mother.
Sally	Believes it [ECT] “saved” her husband’s life	Often felt left out in social and support groups when ECT was not the focus. Felt that she needed help but there was little awareness of ECT.
Sarah	Good results, husband still needs “top ups”.	Response from people was “shocking”, she felt ostracised and alone.
Scott	His wife “recovered”, but not as much as he had hoped.	He was very confused about the response/stigma he experienced. He thought people would have been more helpful.
Simon	Worked well for his son, good result.	Felt ostracised by family and friends due to the stigma of the treatment.
Sophie	Effectiveness of ECT for her husband was not noticeable enough.	Experienced support from family during husband’s treatment but not from professionals
Stephen	Did not notice any changes post treatment in his mother.	Post treatment he felt his mother was not looked after enough and was treated poorly by medical professionals.
Susan	Positive results, felt mother could do with further treatments.	Was often left out by extended family and people were rude towards her and her family when they knew about the treatment.

References

Barber, J. (1985). Mental health policy in South Australia: a job half done. *Australian Journal of Social Issues*, 20(2), 75-86.

Berger, P., & Luckmann, T. (1991). *The social construction of reality: a treatise in the sociology of knowledge*. Penguin Books: New York, USA.

Bland, R,. & Foster, M. (2012). Families and mental illness: contested perspective and implications for practice and policy. *Australian Social Work*, 65 (4), 517-534.

Bland, R., Renouf, N & Tullgren, A. (2009). *Social work practice in mental health*. Crows Nest: Allen & Unwin.

Braun, V., & Clarke. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101.

Burr, V. (2015). *Social constructionism*. (3rd edn) Sussex, UK: Routledge.

Chang, K.H., & Horrocks, S. (2006). Lived experiences of family caregivers of mentally ill relatives. *Journal of Advanced Nursing*, 53(4), 435-443.

Cleary, M., Freeman, A., Hunt, G.E., & Walter, G. (2005). What patients and carers want to know: an exploration of information and resource needs in adult mental health services. *Australian and New Zealand Journal of Psychiatry*, 39(6), 507-213.

Cochrane, J.J., Goering, P.N., & Rogers, J.M. (1997). The mental health of informal caregivers in Ontario: an epidemiological survey. *American Journal of Public Health*, 87(12), 2002-2007.

Courtney, M. & Moulding, N. (2014). Beyond balancing competing needs: Embedding involuntary treatment within a recovery approach to mental health social work. *Australian Social Work*, 67(2), 214-226.

Crotty, M. (1998). *The foundations of social research, meaning and perspective in the research process*. St Leonards, Australia: Allen & Unwin.

Dunne, E. & Rogers, B. (2013). It's us that have to deal with it seven days a week': carers and borderline personality disorder. *Community Mental Health Journal*, 49(6), 643-648.

Erlingsson, C.L., Magnusson, L., & Hanson, E. (2012). Family caregivers' health in connection with providing care. *Qualitative Health Research*, 22(5), 640-655.

Ewertzon, M., Andershed, B., Svensson, E., & Lutzen, K. (2011). Family member's expectation of the psychiatric healthcare professionals' approach towards them. *Journal of Psychiatric and Mental Health Nursing*, 18(2), 146-157.

Ewertzon, M., Lutzen, K., Svensson, E., & Andershed, B. (2010). Family members' involvement in psychiatric care: experiences of the healthcare professionals' approach and feeling of alienation. *Journal of Psychiatric and Mental Health Nursing*, 17(5), 422-432.

Gallagher, B.J. (1980). *The sociology of mental illness*. New Jersey, USA: Prentice-Hall Inc.

Germov, J. (Ed.) (2009). *Second opinion: an introduction to health sociology*. (4th edn). South Melbourne, Victoria: Oxford University Press.

Germov, J., & Poole, M. (2011). *Public sociology: an introduction to Australian society*. (2nd edn). Crows Nest, NSW: Allen & Unwin.

Goodwin, V., & Happell, B. (2007). Consumer and carer participation in mental health care: the carer's perspective: Part 2 – Barriers to effective and genuine participation. *Issues in Mental Health Nursing*, 28(6), 625-638.

Government of South Australia (SA Health). (2014*). The Annual Report of the Chief Psychiatrist of South Australia 2013-14*. SA Health, South Australia.

Jones, I.R., Ahmed, N., Catty, J., McLaren, S., Rose, D., Wykes, T., & Burns, T. (2009). Illness careers and continuity of care in mental health services: a qualitative study of service users and carers. *Social Science and Medicine*, 69(4), 632-639.

Jungbauer, J., Wittmund, B., Dietrich, S., & Angermeyer, M.C. (2004). The disregarded caregivers: subjective burden in spouses of schizophrenia patients. *Schizophrenia Bulletin*, 30(3), 665-675.

Katz, G. (1992). Electroconvulsive therapy from a social work perspective. *Social Work in Health Care*, 16(4), 55-68.

Kokanovic, R., Petersen, A., & Kilmidis, S. (2006). 'Nobody can help me...I am living through it alone': Experiences of caring for people diagnosed with mental illness in ethno-cultural and linguistic minority communities. *Journal of Immigrant and Minority Health*, 8(2), 125-135.

Lawn, S., & McMahon, J. (2014). The importance of relationship in understanding the experiences of spouse mental health carers. *Qualitative Health Research*, 24(2), 254-266.

Link, B.G., Struening, E.L., Neese-Todd, S., Asmussen, S., & Phelan, J.C. (2001). Stigma as a barrier to recovery: the consequences of stigma for the self-esteem of people with mental illnesses. *Psychiatric Services*, 52(12), 1621-1626.

Marshall, S., Deana, F., Crowe, T., White, A., & Kavanagh, D. (2013). Carers' hope, wellbeing and attitudes regarding recovery. *Community Mental Health Journal*, 49(3), 344-353.

McCall, W.V., Dunn, A., & Rosenquist, P.B. (2004). Quality of life and function after electroconvulsive therapy. *British Journal of Psychiatry*, 185(5), 185-405.

McCann, T.V., Lubman, D.I., & Clark, E. (2011). First-time primary caregivers' experience accessing first-episode psychosis services. *Early Intervention in Psychiatry*,5(2), 156-162.

Morse, J. (2008). Editorial: Confusing categories and themes. *Qualitative Health Research*, 18, 727-728.

Neuman, W.L. (2011) *Social Research Methods: qualitative and quantitative approaches*. (7th edn) Boston, USA: Pearson/Allyn& Bacon.

Renouf, N. & Bland, R. (2005) Navigating stormy waters: Challenges and opportunities for social work in mental health. *Australian Social Work,* 58 (4), 419-430.

Ricard, N., Bonin, J.P., & Ezer, H. (1999). Factors associated with burden in primary caregivers of mentally ill patients. *International Journal of Nursing Studies*, 36(1), 73-83.

Rowe, J. (2012). Great expectations: a systematic review of the literature on the role of family carers in severe mental illness, and their relationships and engagement with professionals. *Journal of Psychiatric and Mental Health Nursing*, 19(1), 70-82.

Royal Australian and New Zealand College of Psychiatrists 2016, *Royal Australian and New Zealand College of Psychiatrists*, viewed 1 February 2017, <https://www.ranzcp.org/Mental-health-advice/Electroconvulsive-therapy-(ECT).aspx >.

Rubin, A., & Babbie, E.R. (2014). *Research methods for social work*. (8th edn), Belmont, CA: Brooks/Cole.

Sarantakos, S. (2013). *Social Research*. (4th edn). New York: Palgrave McMillan.

Sawyer, A-M., Stanford, S. & Campbell, J. (2016). Mental Health Social Work: Perspectives on Risk, Regulation, and Therapeutic Interventions. *Australian Social Work*, 69 (2), 129-132.

Sethi, S., & Williams, R.A. (2003). The Family Caregiving Experience of Outpatient ECT. *Journal of the American Psychiatric Nurses Association*, 9(6), 187-194.

Slade, M., Pinfold, V., Rapaport, J., Bellringer, S., Banerjee, S., Kuipers, E., & Huxley, P. (2007). Best practice when services users do not consent to sharing information with carers. *British Journal of Psychiatry*, 198(2), 148-155

Smith, M., Vogler, J., Zarrouf, F., Sheaves, C., & Jesse, J. (2009). Electroconvulsive therapy: the struggles in the decision-making process and the aftermath of treatment. *Mental Health Nursing*, 30(9), 554-559.

Strand, J., Olin, E., & Tidefores, I. (2015). Mental health professionals' views of the parents of patients with psychotic disorders: a participant observation study. *Health and Social Care in the Community*, 23(2), 141-149.

Teh SPC., Xiao AJG., Helmes E. & Drake DG. (2005).Electroconvulsive therapy practice in Western Australia. *Journal of ECT*, 21,145–150.

United Nations (2001). Principles for the protection of persons with mental illness and the improvement of mental health care: General Assembly Resolution 46/119. New York: United Nations.

Victorian Government, Department of Health and Human Services (January, 2016). *Chief Psychiatrist's Annual Report 2014-2015.* Retrieved 22nd April 2016. Available at www.health.vic.gov.au/chiefpsychiatrist.

Walter, M. (2013). *Social research methods*. (3rd ed) Oxford University Press: South Melbourne, Victoria.