Submitted in partial fulfilment of the Lancaster University Doctorate in Clinical Psychology

June 2016

Doctoral Thesis

Relatives' experiences of 'last resort' interventions for people with mental health difficulties

Kerry Irving

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Word Count

	Main Body	Appendices (including abstract, tables, figure and references)	Total
Thesis Abstract	228	n/a	228
Section 1. Literature Review	7,953	7,490	15,443
Section 2. Research Paper	7,989	14,736	22,725
Section 3. Critical Appraisal	4,000	233	4,233
Section 4. Ethics Form	4,668	6,492	11,160
Total	24,838	28,951	53,789

Thesis Abstract

The thesis entitled 'Relatives' experiences of 'last resort' interventions for people with mental health difficulties' explores how families experience the psychiatric hospitalisation of a relative and their treatment with electroconvulsive therapy (ECT).

Section one presents a meta-synthesis of 14 qualitative studies considering how families experience the psychiatric hospitalisation of a relative. The synthesis yielded six key concepts. Four concepts described the process that relatives experienced during the hospitalisation: (1) Seeking help is frustrating and overwhelming; (2) Conflicting emotions on admission; (3) Navigating the hospital environment; and (4) Reconceptualising and coming to terms with altered circumstances. The final two concepts influenced, and were perpetuated by, relatives' experiences: (5) The role of stigma; (6) Power, isolation and exclusion.

Section two presents a research study exploring how families experience their relatives' treatment with ECT. Six participants were interviewed and the data analysed using interpretative phenomenological analysis (IPA). Five overall themes were developed that capture participants' experiences of supporting their relative through the ECT process: (1) You take the treatment because the alternative is just horrific; (2) Professional power silences resistance from relatives; (3) Moving from emotional responses to pragmatic reasoning; (4) Relatives' struggle to find a role in the ECT process; and (5) ECT changes people and relationships.

Section three presents a critical appraisal of the research study, specifically focussing on the importance of researcher reflexivity in qualitative research.

Declaration

This thesis reports to research undertaken between August 2015 and June 2016 as part requirement of the Lancaster University Doctorate in Clinical Psychology. The work documented here is my own except where due reference has been made in the text. This thesis has not been submitted for an award of a higher degree elsewhere.

Signature:

Print name: Kerry Irving

Date:

Acknowledgements

Firstly, I wish to thank the participants who took part in the research study. It was a privilege to hear their stories and I hope that I can do them justice. I would like to thank my supervisors, Dr Suzanne Hodge and Dr Stephen Weatherhead, for their advice and guidance throughout the thesis process. I would also like to acknowledge my tutor, Dr Anna Daiches, for her encouragement throughout training.

I would like to thank my family and friends for their kind words and laughter over the years. I will be forever grateful to my parents, Graham and Leslie, who I cannot thank enough for their love and support and for believing in me unconditionally. I would also like to thank my husband, Andy, for his unwavering kindness, patience and encouragement throughout this process. Finally, to our beloved Grandma Maria who inspired us all every day; thank you for everything.

Contents

Relatives' experiences of psychiatric hospitalisation: a meta-synthesis

Kerry Irving

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Correspondence should be addressed to:

Kerry Irving

Doctorate in Clinical Psychology

Furness College

Lancaster University

Lancaster

LA1 4YG

Email: k.irving@lancaster.ac.uk

Written in accordance with author guidelines for The International Journal of Mental Health Nursing (see Appendix 1-A for author guidelines).

Abstract

The purpose of this paper was to identify and synthesize qualitative research exploring the relative's perspective on the psychiatric hospitalisation of their family member. A meta-ethnographic approach was used to synthesise qualitative research exploring relatives' experiences of psychiatric hospitalisation. A systematic search of four electronic databases was conducted. Fourteen eligible studies were identified and assessed for quality of reporting using the Critical Appraisal Skills Programme (CASP) guidelines. Data were extracted and synthesised using reciprocal translations analysis.

Six key concepts were identified and developed to form a model of relatives' experiences of the process of psychiatric hospitalisation. Four concepts described the chronological process that relatives experienced during the hospitalisation: (1) Seeking help is frustrating and overwhelming, (2) Conflicting emotions on admission, (3) Navigating the hospital environment, (4) Reconceptualising and coming to terms with altered circumstances. The final two overarching concepts influenced, and were perpetuated by, relatives' experiences of the process; (5) The role of stigma, (6) Power, isolation and exclusion.

The findings indicate the need for inpatient mental health services to build two-way relationships with families and carers. Services should aim to reduce the stigma associated with admission and should be aware of power imbalances experienced by families. Attempts should be made to minimise the exclusion of families. The emotional impact of caring for someone in inpatient mental health services must be acknowledged.

Keywords. family, relative, caregiver, psychiatric hospitalisation, mental health.

Introduction

Many people living with mental health difficulties may find themselves admitted to inpatient mental health services at some point during the course of their lives. From its origins in the seventeenth century as a socially stigmatising act to remove individuals from society, psychiatric hospitalisation has evolved to providing therapeutic input with an emphasis on recovery from distress (Foucault & Khalfa, 2006). Now the purposes of psychiatric hospital admissions are to provide a place of safety and care and to provide assessment and interventions (Bowers, 2005). However, inpatient services across Europe are considered poorly resourced, difficult to access and less acceptable to service users than community-based support (WHO, 2014). In a systematic review of 18 studies examining the outcomes of psychiatric hospitalisation, around a third of service users reported no benefit or feeling harmed by their psychiatric admission (Katsakou & Priebe, 2006). Service users identified a number of fundamental problems with psychiatric hospitalisation including restrictions to their autonomy, abuse of their human rights and risk of violence and coercion from powerful professionals (Katsakou & Priebe, 2007).

Given the flaws inherent within psychiatric hospitalisation, the focus of recent service developments across Western countries has been on moving away from long term institutionalisation to short term inpatient stays focusing on active treatment and rehabilitation (Csipke et al., 2013). This deinstitutionalisation began in earnest in the United States and the United Kingdom in the mid 1950's, with many Western European countries following suit within the last 50 years (Pedersen & Kolstad, 2009).

The process of deinstitutionalisation in the 20th century brought with it an increase in the influence of the family on negotiations with psychiatric institutions (Baur, 2013). More recently, this shift has been evident in the legal recognition of the role of nearest relative as

someone who can advocate for the best interests of the individual in services (Andoh & Gogo, 2004). The nearest relative role provides a safeguard against some negative aspects of psychiatric hospitalisation, such as restrictions of liberty and risk of abuse, by aiming to deter "abusive or inappropriate uses of institutional care" (Rapaport, 2004, p.379). Involving relatives in a person's care can empower the service user in decision making, increase feelings of connectedness and provide a valuable safeguard for the individual's rights (Perreualt et al., 1999). A study of service user's preferences during psychiatric hospitalisation found that the majority of service users expressed a wish to involve their relatives in discussions regarding their care and they reported dissatisfaction when their relatives were not consulted (Perreault et al., 1999).

Carr's (2009) review of family interventions in adult mental health services concluded that brief family interventions were effective for a range of mental health difficulties and could be implemented successfully in inpatient settings. Furthermore, active involvement and education of the family during crisis periods has been shown to reduce rates of rehospitalisation (Bustillo et al., 2001).

Despite the benefits of family involvement in inpatient mental health care, evidence suggests that it can be difficult to implement in practice. In a Swedish study of family involvement in inpatient care, over half of families reported not having sufficient involvement in their relatives' care and that their own support needs were not met (Ostman et al., 2000). Similar patterns were evident elsewhere including in Italy, where only 13% of relatives reported satisfaction with their level of involvement in the treatment of hospitalised family members (Gigantesco et al., 2002). A study by Rose et al. (2004) explored the barriers to implementing family involvement and found that families reported conflict with mental health professionals in inpatient services, citing a lack of understanding from staff members regarding the needs of the family. Healthcare professionals described feeling

unskilled when working with families and reported a lack of time and resources as barriers to implementing family involvement in practice (Rose et al., 2004).

Involving families in the care of people who are hospitalised may also bring with it challenges to the relatives' sense of wellbeing. The burden of caring for a family member often comes from having to give up leisure time, socialising and work in order to support a relative through hospitalisation (Ostman et al., 2000; Sales, 2003). Periods of crisis, including psychiatric hospitalisation, can be particularly distressing for relatives as they often experience inpatient wards as intimidating and feel anxious about their relatives' safety (Adeshokan et al., 2010). Families that experience high family burden have been shown to have higher rates of mental health difficulties themselves; therefore the burden of caring for a relative may increase vulnerability to personal mental health difficulties in family members (Ennis & Bunting, 2013).

A recent systematic review of the impact of psychiatric hospitalisation on caregivers reviewed 29 studies which used quantitative, qualitative and mixed-methods approaches and which had a specific focus on the outcomes of psychiatric hospitalisation for caregivers (Weller et al., 2015). The review found that the psychological wellbeing of carers was negatively affected by hospitalisation, with carers reporting feeling isolated, ashamed and confused. Furthermore, caregivers of people who were admitted to hospital reported higher levels of distress and personal mental health difficulties than family members of outpatient service users. The review also found that caregivers experienced disruption to their daily life and increased economic strain as a result.

Weller et al.'s (2015) review provides a comprehensive overview of the outcomes for caregivers following psychiatric hospitalisation of a relative, however they conclude that responses to hospitalisation are heterogeneous and therefore require further detailed

exploration. Given that this review focuses specifically on the outcomes of psychiatric hospitalisation, further exploration of the evidence regarding the experiences of relatives during the process may add to our understanding. Furthermore Weller et al.'s (2015) review includes just six qualitative studies, relying heavily on quantitative studies measuring distress and burden in caregivers through the use of structured psychometric tools. Their method of summarising both the quantitative and qualitative literature adopted an integrative approach concerned primarily with aggregation and summary of the data. Although this approach provides an overview of the impact on caregivers, it does not attempt to synthesise the findings to develop higher order theoretical concepts (Dixon-Woods et al., 2005).

This meta-synthesis is intended to address the shortcomings of the Weller et al. (2015) paper by providing an interpretive review of qualitative research exploring family and carer experiences of psychiatric hospitalisation.

Method

Noblit and Hare's (1988) seven step meta-ethnographic approach to synthesising qualitative research was chosen and is outlined in further detail in Table 1-A. Through the use of this method, it is possible to reduce, compare and translate different accounts into one another to reveal analogies between the accounts (Noblit & Hare, 1988). The advantages of such an approach include the ability to synthesise across qualitative literature whilst "preserving the interpretive properties of the primary data" (Dixon-Woods et al., 2005, p.48).

INSERT TABLE 1-A

Four online databases were searched to identify articles relevant to the meta-synthesis; these were PsycINFO, MEDLINE, the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and the Allied and Complementary Medicine Database

(AMED). Searches were limited by methodology to include focus groups, qualitative studies, interview and empirical studies. They were also limited to papers published in English, and in peer-reviewed journals. The search terms used to identify relevant studies were adapted from the Weller et al. (2015) review and expanded on where necessary in order to address discrepancies in the thesaurus search terms available across the four databases. Relevant search terms are outlined in Table 1-B and were searched for in the keywords, titles and abstracts of the articles. This resulted in the identification of 1,102 articles. Following the initial search, potentially relevant articles were identified based on the title (n=122) and the abstracts of these papers were then reviewed. The full texts of 38 potentially relevant papers were read and assessed against the inclusion/exclusion criteria.

INSERT TABLE 1-B

Inclusion/Exclusion Criteria

Only studies adopting a clear qualitative methodology were included. Studies were excluded from the synthesis if they related to hospital admissions for the primary reasons of physical health, intellectual disability, cognitive impairment, dementia, forensic admissions or admissions for substance addictions. Hospital admissions for individuals with a dual diagnosis can be highly complex and involve unique hospitalisation patterns (Lunsky & Balogh, 2010). Studies were also excluded if the relative or carer of the person admitted to hospital was under the age of 18 as there are particular and different issues affecting young people who have a caring role (Grant et al., 2008).

Ten studies met the inclusion criteria. Additional hand-searching of the reference lists highlighted a further four articles that met the inclusion criteria, resulting in a total of 14 studies. In accordance with guidelines of Preferred Reporting Items for Systematic Reviews

and Meta-Analyses (Moher et al., The PRISMA Group, 2009), a flowchart detailing the selection process of papers is included in Figure 1-A.

INSERT FIGURE 1-A

Quality Appraisal

A structured assessment of the quality of reporting was conducted for each of the 14 included studies, as recommended by the NHS Centre for Reviews and Dissemination (NHS CRD, 2001). Papers were not excluded from the review based on quality appraisal scores. This approach was justified on the basis that only the quality of reporting of each study could be accurately assessed, therefore it was not possible to assess the robustness and quality of the underlying research. Furthermore, the lack of consensus on the criteria for quality appraisal of qualitative research casts doubt on its reliability and therefore undermines the rationale for excluding potentially important studies on this basis (Dixon-Woods et al., 2005). Consequently, quality appraisals were conducted in order to support critical consideration of the studies included in the review and not to exclude papers.

The quality appraisal method was derived from Murray and Forshaw (2012) and is based on assessment of the studies using the Critical Appraisal Skills Programme (CASP, Public Health Resource Unit, 2006). The CASP checklist consists of ten questions designed to examine areas relevant to qualitative studies, such as the research design, ethical issues and value of the research. Using a three point rating scale developed by Duggleby et al. (2010), each study was given a score from one (weak) to three (strong) for each CASP item. The scores for each item were then combined to give a total CASP score for each study (Table 1-C). CASP scores ranged from 15 to 23 for studies included within this review, therefore the quality of reporting was generally of a moderate to strong level.

INSERT TABLE 1-C

Characteristics of Included Studies

Fourteen papers were included in the meta-synthesis (Crisanti, 2000; Clarke & Winsor, 2010; Geraghty et al., 2011; Gerson et al., 2009; Hallam, 2007; Hanson, 1995; Hickman et al., 2015; Jankovic et al., 2011; Rose, 1983; Scharer, 2000; Scharer & Jones, 2004; Ward & Gwinner, 2014; Wilkinson & McAndrew, 2008; and Wood et al., 2013). The papers were published between 1983 and 2015. Four of the papers used samples from the UK; four from America; three from Australia and three from Canada. Sample sizes ranged from three to 50 participants, with a mean sample size of 17. The family position of participants across the papers included parents, grandparents, siblings, spouses, aunts, stepfathers, foster parents and in-laws; however the majority of participants were mothers.

Seven of the studies used forms of thematic analysis, three used phenomenological analysis, one used content analysis and three used forms of grounded theory. Ten of the papers gathered data through face to face individual interviews; two used both individual interviews and focus groups and two collected data from written accounts. Further information on study characteristics is included in Table 1-D.

INSERT TABLE 1-D

The findings of the meta-synthesis are presented below.

Findings

Six key concepts identified through the synthesis are depicted in figure 1-B as a model of the experience of supporting a relative through the process of psychiatric hospitalisation. The first four concepts describe the process that relatives experienced chronologically: (1) Seeking help is frustrating and overwhelming, (2) Conflicting emotions

on admission, (3) Navigating the hospital environment, and (4) Reconceptualising and coming to terms with altered circumstances. Throughout this process, relatives' experiences were influenced by and perpetuated the final two concepts which represent two overarching components in Figure 1-B: (5) The role of stigma, and (6) Power, isolation and exclusion.

INSERT FIGURE 1-B

Seeking help is frustrating and overwhelming

The experience of seeking help for a relative prior to hospitalisation was discussed in six of the reviewed studies (Crisanti, 2000; Hallam, 2007; Hickman et al., 2015; Jankovic et al., 2011; Scharer & Jones, 2004; and Wood et al., 2013). Participants expressed frustration at the lack of preventative, community based services that may have helped to reduce the need for hospitalisation of their relative: "if there was more available for people it would maybe minimise the inpatient stay even further" (Wood et al., 2013, p.124). Many believed that the delays in getting help and reduced resources in community services often led to a deterioration of their relative's wellbeing beyond what they felt they could reasonably manage at home. In some cases, participants believed involuntary admission became necessary when it may otherwise have been avoided (Jankovic et al., 2011).

The absence of information in the pre-hospitalisation phase contributed to participants feeling out of control, overwhelmed and helpless (Hickman et al., 2015 & Jankovic et al., 2011). There was a sense that relatives were not offered the support that they needed to care for their loved one, which led to feelings of stress for the relative: "The lack of support for the carer in the immediate days could definitely be better because it's totally bewildering" (Hickman et al., 2015, p.5). There were some attempts made by participants to regain control of the situation by taking practical steps such as reading material about their loved one's mental health or taking time off work to be with them (Hickman et al., 2015). However,

participants continued to feel unprepared and unsupported: "they [staff] rely too heavily on families to get on with it, without giving them the support they need to do that" (Wood et al., 2013, p.124).

Participants described difficulties accessing inpatient care for their relative as the procedures for hospitalisation were unnecessarily and unreasonably difficult (Crisanti, 2000; Hallam, 2007; and Scharer & Jones, 2004), leaving them feeling "frustrated, bewildered and perplexed" (Crisanti, 2000, p.80). Participants often felt unheard by services with regards to the seriousness of their situation: "It took me years to try and get help for our son and nobody believed me" (Hallam, 2007, p.249). Many participants described being unable to get assistance from services until their loved one was in crisis or acting in a violent or aggressive manner towards others (Hallam, 2007; and Scharer & Jones, 2004). This meant that families were forced to manage great stress and burden without feeling able to secure the appropriate support for their family member: "We could not take him to hospital because he would not satisfy the criteria for commitment. I could not believe this. Our hands were tied" (Crisanti, 2000, p.80).

Conflicting emotions on admission

All of the 14 studies reviewed included stories of strong and often conflicting emotional responses from relatives when their loved ones were admitted to hospital. Families described admission to hospital as a traumatic yet necessary process (Clarke & Winsor, 2010; Gerson et al., 2009; Hanson, 1995; Scharer, 2000; and Scharer & Jones, 2004). Participants described feeling as though they had little choice but to hospitalise their loved one but stated that this was not an easy decision to make, despite them feeling unable to care for the person in the community. Participants described hospitalisation as a "last resort" (Scharer & Jones, 2004, p.89): "so to bring him here…I knew I had no other choice. But it was very traumatic

for both of us" (Scharer & Jones, 2004, p.89). Participants' use of emotive language to describe traumatic stories of admission give an idea of the difficulties that they faced during and after this process: "they had all these trucks and everything outside…everybody was screaming…I thought they might shoot or something like that. Her sister was saying, "don't hurt my sister"" (Gerson et al., 2009, p.813).

In the context of the challenges posed by the admission process it is perhaps unsurprising that the predominant emotion reported by participants was relief, which was explicitly evident in eight of the studies (Clarke & Winsor, 2010; Hallam, 2007; Hanson, 1995; Hickman et al., 2015; Jankovic et al., 2011; Scharer, 2000; Scharer & Jones, 2004 & Ward & Gwinner, 2014). Relief was often complicated by associated feelings of guilt or responsibility for the hospitalised person's situation. Participants reported that given the escalating behaviour of their family member prior to hospitalisation, their eventual admission brought relief from the crisis of managing the person at home: "It's a crisis in the fact that you have lost your child to the point that you can't do anything with her and you have to ask someone to help you out. And then it's [hospitalisation] a relief" (Scharer & Jones, 2004, p.87). This relief came at a price, with participants reporting a sense of having failed the person by virtue of them requiring hospitalisation, but at the same time they acknowledged tremendous relief at the admission: "in the end it was kind of relief that somehow you know neither of us had been harmed...I should have seen it…I felt guilty that I had let it get to that stage" (Jankovic et al., 2011, p.3).

Participants hoped their loved ones found sanctuary in hospital: "The mental health hospital is quite secure actually. So I was quite happy that he was there because it felt safe for us really. And that was a big fear because, you know, anything could happen to him" (Hickman et al., 2015, p.5). The concept of safety appeared important to relatives and some participants reported anxiety and fear about the security of their loved one in the hospital

(Scharer, 2000; and Geraghty et al., 2011). This fear could be contained by forming positive relationships with the hospital staff members in the first few days of the admission (Scharer, 2000).

Many participants expressed a sense of disconnection in response to the perceived trauma of the admission process and described feelings of disbelief and shock at having to leave their loved one at the hospital. A common response was that family members felt "lost" (Scharer, 2000, p.730) and they expressed sentiments such as "it's like…this is not happening" (Clarke & Winsor, 2010, p.244). Disconnection was also perceived by family members in relation to hospital staff and admission processes. Participants described the admission process as "impersonal" and likened it to "dropping the laundry off" (Hanson, 1995, p.533). These experiences contributed to their experience of admission as traumatic.

Navigating the hospital environment

As families come to terms with the conflicting emotions of admission, they begin a process of attempting to navigate the hospital environment. This process was evident in seven of the included studies (Geraghty et al., 2011; Hallam, 2007; Hanson, 1995; Rose, 1983; Scharer, 2000; Scharer & Jones, 2004; and Wood et al., 2013) and is best conceptualised as a three stage process: 1) managing expectations; 2) evaluating the reality and 3) grudging acceptance of the status quo.

Managing expectations

Participants' initial attempts to make sense of the hospital experience were heavily influenced by their prior expectations of what they would encounter (Rose, 1983; Scharer, 2000; and Scharer & Jones, 2004). These expectations were often influenced by media portrayals of psychiatric hospitals: "I guess I had visions of Jack Nicholson [in the movie

One flew Over the Cuckoos' nest] because I really didn't know" (Scharer, 2000, p.735; Rose, 1983). Expectations such as these provoked anxiety initially but appeared to result in participants feeling reassured when they realised that reality was not as they expected (Rose, 1983).

Some participants began the hospital process with optimistic expectations based on previous experiences of medical hospitals and were left confused or disappointed when they received different treatment. Participants expected clear information regarding treatment plans for their relatives, as they might expect if a loved one had attended medical hospital. However, the lack of clarity that they experienced with psychiatric hospitalisation was challenging for participants who began the process with this expectation (Rose, 1983).

Evaluating the reality

Following the initial relief of admission and the period of managing their expectations, participants then appeared to become increasingly aware of the difficulties within the service and began a period of evaluating the reality of the hospital environment (Hanson, 1995; Geraghty et al., 2011). Relationships with ward staff seemed to have a crucial role in relatives' experiences of the hospital environment. Participants described finding staff members condescending and distant towards them, which gave relatives the sense that they should go away. One participant was told, "You're calling too often. You're bothering the staff. Quit being a smother mother" (Hanson, 1995, p.535). Participants often experienced the staff as uncaring and critical (Hanson, 1995; Geraghty et al., 2011), however some participants found staff who made an effort to engage them and provide support. Despite this, many participants expressed concerns that the hospital environment was not therapeutic (Geraghty et al., 2011).

Grudging acceptance of the status quo

The final stage for relatives navigating the hospital experience appeared to involve an acceptance of the hospital environment as less than ideal but nonetheless the best option in the absence of appropriate alternatives (Hanson, 1995; Hallam, 2007). They described accepting what they perceived to be the bureaucracy of the hospitalisation system as an inevitable part of the experience: "that was my first experience with the system, or boxes. That's how I see it. The person is in a box and that box has a job description. This person is in their little box and maybe they're afraid they're going to step out of bounds and run into trouble with the other staff" (Hanson, 1995, p.536).

Participants described developing a grudging acceptance of the distance between themselves and the hospital and the lack of involvement or inclusion in their relatives' care. They describe their loved one "being swallowed up by the system" (Hanson, 1995, p.536) but felt unable to make any difference; therefore they began a process of watching and waiting from a distance. Despite the initial frustration and eventual apathy that occurred, participants appeared to justify their acceptance of the status quo through comparisons with less favourable alternatives to hospitalisation: "I think the alternatives are being dead or long-term jail sentence and in fact I don't think that jail is the right place" (Hallam, 2007, p.251).

Reconceptualising and coming to terms with altered circumstances

The final stage of relatives' experience of hospitalisation involves a process of reflecting on the meaning of the hospitalisation experience. Relatives described reconceptualising their situation and coming to terms with an altered future, both for themselves and for the person who had been in hospital (Clarke & Winsor, 2010; Crisanti, 2000; Rose, 1983; and Scharer & Jones, 2004). The first stage of this process involves relatives redefining the nature of their loved one's difficulties. Participants described reconceptualising behaviours as symptoms of an illness once the person was admitted to

hospital (Scharer & Jones, 2004; Rose, 1983). Participants' use of language such as "now that she's sick" indicated that they perceived a change in the situation following hospitalisation, perhaps reflecting the view within society that hospitals are equated with sickness (Rose, 1983, p.509).

The second stage of reconceptualising involves a process of self-evaluation on the part of the relative. Participants described examining their own behaviours in relation to the development of their loved ones' difficulties, leading some to take responsibility and blame for the situation: "I am too lenient with him…I'm probably a lot of the cause of his problems" (Rose, 1983, p.509). Evaluation of their past behaviour as ineffective or wrong led relatives to change the way they responded to the person following admission, with some participants reporting lower expectations of the person after hospitalisation. They also expressed concerns about how the family system would reorganise itself around the person following their hospitalisation (Rose, 1983; Scharer & Jones, 2004).

Finally, the hospitalisation of their relative often led participants to consider an altered future, bringing with it a sense of grief, loss and uncertainty (Clarke & Winsor, 2010; Crisanti, 2000; and Rose, 1983). Participants described a process of wondering what the future would be like for their relative and grieving for the loss of expectations they may have held previously: "you've lost the person, the expectations, the athletic guy, the pretty good marks, you know, he's got a future…you're losing your dreams of where he will be, of having a normal life…you're grieving for yourself but also grieving for them because you know that they realize…that their lives will be different" (Clarke & Winsor, 2010, p. 245). Relatives described beginning the hospitalisation with hope that the admission might make a difference but experiencing disappointment on discharge when the person is not considered "back to normal" (Rose, 1983, p.510). The lack of a cure or solution that may have been

expected during hospitalisation appeared to leave relatives with feelings of despair and uncertainty about the future (Rose, 1983).

The role of stigma

The role of stigma in the process of psychiatric hospitalisation was described explicitly in five of the included studies (Clarke & Winsor, 2010; Crisanti, 2000; Gerson et al., 2009; and Hickman et al., 2015) but was evident more subtly throughout all the studies. Stigma was perceived to be evident and influential across all of the involved systems, including at societal level, within services and also within families and individuals.

Participants' accounts highlighted the impact of societal stigma and the role that relatives may have had in perpetuating this, inadvertently or otherwise. Participants described making attempts to distance themselves or to conceal the hospitalisation of their relative: "there was so much stigma attached to [the hospital]…he said, I do not want you to tell anybody I'm here" (Clarke & Winsor, 2010, p.244). Examples such as these highlight the insidious nature of stigma in the hospitalisation process, as families perceive stigma in the wider system and respond by making attempts to conceal the admission, which in turn perpetuates the experience: "people tend to stigmatize people who are mentally ill…I'm kind of ashamed really, to tell somebody" (Gerson et al., 2009, p.814).

Relatives believed that old institutions "reinforced the stigma" around psychiatric hospitalisation and they described a preference for modern hospitals that resembled hotels (Wood et al., 2013, p.125). However some relatives felt that attempts to obscure the nature of psychiatric hospitals did not address stigmatising social attitudes: "If you're not ashamed of something, you call a spade a spade…I'm thinking about all this positive work that we are supposed to do to change people's views on mental health, and we aren't hiding it away" (Wood et al., 2013, p. 125).

The role of stigma was evident across the hospital service and participants described feeling "victimized" and "judged" by staff members as a result of the attitudes and beliefs held there (Crisanti, 2000, p.80-81). Relatives often felt that mental health professionals blamed them for their loved ones' difficulties or saw them as attempting to "get rid of the problem" (Crisanti, 2000, p.80) by seeking hospitalisation for them. It is evident throughout the process of hospitalisation outlined above that attitudes of family blaming are internalised by relatives and reinforce the idea that relatives hold some responsibility for their family member's difficulties.

Stigma within services also played a key role in influencing the reconceptualization of the future for the relative and the person who had been hospitalised. Staff attitudes reinforced societal stigma around mental health, with one relative reporting a staff member told them to "get used to it; he [family member] would be like this for the rest of his life" (Gerson et al., 2009, p.814). Relatives appeared to internalise these stigmatising messages, leading some to feel anger about their situation: "Now we have to deal with this 's' word [schizophrenia]…it's like oh, this is a dirty word…I'm going to be dealing with it for the rest of my life and I am angry" (Gerson et al., 2009, p.814.)

Participants themselves responded in a variety of ways to the hospitalisation of their relatives but some described their own internalised stigma, perceptions and judgements as influential in their interpretations of the situation (Gerson et al., 2009; and Hickman et al., 2015). It was suggested that whether or not a participant blamed their relative for their mental health difficulties influenced their beliefs about the role of hospitalisation generally (Hickman et al., 2015). Participants who took a non-blaming position appeared to view hospitalisation as a way of providing a place of safety for their relative. However participants that took a blaming approach, making statements such as "It's all self-inflicted I think",

tended to view hospitalisation as a way of hiding their relative from society (Hickman et al., 2015, p.4).

It is evident that the stigma surrounding psychiatric hospitalisation influences relatives' expectations of the experience and has a role in alienating families from staff teams, communities and even at times, the hospitalised individual. Families may enter this system with pre-existing beliefs or internalise the stigmatising messages from those around them, leading them to feel judged by others or ashamed of the psychiatric hospitalisation of their relative. Their attempts to hide or conceal the nature of the situation from others unfortunately appear to perpetuate the stigma.

Power, isolation and exclusion

Hospitalisation of their loved ones often left relatives feeling powerless, isolated and excluded (Crisanti, 2000; Clarke & Winsor, 2010; Geraghty et al., 2011; Gerson et al., 2009; Hallam, 2007; Hanson, 1995; Hickman et al., 2015; Jankovic et al., 2011; Ward & Gwinner, 2014; Wilkinson & McAndrew, 2008; and Wood et al., 2013). The experience of power, isolation and exclusion lay behind many of the major frustrations and challenges experienced by relatives in the process described above, most influentially in relation to how relatives attempt to make sense of and navigate their own role in the hospital system. Many of the participants' accounts emphasised feelings of powerlessness in relation to the perceived dominance and control of the hospital (Crisanti, 2000; Hallam, 2007; Hanson, 1995; Wilkinson & McAndrew, 2008; and Wood et al., 2013). There was a sense that the exchange of care from families to the hospital was a significant source of conflict for participants, which brought with it feelings of helplessness and inferiority: "It's like as soon as he enters the ward, they (professionals) take over; it's like I give up my son to their care…he's at their mercy" (Wilkinson & McAndrew, 2008, p.395). The language used by participants was

particularly emotive and indicative of the feelings of subjugation they experienced. Participants described the experience as "demeaning" (Crisanti, 2000, p.80) and the hospital as "the only game in town" (Hanson, 1995, p.537). It was noted that even the physical aspects of the hospital environment, such as locks and coded doors, enhanced the feeling of subordination of relatives and patients (Wood et al., 2013).

Many relatives assumed they had no rights within the hospital and those that did attempt to have their voices heard often feared alienating staff and being further excluded from future decision-making (Hanson, 1995; Hallam, 2007; and Wilkinson & McAndrew, 2008). The intrapersonal impact of being in a position of powerlessness was considerable for relatives: "I felt lost and helpless, and well…I just felt useless. I hated myself. I was a failure" (Wilkinson & McAndrew, 2008, p.395). Feeling isolated and excluded from the hospital and from their loved ones was a distressing yet common experience for participants (Clarke & Winsor, 2010; Geraghty et al., 2011; Gerson et al., 2009; Hallam, 2007; Hanson, 1995; Hickman et al., 2015; Jankovic et al., 2011; Ward & Gwinner, 2014; and Wilkinson & McAndrew, 2008). Families felt isolated by the perceived lack of information, support and acknowledgement given to them by hospital staff. Their experiences ranged from feeling frustrated at not receiving information (Geraghty et al., 2011) to feeling actively ignored by nursing staff: "I felt so alone…I had wanted to speak to someone about what was happening but when I tried I was told by the nurse that she couldn't speak to me, I should visit my doctor" (Wilkinson & McAndrew, 2008, p.396).

Relatives' experiences of being abruptly excluded from their loved one's life had an overwhelmingly negative impact on their emotional state. Participants described feeling disregarded, undervalued and disconnected (Ward & Gwinner, 2014; Hickman, et al., 2015) and described themselves as being kept in the dark (Gerson et al., 2009). Exclusion appeared to leave participants feeling like outsiders, which was difficult for them to accept:

"As soon as he was admitted to the ward I became a nobody, an outsider, but I'm not an outsider, I'm his mother!" (Wilkinson & McAndrew, 2008, p.396). The impact of exclusion was evident in participants' relationships with their loved ones, as relatives took some responsibility for the distance that had formed between them during the hospitalisation: "It broke our hearts because we felt as if we deserted him" (Ward & Gwinner, 2014, p.27).

The impact of exclusion on relatives' relationships with staff members was also expressed. Participants "gave up" (Wilkinson & McAndrew, 2008, p.396) trying to speak with the nursing staff and reluctantly accepted the belief that their help was not wanted or needed (Hanson, 1995). There was a sense that even if attempts were made to include relatives, for example inviting relatives to meetings or ward rounds, this was too often tokenistic and participants felt their input was not considered significant: "It felt more like, this is our [the health care team's] plan…it wasn't a joint decision…like it was a place to air concerns but it wasn't a place where decisions were going to be changed" (Clarke & Winsor, 2010; p.245). The impact of exclusion on relationships between relatives and staff appeared to be a lack of trust and a perception of incompetence on the part of the staff and services. Participants acknowledged that their initial sense of hospitalisation as a safe and containing process subsided as their feelings of exclusion increased and relatives began to feel let down by services (Hickman et al., 2015).

Relatives' experiences of power, isolation and exclusion were evident across their accounts as they attempted to find their role and position in relation to the psychiatric hospital. The reorganisation required by family members when a relative moved from their own family system to the new psychiatric system from which they felt excluded generated a significant challenge for relatives, both practically and emotionally. The challenges of attempting to navigate a level of involvement in their loved ones' care in the context of a dominant and potentially subjugating system contributed to the relatives' eventual apathy and

begrudging acceptance of the status quo of psychiatric hospitalisation.

Discussion

The meta-synthesis of 14 studies has highlighted six key concepts that have informed the development of a model of how families and carers experience the psychiatric hospitalisation of their relative (Figure 1-B). Four concepts describe the process that relatives go through during hospitalisation and the final two overarching concepts reflect the key factors that influence, and are influenced by, their experiences. These findings go some way towards improving our understanding of relatives' experiences of psychiatric hospitalisation and particularly how these experiences may lead to the distress and burden that has been found in previous research literature.

It was clear that families found the process of seeking help prior to admission to hospital overwhelming and they were often left feeling frustrated at the lack of community-based services when their relative did not meet criteria for admission. Thornicroft and Strathdee (1994) argue that the need for psychiatric beds is inversely related to the quality of community mental health services, which supports the view of relatives that poor community support increased the need for their family member's hospitalisation. Bridging the gap between the difficulties that families are expected to manage at home and those which require hospitalisation appears to be a difficult task in the era of deinstitutionalisation. The number of inpatient beds available has reduced across the major developed countries (Priebe, 2005) and inpatient hospitalisation is often only available to those most in need (Weich, 2008); therefore families are expected to care for relatives in increasingly more challenging levels of crisis. The behavioural difficulties, such as low motivation and the use of violence or substances, challenge families during these times and lead to increased psychological distress

and poor family functioning for relatives (Saunders, 2003). Families reported that caring for a relative in mental health crisis was "terrifying" due to the risk of aggression they faced but also as a result of feeling abandoned by services (Albert & Simpson, 2015).

Given the difficult context of many psychiatric hospitalisations, it is unsurprising that relatives in the studies reviewed initially experienced relief when their loved one was admitted; however this was often complicated by conflicting emotions such as guilt, fear and a sense of responsibility. Guilt is often reported by caregivers of people admitted to psychiatric hospital, with research suggesting that relatives reporting higher levels of guilt also reported higher levels of distress immediately following admission and in the longer term (Boye et al., 2002). Guilt has been identified as a factor that potentially contributes to distress (Ghatavi et al., 2002) and guilt is often described by people with a diagnosis of depression as a state experienced both through bodily feelings and overwhelming emotional experiences (Ratcliffe, 2010). The family members' experiences of guilt explored in this synthesis echo the experiences found in previous research into caregiver guilt and add to our understanding of the development of distress experienced by relatives of people in psychiatric hospital.

Following the admission stage, families then went through a process of navigating the hospital environment, which included considering their expectations of the hospitalisation, evaluating the reality in reference to this and reluctantly accepting the status quo as the best available intervention, given the lack of alternatives. Previous research has found that navigating mental health services can be a substantial challenge for carers, with one Australian study exploring this process with carers supporting relatives accessing community mental health services (Dawson et al., 2015). They found that carers who felt confident in their "mental health literacy" as a consequence of prior knowledge and personal connections felt more able to navigate services successfully and advocate for themselves and their relative

(Dawson et al., 2015, p.3). However, carers without these advantages had no clear guidance and were vulnerable to higher levels of distress (Dawson et al., 2015). This supports the findings that navigating the hospital service itself is a difficult challenge for many carers and it appears that those without prior knowledge or experience of services may be particularly disadvantaged.

Following hospitalisation, families described needing to redefine their situation based on the hospitalisation of their relative. Reconceptualising their loved one as 'sick' led to a process of self-evaluation and the consideration of an alternative future for themselves and their family, resulting in the experience of grief, loss and uncertainty. Families' experiences of grief in response to mental illness have been extensively studied in the research literature (Bland, 1998). It has been proposed that families experience grief because the onset of mental health difficulties often involves a perceived loss of their relative's personality, their role in the family and their hopes for the future, amongst many other significant losses (McGregor, 1994). Worden (1982) suggested a four stage grief process of adjusting to loss; accepting the reality of the loss, experiencing the pain of grief, adjusting to an environment in which the lost is missing and withdrawing emotional energy. These stages of grief correspond with the stages identified in this synthesis, as relatives moved from the pain of admission and accepting what it meant for their relative to be 'sick', through adjusting to the new system and finally withdrawing their emotional energy, which involved acceptance of the status quo and eventual apathy. It is evident that families experiencing psychiatric hospitalisation of a loved one are required to reconceptualise their situation and grieve for the losses involved.

The findings of the meta-synthesis show that one of the key factors influencing relatives' experiences of psychiatric hospitalisation is the role of stigma. Families experienced stigma in many of the systems around them, including in the community and

wider society, in inpatient services and within their own families. Often, stigmatising attitudes were internalised by relatives and the experience of stigma was connected with how participants made sense of the hospitalisation process. Stigma surrounding mental health difficulties is an ongoing issue (Rüsch, et al., 2005). In fact, recent anti-stigma campaigns focussing on a biological model of mental illness appear to have resulted in stagnant or even worsening public attitudes towards people with mental health difficulties (Schomerus et al., 2012). In addition to societal stigma, internalised self-stigma surrounding psychiatric hospitalisation has been found to correlate with poorer quality of life and reduced self-esteem for the hospitalised individual (Rüsch et al., 2013). Furthermore, stigmatising beliefs held within families tend to lead to distrust, avoidance and pity within relationships between relatives (Moses, 2010). The results of the current synthesis highlight the antagonistic effect that stigma can have on families experiencing psychiatric hospitalisation.

The final concept identified as influential in the hospitalisation experience was families feeling powerless, isolated and excluded from the hospital and from involvement in their relatives' care. This experience often left families feeling inferior and helpless as they struggled to find their role in the hospitalisation process. Power is inherent within the psychiatric hospitalisation process and explicit examples of how psychiatric hospitals exercise power include compulsory admissions, the use of restraint and seclusion and the adoption of locked wards (Roberts, 2005); however Foucault argued that more subtle exercises of power come from hospital staff constantly monitoring individuals (Foucault, 1991). The psychological impact on relatives of feeling powerless was notable throughout the findings of this synthesis. This is echoed in previous research, most notably regarding the learned helplessness theory, which suggests that feeling unable to control significant life events can lead to an increase in difficulties consistent with a diagnosis of depression (O'Leary et al., 1977). It is evident that the power dynamic between the psychiatric hospital

and the family has the potential to negatively influence relatives' own wellbeing and experience throughout the hospitalisation process.

Strengths

This review provides a synthesis of available qualitative research regarding relatives' experiences of psychiatric hospitalisation, which adds to our understanding of how this process may impact on relatives and carers. Although it is clear from Weller et al.'s (2015) review that caring for a hospitalised loved one can be distressing and involve a level of burden on the carer, the concepts identified here go some way towards explaining the processes and experiences behind that distress. The findings of the meta-synthesis are represented as a model of relatives' experiences of psychiatric hospitalisation that helps to enhance our understanding of the hospitalisation process as a whole. Thus the key strength of the synthesis lies in its ability to guide future research and clinical practice in the area of family involvement in psychiatric hospitalisation.

Limitations

The current meta-synthesis provides an overview of research from a number of countries, however because only English language studies could be included it is not possible to generalise these findings outside of these Western contexts. Furthermore, they cannot be generalised without caution to immigrant families living in Western countries as they may make sense of psychiatric hospitalisation differently and this has not been considered in the included studies (Littlewood & Dein, 2013). Consequently, when working with families where a member has been admitted to psychiatric hospital, healthcare professionals should be aware of both visible and invisible differences that may influence the way a family makes sense of that event in order to provide appropriate support (Burnham, 2013).

A further limitation of the meta-synthesis is that the studies included used different methodological approaches: seven studies used forms of thematic analysis, three used phenomenological analysis, one used content analysis and three used forms of grounded theory. The philosophical assumptions underlying each of these approaches are different and therefore the findings in each study will reflect these different assumptions, e.g. with some studies allowing for more author interpretation of the original data than others. Because the meta-ethnographic method used in the current synthesis involves translating both the participant data and the author interpretations in order to retain concepts from the original studies, the assumptions of the authors are inevitably brought into the current synthesis in varying degrees depending on the methodology adopted by the original studies.

Clinical Implications

The findings of the meta-synthesis indicate that families wish to be considered, involved and supported during the hospitalisation of their relative. The development of family-centred community services that can be accessed during crisis may help to provide support for relatives and carers as well as the individuals experiencing difficulties (Bickerton et al., 2014). Additionally, families have expressed a need for a revised understanding within inpatient services of what constitutes a crisis from the existing framework, where violent or suicidal behaviour is used as an indicator, to one where the wider impact of the crisis on the family and relationships is considered (Walter et al., 2006).

Families repeatedly described stigma, exclusion and frustration in inpatient mental health services, which led to mistrust of staff and feelings of hopelessness about their relatives' future. Addressing the breakdown of relationships between families and inpatient services may therefore have a positive impact on families, hospital staff and the individuals who are admitted and allow families to become the positive resource for recovery that they

express a wish to be. One example of an attempt to meet the needs of families in psychiatric hospital is described in Radcliffe et al. (2012). The nurse-led service developed a protocol of family intervention sessions to build relationships between staff and families and to address issues around exclusion, stigma and meeting the emotional needs of the family. Families who were involved reported a high level of satisfaction with the service and it was noted that the approach provided care, created a strong working alliance and improved the two-way exchange of information between staff and families.

Attempts to reduce the power imbalance evident between families and inpatient services have proven to be difficult to implement, however increased collaboration in planning family-focussed services may help to address this (Jubb & Shanley, 2002). Jubb and Shanley (2002) conducted a scoping exercise into the needs of a family involvement project, concluding that education and support for both families and staff was of importance in order to overcome historical ignorance regarding each other's roles. They also recommended that staff invite family members onto locked wards to assist in combating feelings of exclusion. Projects such as this may assist families by allowing them to have their voices heard in 'bottom-up' inpatient services that encourage collaboration in bringing about change to the traditional ways of working (Jubb & Shanley, 2002).

Conclusion

The meta-synthesis of 14 qualitative studies has provided a model of the experience of families and carers when their relative is admitted to psychiatric hospital. These findings indicate the need for inpatient mental health services to consider family interventions and family-centred services, with the aim of building two-way relationships with families and carers. A reduction in the stigma associated with admission should be a focus and inpatient staff members should be aware of power imbalances experienced by families, with attempts

made by services to minimise the exclusion of families from inpatient care. Professionals working with family members should consider and acknowledge the emotional impact of supporting someone in inpatient mental health services. The provision of information, support and opportunities for involvement should be provided for families in an attempt to address the difficulties identified.

References

Adeshokan, E., Radcliffe, J. & Bird, L., 2010. Meeting the needs of families and carers of acute psychiatric inpatients: a nurse-led family service. *British Journal of Wellbeing, 1*(4), pp. 31–34. doi:10.12968/bjow.2010.1.4.49169

Albert, R. & Simpson, A., 2015. Double deprivation: a phenomenological study into the experience of being a carer during a mental health crisis. *Journal of Advanced Nursing, 71*(12), pp. 2753–2762. doi:10.1111/jan.12742

Andoh, B. & Gogo, E., 2004. The nearest relative in mental health law. *Medicine, Science and the Law, 44*(2), pp. 140–150. doi:10.1258/rsmmsl.44.2.140

Baur, N., 2013. Family influence and psychiatric care: Physical treatments in Devon mental hospitals, c. 1920 to the 1970s. *Endeavour, 37*(3), pp. 172–183. doi:10.1016/j.endeavour.2013.06.005

Bickerton, A., Ward, J., Southgate, M. & Hense, T., 2014. The safety first assessment intervention: A whole family approach for young people with high risk mental health presentations. *Australian and New Zealand Journal of Family Therapy, 35*(2), pp. 150–168. doi:10.1002/anzf.1055

Bland, R., 1998. Understanding grief and guilt as common themes in family response to mental illness: Implications for social work practice. *Australian Social Work, 51*(4), pp. 27–34. doi:10.1080/03124079808411241

Bowers, L., 2005. Reasons for admission and their implications for the nature of acute inpatient psychiatric nursing. *Journal of Psychiatric and Mental Health Nursing, 12*(2), pp. 231–236. doi:10.1111/j.1365-2850.2004.00825.x

Boye, B., Bentsen, H. & Malt, U. F., 2002. Does guilt proneness predict acute and long-term distress in relatives of patients with schizophrenia? *Acta Psychiatr Scand, 106*(5), pp. 351–357. doi:10.1034/j.1600-0447.2002.02276.x

Burnham, J., 2013. Developments in Social GGRRAAACCEEESSS: visible-invisible, voiced-unvoiced. In I. Krause (Ed.), *Cultural Reflexivity*. London: Karnac.

Bustillo, J. R., Lauriello, J., Horan, W. P. & Keith, S. J., 2001. The psychosocial treatment of schizophrenia: An update. *American Journal of Psychiatry, 158*(2), pp. 163–175. doi:10.1176/appi.ajp.158.2.163

Carr, A., 2009. The effectiveness of family therapy and systemic interventions for adult-focused problems. *Journal of Family Therapy, 31*(1), pp. 46–74. doi:10.1111/j.1467-6427.2008.00452.x

Clarke, D. & Winsor, J., 2010. Perceptions and needs of parents during a young adult's first psychiatric hospitalization: "We're all on this little island and we're going to drown real soon". *Issues In Mental Health Nursing*, *31*(4), pp. 242-247. doi:10.3109/01612840903383992

Crisanti, A. S., 2000. Experiences with involuntary hospitalization: A qualitative study of mothers of adult children with schizophrenia. *Schizophrenia Research*, *45*(1-2), pp. 79-81. doi:10.1016/S0920-9964(99)00217-0

Csipke, E., Flach, C., McCrone, P., Rose, D., Tilley, J., Wykes, T. & Craig, T, 2013. Inpatient care 50 years after the process of deinstitutionalisation. *Soc Psychiatry Psychiatr Epidemiol, 49*(4), pp. 665–671. doi:10.1007/s00127-013-0788-6

Dawson, S., Gerace, A., Muir-Cochrane, E., O'Kane, D., Henderson, J., Lawn, S. & Fuller, J., 2015. Carers' experiences of accessing and navigating mental health care for older

people in a rural area in Australia. *Aging & mental health*, pp. 1-8. doi:10.1080/13607863.2015.1078283

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B. & Sutton, A., 2005. Synthesising qualitative and quantitative evidence: a review of possible methods. *Journal of Health Services Research and Policy, 10*(1), pp. 45-53. doi:10.1258/1355819052801804

Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C. & Williams, A., 2010. Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research, 20*(2), pp. 148–158. doi:10.1177/1049732309358329

Ennis, E. & Bunting, B. P., 2013. Family burden, family health and personal mental health. *BMC Public Health, 13*(1), pp. 255. doi:10.1186/1471-2458-13-255

Foucault, M., 1991. *Discipline and Punish.* London: Penguin.

Foucault, M. & Khalfa, J., 2006. *History of Madness*. London; New York: Routledge.

Geraghty, K., McCann, K., King, R. & Eichmann, K., 2011. Sharing the load: Parents and carers talk to consumer consultants at a child and youth mental health inpatient unit. *International Journal Of Mental Health Nursing, 20*(4), pp. 253-262. doi:10.1111/j.1447-0349.2011.00730.x

Gerson, R., Davidson, L., Booty, A., McGlashan, T., Malespina, D., Harold Alan Pincus, M. D. & Corcoran, C., 2009. Families' experience with seeking treatment for recent-onset psychosis. *Psychiatric Services, 60*(6), pp. 812-816. doi:10.1176/ps.2009.60.6.812

Ghatavi, K., Nicolson, R., MacDonald, C., Osher, S. & Levitt, A., 2002. Defining guilt in depression: a comparison of subjects with major depression, chronic medical illness and healthy controls. *Journal of Affective Disorders, 68*(2-3), pp. 307–315. doi:10.1016/s0165-0327(01)00335-4

Gigantesco, A., Picardi, A., Chiaia, E., Balbi, A. & Morosini, P., 2002. Patients' and relatives' satisfaction with psychiatric services in a large catchment area in Rome. *European Psychiatry, 17*(3), pp. 139–147. doi:10.1016/s0924-9338(02)00643-0

Grant, G., Repper, J. & Nolan, M., 2008. Young people supporting parents with mental health problems: experiences of assessment and support. *Health & Social Care in the Community, 16*(3), pp. 271–281. doi:10.1111/j.1365-2524.2008.00766.x

Hallam, L., 2007. How involuntary commitment impacts on the burden of care of the family. *International Journal Of Mental Health Nursing, 16*(4), pp. 247-256. doi:10.1111/j.1447-0349.2007.00474.x

Hanson, J. G., 1995. Families' perceptions of psychiatric hospitalization of relatives with a severe mental illness. *Administration And Policy In Mental Health, 22*(5), pp. 531-541. doi:10.1007/BF02106537

Hickman, G., Newton, E., Fenton, K., Thompson, J., Boden, Z. V., & Larkin, M., 2015. The experiential impact of hospitalisation: Parents' accounts of caring for young people with early psychosis. *Clinical Child Psychology And Psychiatry, 21*(1), pp. 145–155. doi:10.1177/1359104515581716

Jankovic, J., Yeeles, K., Katsakou, C., Amos, T., Morris, R., Rose, D. & Priebe, S., 2011. Family caregivers' experiences of involuntary psychiatric hospital admissions of their relatives — a qualitative study. *Plos ONE, 6*(10), doi:10.1371/journal.pone.0025425

Jubb, M. & Shanley, E., 2002. Family involvement: The key to opening locked wards and closed minds. *International Journal of Mental Health Nursing, 11*(1), pp. 47–53. doi:10.1046/j.1440-0979.2002.00225.x

Katsakou, C. & Priebe, S., 2006. Outcomes of involuntary hospital admission - a review. *Acta Psychiatr Scand, 114*(4), pp. 232–241. doi:10.1111/j.1600-0447.2006.00823.x

Katsakou, C. & Priebe, S., 2007. Patient's experiences of involuntary hospital admission and treatment: A review of qualitative studies. *Epidemiologia e Psichiatria Sociale, 16*, pp. 172-178 doi:10.1017/S1121189X00004802

Littlewood, R. & Dein, S., 2013. The doctor's medicine and the ambiguity of amulets: life and suffering among Bangladeshi psychiatric patients and their families in London–an interview study–1. *Anthropology & Medicine, 20*(3), pp. 244-263. doi: 10.1080/13648470.2013.827427

Lunsky, Y. & Balogh, R., 2010. Dual diagnosis: A national study of psychiatric hospitalization patterns of people with developmental disability. *Canadian Journal of Psychiatry, 55*(11), pp. 721. doi: 10.1177/070674371005501106

McGregor, P., 1994. Grief: The unrecognised parental response to mental illness in a child. *Social Work, 39*(2), pp. 160-166. doi: 10.1093/sw/39.2.160

Moher, D., Liberati, A., Tetzlaff, J. & Altman D. G. The PRISMA Group., 2009. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine, 6*(6). doi: 10.3410/f.2352956.1980054

Morse, J. & Field, P., 1995. *Qualitative research methods for health professionals.* (2nd ed.). London: Chapman & Hall.

Moses, T., 2010. Being treated differently: Stigma experiences with family, peers, and school staff among adolescents with mental health disorders. *Social Science & Medicine, 70*(7), pp. 985–993. doi:10.1016/j.socscimed.2009.12.022

Murray, C. D. & Forshaw, M. J., 2012. The experience of amputation and prosthesis use for adults: a metasynthesis. *Disability and Rehabilitation, 35*(14), pp. 1133–1142. doi:10.3109/09638288.2012.723790

NHS Centre for Reviews and Dissemination, 2001. Undertaking systematic reviews of research on effectiveness: CRDs guidance for those carrying out or commissioning reviews. *CRD Report Number 4 (2nd ed).* York: NHS CRD.

Noblit, G. & Hare, R., 1988. *Meta-ethnography: synthesizing qualitative studies.* Newbury Park, California: Sage.

O'Leary, M. R., Donovan, D. M., Cysewski, B. & Chaney, E. F., 1977. Perceived locus of control experienced control, and depression: A trait description of the learned helplessness model of depression. *Journal of Clinical Psychology*, *33*(S1), pp. 164-168. doi: 10.1002/1097-4679(197701)

Ostman, M., Hansson, L. & Andersson, K., 2000. Family Burden, Participation in Care and Mental Health - an 11-Year Comparison of the Situation of Relatives To Compulsorily and Voluntarily Admitted Patients. *International Journal of Social Psychiatry, 46*(3), pp. 191–200. doi:10.1177/002076400004600305

Pedersen, P. B. & Kolstad, A., 2009. De-institutionalisation and trans-institutionalisation - changing trends of inpatient care in Norwegian mental health institutions 1950-2007. *International Journal of Mental Health Systems, 3*(1), pp. 28. doi:10.1186/1752-4458-3-28

Perreault, M., Paquin, G., Kennedy, S., Desmarais, J. & Tardif, H., 1999. Patients' perspective on their relatives' involvement in treatment during a short-term psychiatric hospitalization. *Social psychiatry and psychiatric epidemiology*, *34*(3), pp. 157-165. doi: 10.1007/s001270050128

Priebe, S., 2005. Reinstitutionalisation in mental health care: comparison of data on service provision from six European countries. *BMJ, 330*(7483), pp. 123–126. doi:10.1136/bmj.38296.611215.ae

Public Health Resource Unit., 2006. Critical Appraisal Skills Unit (CASP): Making sense of evidence. England: Public Health Resource Unit. Available at http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf. Accessed 1st November 2015.

Radcliffe, J. J. L., Adeshokan, E. O., Thompson, P. C. & Bakowski, A. J., 2012. Meeting the needs of families and carers on acute psychiatric wards: a nurse-led service. *Journal of Psychiatric and Mental Health Nursing, 19*(8), pp. 751–757. doi:10.1111/j.1365-2850.2012.01932.x

Rapaport, J., 2004. A matter of principle: the nearest relative under the Mental Health Act 1983 and proposals for legislative reform. *Journal of Social Welfare and Family Law, 26*(4), pp. 377–396. doi:10.1080/0964906042000323471

Ratcliffe, M., 2010. Depression, guilt and emotional depth. *Inquiry, 53*(6), pp. 602–626. doi:10.1080/0020174x.2010.526324

Roberts, M., 2005. The production of the psychiatric subject: power, knowledge and Michel Foucault. *Nursing Philosophy, 6*(1), pp. 33–42. doi:10.1111/j.1466-769x.2004.00196.x

Rose, L. E., 1983. Understanding mental illness: the experience of families of psychiatric patients. *Journal of Advanced Nursing, 8*(6), pp. 507-511. doi:10.1111/j.1365-2648.1983.tb00478.x

Rose, L. E., Mallinson, R. K. & Walton-Moss, B., 2004. Barriers to family care in psychiatric settings. *Journal of Nursing Scholarship, 36*(1), pp. 39–47. doi:10.1111/j.1547-5069.2004.04009.x

Rüsch, N., Angermeyer, M. C. & Corrigan, P. W., 2005. Mental illness stigma: Concepts, consequences, and initiatives to reduce stigma. *European Psychiatry, 20*(8), pp. 529–539. doi:10.1016/j.eurpsy.2005.04.004

Rüsch, N., Müller, M., Lay, B., Corrigan, P. W., Zahn, R., Schönenberger, T. & Rössler, W., 2013. Emotional reactions to involuntary psychiatric hospitalization and stigma-related stress among people with mental illness. *European Archives of Psychiatry and Clinical Neuroscience, 264*(1), pp. 35–43. doi:10.1007/s00406-013-0412-5

Sales, E., 2003. Family burden and quality of life. *Quality of life research, 12*(1), pp. 33-41. doi:10.1023/A:1023513218433

Saunders, J. C., 2003. Families living with severe mental illness: A literature review. *Issues in Mental Health Nursing, 24*(2), pp. 175–198. doi:10.1080/01612840305301

Scharer, K., 2000. Admission: A crucial point in relationship building between parents and staff in child psychiatric units. *Issues In Mental Health Nursing, 21*(8), pp. 723-744. doi:10.1080/016128400750044242

Scharer, K. & Jones, D. S., 2004. Child psychiatric hospitalization: The last resort. *Issues In Mental Health Nursing, 25*(1), pp. 79-101. doi:10.1080/01612840490249028-25

Schomerus, G., Schwahn, C., Holzinger, A., Corrigan, P. W., Grabe, H. J., Carta, M. G. & Angermeyer, M. C., 2012. Evolution of public attitudes about mental illness: a systematic review and meta-analysis. *Acta Psychiatrica Scandinavica, 125*(6), pp. 440–452. doi:10.1111/j.1600-0447.2012.01826.x

Thornicroft, G. & Strathdee, G., 1994. How many psychiatric beds? *BMJ, 309*(6960), pp. 970–971. doi:10.1136/bmj.309.6960.970

VanKaam, A., 1969. *Existential Foundations of Psychology.* Doubleday: New York.

Walter, U. M., Petr, C. G. & Davis, S., 2006. Informing best practices for children in psychiatric crises: Perspectives and insights from families. *Families in Society: The Journal of Contemporary Social Services, 87*(4), pp. 612–620. doi:10.1606/1044-3894.3578

Ward, L. & Gwinner, K., 2014. 'It broke our hearts': Understanding parents' lived experiences of their child's admission to an acute mental health care facility. *Journal Of Psychosocial Nursing And Mental Health Services*, *52*(7), pp. 24-29. doi:10.3928/02793695-20140324-02

Weich, S., 2008. Availability of inpatient beds for psychiatric admissions in the NHS. *BMJ, 337*(2), pp. 1561-1561. doi:10.1136/bmj.a1561

Weller, B. E., Faulkner, M., Doyle, O., Daniel, S. S. & Goldston, D. B., 2015. Impact of patients' psychiatric hospitalization on caregivers: A systematic review. *Psychiatric Services, 66*(5), pp. 527–535. doi:10.1176/appi.ps.201400135

World Health Organisation., 2014. Data and statistics. Retrieved March 12, 2016, from http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/data-and-statistics

Wilkinson, C. & McAndrew, S., 2008. 'I'm not an outsider, I'm his mother!'A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings. *International journal of mental health nursing*, *17*(6), pp. 392-401. doi: 10.1111/j.1447-0349.2008.00574.x

Wood, V. J., Curtis, S. E., Gesler, W., Spencer, I. H., Close, H. J., Mason, J. & Reilly, J. G., 2013. Creating 'therapeutic landscapes' for mental health carers in inpatient settings: A dynamic perspective on permeability and inclusivity. *Social Science & Medicine,* 91, pp. 122–129. doi:10.1016/j.socscimed.2012.09.045

Worden, J., 1982. *Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner.* New York: Springer.

Yin, R., 1984. *Case Study Research: Design and Methods.* Newbury Park, California: Sage.

Table 1-A. Noblit and Hare's (1988) seven step meta-ethnographic approach to synthesising qualitative research

Step	Description of the step as applied in this meta-synthesis
(1) Getting started	This phase involved identifying an area of interest within the qualitative literature that justified synthesis. Qualitative studies examining experiences of caring for a relative in psychiatric hospital fulfilled the brief proposed by Yin (1984, p.13) that the focus of synthesis should be on "a contemporary phenomenon within some real-life context".
(2) Deciding what is relevant to the initial interest	Phase two involved justifying and identifying a list of studies to be included in the synthesis. Studies were selected for inclusion if they explored how adult relatives and carers experienced the psychiatric hospitalisation of a family member.
(3) Reading the studies	Phase three of the meta-ethnographic approach involved the repeated reading of and familiarisation with the 14 included studies. During this phase, key metaphors, themes and concepts from each study were noted. These notations included both participant quotes and the authors' accounts of these so that the original interpretations and the "sense of the account" given by authors could be preserved (Noblit & Hare, 1988, p.13).

(4) Determining how the studies are related	This phase involved determining the relationships between the studies by combining the key metaphors, phrases and concepts from each study. The notations that had been extracted from each study were listed and compared in order to explore the relationships between one another.
(5) Translating the studies into one another	The translational phase maintains the central concepts in each study whilst also comparing these concepts and interactions with similar ideas across the set of studies. In this phase, the key themes and concepts extracted from each study were translated into each other so that themes or concepts that were similar across studies were combined.
(6) Synthesizing translations	This phase focussed on synthesizing the concepts in order to make "the whole into something more than the parts alone imply" (Noblit & Hare, 1988, p.28). During this phase, concepts that were similar across the studies were interpreted and developed to form six overarching concepts. Four of these concepts explored how relatives experienced the process of psychiatric hospitalisation and two concepts described the psychological experiences that both influenced and were maintained by their experience of psychiatric hospitalisation.
(7) Expressing the synthesis	The findings of the meta-synthesis were presented.

Table 1-B. Database search terms used to identify relevant literature.

	1. Family and Carer terms (combined with OR)	2. Psychiatric Hospitalisation terms (combined with OR)
Search results from Column 1 (Family and carer terms) and from Column 2 (Psychiatric Hospitalisation terms) were combined using AND	Family Biological Family Extended Family Family of Origin Stepfamily Family Member Parent Sibling Son Spouse Daughter Stepchild* Grandchild* Grandparent Foster Child* Adult Offspring Cousin Caregiver	Hospitali*ation Commitment (Psychiatric) Hospital Admission Psychiatric Hospitali*ation Hospitali*ed Patients Involuntary Treatment Psychiatric Patients Psychiatric Units Psychiatric Hospitals Psychiatric Hospital Admission Psychiatric Hospital Readmission Psychiatric Hospital Discharge

Table 1-C. Critical appraisal of study quality using the CASP qualitative appraisal tool.

Study	Research Design	Sampling	Data Collection	Reflexivity	Ethical Issues	Data Analysis	Findings	Value of Research	Total
Clarke and Winsor	3	3	3	2	1	3	3	3	21
Crisanti	3	3	2	1	2	1	2	2	16
Geraghty et al.	3	3	2	1	3	3	3	3	21
Gerson et al.	3	3	3	1	2	2	2	3	19
Hallam	3	2	3	1	2	3	2	3	19
Hanson	2	2	2	1	1	1	3	3	15
Hickman et al.	3	3	3	2	2	3	3	3	23
Jankovic et al.	3	3	3	1	3	3	3	3	22
Rose	3	2	3	1	1	1	2	3	16
Scharer	3	3	3	2	3	3	2	3	22
Scharer and Jones	3	3	3	2	2	3	3	3	22
Ward and Gwinner	2	3	1	1	2	2	2	3	16
Wilkinson and McAndrew	3	3	3	2	3	3	3	3	23
Wood et al.	3	2	2	2	2	2	2	3	18

Columns 2-9 relate to items 3-10 taken from the CASP checklist. Scores are given as follows -
Weak = 1, Moderate = 2, Strong = 3

Table 1-D. Summary information of the papers selected for the meta-synthesis.

Study	Research Question	Methodology	Participants
Clarke and Winsor	To examine the impact of a young person's (YP) first hospitalisation on his or her parents and to determine the parents' perspectives on their own emotional and practical support needs.	Analysis based on Morse and Field's four stages of qualitative analysis (1995). Face-to-face (FTF) semi-structured interviews.	Sample size: n=10. Age: 40-59. 9 mothers, 1 father of young adults admitted to psychiatric hospital. Setting: local support group for families of YP with a diagnosis of psychotic illness. Canada.
Crisanti	To describe mothers' experiences with the involuntary hospitalisation of their adult child suffering from schizophrenia.	Phenomenological analysis posed by vanKaam (1969). FTF, open-ended interviews.	Sample size: 3. All mothers who had attempted to commit their sons (n=2) or daughter (n=1) to hospital. Setting: Calgary Chapter of the Schizophrenia society of Alberta. Canada.
Geraghty et al.	To investigate how parents use a consumer consultant support service in an inpatient child and YP mental health service and to identify themes in consultations to understand how parents use peer support.	Qualitative content analysis of records of 26 consultancies provided to parents and carers of children who were inpatients.	Sample size: 50 parents/carers of children admitted to a child and YP mental health inpatient unit. 41 parents (both parents or mother only), 5 fathers only, 7 grandparents and 3 siblings. Setting: Child and youth mental health inpatient service. Australia.
Gerson et al.	To understand the experiences of families seeking treatment for YP with recent onset psychosis	Unspecified form of thematic analysis. Open-ended FTF interviews.	Sample size: 14. 9 mothers, 3 fathers, 1 brother, 1 aunt. All were carers of YP (aged 16 to 24) who were inpatients at the time of interview. Setting: New York State Psychiatric Institute.

Hallam	To explore how involuntary commitment under the mental health act impacts on family members of people with mental illness.	Thematic analysis. Focus groups (2 focus groups with 6 participants in each) and 1 individual interview. Semi-structured.	Sample size: 13. Setting: mental health carer support groups and inpatient services. Australia.
Hanson	To report the experience of psychiatric inpatient care of families with mentally ill relatives.	Ethnographic methods using FTF interviews as primary data (9 individual interviews, 26 seen in unspecified number of focus groups)	Sample size: 34. 20 mothers, 9 fathers, 1 child, 2 wives, 2 sisters and 1 in-law. 26 of their family members with mental illness were male. Setting: Support group Alliance for the Mentally Ill (AMI). America.
Hickman et al.	To examine the experiential impact of hospitalisation on the parents of YP with early psychosis.	Interpretative phenomenological analysis. Semi-structured, FTF interviews.	Sample: 6. 4 mothers, 2 fathers. 4 parents were employed full/part time, 1 unemployed and 1 retired. All considered themselves full-time carers. Setting: Midland Early Intervention Service (EIS) and 2 mental health hospitals.
Jankovic et al.	To explore family caregivers' experience of involuntary admission of their relative.	Thematic analysis. FTF interviews.	Sample size: 31. 19 female and 12 male carers. 16 parents, 7 partners, 4 siblings, 2 children, 1 grandmother and 1 elderly relative. Setting: 12 NHS hospitals across England.
Rose	To elicit the family's perspective of their experience of the first hospitalisation of a relative.	Constant comparative analysis. Participants were interviewed FTF on 2 occasions.	Sample size: 7. Setting: 2 acute care psychiatric hospitals in a large metropolitan area. Canada.

Scharer	To describe and explain the relationships between parents and nursing staff in inpatient and day hospital settings during short-term hospitalisation.	Grounded theory. Individual, FTF interviews with parents and staff members.	Sample size: 12. 9 biological parents, 1 foster parent and 2 grandparents who were legal guardians. Age: 26-62, mean age: 42. Employment: full time (n=7), part time (n=2) and in home (n=3). Race: Caucasian (n=9), African-American (n=2) and Latino (n=1). Marital status: Divorced (n=5), married (n=3), remarried (n=3) and single (n=1). Setting: 2 child psychiatry units, 1 inner city and 1 suburban. America.
Scharer and Jones	To describe how parents manage the experience of hospitalising their school-aged child in a psychiatric unit.	Grounded theory. One-time, FTF interviews.	Sample size: 38. 22 mothers, 5 fathers, 2 foster mothers, 4 grandmothers, 1 grandfather, 2 stepfathers and 2 male significant others. Age: 26-73, mean age: 39. Race: European-American (n=24), African-American (n=13) and Hispanic (n=1). Marital status: married (n=9), divorced (n=2), separated (n=3), never married (n=3), remarried (n=8), widowed (n=1) and with significant other (n=3). Setting: 1 public child psychiatric hospital and 1 private, not-for-profit child psychiatric unit. America.
Ward and Gwinner	To evaluate the findings of a program designed to support parents	Thematic analysis. Open- ended questionnaire completed by	Sample size: 10. Age: 34-56. 4 men, 6 women. All were parents of YP (age

	caring for their child who was recently admitted to a psychiatric inpatient care unit (PICU).	participants.	17-20) recently admitted to PICU. Setting: PICU, Australia.
Wilkinson and McAndrew	To explore the perceived level of involvement from the perspective of carers of service users who were admitted to acute inpatient settings within the previous 2 years.	Interpretative phenomenological analysis. FTF interviews (n=3) and interview via the internet, converted to a text document (n=1).	Sample size: 4. 2 mothers, 2 spouses. Age: 31-56. All carers lived with the service user. Setting: Carers centres and carer support groups. England.
Wood et al.	To explore carers' views of aspects of the hospital environment which are important for the wellbeing of carers and the people they look after.	Thematic analysis. FTF focus groups prior to moving to a new hospital, plus follow up individual interviews with 2 of those carers after the move.	Sample size: 11. 7 female, 4 male. All were immediate family members of inpatients. Setting: an old hospital and a new hospital (both NHS) in a mid-sized industrial town in Northern England.

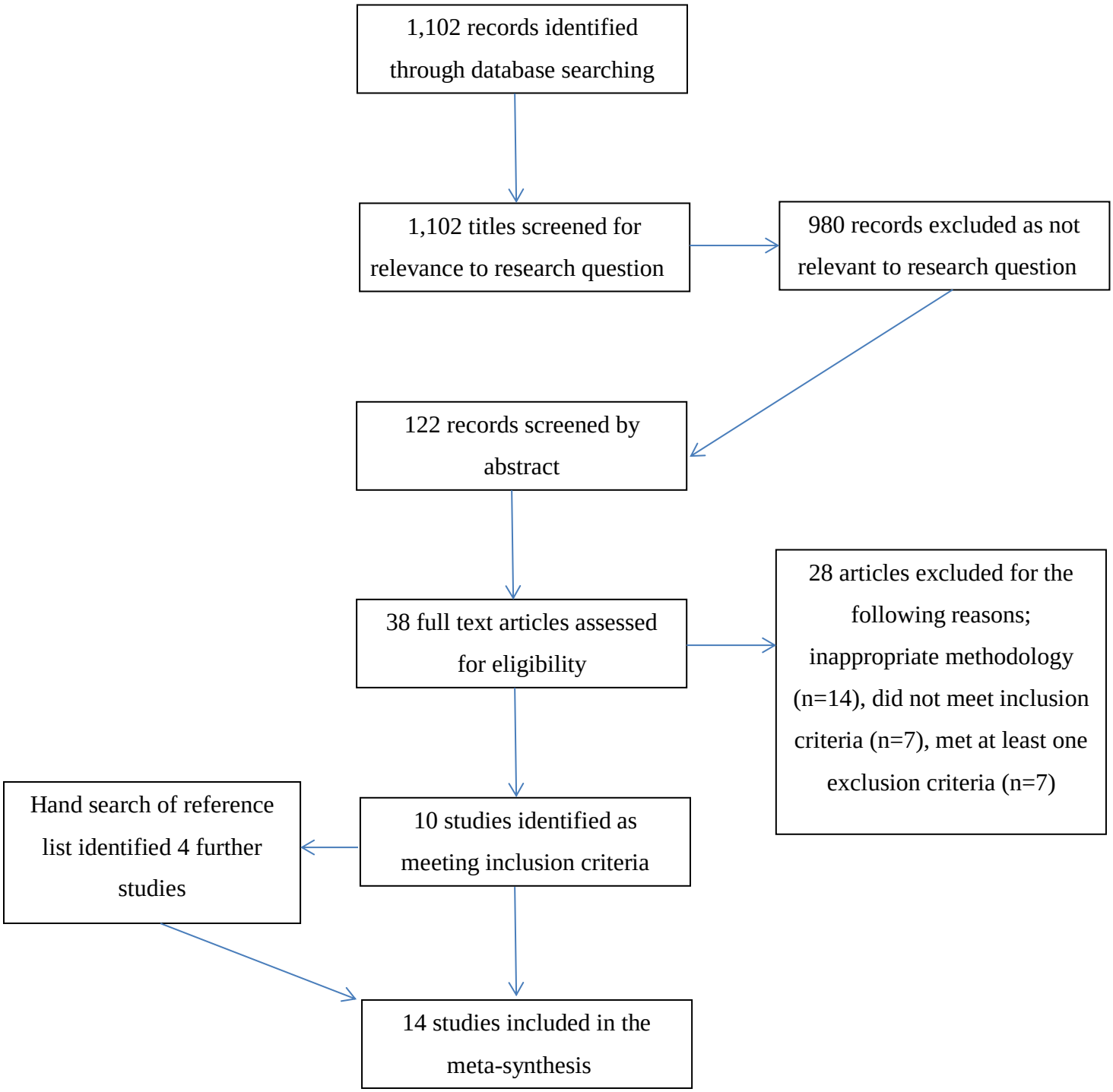

Figure 1-A**.** PRISMA flow diagram for inclusion of papers in the meta-synthesis.

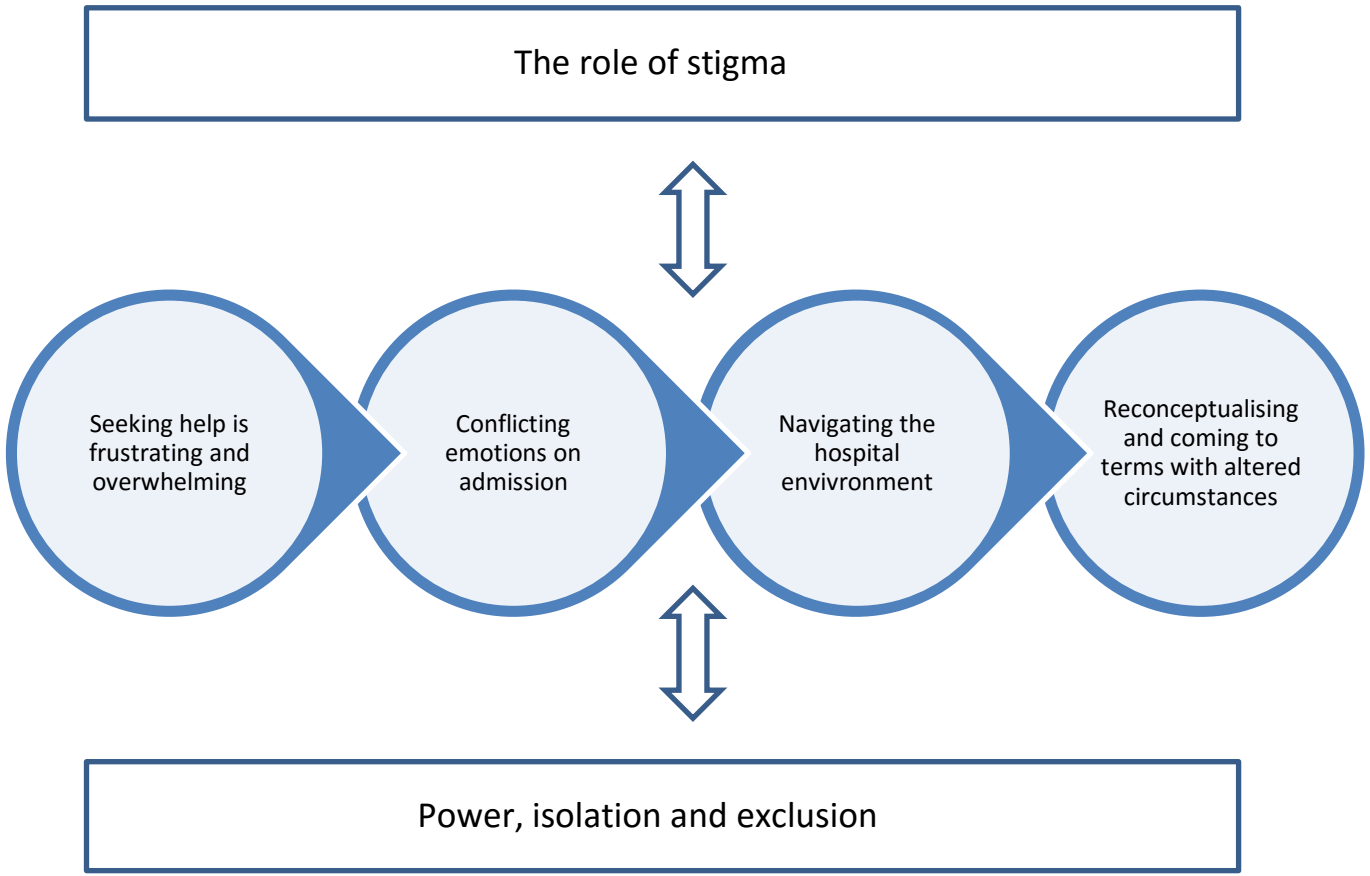

Figure 1-B. Diagrammatic representation of the relationships between the six concepts identified in the meta-synthesis.

Appendix 1-A

Author Guidance

MANUSCRIPT SUBMISSION

Thank you for your interest in International Journal of Mental Health Nursing. Please read the complete Author Guidelines carefully prior to submission, including the section on copyright. To ensure fast peer review and publication, manuscripts that do not adhere to the following instructions will be returned to the corresponding author for technical revision before undergoing peer review.

Note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium. Once you have prepared your submission in accordance with the Guidelines, manuscripts should be submitted online at http://mc.manuscriptcentral.com/ijmhn

We look forward to your submission.

EDITORIAL CONSIDERATIONS

Aims and Scope
The International Journal of Mental Health Nursing (IJMHN) is the official English journal of the Australian College of Mental Health Nurses Inc. The Editors welcome original articles dealing with current trends and developments in mental health nursing. The Editors are also looking for papers that will be widely read and cited, thereby having an international impact on mental health nursing education, practice and research. Papers submitted should be relevant to the Aims and Scope of the IJMHN and written in a manner that makes the relevance of content clear for IJMHN's international readership.

Review and Acceptance
The acceptance criteria for all papers are the quality and originality of the research and its significance and transferability to our readership. Except where otherwise stated, manuscripts are peer reviewed by two anonymous reviewers and the Editor. The Editorial Board reserves the right to refuse any material for publication and advises that authors should retain copies of submitted manuscripts and correspondence as material cannot be returned. Final acceptance or rejection rests with the Editorial Board. There is no process of appeal against rejection and no further correspondence will be entered into regarding rejection decisions.

Manuscripts should be written so that they are intelligible to the professional reader who is not a specialist in the particular field. Where contributions are judged as acceptable for publication on the basis of scientific content, the Editor or the Publisher reserve the right to modify typescripts to eliminate ambiguity and repetition and improve communication between author and reader.

ETHICAL CONSIDERATIONS

Principles for Publication of Research Involving Human Subjects
Manuscripts must contain a statement to the effect that all human studies have been reviewed by

the appropriate ethics committee and have therefore been performed in accordance with the ethical standards laid down in an appropriate version of the Declaration of Helsinki (as revised in Brazil 2013), available at http://www.wma.net/en/30publications/10policies/b3/index.html. It should also state clearly in the text that all persons gave their informed consent prior to their inclusion in the study. Details that might disclose the identity of the subjects under the study should be omitted.

All investigations on human subjects must include a statement that the subject gave informed consent and patient anonymity should be preserved. In general, submission of a case report should be accompanied by the written consent of the subject (or parent/guardian) prior to publication; this is particularly important where photographs are to be used or in cases where the unique nature of the incident reported makes it possible for the patient to be identified. While the Editorial Board recognises that it might not always be possible or appropriate to seek such consent, the onus will be on the authors to demonstrate that this exception applies in their case.

Authorship and Acknowledgements
The journal adheres to the definition of authorship set up by The International Committee of Medical Journal Editors (ICMJE). The ICMJE recommends that authorship be based on the following 4 criteria: i) Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; ii) Drafting the work or revising it critically for important intellectual content; iii) Final approval of the version to be published; and i) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Contributors who do not qualify as authors should be mentioned under 'Acknowledgements'.

Plagiarism Detection
The journal employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

Committee on Publication Ethics
The journal is a member of, and subscribes to the principles of the Committee on Publication Ethics (COPE).

MANUSCRIPT CATEGORIES AND WORD LENGTH

Note that word counts should include abstract and acknowledgements, but not table or figure legends and references. Longer manuscripts may be negotiated by the Editor In Chief in exceptional circumstances.

Original Articles: Original Articles should not exceed 5,000 words. The main text should be structured as follows: Introduction (putting the paper in context - policy, practice or research); Background (literature); Methods (design, data collection and analysis); Results; Discussion; Conclusion; Relevance for clinical practice. The number of words used, excluding abstract, references, tables and figures, should be specified. Pilot studies are not suitable for publication as original articles. We also ask that authors limit their references to 50 in total and all references must be available in English. We ask that you include all information required by the reporting guidelines relevant to your study. For example, use the CONSORT checklist for RCTs.

Review Articles: Qualitative and quantitative literature reviews on any area of research relevant to clinical nursing are welcomed. Submissions should not exceed 8,000 words. Quotes are included in

the overall word count of the main text. Authors are advised to explain their methodology clearly (e.g., overall approach, literature search strategies, data analysis). The PRISMA checklist and flow diagram should be used to guide manuscript development. Systematic review methods are evolving and authors are urged to cite supporting references. The main text should be structured as follows: Introduction; Aims; Methods; Results; Discussion; Conclusion; Relevance for clinical practice. We also ask that authors limit their references to 50 in total and all references must be available in English.

Commentaries and Responses to Commentaries: The Editor-in-Chief welcomes commentaries and Responses to commentaries on papers published in IJMHN. These should be approximately 500 words in length with a maximum of five references (including the original paper) and should offer a critical but constructive perspective on the published paper. All commentaries should be submitted via ScholarOne Manuscripts. Please follow our guidelines when writing a Commentary.

Discursive papers: including position papers and critical reviews of particular bodies of work which do not contain empirical data or use systematic review methods are also welcomed. Submissions should not exceed 5,000 words. These should be structured as follows: Aims; Background; Design (stating that it is a position paper or critical review, for example); Method (how the issues were approached); Conclusions; Relevance for clinical practice.

PREPARATION OF THE MANUSCRIPT

Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. Visit our site to learn about the options. All services are paid for and arranged by the author. Please note using the Wiley English Language Editing Service does not guarantee that your paper will be accepted by this journal.

Optimising Your Article for Search Engines

Many students and researchers looking for information online will use search engines such as Google, Yahoo or similar. By optimising your article for search engines, you will increase the chance of someone finding it. This in turn will make it more likely to be viewed and/or cited in another work. We have compiled these guidelines to enable you to maximise the web-friendliness of the most public part of your article.

Statistics

The advice of a statistician should always be sought for quantitative studies, and this person should be acknowledged in the acknowledgement section if the paper is accepted for publication. Where other than simple descriptive statistics are used, a statistician should be included as one of the authors and identified as such when submitting the paper.

Style

The journal uses UK spelling and authors should therefore follow the latest edition of the Concise Oxford Dictionary.

All measurements must be given in SI units as outlined in the latest edition of Units, Symbols and Abbreviations: A Guide for Medical and Scientific Editors and Authors (Royal Society of Medicine Press, London).

Abbreviations should be used sparingly and only where they ease the reader's task by reducing

repetition of long, technical terms. Initially use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation.

Drugs should be referred to by their generic names, rather than brand names.

Parts of the Manuscript
The manuscript should be submitted in separate files: title page; main text file; figures.

Title page
The title page should contain:
(i) manuscript category
(ii) a short informative title that contains the major key words. The title should not contain abbreviations;
(iii) the full names of the authors;
(iv) the author's institutional affiliations at which the work was carried out;
(v) an authorship declaration: in keeping with the latest guidelines of the International Committee of Medical Journal Editors, each author's contribution to the paper is to be quantified;
(vi) the full postal and email address, plus telephone number, of the author to whom correspondence about the manuscript should be sent;
(viii) authorship statement;
(vii) acknowledgements;
(viii) disclosure statement;
(ix) word count,including abstract and acknowledgements, but not table or figure legends and references.

The present address of any author, if different from that where the work was carried out, should be supplied in a footnote.

Authorship statement
This must acknowledge i) that all authors listed meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors, and ii) that all authors are in agreement with the manuscript.

Acknowledgements
The source of financial grants and other funding should be acknowledged, including a frank declaration of the author's industrial links and affiliations. The contribution of colleagues or institutions should also be acknowledged. Thanks to anonymous reviewers are not allowed

Disclosure
Authors must declare any financial support or relationships that may pose conflict of interest. This includes any financial arrangements authors have with a company whose product figures prominently in the submitted manuscript or with a company making a competing product.

Main text
As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors.

The main text of the manuscript should be presented in the following order: (i) abstract and key

words, (ii) text, (iii) references, (iv) tables (each table complete with title and footnotes), (v) appendices, (vii) figure legends. Figures and supporting information should be submitted as separate files.

Abstract and key words

Articles must have an unstructured abstract that states in 250 words or less the purpose, basic procedures, main findings and principal conclusions of the study. The abstract should not contain abbreviations or references. Five key words, for the purposes of indexing, should be supplied below the abstract, in alphabetical order, and should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list (http://www.nlm.nih.gov/mesh/meshhome.html).

Text

Authors should use subheadings to divide the sections of their manuscript as outlined for each article type.

References

• The Harvard (author, date) system of referencing is used (examples are given below).
• In the text give the author's name followed by the year in parentheses: Sago (2000).
• If there are two authors use 'and: Baskin and Baskin (1998); but if cited within parentheses write use '&': (Smith & Jones 2001).
• When reference is made to a work by three or more authors, the first name followed by et al. should be used: MacDonald et al. (2002).
• If several papers by the same authors and from the same year are cited, a,b,c etc should be inserted after the year of publication.
• In the reference list, references should be listed in alphabetical order.
• In the reference list, cite the names of all authors when there are six or fewer; when seven or more, list the first three followed by et al.
• Do not use ibid. or op cit.
• Personal communication, reference to unpublished data and publications from informal meetings are not to be listed in the reference list but should be listed in full in the text (e.g. Smith A, unpubl. data, 2000).
• All citations mentioned in the text, tables or figures must be listed in the reference list.
• Authors are responsible for the accuracy of the references.

References should be listed in the following form.

Journals

Meehan, T. (1994). Questionnaire construction and design for surveys in mental health. Australian and New Zealand Journal of Mental Health Nursing, 3, 59–62.

Books

Taylor, J. & Muller, D. (1994). Nursing adolescents: Research and psychological perspectives. Oxford: Blackwell Science.

Chapter in a book

Bergen, A. & Labute, L. (1993). Promoting mental health. In: A. Dines & A. Cribb (Eds), Health promotion: Concepts and practice (pp. 93–109). Oxford: Blackwell Science.

Electronic material

World Health Organisation (3 July 2003). Update 94: Preparing for the Next Influenza Season in a World Altered by SARS. http://www.international/csr/disease/influenza/sars. Accessed: 15 September 2003.

Tables

Tables should be self-contained and complement, but not duplicate, information contained in the text. Tables should be numbered consecutively in Arabic numerals. Each table should be presented on a separate sheet of A4 paper with a comprehensive but concise legend above the table. Tables should be double-spaced and vertical lines should not be used to separate columns. Column headings should be brief, with units of measurement in parentheses; all abbreviations should be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. The table and its legend/ footnotes should be understandable without reference to the text.

Figure legends

Legends should be self-explanatory and typed on a separate sheet. The legend should incorporate definitions of any symbols used and all abbreviations and units of measurement should be explained so that the figure and its legend is understandable without reference to the text.

Figures

All illustrations (line drawings and photographs) are classified as figures. Figures should be cited in consecutive order in the text. Figures should be sized to fit within the column (69 mm), intermediate (100 mm) or the full text width (144 mm).

Preparation of Electronic Figures for Publication: Although low quality images are adequate for review purposes, publication requires high quality images to prevent the final product being blurred or fuzzy. Advice on figures can be found at Wiley's guidelines for preparation of figures: http://authorservices.wiley.com/bauthor/illustration.asp

Supporting Information

Supporting information is not essential to the article but provides greater depth and background and may include tables, figures, videos, datasets, etc. This material can be submitted with your manuscript, and will appear online, without editing or typesetting. Guidelines on how to prepare this material and which formats and files sizes are acceptable can be found at: http://authorservices.wiley.com/bauthor/suppmat.asp.

Please note that the provision of supporting information is not encouraged as a general rule. It will be assessed critically by reviewers and editors and will only be accepted if it is essential.

SUBMISSION REQUIREMENTS

Manuscripts should be submitted online at http://mc.manuscriptcentral.com/ijmhn

• Two Word-files need to be included upon submission: A title page file and a main text file that includes all parts of the text in the sequence indicated in the section 'Parts of the manuscript', including tables and figure legends but excluding figures which should be supplied separately.

• The main text file should be prepared using Microsoft Word, doubled-spaced. The top, bottom and side margins should be 30 mm.

• Each figure should be supplied as a separate file, with the figure number incorporated in the file name. For submission, low-resolution figures saved as .jpg or .bmp files should be uploaded, for ease of transmission during the review process. Upon acceptance of the article, high-resolution figures (at least 300 d.p.i.) saved as .eps or .tif files will be required.

Associate your ScholarOne account with your ORCID iD
ORCID iD is a unique and persistent identifier that distinguishes you from every other researcher and connects you and your research activities. We encourage you to register for an ORCID iD and then associate it with your ScholarOne account. Click here to find out how.

COPYRIGHT, LICENSING AND ONLINE OPEN

Accepted papers will be passed to Wiley's production team for publication. The author identified as the formal corresponding author for the paper will receive an email prompting them to login into Wiley's Author Services, where via the Wiley Author Licensing Service (WALS) they will be asked to complete an electronic license agreement on behalf of all authors on the paper.

Authors may choose to publish under the terms of the journal's standard copyright transfer agreement (CTA), or under open access terms made available via Wiley OnlineOpen.

Standard Copyright Transfer Agreement: FAQs about the terms and conditions of the standard CTA in place for the journal, including standard terms regarding archiving of the accepted version of the paper, are available at: Copyright Terms and Conditions FAQs.

Note that in signing the journal's licence agreement authors agree that consent to reproduce figures from another source has been obtained.

OnlineOpen – Wiley's Open Access Option: OnlineOpen is available to authors of articles who wish to make their article freely available to all on Wiley Online Library under a Creative Commons license. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made open access. Authors of OnlineOpen articles are permitted to post the final, published PDF of their article on their personal website, and in an institutional repository or other free public server immediately after publication. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

OnlineOpen licenses. Authors choosing OnlineOpen retain copyright in their article and have a choice of publishing under the following Creative Commons License terms: Creative Commons Attribution License (CC BY); Creative Commons Attribution Non-Commercial License (CC BY NC); Creative Commons Attribution Non-Commercial-NoDerivs License (CC BY NC ND). To preview the terms and conditions of these open access agreements please visit the Copyright Terms and Conditions FAQs.

Funder Open Access and Self-Archiving Compliance: Please click here for more information on Wiley's compliance with specific Funder Open Access and Self Archiving Policies, and click here for more detailed information specifically about Self-Archiving definitions and policies.
PUBLICATION PROCESS AFTER ACCEPTANCE
Wiley's Author Services

Author Services enables authors to track their article through the production process to publication

online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The corresponding author will receive a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit http://www.authorservices.wiley.com/ for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

Proofs

Once the paper has been typeset the corresponding author will receive an e-mail alert containing instructions on how to provide proof corrections to the article. It is therefore essential that a working e-mail address is provided for the corresponding author. Proofs should be corrected carefully; the responsibility for detecting errors lies with the author.

Early View

The journal offers rapid speed to publication via Wiley's Early View service. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. Early View articles are given a Digital Object Identifier (DOI), which allows the article to be cited and tracked before allocation to an issue. After print publication, the DOI remains valid and can continue to be used to cite and access the article. More information about DOIs can be found at http://www.doi.org/faq.html.

POST PUBLICATION

Article PDF for authors

A PDF of the article will be made available to the corresponding author via Author Services.

Printed Offprints

Printed offprints may be ordered online for a fee. Please click on the following link and fill in the necessary details and ensure that you type information in all of the required fields: http://offprint.cosprinters.com/cos. If you have queries about offprints please e-mail: offprint@cosprinters.com.

Author Marketing Toolkit

The Wiley Author Marketing Toolkit provides authors with support on how to use social media, publicity, conferences, multimedia, email and the web to promote their article.

What are relatives' experiences of supporting a family member receiving electroconvulsive therapy? A qualitative exploration

Kerry Irving

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Correspondence should be addressed to:

Kerry Irving

Doctorate in Clinical Psychology

Furness College

Lancaster University

Lancaster

LA1 4YG

Email: k.irving@lancaster.ac.uk

Written in accordance with author guidelines for The International Journal of Mental Health Nursing (see Appendix 2-E for author guidelines).

Abstract

The purpose of this study was to explore relatives' experiences of supporting a family member receiving treatment with electroconvulsive therapy (ECT). Interviews were conducted with six relatives who had been involved in supporting a loved one through treatment with ECT. Interviews were transcribed and analysed using interpretative phenomenological analysis (IPA).

Five overall themes were developed that capture participants' experiences of supporting their relative through the ECT process: (1) You take the treatment because the alternative is just horrific; (2) Professional power silences resistance from relatives; (3) Moving from emotional responses to pragmatic reasoning; (4) Relatives' struggle to find a role in the ECT process; and (5) ECT changes people and relationships.

Relatives' attitudes and experiences of ECT are shaped through coercion and use of power; however mental health professionals are ideally placed to help relatives challenge the dominant biomedical model within the ECT process and make room for alternative discourses. This is particularly important in challenging the 'last resort' narrative of ECT.

Keywords: family, relative, caregiver, electroconvulsive therapy, ECT

Introduction

Electroconvulsive therapy (ECT) is a medical intervention involving the application of an electrical current to the scalp in order to induce an epileptic seizure (American Psychiatric Association, 2001). Initially established in the 1940s as a treatment for depression, the use of ECT declined in the 1970s when psychopharmacological interventions became widely available (McCall, 2001). By this time, ECT had moved from a first-line approach to one only to be considered for persistent, life threatening difficulties (McCall, 2001); however, in 2001 the American Psychiatric Association (APA, 2001) suggested it should not just be used as a last resort. Originally, ECT was conducted without anaesthesia (unmodified ECT) but current standards now dictate the use of anaesthesia and muscle relaxants (modified ECT) (APA, 2001; Royal College of Psychiatrists, 2005); however significant variations in clinical practice have been reported across countries, with large parts of Africa, Japan, India and Thailand continuing to use unmodified ECT (Leiknes et al., 2012).

In the United Kingdom (UK), ECT is recommended for people with a diagnosis of severe depression, catatonia or mania (NICE, 2003) although there is evidence that it is used in many other cases (Buley et al., 2015). UK guidance on the use of ECT states that it should only be considered to improve severe or life-threatening difficulties in cases where other interventions have been unsuccessful (NICE, 2003). However, in the year 2014 to 2015, only half of those who received treatment with ECT in the UK were considered "severely ill" (Buley et al., 2015), therefore it seems that ECT is not restricted to a last resort intervention in practice.

There is no single accepted explanation in the research literature of how ECT works but popular thinking within the areas of psychiatry and biomedicine emphasise the role of the seizure in restoring 'normal' endocrine function (Bolwig, 2011). These theories are based on a disease-centred model of depression that suggests there is a neurochemical abnormality present in those

with a diagnosis of depression which ECT can therefore address; however independent evidence has been unable to confirm that such an abnormality exists (Moncrieff & Cohen, 2006). Consequently, the mechanisms by which ECT is believed to provide therapeutic relief remain unclear (Fink, 2001).

A meta-analysis of ECT concluded it is more effective than other interventions, including antidepressant drugs, for reducing difficulties associated with a diagnosis of depression (Pagnin et al., 2004). Data collected by the UK ECT Accreditation Service, an organisation set up by the Royal College of Psychiatrists to assess the quality of ECT services, stated that 92% of those receiving ECT in the year 2014 to 2015 showed some clinical improvement following treatment (Buley et al., 2015). A multicentre, randomised control trial of ECT concluded that it was a highly effective treatment, resulting in significant reductions on clinical measures of depression (Kellner et al., 2010); however, these measures were completed by psychiatrists and there was no evidence of the service users own views on treatment efficacy. Furthermore, between a quarter and a third of participants dropped out before the end of the trial as a result of unacceptable side effects or a lack of improvement.

Claims that ECT is effective and safe have been disputed by service user groups and user-led research (Rose et al., 2003). A review by Rose et al. (2003) found user-led studies reported lower rates of perceived benefit than clinician-led studies. This was replicated in Read and Bentall's (2010) review of placebo-controlled studies of ECT, which argues that the claims of effectiveness are minimal and too often measured by clinician reports rather than service user measures. Additionally, no consistent benefits of ECT were identified beyond the immediate treatment period, casting doubt on the long term effectiveness of ECT (Read & Bentall, 2010). Furthermore, the potential side effects of ECT include headaches, nausea and confusion and long term effects on cognition, with approximately 55% of people reporting persistent memory loss

following treatment (Rose et al., 2003). Thus ECT remains contentious and whilst it may be offering some benefit, it may also be doing considerable harm.

ECT is generally regarded as the least acceptable of the standard psychiatric treatments (Lauber et al., 2001). A survey study of a population sample in Switzerland found that 57% of respondents believed that ECT was harmful and just 1.2% believed it could be helpful (Lauber et al., 2005). Lauber et al. (2005) argue that public opinion is influenced by negative media depictions of ECT. An American study analysed 22 films depicting ECT and concluded that ECT was portrayed as increasingly negative, with recent films depicting "a brutal, harmful, and abusive manoeuvre with no therapeutic benefit" (McDonald & Walter, 2001). Differing perspectives between clinicians, service users and the general public on the use of ECT lead to a confusing picture.

The Mental Capacity Act (MCA, 2005) states that ECT should only be given in the UK when the individual to receive it provides fully informed consent. The nature of this treatment means that it is particularly important that consent is given free from coercion (Royal College of Psychiatry, 2005). However, the provisions of the Mental Health Act (MHA, 2007) also permit ECT to be given to individuals who cannot provide consent if they have been judged as lacking the capacity to decide under the terms of the MCA (2005). Approximately 40% of those who received ECT in the UK between 2014 and 2015 were considered unable to consent to their treatment (Buley et al., 2015). Even when consent is provided, it has been reported that approximately one third of people may feel coerced or pressured into giving their consent to ECT (Rose et al., 2005). There remains a risk that individuals may be treated with ECT without having an opportunity to decide, against their will or without providing fully informed consent.

When making a decision to treat an individual with ECT, the MHA (2007) stipulates a statutory requirement to consult with deputies, who are most often family members or others who

know the person well. The nearest relative position in the MHA (2007) acknowledges the role of relatives in providing support to those family members struggling with mental health difficulties (Andoh & Gogo, 2004). The inclusion of the nearest relative in law provides clear statutory backing to the importance of involving family members and carers in the process of treatment with ECT. This is further supported by NICE guidance, which states that "the individual's advocate and/or carer should be consulted" in all decisions regarding ECT (NICE, 2003, p.59).

Evidence from service user studies supports the idea that family involvement can be beneficial in the ECT process. Fisher et al. (2011) found that individuals considering ECT often relied on family and friends to provide information about the treatment and many considered their relatives as supportive throughout the process. The roles relatives took varied with some involved in offering advice and information, while others were actively involved in the decision-making process. Furthermore, in inpatient services people tend to express a preference for relatives to be involved in discussions about their care and treatment and they report higher levels of satisfaction with care when family involvement has been supported (Perreault et al., 1999).

Attempts to involve relatives and carers in mental health decision-making generally have proven to be problematic. Rose et al. (2004) examined the barriers to including families in inpatient services and found that staff described not having the training or resources, feeling constrained by issues regarding confidentiality and believing that family involvement was not a priority. Relatives and carers in turn felt ignored; believed their own emotional needs were not met and expressed concern that their perspectives were not considered in relatives' care. These barriers have not been explored specifically in relation to the ECT process but given that most courses of ECT take place in the context of a hospital admission (Buley et al., 2015), it is possible they may impact on relatives' experiences of the ECT process.

Relatives and carers may also experience personal challenges when supporting a family member receiving ECT. Evidence suggests that families also experience coercion to provide consent for their family member to be treated with ECT (Rajkumar et al., 2006). This may not always necessarily be in the form of overt pressure from others to consent to ECT, but may originate in the rhetoric around ECT as a "last resort" treatment (Fisher, 2012). Although the psychological impact of this experience has not been explored with relatives it may be that they share similar experiences with service users, who describe feeling powerless and lacking in control at times during the ECT process (Johnstone, 1999).

Relatives' experiences of ECT may be different to those of their loved one and differing perspectives have been identified, with relatives reporting higher levels of satisfaction and more favourable attitudes towards ECT following treatment (Rajagopal et al., 2012). This finding conflicts with research that people in the general population who were close to someone with a mental health difficulty were more likely to perceive ECT as harmful (Lauber et al, 2005), which perhaps indicates that relatives' opinions shift following contact with ECT. Relatives were also considered more likely to consent to their family member receiving ECT than the service user would for themselves (Rajkumar et al., 2006). The difference in perspectives and impact of this on familial relationships has not been explored in the research to date.

Research regarding relatives' perspectives of the ECT process has been criticised for failing to take into account the complexity of relatives' experiences. Rose et al. (2003) suggest that this is because medical, clinician-led studies typically use simplistic questionnaire measures of factors such as satisfaction, efficacy and attitudes towards ECT. Fisher (2012) proposed that individuals involved in the ECT process are not passive recipients or observers of the treatment, but are actively making sense of their experiences in the context of their own prior beliefs and experiences. Consequently, they recommend that exploratory qualitative studies are used to extend previous research findings and enhance our understanding of relatives' perspectives on this complex and

controversial process. This study aims to address this shortfall in the current evidence base by examining relatives' experiences of supporting a family member receiving treatment with ECT.

Method

Since little is known about how relatives and carers make sense of the process of ECT, an exploratory qualitative research design was adopted utilising an interpretative phenomenological analysis (IPA) approach. IPA studies attempt to explore in detail how participants express and make sense of their own experiences in an idiographic manner by examining each participant's case in detail in order to situate their experience in their own particular contexts (Smith et al., 2009).

Ethics

This study was subject to ethical review and was approved by an NHS Research Ethics Committee (NRES) and locally by the Research and Development departments of the two participating NHS Trusts. Further information on the process of ethical review can be found in Appendix 4-H to 4-L.

Participants

Recruitment was conducted using purposive sampling methods in accordance with pre-specified inclusion criteria. Relatives and carers of people who had received ECT were invited to take part if they had been involved in supporting their family member during treatment with ECT. For the purposes of defining the inclusion criteria for this study, the MHA (2007) guidelines for defining the nearest relative were consulted to form a list of people likely to have a significant relationship with the service user receiving ECT (Appendix 4-A).

To be included in the study, participants needed to have been over the age of 18 at the time of their relative's treatment with ECT. This was because the law dictates that adults will be likely

to have had a different role in supporting relatives through ECT than those under 18 years of age (and therefore legally defined as children under the United Nations Convention on the Rights of the Child). For example, children under 18 years of age cannot legally act as nearest relatives under the MHA (2007). Consequently, only the experiences of adult relatives were explored in this study.

Participants were recruited to the study via a two-step recruitment approach. The first step involved recruiting through two NHS Trusts in the North West of England. Secondary care mental health services and ECT clinics were approached and asked to support recruitment of participants. The researcher attended team meetings within the NHS services to engage staff in the recruitment process. Staff members were asked to introduce the research to families or carers of service users who had received treatment with ECT and provide potential participants with an information sheet (Appendix 4-B) and an expression of interest form (Appendix 4-F) that the family member could return to the researcher. The researcher did not approach any relative or carer directly in an attempt to minimise the potential for coercion. Staff members making the initial approach to families were asked to make it clear that participation was optional and that their decision to refuse or consent to participation would not affect the care of their relative.

The second stage of recruitment involved advertising the study on social media and at relevant local support groups. A short advertisement (Appendix 4-G) was posted on the Lancaster University social media accounts on Facebook and Twitter and was then shared with relevant groups that offer support to families and carers of people with mental health difficulties, including but not limited to Bipolar UK, Mind, Carers Trust and Carers UK. Presentations were also made at local support groups including a Bipolar UK group and a carer support group. Interested relatives and carers were given copies of the study information sheet and consent form (Appendix 4-B & Appendix 4-C) and then had a minimum of 24 hours to consider the information before being contacted again by the researcher.

The study aimed to recruit between 6 and 12 participants based on recommendations from Smith and Osborn (2007) stating that studies adopting Interpretative Phenomenological Analysis (IPA) should use small sample sizes to allow for detailed interpretative analysis of each case. In total, eight people expressed an interest in taking part in the study; however two did not meet the inclusion criteria as they were under the age of 18 at the time of their relatives' treatment. Consequently, six people took part in the study. A decision was made not to seek out further participants given the richness of these six accounts and the in-depth analysis required to capture this.

Demographic information was collected for each of the participants (Table 2-A). Interviews lasted between 41 and 99 minutes. Four of the interviews took place over the telephone and two took place face to face. Four of the participants had relatives who had received more than one course of ECT; however each of them could recall the first treatment that they were involved in as being the most relevant for them. In these cases, participants were asked to keep this treatment episode in mind throughout the interview.

INSERT TABLE 2-A

Data Collection

Semi-structured, in-depth interviews were conducted with participants, during which they were asked questions about their experiences of supporting their relative through ECT. Although a topic guide was used to structure the conversation (Appendix 4-E), participants were encouraged to raise experiences that were of importance to them so that novel issues could be discussed.

Data Analysis

Data analysis was conducted in line with IPA which is suited to analysing how people make sense of their own lived experiences and therefore was considered a suitable approach for exploring relatives' experiences of the ECT process (Smith et al, 2009). Participants' transcripts were analysed using IPA based on the stages of analysis proposed by Smith et al. (2009). They suggest that progression through these stages is not "a linear one" (Smith et al., 2009, p.80) but should always be based on the process of moving from descriptive accounts of the data to interpretive analysis.

In line with IPA's idiographic approach, each transcript was analysed individually in detail before moving on to subsequent cases. The first stage of analysis involved repeated reading of the transcript. Following this familiarisation stage, initial exploratory notes were made on the content and language used within the transcript. In the third stage, the exploratory notes were condensed to produce emergent themes that reflected the participant's original words in combination with the researcher's interpretation of these (Appendix 2-A). The fourth stage of analysis involved searching for connections across the emergent themes, which was achieved by creating lists of similar emergent themes. From these lists, higher level, super-ordinate themes were identified (Appendix 2-B). Once this stage had been completed to sufficient depth for each transcript, the same process was applied to subsequent transcripts so that a set of super-ordinate themes had been developed for each individual participant. A list of these superordinate themes and narrative summaries of each theme are included in Appendix 2-C. Once all of the transcripts had been individually analysed, the super-ordinate themes from each participant were analysed as a whole set. Participant themes that captured similar experiences or understandings were grouped together and further analysed as a new set to identify patterns or higher order concepts across the cases. Appendix 2-D shows how each participant's themes contributed to the development of these final five concepts.

Results

Five overall themes were developed that capture participants' experiences of supporting their relative through the ECT process: (1) You take the treatment because the alternative is just horrific; (2) Professional power silences resistance from relatives; (3) Moving from emotional responses to pragmatic reasoning; (4) Relatives' struggle to find a role in the ECT process; and (5) ECT changes people and relationships. Each of these themes is detailed below.

You take the treatment because the alternative is just horrific

The desperation of the situation prior to ECT made ECT seem necessary to relatives in light of the lack of alternative options available. Participants shared harrowing stories highlighting the unbearableness of their loved ones' difficulties prior to treatment and the severity of the situation was seen to justify the need for ECT. Colleen said:

> I mean it's clearly a very invasive treatment but things were desperate, she was in a very poor state and could only sit and weep, she wasn't doing much else, and something had to happen.

Most of the participants believed that their relatives' difficulties placed them in a life-threatening situation. Anna talked about the fear of her husband attempting suicide if nothing changed, whereas other participants worried that their relative failing to eat, drink or sleep would have been fatal without ECT:

> We thought she was going to die because she-you know you can only last so long without water can't you…I think she'd have just shut down and she would have just died. (Sophie)

The emotional impact of watching a relative suffer was evident throughout all of the participants' accounts. Participants described feelings of loss of their relative and the relationship they shared, with many experiencing sadness when their relative seemed to look through them. Sophie made impassioned pleas for their return through the use of ECT: "Just do the ECT again. Just get her back to the normal person that I know as my mum".

Participants described no meaningful choice available as a result of the limited treatment options within the current psychiatric system. Many of the participants described medication or ECT as the only options for intervention. Colleen said "I certainly wouldn't have chosen it but I didn't see any alternative to it. The drug treatments just weren't working". The term "last resort" was used throughout participants' accounts to capture the sense that ECT was the only available option presented to them in a desperate situation.

The last resort narrative seemed to originate from within the psychiatric system; with participants noting that their options were framed in this way by medical professionals. Eleanor reflected that medical professionals have the power over what treatment options are made available, stating: "You can either have what they offer or you can say no but then nothing else is on offer." Although many of the participants accepted the limited options as the only interventions that could possibly help, some described searching for alternatives and questioned the narrative of ECT as a last resort, stating "there must be something different, a better way where people are actually seen as humans rather than just brains and machines to be restarted" (Anna). Eleanor acknowledged that the current medical paradigm did not allow space for other therapeutic

alternatives, stating, "basically what is on offer is containment when necessary and drugs and that is about it. The therapeutic input was minimal, really minimal".

Following treatment, many of the participants dismissed undesirable consequences of ECT as inconsequential as the treatment was felt to have been necessary given the severity of the situation. Side effects were dismissed because they were perceived to be less distressing, both for themselves and their relatives, than their experiences prior to treatment. Sophie explained:

> You're just desperate. You wouldn't care if they had a lobotomy or not, you just take the treatment because the alternative is just horrific. The alternative is more horrific than the films.

There was a sense in all participants' accounts that they had given up hope of any change prior to the introduction of ECT. Helen said : "by the point it was suggested I was beyond the point where I thought anything was going to make her better." The desperation and severity of the situation for relatives made ECT seem necessary in light of the limited options available in psychiatric services.

Professional power silences resistance from relatives

Participants positioned medical professionals as the most powerful stakeholders in the ECT process and were therefore able to silence participants. Most participants described a power imbalance in relationships with medical professionals with some perceiving professionals as coercive, leading to fear and anxiety: "the first few times [at ward round] I remember feeling like I was going in front of a firing squad just to walk into the room" (Eleanor). Participants described treading a difficult line where they felt unable to raise concerns for fear that the repercussions would mean further exclusion from their relatives' care. Colleen said of the medical staff "if you

want something out of people, you don't go antagonising them do you". Most participants expressed ideas that medical professionals' views were privileged, with the family powerless in comparison: "they were the medical professionals and you were just the family and nobody said anything" (Sophie).

Powerful professionals were seen to provide strategic information about ECT to participants. Although all participants initially felt horrified at the idea of their loved one receiving ECT, this process meant they all eventually acquiesced and agreed to use ECT. Some participants identified this process explicitly as coercive and felt betrayed by having been provided with unbalanced information.

> I never did feel right and I think that he feels quite angry about it still now. It was false hopes in a way, not clear information…the information that was coming from the team was akin to persuasion to agree to the ECT. (Anna)

In contrast, participants who described generally positive relationships with staff perceived that professionals were providing them with reassurance, although it was evident in their examples that their concerns about ECT were being dismissed. Eleanor said:

> I was thinking oh dear, we'd better stop this ECT now because it's had these effects, but my psychiatrist friend was very sanguine about the cognitive impairment, he was really like don't worry about it... He really wasn't very bothered. (Eleanor)

In Eleanor's example the psychiatrist was a friend and not someone directly involved in her brother's care. This suggests the nature of power held by medical professionals is not just related to their position in the system of care but is instead linked to their status in wider society.

There was also a sense that medical professionals' views were privileged over participants' own ideas and discourses:

> When I tried to explain to him about all the things that had been going on in my mum's life that might have caused this, he slapped me down and dismissed it with, no she has this illness and it's nothing to do with what's going on in her life, it's a chemical imbalance in her brain and this is why she does this and this is why we have to do this, and I'm thinking oh alright then. (Sophie)

This theme captures how professional power was used to silence resistance from relatives and impose the views and perspectives of the powerful medical professionals on participants during the ECT process.

Moving from emotional responses to pragmatic reasoning

Participants described a process of moving away from emotive perceptions of ECT and engaging in a conscious reasoning process in an attempt to develop a balanced understanding of ECT. Many described their initial reaction to ECT as one of horror accompanied by the experience of vivid, intrusive images of scenes from films. Some of their initial reactions suggested the stigmatising images surrounding ECT had been internalised by participants:

> In my mind it was this horrific ECT treatment thing, I was thinking of 'One Flew Over the Cuckoo's Nest'…I just thought I can't believe this is happening to me, to my family, because I always thought we were quite normal. (Sophie)

All of the participants made reference to films containing distressing images of ECT when describing their initial emotional responses. Most participants also described struggling to accept the invasive nature of ECT at first:

> I thought ooh, shock treatment, no. Just the word, I think the word is, it has very negative connotations for me I think and just the thought of her having a current or something go through, I thought no, that's not right, that's not a normal thing to do. (Helen)

All but one of the participants then began a process of distancing themselves from these emotive ideas through a process of pragmatic reasoning. Many described the need to "get over it" (Helen)

and acknowledged that the personal relevance of ECT prompted them to move away from emotionally driven thinking to a more pragmatic approach in order to decide whether their relative should have ECT:

> It sounds like a horrific thing to do to somebody, particularly the way it's portrayed in films and things. It's only when it comes to somebody you care about, where you have to weigh up sensibly, that you think no, hang on, I'd rather that happened. (Sophie)

Most participants described developing intellectualised understandings of ECT that often came from medical professionals explaining how ECT was proposed to work. Colleen stated "It made sense when they explained about the epilepsy because I'd never really understood what ECT was for, then I was reasonably in favour". This allowed participants to reappraise the decision to have ECT in a more pragmatic way. However, sometimes the reasoning process led participants to different conclusions. Anna rejected the mechanisms of ECT and therefore was unable to create a rationale for its use:

> And it's not like, you know, appendicitis. It is not the same as a physical thing. You cannot take something there and kind of, switch and rewire it and it's gonna work. It's not like a broken electric machine like a washing machine…So, why?

Anna's experience suggests she also engaged in a process of reasoning in common with the other participants, however she was unable to accept ECT as a consequence of her intellectual

understanding of mental health being at odds with the mechanisms of ECT. She also recognised that her stance influenced the way that she went on to seek out information about ECT, which led to further confirmation of her position:

> I was finding everything against it, he was finding everything for it but I think we had this kind of data bias when you know, we were confirming what you want to find and weed out everything else. (Anna)

Most participants constructed an understanding of how 'new ECT' was different and therefore more acceptable and less distressing than 'old ECT'. Participants used this reasoning to challenge their own and other people's emotive, stereotyped perceptions of ECT:

> it's not like it was in the fifties and the sixties, we do this now and this has changed, if you could sort of explain to them, what's different about what it was like originally, because people think about the horror films. (Sophie)

This theme captures how participants attempted to dismiss their initial emotive responses to ECT and engage in a process of pragmatic reasoning, which helped them to come to a decision about ECT through the evaluation of their intellectualised understandings of the treatment.

Relatives' struggle to find a role in the ECT process

Finding their place as a relative in the ECT process was a particular challenge for participants. They attempted to maintain a neutral, supportive position based on their beliefs that

their relative should decide on ECT; however it became clear that neutrality was not possible and very often they moved into a more active, influencing or decisive role. Helen intended to prioritise her mum's perspective on ECT but she could not avoid pointing out her own view, based on her mum's previous experience of ECT, that the treatment would be beneficial:

> I mean we do say to her it's your decision mum and if you choose, if you decide you don't want it it's your right to do that and obviously we can't and wouldn't stop you doing that but you need to think about what's happened before and how the benefits are. (Helen)

Participants found it hard to remain neutral given that their loved one was often positioned as helpless as a result of their difficulties; therefore participants felt a sense of responsibility to protect and care for them which often meant taking a more active role in decision making:

> My daughter wasn't in any position to make a decision about it herself, that's the problem with mental health issues isn't it, you know we're talking adults but at the time they're not really responsible for themselves. (Colleen)

Participants also found it hard to maintain a neutral position because of their own feelings of distress and their desperation for change, which often led them to become increasingly involved in the decision making process around ECT: "I never made the decision for him but we discussed things and he was so desperate to feel better, so was I for him to feel better" (Anna). Many of the

participants recognised that their own experiences of seeing their relative struggling made it impossible to remain impartial in the decision making process:

> How difficult I found it and how upset I was to see her like that, that partly has an influence too because you can't take self-interest out of the equation and I don't want to see her like that again. I don't want to be going to see her in hospital for five months and have her look straight through me as if she doesn't even know me. (Helen)

Watching their loved one struggle drove participants to become increasingly involved in the ECT decision making process.

Participants described fighting to be acknowledged by services and they felt excluded by medical professionals: "it all seemed to be we just need your consent and then we'll get on with it, then you can go away and just visit her" (Sophie). Feeling excluded from their loved ones' care led participants to feel powerless and fearful. For many, this experience was accepted begrudgingly but some participants described taking up increasingly active positions in response, in an attempt to regain a level of involvement in the process.

Many participants also described needing to be invited to take a position in the process by their relative. Colleen worried that her daughter may have asked staff not to share information with her because "you don't necessarily want your mum told everything"; however Anna described agreeing with her husband that she would take up a more active role in the process in order to avoid the uncomfortable emotions she was experiencing:

> I felt helpless, powerless, had no idea what was going on and this is where I stepped up and sat down with him and we agreed, we had to think of a plan that we'll talk, that I'll help him make decisions and that I'll speak up for him. (Anna)

Given that participants could be excluded from the process by both psychiatric services and their relatives, at times they held the position of least power and influence in the ECT process, whereas at other times they had the ability to influence decision making. This captures the struggle of finding a role or position as a relative in the ECT process.

ECT changes people and relationships

Participants described how ECT changed their relationships with their loved ones. Some participants identified positive relational changes as a result of their involvement in supporting their relative through the ECT process. Aisha described feeling more compassionate towards her dad, stating "I respect him more as in like, I think I used to be quite judgy about it", whereas Eleanor noted that the experience of supporting her brother had brought them closer together and shown him that he was loved: "I think it was a really valuable thing to do to be there for him throughout that…I know it will have made a huge difference to him".

However, the impact of memory loss on participants' relationships with their loved ones was significant and romantic relationships (as opposed to biological relationships) were particularly vulnerable to this because so much of what bonds a couple relies on shared memories. Sophie and her dad took different positions on the impact of her mum's memory loss following ECT:

> I just thought I don't care about memory, let's just get her back to normal. Why does her memory matter? But my dad had obviously had experience of it before and found

> that when she had this, it had changed her, and when it's your partner it matters more doesn't it, that they're changed. I suppose with her being my mum, she would always love her kids, she might not always feel the same about her partner.

There was a sense that the loss of important shared memories had the potential to threaten bonds between relatives. Memory loss was particularly difficult for participants to see because it was perceived to have changed their loved one in many important ways. Eleanor talked about how memory loss changed her brother's sense of himself and ability to live independently.

> [My brother] couldn't get into the computer because he couldn't remember the password… that completely freaked him out because he felt like he'd lost himself because he couldn't do anything. (Eleanor)

Participants described the ECT process generally as upsetting for them because it became such a significant event in their lives. Helen said "It is an emotional thing as well. It reminds me that mum is broken". Despite the sadness and burden of caring that participants experienced, they felt pressure to dismiss or silence their own emotional distress in order to continue providing support for their relative, which often left them with limited access to emotional support for themselves.

> I mean it's the most awful thing dealing with your own child who is unhappy but life has to go on so you have to think in a practical way and only burst into tears at times when things really get on top of you. (Colleen)

This theme captures how the ECT process changes relationships through the strengthening of bonds between relatives that occurs as a result of providing care and support, but also through the potential weakening of bonds as a result of a loved one losing important shared memories and a sense of themselves.

Discussion

The analysis of six participant accounts has produced five key concepts that develop our understanding of how relatives experience the process of their loved one receiving treatment with ECT. The themes capture the desperation and lack of meaningful choice that leads participants to agree to ECT. The knowledge and availability of alternatives is controlled by powerful professionals, who are able to silence resistance to ECT and frame the treatment as the only available option. This was possible as a result of the inherent power held by medical professionals in the ECT process. French and Raven (1959) proposed five bases of power including the base of 'expert power', which is held by those who are perceived to hold increased levels of knowledge, experience and credentials, such as doctors. From this 'expert power' base, medical professionals are able to influence subordinates by convincing them to trust them. Power has become synonymous with mental health services and particularly traditional psychiatry, with the dominant discourse in mental health services providing rules that allow mental health professionals to exercise power and control (Bracken & Thomas, 2001).

As a consequence of their position of expert power, medical professionals are able to construct and reinforce the idea that ECT is a last resort intervention by dismissing or limiting access to alternative discourses outside of the dominant biomedical model. The degree of desperation experienced by relatives and the lack of knowledge around ECT gives medical professionals the power to prioritise the ECT agenda. Although mental health professionals should aim to support the process of informed consent and autonomous decision-making, Cosgrove (2011) argues that meaningful choice and autonomy is not possible when people are presented with a predetermined list of available biomedical treatment options. In these instances, the power remains with medical professionals and therefore service user autonomy in the decision-making process is undermined.

Framing ECT as a 'last resort' places pressure on service users and families to consent to the treatment therefore it has been recommended that the last resort narrative is avoided, particularly if non-pharmacological interventions have not been trialled (Fisher et al., 2011). Instead, Fisher et al. (2011) argue that a range of alternatives should be explored, including the option of not having treatment, and the risks and benefits of these options should be discussed with service users and families throughout the process. Cutliffe and Happell (2009) argue that alternatives to the dominant model of mental health care can be less tied to the use of power. They argue that the recovery paradigm makes space for service users and families to articulate their own experiences as opposed to acquiescing to the predominant biomedical discourse. They propose that services can be truly engaging only when alternative discourses are possible and of particular importance here are service user and family narratives. Consequently, service users and their families need to be encouraged to question the dominant biomedical narratives of medical professionals in order to engage in free choice (McGregor, 2006).

Participants in this study described a process of moving away from their initial emotional responses to ECT and engaging instead in a pragmatic reasoning process, where they made

attempts to evaluate the evidence regarding ECT in order to come to a decision; however this process was also likely to have been influenced by the framing of ECT as a last resort. Research suggests that when people are asked to make a decision about health care, the way in which options are framed by clinicians has a significant impact on the choices that they make (Tversky & Kahneman, 1981). This framing effect means that although participants aimed for objective, rational balancing of arguments regarding ECT; this process would still undoubtedly have been influenced by the last resort narrative of ECT.

Furthermore, it was evident that participants had different responses to this reasoning process and consequently came to opposing conclusions regarding ECT, suggesting that the reasoning process was also shaped by individual differences between participants. The change in attitude towards ECT that some participants experienced during the reasoning process may be explained by cognitive dissonance theory, which proposes that when people hold two conflicting ideas they experience discomfort and therefore seek to restore balance by altering one of the beliefs to reduce cognitive dissonance (Festinger, 1962). Brownstein (2003) proposed that during a decision-making process, people engage in biased pre-decision processing whereby they selectively attend to information that assists them in reappraising and bolstering their preferred option until that choice becomes increasingly obvious, thus reducing cognitive dissonance. This process was evident within participants' accounts, where most people engaged in a process of reappraising ECT as potentially helpful by gathering information that supported its use, such as intellectualised explanations of how it was proposed to work. In contrast, Anna, who was unable to reconcile the dissonance between her own ideas of mental health and the biomedical mechanisms of ECT, was seen to seek out information that confirmed her own beliefs through selectively attending to evidence that supported this. The findings of this study and existing evidence highlight the complex mechanisms by which decisions are influenced by others and also by individuals' own beliefs and attitudes. Consequently, the decision making process in ECT is

inherently complex and relatives may benefit from the opportunity to reflect on and explore how their own position impacts on the decision-making process.

A challenge in participants' accounts of the ECT process involved navigating their involvement as a relative in the decision-making process. Although many aimed to maintain a neutral stance, it may be that taking up different positions in response to the context was the most functional way for them to navigate the ECT process. The circumplex model of marital and family systems (Olson, 2000) suggests that flexibility is one of the major requirements of a balanced couple or family system. The model proposes that flexible couples or families are able to approach decision-making democratically as there is fluid change in roles when the context deems this necessary. In light of this model, the ability of participants to shift position in response to the circumstances (for example taking a more active role when their relative could not) is likely to have allowed the family to adapt to the demands of the ECT process more successfully.

Despite participants in this study describing a desire to be involved in the ECT process, research suggests that relatives' are often excluded from psychiatric services and feel unheard or undervalued by healthcare professionals (Wilkinson & McAndrew, 2008). It is therefore recommended that stronger working alliances between staff and relatives should be encouraged if relatives are to be supported to take part in the ECT process. Collaborative development of family services between nurses and relatives in inpatient settings have led to improved relationships between staff and families (Jubb & Shanley, 2002). Similar approaches may be utilised within ECT services in order to facilitate meaningful involvement for relatives and carers.

The findings of this study indicated that participants felt ECT changed people and that relationships were also changed as a result. Previous research has found that ECT leads to changes in people's sense of self, particularly as a result of memory loss (Johnstone, 1999); however the impact of memory loss on relationships after ECT has not been explored. Participants in this study

suggested that romantic relationships may be more vulnerable to change following ECT. It has been proposed that the social function of autobiographical memory is to initiate, enhance and maintain bonds between people (Alea & Bluck, 2003) and that remembering relationship events can enhance intimacy in romantic relationships (Alea & Bluck, 2007), therefore the implications of losing memory for key events in a couples' romantic history has the potential to undermine the strength and intimacy of that bond. This is evident in a study exploring couples' experiences of memory loss following traumatic brain injury (TBI), which found that couples described having lost the connections in their relationships as a result of memory loss (Godwin et al., 2014). Despite these important relational impacts, clinicians consistently underestimate the impact of memory loss following ECT (Rose et al., 2003). Consequently, clinicians who are responsible for informing families of the side effects of treatment may be less likely to emphasise the potential relational impacts of memory loss in ECT, resulting in implications for informed consent.

Strengths and limitations

This study provides a detailed exploration of relatives' experiences of the ECT process and should be used to inform how mental health professionals work with families and carers who come into contact with ECT. A strength of the study is the detailed, idiographic analysis of participants' accounts, which allows for the identification of aspects of the process that were important to individuals as well as to those that were found in common across the group. Given the complexity of the ECT process from relatives' perspectives, preserving the idiographic nuances within the analysis was of importance. Furthermore, there was a good fit between the IPA methodology and the data collected, as the participants represented a relatively homogenous sample for whom the experience of ECT had been meaningful (Smith et al., 2009). Consequently, the interviews and analysis were able to explore the variability of how the individual participants made sense of a shared experience, namely supporting a relative through ECT.

Adopting an IPA approach to the research question does limit the generalizability of findings given that the accounts and themes developed are situated within individual participants' specific contexts, therefore they cannot be applied outside of this. For example, only female relatives came forward to take part in the study and so it remains unclear whether male relatives and carers might share similar experiences of the ECT process. Subsequent studies may choose to explore the experience of male relatives in order to add to the themes identified here.

Clinical Implications

Relatives' attitudes and experiences of ECT are shaped through coercion and uses of power, such as strategic information sharing. Mental health professionals, including psychologists, are ideally placed to challenge the dominant biomedical model within the ECT process and make room for alternative discourses (Deacon, 2013). They can provide a facilitator role for families, helping to build their sense of self-efficacy and giving them power to share their own narratives within services (Cutliffe & Happell, 2009). In doing so, mental health professionals, service users and families may be able to challenge the last resort narrative of ECT by highlighting alternative options that often lie outside of the dominant biomedical interventions of ECT and psychopharmacology (Fisher et al., 2011). It is particularly important that such challenges are directed not only at specific services but also at policymakers so that alternative options are funded and widely available to service users and families. It is proposed that this can be achieved if service users, families and professionals "build closer alliances in working together to reconstruct practice, safeguard human rights and develop innovative alternatives to a traditional bio-medical model of treatment" (Wilson & Daly, 2007).

The impact of memory loss from ECT on relationships requires further exploration, both in terms of high quality research and in specific interactions between mental health professionals, relatives and service users. It is clear that these side effects, although often considered to be

objectively mild and short-lived by clinicians (Semkovska & McLoughlin, 2010), have the potential to cause significant harm and distress to relatives and service users.

Conclusion

This qualitative exploration of relatives' experiences of ECT has highlighted the important role of professional power, in conjunction with the desperation of their situation, which leaves relatives vulnerable to the last resort narrative of ECT. Relatives' attempts to engage in a process of pragmatic reasoning are further influenced by this narrative, as they seek to evaluate the potential role of ECT in their loved ones' recovery. Relatives struggle to find their voice in the ECT process and often experience exclusion from services, which often leaves them feeling powerless to help. Finally, relatives acknowledged that ECT changes people and they reflected on the impact that these changes have on relationships, including the potential to both strengthen or weaken relationships. The findings highlight the need for relatives to be supported to challenge powerful discourses so that they might feel able to share their own voices and find their role in the ECT process.

References

Alea, N. & Bluck, S., 2003. Why are you telling me that? A conceptual model of the social function of autobiographical memory. *Memory, 11*, pp. 165-178. doi:10.1080/741938207

Alea, N. & Bluck, S., 2007. I'll keep you in mind: Using memory to enhance intimacy in relationships. *Applied Cognitive Psychology, 21,* pp. 1091-1111. doi: 10.1002/acp.1316

American Psychiatric Association., 2001. *The Practice of electroconvulsive therapy: recommendations for treatment, training, and privileging: a task force report of the American Psychiatric Association. VII.* Washington, DC: The American Psychiatric Association.

Andoh, B. & Gogo, E., 2004. The Nearest Relative in Mental Health Law. *Medicine, Science and the Law*, *44*(2), pp. 140–150. doi:10.1258/rsmmsl.44.2.140

Bolwig, T. G., 2011. How does electroconvulsive therapy work? Theories on its mechanism. *Canadian Journal of Psychiatry*, *56*(1), pp. 13-18. doi:10.1177/070674371105600104

Bracken, P. & Thomas, P., 2001. Postpsychiatry: a new direction for mental health. *British Medical Journal, 322*(7288), pp. 724–727. doi:10.1136/bmj.322.7288.724

Brownstein, A.L., 2003. Biased predecision processing. *Psychological Bulletin, 129*(4), pp.545–568. doi:10.1037/0033-2909.129.4.545.

Buley, N., Hodge, S. & Hailey, E., 2015. *ECT Minimum Data Set: Activity Data Report England and Wales.* London: ECTAS.

Cosgrove, L., 2011. The DSM , big pharma, and clinical practice guidelines: Protecting patient autonomy and informed consent . *International Journal of Feminist Approaches to Bioethics, 4(*1), pp. 11–25. doi:10.2979/intjfemappbio.4.1.11

Cutcliffe, J. & Happell, B., 2009. Psychiatry, mental health nurses, and invisible power: Exploring a perturbed relationship within contemporary mental health care. *International Journal of Mental Health Nursing, 18*(2), pp. 116–125. doi:10.1111/j.1447-0349.2008.00591.x

Deacon, B. J., 2013. The biomedical model of mental disorder: A critical analysis of its validity, utility, and effects on psychotherapy research. *Clinical Psychology Review, 33*(7), pp. 846–861. doi:10.1016/j.cpr.2012.09.007

Department of Health., 2005. *Mental Capacity Act.* London: HMSO

Department of Health., 2007. *Mental Health Act.* London: HMSO

Festinger, L., 1962. Cognitive Dissonance. *Scientific American, 207*(4), pp. 93–106. doi: 10.1038/scientificamerican1062-93

Fink, M., 2001. Convulsive therapy: a review of the first 55 years. *Journal of Affective Disorders, 63*(1-3), pp. 1–15. doi:10.1016/s0165-0327(00)00367-0

Fisher, P., 2012. Psychological factors related to the experience of and reaction to electroconvulsive therapy. *Journal of Mental Health, 21*(6), pp. 589–599. doi:10.3109/09638237.2012.734656

Fisher, P., Johnstone, L. & Williamson, K., 2011. Patients' perceptions of the process of consenting to electroconvulsive therapy. *Journal of mental health, 20*(4), pp.347-354. doi: 10.3109/09638237.2011.577116

French, J. R. P. & Raven, B., 1959. The bases of social power. In Cartwright, D. & Zander, A. *Group dynamics.* New York: Harper & Row

Godwin, E., Chappell, B. & Kreutzer, J., 2014. Relationships after TBI: A grounded research study. *Brain injury, 28*(4), pp. 398-413. doi: 10.3109/02699052.2014.880514

Johnstone, L., 1999. Adverse psychological effects of ECT. *Journal of Mental Health*, *8*(1), pp. 69-85. doi:10.1080/09638239917652

Jubb, M. & Shanley, E., 2002. Family involvement: The key to opening locked wards and closed minds. *International Journal of Mental Health Nursing, 11*(1), pp. 47–53. doi:10.1046/j.1440-0979.2002.00225.x

Kellner, C. H., Knapp, R., Husain, M. M., Rasmussen, K., Sampson, S., Cullum, M. & Petrides, G., 2010. Bifrontal, bitemporal and right unilateral electrode placement in ECT: randomised trial. *The British Journal of Psychiatry, 196*(3), pp. 226–234. doi:10.1192/bjp.bp.109.066183

Lauber, C., Nordt, C., Falcato, L. & Rössler, W., 2001. Lay recommendations on how to treat mental disorders. *Social Psychiatry and Psychiatric Epidemiology, 36*(11), pp. 553–556. doi:10.1007/s001270170006.

Lauber, C., Nordt, C., Falcato, L. & Rössler, W., 2005. Can a seizure help? The public's attitude toward electroconvulsive therapy. *Psychiatry research, 134*(2), pp. 205-209. doi:10.1016/j.psychres.2004.07.010.

Leiknes, K. A., Schweder, L. J. & Høie, B., 2012. Contemporary use and practice of electroconvulsive therapy worldwide. *Brain and Behavior, 2*(3), pp. 283–344. doi:10.1002/brb3.37

McCall, W. V., 2001. Electroconvulsive therapy in the era of modern psychopharmacology. *International Journal of Neuropsychopharmacology. 4*(3). doi:10.1017/s1461145701002437

McDonald, A. & Walter, G., 2001. The Portrayal of ECT in American Movies. *The Journal of ECT, 17*(4), pp. 264–274. doi:10.1097/00124509-200112000-00006

McGregor, S., 2006. Roles, power and subjective choice. *Patient Education and Counseling, 60*(1), pp. 5–9. doi:10.1016/j.pec.2004.11.012

Moncrieff, J. & Cohen, D., 2006. Do antidepressants cure or create abnormal brain states? *PLoS Medicine, 3*(7), e240. doi:10.1371/journal.pmed.0030240

National Institute of Clinical Excellence (NICE)., 2003. *Guidance on the use of electro convulsive therapy*. London: NICE Press.

Olson, D. H., 2000. Circumplex model of marital and family systems. *Journal of family therapy, 22*(2), pp. 144-167. doi:10.1111/1467-6427.00144

Pagnin, D., de Queiroz, V., Pini, S. & Cassano, G. B., 2004. Efficacy of ECT in depression: a meta-analytic review. *The Journal of ECT, 20*(1), pp. 13-20. doi:10.1097/00124509-200403000-00004

Perreault, M., Paquin, G., Kennedy, S., Desmarais, J. & Tardif, H., 1999. Patients' perspective on their relatives' involvement in treatment during a short-term psychiatric hospitalization. *Social psychiatry and psychiatric epidemiology*, *34*(3), 157-165. doi:10.1007/s001270050128

Rajagopal, R., Chakrabarti, S., Grover, S. & Khehra, N., 2012. Knowledge, experience & attitudes concerning electroconvulsive therapy among patients & their relatives. *The Indian journal of medical research, 135*(2), pp. 201-210.

Rajkumar, A. P., Saravanan, B. & Jacob, K. S., 2006. Perspectives of patients and relatives about electroconvulsive therapy: a qualitative study from Vellore, India. *The Journal of ECT, 22*(4), pp. 253-258. doi:10.1097/01.yct.0000244237.79672.74

Read, J. & Bentall, R., 2010. The effectiveness of electroconvulsive therapy: a literature review. *Epidemiologia e psichiatria sociale, 19*(04), pp. 333-347. doi:10.1017/s1121189x00000671

Rose, D. S., Fleischmann, P., Wykes, T., Leese, M. & Bindman, J., 2003. Patients' perspectives on electroconvulsive therapy: systematic review. *British Medical Journal*, *326*(7403), pp. 1363. doi:10.1136/bmj.326.7403.1363

Rose, D. S., Wykes, T. H., Bindman, J. P. & Fleischmann, P. S., 2005. Information, consent and perceived coercion: patients' perspectives on electroconvulsive therapy. *The British Journal of Psychiatry, 186*(1), pp. 54-59. doi:10.1192/bjp.186.1.54

Rose, L. E., Mallinson, R. K. & Walton-Moss, B., 2004. Barriers to Family Care in Psychiatric Settings. *J Nursing Scholarship, 36*(1), pp. 39–47. doi:10.1111/j.1547-5069.2004.04009.x

Royal College of Psychiatrists., 2005. *The ECT handbook: the third report of the Royal College of Psychiatrist's Special Committee on ECT. xii*. London: Royal College of Psychiatrists.

Semkovska, M. & McLoughlin, D. M., 2010. Objective Cognitive Performance Associated with Electroconvulsive Therapy for Depression: A Systematic Review and Meta-Analysis. *Biological Psychiatry, 68*(6), pp. 568–577. doi:10.1016/j.biopsych.2010.06.009

Smith, J., A. & Osborn, M., 2007. Interpretative phenomenological analysis. In Smith, J., A., (ed.) *Qualitative psychology: A practical guide to research methods*. London: SAGE.

Smith, J., A., Flowers, P. & Larkin, M., 2009. *Interpretative phenomenological analysis: Theory, method and research.* London: SAGE.

Tversky, A. & Kahneman, D., 1981. The framing of decisions and the psychology of choice. *Science, 211*(4481), pp. 453-458. doi:10.1007/978-1-4613-2391-4_2

Wilkinson, C. & McAndrew, S., 2008. 'I'm not an outsider, I'm his mother!' A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings. *International journal of mental health nursing, 17*(6), pp. 392-401. doi: 10.1111/j.1447-0349.2008.00574.x

Wilson, G. & Daly, M., 2007. Shaping the Future of Mental Health Policy and Legislation in Northern Ireland: The Impact of Service User and Professional Social Work Discourses. *British Journal of Social Work, 37*(3), pp. 423–439. doi:10.1093/bjsw/bcm021

Table 2-A. Participant Demographics.

Pseudonym	Ethnicity	Relationship to SU	Age at time of ECT (years)	Year of ECT	Method of recruitment
Anna	Slovenian	Wife	39	2008	Social media
Aisha	British Asian	Daughter	19	2013	Social media
Eleanor	White British	Sister	53	2015	Social media
Colleen	White British	Mother	56	2008	Support group
Helen	White British	Daughter	44	2010	NHS
Sophie	White British	Daughter	22	1982	Social media

Appendix 2-A

Example of left hand notes forming right hand emergent themes in Anna's transcript.

Initial notes	Text	Emergent Themes
AN1. Her role changed from unaware and external to confronted and needing to act. Set her up as one of main protagonists.	R: Yeah, well, my husband actually was a little bit unwell and at the time I didn't really realise what was going on. He had quite a breakdown in 2007, February 2007, he just sat on the settee and wouldn't get up, said he wasn't going to survive the day, so we got him into the hospital and that was actually my first encounter with severe depression. He was in a hospital for 7 or 8 weeks I believe but at the end of it he was fine…. I think that's an important part of part of how we negotiated ECT at the time, at the end of it he was really fed up. He felt better, he wanted to go home, but he wasn't allowed and me being so completely clueless, I completely trusted everything that I was told as well. You want the best you can for the person. So he came home after about seven weeks, he was home for about two weeks, then back in and that was, I have to admit I still feel terrible about it, it was my worry, I was absolutely petrified that he's gonna…. I didn't sleep for those two weeks because he didn't sleep at night, he was at high risk, basically I was behind him. I had two small children as well, my daughter was three and my son would have been seven, erm, so I was really scared and he was talking about he doesn't want to live anymore. So in the desperation I again went to the psychiatric nurse as she was at the time and er, they actually said "just go in for the assessment. It's not going to be any problem, just go in for the assessment." Once he was there, the way that they explained again everything it was "yeah you have to stay in, it would be good". But the guilt I'm having, which I still feel terrible about, was, you know, "It'll be better for your wife, it'll be better for your children, it's affecting her" and he was in again, for six or, seven or eight weeks. I used to work, visit him every day and drop off my child at school, one, the other one bundled in the car, drive 50 miles, spend the day, back, pick the other child up, come back again in the afternoon with the other child, so it was quite an intense thing and he was again starting to feel better after a while. But they told him, "yes you're here voluntarily" they said (laughs) "however if you want to go you will be sectioned"!	Role changed from passive observer to actively involved Reflecting on crisis as a call to act Crisis defines mental illness Desperation as the catalyst for ECT ECT as a contested issue Was naïve to trust staff Just wanted the best for him Guilt – inability to cope Fear of continuing in unbearable situation Fear of suicide justifies ECT Desperation justifies ECT Staff give strategic information Guilt – her role as 'leverage' Chaos of caring Staff have the power Coercion
AN2. Difficult to see he was unwell at the time, but looking back this is different. "breakdown" = hard to ignore? Suggestive of a crisis that calls for action. Immediate risk to his life meant hospital was necessary.		
AN3. Crisis as first encounter with 'severe depression'. Defined as such by the crisis?		
AN4. How does "fed up" relate to negotiating ECT? **AN5. "negotiated" suggests ECT contested issue from start.** **AN6. Naivety = trusted professionals indiscriminately.** **AN7. Believed advice was the best for the person and that's all she wanted.** **AN8. Guilt as admitted due to her concerns.** **AN9. Petrified of suicide but hard for her to articulate this? No sleep due to monitoring his risk.** **AN10. Try to protect others in the family (children) who depend on her or her husband?** **AN11. Fear of husband completing suicide justifies ECT.** **AN12. Desperation as a call to action. Justify why went behind husband's back?** **AN13. Reassurances from staff. Selected info. No big deal? Does she feel lulled into false sense of security?**		
AN14. Guilt because her struggling to manage was used as leverage to admit him.		
AN15. Managing multiple demands including trying to visit husband in hospital. Need to show others how hard it is		
AN16. Hospital "intense" experience. **AN17. Catch 22 -Here voluntarily but will be sectioned if try to leave. Overt use of power. Laughter =disbelief/annoyance?**		

Appendix 2-B

Example of the development of one participant theme for Anna.

Theme title	Theme AN1: "He feels quite angry about it still now. It was false hopes" - Betrayal of coercion by powerful others
Contributing emergent themes	Decision influenced by strategic information from staff Staff minimise trauma of ECT Strategic information from staff Betrayed by staff strategic use of information ECT failure as betrayal by staff Staff coerce into ECT Staff minimise trauma of ECT Strategic information from staff Betrayed by strategic staff information Staff give strategic information – coercion Torture minimised by procedural changes Mistrust of staff increase need to advocate Staff could not be trusted Staff positioned as others Was naive to trust staff ECT closed process Indoctrination to staff way of thinking Good staff are a break from the norm Staff promoting understanding builds trust Staff have the power Learning as means to regain control Taking power back through negotiations Knowledge gathering in defiance of staff power Decisions shaped by external powerful influences Least powerful permission – needs permission from all to be involved Taking power through gathering information Power of services coercive but hold valuable resources Carer role puts him in powerless 'cared for' role Fear of staff power Knowledge as power Husband least powerful position – 'unwell' role = no voice Taking back power through empowering him Violated by power and lack of choice Resisting power – advocating role Taking power back by taking up an active role Powerless – lack of knowledge Power – person not asked Power – being 'done to' Decision can never belong to an individual alone – external influence Anger takes her voice Convincing herself she had to go along with ECT

Appendix 2-C

List of participant themes and narrative summaries.

Participant Themes	Narrative Summary of Theme
Theme AN1: "He feels quite angry about it still now. It was false hopes" - Betrayal of coercion by powerful others	This theme captures Anna's experience of coercion by the mental health professionals involved in the ECT process. Anna recalled that her husband was threatened with being sectioned if he decided to leave the hospital, despite being there as a voluntary patient. Anna believes that the staff gave her and her husband strategic information about ECT that she described as akin to persuasion to agree to the treatment. Anna felt naïve in hindsight because she trusted the staff initially; going along with the treatment because she believed it was the best for her husband based on the narrative from staff. Both her and her husband felt betrayed by staff when the ECT was unsuccessful because they felt as though the staff had given them false hope through the provision of positively biased information.
Theme AN2: "He was desperate, he was begging me to get him home" - The unbearableness of desperation as a call to action	This theme captures the desperation of the situation for Anna and her family at the point when ECT was introduced to them. Anna believes that the desperation for her husband to get better was the main catalyst for them agreeing to ECT and she described desperation as making her husband vulnerable to agreeing to the treatment. Desperation for Anna was also linked to her not knowing how to help and to her fears that if something did not change her husband may end his life. The sense of desperation that the couple faced was compounded by the narrative from staff that ECT was the only available option given that other options, mainly medication, had been exhausted. Anna's description of the situation as unbearable and needing to change set the context for the need for ECT. Anna describes feeling guilty about supporting the ECT but justifies the position she took by the unbearableness of the situation that she and her husband found themselves in.
Theme AN3: "I could not say anything to him because he had hope" - The importance of protecting hope from risky conversations	This theme captures Anna's belief that ECT gave her husband hope that things could change. Anna described her husband as holding a belief that ECT would help him and this gave him hope where previously he had felt hopeless. Anna disagreed with the use of ECT but felt unable to share her concerns at the risk of destroying her husband's hope. She felt that her husband's hope was what allowed her to continue to support the ECT even when she believed it was not working for him.

	Discussions between Anna and her husband about ECT were avoided because Anna believed this may have risked destroying his hope. Hope was considered important to Anna because she saw it as protective and believed that without hope, her husband would be at risk of further desperation, distress or suicide.
Theme AN4: "It's not like a broken electric machine" - Rejecting the medical paradigm of ECT	This theme captures Anna's intellectual explanation of ECT, which is how she makes sense of the supposed mechanisms of change behind ECT. Anna describes rejecting medicalised, individualistic explanations of distress that locate depression as a brain disorder. She describes her understanding of distress as a reaction to a person's experiences and interactions in the world. Anna rejects the idea that ECT can somehow fix a mechanical fault within a person's brain. The idea of ECT never fit into Anna's model of distress and she describes frustration at its use despite the lack of evidence for it. Anna feels that there must be a better way to relieve distress than ECT and her rejection of ECT has prompted her to retrain as psychotherapist, as this way of working fits with her understanding of the causes of distress.
Theme AN5: "it will be your decision, I will support you whatever you want to do" - The struggle of taking a position in the ECT process	This theme captures the complexity of Anna navigating her position within the ECT process. Anna's position in the process is at times dictated by the situation; for example she begins as a passive observer but her husband's crisis prompts her to move to an active role facilitating treatment. Anna's mistrust of the staff invites her to take an advocating role; however she describes the difficulty of having to prioritise her husband's position and minimise her own needs despite her reservations about his decision. The power inherent within the positions she takes changes throughout; she describes being allowed to speak on her husband's behalf which implies she has little power without such an invitation. In contrast, Anna took a more directive, decisive role at times when she perceived her husband was unable to do so, which resulted in her feeling more in control but she later discovered this left her husband feeling inadequate.
Theme AN6: "it was horrible…the man was shuffling feet…interaction was totally non-existent" - Psychological and relational consequences of ECT	This theme captures the psychological and relational impacts of ECT. Anna described struggling to see her husband displaying side effects following ECT. She talked about the pain of seeing her husband as a zombie and expressed sadness at the impact of ECT on her husband's ability to engage with their children, as she perceived them to have lost their father during treatment. Anna's own reaction to ECT was that it was horrible and barbaric, with little humanity. She described experiencing intrusive, distressing images based upon her experiences of ECT in the media. Anna described a distance between herself and her husband during the process. There was a sense that ECT reorganises relationships and puts pressure on couples. Her husband's memory loss was attributed to ECT and led to arguments and resentment between them, as well as leading to the loss

	of some of their story as a couple. Anna experienced guilt around the process of ECT, particularly around the idea that her burden or inability to cope may have contributed to her husband's decision to agree to ECT. Anna also expressed regret that she had not raised some of her concerns with her husband. She felt that their actions and decisions may have been based on assumptions about the other person, which led to resentment and guilt.
Theme AI1: "I was upstairs because I was never…liked listen to these things" – The effect of taking a passive, sheltered position	This theme captures Aisha's experience of being in a sheltered, passive position during the ECT process. Aisha described being sheltered as a consequence of her age and her position in the family as the youngest daughter. She believed that this position meant her parents did not involve her in discussions about ECT as they believed it was an adult discussion that could not be understood or appreciated by young people. Her parents feared that inviting Aisha to talk about ECT would cause her distress and there was a belief that distancing Aisha from the problem would be protective. Aisha described the impact of this sheltered position as causing her to feel shame and guilt at not having understood her Dad's situation. She also described shock and disbelief at first learning of the intention to use ECT as she had not known Dad had previously been unwell. It was difficult for Aisha to step out of this sheltered position, despite her wish to be more involved, due to the relative safety the position provided. However, she described multiple attempts to engage in information gathering and discussions about ECT, which shows an attempt to become more involved in the process. The distance was maintained between her and her Dad though, as discussions with him were avoided and Aisha sought all of her information and reassurance through Mum.
Theme AI2: "he wasn't happy with going for the treatment obviously because he didn't think he needed it" - Dad's position as the 'patient' meant his voice went unheard	This theme captures the discrepancy between Aisha's view of her Dad's position and how Aisha is able to dismiss Dad's perspective. Aisha's Dad refused ECT as he did not believe he had a mental health difficulty. Aisha describes Dad as inconsistent and helpless; therefore she doubts his view, allowing her to dismiss his version of the problem. Although Aisha acknowledges why her Dad may resist ECT in the abstract, she does not advocate for him or questioning the use of ECT, despite his clear protests and distress, because Aisha and the rest of her family view psychiatry and ECT as the solution. Aisha and her family are able to dismiss Dad's view because they prioritise the medical professionals view over Dad's, given his position as 'unwell'. Their investment in the medical model meant that once no medical explanation could be found for Dad's pain, they believed there was no reality to Dad's experience. The consequence of this is that Aisha's Dad is distanced from the family and Aisha perceives his refusal to have ECT as obstructive. Although in the abstract, Aisha acknowledges that people should not be forced to have ECT she does not see her Dad as having been forced, perhaps because she equates force with physical restraint. This is

	despite the fact that the family and powerful services ignore Dad's protests and threaten him with hospitalisation unless he complies with ECT. The use of powerful external services to overcome Dad's resistance is an example of how power was used to coerce in the absence of physical force. Such examples are dismissed by Aisha and her family given their positioning of Dad as the least reliable and least powerful person as a result of him being 'unwell'.
Theme AI3: "he's either got to comply with the ECT or he's got to end up being in hospital because that's how bad things are" - The severity of the situation justifies the use of ECT	This theme captures Aisha's description of the severity of the situation, which justifies the need for the use of ECT. Aisha described her Dad as skeletal as a result of his weight loss and she talked about him having lost his personality, which was particularly hard for her to see as she lost her father during that time. Dad was also described as highly distressed and crying out in pain, which seemed to be unbearable for the family to hear. Aisha described her Mum's desperation as she sought help for the family and was dismissed by her own GP despite struggling with her emotions. Aisha identified degrees of severity of mental health difficulties, distinguishing between Dad's illness and her description of her own difficulties as being "low". She believed that severe depression (illness) justified ECT. Aisha described services having exhausted all of their other options to help her Dad and so ECT was a last resort for her Dad because no other approaches had been successful. There was a sense in Aisha's account that ECT was necessary, therefore not a choice to be made.
Theme AI4: "after that he went and stuff and he did get better and everything, so yeah" - The outcome justifies the means. The family perceive ECT as the solution, therefore it is justified.	This theme captures Aisha's view that ECT was effective for her Dad, therefore the use of ECT was justified. Aisha and her family believed in ECT from very early on in the process given that Dad had had ECT previously and his recovery had been attributed to this. There was also a sense that ECT fit with Aisha's understanding of depression, which was evident through her use of medical language and the sense that psychiatry were looked to in order to provide the solution. The initial improvements that Aisha saw after the first two treatments seemed to allow her to dismiss Dad's refusal to attend on the basis that the treatment was working. Aisha described relief after seeing visible improvements in her Dad's eating and his ability to laugh and joke with the family, which she saw as her getting her Dad back. When Aisha did have doubts about whether ECT would be effective, she was reassured by her mother who believed in the treatment. Aisha described viewing ECT as no worse than any other treatment because it works for some people.
Theme AI5: "don't tell anyone your Dad's going for ECT, it's not nice" – The stigma of ECT can silence or prompt defiance.	This theme captures Aisha's experience of the stigma surrounding ECT. Aisha described her family as having been rejected by the community in the past because her Dad had been given ECT. Consequently, Aisha's had been ordered not to discuss ECT outside of the family because this would be unsafe, so there was a sense throughout Aisha's account that disclosing her experience of

	ECT was risky. Aisha believed that myths and media representations of ECT perpetuated the stigma surrounding it but she acknowledged ECT's troublesome history as a contributing factor to the negative narrative. However, Aisha justified her position on ECT by distancing it from these accounts, describing "new" ECT as entirely different to "old shock therapy". Aisha's anger and rejection of the demonization of ECT prompted her to speak out and advocate for ECT.
Theme E1: "he was feeling extremely desperate even after he had been admitted, it was difficult to get through the hours" - Desperation and the absence of meaningful choice	This theme captures Eleanor's perception of the situation as so severe and desperate that extreme measures were necessary to create change; however she was left feeling frustrated at the narrow range of psychiatric options available to them. Eleanor's brother had experienced little relief from his difficulties for a number of years and she described the despair of watching and waiting for improvements as "like running a marathon". Eleanor often made reference to the fact that her brother was at risk of ending his life and she described the severity of the risks involved as justification for the extreme measure that was ECT. In addition, Eleanor expressed dissatisfaction with the narrow range of options for helping her brother. Her brother disagreed with the impact medication had on his sense of self and it appeared to Eleanor as though ECT was the only other option available from psychiatry. She described the lack of therapeutic input on the ward, which she put down to cuts to funding, and described an ideal Scandinavian system of safety and sitting with someone in distress as an alternative that was not available in the NHS. Eleanor's perception that the situation was unbearable and therefore necessitated some action or intervention, coupled with her brother's refusal to continue with medication, appeared to leave them with no alternative and therefore no meaningful choice.
Theme E2: "he clearly wanted it, so it was better for him that I was supportive" – His consent was the key to her positive experience of ECT. Prioritising his voice over her own.	This theme captures the position that Eleanor took as a supporter for her brother, given that he had made his own decision to receive ECT and was willing to give his consent. Eleanor suggested that because her brother stated his wishes to have ECT, this allowed her to silence any initial concerns she had around ECT and support his decision as she believed this would make his life easier. Eleanor felt that consent was the most important factor in the ECT process that meant she was able to accept it. She believed that ECT should never be given without consent and that this would make the difference between experiencing ECT as relatively benign or as violating and inhumane. Given her brother was willing to give consent for treatment, Eleanor was able to accept his decision and this appeared to leave her less emotionally affected by the process of ECT herself. Eleanor described the distance between herself and the treatment as protective of her in that distance limited the intensity of her emotional reaction. She felt that if she had to watch someone have ECT, she would no longer feel so comfortable about her brother's decision.

Theme E3: "[My brother] seemed buoyed up by the prospect. He talked about one day getting a house in the country" - ECT gives hope for change	This theme captures Eleanor's view that ECT provided both her and her brother with hope that things would begin to improve. Eleanor described her brother as buoyed up by the prospect of having ECT and gave a striking example of him planning his future, where he had previously been relying on medication to make it through the hours. Eleanor described the effect of hope on her brother as extraordinary. She was also influenced by this herself and made a number of references to her own sense of hope that ECT would lead to improvements for her brother. However, Eleanor also described the catastrophic consequences of losing hope when treatments do not work. She felt that losing the hope that ECT would work left her brother feeling worse than he had previously and resulted in him being hospitalised again.
Theme E4: "I remember feeling like I was going in front of a firing squad just to walk into the room" - Power of psychiatric services	This theme captures the strength of power that Eleanor described within the inpatient ward staff and psychiatry in particular. Eleanor described a very strong sense of 'them and us' between her and the staff on the ward, often describing being ignored or excluded by them. She made many references to psychiatry prioritising their own agendas and offering only the choices that they wanted to offer for her brother. Eleanor talked about psychiatry as being inaccessible and belittling towards her, silencing her and withholding information from both her and her brother. She made many references to being at the mercy of staff on the ward. Eleanor described the way that they were treated by staff as violating and "like rape" because things were done to her and her brother without thought or explanation. Eleanor also described how the power of the service was maintained by silencing feedback from people. Eleanor herself felt she could not provide feedback out of fear of repercussions should her brother ever need to be hospitalised again in the future (this was the only available ward in his area). Eleanor described a desire to defy the power of services and sought to increase her involvement in ward rounds so that she could be there to protect her brother. Although she described this as akin to going in front of a firing squad, she wanted to be with her brother so that they could form a team of two against the powerful others.
Theme E5: "She mouthed platitudes and complacent statements but it wasn't like a human interaction, more like a robot" - Risk aversive and underfunded service context lacks humanity	This theme captures Eleanor's frustrations with the lack of humanity expressed by the staff and the service during the ECT process. Eleanor described a culture of risk aversion and box ticking as stifling any human interactions between staff and herself and her brother. She gave many striking examples of occasions where staff had acted rudely towards her because they had been focussed on completing forms and checklists. Eleanor believed that this "box ticking" culture endangered best practice for patients. Eleanor described staff as robotic, mechanical and inhumane in their interactions. She felt as though staff made no effort to understand the difficulty of her situation or to support her in any way. She described the care of carers as purely theoretical, not happening in

	practice and any attempts to seek her opinion were tokenistic and rushed. Eleanor described understanding some of the pressures on the staff as a result of underfunding in the NHS and a blame culture, whereby staff appeared concerned about being "hauled over the coals".
Theme E6: "Then from talking to my friend the psychiatrist I became quite pro it really and thought, gosh why don't they use it quite a lot more?" - Institutionalisation to ECT by influential others – how Eleanor came to accept the previously unacceptable	This theme captures the process by which Eleanor was institutionalised to accept previously unacceptable aspects of ECT through the influence of trusted others who provided selected information to her. Eleanor's initial ideas about ECT were that it was shocking, violent and inhumane and she likened it to slaughtering meat. She described holding her own moral and ethical 'rules' regarding situations that would justify ECT, including the idea that such an extreme action could only be justified if the effects were long lasting and led to significant improvement. However, each time Eleanor expressed concerns about an aspect of ECT, she was offered reassurance by "pro-ECT" friends and colleagues that minimised her concerns and led to her accepting previously unacceptable terms of ECT. For example, the influence of information from her "pro-ECT" friend, whom she described listening to because she had known him a long time, led to her reconceptualising ECT as a useful short acting treatment designed to "jolt" someone out of a difficult situation. This is in direct contrast to her initial instinctual ideas about when ECT could be justified. It appears that Eleanor was influenced by trusted others because not knowing what to do in the difficult situation made her feel helpless and in need of guidance from others. Eleanor then appeared to seek out selected information that fit with these new perceptions of ECT and dismissed more challenging, contradictory evidence (e.g. her other friends description of a "range of outcomes" and the side effects of ECT discussion with staff). This process also influenced Eleanor's brother, as Eleanor would feedback information from her friend to her brother as a means of reassuring him that the effects of ECT would not be significant. It was clear that her brother was often influenced by her and the information that she provided to him. The most striking example of this was when Eleanor saw the memory loss affecting her brother so significantly that her own reaction was to stop treatment, she was convinced by her friend that this was an insignificant reaction and would be unlikely to continue. Her friend convinced her that stopping treatment due to side effects was akin to giving up on the treatment and that she would then take responsibility for not having given it a proper trial. Eleanor then went back to her brother and reassured him about the memory loss, which led to him choosing to continue treatment despite his initial major concerns. This sense that Eleanor was institutionalised to accept things she had previously found unacceptable was also evident more generally in her experience of psychiatric services.
Theme E7: "that completely freaked him	This theme describes the impact of memory loss on Eleanor and her brother. Eleanor described the

out because he felt like he'd lost himself because he couldn't do anything" - Memory loss destroyed his sense of self	time she was most concerned about ECT as when she realised her brother was unable to finish a calculation he would usually be able to do. She seemed distressed by seeing her brother in such a way and she felt as though he had lost some of the ability that made up her brother. Eleanor also described her brother being "undone" by the memory loss when he went home on leave, as he was unable to remember any passwords or phone numbers. The impact of this memory loss meant that her brother did not feel safe to live independently as he had always done. Eleanor described the memory loss as destroying her brother's sense of himself as a bright and able young man. The distress that this memory loss caused him was so profound that he immediately returned to hospital and plunged back into depression. Eleanor described being unprepared for this given that she appeared not to have considered the side effects (these had been minimised by her friend and the staff on the ward). She also stated that staff did not consider the impact of cognitive impairments on her brother's ability to retain information and it had been up to her to provide written information about ECT, as he was unable to recall conversations he had with staff.
Theme E8: "I think it was a really valuable thing to do to be there for him" – Positive relational factors in the ECT process	This theme captures the positive consequences of the ECT experience on Eleanor's relationship with her brother. Eleanor felt that the need for them to form a team against the powerful staff strengthened their relationship. She believed that her brother would have been reassured by the fact that she was consistently supportive of him and she appreciated having to make more time to be with him during the process, as she "caught up with him" then. She described the human, relational factors around ECT as equally important to recovery as the process itself.
Theme C1: "I certainly wouldn't have chosen it but I didn't see any alternative to it" - Desperation leaves them with no choice but to have ECT	This theme captures the desperation of the situation for Colleen and how this left her feeling as though they had no choice but to use ECT. Colleen did not feel as though they had chosen ECT as she did not feel there was a choice to make; ECT was presented as the only option in a situation that was unbearable and needed to change. Colleen described feeling as though she had lost her daughter prior to ECT and she presented their situation as very desperate and severe. Colleen felt uncomfortable about many aspects of ECT, particularly having to section her daughter to give the treatment without consent, but she always qualified this by explaining that she felt as though there was no other option and something needed to change. Colleen described ECT as necessary rather than a choice. She described ECT as invasive but felt this was relatively benign in comparison to the "woeful" situation that it was hoped ECT would change.
Theme C2: "she'd twice improved quite a lot and then gone downhill, which is the reason why after the ECT it was still	This theme captures the role of hope in the ECT process for Colleen. Colleen described a cycle of improvements and setbacks leading up to the use of ECT which had given her hope but left her devastated and exhausted when the hope for recovery was dashed. Colleen described being

cautious optimism" - Fragility of hope throughout the ECT process	introduced to ECT at that time and this gave her hope that recovery was possible for her daughter. Colleen believed that change would not be immediate with ECT, therefore she did not lose hope when no initial changes were clear. However her hope was reinforced when she began to see small visible changes in her daughter after three treatments. Despite this, Colleen described that sense of hope as fragile even throughout the ECT process given their experiences of setbacks prior to ECT.
Theme C3: "I wouldn't say I was responsible I was just involved, I mean really it's for the doctors" - Taking and handing over positions of power and responsibility during ECT	This theme captures how Colleen was required to navigate changing positions of power and responsibility during the ECT process. Colleen described her daughter as helpless throughout the process, justifying the need for her to take responsibility for her daughter's care initially. She described herself as rescuing her daughter and taking an active position to seek out care on her daughter's behalf. Colleen then described a handing over of responsibility to the hospital staff and doctors once her daughter was hospitalised. Colleen accepted the power then lay with the doctors and she positioned herself as a supporter throughout the ECT, who was present but not responsible for or active in the decision making process. This handover of power left Colleen with mixed emotions of relief and worry. She described feeling relieved that someone else could take responsibility for them and that she did not have to handle decisions and care alone anymore. Colleen described her legal and family position as next of kin as giving her a sense that she had some protected power to be involved in the process and acknowledged by staff and doctors. However, there was also a sense that Colleen was, at times, the least powerful person in the system. Colleen described needing to be invited to be involved by her daughter and although this was often straightforward for them to navigate, there were times that confidentiality restricted her ability to be involved with the ECT process. In addition, Colleen felt that as a parent of an adult child, knowing how involved to be was a challenge. She described the difficulty of needing to allow her daughter privacy and taking up a slightly distanced position. However, distance from the ECT process was described as a luxury that Colleen did not enjoy to the same extent as her husband as a consequence of their differing roles in the process.
Theme C4: "if you want something out of people you don't go antagonising them do you" - The importance and power of relationships with staff	This theme captures the importance that Colleen placed on developing good relationships with staff throughout the ECT process. Colleen described developing good relationships through familiarity and through having a presence on the ward, which allowed staff to get to know her and trust that they could share information with her. Colleen believed that having information from staff helped to avoid the fear and distress that she may have experienced had she not known what was going on for her daughter during that time. Colleen therefore believed that good staff relationships served an important purpose for her and their function was to provide her with information and involve her in

	the process. However, this raised difficulties for Colleen when she noticed issues with her daughter's care on the ward. Colleen described feeling unable to raise these concerns with the staff for fear of jeopardising the relationship. This indicates that although Colleen was able to get her own needs met at times through developing relationships with staff, there was a sense that the staff held more power than her in those relationships, forcing Colleen to tread a careful line.
Theme C5: "it made sense when they explained about the epilepsy because I'd never really understood what ECT was for, then I was reasonably in favour" - Making sense of ECT is important to accepting it	This theme captures Colleen's attempts to develop an intellectual understanding of ECT that helped her to accept the rationale for its use. Colleen described feeling unsure about how ECT worked and it seemed that she had never considered ECT before until it became directly relevant for her and her family. Colleen was reassured by a doctor, who explained the origins of ECT to her and told her more about how it was developed (e.g. that epileptic fits appeared to help relieve depression). It seemed that developing an intellectualised understanding of ECT helped Colleen to accept the treatment as something that may lead to improvements for her daughter. Colleen's understanding of ECT seemed to fit with her existing understanding of her daughter's difficulties as something with a medical or biological basis that ECT could 'jolt' her daughter from. The use of language such as this throughout suggests that Colleen internalised the doctor's explanation of how ECT might work.
Theme C6: "you have to think in a practical way and only burst into tears at times when things really get on top of you" - Minimising her emotional needs as a result of the demands of caring.	This theme captures Colleen's experience of the demands of caring and shows how she minimised her own emotional needs in response in order to continue supporting her daughter through the ECT process. Colleen described the distress she experienced at seeing her daughter so unhappy. She talked about feeling unable to cope with the demands of everyday life as a result of the stress and burden of caring and she had to quit her job in order to be there to support her daughter. Colleen also found that caring left her with little spare capacity for the other relationships in her life. Despite the stress and burden of caring that she experienced, Colleen often dismissed her own emotional needs in order to support her daughter. An example of this was when Colleen was offered tranquillisers to help her sleep but she refused as she felt it was important she could drive to the hospital to be with her daughter. Colleen described caring for her daughter throughout the process as hugely stressful and difficult emotionally.
Theme H1: "The alternative was so bleak for mum that I thought well anything's worth a try" - ECT the last resort in a crippling situation	This theme captures Helen's experience of the "crippling" depression that her mum was experiencing and how the severity of the situation led to the use of ECT as a "last resort" treatment. Helen described the life threatening nature of her mum's difficulties and gave many examples that suggested her mum would not survive without intervention. Helen talked about her shock and despair at the pervasiveness of the depression and she described having lost all hope that anything

	could help her mum. Helen described her sadness at seeing her mum so "broken" and found it devastating when it seemed she had lost her mum as she knew her prior to ECT. The impact of the depression on Helen's bond with her mum was difficult for her to manage. Helen described how the severity of the situation as it was outweighed any potential risks of ECT and it was suggested at a time that Helen had no other hope remaining. Helen described ECT being framed as a "last resort" treatment as none of the usual medications had been successful. Helen believed that ECT was the only thing that may help her mum at that stage and the need to escape such a crippling situation prompted them to agree to ECT. Helen described only two options, ECT or remaining in the current unbearable situation, and she concluded that the alternative to ECT was far bleaker than the treatment.
Theme H2: "we do say to her it's your decision mum and if you choose, if you decide you don't want it it's your right to do…but you need to think about what's happened before" - Difficulty of maintaining a supportive position when you feel responsible	This theme captures Helen's struggle to maintain a balanced, supportive position for her mum whilst at the same time feeling responsible for protecting her best interests. Helen described many attempts to prioritise her mum's perspective over her own and she talked about encouraging her mum to make decisions about ECT for herself. At times, Helen described positioning herself alongside mum during the process, particularly when describing how they were both equally affected emotionally by the process. Helen believed that her role as a family member was to take up a position as supportive and reassuring to her mum but not to make decisions for her or put pressure on her to agree to ECT. However, despite her best attempts to maintain a supportive position, Helen acknowledged that her own positive experience of ECT and her emotional distress during the depression gave her a different perspective to her mum, therefore she may influence her mum as a result. The sense of responsibility Helen felt resulted in high levels of stress and tension when she felt powerless to help her mum. Helen described needing to take up a more active, involved position in the process at times because she felt responsible for Mum's wellbeing and felt she needed to act on her behalf, which she justified by making attempts to hold mum's best interests in mind. Helen appeared to struggle to maintain her idealised position as supportive as her sense of responsibility and belief in the benefits of ECT for her mum pulled her into a more directive, influential position at times.
Theme H3: "nothing's perfect and without risk but I know beyond doubt that she would not have the same quality of life if she didn't have it" - Beginning to accept ECT (part 1) – Visible benefits impact	This theme captures how Helen began to accept the previously unacceptable use of ECT through observing clear and visible benefits for both herself and her mum. Helen described seeing fast improvements in her mum in response to ECT, which she described as like switching a lightbulb back on. Helen believed that ECT gave her mum a quality of life and allowed her to function in a way that nothing else had been able to do previously. She believed that ECT completely blocked

future decisions	any depression for her mum and although she acknowledged it did not fix the underlying issues or solve problems with anxiety, the relief Helen felt was substantial. Helen described getting her mum back as a result of ECT, which was clearly hugely significant for her. Because Helen's experience of ECT was overwhelmingly positive, she believed that ECT was justified and necessary for her mum. Consequently, when maintenance ECT was suggested she agreed to this without question. Additionally, Helen dismissed the distress that her mum felt about ECT as insignificant given the benefits that she perceived ECT gave her mum. Helen acknowledged that her emotional investment in ECT made her more likely to be pro-ECT than the doctors involved in mum's care.
Theme H4: "from my point of view I think it's a good thing she has it, so whether I'm always completely even handed about it I don't know" - Beginning to accept ECT (part 2) – Being influenced and influencing Mum	This theme captures how Helen came to accept ECT as benign and reasonable based on reassurances from trusted members of staff and how she has gone on to influence her own mum in the same way. Helen initially believed that ECT was unacceptable but described coming to accept it as reasonable after being given information and reassurances from staff. Helen believed that the doctors advising her were offering balanced information about ECT based on an assumption that they were not emotionally involved and could be trusted to provide balance. Helen described many occasions where she had initial concerns about ECT but was reassured of its safety by staff members with whom she had good relationships. Helen described her changing attitude towards ECT as due to the doctor's reassurances and it was clear that Helen privileged the doctor's opinions over her own instincts. Helen described attempting to reassure her mum about ECT but worried that this also influenced her decisions about ECT. In fact, Helen did acknowledge that her own position on ECT meant that she influenced her mum by providing strategic information about the process, which may have influenced her mum's decision. Helen shared a few examples of occasions where she had dismissed mum's concerns and offered her own reassurances about ECT because those concerns conflicted with Helen's own experience.
Theme H5: "it was that it used to be electric shock-it just sounds quite a barbaric thing almost, it sounds very extreme and I thought oooh, shock treatment, no." - Beginning to accept ECT (part 3) – The role of emotive versus clinical language in 'old' versus 'new' ECT	This theme captures the importance of language in Helen's changing attitude towards ECT. Helen described perceiving a distinction between 'old' style electric-shock and 'new' style electro-convulsive therapy. Helen described not knowing what ECT was until it was described as "what used to be electric-shock", at which time she described experiencing horrific images of shock treatment in her mind. Helen found the idea of passing an electric current through the brain barbaric. She talked about highly emotive visions of Frankenstein's monster and used other fifties film references that she equated with the 'old' shock treatment. Helen described 'old' shock treatment as having negative connotations for her. However, 'new' ECT was framed as different to shock treatment, as staff had explained 'new' ECT using very clinical, practical language,

	emphasising the differences between what Helen knew from film and media depictions. Helen believed that removing the emotive language around 'old' ECT and using clinical, less emotive language led her to view ECT as more acceptable, despite the fact that the treatment still employs the same mechanisms that were initially so horrific to her. It was clear that Helen rejected the 'old' electro-shock and all of the traumatic, emotive language that she associated with it and she wanted to distance the clinical, reasonable ECT that she knew from the negative historical connotations.
Theme H6: "it is an emotional thing as well, I find it emotional anyway. It reminds me that mum is broken" - The emotional impact of ECT on Helen	This theme captures the emotional impact on Helen of supporting her mum through the ECT process. Helen felt strongly that relatives are closely affected by the emotional distress of their loved ones' and this was evident in her descriptions of her mirroring her mum's emotions throughout the process. Helen talked about the practical demands of ECT as time consuming and inconvenient for carers and she described needing help and support with issues such as paper work. She also described the loneliness and isolation that she felt when her mum was seriously unwell because she believed others struggled to understand severe mental health difficulties. As a result, Helen often found it reassuring to be around other relatives of people receiving ECT, who she felt could understand her feelings and experiences. Helen described ECT as an emotional process because it served as a reminder to her that her mum was "broken". She described sadness at seeing the same people going for maintenance treatment and knowing that they continued to struggle and had not recovered. Helen also described the stress and tension that comes from constantly looking out for and avoiding anything that may have distressed her mum, including avoiding risky conversations about ECT that she would have liked to have with her mum. Despite the immense emotional strain of caring, Helen repeatedly described attempts to dismiss her own needs in order to cope and continue supporting her mum. She believed that the need to carry on offering support day to day limited her ability to take time to reflect on the ECT process.
Theme S1: "we can't go on like this and so it's the lesser of two evils. To me it wasn't a choice" - ECT felt like the only option in a desperate situation	This theme captures the sense of desperation that Sophie felt and how this contributed to her belief that ECT was the only option for her mum. Sophie gave many striking examples of the severity of her mum's difficulties, including the life threatening nature of her behaviour. Sophie expressed great sadness at seeing her mum suffering and she described having lost the person she knew as her mum during this time. Sophie described a hatred of the hospital where her mum was cared for and she explained that she would have done anything to get her mum out. Sophie described seeing her mum in the hospital as more horrific than any treatment, including ECT. It was this desperation to get her mum back and out of the hospital that led Sophie to believe they could not continue as things were and that ECT was necessary. Sophie described dissatisfaction with medication as she

	felt they could not wait for these to work. She also noted that non-medical interventions, such as talking therapy, were dismissed by the consultants. Sophie therefore described ECT as the only option available and the last resort. She explained that seeing her mum so unwell in the hospital was worse than the thought of ECT, therefore ECT was described as the "lesser of two evils".
Theme S2: "it was going from a non-personal point of view, where you just see something random on a film, to a personal point of view when it's happening in your family" - Personal relevance necessitates distancing from the initial emotional response to ECT	This theme captures how Sophie's attitude towards ECT changed when it became personally relevant to her, causing her to distance herself from her initial emotional reaction to ECT in order to accept it. Sophie described learning of ECT from depictions in horror films prior to her mum becoming unwell. Sophie described that when she learnt of ECT in this abstract manner, she believed it was horrific and an awful thing to do to someone. She described her initial reactions as shaped by the traumatic images from films and so when ECT was first introduced with regards to her own mum, she perceived it as threatening. Her early conversations with the consultant were influenced by this view and she reflected that she may have attended to selective information based on her prior ideas about ECT. However, Sophie's attitude began to shift because of the personal investment she had in obtaining a treatment for her mum. Sophie described having to distance herself from the emotion surrounding ECT and "think sensibly" about it as an option for her mum. Sophie appeared to distance herself from the emotions surrounding ECT by telling herself that her mum was not herself and that she would not be aware of the treatment. This seemed to give Sophie some comfort. Sophie also appeared to distance herself from the traumatic images of ECT in films by creating a distinction between 'old' and 'new' ECT. Sophie described 'new' ECT as less barbaric, less catastrophic and more benign than 'old' ECT, which she associated with the scenes from horror films. By doing this, Sophie appeared able to accept the new ECT when she had previously felt unable to do so.
Theme S3: "I just wanted her to be my mum again and it didn't matter what she remembered" - The significance of memory loss is dependent on the relationship	This theme captures Sophie's reflections that the impact of memory loss from ECT affected her and other family members in different ways depending on the nature of the relationship. Sophie described feeling able to dismiss her mum's memory loss as insignificant because it did not affect her directly; Sophie could not recall her mum forgetting anything that was important within their relationship. Sophie did however reflect that her dad held a very different view that the level of memory loss her mum experienced was unacceptable. Sophie believed that the memory loss was significant for her dad because her mum forgot things that were very important to him and their relationship, therefore made up some of their story as a couple. She believed that memory loss could undermine marital relationships in a way that was less likely to impact on parent-child relationships. Sophie reflected that she couldn't understand her dad's position on memory loss as a

	young person at the time of the ECT; however since being married herself she appreciates the impact that memory loss could have on a couple's relationship and sense of connection.
Theme S4: "I wanted to ask questions and things and my dad didn't want to ask questions…and I ended up kicking off" - The difficulty of navigating her level of involvement in the ECT process	This theme captures the difficulty that Sophie experienced in navigating her position and involvement in the ECT process. Initially Sophie appeared to experience relief at handing over care of her mum to the hospital staff, however this became distressing for her when she perceived they were not caring in the same way that Sophie expected. Sophie sought reassurance and containment from staff but was left feeling lost and frustrated when this was not provided. This experience appears to have prompted Sophie to take up a more active position in the process, seeking out information and other avenues for involvement with professionals. Sophie described her mum as helpless and passive, which appeared to require Sophie to take a position of responsibility for protecting her mum. Sophie described striving to make decisions in her mum's best interests and advocating for her on the ward. Sophie positioned herself as active within the ECT process, seeking out information, asking questions and being directive in her views on how to help her mum. Sophie did however describe the difficulties that arose when other family members took different approaches to hers. For example, Sophie's dad was described as someone who was avoidant and did not wish to engage in the information gathering and decision making process around ECT. These different approaches caused conflict between her and her dad. Sophie described her dad's position as privileged legally, given that he was next of kin, however Sophie's belief that ECT was necessary prompted her to direct her dad and influence him towards agreeing to the treatment. Sophie believed that her dad may have benefitted from her directive position, as this would have given him more information on which to base his decision.
Theme S5: "they were the medical professionals and you were just the family…she's here now, you can visit her and then you go away" - The power of professionals to exclude her from the ECT process	This theme captures the power of the professionals to exclude Sophie and her family from the ECT process. Sophie described the psychiatrists as privileging their own perspectives over that of her and her family. This was particularly striking when the consultant privileged his own medical model of mental health and dismissed how Sophie had begun to make sense of her mum's difficulties based on her experiences. Sophie described feeling dismissed and unheard by professionals. She also gave examples of how she and her family were excluded from the process by staff withholding information from them. Although Sophie made some attempts to regain control by seeking a consultation with a psychiatrist, there was a sense that the family had to accept being excluded as inevitable given the status quo of services at the time. Sophie described the loneliness of being a family member ignored by the staff team at each visit to the ward. She described feeling frustrated and powerless throughout the process. Being excluded from the

	process by powerful professionals appeared to increase feelings of uncertainty and fear around the hospital and the ECT process.
Theme S6: "the kids at the school used to have this song about the local looney bin and I had no idea that that's where my mum went" - Stigma surrounding ECT leads to fear and rejection	This theme captures how the stigma surrounding mental health difficulties and ECT led people to be fearful of Sophie's mum. Sophie described feeling angry that others might hold this view whilst at the same time acknowledging that she hid her mum from her own children because she worried they may feel scared of her. This is an example of how stigma has been internalised by Sophie and is acted upon. Sophie appeared to struggle with her own preconceived ideas about what 'mental patients' must be like. There were a number of occasions where Sophie created distance between her mum and 'typical' mentally ill people, suggesting that she rejected the link between this stereotype and her idea of her own mum. Sophie explained that the stigma surrounding ECT meant her dad and others in her family avoided discussing ECT, which Sophie believed made the situation more difficult for her. She described the extended family as aware of the use of ECT but they avoided discussing it because it was "taboo". The impact of this was that she was able to seek practical support from extended family but never emotional support, which she may have found helpful. Sophie also noted how the stigma surrounding ECT silenced discussions within her immediate family as they each wanted to avoid upsetting the other. Although Sophie acknowledged this was done to protect others from risky conversations, she also believed talking about ECT more could have been helpful.

Appendix 2-D

List of how individual participants themes (in brackets) contributed to the development of overall themes (in bold);

Theme 1: You take the treatment because the alternative is just horrific

(AN2, E1, C1, H1, S1, AI3, AI4, H3, C2, AN3, E3)

Theme 2: Professional power silences resistance from relatives

(AN1, E4, E6, C4, H4, S5, AI2, E5)

Theme 3: Moving from emotional responses to pragmatic reasoning

(S2, H5, C5, AN4, S6, AI5)

Theme 4: Relatives' struggle to find a role in the ECT process

(AN5, AI1, E2, C3, H2, S4, C6)

Theme 5: ECT changes people and relationships

(E7, S3, AN6, H6, C6, E8)

Appendix 2-E

Author Guidance

MANUSCRIPT SUBMISSION

Thank you for your interest in International Journal of Mental Health Nursing. Please read the complete Author Guidelines carefully prior to submission, including the section on copyright. To ensure fast peer review and publication, manuscripts that do not adhere to the following instructions will be returned to the corresponding author for technical revision before undergoing peer review.

Note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium. Once you have prepared your submission in accordance with the Guidelines, manuscripts should be submitted online at http://mc.manuscriptcentral.com/ijmhn

We look forward to your submission.

EDITORIAL CONSIDERATIONS

Aims and Scope

The International Journal of Mental Health Nursing (IJMHN) is the official English journal of the Australian College of Mental Health Nurses Inc. The Editors welcome original articles dealing with current trends and developments in mental health nursing. The Editors are also looking for papers that will be widely read and cited, thereby having an international impact on mental health nursing education, practice and research. Papers submitted should be relevant to the Aims and Scope of the IJMHN and written in a manner that makes the relevance of content clear for IJMHN's international readership.

Review and Acceptance

The acceptance criteria for all papers are the quality and originality of the research and its significance and transferability to our readership. Except where otherwise stated, manuscripts are peer reviewed by two anonymous reviewers and the Editor. The Editorial Board reserves

the right to refuse any material for publication and advises that authors should retain copies of submitted manuscripts and correspondence as material cannot be returned. Final acceptance or rejection rests with the Editorial Board. There is no process of appeal against rejection and no further correspondence will be entered into regarding rejection decisions.

Manuscripts should be written so that they are intelligible to the professional reader who is not a specialist in the particular field. Where contributions are judged as acceptable for publication on the basis of scientific content, the Editor or the Publisher reserve the right to modify typescripts to eliminate ambiguity and repetition and improve communication between author and reader.

ETHICAL CONSIDERATIONS

Principles for Publication of Research Involving Human Subjects

Manuscripts must contain a statement to the effect that all human studies have been reviewed by the appropriate ethics committee and have therefore been performed in accordance with the ethical standards laid down in an appropriate version of the Declaration of Helsinki (as revised in Brazil 2013), available at http://www.wma.net/en/30publications/10policies/b3/index.html. It should also state clearly in the text that all persons gave their informed consent prior to their inclusion in the study. Details that might disclose the identity of the subjects under the study should be omitted.

All investigations on human subjects must include a statement that the subject gave informed consent and patient anonymity should be preserved. In general, submission of a case report should be accompanied by the written consent of the subject (or parent/guardian) prior to publication; this is particularly important where photographs are to be used or in cases where the unique nature of the incident reported makes it possible for the patient to be identified. While the Editorial Board recognises that it might not always be possible or appropriate to seek such consent, the onus will be on the authors to demonstrate that this exception applies in their case.

Authorship and Acknowledgements

The journal adheres to the definition of authorship set up by The International Committee of Medical Journal Editors (ICMJE). The ICMJE recommends that authorship be based on the following 4 criteria: i) Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; ii) Drafting the work or

revising it critically for important intellectual content; iii) Final approval of the version to be published; and i) Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Contributors who do not qualify as authors should be mentioned under 'Acknowledgements'.

Plagiarism Detection

The journal employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

Committee on Publication Ethics

The journal is a member of, and subscribes to the principles of the Committee on Publication Ethics (COPE).

MANUSCRIPT CATEGORIES AND WORD LENGTH

Note that word counts should include abstract and acknowledgements, but not table or figure legends and references. Longer manuscripts may be negotiated by the Editor In Chief in exceptional circumstances.

Original Articles: Original Articles should not exceed 5,000 words. The main text should be structured as follows: Introduction (putting the paper in context - policy, practice or research); Background (literature); Methods (design, data collection and analysis); Results; Discussion; Conclusion; Relevance for clinical practice. The number of words used, excluding abstract, references, tables and figures, should be specified. Pilot studies are not suitable for publication as original articles. We also ask that authors limit their references to 50 in total and all references must be available in English. We ask that you include all information required by the reporting guidelines relevant to your study. For example, use the CONSORT checklist for RCTs.

Review Articles: Qualitative and quantitative literature reviews on any area of research relevant to clinical nursing are welcomed. Submissions should not exceed 8,000 words. Quotes are included in the overall word count of the main text. Authors are advised to explain their methodology clearly (e.g., overall approach, literature search strategies, data analysis).

The PRISMA checklist and flow diagram should be used to guide manuscript development. Systematic review methods are evolving and authors are urged to cite supporting references. The main text should be structured as follows: Introduction; Aims; Methods; Results; Discussion; Conclusion; Relevance for clinical practice. We also ask that authors limit their references to 50 in total and all references must be available in English.

Commentaries and Responses to Commentaries: The Editor-in-Chief welcomes commentaries and Responses to commentaries on papers published in IJMHN. These should be approximately 500 words in length with a maximum of five references (including the original paper) and should offer a critical but constructive perspective on the published paper. All commentaries should be submitted via ScholarOne Manuscripts. Please follow our guidelines when writing a Commentary.

Discursive papers: including position papers and critical reviews of particular bodies of work which do not contain empirical data or use systematic review methods are also welcomed. Submissions should not exceed 5,000 words. These should be structured as follows: Aims; Background; Design (stating that it is a position paper or critical review, for example); Method (how the issues were approached); Conclusions; Relevance for clinical practice.

PREPARATION OF THE MANUSCRIPT

Pre-submission English-language editing

Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. Visit our site to learn about the options. All services are paid for and arranged by the author. Please note using the Wiley English Language Editing Service does not guarantee that your paper will be accepted by this journal.

Optimising Your Article for Search Engines

Many students and researchers looking for information online will use search engines such as Google, Yahoo or similar. By optimising your article for search engines, you will increase the chance of someone finding it. This in turn will make it more likely to be viewed and/or cited in another work. We have compiled these guidelines to enable you to maximise the web-friendliness of the most public part of your article.

Statistics

The advice of a statistician should always be sought for quantitative studies, and this person should be acknowledged in the acknowledgement section if the paper is accepted for publication. Where other than simple descriptive statistics are used, a statistician should be included as one of the authors and identified as such when submitting the paper.

Style

The journal uses UK spelling and authors should therefore follow the latest edition of the Concise Oxford Dictionary.

All measurements must be given in SI units as outlined in the latest edition of Units, Symbols and Abbreviations: A Guide for Medical and Scientific Editors and Authors (Royal Society of Medicine Press, London).

Abbreviations should be used sparingly and only where they ease the reader's task by reducing repetition of long, technical terms. Initially use the word in full, followed by the abbreviation in parentheses. Thereafter use the abbreviation.

Drugs should be referred to by their generic names, rather than brand names.

Parts of the Manuscript

The manuscript should be submitted in separate files: title page; main text file; figures.

Title page

The title page should contain:

(i) manuscript category

(ii) a short informative title that contains the major key words. The title should not contain abbreviations;

(iii) the full names of the authors;

(iv) the author's institutional affiliations at which the work was carried out;

(v) an authorship declaration: in keeping with the latest guidelines of the International Committee of Medical Journal Editors, each author's contribution to the paper is to be quantified;

(vi) the full postal and email address, plus telephone number, of the author to whom correspondence about the manuscript should be sent;

(viii) authorship statement;

(vii) acknowledgements;

(viii) disclosure statement;

(ix) word count,including abstract and acknowledgements, but not table or figure legends and references.

The present address of any author, if different from that where the work was carried out, should be supplied in a footnote.

Authorship statement

This must acknowledge i) that all authors listed meet the authorship criteria according to the latest guidelines of the International Committee of Medical Journal Editors, and ii) that all authors are in agreement with the manuscript.

Acknowledgements

The source of financial grants and other funding should be acknowledged, including a frank declaration of the author's industrial links and affiliations. The contribution of colleagues or institutions should also be acknowledged. Thanks to anonymous reviewers are not allowed

Disclosure

Authors must declare any financial support or relationships that may pose conflict of interest. This includes any financial arrangements authors have with a company whose product figures prominently in the submitted manuscript or with a company making a competing product.

Main text

As papers are double-blind peer reviewed the main text file should not include any information that might identify the authors.

The main text of the manuscript should be presented in the following order: (i) abstract and key words, (ii) text, (iii) references, (iv) tables (each table complete with title and footnotes), (v) appendices, (vii) figure legends. Figures and supporting information should be submitted as separate files.

Abstract and key words

Articles must have an unstructured abstract that states in 250 words or less the purpose, basic procedures, main findings and principal conclusions of the study. The abstract should not contain abbreviations or references. Five key words, for the purposes of indexing, should be supplied below the abstract, in alphabetical order, and should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list (http://www.nlm.nih.gov/mesh/meshhome.html).

Text

Authors should use subheadings to divide the sections of their manuscript as outlined for each article type.

References

• The Harvard (author, date) system of referencing is used (examples are given below).

• In the text give the author's name followed by the year in parentheses: Sago (2000).

• If there are two authors use 'and: Baskin and Baskin (1998); but if cited within parentheses write use '&': (Smith & Jones 2001).

• When reference is made to a work by three or more authors, the first name followed by et al. should be used: MacDonald et al. (2002).

• If several papers by the same authors and from the same year are cited, a,b,c etc should be inserted after the year of publication.

• In the reference list, references should be listed in alphabetical order.

• In the reference list, cite the names of all authors when there are six or fewer; when seven or more, list the first three followed by et al.

• Do not use ibid. or op cit.

• Personal communication, reference to unpublished data and publications from informal meetings are not to be listed in the reference list but should be listed in full in the text (e.g. Smith A, unpubl. data, 2000).

• All citations mentioned in the text, tables or figures must be listed in the reference list.

• Authors are responsible for the accuracy of the references.

References should be listed in the following form.

Journals

Meehan, T. (1994). Questionnaire construction and design for surveys in mental health. Australian and New Zealand Journal of Mental Health Nursing, 3, 59–62.

Books

Taylor, J. & Muller, D. (1994). Nursing adolescents: Research and psychological perspectives. Oxford: Blackwell Science.

Chapter in a book

Bergen, A. & Labute, L. (1993). Promoting mental health. In: A. Dines & A. Cribb (Eds), Health promotion: Concepts and practice (pp. 93–109). Oxford: Blackwell Science.

Electronic material

World Health Organisation (3 July 2003). Update 94: Preparing for the Next Influenza Season in a World Altered by SARS. http://www.international/csr/disease/influenza/sars. Accessed: 15 September 2003.

Tables

Tables should be self-contained and complement, but not duplicate, information contained in the text. Tables should be numbered consecutively in Arabic numerals. Each table should be presented on a separate sheet of A4 paper with a comprehensive but concise legend above the table. Tables should be double-spaced and vertical lines should not be used to separate columns. Column headings should be brief, with units of measurement in parentheses; all abbreviations should be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. The table and its legend/ footnotes should be understandable without reference to the text.

Figure legends

Legends should be self-explanatory and typed on a separate sheet. The legend should incorporate definitions of any symbols used and all abbreviations and units of measurement should be explained so that the figure and its legend is understandable without reference to the text.

Figures

All illustrations (line drawings and photographs) are classified as figures. Figures should be cited in consecutive order in the text. Figures should be sized to fit within the column (69 mm), intermediate (100 mm) or the full text width (144 mm).

Preparation of Electronic Figures for Publication: Although low quality images are adequate for review purposes, publication requires high quality images to prevent the final product being blurred or fuzzy. Advice on figures can be found at Wiley's guidelines for preparation of figures: http://authorservices.wiley.com/bauthor/illustration.asp

Supporting Information

Supporting information is not essential to the article but provides greater depth and background and may include tables, figures, videos, datasets, etc. This material can be submitted with your manuscript, and will appear online, without editing or typesetting. Guidelines on how to prepare this material and which formats and files sizes are acceptable can be found at: http://authorservices.wiley.com/bauthor/suppmat.asp.

Please note that the provision of supporting information is not encouraged as a general rule. It will be assessed critically by reviewers and editors and will only be accepted if it is essential.

SUBMISSION REQUIREMENTS

Manuscripts should be submitted online at http://mc.manuscriptcentral.com/ijmhn

• Two Word-files need to be included upon submission: A title page file and a main text file that includes all parts of the text in the sequence indicated in the section 'Parts of the manuscript', including tables and figure legends but excluding figures which should be supplied separately.

• The main text file should be prepared using Microsoft Word, doubled-spaced. The top, bottom and side margins should be 30 mm.

• Each figure should be supplied as a separate file, with the figure number incorporated in the file name. For submission, low-resolution figures saved as .jpg or .bmp files should be uploaded, for ease of transmission during the review process. Upon acceptance of the article, high-resolution figures (at least 300 d.p.i.) saved as .eps or .tif files will be required.

Associate your ScholarOne account with your ORCID iD

ORCID iD is a unique and persistent identifier that distinguishes you from every other researcher and connects you and your research activities. We encourage you to register for an ORCID iD and then associate it with your ScholarOne account. Click here to find out how.

COPYRIGHT, LICENSING AND ONLINE OPEN

Accepted papers will be passed to Wiley's production team for publication. The author identified as the formal corresponding author for the paper will receive an email prompting them to login into Wiley's Author Services, where via the Wiley Author Licensing Service (WALS) they will be asked to complete an electronic license agreement on behalf of all authors on the paper.

Authors may choose to publish under the terms of the journal's standard copyright transfer agreement (CTA), or under open access terms made available via Wiley OnlineOpen.

Standard Copyright Transfer Agreement: FAQs about the terms and conditions of the standard CTA in place for the journal, including standard terms regarding archiving of the accepted version of the paper, are available at: Copyright Terms and Conditions FAQs.

Note that in signing the journal's licence agreement authors agree that consent to reproduce figures from another source has been obtained.

OnlineOpen – Wiley's Open Access Option: OnlineOpen is available to authors of articles who wish to make their article freely available to all on Wiley Online Library under a Creative Commons license. With OnlineOpen, the author, the author's funding agency, or the author's institution pays a fee to ensure that the article is made open access. Authors of OnlineOpen articles are permitted to post the final, published PDF of their article on their personal website, and in an institutional repository or other free public server immediately after publication. All OnlineOpen articles are treated in the same way as any other article. They go through the journal's standard peer-review process and will be accepted or rejected based on their own merit.

OnlineOpen licenses. Authors choosing OnlineOpen retain copyright in their article and have a choice of publishing under the following Creative Commons License terms: Creative Commons Attribution License (CC BY); Creative Commons Attribution Non-Commercial License (CC BY NC); Creative Commons Attribution Non-Commercial-NoDerivs License (CC BY NC ND). To preview the terms and conditions of these open access agreements please visit the Copyright Terms and Conditions FAQs.

Funder Open Access and Self-Archiving Compliance: Please click here for more information on Wiley's compliance with specific Funder Open Access and Self Archiving Policies, and click here for more detailed information specifically about Self-Archiving definitions and policies.

PUBLICATION PROCESS AFTER ACCEPTANCE

Wiley's Author Services

Author Services enables authors to track their article through the production process to publication online and in print. Authors can check the status of their articles online and choose to receive automated e-mails at key stages of production. The corresponding author

will receive a unique link that enables them to register and have their article automatically added to the system. Please ensure that a complete e-mail address is provided when submitting the manuscript. Visit http://www.authorservices.wiley.com/ for more details on online production tracking and for a wealth of resources including FAQs and tips on article preparation, submission and more.

Proofs

Once the paper has been typeset the corresponding author will receive an e-mail alert containing instructions on how to provide proof corrections to the article. It is therefore essential that a working e-mail address is provided for the corresponding author. Proofs should be corrected carefully; the responsibility for detecting errors lies with the author.

Early View

The journal offers rapid speed to publication via Wiley's Early View service. Early View articles are complete full-text articles published online in advance of their publication in a printed issue. Early View articles are complete and final. They have been fully reviewed, revised and edited for publication, and the authors' final corrections have been incorporated. Because they are in final form, no changes can be made after online publication. Early View articles are given a Digital Object Identifier (DOI), which allows the article to be cited and tracked before allocation to an issue. After print publication, the DOI remains valid and can continue to be used to cite and access the article. More information about DOIs can be found at http://www.doi.org/faq.html.

POST PUBLICATION

Article PDF for authors

A PDF of the article will be made available to the corresponding author via Author Services.

Printed Offprints

Critical Review of "Relatives' experiences of 'last resort' interventions for people with mental health difficulties"

Reflections on the electroconvulsive therapy (ECT) process

Kerry Irving

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Correspondence should be addressed to:

Kerry Irving

Doctorate in Clinical Psychology

Furness College

Lancaster University

Lancaster

LA1 4YG

Email: k.irving@lancaster.ac.uk

The following paper will provide a critical appraisal of the empirical study titled ‘Relatives' experiences of 'last resort' interventions for people with mental health difficulties’. I will firstly present a brief overview of the thesis, including the research findings regarding relatives’ experiences of electroconvulsive therapy (ECT) and the literature review regarding relatives’ experiences of psychiatric hospitalisation. I will then outline the importance of researcher reflexivity in the research process and present reflections on my own position to the research question in relation to three key experiences; 1) my own family experience of ECT, 2) observing ECT within ECT services, and 3) engaging with the data.

Overview of the research findings

The interpretative phenomenological analysis (IPA) of six participant transcripts identified five key themes experienced by relatives during the ECT process. Participants described the role of powerful others, such as medical professionals and mental health staff, in silencing concerns about ECT using power and the provision of strategic information. Participants gave a sense of the desperation they experienced prior to treatment and described ECT as a last resort that offered them hope for change. Participants took part in a process of moving away from the stigmatising, emotive reactions to ECT, to the use of pragmatic reasoning. Participants described struggling to find their role in the ECT process as they were unable to ignore self-interest or an urge to protect their loved one, which led them to take an active role in decision making. Finally, relatives described the impact of ECT in changing people and relationships, which included a sense that memory loss could break down relationships and destroy their loved one’s sense of themselves.

Findings from the meta-synthesis of 14 studies regarding relatives’ experiences of psychiatric hospitalisation identified that relatives find seeking help frustrating and overwhelming, leading to conflicting emotions on their loved ones’ admission to hospital.

They struggled to navigate involvement with the hospital environment and were left having to reconceptualise their situation and come to terms with a different future for their family. This process was influenced by the power of services and the stigma of psychiatric hospitalisation, which left relatives isolated and excluded.

The findings raise a number of important implications for clinical practice and future research. Relatives' attitudes and experiences of ECT and hospitalisation were shaped through coercion and power; however mental health professionals, such as psychologists, are ideally placed to help relatives challenge the dominant biomedical model and make room for alternative discourses from families (Cutliffe & Happel, 2009). This is particularly important in challenging the 'last resort' narrative of ECT (Fisher et al., 2011). Furthermore, given the importance of constructing understanding of the ECT process, critical engagement with the evidence around ECT may support relatives, service users and professionals to better understand their relationships with the treatment. In addition, the sharing of knowledge between relatives and staff may benefit all involved by reducing exclusion of families from services and supporting their involvement in care processes.

Researcher reflexivity

To understand the importance of reflexivity in the research process, I will first explore how my role in the research has been shaped by my epistemological position and the methodology employed in order to address the research question. My experiences of co-creating understanding in my work as a clinician have led me to identify with a critical realist epistemology. Critical realism rejects the idea that accurate, objective knowledge of reality is possible and accepts instead that there are multiple perspectives of any one event, grounded in the particular perspectives or worldview of the person making sense of that experience. Therefore although we may say that reality exists independently of our own perceptions,

theories and constructions; our understanding of that reality is a construction based on our own perspectives (Archer et al., 2013). Related specifically to research, the implications of the critical realist approach are that reality cannot be accessed or observed directly but that we can have access to a version of this reality created through participants' subjective experiences of the event, in this instance, their experiences of ECT (Willig, 2001). However, Willig (2001) states that any interpretation made of the participants' accounts will also be based upon the researcher's own assumptions and experience.

Adopting the IPA approach, Smith and Osborn (2003) describe this process as the double hermeneutic; my role as the researcher involves making sense of the participant, who is making sense of their own experience. The IPA approach requires getting as close as possible to the experiences of the participant, whilst acknowledging that this can only be done through the researcher's own, experientially-informed lens (Smith, Flowers & Larkin, 2009). Smith et al (2009) state that in order to avoid imposing an external framework on the data, researchers must engage in reflective practices and a cyclical approach to analysis in an attempt to identify how their own preconceptions impact on the research. Berger (2015) argues that qualitative researchers need to understand the role of the self in the creation of knowledge and carefully monitor the impact of their biases, beliefs and personal experiences on the research. As a consequence of these recommendations, I began keeping a reflective journal during the research process in an attempt to monitor how my own position might impact on the research process. What follows are key learning points and examples taken from this journal, as well as notes made during supervision sessions and throughout the process of data analysis.

Personal experience

My initial interest in the research question came from my own experience of having a family member who had received ECT. Jenny (not her real name) had received ECT on three occasions during periods of what my family described as catatonic depression. All of Jenny's treatments had been given before I was born or when I was a young child, so I had not been aware of or involved in the process of her treatment at the time, although other immediate family members of mine had been. My family made a decision not to discuss Jenny's difficulties with me and my siblings as children, and it was only when I was an adult in my first year of studying psychology at university that I began to learn more from Jenny's daughter. At this point, the narrative within our family was that ECT had been life-saving for Jenny. Jenny's daughter described ardent support for the treatment and I remember being struck by her actively seeking out ECT when Jenny experienced difficulties later on in her life. I saw this as evidence that Jenny's daughter was entirely 'pro-ECT' and held no concerns or conflicts about its use; however she did describe different opinions within the extended family, which had led to disagreements about providing consent. Jenny never talked about her experiences of ECT as her memory for these periods had been significantly affected.

Although the narrative in my immediate family was predominantly 'pro-ECT', I struggled to integrate this with the knowledge I was developing through my own study in undergraduate psychology. During this time I was learning more about ECT, including the mechanisms and historical context, which left me feeling more uneasy about accepting ECT as completely harmless in the way that my family had described. I shared some of my participants' experiences of horror during those first few months of research, however I do believe now that the family narrative I had heard before this diminished the impact of this on me. Despite my reservations, by the end of my undergraduate career I remember thinking

that ECT was not ideal, but as it was only used in 'last resort' situations where nothing else worked, I considered it was perhaps a necessity given it had been life-saving for Jenny.

Over the next five years I spent more time professionally in clinical psychology services and began my training as a clinical psychologist, which led me to more critical engagement with the literature surrounding ECT. My understanding of mental health became increasingly concerned with the impact of experiences on wellbeing and I rejected the dominant biomedical model of mental health difficulties within which ECT sits. I became increasingly aware of alternative interventions and saw in my own clinical work that these were often successful in situations where people's difficulties had been given a label of 'medication-resistant' or 'chronic'. These experiences therefore undermined the assumption I had previously held that those treated with ECT needed it because nothing else could help them. The two seemingly opposite viewpoints that I had developed from my personal and professional experiences left me feeling confused and unsure about both perspectives. I was left wondering how other relatives would make sense of ECT; would they share a similar support for the treatment as I perceived within my own family, or would they also have dilemmas, conflicts and concerns as I did? It was at this point, where my own position felt unresolved and unstable, that I developed the research question and sought to explore how relatives made sense of the ECT process.

Although I held no firm 'pro' or 'anti' ECT agenda in approaching the research, my experiences undoubtedly influenced the areas that I was interested in and therefore contributed to the development of the research question and topic guide. From my own experiences, I wanted to find out whether relatives' attitudes towards ECT changed throughout the ECT process and I was also interested in whether family members ever disagreed about ECT, as had been the case in my own family. However, in asking these questions directly I was in danger of imposing my own narrative on the participants. Berger

(2015) argues that sharing an experience with study participants offers three advantages proposed by Padgett (2008) and Kacen and Chaitin (2006); easier access to and engagement with participants, a head start in knowing about the topic and an understanding of nuanced reactions of participants. However, caution on the part of the researcher should ensure that their own agenda is not prioritised to an extent that it blocks the hearing of other voices (Cloke et al., 2000). Wary of falling into this trap, I approached the research literature and explored existing theories of relatives' involvement in the ECT process so that I could broaden my research questions beyond those concerned with my own experience. I also sought input from others with experience of ECT, including clinicians and service users, who made up the management team for the research project and could advise on other areas of interest that I may not have identified from my reading or my own experience. Finally, I decided that the topic guide and interview style should be open and exploratory so that alternative narratives could emerge from participants' idiographic accounts. One technique that supported this was asking participants an initial opening question requesting some general background to their involvement with ECT, which often alerted me to salient areas of interest within their accounts that may have required further exploration. In taking this approach, I hoped to be able to explore the unique experiences of participants without imposing my own ideas to such an extent that their voices could not be heard.

Engaging with ECT services

My own uncertain position on ECT was then influenced by a number of key events during the research process, the first of which was an interaction with ECT services as I sought approval from the NHS Trust to recruit through their ECT clinic. The ECT lead for the NHS Trust rejected my initial recruitment documents, which contained the wording "electroconvulsive therapy (also known as ECT or electroshock treatment)", on the basis that the term 'electroshock' may be distressing to people attending the clinic. I had included the

term based on recommendations from service users and families that some potential participants may be more familiar with this; an idea that was eventually confirmed by Helen in her interview:

> When the term electroconvulsive therapy was mentioned I didn't actually know what that was and then so it was explained and it was that it used to be electric shock (Helen)

I sought advice from the Research Ethics Committee (REC), who supported the inclusion of the term 'electroshock' on the basis that it helped to ensure potential participants were fully informed about the nature of the treatment in question. Despite this, the ECT lead within the NHS Trust refused to accept the documents. I felt angry about this decision and perceived this as an attempt by the Trust to obscure the negative connotations and problematic historical narrative associated with ECT. Although I appreciated the need to protect people from distress, it seemed that the Trust were allowing strategic information regarding ECT and deliberately withholding information that may have been perceived as negative.

I was struck by the power of ECT services to control the information given to service users and families and wondered how this may have affected the process of providing consent to ECT. My own clinical experiences of supporting informed decision making and attempting to minimise the power imbalance in clinician-client relationships meant that I found this use of power and influence to be insidious and coercive. However, identifying and bracketing my own reaction to power and influence during interviews allowed some alternative views to be expressed; for example, Eleanor perceived the provision of overly-positive information from staff to be reassuring. Reflective supervision during this stage of

analysis was also helpful in identifying when my own assumptions had the potential to dominate the findings. For example, I initially described the process of receiving strategic information from staff as "institutionalising" participants to ECT. However, during discussions it became apparent that this term captured my own feelings about this process and had the potential to obscure the voices of people like Eleanor, who it is likely would not have chosen this language to describe her experience. Consequently, the theme title was revisited in order to more accurately capture the range of experiences of this process in the data.

Observing ECT

The second key experience for me in the research process was observing the administration of ECT. I had not planned or prepared for this experience and had not requested that I have access to this; however whilst visiting the clinic to discuss the research with staff, the lead psychiatrist suggested I might find it helpful to observe ECT in progress. I was told that I "really should" see ECT first hand given that I would be writing about it, which on reflection felt akin to pressure to agree to the observation. In the moment, I had little chance to think about whether I wanted to observe and certainly none of the staff appeared to consider that I might not. I was escorted through to the operating room before I had chance to acknowledge the invitation. There was no acknowledgement from the team that observing ECT might be distressing, I think because staff at this clinic genuinely did not believe this to be the case. In fact, I was struck by the light hearted atmosphere amongst the team, who went about their roles automatically and in a calm, clinical manner. This seemed in stark contrast to the fear and unease that I was experiencing as I waited to see the first person brought in for treatment.

I have since wondered why I felt unable to share my anxieties with the team at that point. I wondered whether my position as an outsider left me powerless, or whether the sense of

routine and inevitability about the way the procedure was conducted gave no room for questioning. The experience of observing was presented as somehow both necessary and insignificant, with the psychiatrist implying that it was important for me to see to inform my research, but at the same time failing to acknowledge that I may be influenced or affected by the process of observing. I wondered whether these experiences pointed towards a lack of critical engagement with the process on the part of the ECT service.

In discussions with the team later on, they seemed eager to share their own keen support for ECT and to dismiss any claims of harm or distress I may have heard. On reflection, it seems understandable then that they would not necessarily consider the potential for observing ECT to be distressing; however I was left wondering whether their own beliefs limited their ability to acknowledge the potential for relatives to be distressed by the process. I wondered whether the staff within the ECT system had become so accustomed to the procedure that it failed to hold any significance for them and was simply considered part of their role. I wondered whether the team often reflected on the procedure or whether they were so used to defending it to others like me that their automatic reaction was to do so without question or critical engagement with the arguments.

The act of observing ECT was particularly difficult for me. As people were brought into the room, I was struck by the fact that they all seemed to be older women and as they nodded and agreed politely with the staff who checked their details, I wondered whether this demographic are particularly vulnerable to the powerful influence of ECT services. Older females are certainly one demographic group disproportionately represented in ECT statistics (Buley et al., 2015). This perhaps reflects my understanding that male professionals (like the psychiatrist in this team) hold inherently more power than older females, even before considering the impact of the power imbalance between clinician and service user. My reaction to this was perhaps also influenced by the fact that these women shared many

demographics with Jenny. I recall feeling an overwhelming sense of sadness at the vulnerability of these women, which was reinforced as they were placed under general anaesthetic and given muscle relaxants to limit their movements. Standing over them during their treatment made them appear helpless and I recall feeling a strong sense of discomfort at the idea that my presence in the room might have made me complicit in this system.

As ECT was administered, I was struck by the incongruity between my perceptions of the seizure and the language of the clinical team. Despite the general anaesthetic and muscle relaxants, the seizures were clearly evident and I felt horrified at seeing this. It was hard for me to believe, having seen this, that people are not harmed by the procedure. However, the team around me were talking about the seizures having been of "good" or "therapeutic" durations. On reflection, this disparity is a good example of how our expectations and beliefs about ECT influence how we make sense of the treatment. Although we all saw the same procedure in progress, my response was very different as a result of my own understanding of what constitutes a "therapeutic" interaction, as well as my belief in the potential for ECT to cause harm and distress. I recall leaving the observation feeling drained and overwhelmed. My position had quickly shifted to one where I could not imagine a situation where I might find ECT to be acceptable.

Given this new position, I was aware that I could be in danger of imposing my own perspective on participants if I failed to fully explore alternative viewpoints to my own within the research interviews. During a conversation with my research supervisor I was able to explore this new position in more detail; however I did find that my experience of observing treatment drew me to be interested in certain aspects of participants' experiences. An example of this occurred during the interview with Eleanor, during which I was drawn to explore a particular reflection she made that resonated with my own experience regarding the language around seizures:

Eleanor: it seems pretty violent and of course, I haven't seen it happen. If I'd seen it happen that would probably make me a bit less sanguine about it, because I'm sure it doesn't look that pretty even with muscle relaxant and general anaesthetic. I mean at one point, in the ward round, when they said they hadn't achieved a therapeutic length of seizure, a few ward rounds after that I heard that they would read off the screen and say "oh yes, nine seconds visual, twenty or eighteen seconds by EEG" and apparently that wasn't good enough, it had to be twenty or twenty-one, I can't remember exactly but something like that. Well that's quite a long time to keep a brain fizzing or fitting or whatever it's doing isn't it? And if you imagine the people doing the treatment watching somebody fitting for nine seconds, even through a general anaesthetic and a muscle relaxant, it's not gonna look that wonderful, so it is quite a thing to do to somebody.

Kerry: I was just wondering about your feelings about that really, so about hearing things like the length of seizure and hearing people talk about a long seizure or not a long enough seizure. How was that?

I chose to follow up this particular reflection with Eleanor because it was an experience that also resonated with me following my observation of ECT. However, I was able to explore how Eleanor made sense of that by asking open, exploratory questions rather than falling into the trap of assuming that I understood the nuances of her experiences. This example demonstrates the importance of being aware of my own beliefs and biases in order to monitor them and allow participants to share different ways of making sense of similar experiences.

Engaging with the data

The importance of researcher reflexivity was particularly important during analysis and presentation of the findings, as it is at this stage that IPA requires an element of interpretation of the research data on the part of the researcher. One example of how I was required to bracket my own beliefs and assumptions during the process of analysis relates to the idea that ECT was viewed by relatives as a last resort. Participants all made references to the idea that ECT was the last available option for them and their relatives in the face of desperate circumstances. However, my understanding of the last resort narrative has also been informed by literature that is critical of this approach, suggesting that often non-medical alternatives have not been given an adequate trial (Fisher et al., 2011). In this case, it was important for me to be aware of the fact that my own ideas are the result of additional knowledge and training that many of the participants did not have access to. Therefore, it was important that during the analysis, I put aside my own position on the last resort narrative in order to reconnect with the feelings of desperation that the participants were voicing in their descriptions of this experience. The double hermeneutic cycle was helpful here, as it required that I go back to the interview transcripts to ensure that my interpretations were grounded in the data. Consequently, I focused on representing the desperation and lack of meaningful choice that participants expressed as part of their last resort narratives and later went on to offer my own critical analysis of this approach within the discussion of the research paper.

Conclusions

The importance of reflexivity in IPA research is well established and is considered of particular importance when the experience under examination is personally relevant (Berger, 2015). This paper has outlined how my own experiences of a family member receiving ECT

influenced my interest in the research question and contributed to the development of the topic guide. I have described how my relationship with ECT has been influenced by experiences in the research process, including engaging with ECT services and observing the use of ECT in clinic. Furthermore, I have shared examples from my reflective journal, supervision notes and transcripts of how I made attempts to monitor the impact of my own position on the data collection, analysis and presentation of findings. It is hoped that this transparency will allow readers to assess the rigor of the method used in this research paper.

References

Archer, M., Bhaskar, R., Collier, A., Lawson, T. & Norrie, A., 2013. *Critical realism: Essential readings*. London: Routledge.

Berger, R., 2015. Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), pp. 219-234. doi:10.1177/1468794112468475

Cloke, P., Cooke, P., Cursons, J., Milbourne, P. & Widdowfield, R., 2000. Ethics, reflexivity and research: Encounters with homeless people. *Ethics, Place & Environment*, *3*(2), pp. 133-154. doi:10.1080/713665889

Cutcliffe, J. & Happell, B., 2009. Psychiatry, mental health nurses, and invisible power: Exploring a perturbed relationship within contemporary mental health care. *International Journal of Mental Health Nursing, 18*(2), pp. 116–125. doi:10.1111/j.1447-0349.2008.00591.x

Fisher, P., Johnstone, L. & Williamson, K., 2011. Patients' perceptions of the process of consenting to electroconvulsive therapy. *Journal of Mental Health, 20*(4), pp. 347-354. doi:10.3109/09638237.2011.577116

Kacen, L. & Chaitin, J., 2006. "The Times They are a Changing" 1: Undertaking Qualitative Research in Ambiguous, Conflictual, and Changing Contexts. *The Qualitative Report*, *11*(2), pp. 209-228. Retrieved from http://nsuworks.nova.edu/tqr/vol11/iss2/1

Padgett, D., K., 2008. *Qualitative Methods in Social Work Research*. Thousand Oaks, California: Sage.

Smith, J., A. & Osborn, M., 2003. Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative Psychology: A Practical Guide to Methods*. London: Sage.

Smith, J., A., Flowers, P. & Larkin, M., 2009. *Interpretative phenomenological analysis: Theory, method and research*. London: Sage.

Willig, C., 2001. *Introducing Qualitative Research in Psychology: Adventures in theory and method.* Berkshire: Open University Press.

Ethics Section

Kerry Irving

Doctorate in Clinical Psychology

Division of Health Research, Lancaster University

Correspondence should be addressed to:

Kerry Irving

Doctorate in Clinical Psychology

Furness College

Lancaster University

Lancaster

LA1 4YG

Email: k.irving@lancaster.ac.uk

Thesis Protocol

What are relatives' experiences of supporting a family member receiving electroconvulsive therapy? A qualitative exploration

Kerry Irving

Lancaster University

Doctorate in Clinical Psychology

Electroconvulsive therapy (ECT) is a treatment recommended for people who experience difficulties consistent with a diagnosis of depression, catatonia or mania (NICE, 2003) although there is evidence that it is used in many other cases (Cresswell & Hodge, 2013). According to the Mental Health Act (2007) ECT should not be given to anyone without their consent; however this can be overruled if an appointed medical practitioner certifies that "the patient is not capable of understanding the nature, purpose and likely effects of the treatment; but that it is appropriate for the treatment to be given". In these cases where ECT is to be given to an individual without their consent, it is best practice to involve a person who speaks on behalf of the service user in decisions about their care (NICE, 2003). The Mental Health Act (2007) outlines the role of the service user's nearest relative, who it states should be consulted in any decision to give ECT to a person against their will.

A report by the ECT Accreditation Service (Cresswell & Hodge, 2013) found that of the 832 people given ECT whilst detained under the Mental Health Act (2007) between April 2012 and March 2013, 695 were assessed as lacking capacity to consent to the treatment. As the majority of people receiving ECT are deemed to lack capacity to consent, in most cases relatives should be included in supporting the service user to make decisions regarding ECT or in advising on their behalf. However research has shown that relatives of people given ECT can feel coerced into providing consent for their family member to be treated (Rajkumar, Saravan & Jacob, 2006). It is also unclear whether the opinions of relatives regarding ECT are similar to those of the service users receiving it, with some studies suggesting a significant difference between their perspectives (Rajkumar et al., 2006). In addition, research into the impact of supporting a family member receiving ECT shows that relatives feel they need more emotional support and information than they currently receive (Sethi & Williams, 2003).

Much of the research described above has been criticised for using measures that fail to take in to account the complexity of relatives' experiences. Rose et al. (2003) argue that this is because medical, clinician-led studies typically use overly simplistic questionnaire measures of factors such as satisfaction, efficacy and attitudes towards ECT. As a result, they recommend that more qualitative exploration studies are used to provide a richer narrative of families' experiences of supporting a relative receiving ECT.

Method

Design

This will be a qualitative project aiming to build on our understanding of relatives' and carers' experiences of supporting someone who is receiving ECT. Semi-structured interviews will be conducted with participants in order to generate a conversation around their own experiences and support needs. As there is little existing qualitative research in this area, topic areas for discussion will be as open as possible in an attempt to encourage participants to raise issues that are of importance to them.

The study will use an Interpretative Phenomenological Analysis (IPA) approach. IPA is suited to analysing people's lived experiences and takes a contextualist approach, acknowledging that people and their experiences must be considered within their wider contexts. Consequently, IPA is a suitable approach with which to consider the complex experiences of participants, which are undoubtedly shaped by the people and systems around them. Furthermore, IPA acknowledges the role of the researcher in interpreting the participant's accounts of their experiences and critically reflecting on the meaning that they make.

Participants

The study will aim to recruit between eight and twelve participants to allow for a detailed analysis of individual stories using interpretative phenomenological analysis (IPA). Smith and Osborn (2007) propose that IPA sample sizes should be limited to allow for detailed interpretative accounts of each case. They provide evidence of successful IPA studies using between one and fifteen participants but state that for student projects, the higher end of this range can be overwhelming and impractical. Therefore, a mid-range sample size between eight and twelve will still allow for detailed analysis within the time scale available for the study, whilst also meeting standards for publication.

If more than twelve potential participants express an interest in the research, the twelve participants that best meet the inclusion criteria will be asked to take part. This will be decided by the researcher using information from the expression of interest form regarding the potential participant's relationship to the person who received ECT. The Mental Health Act (2007) criteria for the identification of the nearest relative will be used as a hierarchy of inclusion (Appendix 4-A). Those relatives with relationships deemed to be at the head of this hierarchy (e.g. spouse, child, parent) will be invited to take part over those with other relationships (e.g. uncle, aunt, cousin). This process aims to ensure that participants are likely to be those relatives who have been or should have been most significantly involved with the person receiving ECT as judged by the Mental Health Act (2007). Any further potential participants will be thanked for their interest and offered the opportunity to receive a summary of the results once the study has been completed. Participants will be recruited through purposive sampling methods, in the sense that they will be recruited in accordance with the pre-specified inclusion criteria.

Inclusion criteria

Relatives and carers of people who have received ECT will be invited to take part if they have been involved in supporting their family member during treatment with ECT. For the purposes of defining the inclusion criteria for this study, the Mental Health Act (2007) guidelines for defining the nearest relative have been consulted to form a list of people likely to have a significant relationship with the service user receiving ECT (Appendix 4-A).

This study will explore the experiences of participants who were aged 18 or over at the time of their relative's treatment. The law dictates that adults will likely have a different role in supporting relatives through ECT than those under 18 years of age (and therefore, legally defined as children under the United Nations Convention on the Rights of the Child). For example, children under 18 years of age cannot legally act as nearest relatives under the Mental Health Act (2007) and therefore are not involved in the decision to give ECT in cases where their family member does not have capacity to decide. Consequently, only the experiences of adult relatives will be explored in this study to allow for a more homogeneous group of participants.

Participants will be excluded from the study if their relative is currently receiving ECT, due to the potential for the person's involvement in the research to unintentionally impact on the treatment of their relative. Furthermore, those people whose relatives have not yet completed their treatment will be unable to reflect on the full process of treatment in the way that we hope would be the case for participants in this project. Additionally, participants will be excluded from the study if their relative is currently an inpatient in a psychiatric hospital, due to the increased likelihood that their relative may receive further ECT treatments during the course of their inpatient stay. There will be no specified minimum length of time from the

end of treatment or discharge from hospital (whichever is later) and participation in this study.

Participants will be excluded from the research if they are unwilling to give consent to interviews being recorded, due to this being a requirement for accurate and auditable data analysis. Participants will not be required to provide information regarding their relatives, including identifiable information or clinical information e.g. diagnosis. Therefore, consent will not need to be taken from the people who have received ECT as the research will only focus on the experiences of their relatives.

To summarise, the inclusion criteria are as follows:

- Participants will have supported a relative/family member through ECT treatment (relative/carer is further defined in Appendix 4-A)
- Participants will have been aged 18 years or over at the time of their relative's treatment
- Participants' relatives will not currently be receiving ECT treatment or be inpatients in a psychiatric hospital
- Participants will agree to interviews being audio recorded

Materials

The information sheet (Appendix 4-B) and consent form (Appendix 4-C) to be shared with potential participants are attached. The topic guide details the potential areas for discussion within the interview (Appendix 4-E). Potential topics to discuss include participants' understanding of and attitude towards ECT generally, their experience of supporting their relative through ECT and their reflections on the decision to use ECT for

their relative. However because previous research is limited in this area, the researcher will be primarily led by the experiences of the participant and the guide will be used as a basis to begin discussions rather than as a prescribed list of questions.

The researcher will liaise with the project management team with regards to the design and wording of all documents to be used in the research.

Procedure

Recruitment of participants

The study will use a two-step recruitment approach, with the first wave focusing on recruitment through NHS Trusts and the second wave involving recruitment through online resources and social media. The second wave of recruitment online will be implemented in the event that the minimum recruitment target is not met through recruitment via NHS services.

Step one – Recruitment through NHS services

The research will require approval to advertise within [redacted] and [redacted]. Recruitment to the study will be supported by an existing working group of staff members within these NHS Trust with a particular focus on ECT, including Dr Stephen Mullin (Consultant Clinical Neuropsychologist, [redacted]) who has agreed to offer advice on recruitment strategies. The working group will also advise on key events and training days where the research could be promoted amongst staff working with relatives and carers of people who have received ECT.

Advertising posters (Appendix 4-D) will be displayed in the waiting rooms of relevant mental health services including community mental health teams. These posters will include details

of the inclusion criteria, the requirements of the study and the contact details of the lead researcher. The researcher will also attend staff meetings at the relevant mental health teams to engage staff in promoting the research with service users and their families. In the event that a relative or carer is informed of the research by NHS staff, the staff member will be asked to briefly introduce the research and provide an information sheet. The staff member will also give the potential participant an expression of interest (EOI) form (Appendix 4-F) and a freepost envelope. The potential participant will write their name and contact details on the EOI form and post this back to the lead researcher. The researcher will not approach any relative or carer directly. At each stage, the member of staff and the researcher should make it clear that participation is optional and that their decision to refuse or consent to participation will not affect their treatment or the care of their relative in any way.

Stage two – online recruitment

Recruitment will begin online if recruitment targets have not been met through NHS recruitment processes within four weeks. A short online advertisement (Appendix 4-G) will be posted outlining the research question and contact details for the lead researcher. This advertisement may be posted on online forums and support groups for relatives and carers providing that the administrators of such websites approve this. The advertisements may also be posted to social media sites including Twitter. In accordance with the BPS guidelines for ethical practice in psychological research online (2007), the researcher will create a dedicated professional profile on any social media websites used so that personal social media profiles are not connected with the research.

Consent procedure

Once the researcher has received an expression of interest in taking part from a potential participant, the researcher will telephone them to discuss the study. The researcher will send

a copy of the study information sheet and consent form by post or email to the participant if they have not already received a copy. The researcher will then also arrange a time to visit the potential participant at their home or at another NHS location. This meeting should be arranged to allow time for the potential participant to receive the information sheet and consent form and have a minimum of 24 hours to consider the information.

At the meeting, the researcher will give the potential participant an opportunity to read through the information sheet and will answer any questions that they may have about the study. The potential participant should also be reminded that they are able to withdraw at any time up to the point of submitting the research for assessment and/or publication and that this will not affect their treatment or the care of their relative in any way. If the potential participant has received all of the information they require and has decided to continue with taking part, they will be asked to sign the consent form in the presence of the researcher. The researcher will then also sign the consent form.

Interview procedure

Participants will be asked to participate in a single face to face semi-structured interview lasting approximately one hour in length. The participant will be informed that the researcher will begin recording the interview once the participant has signed the consent form and recording will continue until the end of the meeting. During this interview, the researcher will collect demographic information and will then ask the participant some questions about their experiences of supporting their relative through ECT. The participant will be given the opportunity to take comfort breaks throughout the interview and advised that they may stop at any time.

At the end of the interview the researcher will debrief the participant, giving them the opportunity to add any comments about the process or ask any questions about what was

discussed during the interview. The researcher will also check the wellbeing of the participant, particularly if distressing issues were discussed during the interview. If either the participant or the researcher feels the participant requires further emotional support, this will be discussed between them and a plan agreed upon. Possible actions may include advising on contact details for listening services such as the Samaritans. In the debrief participants will also be asked if they wish to receive a copy of the themes identified in order to give feedback on the appropriateness of these themes. Their decision should be documented on their consent form and a method of contacting the participant should then be agreed and documented.

Data storage and transcription

After leaving the interview, the researcher will transfer the audio recording to a password protected file on the secure University server as soon as is reasonably possible. The file will be named only with the anonymous participant number assigned to that participant. Consent forms and written demographic information including minimum contact details for feedback (telephone number, email address or home address) will be stored separately to any written notes made in the interview, which will be assigned the same anonymous participant number so that they can be identified by the researcher if needed at a later date. The paper documents will be stored for the duration of the study in two separate locked filing boxes at the home of the researcher.

The audio recordings will be transcribed verbatim by the researcher into an electronic Word document. The electronic document will not contain any identifying information or demographic information and will be saved only with the anonymised participant number as a password protected file on the secure university server. In instances where a paper copy of

the transcription is required (e.g. for supervision purposes) the paper copy will be destroyed immediately following its use.

Audio data collected as part of the study will be shared with Dr Suzanne Hodge and Dr Stephen Weatherhead, supervisors of this project, so that they are able to monitor the quality and adherence to ethical standards of the researcher. Anonymised written transcripts of the interviews may also be shared with Dr Suzanne Hodge and Dr Stephen Weatherhead so that they can provide supervision of the analysis and interpretation of data.

Following the completion of the study and feedback to participants, all contact information will be destroyed. Consent forms will be scanned and stored electronically and paper copies destroyed. The electronic consent forms will then be stored along with all transcription documents, raw data and coded data produced during analysis on the password protected secure University server monitored by the DClinPsy administration team. This electronic data will be stored by the University for ten years after the completion of the study.

Proposed analysis

Following the interviews, the audio recordings will be transcribed verbatim by the researcher. The transcripts will be analysed using IPA based on the stages of analysis proposed by Smith, Flowers and Larkin (2009). They suggest that progression through these stages "will not be a linear one" (Smith et al., 2009, p.80) but should always be based on the process of moving from descriptive accounts of the data to interpretive analysis.

Given the idiographic approach required in IPA, each participant's transcript will be analysed individually before moving on to subsequent cases. The first stage of this analysis involves repeated reading and familiarisation with the transcript. Following this, initial exploratory notes will be made on the content and language used within the transcript.

Moving on to the third stage, the exploratory notes will be condensed to produce emergent themes that reflect the participant's original words in combination with the researcher's interpretation of these. The fourth stage will involve searching for connections across the emergent themes so that higher level, super-ordinate themes may be identified. Once this stage has been completed to sufficient depth for this transcript, the researcher will move on to analysing the next transcript using the same process. Once all of the transcripts have been individually analysed, the researcher will search for patterns or higher order concepts that the cases share.

Once the analysis has reached this stage, the researcher will contact participants who have agreed to provide feedback in order to share the themes and ask them to comment on the appropriateness of them. Comments at this stage will not be included as part of the original data transcriptions but may be used to revisit themes where appropriate.

Practical Issues

Participants will be given the option of the researcher visiting them at their own home to conduct interviews, where it is safe and reasonable to do so (e.g. travel to and from the interview can be completed comfortably in one working day). It is hoped that this will be more convenient for participants and therefore allow more people to access the study. However the researcher acknowledges that there may be occasions where home visits are not feasible, for example due to the participant feeling uncomfortable. In these cases, the researcher will arrange to meet the participant at a convenient venue such as another NHS clinic, General Practitioners surgery or community facility where there is a suitable bookable space for conducting private one to one interviews.

For home visits and visits at any other base, the researcher will work in line with [redacted] Lone Worker Policy including operating a 'buddy'

system. The researcher will nominate a buddy who will be another trainee clinical psychologist employed by [redacted]. The researcher will give the buddy details of the location of the visit, the name, address and contact details of the participant, and details of the researcher's contact numbers and car make, model and registration number. These details will be given to the buddy in a sealed envelope so that they will not be seen by the buddy except in the case of an emergency.

The researcher will give the buddy the arranged start and end times of the meeting and will make a telephone call to the buddy at the arranged end time to confirm that they have left the meeting and are safe. It is the responsibility of the researcher to call the buddy at the earliest opportunity in the event that the interview is expected to run over the proposed end time. If the researcher fails to call the buddy to confirm that they are safe, the buddy should attempt to contact the participant in the first instance and if the researcher cannot be traced, they should call the police and pass on the details of the visit. In the event of an emergency where the researcher cannot leave the visit, the researcher will call the buddy and say "Could you let Ste know I am running late for our meeting?" In this instance, the buddy should call the police to attend the visit location. Once the researcher has confirmed they have left the visit safely, the buddy should destroy the envelope and the enclosed visit information.

For participants who need to travel to a base to attend the interview, travel expenses up to the value of £20 will be offered by the Lancaster University Clinical Psychology Doctorate programme. No other financial incentives or payments will be offered for taking part in the study.

There may be instances, particularly if online recruitment is implemented, where it is not reasonable for the researcher to visit the participant in person due to the distance needed to

travel and the costs of such a journey. In these instances, the researcher will arrange to complete the interview via the telephone.

Ethical Issues

Recruitment

The researcher will not approach any potential participant directly in an attempt to recruit them for the study, as this is likely to place undue pressure on them to take part. Posters giving details of the study will be displayed in waiting rooms so that potential participants will be able to contact the researcher directly if they are interested in receiving further information. Potential participants may also be approached by NHS staff working with their relative if a pre-existing relationship is in place between the staff member and the potential participant. The member of staff can provide details of the study and pass the potential participants information sheets where appropriate. The NHS staff will be asked to make it clear that there is no obligation for them to take part in the research and that by choosing to do so or not, their treatment and the care of their relative will not be affected. The potential participant will then be given an EOI form so that they can contact the researcher directly if they wish to do so.

For online recruitment, the researcher will not make contact with any individual directly in an attempt to discuss the research. The online advertisement will be shared on social media and may be posted to online forums or support groups, only with the express written permission of the administrators of such sites. The researcher will only use her university email address or specially created professional profile to engage in discussion online with potential participants.

Consent and confidentiality

Potential participants will be given a minimum of 24 hours to consider the information sheet before they meet with the researcher as this should allow them adequate time to read the information and make a decision on whether or not to take part. At each stage of contact, the researcher will give the potential participant the opportunity to ask any questions and the opportunity to say no to participation in the study if they wish. At the meeting where the interview will take place, the researcher should read through the information sheet and consent form again and check that the potential participant understands the information before both parties sign the consent form.

On occasions where participants are recruited and interviewed using online methods (e.g. telephone interviews) the researcher will post consent forms to the participant with prepaid envelopes so that the participant can sign and return the consent forms in advance of the online interview taking place. The researcher will take care to make it clear to participants recruited online that they must be over the age of 18 to take part.

Potential risks

Although the aim of the study is not to directly address the wellbeing or mental health of participants, there is a possibility that the interviews may cause participants to reflect on potentially emotional topics with regards to their experiences supporting relatives through ECT, which may cause participants to experience some distress. The researcher will remind the participant at the start of the interview that they may stop at any time if they wish, either to take a rest break or to terminate the interview entirely. The researcher will also take steps to minimise distress by allowing opportunities for comfort breaks and reacting sensitively towards participants.

If the researcher becomes concerned for the welfare of the participant during the interview, they will stop the interview process and discuss with the participant options for supporting

their wellbeing. These options potentially include giving advice for support networks such as the Samaritans. In the unlikely event that participants become extremely distressed and the researcher does not believe it is safe to leave the participant alone, the researcher will accompany the participant to accident and emergency or stay with them until the appropriate services are able to attend.

Because the aim of the study is to explore participants' experiences of their relative's treatment, it is possible that the researcher could be made aware of unacceptable or unethical professional practice. If this happens, the researcher will seek advice from her research supervisor in the first instance and escalate the concerns if it is agreed that this is necessary for the protection of service users, staff or the public. If concerns are identified that do not require escalation but would be helpful for services to be aware of, this will be fed back to the appropriate services as part of the dissemination process on completion of the research. This feedback will be in a general form, anonymised and with no reference to specific individuals or teams.

Analysis and publication of results

All participant quotes will be anonymised in the final report in order to protect the identity of participants. Participants will be asked to choose a pseudonym so that their quotes can be appropriately referenced in the main report. Once the study results have been written up, the researcher will feed back the results to participants by circulating the results by email or post and attending team meetings to present the findings to relevant services. This is an important step of the research process because it is in this way that the research findings may be used to improve practice in the future.

Project Management

The study will be completed by the lead researcher and chief investigator, Kerry Irving, with the support of the project management team. Dr Stephen Weatherhead and Dr Suzanne Hodge from Lancaster University will offer supervision of the project from the perspective of the academic institution and the profession of clinical psychology, including a focus on the methodological rigour and adherence to ethical practice. Project management will also be offered by Gerry Bennison and Bethan Mair Edwards, who are experts by experience with an interest in research exploring ECT. Bethan and Gerry have previously been involved in publishing in academic journals, acting as lay and peer reviewers and contributing to research ethics committees (REC). The project management team will meet monthly to discuss the progress of the project and provide input into next steps.

Timescale

ACTIVITY	**DATE**
Submit ethics proposal	July 2015
Data collection	Sep – Dec 2015
First draft of intro and method ready	January 2016
Data analysis	Dec 2015 – Feb 2016
Submit final report to Lancaster University	March 2016
Submit paper for publication	July 2016

References

Braun, V. & Clarke, V. (2013). *Successful qualitative research: a practical guide for beginners.* London: SAGE.

British Psychological Society (2007). *Report of the working party on conducting research on the internet: Guidelines for ethical practice in psychological research online.* Leicester: BPS.

Cresswell, J. & Hodge, S. (2013). *ECT Minimum Data Set: Activity Data Report England and Wales.* London: ECTAS.

Mental Health Act (2007). Retrieved October 1, 2014, from http://www.opsi.gov.uk/acts/acts2007/ukpga_20070012_en_1

National Institute of Clinical Excellence (NICE). (2003). *Guidance on the use of electro convulsive therapy*. London: NICE Press.

Rajkumar, A. P., Saravanan, B., & Jacob, K. S. (2006). Perspectives of patients and relatives about electroconvulsive therapy: a qualitative study from Vellore, India. *The Journal of ECT*, *22*(4), 253-258.

Rose, D., Fleischmann, P., Wykes, T., Leese, M., & Bindman, J. (2003). Patients' perspectives on electroconvulsive therapy: systematic review. *British Medical Journal*, *326*(7403), 1363.

Sethi, S., & Williams, R. A. (2003). The family caregiving experience of outpatient ECT. *Journal of the American Psychiatric Nurses Association*, *9*(6), 187-194.

Smith, J., A. & Osborn, M. (2007). Interpretative phenomenological analysis. In Smith, J., A., (ed.) *Qualitative psychology: A practical guide to research methods* (p.56). London: SAGE.

Smith, J., A., Flowers, P. & Larkin, M. (2009). Interpretative *phenomenological analysis: Theory, method and research.* London: SAGE.

Appendix 4-A

Definition of Relative/Carer for Inclusion Criteria

Taken from the Mental Health Act 2007; these guidelines detail who can act as nearest relative for a service user. Those individuals that meet these parameters will be considered relatives or carers and therefore will meet the inclusion criteria for the purposes of this study. Additionally, partners who do not live with the service user but who have had a substantial role in supporting the service user through ECT will also be included. Paid carers and those supporting service users in professional capacities will be excluded.

List of who is your nearest relative

- Husband, wife or civil partner (including cohabitee for more than 6 months).
- Son or daughter
- Father or mother
- Brother or sister
- Grandparent
- Grandchild
- Uncle or aunt
- Nephew or niece
- Someone you have lived with or who has cared for you for at least 5 years
- Half blood relatives (like a half brother or sister)
- Adoptive relatives (like an adoptive mother or father)

Appendix 4-B

Participant Information Sheet

What are relatives' experiences of supporting a family member receiving electroconvulsive therapy? A qualitative exploration

My name is Kerry Irving and I am conducting this research as part of my training on the Doctorate in Clinical Psychology programme at Lancaster University.

What is this study about?

The purpose of this study is to learn more about the experiences of people who have been involved in supporting their relative through treatment with electroconvulsive therapy (also known as ECT or electric shock therapy). We hope to find out how people feel about the process, including their own level of involvement with the person and decisions about their care, and whether or not they feel they received enough support and information.

Why have I been approached?

You have been approached because the study requires information from people who have supported a relative, partner or close friend who has been given ECT. To take part in the study, you should have been 18 years or over when your relative received ECT.

Do I have to take part?

No, it is completely up to you to decide whether or not you want to take part in the study. If you decide not to take part, your medical care and legal rights will not be affected.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to meet with me for a one-off interview. This can also be done online or by telephone if you live a long way away. At the meeting you will have the chance to ask any questions about the study and if you are happy, I will ask you to sign a consent form indicating that you have agreed to take part.

I will then ask you some questions about your experiences of supporting your relative through ECT and the interview should last around one hour, although this can vary. You are welcome to take comfort breaks at any time and you should be aware that you can stop at any time during the interview without giving a reason.

I will use a mobile audio recorder to record the interview. This is important so that I can type up what you have said accurately after we have met. After all of the interviews have been completed, I will look at what you and other participants have said and see if there are any

common themes. At this point, I would like to contact you again by email or post to check that the themes I have found make sense to you.

If you decide you would like to withdraw from the study, you are welcome to do so without giving a reason. If you withdraw up to two weeks following the interview your data will removed from the study and will be destroyed, however if you withdraw after this point the data will remain in the study.

Will my data be confidential?

The information you provide will be confidential. The information you give for the study will be stored securely and only the researchers conducting the study will have access to it.

- Audio recordings will be deleted after they have been typed up, checked and analysed.
- Any paper copies and consent forms will be kept in a locked filing cabinet for the duration of the study.
- Electronic files will be stored on a secure drive and password protected so that no-one other than the researcher can access them.
- At the end of the study, all paper copies will be destroyed and the electronic files will be stored by Lancaster University on a secure drive for 10 years.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Direct quotations from you may be used in the reports from the study but these will also be anonymised so your name will not be attached to them. The researcher will make sure you cannot be identified in any reports.

There are limits to confidentiality. If what is said in the interview makes me think that you or someone else is at significant risk of harm, I would need to speak to my research supervisor and possibly other services that might help support you. Wherever possible, I will speak to you first if I have to do this.

Who will know if I decide to take part?

The researcher involved in the study will know that you have decided to take part. The relative that you supported through ECT does not need to know that you are taking part. The study is focusing on your experiences and you will not need to discuss personal information about your relative.

What will happen to the results?

The results will be summarised and written up into a report which will be submitted to Lancaster University for assessment. The report may also be submitted for publication in an

academic journal. If you would like to receive a copy of the final report, please make the researcher aware of this.

Are there any risks?

There are no risks identified with participating in this study. However, if you experience any distress during or following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?

There are no direct benefits to taking part, although you may find participation interesting.

Who has reviewed the project?

This study has been reviewed and approved by the North West NHS Research Ethics Committee at (INSERT MEETING HERE) and by the (INSERT TRUST HERE) Research and Development Department.

Where can I obtain further information about the study?

If you have any further questions about the study, please contact the main researcher:

Kerry Irving

Email: k.irving@lancaster.ac.uk Mobile: To Be Confirmed

Research Supervisor: Dr Suzanne Hodge, Lecturer

Email: s.hodge@lancaster.ac.uk Phone: 01524 592712

Field Supervisor: Dr Stephen Weatherhead, Clinical Psychologist

Email: s.weatherhead@lancaster.ac.uk Phone: 01524 592974

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Jane Simpson, Research Director and Senior Lecturer

Email: j.simpson2@lancaster.ac.uk Phone: 01524 592 858

Doctorate in Clinical Psychology

Division of Health Research

Furness Building

Lancaster University

Bailrigg

Lancaster

LA1 4YG

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Professor Bruce Hollingsworth, Head of the Division of Health Research

Email: b.hollingsworth@lancaster.ac.uk Phone: 0 1524 594154

Division of Health Research

Furness Building

Lancaster University

Bailrigg

Lancaster

LA1 4YG

Resources in the event of distress

Should you feel distressed either as a result of taking part or in the future, the following resources may be of assistance.

Samaritans	**Mind**
www.samaritans.org.uk	www.mind.org.uk
08457 90 90 90	0300 123 3393
	Text 86463
Rethink Mental Illness	**Sane**
www.rethink.org.uk	www.sane.org.uk
0300 5000 927	0845 767 8000

Thank you for taking the time to read this information sheet.

Appendix 4-C

Consent Form

What are relatives' experiences of supporting a family member receiving electroconvulsive therapy? A qualitative exploration

You have been asked to take part in a research project that aims to find out more about your experiences of supporting a relative receiving electroconvulsive therapy (ECT). Before you consent to participating in the study, we ask that you read the participant information sheet and take the opportunity to ask the principal investigator any questions you may have. Then please read each statement below and mark the box with your initials if you agree.

	Please initial each box
1. I confirm that I have read the information sheet and fully understand what is expected of me within this study.	☐
2. I confirm that I have had the opportunity to ask any questions and that they have been answered to my satisfaction.	☐
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.	☐
4. I understand that audio recordings will be kept until the research project has been examined.	☐
5. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care and legal rights being affected.	☐
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn.	☐
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.	☐
8. I consent to be contacted by the principal investigator for the purposes of reading and providing feedback on her interpretation of my data.	☐
9. I consent to information and quotations from my interview being used in reports, conferences and training events.	☐

10. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with her research supervisor. ☐

11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

12. I consent to take part in the above study. ☐

Name of Participant……Signature....…….Date…….

Name of Researcher……Signature…….Date……

Appendix 4-D

Do you have a family member who has received electroconvulsive therapy (also known as ECT or electric shock therapy)?

Were you involved in supporting them through their treatment?

If so, we would be interested in hearing about your experiences as part of a research study.

If you;

- Have supported a relative who was receiving ECT
- Were aged 18 or over at the time that they received treatment
- Would be interested in taking part in a one-off interview about your experiences

Please contact the principal investigator, Kerry Irving, on the details below.

Kerry Irving, Lancaster University
Email: k.irving@lancaster.ac.uk
Phone:

Kerry Irving, Lancaster University
Email: k.irving@lancaster.ac.uk
Phone:
Kerry Irving, Lancaster University
Email: k.irving@lancaster.ac.uk
Phone:
Kerry Irving, Lancaster University
Email: k.irving@lancaster.ac.uk
Phone:
Kerry Irving, Lancaster University
Email: k.irving@lancaster.ac.uk
Phone:
Kerry Irving, Lancaster University
Email: k.irving@lancaster.ac.uk
Phone:
Kerry Irving, Lancaster University
Email: k.irving@lancaster.ac.uk
Phone:
Kerry Irving, Lancaster University
Email: k.irving@lancaster.ac.uk
Phone:
Kerry Irving, Lancaster University
Email: k.irving@lancaster.ac.uk
Phone:

Appendix 4-E

Topic Guide

- Background to research; purpose of interview, any questions?
- Background questions
    - Describe your relationship with the person receiving ECT
- What were your ideas about ECT prior to your relative having it?
    - Where did the ideas come from?
    - Had there ever been discussions within the family about ECT?
- What were your feelings on learning of the intention to treat your relative with ECT?
    - Did you have any concerns?
    - Did you feel relief or similar?
- Were you involved in making the decision for your relative to have ECT?
    - Either way, how did that feel?
    - Would you like more/less say?
- Did you have any information or support whilst your relative had ECT?
    - Where did that come from?
- Has your involvement in supporting your relative through ECT had an impact on you?
- Has your involvement in supporting your relative through ECT had an impact on your relationship with that person?
- If appropriate, what could have helped you?
- Debrief and thanks

Appendix 4-F

Expression of Interest Form (EOI)

Do you have a family member who has received electroconvulsive therapy (also known as ECT or electric shock therapy?)

Were you involved in supporting them through their treatment?

If you are interested in taking part in a one off interview about your experiences, please enter your details and return this form in the addressed freepost envelope provided.

Alternatively, you can contact the researcher, Kerry Irving by email at k.irving@lancaster.ac.uk or by text or phone call to (enter research number here).

Name……..

What is the best way to contact you? Phone/Email (delete as appropriate)

Telephone number…….

Email address……

What is your relationship to the person who received ECT? ……

……

How old were you when you supported your relative through ECT? (If they have had ECT more than once, please say how old you were during the most recent treatment)

……

Appendix 4-G

Online advertisement

Have you been involved in supporting a family member who was having electroconvulsive therapy (ECT)? We would like to hear about your experiences. Email k.irving@lancaster.ac.uk for more info.

Appendix 4-H

IRAS Ethics Form

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
Relatives' experiences of ECT

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product

( ) Clinical investigation or other study of a medical device

( ) Combined trial of an investigational medicinal product and an investigational medical device

( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

( ) Basic science study involving procedures with human participants

( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

(●) Study involving qualitative methods only

( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

( ) Study limited to working with data (specific project only)

( ) Research tissue bank

( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

	Yes	No
a) Does the study involve the use of any ionising radiation?	( )	(●)
b) Will you be taking new human tissue samples (or other human biological samples)?	( )	(●)
c) Will you be using existing human tissue samples (or other human biological samples)?	( )	(●)

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[✓] England
[ ] Scotland
[ ] Wales
[ ] Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

England

Scotland

Wales

Northern Ireland

This study does not involve the NHS

4. Which review bodies are you applying to?

NHS/HSC Research and Development offices
Social Care Research Ethics Committee
Research Ethics Committee
Confidentiality Advisory Group (CAG)
National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

Yes No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

Yes No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

Yes No

If yes, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP) and you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before completing and submitting other applications.

6. Do you plan to include any participants who are children?

Yes No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

Yes ○ ◉ No

9. Is the study or any part of it being undertaken as an educational project?

Yes ◉ ○ No

Please describe briefly the involvement of the student(s):
The study will form part of a doctoral thesis for the Doctorate in Clinical Psychology at Lancaster University

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

Yes ◉ ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes ○ ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes ○ ◉ No

Application Form for Research involving qualitative methods only

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Relatives' experiences of ECT

Please complete these details after you have booked the REC application for review.

REC Name:
NorthWest-LiverpoolCentral

REC Reference Number:
15/NW/0679

Submission date:
07/08/2015

A1. Full title of the research:

What are relatives' experiences of supporting a family member receiving electroconvulsive therapy? A qualitative exploration

A2-1. Educational projects

Name and contact details of student(s):

Student 1

	Title	Forename/Initials	Surname
	Mrs	Kerry A	Irving
Address	Doctorate in Clinical Psychology, Division of Health Research		
	Furness Building, Lancaster University		
	Bailrigg, Lancaster		
Post Code	LA1 4YG		
E-mail	k.irving@lancaster.ac.uk		
Telephone	07557796021		

Give details of the educational course or degree for which this research is being undertaken:

Name and level of course/ degree:
Doctorate in Clinical Psychology

Name of educational establishment:
Lancaster University

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Suzanne	Hodge
Address	Division of Health Research		
	Furness Building, Lancaster University		
	Bailrigg, Lancaster		
Post Code	LA1 4YG		
E-mail	s.hodge@lancaster.ac.uk		
Telephone	01524 592712		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	**Academic supervisor(s)**
Student 1 Mrs Kerry A Irving	Dr Suzanne Hodge

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

Student

Academic supervisor

Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Mrs	Kerry A	Irving
Post	Trainee Clinical Psychologist		
Qualifications	BSc Applied Psychology		
Employer	Lancashire Care NHS Foundation Trust		
Work Address	Doctorate in clinical Psychology, Division of Health Research		
	Furness Building, Lancaster University		
	Bailrigg, Lancaster		
Post Code	LA1 4YG		

Work E-mail k.irving@lancaster.ac.uk

* Personal E-mail
Work Telephone 07557796021
* Personal Telephone/Mobile
Fax

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Ms	Debbie	Knight
Address	Research Support Office		
	B Floor, University House		
	Lancaster University, Lancaster		
Post Code	LA1 4YW		
E-mail	ethics@lancaster.ac.uk		
Telephone	01524592605		
Fax			

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):
Sponsor's/protocol number:
Protocol Version:
Protocol Date:
Funder's reference number:
Project website:

Additional reference number(s):

Ref.Number	Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

Yes ( ) ( ) No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, this summary will be published on the website of the National Research Ethics Service following the ethical review.*

Relatives are often called on to represent the wishes of a family member in cases where the person cannot consent to treatment using electroconvulsive therapy (ECT). Despite the need for involvement of relatives, evidence suggests that relatives often do not share the same opinions as the service users and many feel they are not given enough information or support throughout the process. Additionally, many relatives struggle with the psychological impact of supporting someone who is receiving ECT and the impact on the individual, as well as their relationships, has not been explored.

This will be a qualitative project aiming to build on our understanding of relatives' and carers' experiences of supporting someone receiving ECT. Participants will be eligible to take part if they have supported a family member through ECT and were aged 18 or over at the time. Semi-structured interviews will be conducted with eight to twelve participants in order to improve our understanding of their experiences and support needs.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Recruitment

The researcher will not approach any potential participant directly in an attempt to recruit them for the study, as this is likely to place undue pressure on them to take part. Posters giving details of the study will be displayed in waiting rooms so that potential participants will be able to contact the researcher directly if they are interested in receiving further information. Potential participants may also be approached by NHS staff working with their relative if a pre- existing relationship is in place between the staff member and the potential participant. The member of staff can provide details of the study and pass the potential participants information sheets where appropriate. The NHS staff will be asked to make it clear that there is no obligation for them to take part in the research and that by choosing to do so or not, their treatment and the care of their relative will not be affected. The potential participant will then be given an EOI form so that they can contact the researcher directly if they wish to do so.

For online recruitment, the researcher will not make contact with any individual directly in an attempt to discuss the research. The online advertisement will be shared on social media and may be posted to online forums or support groups, only with the express written permission of the administrators of such sites. The researcher will only use her university email address or specially created professional profile to engage in discussion online with potential participants.

Consent and confidentiality

Potential participants will be given a minimum of 24 hours to consider the information sheet before they meet with the researcher as this should allow them adequate time to read the information and make a decision on whether or not to take part. At each stage of contact, the researcher will give the potential participant the opportunity to ask any questions and the opportunity to say no to participation in the study if they wish. At the meeting where the interview will take place, the researcher should read through the information sheet and consent form again and check that the potential participant understands the information before both parties sign the consent form.

On occasions where participants are recruited and interviewed using online methods (e.g. telephone interviews) the researcher will post consent forms to the participant with prepaid envelopes so that the participant can sign and return the consent forms in advance of the online interview taking place. The researcher will take care to make it clear to participants recruited online that they must be over the age of 18 to take part.

Emotional burden

Although the aim of the study is not to directly address the wellbeing or mental health of participants, there is a possibility that the interviews may cause participants to reflect on potentially emotional topics with regards to their experiences supporting relatives through ECT, which may cause participants to experience some distress. The researcher will remind the participant at the start of the interview that they may stop at any time if they wish, either to take a rest break or to terminate the interview entirely. The researcher will also take steps to minimise distress by allowing opportunities for comfort breaks and reacting sensitively towards participants.

If the researcher becomes concerned for the welfare of the participant during the interview, they will stop the interview process and discuss with the participant options for supporting their wellbeing. These options potentially include giving advice for support networks such as the Samaritans. In the unlikely event that participants become extremely

distressed and the researcher does not believe it is safe to leave the participant alone, the researcher will accompany the participant to accident and emergency or stay with them until the appropriate services are able to attend.

A6-3. Proportionate review of REC application *The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.*

○ Yes - proportionate review ◉ No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply*:

☐ Case series/ case note review
☐ Case control
☐ Cohort observation
☐ Controlled trial without randomisation
☐ Cross-sectional study
☐ Database analysis
☐ Epidemiology
☐ Feasibility/ pilot study
☐ Laboratory study
☐ Metanalysis
☑ Qualitative research
☐ Questionnaire, interview or observation study
☐ Randomised controlled trial
☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

What are relatives' experiences of supporting a family member receiving electroconvulsive therapy?

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

Not applicable

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

According to the Mental Health Act (2007) ECT cannot be given to anyone without their consent; however this can be overruled if the person is assessed as lacking capacity to make this decision and the treatment is considered "appropriate". In these cases, it is best practice to involve a person who speaks on behalf of the service user in decisions about their care (NICE, 2003). The Mental Health Act (2007) outlines the role of the service user's nearest relative, who it states should be consulted in any decision to give ECT to a person against their will.

A report by the ECT Accreditation Service (Cresswell & Hodge, 2013) found that of the 832 people given ECT whilst

detained under the Mental Health Act (2007) between April 2012 and March 2013, 695 were assessed as lacking capacity to consent to the treatment. As the majority of people receiving ECT are deemed to lack capacity to consent,

in most cases relatives should be included in supporting the service user to make decisions regarding ECT or in advising on their behalf. However research has shown that relatives of people given ECT can feel coerced into providing consent for their family member to be treated (Rajkumar, Saravan & Jacob, 2006). It is also unclear whether the opinions of relatives regarding ECT are similar to those of the service users receiving it, with some studies suggesting a significant difference between their perspectives (Rajkumar et al., 2006). In addition, research into the impact of supporting a family member receiving ECT shows that relatives feel they need more emotional support and information than they currently receive (Sethi & Williams, 2003).

Much of the research described above has been criticised for using measures that fail to take in to account the complexity of relatives' experiences. Rose et al. (2003) argue that this is because medical, clinician-led studies typically use overly simplistic questionnaire measures of factors such as satisfaction, efficacy and attitudes towards ECT. As a result, they recommend that more qualitative exploration studies are used to provide a richer narrative of families' experiences of supporting a relative receiving ECT.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

Design
This will be a qualitative project aiming to build on our understanding of relatives' and carers' experiences of supporting someone who is receiving ECT. Semi-structured interviews will be conducted with participants in order to generate a conversation around their own experiences and support needs. As there is little existing qualitative research in this area, topic areas for discussion will be as open as possible in an attempt to encourage participants to raise issues that are of importance to them.

The study will use an Interpretative Phenomenological Analysis (IPA) approach. IPA is suited to analysing people's lived experiences and takes a contextualist approach, acknowledging that people and their experiences must be considered within their wider contexts. Consequently, IPA is a suitable approach with which to consider the complex experiences of participants, which are undoubtedly shaped by the people and systems around them. Furthermore, IPA acknowledges the role of the researcher in interpreting the participant's accounts of their experiences and critically reflecting on the meaning that they make.

Participants
The study will aim to recruit between eight and twelve participants to allow for a detailed analysis of individual stories using interpretative phenomenological analysis (IPA).
The inclusion criteria is as follows:

- Participants will have supported a relative/family member through ECT treatment (relative/carer is further defined in appendix 1)
- Participants will have been aged 18 years or over at the time of their relative's treatment
- Participant's relatives will not currently be receiving ECT treatment or be an inpatient in a psychiatric hospital

Procedure
Recruitment of participants
The study will use a two-step recruitment approach, with the first wave focusing on recruitment through NHS Trusts and the second wave involving recruitment through online resources and social media. The second wave of recruitment online will be implemented in the event that the minimum recruitment target is not met through recruitment via NHS services.

Step one – Recruitment through NHS services
The research will require approval to advertise within [redacted] NHS Foundation Trust and [redacted] NHS Foundation Trust.

Advertising posters will be displayed in the waiting rooms of relevant mental health services including community mental health teams. These posters will include details of the inclusion criteria, the requirements of the study and the contact details of the lead researcher. The researcher will also attend staff meetings at the relevant mental health teams to ask staff to inform potential participants of the research. In the event that a relative or carer is informed of the research by NHS staff, the staff member will be asked to briefly introduce the research and provide an information sheet. The staff member will also give the potential participant an expression of interest (EOI) form and a freepost envelope. The potential participant will write their name and contact details on the EOI form and post this back to the lead researcher. The researcher will not approach any relative or carer directly. At each stage, the member of staff and the researcher should make it clear that participation is optional and that their decision to refuse or consent to participation will not affect their treatment or the care of their relative in any way.

Stage two – online recruitment
Recruitment will begin online if recruitment targets have not been met through NHS recruitment processes within four weeks. A short online advertisement will be posted outlining the research question and contact details for the lead researcher. This advertisement may be posted on online forums and support groups for relatives and carers providing that the administrators of such websites approve this. The advertisements may also be posted to social media sites. In accordance with the BPS guidelines for ethical practice in psychological research online (2007), the researcher will create a dedicated professional profile on any social media websites used (including Twitter) so that personal social media profiles are not connected with the research. Where this is not an option, the researcher will not post the advertisement directly on their personal page but will ask the site administrator to post on her behalf.

Consent procedure
Once the researcher has received an expression of interest in taking part from a potential participant, the researcher will telephone them to discuss the study. The researcher will send a copy of the study information sheet and consent form by post or email to the participant if they have not already received a copy. The researcher will then also arrange a time to visit the potential participant at their home or at another NHS location. This meeting should be arranged to allow time for the potential participant to receive the information sheet and consent form and have a minimum of 24 hours to consider the information.

At the meeting, the researcher will give the potential participant an opportunity to read through the information sheet and will answer any questions that they may have about the study. The potential participant should also be reminded that they are able to withdraw at any time up to the point of submitting the research for assessment and/or publication and that this will not affect their treatment or the care of their relative in any way. If the potential participant has received all of the information they require and has decided to continue with taking part, they will be asked to sign the consent form in the presence of the researcher. The researcher will then also sign the consent form.

Interview procedure
Participants will be asked to participate in a single face to face semi-structured interview lasting approximately one hour in length. The participant will be informed that the researcher will begin recording the interview once the participant has signed the consent form and recording will continue until the end of the meeting. During this interview, the researcher will collect demographic information and will then ask the participant some questions about their experiences of supporting their relative through ECT. The participant will be given the opportunity to take comfort breaks throughout the interview and advised that they may stop at any time.

At the end of the interview the researcher will debrief the participant, giving them the opportunity to add any comments about the process or ask any questions about what was discussed during the interview. The researcher will also check the wellbeing of the participant, particularly if distressing issues were discussed during the interview. If either the participant or the researcher feels the participant requires further emotional support, this will be discussed between them and a plan agreed upon. Possible actions may include advising on contact details for listening services such as the Samaritans. In the debrief participants will also be asked if they wish to receive a copy of the themes identified in order to give feedback on the appropriateness of these themes. Their decision should be documented on their consent form and a method of contacting the participant should then be agreed and documented

Following the interviews, the audio recordings will be transcribed verbatim by the researcher. The transcripts will be analysed using IPA based on the stages of analysis proposed by Smith, Flowers and Larkin (2009).

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

☑ Design of the research
☑ Management of the research
☑ Undertaking the research
☑ Analysis of results
☑ Dissemination of findings
☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
The project management team for this study includes two members of the public who are considered experts by experience, with a particular interest in research into ECT. They also have experience of publishing in academic journals, acting as lay and peer reviewers and contributing to research ethics committees.

The experts by experience have contributed to the design and management of the study at all stages.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

Participants will have supported a relative/family member through ECT treatment.
Participants will have been aged 18 years or over at the time of their relative's treatment.

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

Participants will be excluded from the research if their family member is currently receiving ECT or is currently an inpatient in psychiatric hospital, due to the potential for the person's involvement in the research to unintentionally impact on the treatment of their relative.

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	12	3	4
Telephone call to arrange meeting	1N/A	10 minutes	Kerry Irving will contact participants by telephone
Seeking consent	1N/A	10 minutes	Kerry Irving will seek consent. This meeting will take place at participant's home or at an NHS location.
Interview	1N/A	1 hour	Kerry Irving will conduct the interview. This will take place at the home or NHS location immediately following taking consent.

A21. How long do you expect each participant to be in the study in total?

Participants will be in the study for approximately 5 months.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Although the aim of the study is not to directly address the wellbeing or mental health of participants, there is a possibility that the interviews may cause participants to reflect on potentially emotional topics with regards to their experiences supporting relatives through ECT, which may cause participants to experience some distress. The researcher will remind the participant at the start of the interview that they may stop at any time if they wish, either to take a rest break or to terminate the interview entirely. The researcher will also take steps to minimise distress by allowing opportunities for comfort breaks and reacting sensitively towards participants.

If the researcher becomes concerned for the welfare of the participant during the interview, they will stop the interview process and discuss with the participant options for supporting their wellbeing. These options potentially include

giving advice for support networks such as the Samaritans. In the unlikely event that participants become extremely distressed and the researcher does not believe it is safe to leave the participant alone, the researcher will accompany the participant to accident and emergency or stay with them until the appropriate services are able to attend.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes (●) No ( )

If Yes, please give details of procedures in place to deal with these issues:

Because the aim of the study is to explore participants' experiences of their relative's treatment, it is possible that the researcher could be made aware of unacceptable or unethical professional practice. If this happens, the researcher will seek advice from her research supervisor in the first instance and escalate the concerns if it is agreed that this is necessary for the protection of service users, staff or the public. If concerns are identified that do not require escalation but would be helpful for services to be aware of, this will be fed back to the appropriate services as part of the dissemination process on completion of the research. This feedback will be in a general form, anonymised and with no reference to specific individuals or teams.

A24. What is the potential for benefit to research participants?

There are no direct benefits to taking part, although participants may find participation interesting.

A26. What are the potential risks for the researchers themselves? *(if any)*

For home visits and visits at any other base, the researcher will work in line [redacted] NHS Foundation Trust Lone Worker Policy including operating a 'buddy' system. The researcher will nominate a buddy who will be another trainee clinical psychologist employed by [redacted] NHS Foundation Trust. The researcher will give the buddy details of the location of the visit, the name, address and contact details of the participant, and details of the researcher's contact numbers and car make, model and registration number. These details will be given to the buddy in a sealed envelope so that they will not be seen by the buddy except in the case of an emergency.

The researcher will give the buddy the arranged start and end times of the meeting and will make a telephone call to the buddy at the arranged end time to confirm that they have left the meeting and are safe. It is the responsibility of the researcher to call the buddy at the earliest opportunity in the event that the interview is expected to run over the proposed end time. If the researcher fails to call the buddy to confirm that they are safe, the buddy should attempt to contact the participant in the first instance and if the researcher cannot be traced, they should call the police and pass on the details of the visit. In the event of an emergency where the researcher cannot leave the visit, the researcher will call the buddy and say "Could you let Ste know I am running late for our meeting?" In this instance, the buddy should call the police to attend the visit location. Once the researcher has confirmed they have left the visit safely, the buddy should destroy the envelope and the enclosed visit information.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used?*For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

The study will use a two-step recruitment approach, with the first wave focusing on recruitment through NHS Trusts and the second wave involving recruitment through online resources and social media. The second wave of recruitment online will be implemented in the event that the minimum recruitment target is not met through recruitment via NHS services.

Step one – Recruitment through NHS services
The research will require approval to advertise [redacted] NHS Foundation Trust and [redacted] NHS Foundation Trust.

Advertising posters will be displayed in the waiting rooms of relevant mental health services including community mental health teams. These posters will include details of the inclusion criteria, the requirements of the study and the contact details of the lead researcher. The researcher will also attend staff meetings at the relevant mental health teams to engage staff in promoting the research with service users and their families. In the event that a relative or carer is informed of the research by NHS staff, the staff member will be asked to briefly introduce the research and provide an information sheet. The staff member will also give the potential participant an expression of interest (EOI) form and a freepost envelope. The potential participant will write their name and contact details on the EOI form and post this back to the lead researcher. The researcher will not approach any relative or carer directly. At each stage, the member of staff and the researcher should make it clear that participation is optional and that their decision to refuse or consent to participation will not affect their treatment or the care of their relative in any way.

Stage two – online recruitment
Recruitment will begin online if recruitment targets have not been met through NHS recruitment processes within four weeks. A short online advertisement will be posted outlining the research question and contact details for the lead researcher. This advertisement may be posted on online forums and support groups for relatives and carers providing that the administrators of such websites approve this. The advertisements may also be posted to social media sites. In accordance with the BPS guidelines for ethical practice in psychological research online (2007), the researcher will create a dedicated professional profile on any social media websites used (including Twitter) so that personal social media profiles are not connected with the research.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes ○ ◉ No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes ◉ ○ No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).

Advertising posters will be displayed in the waiting rooms of relevant mental health services including community mental health teams. These posters will include details of the inclusion criteria, the requirements of the study and the contact details of the lead researcher.

A short online advertisement will be posted outlining the research question and contact details for the lead researcher. This advertisement may be posted on online forums and support groups for relatives and carers providing that the administrators of such websites approve this. The advertisement will also be shared on the Lancaster University research page online and on Twitter.

A29. How and by whom will potential participants first be approached?

In the event that a relative or carer is informed of the research by NHS staff, the staff member will be asked to briefly introduce the research and provide an information sheet. The staff member will also give the potential participant an expression of interest (EOI) form and a freepost envelope. The potential participant will write their name and contact details on the EOI form and post this back to the lead researcher. The researcher will not approach any relative or carer directly. At each stage, the member of staff and the researcher should make it clear that participation is optional and that their decision to refuse or consent to participation will not affect their treatment or the care of their relative in any way.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes ◉ ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and

fully informed.

Once the researcher has received an expression of interest in taking part from a potential participant, the researcher will telephone them to discuss the study. The researcher will send a copy of the study information sheet and consent form by post or email to the participant if they have not already received a copy. The researcher will then also arrange a time to visit the potential participant at their home or at another NHS location. This meeting should be arranged to allow time for the potential participant to receive the information sheet and consent form and have a minimum of 24 hours to consider the information.

At the meeting, the researcher will give the potential participant an opportunity to read through the information sheet and will answer any questions that they may have about the study. The potential participant should also be reminded that they are able to withdraw at any time up to the point of submitting the research for assessment and/or publication and that this will not affect their treatment or the care of their relative in any way. If the potential participant has received all of the information they require and has decided to continue with taking part, they will be asked to sign the consent form in the presence of the researcher. The researcher will then also sign the consent form.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

(•) Yes ( ) No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will have the information sheet and consent form for a minimum of 24 hours before they will be asked to consent to take part.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?*(e.g. translation, use of interpreters)*

The Lancaster DClinPsy programme does not routinely allow funding for interpreters in student projects not directly exploring experiences of non-English speakers.
For participants who have difficulty reading written study documentation, the researcher will read all documents out for the participant.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

(•) The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

( ) The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

( ) The participant would continue to be included in the study.

( ) Not applicable – informed consent will not be sought from any participants in this research.

( ) Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

CONFIDENTIALITY

pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)?*(Tick as appropriate)*

- [ ] Access to medical records by those outside the direct healthcare team
- [ ] Electronic transfer by magnetic or optical media, email or computer networks
- [ ] Sharing of personal data with other organisations
- [ ] Export of personal data outside the EEA
- [x] Use of personal addresses, postcodes, faxes, emails or telephone numbers
- [x] Publication of direct quotations from respondents
- [ ] Publication of data that might allow identification of individuals
- [x] Use of audio/visual recording devices
- [x] Storage of personal data on any of the following:

- [x] Manual files including X−rays
- [ ] NHS computers
- [ ] Home or other personal computers
- [x] University computers
- [ ] Private company computers
- [ ] Laptop computers

Further details:

A38. How will you ensure the confidentiality of personal data?*Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All participant quotes will be anonymised in the final report in order to protect the identity of participants. Participants will be asked to choose a pseudonym so that their quotes can be appropriately referenced in the main report.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Audio data collected as part of the study will be shared with Dr Suzanne Hodge and Dr Stephen Weatherhead, supervisors of this project, so that they are able to monitor the quality and adherence to ethical standards of the researcher. Anonymised written transcripts of the interviews may be shared with the supervisors so that they can provide supervision of the analysis and interpretation of data.
Only the chief investigator will have access to the participants' contact details.

Storage and use of data after the end of the study

A43. How long will personal data be stored or accessed after the study has ended?

- (•) Less than 3 months
- ( ) 3 – 6 months
- ( ) 6 – 12 months
- (•) 12 months – 3 years
- ( ) Over 3 years

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

Yes ◉ No ○

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
For participants who need to travel to a base to attend the interview, travel expenses up to the value of £20 will be offered by the Lancaster University Clinical Psychology Doctorate programme. No other financial incentives or payments will be offered for taking part in the study.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

Yes ○ No ◉

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

Yes ○ No ◉

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants ' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

Yes ○ No ◉

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

Yes ○ No ◉

Please give details, or justify if not registering the research.
No suitable register exists

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

☑ Peer reviewed scientific journals
☑ Internal report
☑ Conference presentation
☑ Publication on website

Other publication

Submission to regulatory authorities

Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators

No plans to report or disseminate the results

Other (please specify)

A53. Will you inform participants of the results?

Yes ○ No

Please give details of how you will inform participants or justify if not doing so.
Participants will be given the option of commenting on the appropriateness of the final themes prior to publication of the results. They will also be invited to receive a summary of the final report. At the consent stage, participants will be asked whether they wish to receive this by post or email.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

Independent external review

Review within a company

Review within a multi−centre research group

Review within the Chief Investigator's institution or host organisation

Review within the research team

Review by educational supervisor

Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 12

Total international sample size (including UK): 12

Total in European Economic Area:

Further details:

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

The study will aim to recruit between eight and twelve participants to allow for a detailed analysis of individual stories using interpretative phenomenological analysis (IPA). Smith and Osborn (2007) propose that IPA sample sizes should be limited to allow for detailed interpretative accounts of each case. They provide evidence of successful IPA studies using between one and fifteen participants but state that for student projects, the higher end of this range can be overwhelming and impractical. Therefore, a mid-range sample size between eight and twelve will still allow for detailed analysis within the time scale available for the study, whilst also meeting standards for publication.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

The study will use an Interpretative Phenomenological Analysis (IPA) approach. IPA is suited to analysing people's lived experiences and takes a contextualist approach, acknowledging that people and their experiences must be considered within their wider contexts. Consequently, IPA is a suitable approach with which to consider the complex experiences of participants, which are undoubtedly shaped by the people and systems around them. Furthermore, IPA acknowledges the role of the researcher in interpreting the participant's accounts of their experiences and critically reflecting on the meaning that they make.

The transcripts will be analysed using IPA based on the stages of analysis proposed by Smith, Flowers and Larkin (2009). They suggest that progression through these stages "will not be a linear one" (Smith et al., 2009, p.80) but should always be based on the process of moving from descriptive accounts of the data to interpretive analysis.

Given the idiographic approach required in IPA, each participant's transcript will be analysed individually before moving on to subsequent cases. The first stage of this analysis involves repeated reading and familiarisation with the transcript. Following this, initial exploratory notes will be made on the content and language used within the transcript. Moving on to the third stage, the exploratory notes will be condensed to produce emergent themes that reflect the participant's original words in combination with the researcher's interpretation of these. The fourth stage will involve searching for connections across the emergent themes so that higher level, super-ordinate themes may be identified. Once this stage has been completed to sufficient depth for this transcript, the researcher will move on to analysing the next transcript using the same process. Once all of the transcripts have been individually analysed, the researcher will search for patterns or higher order concepts that the cases share.

Once the analysis has reached this stage, the researcher will contact participants who have agreed to provide feedback in order to share the themes and ask them to comment on the appropriateness of them. Comments at this stage will not be included as part of the original data transcriptions but may be used to revisit themes where appropriate.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co−applicants, protocol co−authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title	Forename/Initials	Surname
	Dr	Stephen	Weatherhead
Post	Clinical Psychologist		
Qualifications	DClinPsy		
Employer	Lancaster University		
Work Address	Doctorate in Clinical Psychology, Division of Health Research		
	Furness Building, Lancaster University		
	Bailrigg, Lancaster		
Post Code	LA1 4YG		
Telephone	01524 592974		
Fax			
Mobile			
Work Email	s.weatherhead@lancaster.ac.uk		

	Title	Forename/Initials	Surname
	Ms	Bethan M	Edwards
Post	Service User Researcher		
Qualifications			
Employer			

Work Address	C/O Kerry Irving, Doctorate in Clinical Psychology, Division of Health Research
	Furness Building, Lancaster University
	Bailrigg, Lancaster
Post Code	LA1 4YG
Telephone	
Fax	
Mobile	
Work Email	bethanmairedwards@hotmail.co.uk

Title	Forename/Initials	Surname
Mr	Gerry	Bennison

Post	Service User Researcher
Qualifications	
Employer	
Work Address	C/O Kerry Irving, Doctorate in Clinical Psychology, Division of Health Research
	Furness Building, Lancaster University
	Bailrigg, Lancaster
Post Code	LA1 4YG
Telephone	
Fax	
Mobile	
Work Email	gerryrbennison@yahoo.co.uk

Title	Forename/Initials	Surname
Dr	Ian	Smith

Post	Clinical Psychologist/Lecturer
Qualifications	DClinPsy
Employer	Lancaster University
Work Address	Doctorate in clinical Psychology, Division of Health Research
	Furness Building, Lancaster University
	Bailrigg, Lancaster
Post Code	LA1 4YG
Telephone	01524 592282
Fax	
Mobile	
Work Email	i.smith@lancaster.ac.uk

Title	Forename/Initials	Surname
Miss	Anna	Duxbury

Post	Trainee Clinical Psychologist
Qualifications	
Employer	Lancashire Care NHS Foundation Trust
Work Address	Doctorate in Clinical Psychology, Division of Health Research
	Furness Building, Lancaster University
	Bailrigg, Lancaster
Post Code	LA1 4YG
Telephone	

Fax
Mobile
Work Email a.duxbury@lancaster.ac.uk

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
- ○ NHS or HSC care organisation
- ◉ Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- ○ Local Authority
- ○ Other social care provider (including voluntary sector or private organisation)
- ○ Other

Commercial status:

If Other, please specify:

Contact person

Name of organisation	Lancaster University
Given name	Debbie
Family name	Knight
Address	Research Support Office, B Floor, University House
Town/city	Lancaster University, Lancaster
Post code	LA1 4YW
Country	UNITED KINGDOM
Telephone	01524592605
Fax	
E-mail	ethics@lancaster.ac.uk

Is the sponsor based outside the UK?

Yes ○ ◉ No

Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.

A65. Has external funding for the research been secured?

- ☐ Funding secured from one or more funders
- ☐ External funding application to one or more funders in progress
- ☑ No application for external funding will be made

What type of research project is this?

- ◉ Standalone project
- ○ Project that is part of a programme grant
- ○ Project that is part of a Centre grant
- ○ Project that is part of a fellowship/ personal award/ research training award
- ○ Other

Other – please state:

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

Yes ○ ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

	Title	Forename/Initials	Surname
	[redacted]	[redacted]	[redacted]

Organisation	[redacted]
Address	[redacted]
	[redacted]
	[redacted]
Post Code	[redacted]
Work Email	[redacted]
Telephone	[redacted]
Fax	
Mobile	

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/09/2015

Planned end date: 31/05/2016

Total duration:

Years: 0 Months: 8 Days: 31

A71-2. Where will the research take place? *(Tick as appropriate)*

☑ England

☐ Scotland

☐ Wales

☐ Northern Ireland

☐ Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?

Yes ○ ◉ No

A72. What host organisations (NHS or other) in the UK will be responsible for the research sites? *Please indicate the type of organisation by ticking the box and give approximate numbers of planned research sites:*

☑ NHS organisations in England 2

☐

NHS organisations in Wales

NHS organisations in Scotland
HSC organisations in Northern Ireland
GP practices in England
GP practices in Wales
GP practices in Scotland
GP practices in Northern Ireland
Social care organisations
Phase 1 trial units
Prison establishments
Probation areas
Independent hospitals
Educational establishments
Independent research units
Other (give details)

Total UK sites in study: 2

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

NHS indemnity scheme will apply (NHS sponsors only)
Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

NHS indemnity scheme will apply (protocol authors with NHS contracts only)
Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability

of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☐ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☒ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For NHS sites, the host organisation is the Trust or Health Board. Where the research site is a primary care site, e.g. GP practice, please insert the host organisation (PCT or Health Board) in the Institution row and insert the research site (e.g. GP practice) in the Department row.*

Research site		Investigator/ Collaborator/ Contact	
Institution name	[redacted]	Title	[redacted]
[redacted]		First name/ Initials	[redacted]
Street address	[redacted]	Surname	[redacted]
Town/city	[redacted]		
Post Code	[redacted]		
Institution name	[redacted]	Title	[redacted]
[redacted]		First name/ Initials	[redacted]
Street address	[redacted]	Surname	[redacted]
Town/city	[redacted]		
Post Code	[redacted]		

PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

3. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

4. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

5. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

6. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

7. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

8. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

9. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    - Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    - May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    - May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    - Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    - May be sent by email to REC members.

10. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

11. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication*(Not applicable for R&D Forms)*

NRES would like to include a contact point with the published summary of the study for those wishing to seek further information. We would be grateful if you would indicate one of the contact points below.

Chief Investigator

Sponso

Study co-ordinator
Student
Other – please give details
None

Access to application for training purposes *(Not applicable for R&D Forms)*
Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by [redacted] on 04/08/2015 09:14.

Job Title/Post: [redacted]

[redacted]

[redacted]

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co−sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The duties of sponsors set out in the Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

Please note: *The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.*

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver a [redacted] on 04/08/2015 14:42.

Job Title/Post: [redacted]

[redacted]

[redacted]

D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the Research Governance Framework for Health and Social Care.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by [redacted] on 04/08/2015 09:39.

Job Title/Post: [redacted]

[redacted]

[redacted]

Appendix 4-I

REC Favourable Opinion Letter

Health Research Authority

National Research Ethics Service

NRES Committee North West - Liverpool Central

3rd Floor
Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 01616257818

09 September 2015

Mrs Kerry A Irving
Trainee Clinical Psychologist
Lancashire Care NHS Foundation Trust
Doctorate in clinical Psychology, Division of Health Research
Furness Building, Lancaster University
Bailrigg, Lancaster
LA1 4YG

Dear Mrs Irving

Study title: **What are relatives' experiences of supporting a family member receiving electroconvulsive therapy? A qualitative exploration**
REC reference: **15/NW/0679**
IRAS project ID: **182137**

The Research Ethics Committee reviewed the above application at the meeting held on 02 September 2015. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager [redacted], nrescommittee.northwest-liverpoolcentral@nhs.net. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

- The Committee would like to see the Participant Information Sheet revised to
  State that the recordings will be kept for about a week until they have been transcribed, and then destroyed
  Give the contacts of local support groups rather than national ones
- The Committee would like to see the Consent Form revised to include the regulatory clause "I understand that data from the study may be looked at by regulatory authorities or by persons from the Trust where it is relevant to my taking part in this study. I agree that these persons can have access to this information"
- The Committee would like to see the on line advert revised to include the words "at Lancaster University" after "we"

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Summary of discussion at the meeting

The Chair welcomed you to the REC and thanked you for attending to discuss the study. The Committee told you that this was a good study.

Social or scientific value; scientific design and conduct of the study

The Committee noted that no mental health groups had been involved in the design of the study and asked the reason.

You stated that there was a project management group which contained patients who had had ECT or supported someone who had ECT and they would stay on as advisors to the study.

Recruitment arrangements and access to health information, and fair participant selection

The Committee asked how long ago participants would have received or given consent for ECT.

You said that there was no time limit but that you would ensure treatment was not being received at the time of the interview.

The Committee pointed out that there have been changes to the Mental Health Act since 1983. Prior to this people were treated with ECT to try to stop them being homosexual. The Committee wondered whether such information would be relevant given that it no longer happens.

You stated that carers would still have been seeing people through the treatment and that you hoped their experiences would still be relevant.

The Committee accepted this.

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee asked how long the recordings would be held.

You stated that you thought it would be about a week until they were transcribed.

Informed consent process and the adequacy and completeness of participant information

The Committee pointed out that the support groups listed on the Participant Information Sheet were national and that they might not be available in the area. The Committee asked that the numbers of local support groups be used instead.

The Committee requested changes as described in the decision below.

Suitability of supporting information

The Committee noted that the internet advert included the words “we would like to hear about your experiences” and asked that the words “at Lancaster University” be inserted after “we” so that prospective participants would know who was addressing them

Mrs Irving had no questions for the Committee.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Participant Recruitment Poster]	V1	06 August 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor insurance]	V1	06 August 2015
Interview schedules or topic guides for participants [Topic Guide]	V1	06 August 2015
Letter from sponsor [Letter from sponsor]	V1	06 August 2015
Letters of invitation to participant [Expression of Interest Form]	V1	06 August 2015
REC Application Form [REC_Form_07082015]		07 August 2015
Research protocol or project proposal [Research Protocol]	V1	06 August 2015
Summary CV for Chief Investigator (CI) [Kerry Irving CV]	V1	06 August 2015
Summary CV for supervisor (student research) [Suzanne Hodge CV]	V1	06 August 2015

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol

- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/NW/0679	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

[redacted]
Chair

E-mail: nrescommittee.northwest-liverpoolcentral@nhs.net

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments

"After ethical review – guidance for researchers"

Copy to: [redacted]

Appendix 4-J

REC Final Approval Letter

National Research Ethics Service

North West - Liverpool Central Research Ethics Committee

3rd Floor
Barlow House
4 Minshull Street
Manchester
M1 3DZ

Telephone: 0207 104 8020

29 September 2015

Mrs Kerry A Irving
Trainee Clinical Psychologist
Lancashire Care NHS Foundation Trust
Doctorate in clinical Psychology
Division of Health Research
Furness Building
Lancaster University
Bailrigg
Lancaster
LA1 4YG

Dear Mrs Irving

Study title: **What are relatives' experiences of supporting a family member receiving electroconvulsive therapy? A qualitative exploration**
REC reference: **15/NW/0679**
IRAS project ID: **182137**

Thank you for your e-mail of 25 September 2015. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 09 September 2015

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants	2	21 September 2015
Participant consent form	2	21 September 2015
Participant information sheet (PIS)	2	21 September 2015

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Participant Recruitment Poster]	V1	06 August 2015
Copies of advertisement materials for research participants	2	21 September 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	V1	06 August 2015
[Sponsor insurance]		
Interview schedules or topic guides for participants [Topic Guide]	V1	06August 2015
Letter from sponsor [Letter from sponsor]	V1	06August 2015
Letters of invitation to participant [Expression of Interest Form]	V1	06August 2015
Participant consent form	2	21September 2015
Participant information sheet (PIS)	2	21September 2015
REC Application Form [REC_Form_07082015]		07August 2015
Research protocol or project proposal [Research Protocol]	V1	06August 2015
Summary CV for Chief Investigator (CI) [Kerry Irving CV]	V1	06August 2015
Summary CV for supervisor (student research) [Suzanne Hodge CV]	V1	06August 2015

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

15/NW/0679 **Please quote this number on all correspondence**

Yours sincerely

[redacted]
REC Assistant

E-mail: [redacted]

[redacted]

[redacted]

Appendix 4-K

NHS Trust 1 Approval Letter

Our Ref: S1716

Research & Development Department
[redacted]

Date: 08th February 2016

[redacted]

Kerry Irving
Trainee Clinical Psychologist
Faculty of Health and Medicine
Furness College
Lancaster University
LA1 4YG

Dear Kerry,

Re: NHS Trust Permission to Proceed

Project Reference: S1716

Project Title: **What are relatives' experiences of supporting a family member receiving electroconvulsive therapy? A qualitative exploration**

I am pleased to inform you that the above project has received research governance permission.

Please take the time to read through this letter carefully and contact me if you would like any further information. You will need this letter as proof of your permission.

Trust R&D permission covers all locations within the Trust; however you will only be allowed to recruit from the sites/services you have indicated in section 3 of the SSI application form. If you would like to expand recruitment into other services in the Trust that are not on the original SSI then you must contact the R&D department immediately to discuss this before doing so.

You also must ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing recruitment in that service and you must contact the relevant service/ward managers prior to accessing the service to make an appointment to visit before you can commence your study in the Trust.

Please make sure that you take your Trust permission letter with you when accessing Trust premises and please include the Trust reference number on any correspondence/emails so that the services are assured permission has been granted.

Recruitment

Researchers must recruit the first participant to [redacted] Trust within 30 days of being granted Trust permission and ensure that studies recruit to time and target.

National guidelines expect Trusts to report the date when the first participant is recruited to the study, therefore please can you provide this information at that point to the R&D department at [redacted]

If you have any concerns with recruitment please contact the R&D team immediately for assistance.

Monitoring

If your study duration is less than one year, you will be required to complete an end of study feedback report on completion. However if your study duration is more than one year, you will be required to complete a short electronic progress report quarterly and an end of study report on completion. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this Trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum; however, if you fail to supply the information requested, the Trust may withdraw permission.

Honorary Research contracts (HRC)

All researchers with no contractual relationship with any NHS body, who are to interact with individuals in a way that directly affects the quality of their care, should hold Honorary Research NHS contracts. Researchers have a contractual relationship with an NHS body either when they are employees or when they are contracted to provide NHS services, for example as independent practitioners or when they are employed by an independent practitioner (*Research Governance Framework for Health and Social Care,* 2005). If a researcher does not require an HRC, they would require a Letter of Access (LoA). For more information on whether you or any of your research team will require an HRC or LoA please liaise with this office. It is your responsibility to inform us if any of your team do not hold Honorary Research NHS contracts/Letters of Access.

Staff involved in research in NHS organisations may frequently change during the course of a research project. Any changes to the research team or any changes in the circumstances of researchers that may have an impact on their suitability to conduct research MUST be notified to the Trust immediately by the Principal Investigator (or nominated person) so that the necessary arrangements can be put in place

Research Governance

The Research Governance Sponsor for this study is **Lancaster University**. Whilst conducting this study you must fully comply with the Research Governance Framework. This can be accessed at: [redacted]

For further information or guidance concerning your responsibilities, please contact your research governance sponsor or your local R&D office.

Risk and Incident Reporting

Much effort goes into designing and planning high quality research which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on Trust premises, or involve Trust service users, carers or staff, you must report the incident within 48 hours via the Trust

incident reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact us for support and guidance.

Regardless of who your employer is when undertaking the research within [redacted] you must adhere to Trust policies and procedures at all times.

Confidentiality and Information Governance

All personnel working on this project are bound by a duty of confidentiality. All material accessed in the Trust must be treated in accordance with the Data Protection Act (1998). For good practice guidance on information governance contact us.

Protocol / Substantial Amendments

You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

Final Reports

At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the NHS Trust internet site to ensure findings are disseminated as widely as possible to stakeholders.

On behalf of this Trust, may I wish you every success with your research. Please do not hesitate to contact us for further information or guidance.

Yours sincerely,

[redacted]
Research & Development Manager

Cc: [redacted]

Appendix 4-L

NHS Trust 2 Approval Letter

[redacted]

5th October 2015

Mrs Kerry A Irving
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
Division of Health Research
Furness Building
Lancaster University
Bailrigg
Lancaster, LA1 4YG

Dear *Mrs Irving*,

Re: NHS Trust Permission to Proceed

Project Reference: 15/18

Project Title: What are relatives' experiences of supporting a family member receiving electroconvulsive therapy? A qualitative exploration

I am pleased to inform you that the above project has received research governance permission.

Please take the time to read through this letter carefully and contact me if you would like any further information. You will need this letter as proof of your permission.

Trust R&D permission covers all locations within the Trust; however you will only be allowed to recruit from the sites/services you have indicated in section 3 of the SSI application form. If you would like to expand recruitment into other services in the Trust that are not on the original SSI then you must contact the R&D department immediately to discuss this before doing so.

You also must ensure you have liaised with and obtained the agreement of individual service/ward managers before commencing recruitment in that service and you must contact the relevant service/ward managers prior to accessing the service to make an appointment to visit before you can commence your study in the trust.

Please make sure that you take your Trust permission letter with you when accessing Trust premises and please include the Trust reference number on any correspondence/emails so that the services are assured permission has been granted.

Honorary Research contracts (HRC)

All researchers with no contractual relationship with any NHS body, who are to interact with individuals in a way that **directly affects the quality of their care**, should hold Honorary Research NHS contracts. Researchers have a contractual relationship with an NHS body either when they are employees or when they are contracted to provide NHS services, for example as independent practitioners or when they are employed by an independent practitioner (*Research Governance Framework for Health and Social Care,* 2005). If a researcher does not require an HRC, they would require a Letter of Access (LoA). For more information on whether you or any of your research team will require an HRC or LoA please liaise with this office. It is your responsibility to inform us if any of your team do not hold Honorary Research NHS contracts/Letters of Access.

Staff involved in research in NHS organisations may frequently change during the course of a research project. Any changes to the research team or any changes in the circumstances of researchers that may have an impact on their suitability to conduct research MUST be notified to the Trust immediately by the Principal Investigator (or nominated person) so that the necessary arrangements can be put in place

Research Governance

The Research Governance Sponsor for this study is Lancaster University. Whilst conducting this study you must fully comply with the Research Governance Framework. This can be accessed at:

[redacted]

For further information or guidance concerning your responsibilities, please contact your research governance sponsor or your local R&D office.

Good Clinical Practice (GCP)

GCP is an international ethical and scientific quality standard for designing, conducting, recording and reporting trials that involve the participation of human subjects. It is the responsibility of all researchers who are carrying out a research project involving NHS patients and carers to complete GCP training and to update this every 2 years. All training certificates must be forwarded to the R&D department to comply with Trust permission. Please note that student projects are exempt from this process.

Risk and Incident Reporting

Much effort goes into designing and planning high quality research which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on trust premises, or involve trust

service users, carers or staff, you must report the incident within 48 hours via the Trust incident reporting system. If you are in any doubt whatsoever whether an incident should be reported, please contact us for support and guidance.

Regardless of who your employer is when undertaking the research within [redacted] you must adhere to trust policies and procedures at all times.

Confidentiality and Information Governance

All personnel working on this project are bound by a duty of confidentiality. All material accessed in the trust must be treated in accordance with the Data Protection Act (1998) For good practice guidance on information governance contact us.

Protocol / Substantial Amendments

You must ensure that the approved protocol is followed at all times. Should you need to amend the protocol, please follow the Research Ethics Committee procedures and inform all NHS organisations participating in your research.

Monitoring / Participant Recruitment Details

If your study duration is less than one year, you will be required to complete an end of study feedback report on completion. However if your study duration is more than one year, you will be required to complete a short electronic progress report annually and an end of study report on completion. As part of this requirement, please ensure that you are able to supply an accurate breakdown of research participant numbers for this trust (recruitment target, actual numbers recruited). To reduce bureaucracy, progress reporting is kept to a minimum; however, if you fail to supply the information requested, the trust may withdraw permission.

Recruitment

Please provide the trust details of your recruitment numbers when requested. If you have any concerns with recruitment please contact the R&D team immediately for assistance.

Final Reports

At the end of your research study, we will request a final summary report so that your findings are made available to local NHS staff. The details from this report may be published on the NHS Trust internet site to ensure findings are disseminated as widely as possible to stakeholders. You may also be invited to present your findings to the Trust at an event or meeting.

On behalf of this Trust, may I wish you every success with your research. Please do not hesitate to contact us for further information or guidance.

Yours sincerely,

[redacted]
R&D Director

Cc: [redacted]