Power Dynamics in Mental Health Services

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List of Abbreviations

ACT – Acceptance and Commitment Therapy
BPS – British Psychological Society
CASP – Critical Appraisal and Skills Programme
CINAHL – Cumulated Index to Nursing and Allied Health Literature
ECT – Electroconvulsive Therapy
GET – Group Experiential Theme
GP – General Practitioner
IPA – Interpretative Phenomenological Analysis
M – Mean
MEDLINE – Medical Literature Analysis and Retrieval System Online
MH – Mental Health
MHA – Mental Health Act
NHS – National Health Service
NICE – National Institute for Health and Care Excellence
PET – Personal Experiential Theme
POGM – People of the Global Majority
PRISMA – Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PTMF – Power Threat Meaning Framework
QR – Quality Rating
SPIDER – Sample, Phenomenon of Interest, Design, Evaluation, Research Type
SU – Service User
TV – Television
UK – United Kingdom
Acknowledgements

First, I would like to thank my participants. Without you, this research would not have been possible. Thank you for sharing your stories and allowing me to tell them. I have learned so much from each of you and I am grateful that our paths crossed. I hope to take this research forward so that others can learn from this too. I hope that together we can change services for the better.

Second, I would like to thank my research supervision team, Dr Magda Marczak and Dr Jo Kucharska – for letting me go at the pace I needed to, for always asking me how I was doing and not just how my research was going, for helping me to reflect and grow through this process, for telling me when I was overthinking things (which was quite often!) but listening anyway, for always having the answer or helping me to find it, and for sharing my passion for this research.

And third, to all my important people – I feel so lucky to have you in my life. To Mom and Dad – for giving me the passion to try to make the world a better place, and for always loving and believing in me. To Mom, Beck, and Jen – for giving me the best possible examples of what it means to be a strong woman, and for helping me to feel strong too. To Joe – for telling me that I make you proud and for making me proud too (and for sending me photos and making me jealous while you were away on your travels!). To my wonderful niece and nephews – for making me the proudest Auntie Alys, for laughing at my rubbish jokes, and for always making me laugh! To Brandon – for the endless supply of cuddles and iced buns, and for making me smile even at the end of the toughest days. And to Luisa – for making me tell you how I was actually doing all those times I said I was ‘fine’, and for being right by my side to the end (even though it took me a little bit longer!).
Declaration

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate in Clinical Psychology at Coventry University and the University of Warwick. It has been composed by myself and has not been submitted for any degree at any other institution. The work presented was carried out by the author under the academic supervision of Dr Magda Marczak (Chartered Psychologist and Research Tutor for the Doctorate in Clinical Psychology, Coventry University) and Dr Jo Kucharska (previously Clinical Director and Senior Lecturer in Clinical Psychology, Coventry University; currently Consultant Clinical Psychologist and Clinical Lead for Mental Health and Wellbeing Hub, Coventry and Warwickshire Partnership NHS Trust). The systematic literature review will be submitted to The Journal of ECT for publication, and the empirical paper will be submitted to Social Science and Medicine.

The word count for each chapter, excluding footnotes, tables, figures, references, and appendices is as follows:

Chapter I: 8,015
Chapter II: 8,884
Chapter III: 3,455

Overall word count: 20,354
Summary

This thesis is comprised of three chapters. Chapter one outlines a systematic review of the literature on women service users’ and staff members’ experiences of electroconvulsive therapy (ECT). Findings from ten studies were synthesised using thematic synthesis, highlighting two main themes: ‘Power in the ECT experience’ and ‘Life after ECT’. Women ECT recipients often had limited power and control during the decision-making and treatment processes, and some staff members also experienced feeling powerless. Staff members reported generally positive experiences regarding the impact of ECT for recipients, but women recipients described predominantly negative experiences. This review highlighted the need for improvements to the ECT consent process and provision of follow-up support.

Chapter two describes a qualitative research study exploring service users’ experiences of power dynamics during ‘voluntary’ admissions to ‘acute mental health’ wards in the United Kingdom. Data from semi-structured interviews with nine participants was analysed using interpretative phenomenological analysis, revealing two group experiential themes: ‘Being moulded’ and ‘De facto detention’. Participants experienced an absence of compassion which was often perceived to mean that they did not deserve care. This communicated a narrative that there is a correct way to experience distress. Furthermore, ‘voluntary’ admissions often did not feel voluntary, and many participants re-lived previous feelings of powerlessness. Recommendations are made for addressing power dynamics and fostering compassion on mental health wards, as well as creating policy to protect individuals’ rights.

Chapter three is a reflective paper outlining the author’s reflections on the process of conducting this research in the context of their life over the past three years. Reflections are structured using the Acceptance and Commitment Therapy matrix, and considerations are given to personal and professional development.
Chapter I – Women Service Users’ and Staff Members’ Experiences of Electroconvulsive Therapy (ECT): A Systematic Review and Meta-Synthesis of Qualitative Literature

In preparation for submission to The Journal of ECT – amendments to be made accordingly

(see Appendix A for submission guidelines)

Chapter word count (excluding footnotes, tables, figures, and references): 8,015
Abstract

Treating those who experience psychological distress with electroconvulsive therapy (ECT) is widely debated, with arguments grounded in efficacy, experience, and impact. A significant proportion of ECT recipients are women, and staff members from multiple professions are involved in its administration. This review aimed to explore the experience of ECT from the perspectives of women recipients and staff members who have participated in providing ECT. A systematic literature search identified ten studies meeting inclusion criteria. Through thematic synthesis two main themes emerged: ‘Power in the ECT experience’, highlighting the role of power in the ECT decision-making process and during the treatment procedure, and ‘Life after ECT’, describing the impact of ECT. Findings were generally consistent with those of previous relevant reviews, and additional insights were provided by considering both staff and women recipients’ experiences. Clinical implications included improvements to the consent process through survivor-led staff training, staff reflective practice, and independent ECT advocates, in addition to the provision of follow-up support.
1.0 Introduction

1.1 Review Subject and Significance

This study reviewed the evidence base regarding staff and adult women service users’ (SUs’) experiences of electroconvulsive therapy (ECT) for treatment of psychological difficulties or distress. ECT is a procedure during which an electric current is passed through the brain to induce a seizure (Royal College of Psychiatrists, 2022). Within the United Kingdom (UK), National Institute for Health and Care Excellence (NICE) guidelines recommend the use of ECT for people with a diagnosis of “severe depression” (NICE, 2009, p. 37), “catatonia” or a “prolonged or severe manic episode” (NICE, 2003, p. 4), when the individual’s difficulties are “life-threatening” and where other forms of treatment have been tried and considered ineffective\(^1\). There is continued debate regarding the use of ECT; while there is evidence to indicate ECT has a significant positive short-term impact on mood and quality of life (McCall et al., 2013; Medda et al., 2014), other findings suggest ECT may be no more effective than a placebo where individuals were given anaesthetic but did not undergo the procedure (Read & Arnold, 2017). Furthermore, research has demonstrated significant side effects associated with ECT, including memory loss and other cognitive impairments (Fraser et al., 2008; Porter at al., 2020).

SUs’ experiences and perspectives are vital in the development of mental health (MH) services (Thornicroft & Tansella, 2005). This review aims to bring the voice of the individuals who have experienced ECT to the debate regarding the appropriateness of this procedure as an intervention for psychological difficulties. Based on data from 37 NHS trusts, an estimated

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\(^1\)Some medical/diagnostic language is used in this paper. This is not necessarily reflective of the author’s stance but is used by some of the women and staff members who have described their experiences of ECT and academics who have commented on this topic. These terms may not fit for everyone; every individual has a right to their own preferences regarding language and how they and their experiences are described.
2,974 people in England received ECT in 2019 (Read et al., 2021). Data from NHS trusts which reported gender of recipients indicated that 66.7% were women; twice as many women as men received ECT in 20 trusts, and four times as many in three trusts (Read et al., 2021). This review will, therefore, focus specifically on the experiences of women recipients of ECT. Furthermore, multiple staff members are involved in administering ECT and providing associated care and support (ECT Accreditation Service, 2019), including psychiatrists, nursing staff, and anaesthetists. Considering the perspectives of staff alongside those of women SUs allows for a holistic understanding of this process, informing clinical implications arising from this review.

1.2 Previous Reviews

Wells et al. (2021) conducted a meta-synthesis of 16 studies investigating the long-term impact of ECT from recipients’ perspectives and identified 11 main long-term impacts. Some recipients highlighted the benefits of receiving ECT; for example, they viewed ECT as a life-saving intervention which had impacted positively on mental wellbeing and identity. Others highlighted negative consequences following ECT, including physical and cognitive impairments, fear and trauma, loss of identity, and difficult emotional and relational experiences. Certain social influences appeared to affect the extent to which participants experienced these long-term impacts. Support from friends, family and peers was deemed helpful, while social stigma surrounding ECT and a lack of validation and support from professionals were found to exacerbate negative long-term impacts. To cope with the long-term impacts of ECT, useful coping strategies included approaches to managing memory difficulties, re-building a sense of self, taking charge of one’s own experiences by developing assertiveness, and attempting to challenge stigma and stereotypes surrounding ECT.

Chakrabarti et al. (2010) reviewed evidence from 75 studies regarding knowledge, experiences, views, and attitudes of individuals who had received ECT. Recipients were often
not provided sufficient information regarding the procedure and approximately one third reported feeling coerced to undergo ECT. Many experienced fear and anxiety relating to ECT, and, on average, two thirds of recipients reported negative side effects. While Chakrabarti et al. (2010) concluded the majority of recipients found ECT helpful, a variable but significant number expressed negative views of ECT across the included studies. They also noted that the perceived benefit of ECT was reported to be much lower in consumer-led research than in clinician-led research. The authors suggested consumer-led research may be more likely to include recipients with negative views of ECT, but also that clinician-led research may over-estimate its perceived benefits.

Sweetmore (2021) conducted a critical realist review of the literature regarding ethical considerations and decision-making relating to the administration of ECT, with a focus on informing the practice of MH nurses working with ECT recipients. The author reviewed nine papers, including empirical and non-empirical articles, and identified five themes. These highlighted the MH nurse’s role of advocating for their patients and associated conflict when supporting recipients of ECT, difficulties relating to consent processes, challenges in managing the questionable efficacy of ECT, balancing the potential negative impact of side effects with the potential benefits of ECT, and the impact of legal guidelines. Suggestions for how MH nurses may navigate the ethical dilemmas involved in supporting recipients of ECT were made (Sweetmore, 2021).

1.3 Rationale for the Current Review

There are three main ways in which existing reviews could be built upon to develop understanding of this subject and inform future service development and clinical practice. Firstly, two of the reviews did not focus solely on subjective experiences relating to ECT. Chakrabarti et al. (2010) included studies which utilised observer-reported measures, and Sweetmore (2021) reviewed non-empirical papers and took a critical realist approach, which
they acknowledged could result in drawing conclusions not fully grounded in the available evidence. Secondly, reviews aiming to synthesise findings in relation to SUs’ experiences of ECT (Wells et al., 2021; Chakrabarti et al., 2010) have not focused on specific sub-groups of ECT recipients, such as women. The current review will synthesise research which has focused specifically on women’s experiences of ECT. This will allow for consideration of specific aspects of their experience and may include experiences which have not previously been highlighted. Furthermore, two of the reviews focused only on certain aspects of the ECT experience; Wells et al. (2021) focused on SUs’ experiences of the long-term impact of ECT, and Sweetmore (2021) focused on ethical considerations and decision-making processes for MH nurses who support ECT recipients. To address these limitations, the following review question was developed: what is known about the experience of ECT from the perspectives of women SUs who have undergone the procedure and staff members who have been part of the team providing ECT?

2.0 Methods

2.1 Systematic Literature Search

Ethical approval was granted by Coventry University Ethics Committee (Appendix B). The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 Checklist was completed to illustrate the review process (Page et al., 2021; Appendix C).

2.1.1 Search Process

Searches were conducted between April-May 2022. Five databases were used: Medical Literature Analysis and Retrieval System Online (MEDLINE), PsycINFO, Scopus, Web of Science and Cumulated Index to Nursing and Allied Health Literature (CINAHL). Google Scholar (first five pages of results, 50 records) and reference lists were searched to identify additional articles not captured within database searches.
2.1.2 Search Terms

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type) tool (Cooke et al., 2012) was utilised to inform development of search terms. Search terms were also informed by those used in a previous review (Wells et al., 2021), consultation with the university librarian, and indexing. Search terms are presented in Table 1 and the search string with Boolean operators can be found in Appendix D.
## Table 1

### Search Terms

<table>
<thead>
<tr>
<th>SPIDER Component</th>
<th>Main Concept</th>
<th>Synonyms</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>S (Sample)</td>
<td>Staff and adult women service users</td>
<td>women* woman* female* professional* staff* worker* psychiatrist* doctor*</td>
<td>Abstract+ *</td>
</tr>
<tr>
<td></td>
<td></td>
<td>consultant* physician* nurse* nursing anaesthetist* anaesthesiologist* psychologist* therapist*</td>
<td></td>
</tr>
<tr>
<td>PI (Phenomenon of interest)</td>
<td>ECT for psychological difficulties or distress</td>
<td>electro* shock electrical stimulation shock therapy electroconvulsive shock therapy (index term) electro-convulsive shock therapy electro convulsive therapy electroconvulsive therapy (index term) electro-convulsive therapy shock therapy shock treatment convulsive therapy</td>
<td>Abstract+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>abstract+</td>
<td></td>
</tr>
<tr>
<td>D (Design)</td>
<td>Qualitative research designs</td>
<td>interview* focus group* case stud*</td>
<td>Abstract+</td>
</tr>
<tr>
<td>E (Evaluation)</td>
<td>Subjective experiences, perspectives, and views</td>
<td>perspective* experience* view* perception* account*</td>
<td>Abstract+</td>
</tr>
<tr>
<td></td>
<td></td>
<td>reason* attitude* belief* decision making decision-making</td>
<td></td>
</tr>
<tr>
<td>R (Research type)</td>
<td>Empirical qualitative research</td>
<td>qualitative mixed method*</td>
<td>Abstract+</td>
</tr>
</tbody>
</table>

* Anywhere except full text (Medline, PsycINFO); title, abstract, keywords (Scopus, Web of Science); abstract (CINAHL)
2.2 Inclusion and Exclusion Criteria

Articles’ titles and abstracts were screened and retained if they related to staff and/or women SUs’ experiences of ECT. Following initial screening, full text articles were assessed for eligibility according to specific inclusion and exclusion criteria (Table 2).
### Table 2

**Inclusion and Exclusion Criteria**

<table>
<thead>
<tr>
<th>SPIDER Component</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>S</strong></td>
<td>Adult women service users who have received ECT</td>
<td>Individuals who have not received ECT or been part of the staff team delivering ECT</td>
</tr>
<tr>
<td></td>
<td>Mental health professionals who have been part of the team delivering ECT</td>
<td>ECT recipients who do not identify as women</td>
</tr>
<tr>
<td></td>
<td>For both women and staff, their most recent experience of ECT must have occurred from 1980 onwards</td>
<td>ECT recipients who are children or adolescents (&lt;18)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Family members or carers of ECT recipients</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Non-human subjects</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Women or staff whose most recent experience of ECT was prior to 1980</td>
</tr>
<tr>
<td><strong>PI</strong></td>
<td>ECT prescribed to treat psychological difficulties or distress</td>
<td>Other brain stimulation therapies (e.g., TMS)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other treatments involving use of an electrical current (e.g., TENS)</td>
</tr>
<tr>
<td><strong>D</strong></td>
<td>Qualitative research designs or mixed methods studies where qualitative data can be extracted</td>
<td>Quantitative research designs or mixed methods studies where qualitative data cannot be extracted</td>
</tr>
<tr>
<td><strong>E</strong></td>
<td>Studies which focus on subjective experiences of ECT, including the decision making and consent process</td>
<td>Studies which do not focus on subjective experiences (e.g., those which focus on treatment efficacy as determined by other means)</td>
</tr>
<tr>
<td><strong>R</strong></td>
<td>Empirical qualitative research written in English and published in a peer-reviewed journal</td>
<td>Personal narratives or discursive articles</td>
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<td></td>
<td></td>
<td>Quantitative research</td>
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<tr>
<td></td>
<td></td>
<td>Papers not written in English</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Grey literature (e.g., dissertation/thesis papers which have not been published)</td>
</tr>
</tbody>
</table>
Studies focusing on subjective experiences of adult women recipients of ECT for psychological difficulties, and/or MH professionals who had been part of a team administering ECT were included. Only data from participants who last experienced ECT from 1980 onwards was included as significant changes were made to the techniques used to deliver ECT at this time (Fink, 2002; Wells et al., 2021). Papers including participants who had not experienced ECT since 1980 were retained if data for those who had experienced ECT since this time could be extracted. As this review aimed to focus on experiences of individuals who have been directly involved in the ECT process, either through receiving or administering ECT, studies exploring perspectives of family members, carers and the public were excluded. Studies focusing on perspectives of child and adolescent recipients were excluded due to key differences in the ECT experience for children and adolescents, specifically regarding observed side effects, consent procedures, and the impact of development (Benson & Seiner, 2019). To ensure methodological rigour, only empirical research published in peer-reviewed journals was included in the current review. Search results were limited to papers written in English.

Appendix E illustrates all studies included in the review met these inclusion criteria and indicates where evidence of this can be found in each article. This process was completed independently by the review’s author and a peer reviewer (Appendix F).

2.3 Classification of Studies

The process of study selection was recorded on a PRISMA flow diagram (Page et al., 2021; Figure 1).
Figure 1

PRISMA Flow Diagram for the Current Review

Identification of studies via databases and registers

- Records identified from:
  - Medline (n = 170)
  - PsycINFO (n = 184)
  - Scopus (n = 346)
  - Web of Science (n = 110)
  - CINAHL (n = 94)
  - Total (N = 904)

- Records screened (N = 904-390) = 514

- Reports sought for retrieval (N = 514-474) = 40

- Reports assessed for eligibility (N = 40)

- Studies/reports included in review (N = 40-30) + (66-66) = 10 + 0 = 10

Identification of studies via other methods

- Records identified from:
  - Websites - Google Scholar (n = 50)
  - Citation searching (n = 16)
  - Total (N = 66)

- Records removed before screening:
  - Duplicate records removed:
    - EndNote (n = 322)
    - Manually (n = 68)
    - Total (N = 390)

- Records excluded:
  - Not relevant to subject (n = 451)
  - Not research study (n = 20)
  - Thesis/dissertation (n = 3)
  - Total (N = 474)

- Reports sought for retrieval (N = 66)

- Reports assessed for eligibility (N = 66)

- Reports excluded:
  - Duplicate - Medline (n = 9)
  - Duplicate - PsycINFO (n = 4)
  - Duplicate - Scopus (n = 5)
  - Not relevant to subject (n = 13)
  - Not research study (n = 17)
  - Thesis/dissertation (n = 5)
  - Sample (n = 6)
  - Design (n = 7)
  - Total (N = 66)

- Reports not retrieved (N = 0)
In total, 904 records were identified from database searches and imported into EndNote. Next, 390 duplicate records were identified using EndNote (n=322) and through manual searching (n=68). Removal of duplicates left 514 records for initial screening. Of these, 474 were excluded as they were not relevant to the review subject (n=451), were not a research study (n=20) or were a thesis/dissertation (n=3). This left 40 reports which were sought for retrieval; all 40 were retrieved and full texts were assessed for eligibility against inclusion and exclusion criteria. Of these, 30 were excluded as they did not meet criteria in relation to the sample (n=17), phenomenon of interest (n=3), design (n=3), evaluation (n=5), or research type (n=2). This left 10 studies to be included in the review.

Additionally, 66 records were identified via other methods including the Google Scholar search (n=50) and manual citation searching (n=16). These were sought for retrieval and assessed for eligibility. All 66 were excluded as they did not meet the inclusion criteria. Therefore, combining the database searches and sources identified via other methods, 10 studies met criteria to be included in the review.

2.4 Quality Assessment Checks

The Critical Appraisal and Skills Programme (CASP) checklist for qualitative studies was used to assess the quality of studies included in the current review (CASP, 2018; Appendix G). The CASP presents an accessible method for assessing the quality of qualitative research (Long et al., 2020). The checklist comprises ten items. Item scores are assigned to indicate whether each point is addressed (0 – no; 1 – can’t tell; 2 – yes) and are combined to determine an overall quality assessment rating.

The ten studies included in this review achieved a mean quality assessment score of 16.8, with scores ranging between 15-19 out of a possible 20 points (Appendix H). There were two common areas in which studies lost points: consideration of the researcher-participant relationship (item 6) and value of the research (item 10). Only two studies (Duxbury et al.,
2018; van Daalen-Smith, 2011) did not lose points in relation to consideration of the researcher-participant relationship. The eight remaining studies provided limited or no evidence that this had been considered. Considering the role of subjectivity in qualitative research (Ratner, 2002), it is interesting that further consideration was not given to this relationship and how this may have impacted the research process. Additionally, five articles lost points in relation to the perceived value of their research (Ejaredar & Hagen, 2013; Gass, 2008; Lonergan et al., 2021; Orr & O’Connor, 2005; van Daalen-Smith, 2011). While authors generally discussed the contribution of their research and made clinical recommendations, limited suggestions were made in terms of future research directions. It is important to clarify that low scores in these areas do not necessarily indicate that the studies were not methodologically sound or of value. Study authors are somewhat bound by constraints of journal guidelines when publishing research articles (Perestela- Pérez, 2012). This may limit the extent to which authors can evidence the methodological rigour and value of their study.

Studies were independently assessed against the CASP by two assessors, allowing for calculations of inter-rater reliability. Subsequent discussion of discrepancies in scoring provided sufficient evidence in some cases for a unanimous decision to be reached regarding item scores. The overall Kappa coefficient of $\kappa=.87$ indicates almost perfect agreement between raters (Viera & Garrett, 2005). Kappa coefficients for individual studies ranged from $\kappa=.62$ to $\kappa=1$ (Appendix H).

2.5 Characteristics of the Literature

Table 3 outlines characteristics and key findings of the ten studies. Appendix I contains a summary of the characteristics presented in this table. The data extraction process was completed independently by a peer reviewer for a sample of two papers to review accuracy of extracted data (Appendix J).
<table>
<thead>
<tr>
<th>Author, year, country, quality rating (QR), inter-rater reliability (Kappa)</th>
<th>Research aim</th>
<th>Sampling method</th>
<th>Sample characteristics a</th>
<th>Method of data collection, method of data analysis</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clark et al. 2018 Australia QR=18 (\kappa=0.62)</td>
<td>To explore women’s accounts of making the decision to receive ECT</td>
<td>Purposive sampling from local general practitioner (GP) network website</td>
<td>(N=7) women recipients</td>
<td>Interviews Thematic analysis (Fereday &amp; Muir-Cochrane, 2006)</td>
<td>One main theme, ‘Making the decision to have ECT’, highlighted the ECT decision-making and consent process for the women in the study.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(M) age = 53.57 years</td>
<td></td>
<td>Four sub-themes: (i) ‘Not enough information’ describes how much information was given to women prior to receiving ECT; (ii) ‘I had no other choice’ highlights the decision-making process for the women; (iii) ‘Just go along with it’ describes whether the women felt they were able to influence or take part in the decision-making process; (iv) ‘Lacking capacity’ highlights whether the women perceived that they were able to make the decision</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Age range = 44-60 years</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Background: (n=6) – White and English speaking (n=1) – Australian Indigenous</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(M) age when first had ECT = 47.57 years</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(M) total number of ECT treatments = 21.50 (one</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
participant unable to recall

\[ M \text{ time since last ECT} = 5.43 \text{ years} \]

| Duxbury et al. 2018 | To understand staff perspectives on making the decision to administer ECT | Theoretical sampling from two national health service (NHS) trusts and via social media platforms | \( N=10 \) staff members | Interviews | Five core categories/layers to the ECT decision-making process:
(i) ‘Personal and professional identity’ outlines the boundaries of the model;
(ii) ‘Subjective vs. objective’ describes different professionals’ views of ECT and willingness to prescribe this as a treatment method;
(iii) ‘Guidelines or clinical instinct?’ highlights the decision regarding who should receive ECT and when this should be administered;
(iv) ‘Someone has to take responsibility’ describes who holds the power and responsibility to make this decision;
(v) ‘The decision in action’ highlights the different ways that staff put the decision into action and interacted with service users (i.e., advocating, reassuring/persuading, enabling autonomy) |
---|---|---|---|---|---|
United Kingdom QR=18 | Gender: \( n=4 \) – female, \( n=6 \) – male | Grounded theory (Charmaz, 2011) | \( M \text{ age } = 40 \text{ years (not reported for 2 participants)} \) | | |
\( \kappa=0.62 \) | Ethnicity/nationality: \( n=7 \) – White British, \( n=1 \) – Indian, \( n=2 \) – not reported | | | | |
<p>| | Profession: ( n=2 ) – psychologist, ( n=2 ) – ECT nurse, ( n=2 ) – ward manager/deputy, ( n=2 ) – psychiatrist, ( n=1 ) – recovery worker, ( n=1 ) – advanced mental health practitioner | | | | |</p>
<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Country</th>
<th>Design Methodology</th>
<th>Sample Size</th>
<th>Data Collection Method</th>
<th>Main Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ejaredar &amp; Hagen</td>
<td>2013</td>
<td>Canada</td>
<td>Convenience sampling from the general community (using posters and word of mouth)</td>
<td>$N=9$ women recipients</td>
<td>Interviews</td>
<td>Four main themes relating to benefits and side effects of ECT: (i) ‘It’s sort of like housecleaning’ describes the women’s experiences of benefits or the positive impact of ECT; (ii) ‘I don’t remember the wedding’ highlights the persistent memory loss experienced by most participants after receiving ECT; (iii) ‘Made me stupider’ describes experiences of cognitive decline which the women attributed to ECT; (iv) ‘Putting them in a cage with a bear’ highlights experiences of fear, embarrassment and/or stigma related to ECT.</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>$M$ age = 42.22 years</td>
<td>Thematic analysis (Braun &amp; Clarke, 2006)</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Age range = 22-63 years</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>$M$ age when first had ECT = 32.44 years</td>
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<td>Total number of ECT treatments: $n=5–0-25$</td>
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<td>$n=1–25-50$</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>$n=1–50-75$</td>
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<td></td>
<td></td>
<td></td>
<td>$n=0–75-100$</td>
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<td></td>
<td></td>
<td></td>
<td>$n=2–&gt;100$</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>$M$ time since last ECT = 8.15 years</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Ejaredar &amp; Hagen</td>
<td>2014</td>
<td>Canada</td>
<td>Convenience sampling from the general community (using posters and word of mouth)</td>
<td>$N=9$ women recipients</td>
<td>Interviews</td>
<td>Four main themes relating to women’s experiences of ECT: (i) ‘He didn’t really say much’ describes the women feeling they were provided with inadequate/over-simplified/misleading information regarding ECT; (ii) ‘I’m going to be very upset with you’ highlights to what extent the women felt pressured/coerced into agreeing to have ECT; (iii) ‘I was just desperate’ describes the women’s experiences of desperation and vulnerability and how this impacted on their decision;</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>$M$ age = 42.22 years</td>
<td>Thematic analysis (Braun &amp; Clarke, 2006)</td>
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<td></td>
<td>Age range = 22-63 years</td>
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<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>$M$ age when first had ECT = 32.44 years</td>
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</table>


| Gass | To explore the role of mental health nurses in supporting individuals who receive ECT | Purposive and theoretical sampling from NHS hospitals in Scotland | N=24 staff members | Observation and interviews | Two main roles for nurses: 
(i) ‘Relational roles’ describes their role in relationships with service users;  
(ii) ‘Treatment roles’ highlights their practical role in administering ECT and supporting this process |
|---|---|---|---|---|---|
| 2008 | | | Observation and interviews | Grounded theory – hybrid approach (Glaser & Strauss, 1967; Strauss & Corbin, 1990) | Two main dilemmas experienced by nurses: 
(i) ‘Uncertain role’ describes how ward nurses felt uncertain about their role during the ECT treatment process;  
(ii) ‘Uncertain relationships’ highlights nurses’ experiences taking someone to have ECT against their will and the impact of this on the relationship. |
| United Kingdom | | | | | One core category: ‘Being there’ describes nurse’s actions when working with service users receiving ECT. Comprised of three sub-categories:  
(i) ‘Engaged’ nurses who aim to understand the service user’s feelings/concerns;  
(ii) ‘Present’ nurses who focus on ensuring the ECT treatment goes ahead; |
| QR=17 | | | | | |
| k=0.78 | | | | | |

Total number of ECT treatments:
- n=5 – 0-25
- n=1 – 25-50
- n=1 – 50-75
- n=0 – 75-100
- n=2 – >100

M time since last ECT = 8.15 years

(iv) ‘It was like we were cattle’ highlights how some women were dehumanised and depersonalised by the ECT process
### Study 1: Kring et al. (2018)
- **Objective:** To explore the experiences and attitudes of individuals who have previously received ECT.
- **Method:** Criterion sampling from the general community (using newspaper adverts, websites of psychiatric affiliations and posters).
- **Participants:**
  - $N=4$ women recipients
  - Age range = 51-59 years old
  - Employment: $n=3$ – early retirees, $n=1$ – unemployed
  - Marital status: $n=2$ – married, $n=2$ – divorced
  - Time since last ECT range = 7-18 years
- **Analysis:** Focus group interview and Framework analysis (Rabiee, 2004)
- **Themes:**
  1. **Ambivalent attitudes** describes the women’s mixed feelings and attitudes towards ECT.
  2. **Discrediting and exclusion** highlights the impact of negative societal perceptions regarding ECT on the women and the need to adopt a new identity after loss of social skills and social recognition following ECT.
  3. **Survival strategies** describes how women managed the dilemmas they faced after ECT.

### Study 2: Lonergan et al. (2021)
- **Objective:** To explore mental health nurse’s views and perspectives on caring for older adults receiving ECT.
- **Method:** Purposive sampling from a private hospital which runs the largest ECT clinic in Ireland.
- **Participants:**
  - $N=14$ staff members
  - Age (years):
    - $n=4$ – 20-30
    - $n=2$ – 31-40
    - $n=3$ – 41-50
    - $n=4$ – 51-60
  - Education level:
    - $n=2$ – diploma level
    - $n=7$ – degree level
    - $n=2$ – masters degree
- **Analysis:** Focus groups and Thematic analysis (Braun & Clarke, 2006)
- **Themes:**
  1. **Exploring attitudinal changes** describes the change in nurse’s attitudes towards ECT after seeing the procedure and associated outcomes.
  2. **Managing patient dignity** highlights how nurses tried to maintain service users’ dignity and confidentiality while carrying out nursing tasks.
  3. **Reflecting changes in practice** refers to the change in ECT practice observed by nurses over time.
  4. **Managing the unknown** describes the nurse’s role in managing service user and relative’s anxiety relating to the uncertainty around how ECT works.
| Orr & O’Connor 2005 | To explore the subjective experiences of women who have received ECT as older adults (65+) in relation to a diagnosis of ‘major depression’ | Purposive sampling via community mental health services | N=6 women recipients | Interviews | Central theme: ‘Dimensions of power’ refers to the context of the ECT experience and the different forms of power impacting on the experience for these women. Three main dimensions described:
(i) ‘The experience of depression: An unexpected, external and all-consuming force’ describes how ECT was understood within a broader context of the women’s experiences of depression;
(ii) ‘Seeking help: Developing allies’ highlights how the women turned to mental health service for support in managing their experiences of depression;
(iii) ‘Conceptualising the ECT experience’ describes how women experienced and recalled the ECT process |
<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td></td>
<td></td>
<td>M age = 80.67 years</td>
<td>Analysis method not specified; data analysed for themes</td>
<td></td>
</tr>
<tr>
<td>QR=16</td>
<td></td>
<td>Age range = 71–89 years</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(\kappa=1)</td>
<td></td>
<td>Ethnicity: n=6 – White</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Education level: n=2 – high school n=1 – university degree n=3 – not reported</td>
<td></td>
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</tr>
</tbody>
</table>
| Stevens & Harper | To explore the accounts of staff members who have administered ECT | Purposive sampling from departments of anaesthetics and older age psychiatry | $N=8$ staff members | Interviews | ECT recipients were described using diagnostic medical language and constructed as being ‘severely ill’.

Four main claims:

(i) ‘Who is appropriate for ECT?’ highlights how staff members determined who may benefit from ECT;

(ii) ‘ECT as life-saving’ describes how staff members justified the use of ECT when the individual was perceived to be experiencing life-threatening difficulties;

(iii) ‘Locating the focus of concern at the biological level’ highlights how staff members described service users’ difficulties in biological terms by describing life-threatening physical health problems (staff perceived that depression led to self-destructive behaviour which led to life-threatening physical health problems);

(iv) ‘Exclusion of non-physical interventions’ describes how ECT was viewed as an ‘effective treatment’ and alternative interventions (e.g. psychotherapy or social support) were not discussed in staff members’ accounts.

| Gender: | $n=4$ – female | $n=4$ – male |
| Age (years): | $n=3$ – 30-39 | $n=3$ – 40-49 | $n=2$ – 50-59 |
| Profession: | $n=2$ – mental health nurse | $n=4$ – psychiatrist | $n=2$ – anaesthetist |
Concerns about ECT were managed in four main ways:
(i) ‘Acknowledging grounds for concern: Weighing up risks and benefits’ describes how staff presented service users with the pros and cons of ECT;
(ii) ‘Rendering ECT as a medical procedure’ highlights how ECT was presented by staff as being similar to general medical procedures, thereby minimising its status as a controversial intervention;
(iii) ‘Downplaying debate: The evidence is becoming clearer’ describes how staff downplayed concerns in relation to the lack of clarity around ECT efficacy;
(iv) ‘Managing criticism of ECT: who has rights to speak?’ highlights how staff members devalued the perspectives of ECT critics.

van Daalen-Smith 2011 Canada QR=19 $\kappa=1$

(i) To explore women’s lived experiences of ECT, including the impact of ECT on their lives and the role nursing played in receiving ECT

(ii) To explore the experiences of ECT recipients:

<table>
<thead>
<tr>
<th>Women recipients:</th>
<th>N=22 participants</th>
<th>Women recipients:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Purposive sampling through posters hung at ECT clinics and snowballing sampling through word of mouth of practitioners</td>
<td>n=7 – female recipients</td>
<td>n=15 – staff members</td>
</tr>
</tbody>
</table>

Age range = 44-65 years

Ethnicity: n=6 – White

n=1 – not reported

Staff members:

Interviews and focus groups

Three main themes:
(i) ‘A spectrum of vulnerability: Desperation, shame, powerlessness, misinformation, fear’ describes the vulnerability experienced by the women who received ECT and illustrates how this vulnerability was sometimes created by those in a position of power (e.g., mental health professionals);
(ii) ‘That’s not what I needed: The women’s perspective’ highlights how the women sought help from mental health services but felt ECT was not what they needed and felt their wishes were not heard;
(iii) ‘A disconnect between nurses and the patients in this study’ describes how perspectives differed between the women recipients and nurses; this theme also highlights how some nurses experienced a lack
and perceptions of nurses involved in administering ECT

<table>
<thead>
<tr>
<th>Staff members: Purposive sampling from psychiatric nursing units</th>
</tr>
</thead>
</table>
| **Profession:**
| $n=15$ – mental health nurse |
| **Constant-comparison** (Lincoln & Guba, 1985) |

of power in relation to administering ECT which could be similar in some ways to the power imbalances experienced by the women receiving ECT.

---

a The following sample characteristics are reported in the table if specified in the original study: gender, age, background/nationality/ethnicity, education, employment, marital status, information about ECT treatments (for women recipients), profession and time qualified (for staff members).

b Kring et al. (2018) also aimed to explore the attitudes of staff, but this part of the study did not meet inclusion criteria for the current review.

c Seven women recipients of ECT participated in this study (van Daalen-Smith, 2011); data from two women could not be included as they did not meet inclusion criteria for the current review.
2.6 Analytic Review Strategy

Thematic synthesis (Thomas & Harden, 2008) was used to analyse data extracted from articles included in this review. Meta-ethnography (Noblit & Hare, 1988) was also considered; this interpretative approach synthesises and re-conceptualises findings from empirical studies focused on participants’ experiences. However, due to the scarcity of research regarding experiences of ECT, the review’s author decided to use a less interpretative synthesis method to remain closer to the original data and draw out key patterns in existing studies on this topic (Snilstveit et al., 2012). Thematic synthesis has been applied to systematic reviews as a way of integrating findings from multiple qualitative studies (Thomas & Harden, 2008). This comprises three stages: (1) line-by-line coding of data according to meaning and content, (2) development of descriptive themes by grouping codes into related areas, and (3) generation of analytical themes, allowing for consideration of novel interpretations of the data. Images illustrating the analysis process are presented in Appendix K alongside a description of the steps taken.

3.0 Results

Thematic synthesis of findings from ten studies revealed two main themes: ‘Power in the ECT experience’ and ‘Life after ECT’ (see Table 4).

Table 4

<table>
<thead>
<tr>
<th>Themes and Sub-themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme</strong></td>
</tr>
<tr>
<td>Power in the ECT experience</td>
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<tr>
<td></td>
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<tr>
<td>Life after ECT</td>
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</table>

Table 5 outlines which studies supported each theme and sub-theme. Themes are described below, and additional illustrative quotes can be found in Appendix L.
Table 5

Studies Contributing to Themes and Sub-themes

<table>
<thead>
<tr>
<th>Study</th>
<th>Recipients or staff</th>
<th>Theme 1: Power in the ECT experience</th>
<th>Theme 2: Life after ECT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Before ECT</td>
<td>During ECT</td>
</tr>
<tr>
<td>Clark et al. (2018)</td>
<td>Recipients</td>
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<td>✓</td>
</tr>
<tr>
<td>Duxbury et al. (2018)</td>
<td>Staff</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Ejaredar &amp; Hagen (2013)</td>
<td>Recipients</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Ejaredar &amp; Hagen (2014)</td>
<td>Recipients</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Gass (2008)</td>
<td>Staff</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Kring et al. (2018)</td>
<td>Recipients</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Lonergan et al. (2021)</td>
<td>Staff</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Orr &amp; O’Connor (2005)</td>
<td>Recipients</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Stevens &amp; Harper (2007)</td>
<td>Staff</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>van Daalen-Smith (2011)</td>
<td>Both</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

3.1 Power in the ECT Experience

The main theme ‘Power in the ECT experience’ highlights the role of power in staff and women recipients’ experiences of ECT. This theme includes two sub-themes: ‘Before ECT’ describing the complex process of deciding to receive or administer ECT, and ‘During ECT’ highlighting experiences of the treatment itself and how staff-recipient relationships developed at this stage in the ECT journey.

3.1.1 Before ECT

Women recipients described having limited power when deciding whether to have ECT (Clark et al., 2018; Ejaredar & Hagen, 2014; Orr & O’Connor, 2005; van Daalen-Smith, 2011); “None of the participants gave any indication that they saw themselves as having any choice in the matter, despite their signing of the informed consent” (Orr & O’Connor, 2005, p.29). Women reported ECT was presented as the only option: “Either you stay here in this hospital..."
for the rest of your life or you have ECT. I do not see that there was any alternative. At least, none that was given to me” (Clark et al., 2018, p. 1081). Many did not want or feel they needed ECT but described feeling that their wishes were not heard: “It’s like, ‘we (the doctors) know what’s best for you, so just quiet down dear’” (Ejaredar & Hagen, 2014, p. 34).

Women recipients described how healthcare professionals influenced their decision to receive ECT, illustrating power imbalances between staff and SUs (Clark et al., 2018; Ejaredar & Hagen, 2014; Orr & O’Connor, 2005; van Daalen-Smith, 2011). Ejaredar and Hagen (2014) referenced women being pressured or coerced into having ECT; pressure was sometimes explicit and, at other times, “subtle but effective, such as the psychiatrist who told Natalie that he would be ‘very upset’ with her if she refused ECT” (p. 33). Some women feared they might lose professionals’ support if they did not agree to ECT: “They cannot question the health care team for fear of alienating and being left to struggle alone with the power of the depression” (Orr & O’Connor, 2005, p. 32). Some reported “feeling a strong sense of passive persuasion” (Clark et al, 2018, p. 1081), doing as they were told and demonstrating a “blind, yet powerful, trust and faith in systems that promised to help” (van Daalen-Smith, 2011, p. 463). Some assumed the doctors knew what was best for them (Clark et al., 2018; Orr & O’Connor, 2005). Others experienced “conflict between trusting that doctors knew what they were doing and simultaneously feeling powerless and frightened at the unknown” (Clark et al., 2018, p. 1081).

Interestingly, van Daalen-Smith’s (2011) participants “commented on the little power nursing seemed to have in the hospital” (p.464).

Power in the decision-making process was evident in how ECT was presented to the women. Some described a narrative that ECT would make them ‘better’ (Clark et al., 2018; Ejaredar & Hagen, 2014; van Daalen-Smith, 2011): “The common thing that all the women were told about ECT was that their individual situation was what warranted it, that they needed it if they ever hoped to be better, and that medications ‘don’t seem to work for them’” (van
Daalen-Smith, 2011, p. 463). Some did not recall receiving information about ECT (Ejaredar & Hagen, 2014; van Daalen-Smith, 2011) or “felt they had not been given enough information on which to base their decision” (Clark et al., 2018, p. 1080). Some recalled being given oversimplified explanations such as “I was told that it restarts your brain” (Ejaredar & Hagen, 2014, p. 33). This lack of information further limited the women’s power when making this decision: “He didn’t give me any of the negative side effects until it was too late” (Ejaredar & Hagen, 2014, p. 33).

Some women recipients reported experiencing extreme distress prior to having ECT and having to turn to MH services for support (Clark et al., 2018; Kring et al., 2018; Orr & O’Connor, 2005; van Daalen-Smith, 2011). Due to the level of distress they were experiencing, some felt “[they] didn’t have the capacity to make a decision like this” (Clark et al., 2018, p. 1081). Some “described mental illness as being overwhelmingly unbearable and debilitating, making familiar and professional help indispensable” (Kring et al., 2018, p. 361). While some viewed MH services as “allies to combat the invading force of depression” (Orr & O’Connor, 2005, p. 26), others indicated that professionals’ medical response to their distress was not what they needed.

Additionally, women agreed to ECT out of desperation (Clark et al., 2018; Ejaredar & Hagen, 2014; Orr & O’Connor, 2005; van Daalen-Smith, 2011); they were willing to try anything to feel better: “Because I was so acutely unwell and just desperate for anything that would work, I think I agreed […]” (Clark et al., 2018, p. 1081). Ejaredar and Hagen (2014) highlighted “participants felt so vulnerable, it [made] any perceived coercion even more problematic, and the idea of an informed ‘decision’ even more illusionary” (p. 34).

Staff members discussed their role in the ECT decision-making process (Duxbury et al., 2018; Gass, 2008; Lonergan et al., 2021; Stevens & Harper, 2007; van Daalen-Smith,
2011). Some acknowledged the lack of power held by SUs and questioned the validity of informed consent:

Although the clients had written consents on their charts (by themselves or a substitute decision-maker), I always wondered about unintended coercion. Clients in such a disadvantaged position, i.e., ‘You won’t be able to go home unless you get better.’ I always wondered, is that really full consent? (van Daalen-Smith, 2011, p. 467)

When SUs were perceived as lacking power and control, some staff members “felt they had to advocate on behalf of the patient” (Duxbury et al., 2018, p. 790). Moreover, staff members spoke about the importance of respecting SUs’ wishes, including the decision to decline ECT (Duxbury et al., 2018; Gass, 2008; Lonergan et al., 2021; van Daalen-Smith, 2011). This was, however, sometimes dependent on whether the individual was deemed to have capacity to make the decision. Some staff members felt the ECT consent process had “improved greatly” over time (Lonergan et al., 2021, p. 313).

On the other hand, some staff described feeling they knew what was best for the SU and felt it was their job to persuade them to consent to ECT: “Well you just try and try and try to get them to come round to your way of thinking” (Gass, 2008, p. 198). This illustrates how staff used their power, perhaps unknowingly, to influence the decision. A consultant psychiatrist from Sevens and Harper’s (2007) study spoke about how they would present the pros and cons to ECT but would ultimately tell the individual: “I really think this is the treatment you should be having” (p. 1481). Many staff spoke about their role in reassuring SUs that ECT was a good option. Some felt they were “supporting choice” by offering reassurance, whereas others “saw reassurance as persuasion” (Duxbury et al., 2018, p. 790).

Staff members from various professions reported believing ECT would help people to “get better” (Duxbury et al., 2018, p. 788) or described ECT as “lifesaving” (Stevens & Harper, 2007, p. 1480). Staff referenced the negative societal perception of ECT and described their
role in countering this (Duxbury et al., 2018; Lonergan et al., 2021; Stevens & Harper, 2007). Some discredited ECT recipients who spoke out against ECT by describing them as “poorly informed and forgetful” and suggested “those who are critical of the procedure, but who have not been recipients, are implicitly positioned as even less authorised to criticise ECT” (Stevens & Harper, 2007, p. 1483).

Additionally, staff members reported providing information about ECT to potential recipients and their families (Duxbury et al., 2018; Gass, 2008; Lonergan et al., 2021; Stevens & Harper, 2007; van Daalen-Smith, 2011). Some staff members, however, highlighted the lack of clarity regarding how ECT works: “I wasn’t sure what it (ECT) actually did and nobody could ever give me an explanation of it” (Lonergan et al., 2021, p. 313). This lack of clarity left staff feeling “ill-equipped to deal with some of the concerns of patients and family members” (p. 314). Some nurses described hiding their own views on ECT and providing SUs with information which they did not believe themselves (Gass, 2008).

Moreover, staff members described how ECT was given to people who were experiencing very high levels of distress (Duxbury et al., 2018; Lonergan et al., 2021; Stevens & Harper, 2007; van Daalen-Smith, 2011). Distress was described as significantly impacting functioning and was sometimes considered to be life-threatening, with ECT recipients being described as “severely ill” (Stevens & Harper, 2007, p. 1483) prior to having ECT. Some staff members said they had observed SUs agreeing to ECT “out of desperation” (van Daalen-Smith, 2011, p. 466) and spoke about the challenges of supporting someone who was experiencing such significant distress: “well it is awful. It’s awful…this job it will emotionally pull you. We are only human” (Duxbury et al., 2018, p. 789).

Staff members spoke about power differences between staff disciplines regarding the decision to administer ECT. Some stated the doctor holds the most power: “The team decision was said to be dependent on the consultant psychiatrist whom all ten participants described as
having ultimate power in the process” (Duxbury et al., 2018, p. 789). Some nurses questioned their own power to affect change if they had concerns about the consent process: “What can you do about it as a staff nurse, when all the paperwork lines up and clients verbally agree?” (van Daalen-Smith, 2011, p. 467).

3.1.2 During ECT

Women recipients described their feelings during the ECT procedure (Ejaredar & Hagen, 2013, 2014; Kring et al., 2018; Orr & O’Connor, 2005; van Daalen-Smith, 2011). Some voiced they “remained hopeful that the years of depression where ‘medication didn’t help’, or ‘made [them] feel worse’, would be lifted” (van Daalen-Smith, 2011, p. 464). Others described experiencing fear, anxiety, and disgust (Ejaredar & Hagen, 2013; Ejaredar & Hagen, 2014; Kring et al., 2018; Orr & O’Connor, 2005; van Daalen-Smith, 2011).

Some women described feeling ‘done to’ during the process, illustrating that many continued to feel powerless while receiving ECT; they described ECT as “dehumanizing and depersonalizing”, with one woman stating: ‘It’s kind of like we were cattle or something” (Ejaredar & Hagen, 2014, p. 34). Some called it “frightening” (Kring et al., 2018, p. 361) and compared it with “taking somebody who’s afraid of a bear and putting them in a cage with a bear” (Ejaredar & Hagen, 2013, p.150). Contrastingly, some women reported looking forward to the peace and loss of control that came with the procedure: “But when they put you under, I always looked forward to that, because it was so peaceful. Like, cause you’re just so relaxed and there’s absolutely nothing” (Ejaredar & Hagen, 2014, p.34).

Furthermore, women recipients described their relationships with staff members during the treatment process (Orr & O’Connor, 2005; van Daalen-Smith, 2011). Some developed trusting alliances with staff, based on perceived knowledge and interpersonal qualities. One woman recalled her nurses being “concerned” about the impact that ECT was having on her (van Daalen-Smith, 2011, p. 464). Others, however, experienced staff as unsupportive, punitive
and/or cold: “The nurses were there, but not really. Very cold, cold stares, just doing their job and listening to the psychiatrist’s instructions” (van Daalen-Smith, 2011, p. 464). For some, the power imbalance in favour of medical staff remained evident: “Fran pleaded with her physician to stop because the ‘shock was making me forget everything and everybody I was supposed to know’. According to Fran, her doctor responded, ‘What difference does it make?’” (van Daalen-Smith, 2011, pp. 463-464).

Staff members spoke about the role of the nurse during the treatment procedure (Gass, 2008; Lonergan et al., 2021; van Daalen-Smith, 2011). Some described their responsibility to support the individual’s plan of care and reported “their role was to ‘support the psychiatrist’s decision’ and make sure the patient was ‘up and ready’ on treatment morning” (van Daalen-Smith, 2011, p. 466). Others described being in a position where they had to go along with the ECT process: “I know deep down in my gut my feeling is that ECT is wrong no question but you still go through with it” (Gass, 2008, p. 196).

While ECT nurses had a clear role in administering the treatment, some ward nurses felt uncertain regarding their role at this stage in the process. They described “a sense of not belonging”, feeling “as though you’re a bit of an inconvenience”, and being “elbowed out of the way for the machinery” (Gass, 2008, pp. 195-196). Some staff members reported becoming “task orientated” and “mechanical” to cope with the demands of supporting a SU through ECT (Lonergan et al., 2021, p. 313). Additionally, staff described experiences of having to give ECT against the recipient’s will (Duxbury et al., 2018; Gass, 2008; Stevens & Harper, 2007). Many voiced the discomfort of having to physically force someone to have ECT, but some felt this was justified: “Even though it is horrible at first and you do have to put hands on and take someone round there you can justify it in your head because you think I know it will get better for that person…” (Duxbury et al., 2018, p. 788).
Staff members also described their relationship with ECT recipients during treatment (Duxbury et al., 2018; Gass, 2008; Lonergan et al., 2021; van Daalen-Smith, 2011). For some, “sustaining the relationship [was] viewed as an essential part of their work” (Gass, 2008, p. 194). Some highlighted the importance of understanding the recipient’s internal world and tried to “remain conscious of what the patient may be experiencing” (Lonergan et al., 2021, p. 313). There were, however, “potential emotional difficulties of getting too close to the patient” (Gass, 2008, p. 198), and some nurses became less engaged and distanced themselves for self-protection. Some avoided working with individuals receiving ECT altogether by swapping shifts with other staff who “didn’t mind” (van Daalen-Smith, 2011, p. 467).

The relationship with the SU was seen by some staff as instrumental in ensuring ECT went ahead; the relationship was “orientated towards an agenda created by the nurse rather than with the patient” (Gass, 2008, p. 198). Some staff members described the detrimental impact of forced ECT on their relationship with the recipient: “I expected the trust to have gone, well what little trust was there […] and it had” (Gass, 2008, p. 198).

3.2 Life After ECT

The main theme of ‘Life after ECT’ highlights experiences of the impact of ECT. This theme includes two sub-themes: ‘Women recipients’ describing the positive impact, the losses, and the role of stigma experienced by women who received ECT, and ‘Staff members’ highlighting the positive impact and harmful side effects of ECT observed by professionals administering the procedure.

3.2.1 Women Recipients

The reported positive impact of ECT varied across the studies. Positive consequences were described by a minority of women in Ejaredar & Hagen’s (2013) study, just under half in van Daalen-Smith’s (2011) study, and all in Kring et al.’s (2018) study. One woman described how ECT “can sort of lift you out of that darkness, that heaviness” and stated, “you just feel
lighter after you’ve had some ECT” (Ejaredar & Hagen, 2013 p. 148). This positive impact was, however, often described as short-term, and maintenance ECT was required to keep the positive effects going:

There’s a lot of difference in treatments, and not every treatment is successful. I found even the good ones only last about two weeks...so to keep on some sort of sustainable level where you’re not going back into depression, I need it (maintenance ECT). (Ejaredar & Hagen, 2013, p. 149)

Women recipients described the losses they experienced following ECT (Clark et al., 2018; Ejaredar & Hagen, 2013; Kring et al., 2018; Orr & O’Connor, 2005; van Daalen-Smith, 2011). One woman described persistent “debilitating pain” and mobility loss because of a treatment complication where the muscle relaxant was not correctly administered and her kneecap dislocated during an ECT seizure (van Daalen-Smith, 2011, p. 463). Some described the psychological impact of ECT, including experiences of “strange” and “disturbing” flashbacks (van Daalen-Smith, 2011, p. 462).

Many experienced cognitive decline after ECT, coupled with work and educational losses:

Well I felt like it (ECT) made me stupider in some ways. Like I was a university student, got depressed, and then started having ECT. I then had to drop out, and um, I feel like after it (ECT) I couldn’t comprehend things as well as I used to be able to. And much of the knowledge from schooling is lost now. (Ejaredar & Hagen, 2013, p. 150)

Women reported losing connections with themselves and others (Clark et al., 2018; Ejaredar & Hagen, 2013; Kring et al., 2018; Orr & O’Connor, 2005; van Daalen-Smith, 2011). They described the pain of losing memories of important people and events from their past:

It (ECT) did erase a lot of my past memories. My siblings will come up to me and go ‘don’t you remember when we did this or that?’ and I’ll have no recollection of any of
it…I can’t even remember my grandmother or any of that stuff…and it hurts, hurts more than ever. (Ejaredar & Hagen, 2013, p. 149)

Women described how they lost memories of whole “chunks” of time (Orr & O’Connor, 2005, p. 31) and many reported losing childhood memories. The extent to which the women were impacted by memory loss varied: “Everyone had experienced memory loss, some considering this a minor detail compared to the severity of the illness, whereas others found it highly debilitating” (Kring et al., 2018, p.361). Additionally, some described losing a sense of who they were following ECT: “Linda explains that she feels as though a part of her has been taken away. She doesn’t really know who she is […]” (van Daalen-Smith, 2011, p. 462).

Women experienced difficulties with social interactions after ECT (Ejaredar and Hagen, 2013; Kring et al, 2018; van Daalen-Smith, 2011). Some described difficulties remembering what they wanted to say during conversations: “[…] I’m interrupting them because I’m worried I can’t remember what to say…it really affects my social skills” (Ejaredar & Hagen, 2013, p. 150). Some reported “a sense of social isolation and low self-esteem when in the company of others, apart from their closest relatives” (Kring et al., 2018, p. 362).

Women recipients also discussed stigma and reported feeling judged by others after receiving ECT (Ejaredar & Hagen, 2013; Kring et al., 2018; Orr & O’Connor, 2005; van Daalen-Smith, 2011): “My family always told me that it’s just for crazy people, and even my dad looked down on me for having it done” (Ejaredar & Hagen, 2013, p. 151). Many described being reluctant to tell others they had received ECT: “several participants were sufficiently concerned about how others would respond that they rarely and selectively spoke about their experience” (Orr & O’Connor, 2005, p. 32). Some women, however, actively challenged negative perceptions of ECT to “gain acceptance and recognition” (Kring et al., 2018, p. 361).
3.2.2 Staff Members

Staff members described observing the positive impact of ECT (Duxbury et al., 2018, Lonergan et al., 2021; van Daalen-Smith, 2011):

All participants had witnessed some form of ‘dramatic’ improvement in individual patients and this undoubtedly influenced their subsequent decision making. Any difficulties they perceived as being potentially caused by giving someone ECT, particularly against their will, were often seen as being mitigated by these improvements. (Duxbury et al., 2018, p. 787)

Many held negative views of ECT prior to working in an ECT department but reported feeling differently after witnessing the effects of the procedure: “I’ve seen it (ECT) do amazing things for people who are catatonic and not able to talk or move or eat or you know really are profoundly depressed. I suppose now I would have largely positive views” (Lonergan et al., 2021, p. 312). Some nurses described helping people by giving them ECT, stating “we give them their life back” and “we are going to make them better” (van Daalen-Smith, 2011, p. 467). These visible changes observed by staff members occurred in the immediate period following ECT. As highlighted by van Daalen-Smith (2011), “None of the 15 nurses interviewed had any knowledge regarding the status of any individuals after discharge, unless they were re-hospitalized or returned for ‘maintenance’ ECT” (p. 467).

While most staff described observing the positive impact of ECT, some staff members referred to side effects associated with the procedure (Duxbury et al., 2018; Lonergan et al., 2021; Stevens & Harper, 2007; van Daalen-Smith, 2011). Some mentioned physical and cognitive side effects which may occur. Additionally, staff members in one study spoke of the psychological harm people experienced after being given ECT forcibly: “It is going back to the old days of strapping them to the bed and giving them a treatment and all the ensuing memories that could dredge up” (Duxbury et al., 2018, p. 789).
4.0 Discussion

This review synthesised qualitative research on the experiences of ECT from the perspectives of women recipients and staff members involved in administering the procedure. Two main themes emerged: ‘Power in the ECT experience’, describing the role of power in decision-making and throughout the treatment procedure, and ‘Life after ECT’, highlighting the impact of ECT.

Sweetmore’s (2021) commentary on the conflict experienced by MH nurses in the ECT process and power hierarchies within staff teams was supported by the current review. Additionally, staff and women recipients in the current review indicated that medical professionals held the most power in the ECT decision-making process, followed by nurses, then recipients. Regarding the decision to have ECT, many women reported feeling they had no choice, there was no other option, and their wishes were not heard. The current review supports Chakrabarti et al.’s (2010) review findings that most ECT recipients were dissatisfied with the information they received beforehand, and many felt coerced into having ECT. Staff described how a lack of clarity regarding the mechanism and efficacy of ECT made giving information about ECT to SUs and their families difficult, a finding also noted by Sweetmore (2021). The current review ultimately highlighted that many women made the decision to have ECT from a place of desperation and pressurisation.

Some staff members described relationships with SUs as instrumental in ensuring ECT went ahead, which was also highlighted in Sweetmore’s (2010) review. The current review identified that while some felt it was important to respect and advocate for SUs’ wishes, others believed ECT was the best option and therefore felt it was their role to secure consent. This supports Sweetmore’s (2010) review finding regarding the “fine line” (p. 207) between staff members offering reassurance which enables autonomous decision-making, versus persuading SUs to agree to ECT.
The current review further highlighted the different emotions experienced by women ECT recipients during treatment and illustrated how the role of power remained evident at this stage in the ECT process. Some staff members felt they had to go along with administering ECT, supporting Sweetmore’s (2021) finding that nurses often felt professionally obligated to support the psychiatrist’s decision to administer ECT, even when this did not fit with what they believed was right. Ward nurses discussed uncertainties around their role during the treatment process and many experienced discomfort giving ECT against the recipient’s will.

Chakrabarti et al. (2010) highlighted that a majority of ECT recipients perceived ECT as helpful. This was in contrast with the current review, in which participants described predominantly negative consequences. Descriptions of the impact of ECT from women recipients were mostly consistent with those highlighted by ECT recipients in previous reviews (Chakrabarti et al., 2010; Wells et al., 2021). Many of the negative consequences described by Wells et al. (2021), including memory loss, cognitive decline, physical impairments, and grief or loss after ECT, were also highlighted in the current review. The current review expands on this by illustrating how losing significant periods of memory impacted both the women’s sense of who they were and their ability to connect with others. Experiences of stigma and judgement from others led to further feelings of isolation.

Wells et al. (2021) reported that some of the negative impacts of ECT were intensified when recipients felt professionals had invalidated their perspective or dismissed their experiences of side effects. The current review offers a possible explanation for why professionals may be experienced this way. Findings suggest that staff members may dismiss recipients’ concerns when they feel ECT is best for the individual, when they feel they do not have power to change the situation, or when they are trying to manage their own discomfort with their role in the process.
4.1 Clinical Implications

The detrimental impact of ECT on the lives of many women recipients raises the question as to whether ECT should be offered as a treatment option. Burstow (2006) argued that ECT is “a form of violence generally and a form of violence against women in particular” (Burstow, 2006, p. 372) and should be prohibited. MH services exist to support individuals experiencing psychological distress and, as such, the experiences and perspectives of those individuals should shape service delivery (Thornicroft & Tansella, 2005). In this review, professionals who encouraged acceptance of ECT believed themselves to be acting in the best interests of the SU, but many women ECT recipients expressed that ECT was not what they needed or wanted. Not listening to the voices of these women could be another way in which power and control is taken from them.

There are, however, some women recipients who describe dramatically positive and lifesaving consequences of ECT. Removing this treatment option may, therefore, be perceived as detrimental for some. If services continue offering ECT, they must ensure validity of the consent process and ensure those who experience negative consequences are supported to manage this rather than having their concerns dismissed or invalidated. Furthermore, alternatives to ECT must be explored and offered, to avoid this being presented as the only option.

While NICE guidelines on the use of ECT highlight important aspects of the informed consent process (NICE, 2003), this must be reflected in practice. In this review, many staff members viewed ECT as the best course of action and presented this to potential recipients as a solution to their distress. Women recipients, however, described largely negative experiences of the impact of ECT and reported feeling ill-informed beforehand. It is, therefore, recommended that a more balanced picture of ECT, representative of the variety of experiences and impacts, should be presented to individuals being offered ECT. This could be achieved
through staff training regarding ECT’s potential helpful and harmful consequences, thereby allowing staff to communicate this to SUs.

Training regarding the impact of ECT may be significantly more meaningful and effective if co-facilitated by previous recipients of ECT with a range of experiences of the procedure. Staff training delivered by people with personal experience of accessing services, particularly where individual stories are shared, can help provide insight and guide improvements in service delivery (Happell et al., 2013; Repper & Breeze, 2007). If previous recipients of ECT choose to be involved in such training, organisations must consider the support required during this process as this has previously been neglected (Fraser et al., 2017). Basset at al. (2006) provide guidance for thoughtful co-production of MH training with SUs and survivors.

Furthermore, developing a culture of reflective practice in staff teams who administer ECT could provide opportunities for staff to address team dynamics, develop awareness of their own perspectives on ECT, including how this may influence their practice in supporting SUs, and consider the emotional impact of working in a team administering ECT. Working with individuals experiencing high levels of distress can lead to burnout in health professionals, impacting their ability to provide compassionate care (Cocker & Joss, 2016). Providing safe spaces for staff members to express and process emotions can improve staff wellbeing and allow staff to remain more engaged in their work (Knight, 2015). Reflective practice may, therefore, provide staff with more capacity to consider and advocate for wishes of SUs during ECT decision-making processes. Models of reflective practice such as the Heads and Hearts model and the 20 Minute Care Space have been developed during the Coronavirus pandemic to provide accessible ways of bringing reflective practice into high-pressured healthcare settings (Jones, 2020; Kurtz et al., 2020).
Many nurses in the current review voiced the importance of advocating for SUs, but also expressed feeling powerless to influence the ECT process; power hierarchies could be preventing action. This could partly be addressed by introducing independent ECT advocates who are neutral and can advocate for the wishes of the SU. Within UK MH services, Independent Mental Health Advocates support individuals being assessed or treated under the Mental Health Act (1983, 2007) and Independent Mental Capacity Advocates support those who are not deemed to have capacity to make a specific decision in relation to their treatment under the Mental Capacity Act (2005). This review, however, has highlighted the need for independent advocacy for any individual presented with ECT as a treatment option. Whilst advocacy services are provided by third sector organisations in some areas, there is a need for this to be introduced into policy to ensure equal access to independent support for everyone offered ECT.

Reviews consistently suggest that a significant proportion of ECT recipients experience side effects or negative consequences. It is, therefore, recommended that robust multidisciplinary follow-up support should be available to individuals who have received ECT. In addition to providing practical support with managing the impact of ECT, this could help services to move away from invalidating individual experiences and exacerbating negative effects of ECT (Wells et al., 2021).

4.2 Limitations

There are some limitations to this review. First, some studies were excluded because it was not possible to determine whether women recipients last received ECT post-1980. Additionally, studies were excluded where only some participants had not received ECT post-1980, but data for those who had could not be extracted. Exclusion of these studies may have removed data relating to novel concepts not identified in the current review.
Due to the scarcity of research on this topic, the studies included in this review were conducted at different times and in different countries. Only van Daalen-Smith’s (2011) study investigated the experiences of both women and staff members at the same point in time within the same service. Variations in ECT practice across countries and MH systems include the use of modified (with anaesthetic and muscle relaxant) versus unmodified (without anaesthetic and muscle relaxant) ECT, bilateral (across both hemispheres) versus unilateral (across one hemisphere) electrode placement, the type of equipment used, the demographic of people more likely to receive ECT, consent processes, the use of forced ECT, staff training, and adherence to guidelines (Leiknes et al., 2012). Experiences of ECT synthesised in this review may, therefore, have been influenced by changes in ECT practice over time and differences in practice across different countries and MH systems. This review included studies conducted in Canada, Australia, Denmark, the UK, and Ireland. Participants contributing to these studies may have had different experiences of the ECT process. Furthermore, it is not possible to say with certainty how these findings relate to the experiences of women and staff in other countries where ECT practices may be different.

Only literature published in peer-reviewed journals was included in the current review. While this was done to ensure methodological rigour, grey literature sources may offer additional insights into experiences of ECT (Wells et al., 2021). Additionally, only papers written in English were included. This could mean that potentially important literature was excluded.

**4.3 Future Research**

The current review specifically explored experiences of women ECT recipients. Further research could explore experiences of male ECT recipients to consider similarities and differences. Additionally, future research should focus on the ECT experience for different demographic groups and consider how the power dynamics involved in this experience may
intersect with different aspects of identity. Furthermore, it may be beneficial for future research on ECT experiences to consider the perspectives of both staff and recipients. This could lead to a deeper understanding of this process and inform meaningful steps towards change. Finally, to assist with future reviews on this topic, it would be beneficial for researchers to report the time, at the point of data collection, since their participants’ last experiences of ECT.

4.4 Conclusion

This review highlights power dynamics involved in the ECT journey, both for staff and women recipients. Women recipients generally held very limited power and control throughout the decision-making and treatment process, and it is evident that some staff also felt powerless to influence the process. Furthermore, there is evidence of a disconnect between the experiences of women recipients and staff members regarding the impact of ECT. Women recipients’ experiences of the negative consequences of ECT were not reflected in staff members’ accounts of ECT as something which gives people their lives back. Rather, for many women recipients, there was a sense of loss associated with ECT. If ECT is to continue to be offered, meaningful changes should be made to the informed consent process and the provision of follow-up support.
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Chapter II – Service Users’ Experiences of Power Dynamics during ‘Voluntary’ Admission to ‘Acute Mental Health’ Wards

In preparation for submission to Social Science and Medicine – amendments to be made accordingly (see Appendix M for submission guidelines)

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Abstract

Previous research highlights how service users (SUs) have felt disempowered by mental health (MH) services. Patients on MH wards have felt they are seen only as patients, with other aspects of their identity lost or dismissed, emphasising power imbalances in favour of staff. Individuals have often felt coerced into ‘voluntary’ admission and treatment, and many were unaware of their rights. This research aimed to explore SUs’ experiences of power dynamics during admission and treatment as a voluntary patient on acute MH wards in the UK. Semi-structured interviews were conducted with nine participants. Interpretative phenomenological analysis (IPA) revealed two main themes: ‘Being moulded’ describes how staff and services had the power to withhold compassionate care, leaving participants feeling they did not deserve care because they were not experiencing their distress in the right way, and “De facto detention” highlights how the admission did not feel voluntary and participants experienced a repeat of previous feelings of powerlessness, often becoming passive to cope with this. Suggestions are made for steps towards making acute MH wards more compassionate and less restrictive places for voluntary patients. In the meantime, there is a need for transparency from services and the development of policy and practice to protect the rights of voluntary inpatients.
1.0 Introduction

1.1 Research Aim and Significance

The aim of this research project was to understand service users’ (SUs’) experiences of power dynamics during admission and treatment as a voluntary patient. The term ‘voluntary patient’ is used to refer to individuals who have consented to stay on an inpatient mental health (MH) ward for assessment and/or treatment, as opposed to an ‘involuntary patient’ who has been detained under the Mental Health Act (MHA; 1983, 2007)². Policy indicates that voluntary patients have the right to refuse treatment and to leave hospital (Department of Health & Social Care, 2012).

The number of inpatient MH beds in England has steadily reduced over time as government policy has shifted towards MH support in the community; recent available data shows that in 2018, there were 18,300 inpatient MH beds and occupancy was at 90% (Wyatt et al., 2019). The most recent reported data on voluntary admissions, taken from 2015/16, demonstrates that a significant proportion of admissions were voluntary (approximately 44%). This has reduced over time as MHA admissions have increased, and it is likely that this percentage will have been lower in recent years (Wyatt et al., 2019). Despite this reduction, it is evident that a significant number of people in England continue to experience voluntary admission to a MH ward.

In MH services, there is often a power imbalance in favour of the professional (Johnstone & Boyle, 2018). Power is defined as “the means of obtaining security and advantage” (Smail, 2005, p. 28). Foucault (1980) suggested that power should be understood as a relation, occurring in the interactions between people and institutions. The very nature of inpatient services, where SUs are expected to comply with ward routines and doors are often open.

² The term ‘patient’ is used in services but does not fit for everyone. The participants in this study did not have specific preferences regarding terminology, so ‘patient’ and ‘service user’ are used in this report.
kept locked, further emphasises this power imbalance. SUs’ dissatisfaction during inpatient admission is associated with poorer service-defined outcomes, and a common theme reported by those who negatively appraise their inpatient experience is a perceived abuse of power (Chevalier et al., 2018). Considering the negative impact of coercion and power imbalances in MH services, the United Nations (2017) has called for change in psychiatry practice to protect SUs’ rights. Research that helps gain appreciation of how voluntary inpatients experience power dynamics on MH wards can inform future practice.

1.2 Previous Literature

In a UK study, Bacha et al. (2019) used interpretative phenomenological analysis (IPA) to explore eight SUs’ experiences of relationships with MH practitioners. The study revealed a dominant theme whereby SUs felt disempowered by services, and this was reported to have a negative emotional impact on them. Participants described lying, disengaging, and harming themselves to regain control and protect themselves against feelings of disempowerment, vulnerability, and threat. Verbeke et al.’s (2019) IPA study examined the experience of power and coercion in a sample of 12 participants who had been inpatients in a psychiatric hospital in Belgium. Participants reported feeling that staff saw them only as patients and lost sight of the other aspects of their identity. This process was referred to as ‘de-subjectivation’. The authors proposed an interactional model of coercion, suggesting that segregation between staff and patients creates an ‘us and them’ divide which leads to this process of de-subjectivation, emphasising a power imbalance in favour of the staff.

Sheehan and Burns (2011) explored the association between perceived coercion and interpersonal relationships with MH professionals during psychiatric admission in the UK. Of the 128 voluntary patients included in the study, 48% scored highly for perceived coercion. For both voluntary and involuntary patients, perceived coercion was associated with lower ratings for therapeutic alliance.
Gilburt et al. (2008) explored past experiences of admission to and treatment on MH wards in the UK. Findings highlighted the importance of relationships in shaping participants’ experiences, given all participants reported negative experiences of coercion and some described situations where they felt MH professionals had abused their power. Katsakou et al. (2011) explored factors relating to perceived coercion for voluntary patients in the UK. Of the 270 participants initially screened, 34% felt coerced into admission with half of those continuing to feel coerced one month later. Additionally, those participants who had felt coerced at admission were not satisfied with the treatment provided; they felt they had not been involved in decisions regarding their care and that staff did not respect or care about them.

Lomax et al.’s (2012) audit on SUs’ knowledge and understanding of their rights during inpatient admission highlighted that a significant number of voluntary patients were not aware of their legal status or their rights to leave the ward or refuse treatment.

1.3 Rationale and Research Question

Previous literature relating to this subject presents three significant limitations. Firstly, although some studies have taken legal status into consideration during analysis, few have focussed specifically on the experience of voluntary inpatients. Secondly, as highlighted by Prebble et al. (2015), much of the research in this area employs quantitative methods. Two studies mentioned above (Gilburt et al., 2008; Katsakou et al., 2011) used thematic analysis. It has been argued that alternative methods, such as IPA, can provide a more in-depth understanding of how individuals make sense of their own experiences (Smith et al., 2009). Finally, many of the studies in this field have focussed specifically on perceived coercion and may have failed to capture experiences of other forms of power operating in this setting.

Although Verbeke et al. (2019) used IPA to consider individuals’ experiences of power and coercion during their time as an inpatient on a MH ward, this study took place in Belgium. MH systems vary in different countries and, as such, experiences of power dynamics within
these systems may also present differently. It is, therefore, important to use IPA to consider these experiences in a UK population to inform future UK service development and delivery.

The proposed research will attempt to address these limitations by asking the following question: What are service users’ experiences of power dynamics during admission and treatment as a voluntary patient on acute mental health wards in the UK?

2.0 Methods

2.1 Research Design

This research assumed an interpretivist epistemological position, which acknowledges that human beings consciously experience the world through social interaction and attribute subjective meaning to their experiences (Bryman, 2016). Interpretivist approaches recognise people as unique. The researcher aimed to view the world through the eyes of their participants to gain insight into their reality (Von Wright, 1971).

In line with this position, this project utilised IPA (Smith et al., 2009). This approach facilitates exploration of how people make sense of significant life experiences. Research using IPA attempts to understand the perspective of each participant before considering shared experiences.

2.2 Sampling Design

This research utilised non-probability sampling, given IPA does not aim to generalise findings to the sample population (Smith et al., 2009). Purposive sampling was used as this facilitates selection of a homogenous group of participants who have experience of a particular phenomenon (Etikan et al., 2016). Sample homogeneity can be defined in different ways depending on the research (Smith et al., 2009). In this study, the specific experience being investigated defined the homogeneity of the sample. Furthermore, snowball sampling was used (Johnson, 2014), where an existing participant referred another to take part in the study.

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3 See Appendix N for further information regarding the theoretical concepts underpinning IPA.
Participants were recruited via third sector organisations and social media platforms (Appendix O) using a project advert (Appendix P) that provided brief details and a link to the project website (Appendix Q). A video of the lead researcher speaking about the project was embedded within the website to allow potential participants to learn more and familiarise themselves with the researcher who would be conducting the interviews. Participants expressed interest by directly contacting the lead researcher using details from the advert/website, interacting with social media posts, or liaising with third sector organisation representatives who supported them to make contact. Screening questions were completed via telephone or video call with the lead researcher (Appendix R). Information sheets and consent forms (Appendices S & T) were sent by email and opportunities to ask further questions were provided. Participants gave consent verbally or by signing the consent form and returning this by email; additionally, all participants consented for interviews to be audio recorded for transcribing and to be contacted at a later point for wellbeing checks and respondent validation. Participant numbers were assigned to maintain confidentiality.

Ten participants were interviewed, but a technological complication meant that it was not possible to use the data for one participant\(^4\). This resulted in a sample of nine\(^5\). Table 6 shows participants’ demographics and Appendix V outlines inclusion and exclusion criteria used to define the sample.

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\(^4\) See Appendix U for further details.

\(^5\) Within IPA, a relatively small sample size of 6-10 participants is recommended as this allows for in-depth analysis of the experience of each participant but also provides opportunities to explore similarities and differences in experiences across the sample (Smith et al., 2009).
Table 6

Participants’ Demographics

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<tbody>
<tr>
<td><strong>Age</strong></td>
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</tr>
<tr>
<td>18-29 (n = 2)</td>
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</tr>
<tr>
<td>30-39 (n = 3)</td>
<td></td>
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<tr>
<td>40-49 (n = 2)</td>
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<tr>
<td>Male (n = 2)</td>
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<tr>
<td><strong>Sexual Orientation</strong></td>
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<tr>
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</tr>
<tr>
<td>Homosexual woman/lesbian</td>
<td>(n = 2)</td>
</tr>
<tr>
<td>Bisexual</td>
<td>(n = 1)</td>
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<tr>
<td><strong>Ethnicity</strong></td>
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<td>White British (n = 9)</td>
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<tr>
<td><strong>Disability</strong></td>
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</tr>
<tr>
<td>No (n = 2)</td>
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<tr>
<td><strong>Socioeconomic Status</strong></td>
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<tr>
<td>Lower managerial/administrative/professional (n = 1)</td>
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<td>Full time student (n = 1)</td>
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<tr>
<td>Never worked/long-term unemployed (n = 3)</td>
<td></td>
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<tr>
<td>Unsure (n = 2)</td>
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</tbody>
</table>

2.3 Materials

The broad area of focus in the current study was the experience of power dynamics during admission and treatment as a voluntary patient. As recommended by Smith et al. (2009), the interview schedule for this project (Appendix W) included questions which aimed to yield both descriptive and evaluative responses. Topic areas were informed by a previous review (Prebble et al., 2015) and included: process surrounding admission, involvement in decisions relating to their care, relationships with staff, and experience of treatment on the ward. These
topic areas acted as a guide, but the interview schedule was created to be used flexibly, allowing space for participants to articulate what was important to them regarding this experience.

2.4 Procedure

Data was collected through one-to-one semi-structured interviews, giving participants the opportunity to “tell their own stories, in their own words” (Smith et al., 2009, p. 57). Furthermore, Smith et al. (2009) described how this data collection method allows for a dialogue between the researcher and the participant, both of whom play an active role in the research process. The researcher addresses pre-determined topics of interest while leaving space for the participant to shape the focus and meaning of the research (Galletta, 2013).

Interviews were conducted between October 2021-March 2022. They were scheduled at a time suitable for the participant and took place through telephone or video call due to Covid-19 pandemic restrictions. Demographic information was gathered from participants at the beginning of the interview to provide a context to the interview data (Smith et al., 2009). Interviews lasted approximately an hour and a half, with the option to take a break where needed. Interviews were audio recorded and later transcribed verbatim.

2.5 Ethical Considerations

Ethical approval was granted by Coventry University Ethics Committee (Appendix X). The British Psychological Society Code of Human Research Ethics (BPS, 2014) and Code of Ethics and Conduct (BPS, 2018) were followed throughout planning and execution of this research. Two experts by experience were consulted in the planning of this research project to ensure appropriateness of the procedure followed and documents used (Appendix Y).

To facilitate free consent and participation in this research and limit the potential for harm, it was decided that interviews would be conducted retrospectively with participants living in the community who had previous experience of a voluntary admission. Additionally, it was important to consider the potential negative impact on participants of asking them to re-
visit a previous significant experience and speak about this in detail, reflecting on thoughts and feelings associated with the experience. The participant information sheet provided information about the study and potential risks associated with taking part (Appendix S). The researcher used a distress protocol (Appendix Z) in case participants appeared distressed during their interview (Draucker et al., 2009; Haigh & Witham, 2015). At the end of the interview, participants were provided with a debrief form outlining further information about the project and suggesting avenues for seeking further support (Appendix AA). Wellbeing checks were made via telephone or video call at an agreed time in the week following the interview. This was an opportunity for the researcher to check in, answer questions, and signpost for support if needed.

Participant data was anonymised, referred to by unique participant numbers, and was only accessible to the immediate research team. Additionally, gender-neutral pseudonyms were allocated to participants for the purpose of analysis and reporting findings. All electronic data was stored and will be destroyed as per Coventry University policies and procedures.

2.6 Method of Data Analysis

The IPA analysis stages described by Smith et al. (2009) were followed (Appendices AB & AC). Updated terminology from recent guidance was used in this report, although the analysis process has remained the same (Smith et al., 2021). Transcripts were coded by one researcher. The development of personal experiential themes (PETs), relating to individual participants, and group experiential themes (GETs), relating to multiple participants, was discussed with the research supervisors. To ensure that the analysis was reflective of participants’ experiences, the initial draft of the results was sent to all participants. This process of respondent validation ensures the credibility of results (Birt et al., 2016). Furthermore, reflexivity was considered (Appendix AD).
3.0 Results

Two GETs were identified through IPA: ‘Being moulded’ and “De facto detention” (Table 7).

<table>
<thead>
<tr>
<th>Group experiential theme</th>
<th>Sub-theme</th>
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</thead>
<tbody>
<tr>
<td>Being moulded</td>
<td>Getting the cold shoulder</td>
</tr>
<tr>
<td></td>
<td>Not deserving support</td>
</tr>
<tr>
<td>“De facto detention”</td>
<td>Re-living powerlessness</td>
</tr>
<tr>
<td></td>
<td>Not having any fight left</td>
</tr>
</tbody>
</table>

All participants contributed to both GETs (Appendix AE) which are described below. Additional illustrative extracts can be found in (Appendix AF).

3.1 Being Moulded

This GET addresses participants’ descriptions of their interactions with staff members on the ward and the impact this had on participants’ views of themselves. It is comprised of two sub-themes; ‘Getting the cold shoulder’ highlights participants’ experiences of care being withheld, and ‘Not deserving support’ illustrates how participants often attributed this internally and questioned whether they deserved care. Many participants felt they had to present differently to receive the care they needed, although some felt unable to do this and so continued without support. This suggests interactions with staff on the ward sometimes resulted in participants being moulded to fit service parameters, rather than services adapting to their needs.

3.1.1 Getting the Cold Shoulder

Many participants described times when they were unable to access the care they needed on the ward. To varying degrees, all participants experienced an absence of compassion during their admission. The extent to which compassion was present in participants’
interactions with staff on the ward appeared to exist on a continuum. At one end of the continuum, participants described good relationships and compassionate interactions with the staff team. At the other, participants described a significant absence of compassion throughout their experience. In between these two extremes, others described a “mixed bag” (Ashley, p.30), with some interactions compassionate and others not.

Charlie and Jordan described having good relationships with the staff team and found comfort in compassionate interactions:

But she, she even remembers your name and she will give you a cuddle. And it's like all of a sudden, you-. That is such a great welcome, d’you know what I mean? It's like, sort of, you don't get that very often. (Jordan, p. 40-41)

Both Charlie and Jordan described how a compassionate approach from staff helped them to feel welcome when they arrived on the ward: “[staff] helped setting up my room, stuff like that, and explaining what went on in the ward” (Charlie, p. 17). However, Jordan’s comment that “you don’t get that very often” (p. 41) suggests this may be outside of the perceived norm. This was further emphasised by Jordan stating: “I’ve always had a good relationship with staff on the ward because they seem to be a different breed” (p. 40). This contrasted with Jordan’s experiences of the assessment unit where they described “uncaring” staff and feeling like “you’re a pain in the backside” (p. 36).

For some, it was interactions with certain professionals which lacked compassion. Charlie spoke about the wall of laptops that maintained a distance between them and the doctors: “you’d walk in, into a room full of professionals all behind their laptops” (p. 24). Max also described a lack of connection with the doctors during ward round meetings, “with six of them sitting there, three either side with notepads. Just staring at me. Staring at me, not blinking” (p. 18). Jordan said that one nurse was stricter than the others and, when they were on shift, there would be “a very different vibe for the ward” (p.43). Harper found most of the
ward staff to be friendly and caring but felt the ward manager “didn’t care” (p. 33) and said that the other staff were less caring when the manager was around:

   Most staff were good that knew me, they were good. Um, you know, obviously they were stricter in what they could do when that manager was around or, you know, certain consultants and that, you know, they couldn't be as caring. (Harper, p. 36)

Ashley felt some staff genuinely cared and gave encouragement and tools to cope but described a significant absence of compassion, and sometimes hostility, from others:

   You just feel this, kind of, hostility or coldness. And I feel like that makes you feel a lot more alone, and I do think when you’re in a lot of distress, sometimes, um, that kind of human compassion and someone giving you their time does make a difference. (Ashley, p. 41)

Although compassion was present in some interactions for these participants, the times when it was absent had a significant impact on their experience. Participants’ descriptions give a sense of distance between themselves and the staff on the ward during these experiences.

   Alex and Max described ward staff as “supportive” (Alex, p. 30) and “wonderful” (Max, p. 12) but said that they were unavailable. Max described the ward as simply “a bed, medication and food on the table” (p. 7) and added: “Basically, you were left to yourself. I used to spend time in my bedroom a lot’’ (p. 20). Alex stated: “You don’t get the attention or help, not that I’m an attention seeker, I don’t mean in that sort of sense, I mean, um, you know being able to speak to somebody when you’re not in a good place” (p. 5). Alex appeared concerned that expressing a need for attention might be perceived negatively. It is possible that being unable to get the support they needed left them feeling that they were wrong to expect this.

   For Taylor, Sam and Jamie, an absence of compassion appeared to characterise their entire experience, with moments of compassion standing out as unusual or unexpected. Sam described how staff were physically present but did not show warmth or interaction, reporting
a real sense of “silence” (p. 11). Sam felt this was a conscious decision on the staff’s part: “Um, I feel like they were trying not to engage with me because they didn’t want me to get attached to anybody or want to stay in hospital” (p. 49). Again, this highlights how an absence of warmth and compassion may have led to participants feeling they were somehow at fault for needing care or connection. Taylor felt that staff did not try to understand and were just doing their job: “Some were, I think just set in doing the same thing continuously […] they kind of lost their compassion […] I don't think any of the staff [pause] ever really spoke to me” (p. 32). Taylor’s use of the phrase “lost their compassion” (p. 32) suggests a perception that this was present in the past. Nonetheless, this sense that staff were just there to do a job could have emphasised participants’ feelings of being disconnected from the staff team and isolated in their distress.

Jamie did not feel welcome on arrival to the ward and stated: “the staff were very much not happy to see me back” (p. 13). They described the ward as “a place of containment” where there was “very little care” (p. 20) and expressed their view that staff on the ward “had absolutely no respect for patients, and actually disdain for patients” (p. 34). Jamie spoke about valuing kindness, thoughtfulness, and sensitivity: “The minute you find the couple of people around who do have those good qualities, it’s like a tiny little bit of sanctuary, it’s like a tiny little bit of escape” (p. 53). For these participants, moments when they were shown compassion stood out in stark contrast against their overall experience.

Additionally, participants described instances where they were unable to get other needs met on the ward. Alex “went for about five days without a proper meal” (p.30) because the ward did not cater to their dietary requirements and both Taylor and Charlie said that the food was unhealthy. Ashley described how it was agreed in their care planning that staff would bring them food, but this did not happen:

[…] they kind of were like ‘just go down there and get food’, and I remember being really upset and them being like ‘well, I can come with you’ and me being like ‘no, it’s
agreed in my care plan that I can’t, that I can’t cope’, and I remember her, kind of, shouting at me. (Ashley, p. 29)

Here, not only were Ashley’s needs not met, but the response when they asked for this support felt punitive. There were other instances where participants described punitive responses to their distress; Sam recalled being “told off” (p. 31) for sleeping on the floor even though this helped them to feel safe and Ashley described a time when they were extremely distressed, and this was made worse by a staff member “shouting at [them] to stop screaming” (p. 24). Max said the doctor on the ward was “horrible” to them. These punitive responses could have further compounded participants’ feelings that they were at fault.

For many participants, there was a clear disconnect between the support that was offered to them and the support they felt they needed. Jamie described the decisions made about their treatment as “something completely separate to me” (p.51). Many spoke about how medication was often the only solution presented to them: “There are no other suggestions or, like, offers. They didn’t even offer to, kind of, go through skills with me or anything. It was literally just medication […]” (Sam, p. 27). The absence of a person-centred approach may have communicated to these participants that services would not adapt to their needs.

These participants’ accounts indicate that professionals and services have the power to withhold care: “I felt like I wasn’t worth [pause] the care” (Alex, p.15). Ashley summarised this by saying: “And I feel like if you don’t jump through hoops just the right way, they kind of will withdraw that compassion” (p. 32).

3.1.2 Not Deserving Support

Participants’ experiences of not receiving care on the ward were internalised. They needed to prove themselves to receive support; this was not given unconditionally but had to be earned. Many described experiences of being assessed and monitored by staff. Jordan spoke about being placed on an assessment unit in the first instance to determine whether they would
be admitted to the ward: “[…] no one sees you, no one speaks to you, and you're just being observed, so to speak” (p. 29). Both Alex and Taylor described how nurses on the ward reported back to the doctor “what [they’ve] noticed” (Taylor, p.40) and Harper recalled staff “constantly” (p. 14) being around them. Sam stated: “you can never relax because someone was always, like, peering in at you every quarter of an hour or half an hour or whatever” (p. 30-31).

Many participants described a sense of having to present in a certain way and prove a need for care, suggesting an implicit message from services that there is a correct way to experience distress. Jordan recalled how professionals “always” (p.15) tried to convince them they did not need to go into hospital, which left them feeling they had to justify this. Although many participants felt they needed to satisfy certain unspoken criteria to receive care, these criteria varied depending on participants’ experiences. Some perceived that more support would be provided on the ward to individuals who were more vocal, while others experienced the opposite. Taylor and Alex said people who are quiet are “overlooked” (Alex, p. 53) and “don’t get anything” (Taylor, p. 35), and Sam recalled a member of staff saying “‘oh, you seem fine because you’ve been doing your colouring all day’” (p.13). Conversely, Jamie spoke about how staff were more caring towards them when they were “down and docile” (p.29) and Ashley felt they were treated with more care because they were “well-behaved” (p. 32). Harper recalled being moved to a different ward: “basically they said that they couldn't handle me, um, but I wasn’t doing anything wrong” (p. 12).

Many participants were left feeling that they were not distressed or ‘unwell’ enough, that they should be able to manage by themselves, or that they were a burden. Charlie spoke about being made to feel they did not have a “real mental illness” (p.34) or a “valid reason to have an admission” (p. 12). Jordan described how, although the emergency response staff were “lovely” (p. 34), they felt these services were “not really there for mental health” (p. 16) and
saw themselves as creating “an issue” (p. 23) or being “too much hassle” (p.25). Sam had similar thoughts when speaking about how their admission was reluctantly given: “I felt completely worthless actually. Um, I felt like I didn’t deserve any care, um, and that nobody really cared if I was alive or not” (p. 33). Others described feeling like a burden during their time on the ward. Taylor felt: “like, an inconvenience that they've got to sort out” (p. 16). For Max, not receiving care on the ward is likely to have intensified their sense that they deserved to be punished rather than cared for: “I’ve sinned at lot of sins in my lifetime […] I’m being punished for them. I know I am. I know” (p.34). Some participants had also worked in the NHS, and their increased insight into the limits on resources further contributed to feelings of guilt for taking up space.

Participants were left feeling insignificant and undeserving of care, and felt others needed or deserved this more. Sam described an internal conflict:

I was split between, kind of, feeling utterly, kind of, raging because I was in so much pain and […] I dunno, it just felt invisible […] I also felt massive shame and like I shouldn’t, I shouldn’t even be asking for help. (Sam, p. 33)

Although Sam felt anger at not receiving support, the way they had been treated led them to question whether this was even something they deserved.

3.2 “De Facto Detention”

This GET describes how participants felt that, although they were technically ‘voluntary patients’, their admissions were not truly voluntary. It has two subthemes; ‘Re-living powerlessness’ highlights experiences of limited power and agency and illustrates how these often linked with previous experiences of feeling powerless, and ‘Not having any fight left’ describes how participants often became passive as a way of coping with their situation on the ward, either because they did not have the energy to fight or because they perceived that fighting would only make things worse.
3.2.1 Re-living Powerlessness

All participants described experiences during their admission and time on the ward where they had limited power and control over their situation. This included times when their decisions and actions were influenced by the threat of being sectioned, when they felt trapped in an unsafe environment, when their day-to-day lives were dictated by ward restrictions, and when staff shaped their stories in ways that did not fit with their own understanding of their experiences.

Many participants described how the threat of being sectioned, whether implicit or explicit, had a significant impact on their decision to go into hospital:

And the lady from the home treatment team, she sort of said, ‘well, essentially you kind of need to agree to go to hospital or we’re just gonna put you in hospital anyway’. And I didn't wanna get put on a section because then I’d be stuck there for longer. (Taylor, p. 6)

Charlie described their admission as “de facto detention” (p. 1) and explained: “it's kind of like, you are, you are detained but you're not. And I think it becomes like, it becomes a way of restricting people’s rights, but without actually putting any support around that” (p. 44). This suggests that agreeing to a ‘voluntary’ admission and essentially doing as they were told seems to have felt like the only way for participants to avoid further restrictions being placed on them.

Some participants described hospital as a “place of safety when your head goes” (Max, p. 15), where “you know you’re gonna be okay” (Alex, p.9). Although Jordan spoke about hospital as a place where “no one can touch you” (p. 18), most participants felt that in a hospital they would be safe from themselves but not necessarily from being harmed by others. When it came to potential external threats, many participants felt unsafe and trapped in the ward environment: “And I didn't want [pause] any sort of confrontation or anything like that. And I just, I wanted to, like, make sure that I was safe, but I didn't feel safe, and I couldn't escape
because there was no way out” (Taylor, p. 30). Participants described incidents that happened on the ward and alluded to a sense of unpredictability which may have added to feeling unsafe. For Alex, it was not only the incidents but the staff response that was scary: “it’s like a herd of elephants, literally like thunder, all these feet, um, running past your room. And you know that when they get there, they’re gonna be either restraining or, um, you know, injecting […]” (p. 28).

Participants described how their time on the ward was dictated by blanket rules and restrictions. Some participants appeared to have accepted that this is just how it was on the ward, explaining the routine in a matter-of-fact manner: “Last meds are at ten o’clock. TV room and everything else is locked at twelve o’clock” (Alex, p. 22). Others, however, commented on the restrictive nature of these blanket rules:

The point is that you put in things that, sort of, restricts the whole, you know, elements of freedom or liberty, so to speak, for everyone. Well, if that's the way, then why have informal patients in the first place? Just section every single bloody person (Jordan, p. 58)

Ashley questioned how this could be the case: “I did kind of feel like, ‘I’m voluntary, how can you?’” (p. 61). Jordan reported finding it difficult when individuals on the ward who had been sectioned would say things like “it’s just easy for you, you know, you can go out, come and go as you want, you’re allowed to leave” (p. 9). There appeared to be a perception that being ‘voluntary’ was easy, when in fact this was a very difficult and often restrictive experience too.

Additionally, some participants felt they had limited influence over their own narrative on the ward. Staff often held the dominant narrative, sometimes explaining their experiences in ways that were inaccurate. Ashley noticed this when looking back at the clinical notes staff had written about them: “I felt, looking back at my notes, like staff could exert their power to essentially write whatever they wanted” (p. 43). Alex noticed this during interactions on the
ward: “The doctor that did the admission thing […] kept talking over me. So, didn’t really listen. Tried making up her own [pause] narrative, and it was completely incorrect” (p. 15-16). This illustrates how, for some participants, there was very little during this experience that they were able to retain control over. The ward restricted what they were able to do, but it also stopped them from being able to take personal meaning from their experiences and tell their own story.

Participants’ experiences of the admission exist within the context of their previous experiences. For many, this was not the first time they had been in a position of limited power. Participants reported previous experiences when their power and agency were reduced, whether this was in personal relationships, experiences of services, or how they had experienced their distress.

Both Alex and Jamie experienced abuse from a parent when they were children. Alex described being “on the at-risk register from the age of two” (p. 2) and, when speaking about their mother, stated: “as an adult it was her responsibility to keep me safe” (p. 3). Jamie described how the trauma they experienced on the ward was as bad as the trauma they experienced in childhood: “because it was institutional, and because it was systemic, and because it was people who were paid to care for me [pause], it was, it was as bad actually” (Jamie, p. 35). Alex, Sam, and Jamie all had previous experiences of relationships where their partner had been “controlling” (Jamie, p. 4) or abusive towards them; Sam described leaving a “coercive and brainwashing marriage of eight years” (p. 23) and Alex stated that their “first marriage broke down because of violence, uh, towards me and my children” (p. 3). Harper described being harassed and “assaulted” (p. 3) by their neighbours. Some participants alluded to the pain of experiencing abuse from someone who should have cared for and protected them. This suggests that participants who experienced power abuses on the ward are also likely to have felt let down by services that were supposed to help.
Some participants described overwhelming past experiences of distress which left them feeling they did not have control over their lives. Taylor described how their life experiences prior to the admission became “more and more intense” and made their brain “way too noisy” (p. 4) and Alex recalled how flashbacks and distress “took over [their] life” (p. 1). Max used the terms “mental torture” and “mental cruelty” (p. 25) to describe their distress and said a professional had once told them they had “demons in [their] head” (p14). Additionally, many participants described feeling powerless in interactions with MH services. Ashley recalled a previous experience with a consultant: “he didn’t offer me anything, sent me away in crisis, and he took me off my medication” (p. 3). Jamie’s ‘voluntary’ admission took place shortly after an involuntary admission where staff were described as “very abusive in different ways” (p. 7). Sam, Taylor, and Jamie had all made previous complaints about treatment they had received within MH services, and all three reported struggling to get their concerns taken seriously. Therefore, experiences of the last voluntary admission may have felt like a repeat of the past for many participants. While the circumstances were different, participants are likely to have re-lived these feelings of powerlessness and a sense of being let down by those who were supposed to help.

3.2.2 Not Having Any Fight Left

Participants implied that it was “a fight” (Ashley, p.54) to get their voice heard in relation to decisions being made about them on the ward. These decisions might be in relation to being admitted to the ward, being able to go out on leave, being discharged, or day-to-day events. Jamie spoke about feeling that “everything is a battle” (p. 25). Though some participants spoke about times when their voice was heard or encouraged, there seem to have been many instances where there was no space for discussion or compromise and the only options were to fight or comply. When speaking about times they did feel listened to, some participants appeared surprised by this and suggested that this was “unusual” (Sam, p. 21).
Some recalled specific staff members who advocated for them or encouraged them to advocate for themselves, and this helped them to feel “respected” (Ashley p. 63) and “involved rather than it being, sort of, dictated to” (Taylor, p. 33).

Alex described how they would sometimes “argue [their] corner” but this required them to “have sound reasoning” to “argue [their] point”, and they were “not always in the right place to do that” (p. 37-38). Jordan, who often felt more able to advocate for themselves, described how they would sometimes wait to raise their concerns with a member of staff who they felt would be more likely to listen. Furthermore, Jordan spoke about the need to raise concerns “in a nice way” (p. 59) rather than showing anger but acknowledged that this is difficult to do when you are struggling: “Unfortunately, though, you don't have that sort of mindset when you're unwell. Because when you're unwell, you wanna try and challenge, but it may come across a different way” (p.61). This suggests that fighting required a certain level of energy and clear-headedness, which participants did not always feel they had.

Additionally, all participants described situations where their perspective was dismissed or not heard. They were made to feel that their voice did not count:

Um, so my experience had kind of been that my version of reality never counts, it’s always someone else’s. And services are just like that. Like they tell you what’s wrong with you, and they tell you that you can’t be experiencing things that you are […] (Sam, p. 23)

Max stated: “I just wanted people to believe me” (p. 13), indicating that there had been times they did not feel believed. Jordan said that some staff would think they were just “moaning” (p. 58) if they disagreed, and others described how this was “seen as part of [their] presentation rather than [them] having a valid, uh, perspective on what was happening” (Charlie, p. 2). Taylor spoke about how they would tell themselves to “just wait it out” because if they asked to leave the hospital quicker, they could be viewed as being “disruptive” (p. 42). Sam, Alex
and Harper all described being superficially involved in decisions; they were invited to the meetings, but the decision had already been made. Being aware that their challenges could be viewed negatively, or that they would have no influence anyway, is likely to have made it even more difficult for participants to voice their perspective. Harper recalled asking themselves the question: “what’s the point me actually being here? Cause no one’s even listening to me” (p. 32).

Participants all described times when they became “really passive” (Sam, p. 43) as a way of getting through. Alex became “robotic”, feeling that they were “just along for the ride” (p. 11). Jamie described how they had previously fought against unfair and abusive treatment from services, but they did not have the energy to do this as well as work through their own difficult situation, so this “took a back seat” and became something they had to “tolerate” (p. 25). They “reluctantly agreed” (p. 39) to take medication which they did not want so that they could focus their energy on trying to find a solution to becoming homeless. Participants simply did not have the energy to fight every decision and began to question themselves after countless experiences of not being heard; for many, going along with things became a key survival strategy.

Finally, some participants said that challenging things which they did not agree with, or asking to be discharged, might mean they would “end up staying longer” (Charlie, p. 4) on the ward. Harper also reflected on how staff would become more restrictive if they disagreed with them: “I couldn't respond cause if I responded I’ll get sedated so, you know what I mean? You don't, you don't really have a say, you just have to put up with it.” (p. 37). This suggests that, for some participants, there was a risk that things might get worse for them if they were to voice their perspectives or fight to be heard. Understandably, this often resulted in participants being silenced.
3.3 Respondent Validation

Of the nine participants contacted for RV, five responded and confirmed that the results of this analysis reflected their experiences (Appendix AG).

4.0 Discussion

This research used IPA to explore SUs’ experiences of power dynamics during admission and treatment as a voluntary patient on acute MH wards in the UK. Two GETs were identified: ‘Being moulded’ describes how participants experienced absences of compassion from ward staff, began to feel they did not deserve care, and were subsequently moulded to fit service parameters, and “De facto detention” highlights participants’ experiences of feeling the admission was not truly voluntary, replicating previous experiences of feeling powerless.

Participants described circumstances where they felt they needed compassion from staff, but this was withheld. Some felt staff were just doing their job and described how the ward provided physical containment but not care. Similarly, Katsakou et al. (2011) described how over half of the voluntary patients in their study felt staff did not care about or respect them. Some participants in the current study referred to the silence they experienced from staff members, supporting previous findings that experiences of coercion from MH staff were “accompanied with a deafening silence” (Verbeke et al., 2019, p. 93). Furthermore, findings from the current study support previous research indicating that individuals admitted to acute MH wards have felt ignored and held at a distance by staff (Chevalier et al., 2018).

Indeed, previous research has highlighted a “them and us” (Chevalier et al., 2018, p. 11) divide between staff and SUs on acute MH wards. Verbeke at al. (2019) described how individuals accessing MH services felt they were viewed by staff as simply a sick patient and other aspects of their identity were lost, emphasising the power imbalance in favour of staff. Furthermore, participants in Verbeke et al.’s (2019) study describe how staff members could decide whether to address or ignore the topics they raised. This is supported by the current
Participants in the current study felt they had to present in a certain way to receive care. This supports previous findings that SUs felt they had to “perform the patient role to get help and to avoid coercion” and this involved presenting in a certain way, “not being too weird, but also not functioning too well” (Verbeke et al., 2019, p. 93). The current study builds on this finding by suggesting that there is an implicit narrative communicated to voluntary inpatients: that there is a correct way to experience distress. Participants in the current study were often made to feel that the way in which they experienced their distress was wrong, and they therefore did not deserve care. Johnstone and Boyle (2018) highlight the concept of ideological power, which shapes meaning and creates narratives within society. Ideological power leads to the development of norms against which people are judged. The current study illustrates how ideological power operated for these participants, creating a narrative around how they should experience their distress. Participants were subsequently judged against this narrative, both by others and, when this was internalised, by themselves.

The current study highlighted participants’ experiences of feeling powerless during their time on the ward, reinforcing previous findings that individuals have felt disempowered by MH services (Bacha et al., 2019; Gilburt et al., 2008). As in the current study, previous research indicates that voluntary inpatients are often not involved in decisions regarding their care (Katsakou et al., 2011; Wallsten & Kjellin, 2004). Many participants in the current study felt they were superficially involved; they were asked their opinion, but the decision had already been made. This further emphasised feelings that their perspective did not count. Lomax et al. (2012) illustrated that many voluntary patients were not aware of their rights to leave hospital and refuse treatment. In the current study, participants were aware of their rights but often felt they had to comply due to the threat of being sectioned. This is in line with
previous findings that voluntary admissions are often not experienced as voluntary due to SUs’ fears that they will be formally detained if they do not consent to the admission (Prebble et al., 2015). As in the current study, where at least one participant was forced to take sedative medication, Sørgaard (2007) highlighted that a minority of voluntary inpatients were forced to take medication during their admission. The current study builds on previous research by highlighting how feelings of powerlessness during voluntary admission were experienced by participants as a repeat of previous experiences of feeling powerless, both when accessing MH services and in their personal relationships.

Fenton et al. (2014) described how young adults who were admitted to acute MH wards had conflicting experiences of the ward as “both safe and containing, and unsafe and chaotic” (p. 234). There were times when participants felt safe and cared for, and times where the chaotic and restrictive ward environment led them to feel unsafe and trapped. This was reflected in the accounts of participants in the current study, and it was suggested that, for many, this distinction related to participants feeling safe in terms of their risks to themselves, but not in terms of the risk of potential harm from others in the ward environment. Not only did participants feel powerless and trapped, but they also often felt unsafe.

Johnstone and Boyle (2018) presented the Power Threat Meaning Framework (PTMF), highlighting how power operates in peoples’ lives in different ways which can pose threats to the individual. The PTMF places emphasis on the personal meaning individuals take from these experiences, and the things they have to do in order to survive. These threat responses are viewed as understandable responses to difficult life situations. Bacha et al. (2019) highlighted how individuals accessing MH services described lying to staff, disengaging, and self-harming as ways to cope with feelings of powerlessness. For the participants in the current study, one of their threat responses as a voluntary patient was to become passive and compliant.
4.1 Implications for Policy and Practice

Work must be done to make acute MH wards more compassionate and less restrictive places for voluntary patients, with the aim of improving SUs’ experiences and transforming these environments into places that help rather than harm. Fenton et al. (2014) highlighted the need to create welcoming environments on MH wards, as opposed to them being places of “passive seclusion” (p. 239). The Royal College of Psychiatrists (2017) have outlined standards for inpatient MH services which include consideration of consent, collaborative care planning and SU involvement, and treating SUs with compassion, dignity, and respect. Though these standards exist, this study and previous literature outline SU experiences which suggest they are often not being adhered to.

From a practical standpoint, power dynamics during voluntary admissions could partly be addressed by having separate ward spaces for individuals based on level of need. At present, the same ward spaces are shared by both voluntary and involuntary patients, meaning blanket restrictions are often applied without consideration of individuals’ needs (Restraint Reduction Network, 2021), making interventions less meaningful (Foye et al., 2020). While it may be challenging to create an environment which meets the needs of multiple individuals, blanket restrictions have had a detrimental impact for SUs in this study and others in previous research. Such blanket restrictions affect the environment (e.g., locked doors) but also staff members’ decision making. It could be difficult for staff members to shift into a less risk-focused and less restrictive stance in such a risk-focused, restrictive environment (Care Quality Commission, 2017). This is not to suggest that consideration does not need to be given to improving ward environments for involuntary patients, but this is not the focus of the current research.

Steps must be taken to involve voluntary inpatients in decisions about their care, meaningfully listen to their perspectives, and treat them with the care and compassion that every human being deserves. Furthermore, this should not be conditional on them experiencing
their distress in a certain way. Individual incidences of malpractice clearly happen and must be highlighted and addressed. Participants in the current study reported previous experiences of making complaints about services and struggling to get their concerns taken seriously. Some spoke about feeling powerless against abusive staff and environments. Complaints processes for SUs in inpatient MH settings must be improved to ensure SUs are heard, concerns are addressed, and individuals are protected.

Attempts at reducing coercion on MH wards have been successful when ethics, culture and power dynamics have been addressed, rather than focusing on specific interventions (Vandevelde et al., 2015; Verbeke et al., 2019). Reflective practice groups (RPGs) could provide space to tackle these issues. RPGs for MH ward staff have been demonstrated to enhance staff members’ capacity for mentalization which, in turn, allowed staff to hold a more compassionate stance when working with SUs on the ward (Collins, 2011).

Until steps are taken to change the way voluntary patients are treated on MH wards, there is a need for transparency with regards to what voluntary admission means. These admissions are often not experienced as voluntary and, until this changes, the terminology must be altered to reflect this. At present, calling these admissions ‘voluntary’ implies a free and informed choice requiring less need for supporting policy and practice. Participants in this study and previous research have illustrated that this is not the case, and there is a need for policies and procedures which protect their rights.

4.2 Limitations

This study has some limitations. Firstly, while it was not the intention to only recruit White British participants, it is possible that some aspect of the recruitment process made this study less accessible to people of the global majority (POGM).

6 The POGM term is used as this affirms individuals’ “inherent power as the majority of the world’s population” (Lim, 2020, para. 18) as opposed to terms which use the words ‘non-White’ or ‘minority’ and emphasise White as the default.
Additionally, sources used to recruit participants in this study may have resulted in a biased sample, consisting of individuals who are more likely to have had negative experiences in MH services. The majority of participants were recruited using the Drop the Disorder Facebook page and Twitter, where the research advert was shared, among others, by individuals who advocate for alternatives to medical understandings of distress. Individuals following these movements may, therefore, be less satisfied with MH services which commonly adopt medical approaches to distress. Additionally, through interacting with movements such as Drop the Disorder, participants may have previously considered their experiences of power dynamics and so narratives from the interviews may not have been spontaneous (Verbeke et al., 2019).

Furthermore, although IPA can provide in-depth insights in relation to a small group of participants’ experience of a particular phenomenon, findings are not said to be generalisable (Smith et al., 2009). It has, however, been demonstrated that many of the findings in the current study are supported by previous research.

4.3 Future Research

Future research should continue to explore ideological power and narratives during voluntary admissions to acute MH wards and threat responses used to survive this experience. Research should also explore experiences of power dynamics during voluntary admission for different groups, including POGM, and should consider how different demographic characteristics intersect with one another to shape experiences of power in this environment (Collins, 2015; Crenshaw, 1989). Additionally, research on this subject should also include perspectives of individuals who may have had positive experiences of voluntary admission with the aim to provide a balanced, representative picture of this experience and consider what might be experienced as helpful so that this can be built upon. Furthermore, future research could adopt a grounded theory approach (Charmaz, 2011) to allow for the consideration of staff
perspectives on power dynamics during voluntary admission as well as researchers’ observations of these power dynamics playing out. This could help to inform recommendations for changes in service delivery.

4.4 Conclusion

This research provides a detailed insight into nine participants’ experiences of voluntary admission to acute MH wards in the UK. Findings highlight that this experience often did not feel voluntary at all; between the threat of being detained and the restrictive ward environment, participants often found that becoming passive was the best way to survive. Additionally, findings illustrated how participants’ perspectives were often denied and seen as secondary to the dominant narrative held by services and staff. Considering these findings, and the support they offer to previous research, there is a clear need for change to ward environments for voluntary patients. Until this happens, services must be open and transparent about what ‘voluntary’ admissions entail and should develop policy and practice to protect individuals in this position.
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Chapter III – Reflecting on Conducting Research into People’s Experiences of ECT and ‘Voluntary’ Admission

Chapter word count (excluding footnotes, tables, figures, and references): 3,455
1.0 The Importance of Reflective Practice

Reflective practice is a requirement for psychologists (British Psychological Society, 2017); it helps us to reflect on our biases, learn from our experiences, and grow as people and practitioners (Kolb et al., 2001). Reynolds (2013) described the importance of practitioners creating spaces for vulnerability rather than presenting “fixed stories of their competence” (p.6). Something that is important to me, as a psychologist and as a person, is that I do not put myself on a pedestal. As someone who has often felt the need to appear competent and in control, reflective practice is one of the tools that allows me to be vulnerable and embrace the messiness that comes with being human.

2.0 Acceptance and Commitment Therapy

Pain and suffering are unavoidable parts of life (Harris, 2019). Acceptance and Commitment Therapy (ACT; Hayes et al., 1999, 2011) helps us move towards the people and things that are important to us and live personally meaningful lives, even in the presence of pain. The capacity to do this is termed psychological flexibility. Harris (2019) describes six core processes which are focused on to increase psychological flexibility (Figure 2); those most relevant to my experience of conducting this research are considered in this chapter.
Furthermore, The ACT matrix is a tool which can be used to make sense of our experiences; it considers values, difficult internal experiences, and behaviours (Figure 3; Polk & Schoendorff, 2014).
I have found the matrix useful in understanding the motivations behind my behaviours and refocusing me on my values. ‘Me noticing’ at the centre of the matrix highlights the part of us that notices our internal and external experiences, emphasising how we are the experts when it comes to ourselves (Harris, 2019).

3.0 My ACT Matrix

The ACT matrix was used to structure my reflections on the research process (Figure 4).
Figure 4

*My ACT Matrix*
3.1 Values

Figuring out who and what is important to us gives the context and motivation we need to live a value-driven life (Wilson & Murrell, 2011). There are many important people in my life – family, friends, and my partner. They give me strength; bring me joy and laughter, bring out my playfulness, and help me to find the courage to stay true to who I am. To them, I am incredibly grateful. Also important to me are the people who have shared their stories with me through this research and in other areas of my work. They help me to remember why I do the work that I do, and their stories give me the motivation I need to keep pushing for change in services and society.

Metaphors are used to bring ACT concepts to life (Stoddard & Afari, 2014). During my first placement on clinical training, my supervisor used a metaphor to describe values. She spoke about a beaded necklace and described how we all have different experiences in life (the beads), but we also have the more constant things that make us who we are, including our values (the string). Though our values may develop and change, they cannot be taken away from us and they remain part of us, whether we are acting in line with them or not. I have found this metaphor comforting, especially at times when I have felt I have not lived in line with my values as much as I would have liked. While I have many values, I have chosen to focus on the two most prominent during my research: advocacy and compassion.

Advocacy has been one of my values for as long as I can remember. I can trace this back to both of my parents, who have fought against social injustice in their careers and personal lives. Working on mental health wards in the past, I have witnessed abuses of power. I have seen people accept treatment they do not want and have observed huge power imbalances in favour of services. I have also observed how staff sometimes feel powerless to change the system, and I have felt this too. Through this research, I have witnessed individuals’ stories of trauma and experiences of powerlessness, both in the ECT process and during
voluntary admission. These experiences have all strengthened my value of advocacy. This has been supported by my familiarity with the Power Threat Meaning Framework (PTMF), which advocates for alternative approaches to the medical model of understanding distress (Johnstone & Boyle, 2018). The PTMF suggests a shift towards thinking about how people make sense of difficult situations and find ways to survive. Many of the values embedded in the PTMF are closely aligned with my own.

There is an important distinction to be made between advocating and trying to rescue. I have previously noticed a tendency to be pulled towards the role of rescuer, both in my personal and professional life, wanting to ‘make things better’ and to ease the pain and suffering of others. However, taking on a rescuer role can place the other person in the role of the victim rather than emphasising their strengths and resources (Karpman, 1968). Shmelev (2015) suggested therapists should step outside of this rescuer role and help their clients to take control and find answers for themselves. I think that this can also be applied to the research process. My value of advocacy in this research has not been about rescuing people who have shared their stories about ECT and voluntary admission. Instead, it has been about providing space for people to tell their story, in their own words and in the way they needed to tell it, and helping create platforms for these stories to be shared. I have not rescued anybody – we have worked together to bring about change.

Compassion is another value which I have held for a very long time. Something I have identified that I would like to move closer to is being compassionate towards myself and seeing myself as important. I was once told that we cannot give the best care to others if we do not care for ourselves. I can see how caring for myself helps me to be there for my loved ones and makes me a better advocate. However, I do not simply want to care for myself so that I can care for others. I know I will continue to care and advocate for others because that is part of who I am, but I want to care for myself because I am important too.
3.2 Difficult Internal Experiences

When we try to live in line with our values, we undoubtedly come up against difficult internal experiences (Polk & Schoendorff, 2014). I have experienced a lot of anxiety during the process of conducting this research. This has been linked with fears of abusing my power and becoming part of a system that might harm rather than help. This is illustrated by an extract from my reflective diary: “I felt as though I was being seen as part of this system and someone who the service users (SUs) on the wards needed protecting from” (March 2021). At this point, I had met with an expert by experience who raised concerns about the potential impact on my future participants if I were to interview people still living through voluntary admissions. This person spoke about their duty to protect people on the wards. I struggled with the idea that I might be someone people needed protecting from, and that in trying to help I could end up causing harm. I am grateful to this person for raising these concerns and I subsequently made changes to the research.

Another extract illustrates my concerns when developing my interview guide: “I don’t want to become another person pushing another narrative. I want to hear what people have to say, not what I want them to say” (March 2021). I was aware of my own position and assumptions, and I worried that I would ask leading questions rather than being open and curious about my participants’ experiences. I had the same concerns at the analysis stage for both my systematic review and my research project. It was important to me to represent the voices of the participants in both projects, and I felt anxious about getting this wrong. I have not personally been through the ECT process or been a SU on a voluntary admission, and I questioned my authority to speak on these topics. Adding to this anxiety was a fear of being rejected if I got it wrong, both by the people whom I was advocating for and by the services I felt needed to change.
At times during this project, I found myself losing hope that services could change and sometimes felt stuck. Harris (2019) described the ‘Hands as Thoughts and Feelings’ metaphor, where you are asked to imagine all the things important to you in your life are in the room with you. You are then invited to hold both hands up in front of your face, imagining that they represent the difficult thoughts and feelings that come up, and notice how this affects your ability to engage with the important things in the room. I am reminded of this metaphor when thinking back to my feelings of sadness and hopelessness. There were times when, metaphorically, my hands were so close to my face that I could barely see around them, making it difficult to move forwards.

I have experienced personal challenges while conducting this research. There was a particular period of time when I noticed feeling a lot of guilt. Guilt for not being fully present with my research and honouring the people who had shared their experiences, and guilt for not being fully present with my family who were going through difficult times too. For a while, I became stuck on really painful thoughts: that I was a s**t sister, daughter, girlfriend, friend, researcher, and psychologist. These thoughts got in the way of me being compassionate towards myself.

I have sometimes found it difficult to hold all my values alongside one another and have felt they are competing. I have questioned how I can possibly be an advocate for social justice and fight against power abuses, whilst also being there for my family, and somehow finding space to look after and prioritise myself too. When thinking about this, I am reminded of lines from a song in the film production of Les Misérables. In this scene, one of the main characters who is fighting in the French revolution is speaking of personal heartache, and one of his comrades sings:
Who cares about your lonely soul?

We strive towards a larger goal.

Our little lives don’t count at all. (Hooper, 2012, 01:18:45)

I have often felt overindulgent for thinking about my own emotions and needs. I think this partly comes from ideas within British society that we have to ‘hold it together’ and ‘get on with it’, partly from experiences in previous jobs where staff were shamed if they were struggling, and partly from my experiences of how psychologists are often seen as the person who holds others’ difficult emotions. The bigger picture is important and so are individual stories, and I am trying to remember that this includes my own.

3.3 Away Moves

We all find ways of coping with difficult internal experiences. One way that we often do this is to engage in behaviours that move us away from those experiences or reduce their intensity, like turning down the volume on the TV when it gets too loud (Harris, 2019). ACT describes these behaviours as ‘away moves’. I like that ACT does not tell us these behaviours are wrong; it recognises that these are the ways we have survived difficult things in the past. Emphasis is placed on ‘workability’, asking whether this behaviour is working now to help us move towards the life we want to lead (Harris, 2019).

When thinking about my value of advocacy, and the anxiety and hopelessness that sometimes get in the way, I know that one way I have coped in the past is to not speak up or take action. I have been silenced by my own fears of what might happen if I try to change things, and I have avoided putting myself in situations where I run the risk of ‘getting it wrong’. There were times when avoiding speaking up would help my anxiety reduce temporarily, but then another situation would come up and it would rocket up again. Pushing away these thoughts and feelings can be likened to trying to push an inflatable beach ball under the water; it will always pop back up (Vivyan, 2009).
Acceptance can be likened to giving up this struggle and letting the beach ball float in the water around us, making space for the difficult thoughts and feelings so that we can continue moving towards what is important (Harris, 2007). Avoiding speaking up was not helping me move towards what was important to me. In fact, it was adding to my feelings of guilt and hopelessness. As I have progressed through training, I have started to recognise that I am moving into positions of power and influence within organisations and teams, and it has therefore become even more important that I stay true to the practitioner that I want to be and advocate for staff and SUs. Understanding that my values go hand in hand with my pain has helped me to accept the difficult stuff that comes up and make the choice to advocate and fight for change.

Sometimes, we can come to hold rigid and incomplete descriptions of ourselves and the things we struggle with (Brown & Augusta-Scott, 2006). For a long time, I have thought of myself as someone who avoids the things that make them feel anxious. I took one aspect of my experience and used this to define myself. What I have learned over the past three years and through the course of this research is that I am so much more than an ‘avoider’. When I have that urge to run away from something, it is usually a sign that I really care about it. Through the processes of defusion and learning to see the self-as-context (Harris, 2019), I have been able to take a step back from this description of myself. I can now see that the urge to avoid difficult thoughts and feelings is just one part of my experience.

Another strategy I have used to move away from my feelings of guilt about not being present enough at home or at work is to over-compensate. I have set high standards for myself and tried to do everything perfectly. Research indicates that trainee therapists sometimes become overly controlled during therapy sessions in an attempt to appear competent and manage their anxiety (Tannen et al., 2019). Applying this to my research process, I experienced the urge to hold on tightly to structure and plans, which only proved to increase my anxiety...
when things did not go to plan, or changes had to be made. Additionally, I tried to do everything by giving all my time to my research and my loved ones, and I found it difficult to take breaks. In doing this, I avoided connecting with the emotion of what has been going on in my personal life. And perhaps this is what I needed to do to get through; sometimes away moves are what we need in that moment (Harris, 2019). This is, however, where I struggled to show myself compassion and I put myself at the bottom of the list.

3.4 Towards Moves

Towards moves are behaviours that help us move towards the people and things that are important to us; they help us live in line with our values and be the type of person we want to be (Harris, 2019). A big part of this for me was vulnerability. During my first year of training, I read Brown’s (2015) book, ‘Daring Greatly’. The author highlighted how some of us strive for perfection to avoid uncomfortable feelings, but perfection is unattainable and striving for this prevents us from being present; it means that we miss out. This helped me to see that being vulnerable and putting myself into situations that might make me feel uncomfortable could also bring a sense of purpose and meaning to my life. Completing this research has been a big towards move for me. I am proud that I have spoken up by helping to create a space where others could speak up too.

Another towards move I engaged in during the research process, was to keep the research on course. There were times when this required me to be flexible and make changes, taking on others’ feedback, and there were times when this required me to hold my ground. Planning this project during the Covid-19 pandemic, my research team and I came up against logistical challenges. I recall times when I was encouraged to change the project and, for example, focus on the impact of Covid-19 during voluntary admissions, but I chose not to do this. I could not deny that Covid-19 would have had an impact, but there were issues in relation
to power in services that were present long before the pandemic and would likely remain present long after.

Being present also helped me move towards my values when conducting this research. When the therapist is more present during a therapy session, this increases connectedness (Tannen et al., 2019). When conducting interviews with my participants, I tried to be present and connect with them and their experiences. I continued this through the analysis process, spending time with my data. Engward and Goldspink (2020) used the metaphor of lodgers in a house to describe how they spent time with their “data lodgers” (p. 3). This allowed them the opportunity to really get to know the data and question which interpretations belonged to their participants, and which belonged to them. For both my systematic and empirical projects, I set myself deadlines for when I would have my analysis completed. I had to revise these deadlines as I needed to really give myself time to be with the data. Doing this helped me to stay closer to the participants’ experiences. There is a requirement to be interpretative in IPA, but these interpretations should always be grounded in participants’ experiences (Smith et al., 2009). Using respondent validation, I was able to continue moving towards my value of advocating for others not by speaking for them, but by helping to create a platform for them to speak for themselves.

Making connections with others has helped to keep me on course and moving towards my values in this research process. I have been very fortunate to have reflective spaces with my research supervisors and my peers where I have been able to take a step back from feeling stuck on the difficult thoughts and feelings and re-connect with what is important. I have also found allies in other groups of people who value advocacy. I recall one moment during the height of the Covid-19 pandemic when I attended a virtual Drop the Disorder poetry evening. Despite being sat alone with my laptop in my living room, I felt so connected with the people on the screen sharing their experiences and advocating for change.
Something I have struggled a little more with moving towards, is self-compassion. This is a priority for me going forwards, and some of the ways I plan to move towards this are getting back into exercise, accessing therapy, and taking time for myself. I know that this is something I want to focus on, and perhaps that should be the first committed action I take in moving towards this value: just to start thinking about this a little more each day.

4.0 Conclusion

During the last couple of days of training, we were asked to reflect on how confident we were at the start of the course compared to now. I reflected that my confidence has increased, but not because I know more things. It has increased because I am more strongly connected with the values that drive me. Joiner (2017, 00:13) said: “when you know your why, your what becomes more clear and more impactful”; knowing your values gives purpose and meaning to your actions. In so many ways, this research has brought me closer to my why. I find real strength in knowing who and what is important to me, knowing the person I want to be, and knowing the values I want to live by. I will continue to advocate for others, even when the prospect of that is terrifying, and I will make sure to save some of the fight for myself.
5.0 References


https://doi.org/10.1080/14623943.2019.1708305


https://cms.bps.org.uk/sites/default/files/2022-07/PTM%20Framework%20%28January%202018%29_0.pdf

https://www.youtube.com/watch?v=1ytFB8TrkTo


https://doi.org/10.4324/9781410605986-9


https://www.getselfhelp.co.uk/metaphors.htm

Lineham (Eds.), *Mindfulness and acceptance: Expanding the cognitive-behavioural tradition* (pp. 120-151). Guilford Press.
Appendix A

The Journal of ECT – Submission Guidelines


The Journal of ECT
Online Submission and Review System

Scope
The Journal of ECT is an international journal that aims at a greater understanding of the effects of induced seizures on behavior and organ systems, both in animals and in humans, and of seizures, their mode of induction, their occurrence, and their propagation. The Journal is a forum for original scientific articles, reviews, commentaries, and letters.

The scope of articles may be broad, encompassing anatomic, structural, physiologic, biochemical, psychologic, and neurophysiologic studies of the effects of seizures and of the seizure process itself. Discussions of sociologic, legal, and ethical aspects of research and clinical practice are of interest. The Editors believe that the Journal can make a special contribution to clinical practice by providing a clinical forum for the reporting of both basic and clinical research into the convulsive therapy process. Rapid communications of new information are welcomed.

The journal has limited capacity to assist with correcting problems in written English. Articles submitted to the journal must be written with a solid grasp of the English language. If you need assistance in this area, use of an editorial service is at the discretion and cost of the authors, and will not guarantee acceptance for publication in the journal.

If you need assistance with English, consider visiting a service that can help, such as:

http://journals.lww.com/ectjournal/_layouts/1033/oaks.journals/editservices.aspx

Ethical/Legal Considerations – A submitted manuscript must be an original contribution not previously published (except as an abstract or a preliminary report), must not be under consideration for publication elsewhere, and, if accepted, must not be published elsewhere in similar form, in any language, without the consent of Lippincott Williams & Wilkins. Each person listed as an author is expected to have participated in the study to a significant extent. Although the editors and referees make every effort to ensure the validity of published manuscripts, the final responsibility rests with the authors, not with the Journal, its editors, or the publisher. All manuscripts must be submitted on-line through the journal’s Web site at http://ject.edmgr.com. See submission instructions on the next page, under “On-line manuscript submission."

Conflicts of Interest – Authors must state all possible conflicts of interest in the manuscript, including financial, consultant, institutional and other and other relationships that might lead to bias or a conflict of interest. If there is no conflict of interest, this should also be explicitly stated as none declared. All sources of funding should be acknowledged in the manuscript. All relevant conflicts of interest and sources of funding should be included on the title page of the manuscript with the heading “Conflicts of Interest and Source of Funding:”. For example:
Conflicts of Interest and Source of Funding: A has received honoraria from Company Z. B is currently receiving a grant (#12345) from Organization Y, and is on the speaker’s bureau for Organization X – the CME organizers for Company A. For the remaining authors none were declared.

Copyright: In addition, each author must complete and submit the journal's copyright transfer agreement, which includes a section on the disclosure of potential conflicts of interest based on the recommendations of the International Committee of Medical Journal Editors, "Uniform Requirements for Manuscripts Submitted to Biomedical Journals" (www.icmje.org/update.html).

A copy of the form is made available to the submitting author within the Editorial Manager submission process. Co-authors will automatically receive an Email with instructions on completing the form upon submission.

Patient Anonymity and Informed Consent – It is the authors’ responsibility to ensure that patients’ anonymity is carefully protected and to verify that any experimental investigation with human subjects reported in the manuscript was performed with informed consent and followed all the guidelines for experimental investigation with human subjects required by the institution(s) with which all the authors are affiliated. Authors should remove patients' names and other identifying information from figures. If any identifying details appear in text, tables, and/or figures, the author must provide proof of informed consent obtained from the patient (i.e., a signed permissions form). Photographs with bars placed over eyes of patients should NOT be used in publication. If they are used, permission from the patient is required.

Compliance with NIH and Other Research Funding Agency Public Access Requirements – A number of research funding agencies require or request authors to submit the post-print (the article after peer review and acceptance but not the final published article) to a repository that is accessible online by all without charge. As a service to our authors, WK will identify to the National Library of Medicine (NLM) articles that require deposit and will transmit the post-print of an article based on research funded in whole or in part by the National Institutes of Health, Wellcome Trust, or Howard Hughes Medical Institute, to PubMed Central. Authors may indicate such funding when completing the Copyright Transfer Agreement.

Open access – Authors of accepted peer-reviewed articles have the choice to pay a fee to allow perpetual unrestricted online access to their published article to readers globally, immediately upon publication. Authors may take advantage of the open access option at the point of acceptance to ensure that this choice has no influence on the peer review and acceptance process. These articles are subject to the journal’s standard peer-review process and will be accepted or rejected based on their own merit.

The article processing charge (APC) is charged on acceptance of the article and should be paid within 30 days by the author, funding agency or institution. Payment must be processed for the article to be published open access. For a list of journals and pricing please visit our Wolters Kluwer Open Health Journals page.

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Compliance with funder mandated open access policies – An author whose work is funded by an organization that mandates the use of the Creative Commons Attribution (CC BY) license is able to meet that requirement through the available open access license for approved funders. Information about the approved funders can be found here: http://www.wkopenhealth.com/inst-fund.php

FAQ for open access – http://www.wkopenhealth.com/openaccessfaq.php

Permissions: Authors must submit written permission from the copyright owner (usually the publisher) to use direct quotations, tables, or illustrations that have appeared in copyrighted form elsewhere, along with complete details about the source. Any permissions fees that might be required by the copyright owner are the responsibility of the authors requesting use of the borrowed material, not the responsibility of Lippincott Williams & Wilkins.

Manuscript Submission

On-line manuscript submission: All manuscripts must be submitted on-line at http://ject.edmgr.com/.

First-time users: Please click the Register button from the menu above and enter the requested information. On successful registration, you will be sent an e-mail indicating your user name and password. Note: If you have received an e-mail from us with an assigned user ID and password, or if you are a repeat user, do not register again. Just log in. Once you have an assigned ID and password, you do not have to re-register, even if your status changes (that is, author, reviewer, or editor).

Authors: Please click the log-in button from the menu at the top of the page and log in to the system as an Author. Submit your manuscript according to the author instructions. You will be able to track the progress of your manuscript through the system. If you experience any problems, please contact the Editorial Office: emily.hurd@wolterskluwer.com.

Article Types – The Journal accepts for publication the following types of articles. Please contact the Editorial Office with any questions regarding submission requirements for a specific article type.

Original Study – reports of both basic and clinical research into electroconvulsive therapy and other forms of therapeutic brain stimulation for mental disorders are welcomed. Original Studies should be no more than 5000 words and include the following headings: Introduction, Methods, Results, and Discussion. For all studies reporting animal or human research, the Materials and Methods section must include a statement regarding review board approval and adherence to ethical standards; for human research, this includes a statement regarding informed consent. A structured abstract must be provided.

Case report – Case Reports will be considered for publication as either a regular, full “Case Report” or a more brief “Letter to the Editor”. To be considered as a full Case Report, the submission must include a truly novel case that has the potential to change thinking within the field of therapeutic
brain stimulation, and the submission should include a thorough review of the existing literature and explanation of how this case advances the field. Case Reports should be no more than 2000 words, contain a maximum of 5 references, and include an unstructured abstract. The report itself should include the following headings: Introduction, Case Report, and Discussion. In contrast, cases that are less novel or replications of prior reports should be submitted as a Letter to the Editor, with no abstract, no more than 1000 words, no tables or figures, and no more than 5 references. The Editorial Board reserves the right to recommend that cases submitted as 'Case Reports' be revised as Letters to the Editor.

**Review Article** – Review Articles focusing on various aspects of electroconvulsive therapy and other forms of therapeutic brain stimulation for mental disorders, historical issues of relevance to current practice, or international aspects of the practice are welcomed. Review Articles must be no more than 5000 words and include an unstructured abstract.

**Images in Clinical ECT** – Images of EEG recordings or of items of clinical interest to practitioners of electroconvulsive therapy and other forms of therapeutic brain stimulation for mental disorders may be submitted for consideration. The image or picture should tell the story; the text must not exceed 500 words. If text >500 words is required, then the article should be submitted as a case report. Articles should be submitted without an abstract.

**Commentary** – Commentaries may focus on timely issues of interest to the international ECT community. Commentary submissions do not require an abstract.

**Letter to the Editor** – Letters should focus on articles recently published in the Journal, or may describe brief case reports (see above). In general, letters to the editor should be submitted with no abstract, no more than 1000 words, no tables or figures, and no more than 5 references. If the authors’ comments do not directly relate to a recently-published article or describe a brief case report, the paper should be submitted as a Commentary. All letters should begin with the salutation "Dear Sir."

**Caution regarding the use of statistics**

**General approach** – Presentation of results from inferential statistical testing should include sufficient information such as test statistic (t, F, X^2, etc.) and degrees of freedom (df) accompanying the p-value to document the appropriateness of the analyses. An example of results of an independent sample t-test comparison of an outcome in two groups would be (p=<0.001; t=12.5, df=50). It is also acceptable, particularly when reporting of the test statistic and df is not straightforward (as occurs in some regression modeling situations) to simply identify the inferential procedure and relevant additional information associated with the reported p-value, e.g., (p<0.001; timeXtreatment interaction, mixed effects model). All statistical procedures should be described with sufficient detail in the methods section and identified in the footnotes of tables and figures.

**Repeated observations in the same subject** – The nature of therapeutic brain stimulation is such that patients usually receive multiple, repeated treatment sessions over a specified period of time. Our statisticians on our editorial board have noted several common mistakes in the conduct and reporting of statistics, particularly in relation to inferential statistical tests performed on repeated observation in the same patient. Depression scores, seizure duration scores, vital signs, etc. from serial treatments within the same patient are assumed to be intercorrelated within that patient, and hence violate the usual assumptions of independence of observations required for most statistical tests involving between group comparisons. For example, 10 individuals each having 3 measurements of HRSD scores over time (sessions) does not result in a sample size of 30
independent HRSD scores for this group. For study designs involving repeated measures within individuals, a statistical method that takes into account the repeated measures must be used.

Small negative studies – Ideally, before any comparative trial is initiated, a valid power analysis is carried out and a sample size having sufficient power to detect a pre-specified clinically important effect is determined. However, occasionally studies are undertaken in which no a priori sample size determination was made (and only available patients were used) or the pre-determined sample size is not achieved. For either of these cases in which a negative (non-statistically significant) result is obtained for the primary outcome variable(s), a post hoc power analysis should be carried out. If this analysis indicates power less than 80%, the results must be presented as a small descriptive and/or pilot study (and reflected in the title of the paper) rather than a confirmatory comparative study involving inferential statistical procedures. Specifically, as a small descriptive and/or pilot study, comparative results should be presented in terms of descriptive measures such as intervention effect sizes (e.g. difference in treatment means or response proportions) accompanied by appropriate confidence intervals on these differences. In the pilot study context, feasibility measures such as study refusal and dropout proportions and estimates of variances for outcome variables are relevant outcome variables and provide useful input information in the event the small study is replicated in a larger, adequately-powered sample. When a study lacks power to detect clinical important intervention group differences, the negative study results (non-significant intervention differences) produced by the inferential statistical procedures must be interpreted as "study findings are inconclusive" or more harshly as a "failed trial." This is because the failure to detect intervention group differences for the primary outcome(s) may be due to the fact that (a) the relevant clinically important differences do not exist in the population to which inferences are being made or (b) the statistical test simply did not have sufficient power to detect the specified important population differences that actually exist. To be able to conclude (a) above, we must be assured that power was adequate to have found the relevant difference if it exists in the population of inference [i.e. that (b) is not the explanation for the negative finding]. When power is known to be low, the second option prevails for negative findings. For this reason, simple descriptive measures rather than inferential statistical procedures (with their accompanying p-values) should be reported for the small negative trials published in JECT. Note that regardless of power, if statistically significant differences are found for the primary outcome(s), the study qualifies for consideration for publication as a confirmatory comparative study. For this case, negative results for secondary outcomes produced using inferential methods must be interpreted as described above.

Preparation of Manuscript – Manuscripts that do not adhere to the following instructions will be returned to the corresponding author for technical revision before undergoing peer review.

Manuscripts must be double-spaced and include continuous line numbering throughout.

Title page: Include on the title page (a) complete manuscript title; (b) authors' full names, highest academic degrees, and affiliations; (c) name and address for correspondence, including fax number, telephone number, and e-mail address; (d) address for reprints if different from that of corresponding author; and (e) a conflict of interest disclosure statement (see the "Conflicts of Interest" section above) including any sources of support that require acknowledgment. This includes disclosure of funding received for the work from any of the following organizations: National Institutes of Health (NIH); Wellcome Trust; Howard Hughes Medical Institute (HHMI); and other(s). If there are no potential conflicts of interest to disclose, please include a statement to that effect.

Structured abstract and key words: Limit the abstract to 250 words. Do not cite references in the abstract. Limit the use of abbreviations and acronyms. Use the following subheads: Objectives, Methods, Results, and Conclusions. List three to five key words.
Unstructured abstract and key words: Limit the abstract to 250 words. It must be factual and comprehensive. Limit the use of abbreviations and acronyms, and avoid general statements (e.g., “the significance of the results is discussed”). List three to five key words or phrases.

Text: Organize the manuscript into four main headings: Introduction, Materials and Methods, Results, and Discussion. Define abbreviations at first mention in text and in each table and figure. If a brand name is cited, supply the manufacturer’s name and address (city and state/country). Acknowledge all forms of support, including pharmaceutical and industry support, on the title page of the manuscript.

Abbreviations: For a list of standard abbreviations, consult the Council of Biology Editors Style Guide (available from the Council of Science Editors, 9650 Rockville Pike, Bethesda, MD 20814) or other standard sources. Write out the full term for each abbreviation at its first use unless it is a standard unit of measure.

Technical Parameters of ECT devices and other brain stimulation devices: Authors should routinely report the make and model of brain stimulation devices, along with the location of the manufacturer. Where relevant, stimulus waveform, stimulus intensity, electrode placement, and seizure duration should be reported. The stimulus waveform, stimulus intensity, electrode placement, and seizure duration monitoring details for ECT should follow the suggestions of “Reporting of Technical Parameters in ECT Publications: Recommendations for Authors,” by R. D. Weiner, L. A. Weaver, Jr., and H. A. Sackeim, Convulsive Ther 1988;4:88-91. Copies of the recommendations are available from the Editorial Office.

References: The authors are responsible for the accuracy of the references. Cite the references in the text in the order of appearance using superscripts. Include a double-spaced referenced list, at the end of the manuscript, listing references in order of appearance. Cite unpublished data—such as papers submitted but not yet accepted for publication and personal communications, including e-mail communications—in parentheses in the text. If there are more than three authors, name only the first three authors and then use et al. Refer to the List of Journals Indexed in Index Medicus for abbreviations of journal names, or access the list at http://www.nlm.nih.gov/tsd/serials/lji.html.

Sample references are given below:

Journal article

Book chapter

 Entire book

Software

Online journals

Database

World Wide Web

Figures:

A) Creating Digital Artwork

1. Learn about the publication requirements for Digital Artwork: http://links.lww.com/ES/A42
2. Create, Scan and Save your artwork and compare your final figure to the Digital Artwork Guideline Checklist (below).
3. Upload each figure to Editorial Manager in conjunction with your manuscript text and tables.

B) Digital Artwork Guideline Checklist

Here are the basics to have in place before submitting your digital art:

- Artwork should be saved as TIFF, PDF, Word Doc, PPT, or EPS files.
- Artwork is created as the actual size (or slightly larger) it will appear in the journal. (To get an idea of the size images should be when they print, study a copy of the journal to which you wish to submit. Measure the artwork typically shown and scale your image to match.)
- Crop out any white or black space surrounding the image.
- Diagrams, drawings, graphs, and other line art must be vector or saved at a resolution of at least 1200 dpi. If the art is created in an MS Office program, convert to a hi-res PDF. If the PDF creation process is unfamiliar then submit the MS Office doc.
- Photographs, radiographs and other halftone images must be saved at a resolution of at least 300 dpi.
- Photographs and radiographs with text must be saved as postscript or at a resolution of at least 600 dpi.
- Each figure must be saved and submitted as a separate file. Figures should not be embedded in the manuscript text file.

Remember:

- Cite figures consecutively in your manuscript.
- Number figures in the figure legend in the order in which they are discussed.
- Upload figures consecutively to the Editorial Manager web site and number figures consecutively in the Description box during upload.

Figure legends: Include legends for all figures. They should be brief and specific, and they should appear after the text and before the references. Use scale markers in the image for electron micrographs, and indicate the type of stain used.
**Color figures:** The journal accepts for publication color figures that will enhance an article. Authors who submit color figures will receive an estimate of the cost for color reproduction. If they decide not to pay for color reproduction, they can request that the figures be converted to black and white at no charge.

**Tables:** Create tables using the table creating and editing feature of your word processing software (e.g., Word, WordPerfect). Do not use Excel or comparable spreadsheet programs. Do not submit tables as image files (e.g., TIFF, JPG, EPS). Submit each table in a separate file. Cite tables consecutively in the text, and number them in that order. Each table should appear on a separate sheet and should include the table title, appropriate column heads, and explanatory legends (including definitions of any abbreviations used). Do not embed tables within the body of the manuscript. They should be self-explanatory and should supplement, rather than duplicate, the material in the text.

**Style:** In general, style should be patterned after the *American Medical Association Manual of Style* (9th edition). *Stedman’s Medical Dictionary* (27th edition) and *Merriam Webster’s Collegiate Dictionary* (10th edition) should be used as standard references. Drugs and therapeutic agents should be referred to by their accepted generic or chemical names. The name should not be abbreviated. Code numbers should be used only when a generic name is not yet available. In that case, the chemical name and a figure giving the chemical structure of the drug is required. Copyright or trade names of drugs should be capitalized and placed in parentheses after the name of the drug. Names and locations (city and state in USA; city and country outside USA) of manufacturers of drugs, supplies, or equipment cited in a manuscript are required to comply with trademark law and should be provided in parentheses. Units of measure should be expressed in the metric system, and temperatures should be expressed in degrees Celsius. Conventional units should be written as SI units as appropriate.

**Supplemental Digital Content**

**Supplemental Digital Content (SDC):** Authors may submit SDC via Editorial Manager to LWW journals that enhance their article’s text to be considered for online posting. SDC may include standard media such as text documents, graphs, audio, video, etc. On the Attach Files page of the submission process, please select Supplemental Audio, Video, or Data for your uploaded file as the Submission Item. If an article with SDC is accepted, our production staff will create a URL with the SDC file. The URL will be placed in the call-out within the article. SDC files are not copy-edited by LWW staff, they will be presented digitally as submitted. For a list of all available file types and detailed instructions, please visit [http://links.lww.com/A142](http://links.lww.com/A142).

**SDC Call-outs** – Supplemental Digital Content must be cited consecutively in the text of the submitted manuscript. Citations should include the type of material submitted (Audio, Figure, Table, etc.), be clearly labeled as “Supplemental Digital Content,” include the sequential list number, and provide a description of the supplemental content. All descriptive text should be included in the call-out as it will not appear elsewhere in the article.

Example:
We performed many tests on the degrees of flexibility in the elbow (see Video, Supplemental Digital Content 1, which demonstrates elbow flexibility) and found our results inconclusive.

**List of Supplemental Digital Content** – A listing of Supplemental Digital Content must be submitted at the end of the manuscript file. Include the SDC number and file type of the Supplemental Digital Content. This text will be removed by our production staff and not be published.
Example:
Supplemental Digital Content 1.wmv

**SDC File Requirements** – All acceptable file types are permissible up to 10 MBs. For audio or video files greater than 10 MBs, authors should first query the journal office for approval. For a list of all available file types and detailed instructions, please visit [http://links.lww.com/A142](http://links.lww.com/A142).

**After Acceptance**

_**Page proofs and corrections:**_ Corresponding authors will receive electronic page proofs to check the copyedited and typeset article before publication. Portable document format (PDF) files of the typeset pages and support documents (e.g., reprint order form) will be sent to the corresponding author by e-mail. Complete instructions will be provided with the e-mail for downloading and printing the files and for faxing the corrected page proofs to the publisher. Those authors without an e-mail address will receive traditional page proofs. It is the author’s responsibility to ensure that there are no errors in the proofs. Changes that have been made to conform to journal style will stand if they do not alter the authors’ meaning. Only the most critical changes to the accuracy of the content will be made. Changes that are stylistic or are a reworking of previously accepted material will be disallowed. The publisher reserves the right to deny any changes that do not affect the accuracy of the content. Authors may be charged for alterations to the proofs beyond those required to correct errors or to answer queries. Proofs must be checked carefully and corrections faxed within 24 to 48 hours of receipt, as requested in the cover letter accompanying the page proofs.

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Philadelphia, PA 19103

Email: emily.hurd@wolterskluwer.com
Appendix B

Ethical Approval – Review

Certificate of Ethical Approval

Applicant: Alys Frankham

Project Title: Staff and Female Service Users' Experiences of Electro Convulsive Therapy (ECT): A Systematic Review of Qualitative Literature

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Low Risk

Date of approval: 05 Apr 2022
Project Reference Number: P130901
## Appendix C

### PRISMA 2020 Checklist

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<td>Data items</td>
<td>10a</td>
<td>List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.</td>
<td>Not applicable</td>
</tr>
<tr>
<td></td>
<td>10b</td>
<td>List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Study risk of bias assessment</td>
<td>11</td>
<td>Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.</td>
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<td>Effect measures</td>
<td>12</td>
<td>Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.</td>
<td>Not applicable</td>
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<tr>
<td>Section and Topic</td>
<td>Item #</td>
<td>Checklist item</td>
<td>Location where item is reported</td>
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<td>Synthesis methods</td>
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<td>Not applicable</td>
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<td></td>
<td>13d</td>
<td>Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.</td>
<td>p. 35</td>
</tr>
<tr>
<td></td>
<td>13e</td>
<td>Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).</td>
<td>Not applicable</td>
</tr>
<tr>
<td></td>
<td>13f</td>
<td>Describe any sensitivity analyses conducted to assess robustness of the synthesized results.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Reporting bias assessment</td>
<td>14</td>
<td>Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Certainty assessment</td>
<td>15</td>
<td>Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.</td>
<td>Not applicable</td>
</tr>
<tr>
<td><strong>RESULTS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study selection</td>
<td>16a</td>
<td>Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.</td>
<td>pp. 22-24</td>
</tr>
<tr>
<td></td>
<td>16b</td>
<td>Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.</td>
<td>p. 23</td>
</tr>
<tr>
<td>Study characteristics</td>
<td>17</td>
<td>Cite each included study and present its characteristics.</td>
<td>pp. 26-34</td>
</tr>
<tr>
<td>Risk of bias in studies</td>
<td>18</td>
<td>Present assessments of risk of bias for each included study.</td>
<td>pp. 24-25, pp. 134-141</td>
</tr>
<tr>
<td>Results of individual studies</td>
<td>19</td>
<td>For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Results of syntheses</td>
<td>20a</td>
<td>For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.</td>
<td>pp. 26-34, pp. 142-143</td>
</tr>
<tr>
<td></td>
<td>20b</td>
<td>Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.</td>
<td>Not applicable</td>
</tr>
<tr>
<td></td>
<td>20c</td>
<td>Present results of all investigations of possible causes of heterogeneity among study results.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Section and Topic</td>
<td>Item #</td>
<td>Checklist item</td>
<td>Location where item is reported</td>
</tr>
<tr>
<td>-------------------</td>
<td>--------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>Reporting biases</td>
<td>20d</td>
<td>Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Certainty of evidence</td>
<td>21</td>
<td>Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Certainty of evidence</td>
<td>22</td>
<td>Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.</td>
<td>pp. 24-25, pp. 140-141</td>
</tr>
<tr>
<td>DISCUSSION</td>
<td>23a</td>
<td>Provide a general interpretation of the results in the context of other evidence.</td>
<td>pp. 47-49</td>
</tr>
<tr>
<td></td>
<td>23b</td>
<td>Discuss any limitations of the evidence included in the review.</td>
<td>pp. 24-25</td>
</tr>
<tr>
<td></td>
<td>23c</td>
<td>Discuss any limitations of the review processes used.</td>
<td>pp. 51-52</td>
</tr>
<tr>
<td></td>
<td>23d</td>
<td>Discuss implications of the results for practice, policy, and future research.</td>
<td>pp. 49-51</td>
</tr>
<tr>
<td>OTHER INFORMATION</td>
<td>24a</td>
<td>Provide registration information for the review, including register name and registration number, or state that the review was not registered.</td>
<td>Not registered</td>
</tr>
<tr>
<td></td>
<td>24b</td>
<td>Indicate where the review protocol can be accessed, or state that a protocol was not prepared.</td>
<td>Contact author</td>
</tr>
<tr>
<td></td>
<td>24c</td>
<td>Describe and explain any amendments to information provided at registration or in the protocol.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Support</td>
<td>25</td>
<td>Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Competing interests</td>
<td>26</td>
<td>Declare any competing interests of review authors.</td>
<td>Not applicable</td>
</tr>
<tr>
<td>Availability of data, code and other materials</td>
<td>27</td>
<td>Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

For more information, visit: http://www.prisma-statement.org/
Appendix D

Search Strategy

Boolean operators (‘AND’ and ‘OR’) were used to link search terms and truncation was used to retrieve all variations of word endings, denoted using the asterisk (*) symbol. A simplified search strategy was used to search Google Scholar, incorporating main search terms for each key concept. Filters were applied to limit results to articles published from 1980 onwards and written in English. Search strings are presented below.

<table>
<thead>
<tr>
<th>Location of Search</th>
<th>Search String</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selected databases</td>
<td>(women* or woman* or female* or professional* or staff* or worker* or psychiatrist* or doctor* or consultant* or physician* or nurse* or nursing or anaesthetist* or anaesthesiologist* or psychologist* or therapist*) AND (perspective* or experience* or view* or perception* or account* or reason* or attitude* or belief* or &quot;decision making&quot; or decision-making) AND (&quot;electro* shock&quot; or &quot;electrical stimulation&quot; or &quot;electro convulsive shock therapy&quot; or “electroconvulsive shock therapy” or “electro-convulsive shock therapy” or “electro convulsive therapy” or “electroconvulsive therapy” or “electro-convulsive therapy” or &quot;shock therapy&quot; or &quot;shock treatment&quot; or &quot;convulsive therapy&quot; or &quot;ECT&quot;) AND (qualitative or “mixed method*” or interview* or “focus group*” or “case stud*”)</td>
</tr>
<tr>
<td>Google scholar</td>
<td>(staff OR adult female service users) AND electro convulsive shock therapy AND experiences AND qualitative</td>
</tr>
</tbody>
</table>
Appendix E

Checking Inclusion Criteria for Studies Included in the Review

The table presented below illustrates the process of ensuring all ten papers included in the current review satisfied the inclusion/exclusion criteria. Each row of the table relates to one paper and each column relates to criteria for inclusion. Tick symbols have been used to illustrate that there was evidence in the article to indicate that each of the criteria was satisfied, and abbreviations were used to indicate where this evidence was located in the article (Ab = abstract, I = introduction, M = method, R = results). The ‘notes’ column indicates any additional information which was key in considering the inclusion of each paper. The review’s author found all ten papers to meet criteria for inclusion in the current review. One of the studies (Kring et al., 2018) collected data from both women ECT recipients and staff members. While the data from women recipients met criteria for inclusion in the review, the data for staff members related to attitudes rather than experiences and, as such, could not be included. The study reported results for each group separately and so it was possible to extract only the data that was collected from women recipients. Another study (van Daalen-Smith, 2011) collected data from both women ECT recipients and staff members. Data from staff met criteria for inclusion in the current review and was reported separately so could be extracted. Of the six women ECT recipients who participated in this study, it was only possible to determine that four had their last ECT experience after 1980. As such, data for two of the women could not be included in the current review. The study indicated which quotes were taken from interviews with which participant, and so it was possible to only extract data relating to the four recipients who met inclusion criteria.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Publication type</th>
<th>Study Characteristics</th>
<th>Phenomenon of Interest</th>
<th>Design</th>
<th>Evaluation</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clark et al. (2018)</td>
<td>V</td>
<td>V Ab+M</td>
<td>V Ab+M</td>
<td>V M</td>
<td>V Ab+M</td>
<td>V Ab+i+mM Female recipients - data collected 2014-15, time since last ECT 3-9 years</td>
</tr>
<tr>
<td>Duxbury et al. (2018)</td>
<td>V</td>
<td>V Ab+1+iM</td>
<td>V Ab+M</td>
<td>V M</td>
<td>V I</td>
<td>V Ab+M            Staff - working in services that administer ECT at time of study</td>
</tr>
<tr>
<td>Ejaredar &amp; Hagan (2013)</td>
<td>V</td>
<td>V Ab+1+iM</td>
<td>V Ab+M</td>
<td>V M</td>
<td>V Ab+M</td>
<td>V Ab+i+mM Female recipients - time since last ECT treatment 2 days-22 years</td>
</tr>
<tr>
<td>Ejaredar &amp; Hagan (2014)</td>
<td>V</td>
<td>V Ab+1+iM</td>
<td>V Ab+M</td>
<td>V M</td>
<td>V Ab+i+mM</td>
<td>V Ab+i+mM Female recipients - time since last ECT treatment 2 days-22 years</td>
</tr>
<tr>
<td>Gass (2008)</td>
<td>V</td>
<td>V Ab+M</td>
<td>V Ab+M</td>
<td>V M</td>
<td>V M</td>
<td>V M            Staff - working in services that administer ECT at time of study</td>
</tr>
<tr>
<td>Kring et al. (2018)</td>
<td>V</td>
<td>V Ab+M+R</td>
<td>V Ab+M+R</td>
<td>V R</td>
<td>V Ab+i+mM</td>
<td>V Ab+i+mM Female recipients - last ECT took place from 2000-2011; exclude staff FG data (attitudes not experiences)</td>
</tr>
<tr>
<td>Lonerger et al. (2021)</td>
<td>V</td>
<td>V Ab+1+iM</td>
<td>V Ab+1+iM</td>
<td>V Ab</td>
<td>V Ab+i+r</td>
<td>V Ab+M            Staff - working in services that administer ECT at time of study</td>
</tr>
<tr>
<td>Orr &amp; O'Connor (2005)</td>
<td>V</td>
<td>V Ab+1+iM</td>
<td>V Ab+1+iM</td>
<td>V M</td>
<td>V Ab+i+mM</td>
<td>V Ab+i+mM Older age female recipients - women aged 71-89 at time of study and had ECT as older adult (age 65+) so must have had ECT post-1980 to be included</td>
</tr>
<tr>
<td>Stevens &amp; Harper (2007)</td>
<td>V</td>
<td>V Ab+1+iM</td>
<td>V Ab+1+iM</td>
<td>V M</td>
<td>V Ab+i</td>
<td>V Ab+i+mM        Staff - working in services that administer ECT at time of study</td>
</tr>
<tr>
<td>van Daalen-Smith (2011)</td>
<td>V</td>
<td>V Ab+M</td>
<td>V Ab+M</td>
<td>V M+R</td>
<td>V I</td>
<td>V Ab+M            Staff - working in services that administer ECT at time of study, female recipients - only include data for Ruth, Sandra, Linda, Cathy and Fran (can't determine if last ECT was post-1980 for other two participants)</td>
</tr>
</tbody>
</table>

*Include papers where experiences of adult female service users or mental health professionals can be extracted

**Include papers where ECT has been considered alongside other treatments and ECT data can be extracted

***Include papers with mixed methods designs where qualitative data can be extracted
Appendix F

Peer Review of Checking Inclusion Criteria

The process of checking each of the ten studies met criteria for inclusion in this review was conducted independently by a peer reviewer to ensure accuracy and reliability of the process. The same process was followed as was completed by the review’s author and, as such, the same table and symbols were used. The following abbreviations were used by the peer reviewer to indicate where evidence was located in the article (A = abstract, I = introduction, M = method, R = results, D = discussion). While the review’s author noted all locations where they found evidence for each paper meeting each of the inclusion criteria, the peer reviewer noted only the first place where they came across evidence. The peer reviewer found all ten papers to meet criteria for inclusion in the current review. As illustrated in the table, the peer reviewer queried whether Ejaredar and Hagen’s (2013) study contained evidence that participants had received ECT in relation to psychological difficulties or distress. The review’s author and peer reviewer met to discuss this and agreed that the article makes multiple references to a context of mental health services and ECT being used as a psychiatric intervention. It was, therefore, agreed that this paper met criteria for inclusion in the review.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Publication type</th>
<th>Study Characteristics</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clark et al. (2018)</td>
<td>√ (A)</td>
<td>√ (A)</td>
<td>√ (M)</td>
</tr>
<tr>
<td>Duxbury et al. (2018)</td>
<td>√ (A)</td>
<td>√ (M)</td>
<td>√ (A)</td>
</tr>
<tr>
<td>Ejaredar &amp; Hagan (2013)</td>
<td>√ (A)</td>
<td>√ (M)</td>
<td>√ (A)</td>
</tr>
<tr>
<td>Ejaredar &amp; Hagan (2014)</td>
<td>√ (A)</td>
<td>√ (A)</td>
<td>√ (A)</td>
</tr>
<tr>
<td>Gass (2008)</td>
<td>√ (A)</td>
<td>√ (A)</td>
<td>√ (A)</td>
</tr>
<tr>
<td>Kring et al. (2018)</td>
<td>√ (A)</td>
<td>√ (M)</td>
<td>√ (M)</td>
</tr>
<tr>
<td>Lonergan et al. (2021)</td>
<td>√ (A)</td>
<td>√ (A)</td>
<td>√ (A)</td>
</tr>
<tr>
<td>Orr &amp; O’Connor (2005)</td>
<td>√ (A)</td>
<td>√ (A)</td>
<td>√ (A)</td>
</tr>
<tr>
<td>Stevens &amp; Harper (2007)</td>
<td>√ (A)</td>
<td>√ (A)</td>
<td>√ (A)</td>
</tr>
<tr>
<td>van Daalen-Smith (2011)</td>
<td>√ (A)</td>
<td>√ (A)</td>
<td>√ (A)</td>
</tr>
</tbody>
</table>

*Include papers where experiences of adult female service users or mental health professionals can be extracted

**Include papers where ECT has been considered alongside other treatments and ECT data can be extracted

***Include papers with mixed methods designs where qualitative data can be extracted
Appendix G

Critical Appraisal and Skills Programme Checklist for Qualitative Studies (CASP, 2018)

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.

©CASP this work is licensed under the Creative Commons Attribution – Non-Commercial-Share A like. To view a copy of this license, visit http://creativecommons.org/licenses/by-nc-sa/3.0/ www.casp-uk.net
Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?
   - Yes
   - Can’t Tell
   - No
   
   HINT: Consider
   - what was the goal of the research
   - why it was thought important
   - its relevance

Comments:

2. Is a qualitative methodology appropriate?
   - Yes
   - Can’t Tell
   - No
   
   HINT: Consider
   - if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
   - is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?
   - Yes
   - Can’t Tell
   - No
   
   HINT: Consider
   - if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)

Comments:
4. Was the recruitment strategy appropriate to the aims of the research?

Yes
Can’t Tell
No

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g., why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes
Can’t Tell
No

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g., focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g., for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g., tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:
6. Has the relationship between researcher and participants been adequately considered?

Yes  
Can’t Tell  
No

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes  
Can’t Tell  
No

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:
8. Was the data analysis sufficiently rigorous?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Can't Tell</th>
<th>No</th>
</tr>
</thead>
</table>

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>Can't Tell</th>
<th>No</th>
</tr>
</thead>
</table>

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher’s arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:
**Section C: Will the results help locally?**

10. How valuable is the research?

**HINT:** Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

**Comments:**

---

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Appendix H

CASP Item Scores, Quality Ratings and Kappa Coefficients

This table contains the item scores and total quality ratings assigned for each paper using the CASP checklist (CASP, 2018). Each row in the table represents one study. Scores assigned by the review’s author are located in white boxes and scores assigned by the peer reviewer are located in grey boxes. The ‘Kappa statistic and significance’ column indicates the Kappa inter-rater reliability coefficient for each study and the level of significance. Additionally, the overall Kappa coefficient is provided. Viera and Garrett (2005) suggest that a Kappa statistic between 0.61-0.80 indicates substantial agreement between raters and a Kappa statistic between 0.81-1 indicates almost perfect agreement. Significance levels of less than 0.05 were observed for all Kappa coefficients, indicating statistical significance.
<table>
<thead>
<tr>
<th>Reference</th>
<th>Reviewer</th>
<th>CASP Item</th>
<th>Total CASP Score (/20)</th>
<th>Kappa Statistic and Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Q1</td>
<td>Q2</td>
<td>Q3</td>
</tr>
<tr>
<td>Clark et al. (2018)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Duxbury et al. (2018)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Ejaredar &amp; Hagan (2013)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Ejaredar &amp; Hagan (2014)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Gass (2008)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Kring et al. (2018)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Lonergan et al. (2021)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Orr &amp; O’Connor (2005)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Stevens &amp; Harper (2007)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>van Daalen-Smith (2011)</td>
<td>Review author</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Peer reviewer</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Overall (all studies)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix I

Summary of Characteristics Table

Data for women recipients was extracted from six studies and included ECT experiences of 31 women living in three countries: Canada (Ejaredar & Hagen, 2013; Ejaredar & Hagen, 2014; Orr & O’Connor, 2005; van Daalen-Smith, 2011), Australia (Clark et al., 2018), and Denmark (Kring et al., 2018). The mean age for women who participated in four of the studies was over 40 years (Clark et al., 2018; Ejaredar & Hagen, 2013; Ejaredar & Hagen, 2014; Orr & O’Connor, 2005). For two studies it was not possible to calculate participants’ mean ages, but age ranges were 44-65 years (van Daalen-Smith, 2011) and 51-59 years (Kring et al., 2018). Participants were recruited from the general community (Clark et al., 2018; Ejaredar & Hagen, 2013; Ejaredar & Hagen, 2014; Kring et al., 2018) or via mental health services (Orr & O’Connor, 2005; van Daalen-Smith, 2011). Data was collected through interviews (Clark et al., 2018; Ejaredar & Hagen, 2013; Ejaredar & Hagen, 2014; Orr & O’Connor, 2005; van Daalen-Smith, 2011) or focus groups (Kring et al., 2018). Data was analysed using thematic analysis (Clark et al., 2018; Ejaredar & Hagen, 2013; Ejaredar & Hagen, 2014), framework analysis (Kring et al., 2018), and constant comparison (van Daalen-Smith, 2011). One study did not specify the analysis method but reported key themes emerging from qualitative data (Orr & O’Connor, 2005). Data from two studies came from interviews with the same group of participants but focused on different aspects of the ECT experience (Ejaredar & Hagen, 2013; Ejaredar & Hagen, 2014).

Data for staff members was extracted from five studies and included the ECT experiences of 71 healthcare professionals living in three different countries: United Kingdom (Duxbury et al., 2018; Gass, 2008; Stevens & Harper, 2007), Ireland (Lonergan et al., 2021) and Canada (van Daalen-Smith, 2011). Data for both women recipients and staff members was extracted from one of the ten studies (van Daalen-Smith, 2011). Three studies focused on
experiences of mental health nurses (Gass, 2008; Lonergan et al., 2021; van Daalen-Smith, 2011) and two included a range of professionals involved in administering ECT (Duxbury et al., 2018; Stevens & Harper, 2007). Participants in all five studies were recruited via hospitals and mental health settings where ECT was administered. Data was collected using a combination of interviews (Duxbury et al., 2018; Gass, 2008; Stevens & Harper, 2007; van Daalen-Smith, 2011), focus groups (Lonergan et al., 2021; van Daalen-Smith, 2011) and observation (Gass, 2008). Two studies were informed by grounded theory (Duxbury et al., 2018; Gass, 2008), one used thematic analysis (Lonergan et al., 2021), and one used discourse analysis (Stevens & Harper, 2007). One study, which explored both nurses’ and women ECT recipients’ experiences, took a feminist standpoint and used constant comparison analysis (van Daalen-Smith, 2011).
Appendix J
Data Extraction Completed by Peer Reviewer

This table was completed by the peer reviewer for a sample of two papers (Clark et al., 2018; Duxbury et al., 2018) to check the accuracy and reliability of information presented in the characteristics table by the review’s author. Differences between data extracted by the review’s author and the peer reviewer mainly related to the level of detail reported and the way in which information was presented. For example, for Clark et al. (2018), the review’s author reported that participants were recruited using purposive sampling from a local GP network website. The peer reviewer also reported that purposive sampling was used and that participants voluntarily contacted the researcher but did not report where participants were recruited from. There were slight variations in how the key findings were described, but no contradictions. The review’s author provided mean values (e.g., mean age of participants) to two decimal places while the peer reviewer rounded to the nearest whole number.

One contradiction was noted and has been highlighted in the table below. For Clarke et al. (2018), the review’s author reported that the mean number of ECT treatments received by participants in the study was 21.50, with one participant being excluded from this calculation as they were unable to recall this information. The peer reviewer, however, reported the mean number of ECT treatments to be 18. After a discussion between the review’s author and the peer reviewer, it was deduced that the peer reviewer had added the total number of ECT treatments received by the six participants who had been able to recall this but had mistakenly divided this total by seven (the total number of participants in the study) rather than 6 (the total number of participants who could recall how many treatments they had received). The figure reported in the characteristics table of this review (p. 26) is, therefore, correct.
<table>
<thead>
<tr>
<th>Author, year, country</th>
<th>Research aim</th>
<th>Sampling method</th>
<th>Sample characteristics*</th>
<th>Method of data collection, method of data analysis</th>
<th>Key findings</th>
</tr>
</thead>
</table>
| Clarke, Barnes, Ross (2018) Australia | To explore women’s experiences of deciding to receive ECT by analysing their narratives. | Purposive sampling – women voluntarily contacted the researcher | Seven women, age ranging from 44 to 60 (M = 54). Six women identified as White, while one woman identified as having an Australian Indigenous background. The women’s ages of having ECT for the first time ranged between 40 to 56 (M = 48). The average total number of ECT treatments across all seven women was 18 and it had been an average 5 years since their last ECT. | Data was collected between September 2014 and March 2015 through recording semi-structured interviews. These were then transcribed and analysed using thematic analysis. | Four sub-themes relating to the decision making process of consenting to ECT were identified.  
- *Not enough information.* The women explained that they did not feel they had sufficient information given to them to understand the process of ECT  
- *I had no other choice.* The women explained that they felt that ECT was their only option, after having tried a selection of other treatments prior.  
- *Just go along with it.* The women spoke about not feeling that they had the power to be active decision makers in their own treatment, including making a decision around whether or not to have ECT.  
- *Lacking capacity.* The women explained that they themselves did not feel they had the ability to make decisions for themselves. This was due to having memory-loss as a consequence of previous ECT, and witnessing the negative reaction in others when they made decision for themselves. |
Duxbury et al. (2018) United Kingdom

To explore the decision-making process of professionals around whether or not to administer ECT.

Data was collected through theoretical sampling. Participants were recruited through NHS trusts and online social media platforms.

Ten participants were recruited as the final sample, which included six men and four women, with an average age of 40. Seven participants identified as White British, while one participant identified as Indian and two did not report their ethnicity. Six individuals worked in acute mental health wards, while one worked with older adults another in community mental health settings and two did not say. Professions ranged from two Clinical Psychologists, two Consultant Psychiatrists, a Ward Manager and deputy ward manager, as well as a lead ECT nurse, a specialist ECT nurse, support worker and an advanced practitioner.

Data was collected through face-to-face semi-structured interviews with the use of a flexible topic guide. These were then analysed using grounded theory.

The research developed a grounded theory model to explain the process of decision-making for ECT by the professionals interviewed in this study.

- In first line professionals spoke about their optimism about the effects of ECT and acknowledge the potential benefits it may have on a person’s life.
- Further considerations include offering alternative treatments before ECT. Clinical judgement and diagnostic criteria were also used to establish whether ECT was an appropriate treatment for an individual, while acknowledging the possible side effects of the intervention.
- While the participants acknowledge that it is a team discussion as to whether or not to offer ECT, it is the consultant psychiatrist that is named as the Responsible Clinician, who will ultimately have the final say and take responsibility for the decision, if the patient themselves lacks capacity.
- Once a decision has been made, the professionals will advocate for the patient, offer reassurance to the patient and enable autonomy of the patient.
Appendix K

The Analysis Process – Description and Pictures

Data from the results sections of the ten studies was extracted and placed into two Microsoft Word documents, one for data relating to women recipients’ experiences and another for data relating to staff members’ experiences. Using the comment feature, each sentence of data was assigned one or more codes based on the meaning and content of what was being stated. Coding was completed by the review’s author who consulted with the supervisory team and shared examples to ensure codes were descriptive and not interpretative or influenced by the review author’s own perspectives on the topic. While coding, the review’s author noted down reflections and themes which appeared to be emerging from the data. Codes were transferred into a Microsoft Excel spreadsheet where they were grouped by meaning, leading to the development of descriptive themes. Post-it notes and diagrams were used to consider how the descriptive themes linked to one another. Finally, the review’s author met with the supervisory team and presented the descriptive themes. From these, the analytical themes were developed, and a diagram was created to illustrate how these linked together. The following images illustrate the steps outlined above:

• Screenshots taken to illustrate line-by-line coding
• Screenshots taken to illustrate grouping codes into descriptive themes (key included below)
• Images of the diagrams created to illustrate how descriptive themes linked together
• Image of the diagram created to illustrate how analytic themes link together

When grouping codes into descriptive themes, a key was used to keep track of which codes related to which study. Codes in bold relate to data collected from women ECT recipients and
codes in *italics* relate to data collected from staff members. The following text colours were used to represent codes relating to each study:

- Clark et al. (2018)
- Duxbury et al. (2018)
- Ejaredar and Hagen (2013)
- Ejaredar and Hagen (2014)
- Gass (2008)
- Kring et al. (2018)
- Lonergan et al. (2021)
- Orr & O’Connor (2005)
- Stevens & Harper (2007)
- Van Daalen-Smith (2011)
Example 1 of line-by-line coding (data extracted from Clark et al., 2018):

Kate was given the ‘dysfunctional computer’ analogy, as a way of providing information about ECT:

> They said, “Your brain’s a computer. ECT’s like a reboot system.” I remember them saying that they really don’t know how it works; they just know that after a person feels they are usually well mentally. Other than that, there wasn’t that much they told me. (Kate)

Robyn, on the other hand, gave the hospital the benefit of the doubt:

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

I had no other choice

Many of the women described feeling that ECT was their only option. They had all tried various medications, describing conversations with their doctors in which ECT was offered as the final treatment available. Pauline described it as the last available option:

> This was the last resort. I didn’t have much of a choice about it. I had to be okay with it because there wasn’t any other door open. The decision was made for me. This was the way it was going to be. (Pauline)

Margaret expressed anger for giving in to the doctor’s decision-making and not having her own wishes heard. She had received previous ECT, and she had made herself a promise never to repeat it:

> I hated the idea. Last time was so awful. But they said, “If you don’t do this, them what do you want from us?” And I hated the fact that I was doing something I had promised myself I would never do again. (Margaret)
Example 2 of line-by-line coding (data extracted from Duxbury et al., 2018):

Advocating The participants talked about times when the patient did not have capacity or when the patient complied with a consultant’s decision even if they did not agree with it:

“I want to do the best job that I can... And if that means standing up to a consultant because we have been advocates for patients in the past and it hasn’t all been smooth” (P2, Specialist ECT Nurse).

Participants also talked about how some people, particularly older patients, would never challenge the views of the psychiatrists and even if they did have capacity they would often go along with what the consultant was saying. In these situations, the participants felt they had to advocate on behalf of the patient. This was driven by a need to either promote the patient’s autonomy, or promote the participant’s opinion over the decision made because they felt it was in the patient’s best interests to make their own decisions:

Reassure/persuade A patient may have held the power to say no to the treatment; however sometimes the participants still believed the treatment was the best option for the patient. In these situations, many of the participants saw a main part of their role being to reassure patient ECT was a good treatment choice including showing people around the ECT suite “we also facilitate patients coming down to the unit before they are treated so they can have a look around if necessary” (P2, Specialist ECT Nurse); alleviating stigma “well first off it is trying to alleviate the stigma of ECT: the myth about it being a painful process which it is not” (P4, Consultant Psychiatrist), and talking people carefully through the process:
Example 1 of codes being grouped into descriptive themes:

151
Example 2 of codes being grouped into descriptive themes:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>34</td>
<td>Power and choice - whose decision?</td>
<td>Staff perspectives on relationships with patients</td>
</tr>
<tr>
<td>35</td>
<td>[W199] Power and choice are critical in understanding experiences of ECT</td>
<td>Importance of relationship</td>
</tr>
<tr>
<td>36</td>
<td>[W414] An explanation of the treatment was not provided to the patient</td>
<td>[W106] Nurse describes the presence throughout the ECT process</td>
</tr>
<tr>
<td>37</td>
<td>[W177] Patient's idea of ECT</td>
<td>[W190] Nurse described the journey (decision, treatment, recovery)</td>
</tr>
<tr>
<td>38</td>
<td>[W454] Recipient felt she didn't need ECT</td>
<td>[W189] Nurse-patient relationship understood as a continuum - from close to unresponsive, nurse is present</td>
</tr>
<tr>
<td>39</td>
<td>[W53] Recipient and doctors felt differently (about having ECT)</td>
<td>[W159] Nurse-patient relationship - between two extremes (close/unresponsive), nurse is present</td>
</tr>
<tr>
<td>40</td>
<td>[W323] Recipient did not agree with doctor about needing ECT</td>
<td>[W159] Staff nurse-patient relationship - does, nurse reveals more of themselves</td>
</tr>
<tr>
<td>41</td>
<td>[W338] Recipient didn't think she needed ECT</td>
<td>[W159] Engaged nurse-patient relationship - nurse is exposed and visible</td>
</tr>
<tr>
<td>42</td>
<td>[W458] At time of ECT - overwhelmed with life situation, not depressed or suicidal</td>
<td>[W159] Way the nurse takes on their relational and treatment roles is influenced by whether they are detached/present/engaged in the patient experience</td>
</tr>
<tr>
<td>43</td>
<td>[W453] Felt ECT was not what she needed when she asked for help</td>
<td></td>
</tr>
<tr>
<td>44</td>
<td>[W106] Was reluctant to agree to ECT</td>
<td></td>
</tr>
<tr>
<td>45</td>
<td>Didn't have a choice</td>
<td>Understanding, empathising, engaging</td>
</tr>
<tr>
<td>46</td>
<td>[W106] Not much of a choice (about having ECT)</td>
<td>Trying to understand the recipient's perspective</td>
</tr>
<tr>
<td>47</td>
<td>[W24] Not having a say/choice (about the decision to have ECT)</td>
<td>[W190] Engaged nurses develop an understanding of the patient's perspective</td>
</tr>
<tr>
<td>48</td>
<td>[W110] Recipient told she had no choice</td>
<td>[W159] Engaged nurse came to understand the patient's world</td>
</tr>
<tr>
<td>49</td>
<td>[W376] ECT seen as something you had to do</td>
<td>[W190] Nurse, trying to imagine being in the patient's position</td>
</tr>
<tr>
<td>50</td>
<td>[W376] Not experienced as being a choice - you had to go'</td>
<td>[W190] Engaged nurses empathise with patient's experience of treatment</td>
</tr>
<tr>
<td>51</td>
<td>[W375] Recipients signed consent forms but didn't feel they had a choice (reg. having ECT)</td>
<td>[W190] Sense of the nurse being with the patient through the process</td>
</tr>
<tr>
<td>52</td>
<td>It was their decision</td>
<td>[W290] Engaged nurses try to understand and empathise with the patient's experience of ECT</td>
</tr>
<tr>
<td>53</td>
<td>[W43] Not recipient's decision (to have ECT)</td>
<td>[W190] Nurses trying to be approachable - someone the patient can talk to</td>
</tr>
<tr>
<td>54</td>
<td>[W107] Recipient felt it wasn't their decision (to have ECT)</td>
<td>[W240] An 'engaged' nurse would communicate more directly with the patient and ensure their needs are met</td>
</tr>
<tr>
<td>55</td>
<td>[W353] Healthcare professionals had ultimate control regarding decisions</td>
<td>[W262] Engaged nurse - seeks interaction with patient</td>
</tr>
<tr>
<td>56</td>
<td>[W167] Felt they couldn't influence decisions about their care</td>
<td>[W190] Nurse, trying to support</td>
</tr>
<tr>
<td>57</td>
<td>No alternative to ECT</td>
<td>[W126] Nurses supporting patients while they wait for ECT treatment (e.g. distraction)</td>
</tr>
<tr>
<td>58</td>
<td>[W117] ECT was the only option</td>
<td>[W127] Different ways nurses reduce tension while patient is waiting for ECT</td>
</tr>
<tr>
<td>59</td>
<td>[W232] ECT was the only option - had to accept it</td>
<td>[W138] Nurses trying to make patients less anxious and reduce tension</td>
</tr>
<tr>
<td>60</td>
<td>[W259] Staff asked how they could help her otherwise (if she didn't have ECT)</td>
<td>[S179] Meeting the patient beforehand (so they know that ECT nurse)</td>
</tr>
<tr>
<td>61</td>
<td>[W342] ECT presented as the only option</td>
<td>[S332] ECT staff invite patients to see ECT dept</td>
</tr>
<tr>
<td>62</td>
<td></td>
<td>[S174] Patients observed to have lots of contact with the ECT team</td>
</tr>
</tbody>
</table>

152
Example 3 of codes being grouped into descriptive themes:
Example 4 of codes being grouped into descriptive themes:

<table>
<thead>
<tr>
<th>A</th>
<th>B</th>
</tr>
</thead>
<tbody>
<tr>
<td>298</td>
<td>[213] Persisting patient to go through with ECT only if support (talk them through it)</td>
</tr>
<tr>
<td>299</td>
<td>[227] Nurses made efforts to maintain patient dignity surrounding ECT</td>
</tr>
<tr>
<td>300</td>
<td><strong>Staff power hierarchies</strong></td>
</tr>
<tr>
<td>301</td>
<td><strong>Team decision</strong></td>
</tr>
<tr>
<td>302</td>
<td>[212] Person does not have capacity - MDT decision about whether to deliver ECT</td>
</tr>
<tr>
<td>303</td>
<td>[210] Consultants describe collaborative decision with MDT (re giving ECT)</td>
</tr>
<tr>
<td>304</td>
<td>[210] Consultant couldn’t recall disagreeing with nursing staff on decision to give ECT</td>
</tr>
<tr>
<td>305</td>
<td>[210] Consultant couldn’t recall disagreeing with nursing staff on decision to give ECT</td>
</tr>
<tr>
<td>306</td>
<td>[212] Consideration for safety, particularly men and women</td>
</tr>
<tr>
<td>307</td>
<td>[212] Consideration for safety, particularly men and women</td>
</tr>
<tr>
<td>308</td>
<td>[212] Different staff hold different amounts of power</td>
</tr>
<tr>
<td>309</td>
<td>[212] More power = more likely decision will be followed</td>
</tr>
<tr>
<td>310</td>
<td>[212] Some individuals in team have more influence over whether ECT is given to someone without capacity to make decision</td>
</tr>
<tr>
<td>311</td>
<td><strong>Different opinions among staff</strong></td>
</tr>
<tr>
<td>312</td>
<td>[210] Nurses had a variety of opinions regarding ECT</td>
</tr>
<tr>
<td>313</td>
<td>[210] Nurses had a variety of opinions regarding ECT</td>
</tr>
<tr>
<td>314</td>
<td>[210] Nurses would never prescribe ECT</td>
</tr>
<tr>
<td>315</td>
<td>[210] Good ECT nurse aware of some consultants who don’t prescribe ECT</td>
</tr>
<tr>
<td>316</td>
<td>[210] Staff had mixed views on not prescribing ECT - depriving of potentially helpful treatment vs withholding a harmful treatment</td>
</tr>
<tr>
<td>317</td>
<td>[210] Some staff felt ECT was not the best option for the person</td>
</tr>
<tr>
<td>318</td>
<td>[213] Some staff commented on how ECT is controversial</td>
</tr>
<tr>
<td>319</td>
<td>[213] Nurses expressed opinion about ECT - not confident either way (for or against)</td>
</tr>
<tr>
<td>320</td>
<td>[213] Nurses expressed reservations about use of ECT</td>
</tr>
<tr>
<td>321</td>
<td>[213] Doing views on ECT in nursing - some against it, some frustrated with those who are against it</td>
</tr>
<tr>
<td>322</td>
<td>[213] Nurse questioning if there was an alternative to ECT</td>
</tr>
<tr>
<td>323</td>
<td><strong>Doctor/consultant holds the power</strong></td>
</tr>
<tr>
<td>324</td>
<td>[212] Doctor/consultant was confident in his decision to give ECT when no capacity to consent</td>
</tr>
<tr>
<td>325</td>
<td>[212] Consultant psychiatrist was ultimate power in ECT decision-making process (person does not have capacity to make decision)</td>
</tr>
<tr>
<td>326</td>
<td>[212] Intent to which a team decision is made (about giving ECT to a person without capacity to consent) depends on whether psychiatrist</td>
</tr>
<tr>
<td>327</td>
<td>[212] Psychiatrists are responsible clinician - may not take account of others’ opinions</td>
</tr>
<tr>
<td>328</td>
<td>[212] Consultants describe selves as ultimately responsible for decision to give ECT</td>
</tr>
<tr>
<td>329</td>
<td>[212] Consultant seen as having the answers (by other team members)</td>
</tr>
<tr>
<td>330</td>
<td>[212] Doctor viewed as the expert and so their perspective on ECT is given more weight</td>
</tr>
<tr>
<td>331</td>
<td><strong>Nurses lacking power</strong></td>
</tr>
<tr>
<td>332</td>
<td>[212] Nurses conflicted with taking nurse’s ECT is effective when there isn’t enough evidence that it will be effective</td>
</tr>
<tr>
<td>333</td>
<td>[212] Nurses conflict with taking nurse’s ECT is effective when there isn’t enough evidence that it will be effective</td>
</tr>
<tr>
<td>334</td>
<td>[212] Nurses conflict with taking nurse’s ECT is effective when there isn’t enough evidence that it will be effective</td>
</tr>
<tr>
<td>335</td>
<td>[212] Nurses conflict with taking nurse’s ECT is effective when there isn’t enough evidence that it will be effective</td>
</tr>
</tbody>
</table>

*Note: All codes are linked to specific sections of the paper.*
Example 5 of codes being grouped into descriptive themes:

- **Life after ECT/The impact of ECT**
  - **Negative impact of ECT**
    - General, physical, psychological, cognitive, work/education
      - Majority of the women spoke about negative side effects of ECT
      - Women initially described ECT as neutral
      - More information about ECT impact given as women discussed this further
      - Women initially described ECT as having minimal impact but then described more of an impact as the interview progressed
      - Struggling to move past the experience (hospital/meds/ECT)
      - Not having a life because of ECT
      - Debilitating side effects after ECT
      - Struggling to connect with life after ECT
      - Life after ECT - 'going through the motions'
      - During everything (in process of ECT)
      - Life was going well before ECT (career, health, intelligence)
      - Trust in oneself after ECT
      - Women who had ECT in the past defined as 'shock survivors'
      - Women believe she has experienced those negative side effects as a result of something doctors did to her
      - Described harmful side effects of ECT - memory loss, confusion, headaches, nausea
      - Nurse mentions ECT side effects (memory loss, muscle pain)
      - Psychiatric registrar describes patient and relatives as confused about cause of behaviour after ECT
      - Psychiatric registrar comments that relatives and patients might blame ECT for things caused by their 'stress' (e.g. memory loss)
      - Psychiatric registrar suggests patients behaviour following ECT could be result of ECT or their 'stress'

- **Physical**
  - Damage to CV system after ECT
  - Physical damage of ECT
  - Ongoing pain and mobility problems following dissociated lens during ECT
  - Physical side effects - dry mouth, feeling weak
Example 6 of codes being grouped into descriptive themes:

<table>
<thead>
<tr>
<th>Codes</th>
<th>Thematic Area</th>
</tr>
</thead>
<tbody>
<tr>
<td>[W461]</td>
<td>Loss of career after ECT</td>
</tr>
<tr>
<td>[W462]</td>
<td>Memory and identity - losing connections to self and others</td>
</tr>
<tr>
<td>[W463]</td>
<td>Memory loss following ECT</td>
</tr>
<tr>
<td>[W464]</td>
<td>Memory difficulties after ECT - having to write everything down to remember</td>
</tr>
<tr>
<td>[W465]</td>
<td>Loss of memory after ECT - making her forget everything/everyone</td>
</tr>
<tr>
<td>[W466]</td>
<td>ECT took away ability to tell stories of their lives</td>
</tr>
<tr>
<td>[W467]</td>
<td>Feeling numb and forgetful after ECT</td>
</tr>
<tr>
<td>[W468]</td>
<td>Doctor asked why it mattered that ECT was causing memory loss</td>
</tr>
<tr>
<td>[E380]</td>
<td>Psychiatric patient speaks about patient who lost memories of holidays after ECT</td>
</tr>
<tr>
<td>[W114]</td>
<td>Short-term/lung term</td>
</tr>
<tr>
<td>[W115]</td>
<td>Memory loss after ECT (destroyed)</td>
</tr>
<tr>
<td>[W465]</td>
<td>Described lasting effects of memory loss after ECT treatment</td>
</tr>
<tr>
<td>[W464]</td>
<td>Recollection of memory loss after first ECT treatment but then memory gradually improved</td>
</tr>
<tr>
<td>[W469]</td>
<td>Temporary memory loss following ECT treatment</td>
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<tr>
<td>[W460]</td>
<td>Losing memory of whole period of time (after ECT)</td>
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A1: The decision to have ECT
Example 7 of codes being grouped into descriptive themes:

Positive impact of ECT (links with ‘ECT will make you better’) - staff

Positive impacts observed by staff

Staf[d attached experience of seeing ECT improve recipient’s mood

Staff had direct experience of seeing ECT dramatically improve patient’s mood

Defining effectiveness of ECT - eating/drinking again

Defining effectiveness of ECT - motivated to engage with life

Staff observed ECT help people who were really struggling

Staff member observed immediate improvement in recipient’s mood and interactions after ECT

Encouraged to be a successful treatment

Staff observed positive change for patient following ECT

ECT observed to be more effective for older people

ECT observed to improve quality of life for older people

ECT team as ‘making a difference’

ECT team as meaningful in their work

ECT staff spoke about witnessing a tangible benefit for patients

ECT staff spoke about ECT recipients returning them for ‘giving their life back’

ECT staff observed positive impact of ECT on mood but still had concerns about ECT

ECT staff commented on seeing positive effects of ECT

ECT staff observed improvement in mood and daily functioning after ECT

Step-perspective of themselves helping others with ECT

ECT staff saw themselves as part of the team who ‘found’ the person with ECT

ECT staff saw themselves as part of the team who guided the person to help with ECT

ECT staff felt they had changed lives and given people their ‘life back’

ECT staff commented they had helped patients get ‘better’ and ‘improve quality of life with ECT”

Staff described previous negative views on ECT

Negative view of ECT at beginning of training career

Negative view of ECT prior to working in ECT unit

Negative view of ECT when first started working at the hospital

Negative view of ECT before working at the hospital

Negative view of ECT about giving ECT to older woman

Questioned whether it was the right thing

Change in staff attitudes towards ECT after seeing effects

Prior negative views about ECT were based on stigma and limited knowledge of ECT

Experienced change in their attitude towards ECT when they were exposed to the treatment and it’s unseen

Attitude towards ECT changed when they saw people with severe depression ‘recover’ after ECT

No longer had doubts about ECT after observing effects on patient’s mood

Observations of ECT as beneficial weakened staff members’ initial concerns about the treatment

Observing physical changes in patients following ECT challenged staff members’ initial doubts about ECT

More positive after seeing this in practice
Example 8 of codes being grouped into descriptive themes:
Example 9 of codes being grouped into descriptive themes:
Example 10 of codes being grouped into descriptive themes:

<table>
<thead>
<tr>
<th>A1</th>
<th>B</th>
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<tr>
<td>The decision to have ECT</td>
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</table>

**Distress and desperation - link with capacity**

- [W034] Recipients describe context of distress (sometimes described medically, sometimes not) and seeking support
- [W035] Recipients had experienced 'severe mental illness' and suicide attempts
- [W036] Recipients described 'mental illness'
- [W037] Recipients described 'mental illness'
- [W038] Recipients described 'mental illness'
- [W039] Recipients described 'mental illness'
- [W040] Recipients described 'mental illness'
- [W041] Recipients described 'mental illness'
- [W042] Recipients described 'mental illness'
- [W043] Recipients described 'mental illness'

**Depression**

- [W044] Depressed described as 'feeling overwhelmed due to life situation at time of having ECT'
- [W045] Antidepressants prescribed as 'new drug'
- [W046] Antidepressants prescribed as 'new drug'
- [W047] Antidepressants prescribed as 'new drug'
- [W048] Antidepressants prescribed as 'new drug'
- [W049] Antidepressants prescribed as 'new drug'
- [W050] Antidepressants prescribed as 'new drug'

**Treating depression**

- [W051] Treating depression with antidepressants
- [W052] Treating depression with antidepressants
- [W053] Treating depression with antidepressants
- [W054] Treating depression with antidepressants
- [W055] Treating depression with antidepressants
- [W056] Treating depression with antidepressants
- [W057] Treating depression with antidepressants
- [W058] Treating depression with antidepressants

**Accepting help with depression**

- [W059] Accepting help with depression was difficult
- [W060] Accepting help with depression was difficult
- [W061] Accepting help with depression was difficult
- [W062] Accepting help with depression was difficult
- [W063] Accepting help with depression was difficult
- [W064] Accepting help with depression was difficult
- [W065] Accepting help with depression was difficult
- [W066] Accepting help with depression was difficult

**Seeking support**

- [W067] Seeking help from family and professionals
- [W068] Seeking help from family and professionals
- [W069] Seeking help from family and professionals
- [W070] Seeking help from family and professionals
- [W071] Seeking help from family and professionals
- [W072] Seeking help from family and professionals
- [W073] Seeking help from family and professionals
- [W074] Seeking help from family and professionals

**Turning to healthcare system**

- [W075] Turning to healthcare system for support with depression
- [W076] Turning to healthcare system for support with depression
- [W077] Turning to healthcare system for support with depression
- [W078] Turning to healthcare system for support with depression
- [W079] Turning to healthcare system for support with depression
- [W080] Turning to healthcare system for support with depression
- [W081] Turning to healthcare system for support with depression
- [W082] Turning to healthcare system for support with depression

**Initial resistance to help**

- [W083] Initial resistance to help with depression
- [W084] Initial resistance to help with depression
- [W085] Initial resistance to help with depression
- [W086] Initial resistance to help with depression
- [W087] Initial resistance to help with depression
- [W088] Initial resistance to help with depression
- [W089] Initial resistance to help with depression
- [W090] Initial resistance to help with depression

**Help to manage depression seen as essential**

- [W091] Help to manage depression seen as essential
- [W092] Help to manage depression seen as essential
- [W093] Help to manage depression seen as essential
- [W094] Help to manage depression seen as essential
- [W095] Help to manage depression seen as essential
- [W096] Help to manage depression seen as essential
- [W097] Help to manage depression seen as essential
- [W098] Help to manage depression seen as essential

**Accessing help with depression**

- [W099] Accessing help with depression was difficult
- [W100] Accessing help with depression was difficult
- [W101] Accessing help with depression was difficult
- [W102] Accessing help with depression was difficult
- [W103] Accessing help with depression was difficult
- [W104] Accessing help with depression was difficult
- [W105] Accessing help with depression was difficult
- [W106] Accessing help with depression was difficult

**Strategies for managing depression**

- [W107] Strategies for managing depression
- [W108] Strategies for managing depression
- [W109] Strategies for managing depression
- [W110] Strategies for managing depression
- [W111] Strategies for managing depression
- [W112] Strategies for managing depression
- [W113] Strategies for managing depression
- [W114] Strategies for managing depression
Diagram illustrating first main descriptive theme – the decision to have ECT:

Post-it notes illustrating first main descriptive theme – the decision to have ECT:
Diagram illustrating second main descriptive theme – having ECT:

Post-it notes illustrating second main descriptive theme – having ECT:
Diagram illustrating third main descriptive theme – life after ECT/the impact of ECT:

Post-it notes illustrating third main descriptive theme – life after ECT/the impact of ECT:
Diagram illustrating how descriptive themes linked together:

Diagram illustrating analytic themes and how these linked together:
Appendix L

Additional Quotes Illustrating Themes

Power in the ECT experience – before ECT

Women recipients:

- This was the last resort. I didn’t have much of a choice about it. I had to be okay with it because there wasn’t any other door open. The decision was made for me. This was the way it was going to be. (Clark et al., 2018, p. 1080)
- I hated the idea. Last time was so awful. But they said, ‘If you don’t do this, then what do you want from us?’ ... I hated the fact that I was doing something I had promised myself I would never do again. (Clark et al., 2018, p. 1081)
- Another way that participants felt ‘powered over’ into have ECT was the manner in which ECT was pitched to them as their only choice. (Ejaredar & Hagen, 2014, p. 34)
- It (ECT) was just something that you had to go through. Well they came for you and that was that. You couldn’t, what could you do? You had to go... But I don’t remember having been asked if I wanted it done. (Orr & O’Connor, 2005, p. 29)
- I reluctantly agreed to this procedure being ignorant about the risks. (van Daalen-Smith, 2011, p. 463)
- I think I was pretty resolved to what they were going to do, regardless of what I thought. It wasn’t what I wanted. I just went along with it. (Clark et al., 2018, p. 1081)
- None of the participants questioned the ultimate control of the health professional in making decisions on her behalf in relation to their depression and if efforts were made by health professionals to involve the women, these efforts were unseen by the women. (Orr & O’Connor, 2005, p. 27)
- They talked about ECT. I just accepted it. I didn’t make a fuss or say, ‘I’m not that bad,’ or anything like that. I figured they must have known better than me so I went along with it. (Clark et al., 2018, p. 1081)
- Every health care professional associated with psychiatry with whom the women were involved either believed that ECT was a good thing, a necessary thing, or didn’t acknowledge if they didn’t. (van Daalen-Smith, 2011, p. 463)
- I’m really frustrated, you know, because looking back on it, he pushed me into it. I had my doctor saying ‘you gotta do it, we’ve run out of any other options.’ You know, he was really pushing me in that direction. (Ejaredar & Hagen, 2014, p. 34)
- I was raised thinking that doctors know best, you know? They went to university, they were smart people. I was frightened and despairing, so I just went along with whatever they told me to do. (Clark et al., 2018, p. 1081)
- Ultimately, however, despite this questioning of expert knowledge, both these women did concede to the belief in the expert knowledge of the health care team and the necessity of deferring to them. (Orr & O’Connor, 2005, p. 26)
- He really screwed me over, when I think about it. He never really gave me any information about memory loss; he just said ‘here, if you do this, you’re going to feel way better.’ (Ejaredar & Hagen, 2014, p. 33)
- They consistently described receiving very little information about side effects such as memory loss. (Clark et al., 2018, p. 1080)
I think because I’d had it before they didn’t think I needed any more information, they didn’t need to talk to me about it anymore. That’s how it seemed, because I didn’t get any information. (Clark et al., 2018, p. 1080)

Most participants stated that they were given little knowledge about ECT before the procedure. Therefore, participants had little capacity and power to make a truly informed decision about whether or not to have ECT. (Ejaredar & Hagen, 2014, p. 33)

Two other women, when asked what they were told about ECT, couldn’t remember. (van Daalen-Smith, 2011, p. 463)

In order to understand the ECT experience, all of the women felt it was imperative to first contextualize it within the broader depression experiences. For all, the depression was presented as a powerful, unexpected and all-consuming force that descended upon them suddenly and seemingly without warning. (Orr & O’Connor, 2005, p. 24)

Sandra had experienced depression since childhood and because a myriad of medication combinations didn’t work, shock was suggested and agreed to ‘as a last resort.’ (van Daalen-Smith, 2011, p. 461)

Linda explained that she was not depressed or suicidal. She was overwhelmed with a 3- and a 6-year-old and an uncertain future. She asked for help and told me ‘ECT? That’s not what I needed.’ (van Daalen-Smith, 2011, p. 461)

Carla gave voice to this sense of desperation and vulnerability: ‘when they suggested ECT, it was pretty much, I was just desperate, and I was willing to do whatever they told me to do.’ (Ejaredar & Hagen, 2014, p. 34)

First, these women felt entirely powerless to combat the depression and were desperate for help. Second, in seeking help, the women gained the impression of being supported but ironically relinquished further power. (Orr & O’Connor, 2005, p. 28)

She explained that she felt like she was taking a risk doing shock ‘because nobody knows what the end result will be. But I have suffered from depression for probably close to 30 years, so I’ll try anything to feel better.’ (van Daalen-Smith, 2011, p. 461)

Staff members:

There also seemed to me, people who were disenfranchised in some ways got ECT sooner than other people so people without advocacy, people without family, they got ECT sooner than other people so that made me uncomfortable. (Duxbury at al., 2018, p. 790)

I remember a few clients stating that ‘they would try anything,’ and that ‘the doctor thinks this is best.’ I just remember the women always seeming so very vulnerable. (van Daalen-Smith, 2011, p. 466)

If somebody came through the door and erm, er, they disagreed they would get sent back to the ward. (Gass, 2008, p. 195)

There was certainty in all of the participants’ accounts that if a patient had capacity then it was for the patient to make the decision to have ECT or not. (Duxbury at al., 2018, p. 789)

Ways to ensure patients had more ‘say’ in their treatment included offering advocacy and having more family carer involvement. (Duxbury at al., 2018, p. 790)

Some of the nurses commented on their need to advocate for the dignified treatment of ‘their’ patients. (van Daalen-Smith, 2011, p. 466)

There was a sense from the participants that patients had greater control of their ECT treatment as they retained the capacity to choose to stop or continue. (Lonergan et al., 2021, p. 313)
• A patient may have held the power to say no to the treatment; however sometimes the participants still believed the treatment was the best option for the patient. (Duxbury at al., 2018, p. 790)
• You would hope to get someone to agree, first and foremost or like you’ve got to go through a section. (Gass, 2008, p. 194)
• I think at the time it probably is the right treatment to do from a life-saving point of view. (Duxbury at al., 2018, p. 789)
• ECT was thus constructed not only as a reasonable intervention, but also an obvious one because it was viewed as fast-working and effective. (Stevens & Harper, 2007, p. 1480)
• They were sure that the work they were doing was beneficent, and for the most part believed strongly in ECT’s efficacy and ethics. (van Daalen-Smith, 2011, p. 467)
• Well first off it is trying to alleviate the stigma of ECT: the myth about it being a painful process which it is not. (Duxbury at al., 2018, p. 790)
• When ECTs mentioned, they (family) have heard horror stories… through media or through word of, of how terrible this thing is… and how barbaric it is and everything … which is a pity because it delays the progress. (Lonergan et al., 2021, p. 314)
• I think there is a lot of stigma around it and I think especially with films and what they have seen. It’s completely different and they can go and have a look around the ECT suite if they want to, they can have all that information so they can see it’s not this barbaric treatment. (Duxbury at al., 2018, p. 790)
• Providing details about the ECT process and responding to patients’ questions and concerns. (Gass, 2008, p. 194).
• The ECT department staff spoke about trying to ensure that the patient and their families are provided with evidence-based information including references and invitations to visit the ECT department and attend family meetings to allay their fears and address any questions they may have. (Lonergan et al., 2021, p. 314)
• Nurse Sidney stated that their ‘health teaching’ was done so that the patient could decide if ECT was for them, stating ‘we don’t try to push it on them,’ and that after the health-teaching, patients could either consent or refuse. (van Daalen-Smith, 2011, p. 466)
• It’s hard for them to perceive why it’s happening especially if it’s the first time it’s happened so you’re trying to break it down into chunks. (Gass, 2008, p. 194)
• Many participants felt challenged by the experience of patients and family members not having clear explanations of how ECT treatment works. (Lonergan et al., 2021, p. 313)
• This nurse indicates he cannot be as honest as he would like. It appears that his own experience contradicts what he is able to convey to the patient about the treatment. In this way he covers up or masks his own beliefs about what may happen. (Gass, 2008, p. 198)
• The majority of the participants spent most of the interview discussing ECT in regards to life-threatening situations or in regards to severely distressed people who were ‘stuck’ in their distress. (Duxbury at al., 2018, p. 788)
• For example, asked who was most likely to receive ECT, Dr. A responded ‘patients with severe depression who may be in a depressive stupor — that means that they’re sort of bed-bound, immobile, not eating not drinking’. (Stevens & Harper, 2007, p. 1479)
• Most stated that ECT was for patients with severe depression for whom medications don’t work. (van Daalen-Smith, 2011, p. 466)
• Feelings associated with nursing or caring for a person in so much distress was also distressing and appeared to be a factor that influenced how people made their decision. (Duxbury at al., 2018, p. 789)
• This participant had felt that had this man received ECT earlier, then he would not have been subject to the same loss of dignity in his personhood. This concern was expressed by
several participants who found it challenging to observe severely depressed older patients decline both physically and mentally. (Lonergan et al., 2021, p. 313)

- I think it comes down to the personality of the consultant and whether that is someone who values the skill, experience, opinion of their team because my experience of working on the wards is that some consultants really appreciate and absorb that and others don’t. (Duxbury et al., 2018, p. 789)
- All the consultants in the study stated they were ultimately responsible for the decision. However, they also suggested the decision to give ECT was made in collaboration with their MDT and felt there were never disagreements around the decision. (Duxbury et al., 2018, p. 789)
- The decision to treat with the support of the multidisciplinary team is medical, but nurses make it happen, albeit acting in a subordinate role to medical authority. (Gass, 2008, p. 195)

**Power in the ECT experience – during ECT**

*Women recipients:*

- One of the women who was in the middle of her ECT series described being hopeful. (van Daalen-Smith, 2011, p. 463)
- One woman spoke of the anxiety and discomfort on the day of her treatments. (van Daalen-Smith, 2011, p. 462)
- She explained that she felt like she was taking a risk doing shock ‘because nobody knows what the end result will be.’ (van Daalen-Smith, 2011, p. 461)
- I feared that I was gonna lose my mind, and that the ECT would destroy my brain the way it had my mother’s. (Ejaredar & Hagen, 2013, p. 150)
- Bonnie also described being scared before ECT, simply stating: ‘I was scared . . . that I might not wake up, that I might lose my memory, like a big gap.’ (Ejaredar & Hagen, 2013, p. 151)
- The feeling when they put the needle in you, you start feeling like you want to throw-up. And then they cover your mouth and you feel like you’re choking. (Orr & O’Connor, 2005, p. 30)
- I was petrified of when they, you know, put this mask over your face, you feel like choking, it’s an awful feeling .... Ya, and I felt every time I had one I felt terrified but then I thought you know this is the only way I’m going to get out of this depression! (Orr & O’Connor, 2005, p. 32)
- In particular, the preparation for the ECT was distressing for three of the women. (Orr & O’Connor, 2005, p. 30)
- Well, I remember, there’s like the whole bunch of us that all got it done at the same time – they scheduled it that way. And we were all lined up kinda like a train. And we had to all wait, and then they took turns knocking us all out. (Ejaredar & Hagen, 2014, p. 34)
- Well, when I think about it, it’s actually kind of sad. But when they put you under, I always looked forward to that, because it was so peaceful. Like, cause you’re just so relaxed and there’s absolutely nothing. So I remember looking forward to being put out – it was my only relief. That’s why I did it. (Ejaredar & Hagen, 2014, p. 34)
- They just stick an IV in you, knock you out, and then you wake up tired. (Ejaredar & Hagen, 2014, p. 33)
- After I go home after the ECT, I’m wiped out. (van Daalen-Smith, 2011, p. 462)
• In several interviews when participants were asked about trust in the health care professionals, they initially discussed the importance of knowledge and abilities but usually ended up equating trust with how well they got along with the medical professional. (Orr & O’Connor, 2005, p. 27)
• Discussing her relationship with her physician, one woman commented that ‘And Dr. [name], I mean she’s a very...knowledgeable person, so you know I rely on, I trust her...I’m sure I get along good with her. I always feel comfortable with her...’. (Orr & O’Connor, 2005, p. 27)
• Their nurses were their supports and their doctors their partners in health. (van Daalen-Smith, 2011, p. 463)
• The two women currently receiving ECT as outpatients, experienced their nurses as key supports and educators: ‘They answer my questions, reassure me, and explain what will happen on the day of my treatment.’ (van Daalen-Smith, 2011, p. 464)
• There were nurses who were horrified at what was happening to me...the deterioration of my health, personality, life. I’ve been told that two nurses quit during or shortly after my experience because they could no longer stand by. (van Daalen-Smith, 2011, p. 464)
• Fran’s experience with nurses was different and quite negative. She didn’t feel any degree of support from them and explained circumstances where she asked for Tylenol after ECT and was yelled at for ‘asking for attention’ and ‘focusing on yourself and your symptoms.’ (van Daalen-Smith, 2011, p. 464)

Staff members:

• In general, the nurses concerned themselves with the physical monitoring of women receiving electroshock, be that just before, during, or upon returning to the ward, ‘completing the checklists as we would any surgical patient.’ (van Daalen-Smith, 2011, p. 466)
• This specialist technical and supportive role enhances the differences between the ECT nurse and other nursing colleagues. (Gass, 2008, p. 195)
• Although nurses are required to attend treatment with the patient establishing a role is difficult within the ‘treatment culture’ of the ECT environment. (Gass, 2008, p. 196)
• We’re just so task orientated. How can I save myself some time because I’m going to have other jobs to do? (Lonergan et al., 2021, p. 313)
• One effect of the ‘life-saving’ repertoire was to sanction the use of ECT under conditions of compulsory psychiatric treatment (i.e., without requiring recipients’ consent). This was termed ‘emergency ECT’ by participants. (Stevens & Harper, 2007, p. 1480)
• It makes you feel terrible because you’re physically manhandling somebody. (Gass, 2008, p. 196)
• For some, the dilemma is recognising that forcible intervention is wrong but that nothing can be done about it. There is no control of the situation; the prescription of the treatment is a medical and multidisciplinary team matter and nurses are required to get the patient to the treatment. Not only does the patient experience powerlessness in this situation but so does the nurse. (Gass, 2008, p. 196)
• Me being with somebody, not just physically being with somebody but being with somebody in your head. (Gass, 2008, p. 197)
• We try to give them as much reassurance as possible. That also is, it’s like, a face to face so they will have, so that they will know us when they are here. (Duxbury at al., 2018, p. 790)
One participant reflected that this tendency towards being task-oriented meant that nurses could become nonchalant when escorting patients in the waiting room to be called for ECT. He felt it was important to remain conscious of what the patient may be experiencing. (Lonergan et al., 2021, p. 313)

Comfort measures were mentioned as well as ensuring patients understood ‘what they were here for,’ or ‘what had just happened to them.’ (van Daalen-Smith, 2011, p. 466)

However, putting themselves in the patients’ position, seeking to understand their experience evokes strong feelings; particularly when nurses become cognisant of their own feelings about the patients’ existential state. (Gass, 2008, p. 197)

It is characterised by the distancing technique adopted by professionals aware of the potential emotional difficulties of getting too close to the patient. These nurses act in a manner that avoids internalising feelings from the patient. (Gass, 2008, p. 198)

I sometimes think that because we're here working here we're a bit blasé. (Lonergan et al., 2021, p. 313)

Some nurses discussed how many of their colleagues didn’t want ECT duties on a given shift, and that switching shifts frequently occurred with others who ‘didn’t mind.’ (van Daalen-Smith, 2011, p. 467)

Life after ECT – women recipients

Of the nine women interviewed, only three women expressed positive views and were able to identify specific benefits associated with ECT. (Ejaredar & Hagen, 2013, p. 148)

One of the consequences, of course, is that you get well! (Kring et al., 2018, p. 361)

She had received six treatments and stated her mood seemed to be better. (van Daalen-Smith, 2011, p. 461)

Ruth explained feeling lighter for a while: ‘For a few weeks I feel lighter. I feel like I have nothing to worry about.’ (van Daalen-Smith, 2011, p. 462)

Paula also noted that ECT gave her some benefit, stating that ‘ECT just takes you to a much more contented place, and sometimes I can notice the effects the same day.’ However, like both Anna and Carla, Paula stated that the beneficial effects of ECT rarely lasted more than two weeks – and she ultimately was told she needed ‘maintenance’ ECT, which she was getting at the time of the interviews. (Ejaredar & Hagen, 2013, p. 149)

On the contrary, all participants described a rapid and profound effect of ECT on their depressive symptoms although one participant had relapsed quickly after treatment ended. (Kring et al., 2018, p. 361)

I feel more positive for a few weeks. Then I come and get ‘topped up.’ (van Daalen-Smith, 2011, p. 463)

Like sometimes I wonder if they make it so that I will be an old lady and I am still gonna have to be going to the hospital every two weeks to get maintenance ECT! (Ejaredar & Hagen, 2013, p. 149)

In the process of ECT, I lost everything. (van Daalen-Smith, 2011, p. 462)

I don’t know whether it’s worse not to have had a life because you had ECT, or to have had a life and not remember it because you had ECT. (van Daalen-Smith, 2011, p. 462)

I lost my bladder every time I had it – I just don’t like being that out of control; I was pretty embarrassed and ashamed. (Ejaredar & Hagen, 2013, p. 151)

The deep emotions that were a part of me have disappeared. Lost somewhere. My life is as if I’m looking through a window watching the activity going on inside and trying
to be a part of that, but never being able to truly connect. My life now? I’m going through the motions. (van Daalen-Smith, 2011, p. 462)

- A majority of the participants (six out of nine) also reported significant and persistent cognitive effects that they directly attributed to ECT. (Ejaredar & Hagen, 2013, p. 150)
- It’s horrible, like I can’t even read a book anymore, because I’ll get through the first paragraph and I can’t even remember what I just read. (Ejaredar & Hagen, 2013, p. 150)
- The women who were post-ECT unanimously felt that the impact of ECT on their cognitive abilities was devastating. (van Daalen-Smith, 2011, p. 464)
- Like Margaret, Helen also experienced memory loss following a previous course of ECT. (Clark et al., 2018, p. 1082)
- It still boggles my mind some days to know that this memory loss occurred as a result of brain damage purposely done by doctors in the name of helping me. (van Daalen-Smith, 2011, p. 462)
- So I had three ECT’s, and I have a lot of lost memory. It’s just like there’s a whole block of time gone. (Ejaredar & Hagen, 2013, p. 149)
- Well, for example, my mom will talk about something important that happened a few years ago. And it obviously involved me and I was an active part of it, and all I have is a void. I don’t even remember bits and pieces of it – it’s just like a complete void. (Ejaredar & Hagen, 2013, p. 149)
- She went on to note the embarrassment she felt due to her memory loss and the problems it had created for her being unable to locate items. (Orr & O’Connor, 2005, p. 31)
- But, it’s disturbing because I can’t hold on to the memory. It kind of floats by. (van Daalen-Smith, 2011, p. 462)
- ECT destroyed brain cells filled with memory. (van Daalen-Smith, 2011, p. 462)
- It’s sad, because I can’t remember things that happened to me as a kid, you know? Cause most people you know have these precious childhood memories – you know, places they’ve been and traveled to when they were a kid. I don’t. It’s gone. (Ejaredar & Hagen, 2013, p. 149)
- Yeah, but for me it’s been sorrowful – I truly feel that I’ve lost myself somehow or another. (Kring et al., 2018, p. 362)
- You have to learn to get to know yourself again, actually…That’s the feeling I have, and it’s difficult, ya know, because who am I then? It can be quite daunting. Am I really like that? (Kring et al., 2018, p. 362)
- I was therefore forced to create/invent a new life. (van Daalen-Smith, 2011, p. 462)
- I miss the person that got away from me. (van Daalen-Smith, 2011, p. 464)
- For the post-treatment women, ECT eroded their previous ability to describe, recount, or explain situations or stories in a tightly woven fashion. Instead their descriptions were choppy, periodically out of order, and occasionally repetitive. Because of this, they have lost their ability to be heard, believed, and trusted. (van Daalen-Smith, 2011, p. 465)
- One woman spoke of the anxiety and discomfort on the day of her treatments and mentioned the judgment she was enduring from her family members, friends, and family doctor. (van Daalen-Smith, 2011, p. 462)
- Everyone believed that mental illness and especially ECT caused others to underestimate them and led to social alienation. Some participants worked fiercely to oppose being devaluated like this, but stated that doing so required expending
inordinate amounts of energy to disprove stereotypes and instead gain acceptance and recognition. (Kring et al., 2018, p. 361)

• I meant the stigma I might have had to face returning to work as a depressed, as a hospitalized mental patient...I gather that ECT, ECT treatments maybe regarded by some people as much more drastic a treatment than pharmaceuticals and therefore indicating maybe a more drastic problem that seems to require the use of it. (Orr & O’Connor, 2005, p. 32)

Life after ECT – staff members

• Effectiveness was viewed as boosting a person’s motivation to engage with life again. (Duxbury at al., 2018, p. 789)
• They witnessed severely depressed patients who were unable to care for themselves, recover their mental health after receiving ECT. (Lonergan et al., 2021, p. 312)
• We had an elderly lady come in for ECT...why would you give her ECT at this age? it was given to her...she was great the next day. She was much more…talkative, brighter, you could definitely see the improvement…gosh, it did work! (Lonergan et al., 2021, p. 312)
• Despite seeing patients become ‘more animated and interactive,’ some of the nurses expressed lingering doubts about ECT and wondered if there was another way. (van Daalen-Smith, 2011, p. 467)
• All the nurses interviewed stated seeing improvements in mood and ability to perform Activities of Daily Living shortly after electroshock. (van Daalen-Smith, 2011, p. 467)
• I started off my career with a fairly negative view of it [ECT] really. (Duxbury at al., 2018, p. 790)
• Participants were able to express their initial hesitation or scepticism about ECT as a treatment for severe depression, but on-site experiences appeared to weaken these concerns. (Lonergan et al., 2021, p. 312)
• When asked why ECT was not considered in the first instance the participants cited examples of side effects such as memory loss, confusion, headaches and nausea. (Duxbury at al., 2018, p. 788)
• Some patients can become confused following ECT and they may be unable to recall that they had ECT. (Lonergan et al., 2021, p. 313)
• I know there is the possibility of the short-term memory loss and the muscle pain and the other stuff. (van Daalen-Smith, 2011, p. 467)
• What I do believe I understand is the humiliation of having to have the treatment. (van Daalen-Smith, 2011, p. 467)
• ECT is given to people who are very ill. And it’s very easy for relatives and patients (.) to (.) mix the two, sort of to (.) blame (.) ECT, the ECT for things that are to do with the illness. (Stevens & Harper, 2007, p. 1482)
• In this sense, some participants appeared to see psychological distress as something different from the ‘illness’ the ECT was treating or a sense that more psychological harm would be caused/maintained by not treating the depression. (Duxbury at al., 2018, p. 789)
Appendix M

Social Science and Medicine – Submission Guidelines

*Social Science & Medicine* provides an international and interdisciplinary forum for the dissemination of social science research on health. We publish original research articles (both empirical and theoretical), reviews, position papers and commentaries on health issues, to inform current research, policy and practice in all areas of common interest to social scientists, health practitioners, and policy makers. The journal publishes material relevant to any aspect of health and healthcare from a wide range of social science disciplines (anthropology, economics, epidemiology, geography, policy, psychology, and sociology), and material relevant to the social sciences from any of the professions concerned with physical and mental health, health care, clinical practice, and health policy and the organization of healthcare. We encourage material which is of general interest to an international readership.

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    - All tables (including titles, description, footnotes)
    - Ensure all figure and table citations in the text match the files provided
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Appendix N

Theoretical Concepts Underpinning Interpretative Phenomenological Analysis

Three theoretical concepts underpin IPA: phenomenology, hermeneutics and idiography (Smith et al., 2009). Phenomenology refers to the study of lived experience. This approach does not try to fit individuals’ experiences into predetermined categories; it understands those experiences as unique to the individual and occurring in the context of their relationship to the world. Hermeneutics is concerned with interpretation. Human beings search for meaning in their experiences; using IPA, the researcher attempts to find meaning in the participant’s interpretation of their own experience, referred to as a “double hermeneutic” (Smith et al., 2009, p. 3). Idiography highlights the detailed focus on an individual’s experience.
Appendix O

Recruitment

<table>
<thead>
<tr>
<th>Third Sector Organisations</th>
<th>Participants recruited</th>
<th>Participants screened but did not meet criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involve Coventry</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>The Pod</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Leicestershire Action for Mental Health Project (LAMP)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Social Media</td>
<td>Facebook – Drop the Disorder</td>
<td>4 (3)</td>
</tr>
<tr>
<td></td>
<td>Twitter</td>
<td>4</td>
</tr>
<tr>
<td>Snowball Sampling</td>
<td>Word of mouth</td>
<td>1</td>
</tr>
</tbody>
</table>

Three third sector organisations agreed to support with recruitment by posting the project advert to their social media pages and/or website and informing service users about the project. The project advert was posted on the ‘Drop the Disorder’ Facebook page and was posted on a Twitter research account created by the lead researcher.

Two people expressed interest via Involve Coventry. One did not meet study inclusion criteria – their most recent admission was more than 5 years ago. One was recruited to the study. Nine people expressed interest via the Drop the Disorder Facebook Page. Five did not meet inclusion criteria – three had admissions outside of the UK, one had been admitted to a specialist ward (not an acute ward), and one had most recently had an involuntary admission. Four were recruited to the study but data could only be used for three due to a technology issue with one interview. Seven people expressed interest via the Twitter post. Two did not meet study inclusion criteria – one had most recently had a voluntary admission more than five years ago and one had most recently had an involuntary admission – and one could not take part as they wished to speak about a historical admission and could not remember their most recent
admission. Four were recruited to the study. One person was referred to the study by word of mouth from another participant and was recruited.

This resulted in a total of nine people who could not take part in the study and ten who were recruited. Due to data being lost for one participant, data for nine was included in the analysis.
Appendix P

Project Advert

For more information, visit the project website:
https://thesisresearchstudy.wordpress.com/

Research participants needed!

Would you like to take part in a research project exploring people’s experiences of being a ‘voluntary’ patient or service user on an ‘inpatient mental health’ ward?

If you are interested and you have had a ‘voluntary’ or ‘informal’ admission to an adult ‘mental health’ ward in the past five years, please get in touch:
Lead researcher: Alys Frankham
Contact email: frankhaa@uni.coventry.ac.uk

We would really value the opportunity to hear about your experiences.

This research project is part of a Doctorate in Clinical Psychology - funded by the NHS. All contact will be confidential.

Lead researcher: Alys Frankham
frankhaa@uni.coventry.ac.uk
Appendix Q

Screenshots of Project Website

Service users’ experiences of power dynamics during ‘voluntary’ admission to ‘inpatient mental health’ wards

Find out more information about this research study and how you can take part!

Home

A note about language...

We know that not everyone will identify with some of the language we have used on this website. We acknowledge that people who have accessed services will have different preferences when it comes to terms like ‘patient’ and ‘service user’. We have also used terms like ‘mental health’ and ‘voluntary admission’ because these are the terms currently used in services – not everyone finds this language helpful and we know that this might not fit for everyone.

If you have any thoughts about this and would like to voice these with us, please do get in touch. We would like to be as inclusive as possible and we are always striving to think about the impact of the language we use.

Meet Alys!

Take a look at this video of Alys, our lead researcher, talking about the study and how you can get involved.

Follow Mv Blor

If you want to get in touch with any questions or comments, you can contact Alys by email: frankhaa@uni.coventry.ac.uk or go to the ‘Contact Us’ page for more information.
### Appendix R

**Screening Questions**

<table>
<thead>
<tr>
<th>Question</th>
<th>Eligibility criteria met if following answers provided:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong> Are you an adult (aged 18 or over)?</td>
<td>Yes</td>
</tr>
<tr>
<td>Yes  No</td>
<td></td>
</tr>
<tr>
<td><strong>2.</strong> Do you speak fluent English?</td>
<td>Yes</td>
</tr>
<tr>
<td>Yes  No</td>
<td></td>
</tr>
<tr>
<td><strong>3.</strong> Have you ever been an inpatient on a mental health ward?</td>
<td>Yes</td>
</tr>
<tr>
<td>Yes  No</td>
<td></td>
</tr>
<tr>
<td><strong>4.</strong> How many times have you been an inpatient on a mental health ward?</td>
<td>If multiple, ask following questions in relation to most recent admission</td>
</tr>
<tr>
<td>__________</td>
<td></td>
</tr>
<tr>
<td><strong>5.</strong> Was this admission voluntary (as opposed to being admitted to the</td>
<td>Yes</td>
</tr>
<tr>
<td>ward formally or under a section of the mental health act)?</td>
<td></td>
</tr>
<tr>
<td>Yes  No</td>
<td></td>
</tr>
<tr>
<td><strong>6.</strong> What type of mental health ward did you stay on?</td>
<td>Acute</td>
</tr>
<tr>
<td>Acute Psychiatric Intensive Care Unit (PICU)</td>
<td></td>
</tr>
<tr>
<td>Rehab Specialist (e.g. Eating Disorders Unit, Addictions Ward)</td>
<td></td>
</tr>
<tr>
<td>Other (please specify) _________________</td>
<td></td>
</tr>
<tr>
<td><strong>7.</strong> How long has it been since you were discharged from or left the</td>
<td>&lt; 5 years</td>
</tr>
<tr>
<td>ward?</td>
<td></td>
</tr>
<tr>
<td>__________</td>
<td></td>
</tr>
</tbody>
</table>
Appendix S

Information Sheet

**Service Users’ Experiences of Power Dynamics during Voluntary Admission to ‘Inpatient Mental Health’ Wards**

**PARTICIPANT INFORMATION SHEET**

We are inviting you to take part in research on service users’ experiences of ‘voluntary’ or ‘informal’ admission to ‘inpatient mental health’ wards. Alys Frankham, Trainee Clinical Psychologist at Coventry University, is leading this research. Before you decide to take part, it is important you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully.

The terms ‘service user’ and ‘patient’ are used for the purpose of this document. The research team acknowledges and respects that people might have different preferences in relation to these terms. We appreciate that not everyone will identify with the terms used.

**What is the purpose of the study?**

The purpose of this study is to gain an in-depth understanding of service users’ experiences of power dynamics during admission and treatment as a voluntary patient on an acute mental health ward. Power is a person’s ability to have influence and control. Power dynamics describes how power affects a relationship between two or more people. With this study, we will be considering the ways that power affected your experience of admission and treatment on the ward and the relationships you had with the staff who were involved in your care.

There is limited research that focuses specifically on the experience of voluntary patients. This study aims to contribute to the research that is currently available and provide a richer understanding of service users’ experiences of accessing these services.

**Why have I been chosen to take part?**

You are being invited to participate in this study because you were previously a service user staying on an inpatient acute mental health ward and your admission was classed as ‘voluntary’ or ‘informal’.

**What are the benefits of taking part?**

By sharing your experiences with us, you will be contributing to the research in this area. This research will help others to better understand service users’ experiences of being a voluntary or informal patient in this setting. This information could be used to inform future developments in services.

**Are there any risks associated with taking part?**

This study has been reviewed and approved through Coventry University’s formal research ethics procedures.

Research can sometimes cause distress to participants, particularly when it involves discussing potentially sensitive topics. It is possible that you may experience distress as a result of taking part in this study and speaking about your experiences.
If you are feeling distressed on the day of the interview, then we can discuss whether you would like to reschedule. If you would like to take a break or stop the interview at any time, you will have this option. After the interview, we will discuss what support is available to you in case you feel you might need this.

Do I have to take part?
No – it is entirely up to you whether you choose to take part in this study. If you do decide to take part, please keep this Information Sheet and complete the Informed Consent Form to show that you understand your rights in relation to the research, and that you are happy to participate.

Please note down your participant number (which is on the Consent Form) and provide this to the lead researcher if you wish to withdraw from the study at a later date. You are free to withdraw from the study and you can request for your information to be removed from the project data set at any time before 31st March 2022.

To withdraw, please contact the lead researcher, Alys Frankham, using the details below. Please also contact the Research Support Office (ethics.bhs@coventry.ac.uk; telephone +44(0)247 765 8461) so that your request can be dealt with promptly in the event of the lead researcher’s absence.

If you decide you would not like to take part in the study, or if you decide to withdraw at a later date, you don’t need to give a reason for this.

What will happen if I decide to take part?
You will take part in an interview where you will be asked a number of questions about your experiences of admission to the ward and being a voluntary patient on the ward. This might include speaking about your day-to-day experiences of life on the ward and your interactions with others.

Due to the current Coronavirus pandemic, we will not be able to meet in person and so the interview will be conducted remotely. You can choose whether you would like the interview to be over the telephone or by video call using Zoom, Microsoft Teams or Skype. We would like to audio record your responses (with your consent) and so we ask that you sit in a quiet area to take the call if possible. The interview will be scheduled at a time that is convenient for you and should take up to an hour and a half to complete. We can take a break during the interview if you would find this helpful. In the event of a recording failure, you will be contacted after the interview and made aware of this, and you will have the opportunity to discuss options with the researcher.

In the week after the interview, we will contact you for a wellbeing check - we will check-in with you and ask whether you have any further questions. We can contact you for this wellbeing check over the phone or by video call. We will agree a date, time and method of contact for the wellbeing check with you at the end of the interview.

Once we have analysed your responses and the responses of other people who take part in the study, we may, if you consent, contact you for ‘respondent validation’ - this means that
we will check whether you think the results of the analysis are accurate and reflect your experiences.

Data Protection and Confidentiality
All of the information collected about you and any experiences you share in your interview will remain confidential, with the exception of any information which indicates that there is a risk to you or to someone else.

Your data will only be viewed by the research team. Themes and direct quotes from your interview may be included in the written thesis report and any associated journal articles, but this information will be presented anonymously - your name and identifying information will not be included.

Your data will be processed in accordance with the General Data Protection Regulation 2016 and the Data Protection Act 2018. Unless they are fully anonymised in our records, your data will be referred to by a unique participant number rather than by name. If you consent to being audio recorded, all recordings will be destroyed once they have been transcribed.

All electronic data will be stored on a password-protected computer file saved on Coventry University one drive. Any paper records will be scanned to become electronic data; paper copies will then be shredded and disposed of securely. Your consent information will be kept separately from your responses to minimise risk in the event of a data breach. The research supervisor will take responsibility for data destruction, and all collected data will be destroyed on or before 30th September 2027, in accordance with Coventry University policies and procedures.

Data Protection Rights
Coventry University is a Data Controller for the information you provide. You have the right to access information held about you. Your right of access can be exercised in accordance with the General Data Protection Regulation 2016 and the Data Protection Act 2018. You also have other rights including rights of correction, erasure, objection, and data portability. For more details, including the right to lodge a complaint with the Information Commissioner’s Office, please visit www.ico.org.uk. Questions, comments and requests about your personal data can also be sent to the University Data Protection Officer - enquiry.igeu@coventry.ac.uk

What will happen with the results of this study?
The results of this study may be summarised in published articles, reports and presentations. Quotes or key findings will always be made anonymous in any formal outputs unless we have your prior and explicit written permission to attribute them to you by name.

Making a Complaint
If you are unhappy with any aspect of this research, please first contact the lead researcher, Alys Frankham (contact details provided below). If you still have concerns and wish to make a formal complaint, please write to the research supervisors, Dr Magda Marczak and Dr Jo Kucharska (contact details provided below). In your letter, please provide information about the research project, specify the name of the researcher and detail the nature of your complaint.
Thank you for reading this information and considering taking part in this study.

<table>
<thead>
<tr>
<th>Lead researcher</th>
<th>Research supervisors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alys Frankham</td>
<td>Dr Magda Marczak</td>
</tr>
<tr>
<td>Trainee Clinical Psychologist</td>
<td>Chartered Psychologist and Lecturer in</td>
</tr>
<tr>
<td>Coventry University</td>
<td>Clinical Psychology</td>
</tr>
<tr>
<td>Coventry CV1 5FB</td>
<td>Coventry University CV1 5FB</td>
</tr>
<tr>
<td>Email: <a href="mailto:frankhaa@uni.coventry.ac.uk">frankhaa@uni.coventry.ac.uk</a></td>
<td>Email: <a href="mailto:magdalena.marczak@coventry.ac.uk">magdalena.marczak@coventry.ac.uk</a></td>
</tr>
<tr>
<td></td>
<td>Dr Jo Kucharska</td>
</tr>
<tr>
<td></td>
<td>Clinical Director and Senior Lecturer in</td>
</tr>
<tr>
<td></td>
<td>Clinical Psychology</td>
</tr>
<tr>
<td></td>
<td>Coventry University CV1 5FB</td>
</tr>
<tr>
<td></td>
<td>Email: <a href="mailto:jo.kucharska@coventry.ac.uk">jo.kucharska@coventry.ac.uk</a></td>
</tr>
</tbody>
</table>
Appendix T

Consent Form

INFORMED CONSENT FORM:
Service Users’ Experiences of Power Dynamics during Voluntary Admission to ‘Inpatient Mental Health’ Wards

You are being invited to take part in this research study for the purpose of collecting data on service users’ experiences of ‘voluntary’ or ‘informal’ admission to ‘inpatient mental health’ wards.

Before you decide to take part, you must read the accompanying Participant Information Sheet.

Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the time you need to decide whether or not you wish to take part.

If you are happy to participate, please confirm your consent by circling or highlighting YES against statements 1-10 below and then signing and dating the form as a participant.

Please indicate under statement 11 whether you would like to receive a summary of the study results by email.

<table>
<thead>
<tr>
<th>Statement</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 I confirm that I have read and understood the Participant Information Sheet for the above study and have had the opportunity to ask questions.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 I understand my participation is voluntary and that I am free to withdraw my data, without giving a reason, by contacting the lead researcher and the Research Support Office at any time until the date specified in the Participant Information Sheet.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 I have noted down my participant number (top left of this Consent Form) which may be required by the lead researcher if I wish to withdraw from the study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 I understand that all the information I provide will be held securely and treated confidentially.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 I am happy for the information I provide to be used anonymously in academic papers and other formal research outputs.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 I am happy for the interview to be audio recorded.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 I am happy to be contacted via email in the case of any technical difficulties with the recording of the interview.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 I am happy to be contacted by the lead researcher for a wellbeing check in the week following the study (the date, time and method of contact for this wellbeing check will be agreed at the end of the interview).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 I am happy to be contacted by the lead researcher at a later date for the purpose of ‘respondent validation’ (so that they can ask for my thoughts about the results of the analysis).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 I agree to take part in the above study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 I would like to be sent a summary of the results of the study by email.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Thank you for your participation in this study. Your help is very much appreciated.

<table>
<thead>
<tr>
<th>Participant’s Name</th>
<th>Date</th>
<th>Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Researcher</th>
<th>Date</th>
<th>Signature</th>
</tr>
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<tr>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>
Appendix U

Lost Data – Technology Issue

Unfortunately, one participant’s data was lost due to a technology issue; the audio recording failed to save. The researcher considered whether it would be possible to recall themes from the interview so that this could still be included within the analysis, but it was decided between the research team that this would not be feasible due to the methodological requirements of IPA. Recalling general themes discussed in the interview would not replicate the data provided by an audio recording and may have emphasised the impact of researcher bias (Chenail, 2011), resulting in the participant’s voice being distorted by the researcher’s own perspective of the interview. When the researcher contacted this participant for the wellbeing check, they explained the situation and offered for the interview to be repeated but the participant was not able to do this. The contribution of each participant is greatly valued, and it is regrettable that the time, effort, and expertise offered by this individual during their interview could not be recognised in the results of the study.
**Appendix V**

**Study Inclusion and Exclusion Criteria**

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>18+ years old</td>
<td>&lt;18 years old</td>
</tr>
<tr>
<td>Experience</td>
<td>Previous experience of inpatient MH admission</td>
<td>No previous experience of inpatient MH admission</td>
</tr>
<tr>
<td>Type of admission</td>
<td>Most recent admission was ‘voluntary’/informal</td>
<td>Most recent admission was involuntary/formal</td>
</tr>
<tr>
<td>Type of ward</td>
<td>Most recent admission was to an acute/treatment ward in the United Kingdom (UK)</td>
<td>Most recent admission was to any other type of inpatient MH ward (e.g., rehabilitation ward, Psychiatric Intensive Care Unit [PICU]) or was not in the UK</td>
</tr>
<tr>
<td>Time since admission</td>
<td>Most recent admission ended no more than 5 years ago</td>
<td>Most recent admission ended more than 5 years ago</td>
</tr>
<tr>
<td>Language</td>
<td>Fluent in English</td>
<td>Not fluent in English</td>
</tr>
</tbody>
</table>

Only adults were included as inpatient services for children and adolescents differ significantly from adult services. Participants were required to speak fluent English to engage directly in interviews. Additionally, it was considered that power dynamics between staff and SUs are likely to be impacted differently when communication occurs across different life stages (adult-to-child) or between people speaking different languages (Johnstone & Boyle, 2018).

As in Gilburt et al.’s (2008) study, participants included individuals living in the community who had previous experience of inpatient admission. Only those whose most recent admission was a ‘voluntary’ admission to an acute MH ward in the UK were included to ensure sample homogeneity. This type of ward was selected as SUs on ‘acute’ wards may be less
inclined to ask questions and take an active involvement in their care planning (Lomax et al., 2012).

To minimise the impact of recall bias, where an individual’s recollection of treatment is affected by events occurring since treatment (Pannucci & Wilkins, 2010), only individuals who had been discharged from hospital in the past five years were included in the study. All participants included in the final sample experienced their admission in the past three years.
Appendix W

Interview Schedule

Pre-Interview Information

At the beginning of the interview session:

- **Check out preferred terms for use during interview**
  - (Name they prefer to be called, preferred pronouns, whether they prefer patient/service user/something else)

- I will be asking you questions about your past experience of being admitted to an ‘inpatient mental health’ ward as a ‘voluntary’ patient or service user. I am interested in your experiences so there are no right or wrong answers.

- If you share something with me today that makes me concerned that there is a risk to you or somebody else, then I will need to share this information. Otherwise, everything you talk about today will be kept confidential (refer to confidentiality section on info. sheet).

- More information about this research and your rights can be found in the participant information sheet which you have a copy of.

- If you are finding the interview difficult and would like to have a break or end the interview early, please let me know (give option to plan a break in advance).

- Give participant the chance to ask any questions they may have.

- **Check still happy to go ahead with interview.**
  - If happy to proceed, complete demographic questions (see separate form) and interview questions (see below).

Interview Questions

*Note: prompts are included for each question, these are optional and can be used to encourage the client to provide rich responses to questions.*

1. Can you tell me a little bit about yourself and what drew you to this research?

2. Please could you tell me about the events that led to you being admitted to the ward?
   - *How did you reach the decision to go into hospital?*
   - *What affected your decision?*

3. Can you tell me about your experience of going into hospital?
   - *What images come to your mind when you think about this?*
   - *How did you feel about what was happening?*
4. Please could you tell me about day-to-day life on the ward?
   - What sort of things did you do?
   - What was it like?
   - Can you tell me about your relationships with the staff who were involved in your care on the ward?
   - What did you think/feel about it?
   - What was helpful/unhelpful?

5. What was your experience of the decisions made on the ward about you and your treatment?
   - E.g. ward rounds, assessment, diagnosis, therapy, medication, daily routines
   - How were decisions made?
   - Who was involved in making these decisions?
   - What was that like for you?
   - How did that make you feel?

6. Can you tell me about your experience of receiving treatment on the ward?
   - E.g. medication, therapy, support from staff, groups
   - What did you think/feel about it?
   - How did you reach your decisions about whether to engage in treatment on the ward? What affected your decisions?

7. Is there anything else you would like to say about your experiences or anything I have not asked that you would like to talk about?

**General Prompts**

- Can you tell me more about that?
- What sense did you make of that?
- What was that like?
- What did/does that mean for you?
- What meaning did/does that have for you?
- How did you experience that?
- How did you feel about that?
Post-Interview Information

- Thank participant for taking part in the research, for sharing their experiences and for their valuable contribution.

- Inform participant that they will now be emailed a debrief form which will contain further information about the project and suggest avenues for seeking support if needed.

- Inform participant that some people find it helpful to have a person in mind who they can speak to afterwards if they need to. Advise that they might wish to think about who they could speak to (either someone they know or via one of the services in the debrief sheet).

- Remind participant that they have consented to be contacted in the following week for a wellbeing check.
  - Arrange date and time for wellbeing check.
  - Clarify preferred method of communication for wellbeing check (telephone, MS Teams, Zoom or Skype).

- Remind participant that they have consented to be contacted at a later date for the purpose of response validation.

- Give participant the chance to ask any final questions.
Appendix X

Ethical Approval – Research Study

Certificate of Ethical Approval

Applicant: Alys Frankham
Project Title: Service Users' Experiences of Power Dynamics during 'Voluntary' Admission to an 'Inpatient Mental Health' Ward: A Retrospective Study

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval: 30 Jun 2021
Project Reference Number: P121481
Appendix Y

Consultation with Experts by Experience

Two experts by experience (EBEs) offered their support in the planning of this study, both of whom had experience of voluntary admissions and of working in MH services. One EBE was contacted via the third sector organisation Coventry and Warwickshire Mind, and another was contacted via Gloucestershire Health and Care NHS Trust. Drafts of the following documents were sent to the EBEs to check wording was clear and appropriate, and changes were made according to their feedback:

- Consent form
- Participant information sheet
- Interview schedule
- Debrief sheet

Additionally, one of the EBEs offered their thoughts in relation to the timing of the interviews. It was initially intended to conduct this research with participants residing on inpatient wards at the time of the interview as research suggests that appraisals of this experience can change over time following discharge (Kuosmanen et al., 2006). However, the EBE highlighted significant potential power issues with conducting interviews while individuals remained in the ward environment, particularly during the Covid-19 pandemic where services have been under additional pressure. They expressed concerns that this might raise tensions on the ward and have a detrimental impact for the individuals who took part in the study. It was therefore decided that the interviews would be conducted with individuals living in the community who had previous experience of voluntary admission.
Appendix Z

Distress Protocol


Distress Protocol 1: The protocol for managing distress in the context of a research focus group/interview

Distress
- A participant indicates they are experiencing a high level of stress or emotional distress OR
- exhibit behaviours suggestive that the discussion/interview is too stressful such as uncontrolled crying, shaking etc

Stage 1 Response
- Stop the discussion/interview.
- One of the researchers (who is a health professional) will offer immediate support
- Assess mental status:
  - Tell me what thoughts you are having?
  - Tell me what you are feeling right now?
  - Do you feel you are able to go on about your day?
  - Do you feel safe?

Review
- If participant feels able to carry on; resume interview/discussion
- If participant is unable to carry on
  - Go to stage 2

Stage 2 Response
- Remove participant from discussion and accompany to quiet area or discontinue interview
- Encourage the participant to contact their GP or mental health provider OR
- Offer, with participant consent, for a member of the research team to do so OR
- With participant consent contact a member of the health care team treating them at for further advice/support

Follow up
- Follow participant up with courtesy call (if participant consents) OR
- Encourage the participant to call either if he/she experiences increased distress in the hours/days following the focus group
Appendix AA

Debrief Form

Service Users’ Experiences of Power Dynamics during Voluntary Admission to ‘Inpatient Mental Health’ Wards

PARTICIPANT DEBRIEF SHEET

Thank you for taking part in this study, your contribution is very valuable and is greatly appreciated. This debrief sheet will give you some more information about the study. It will also give you information about where you can go to seek emotional support if you feel you need this after taking part in the study.

The aim of this research is to understand service users’ experiences of power dynamics during admission and treatment as a ‘voluntary’ patient on an ‘acute mental health’ ward.

Previous Research

In mental health services, the staff often hold more power than the service users who are accessing the service (Johnstone & Boyle, 2018). On inpatient wards, where service users do not have as much freedom as they normally would have at home, there is even more of a power imbalance.

Many service users who have had negative experiences of being an inpatient on a mental health ward say that they felt there were times when the staff abused their power (Chevalier et al., 2018). Voluntary patients should have the right to refuse treatment and leave hospital, but research shows that many voluntary patients felt they were coerced during their admission and felt they had not been involved enough in decisions about their care (Katsakou et al., 2011; Sheehan & Burns, 2011).

The United Nations (2017) has said that there needs to be a change in practice to protect the rights of service users. Research like this which helps us to understand service users’ experiences can help to inform future practice and service developments.

Continued Support

We understand that answering questions about your experiences of hospital admission and the time you spent in hospital might be challenging. You have consented to be contacted for a wellbeing check in the next week, at the time we have agreed with you. We will use your preferred method of contact (phone or video call) to check-in with you and ask whether you have any further questions.

If you feel you need support after taking part in this study, we recommend that you contact a service such as the charity Samaritans who offer free, confidential emotional support 24 hours a day, 365 days a year. You can contact the Samaritans by calling 116 123 or by visiting their website: www.samaritans.org/

If you are currently receiving support through the NHS from a Community Mental Health Team, we recommend that you contact your allocated clinician to seek emotional support.
Support from NHS community mental health services would usually be available Monday-Friday, 9am-5pm, but this might vary so we would encourage you to check this with your allocated clinician.

If you have any further questions about the research, then you are welcome to get in touch with the lead researcher or the research supervisors (contact details provided below).

Respondent Validation

You may have consented to be contacted at a later date for ‘respondent validation’ - this means that once we have analysed your responses and the responses of other people who have taken part in the study, we may contact you to check whether you think the results of the analysis are accurate and reflect your experiences.

Withdrawing from the Research

If you have changed your mind about taking part in this research project, you are welcome to withdraw your data up until the 31st March 2022. You do not need to give a reason for withdrawing.

To withdraw, please contact the lead researcher, Alys Frankham, using the details below. Please also contact the Research Support Office (ethics.bls@coventry.ac.uk; telephone +44(0)247 765 8461). You will need to provide your participant number (which was on your consent form) in order to withdraw from the study.

Research Team Contact Details

<table>
<thead>
<tr>
<th>Lead researcher</th>
<th>Research supervisors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alys Frankham</td>
<td>Dr Magda Marczak</td>
</tr>
<tr>
<td>Trainee Clinical Psychologist</td>
<td>Chartered Psychologist and Lecturer in</td>
</tr>
<tr>
<td>Coventry University</td>
<td>Clinical Psychology</td>
</tr>
<tr>
<td>Coventry CV1 5FB</td>
<td>Coventry University</td>
</tr>
<tr>
<td>Email: <a href="mailto:frankhaa@uni.coventry.ac.uk">frankhaa@uni.coventry.ac.uk</a></td>
<td>CV1 5FB</td>
</tr>
<tr>
<td></td>
<td>Email: <a href="mailto:magdalena.marczak@coventry.ac.uk">magdalena.marczak@coventry.ac.uk</a></td>
</tr>
<tr>
<td></td>
<td>Dr Jo Kucharska</td>
</tr>
<tr>
<td></td>
<td>Clinical Director and Senior Lecturer in</td>
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<td></td>
<td>Clinical Psychology</td>
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<td></td>
<td>Coventry University</td>
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<td></td>
<td>Coventry CV1 5FB</td>
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<tr>
<td></td>
<td>Email: <a href="mailto:jo.kucharska@coventry.ac.uk">jo.kucharska@coventry.ac.uk</a></td>
</tr>
</tbody>
</table>
Further Reading

If you are interested in this topic and would like to read more about this, the information in this document was taken from the following research articles:


Thank you again for your participation
Appendix AB

Staged Analysis for Interpretative Phenomenological Analysis

Stages of IPA analysis followed in this study (Smith et al., 2009; Smith et al., 2021).

<table>
<thead>
<tr>
<th>Stage</th>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Reading and re-reading&lt;br&gt;The researcher immerses themselves in the data; first by listening to the audio recording of the interview and then by reading and re-reading the transcript. This brings the participant to the forefront of the analysis. The researcher may choose to write down but not explore their own initial reflections, allowing them to remain focused on the data.</td>
</tr>
<tr>
<td>2</td>
<td>Initial noting&lt;br&gt;The researcher works through each line of the transcript and produces detailed exploratory comments relating to the data. This can be done by annotating the transcript with descriptive comments (focused on content), linguistic comments (focused on language used) and conceptual comments (focused on interpretation).</td>
</tr>
<tr>
<td>3</td>
<td>Developing personal experiential themes (PETs)&lt;br&gt;The researcher begins to identify PETs emerging from the data for the individual participant. PETs are expressed as short phrases; they reflect both the participant’s words and the researcher’s interpretation of these words.</td>
</tr>
<tr>
<td>4</td>
<td>Searching for connections across personal experiential themes (PETs)&lt;br&gt;The researcher pulls together the PETs by finding patterns and connections. Various strategies can be used to find such patterns (e.g., grouping similar PETs, observing how different PETs may have oppositional relationships, considering the function of PETs). PETs are then organised into a visual structure (e.g., a table or diagram).</td>
</tr>
<tr>
<td>5</td>
<td>Moving to the next case&lt;br&gt;The above process is repeated for each participant. The researcher is encouraged to respect the individuality of each case and put to one side the ideas which have emerged from analysis of previous transcripts, allowing for the emergence of new themes.</td>
</tr>
<tr>
<td>6</td>
<td>Looking for patterns across cases&lt;br&gt;The researcher considers the frameworks of PETs created for each participant alongside one another to identify connections across cases, leading to the identification of group experiential themes (GETs). Identifying GETs helps to take the analysis to a theoretical level.</td>
</tr>
</tbody>
</table>
Appendix AC

Screenshots and Pictures of the Analysis Process

The following images illustrate the process that was followed during the analysis (gender-identifying words were redacted or changed to ‘they/them’ to protect anonymity):

- Images 1 and 2 – examples of initial noting (stage 2) and developing PETs (stage 3) for one participant, Alex. The initial noting is shown on the right (red – descriptive comments, blue – linguistic comments, orange – conceptual comments) and the PETs are shown on the left (black).
- Images 3 and 4 – illustrating the process of searching for connections across PETs (stage 4) for Alex.
- Image 5 – illustrating the process of looking for patterns across participants’ experiences to identify GETs.
- Image 6 – illustrating the final GETs.
Shake in lines
Waiting
After many years
Carry on impersonal

Likewise prior
Do I hold the keys

No control over when
Your program point matter

Look inside I don’t 
 agree or do it

208

Practical implication of being told one thing and another beginning - not knowing enough things with

For the admission

Can’t in the back seat – can’t iron things, but knowing how to drive doesn’t have to be skillful, no -

Paper – nothing happening, nothing is something to happen, don’t know what will happen, I just follow it, don’t happen, - it doesn’t happen.

Being quite sure

Your worry into about language admission

Without any full care and worry in itself, one used to or longer admissions.

Circulation - imprisonment

Beginning to try learn from word not able to -

Deepening that, you stay and can you do what you do to obtain some anger?

Drawing lines in the book - that say you can’t ready to try, you don’t say. But having control

It’s the education, being that you think about another, if shut (do it) I want you to say, your thing.

Tell you back insight if you don’t insight it.
Appendix AD

Reflexivity

Dodgson (2019) described how “all qualitative research is contextual” (p. 220), occurring between the researcher and their participants within a specific time and place. This highlights the importance of reflexivity, where the researcher considers how their own position influences the process and outcome of the research (Berger, 2015). The researcher for this study was a 30-year-old, White British, heterosexual woman who was completing clinical psychology training. They had previously worked in inpatient MH settings, including a medium secure unit, a ward for people with eating difficulties, and an acute MH ward, and had experienced first-hand some of the power dynamics that can occur in these settings. Furthermore, through the ‘Drop the Disorder’ movement, the researcher had heard the stories of survivors who have had difficult experiences in MH services and who have found the medical model for understanding distress, prominent in many ward settings, to be harmful rather than helpful. The researcher believes that while this model may fit for some, it can be experienced as detrimental by others.

The researcher aimed to remain conscious of their own position and biases throughout the research process. The interview schedule was reviewed with the supervision team to ensure questions were sufficiently open and not leading (Smith et al., 2009). A bracketing interview was conducted by the research team prior to data collection. This helped to identify preconceptions held by the research team, thereby reducing the likelihood of these assumptions affecting the process of data collection and analysis (Fischer, 2008). The researcher noted down reflections while conducting the analysis, documenting the process and their own observations. This allowed the researcher to record their observations and then put them to one side, staying with the participant’s experience (Smith et al., 2009).
Using an interpretative approach such as IPA, it is acknowledged that interpretations are influenced by the researcher’s own experience (Smith, 2004). While steps were taken for the researcher to remain aware of their own assumptions, it is impossible to completely let go of one’s assumptions. Engward and Goldspink (2020) describe the importance of the way in which the researcher spends time with the data, interacting with the data in a “fluid and continuous” manner (p. 43) and questioning “whose voice is whose?” (p. 44). Additionally, research supervision was used to reflect on this process and examine the space occupied by both researcher and participant.
## Appendix AE

### Participants’ Accounts Contributing to Group Experiential Themes

<table>
<thead>
<tr>
<th>Participant</th>
<th>Theme 1: Being moulded</th>
<th>Theme 2: “De facto detention”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Getting the cold shoulder</td>
<td>Not deserving support</td>
</tr>
<tr>
<td>Alex</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sam</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Jamie</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Charlie</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Ashley</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Harper</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Jordan</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Max</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Taylor</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>
Appendix AF

Additional Illustrative Extracts

Being moulded – getting the cold shoulder

Moments of compassion:
- Um, but, I always think, you know, we can put a lot of complex interventions in place, but that sense of people having a sense of connection with someone and a cuppa are probably the most important things, and I think support workers are really good at doing that, actually. They, they often have much more time than, than kind of, clinicians to do that so that was really helpful. (Charlie, p. 18)
- Um, and they, they’re a staff team that, uh, like to laugh. And that was really nice sometimes when you need that. So that, that worked really well. Um, yeah, so they tried really hard. (Charlie, p. 26)
- There were others that I felt genuinely did care, um. I remember there was one occasion when I’d self-harmed on leave and I came back and the member of staff on, kind of, dealt with it and, you know, chatted to me and didn’t kind of just ignore me and be unkind to me, kind of like ‘oh she’s acting up’, um, she kind of put Steri-Strips on and kind of spent time with me. (Ashley, p. 34)
- But that was only because the OT made the effort to try and like come to me, to try and encourage me to get, you know, to make some changes and obviously come out of my room, sort of thing. She would bring me a cup of tea and that, so slowly I started to get used to them and, you know, trust them. (Harper, p. 40)
- And she’d talk to you like, just a normal human being. She was almost like a mum. (Jordan, p. 50)
- […] they’re carers aren’t they […] I used to talk to them like, you know. […] Yeah, the staff were good. (Max, p. 13)
- Um, I don’t know. We had like a [pause] activities lady, and she, she was really good. She remembered me as well from the previous year. When I was in isolation because of waiting for the Covid test. […] She brought me some, like, pastels and some paper so I could do something, so I thought that was nice. (Taylor, p. 35)

Absence of compassion:
- [Exhale]. Well, it’s a different person every time. Your named nurse is different every time you come in so, um, I have spent probably in the region of an hour and a half with my named nurse on any one admission, totally, for the amount of time that I’m in hospital. (Alex, p. 29)
- They put me in my room and then probably forgot about me, so I didn’t get any meals that day. (Alex, p. 15)
- They were friendly […] They were efficient, but they weren’t available. (Alex, p. 12)
- I just remember, I do remember like nobody speaking to me, like I, yeah, it’s weird cause they must have done, um, and they, yeah, they will have done, but I remember just being alone a lot, or having like, I think I had a HCA like sat at the end of my bed um, but they didn’t talk to me, there was a real, kind of, silence, like yeah. (Sam, p. 11)
- Uh, I think it was just really familiar. Cause my experiences have been very much like just being watched, um, and not spoken to [laugh]. (Sam, p. 12)
- Um, they were, they were polite, I don’t remember them talking to me though, there wasn’t any, kind of, communication […]. (Sam, p. 19)
...and I was so, so distressed. Acutely, like, um, and there was nothing, it was just a, kind of, ‘just stay in a room and wait for it to pass’, um, which it eventually did [...]. (Sam, p. 19)

Um, staff didn’t come and talk to patients. It was a place of containment really [...] Um, very little to do, very little care, um, it was an effort to get anything from anyone [...]. (Jamie, p. 20)

They would just, sort of, sit in the office and type on their, uh, computers a lot and sort of shout and tell you to go away and stuff if you asked for anything. (Jamie, p.22)

Um, there was this, just, sense of otherness. Staff othered patients, they, you know we, were subhuman or something. (Jamie, p. 35)

But there were just a handful of moments when people were caring on that ward, don’t get me wrong, in the whole admission. (Jamie, p. 31)

 [...] everyone was sitting behind computers, not really looking at me [...]. (Charlie, p. 31)

I don’t really know what they were doing, but I guess they were just doing paperwork and stuff and they just kind of left me [...]” … “I just kind of stood there by myself on the ward [...]. (Ashley, p. 18)

Um, and I just, yeah, I remember feeling like, kind of a mixed bag. Some of the staff I probably felt more comfortable around than others. (Ashley, p. 30)

And she sat with her body facing away from me in a really, kind of, hostile posture and kind of chewed on her nails and kept looking away and, kind of, acting really bored and she said ‘Am I real?’ And I remember it kind of fucking with my head and being, kind of being like, uh, ‘I don’t know, I think so’, and her kind of saying, ‘I’m not real’. And me looking back, I feel like that was quite abusive. (Ashley, p. 25)

I think my worst experiences were with agency staff, um, a lot of them I felt didn’t really care. Like I felt like they were just there for, kind of, money. (Ashley, p. 22)

It was like they didn’t care, you know what I mean? (Harper, p. 33)

 [...] but there’s some people who, you know, God knows how they got the job, because they’re so uncaring it’s beyond belief. It’s like you, you’re a pain in the backside. (Jordan, p. 36)

And one night of the week, it’s normally Wednesdays, another person comes in and this person that comes in is just, sort of, it’s just a very different vibe for the ward. (Jordan, p. 43)

 [...] and the staff would sit behind the counter. (Max, p. 19)

It was horrible cause it was, like, in the hospital. And there was like one chair and no windows, and the door was locked and [pause] I couldn't get hold of anyone. Like, they didn't really tell me [pause], you know, what to do. (Taylor, p. 17)

I don't really think that they were, sort of, trying to understand, I guess. I think [pause] it was kind of like [pause], that's just a, like a sort of standard process for them, and they sort of were just ticking boxes rather than trying to reassure me. (Taylor, p. 20)

I would have felt a lot less anxious and probably more safe if someone had taken time just to have a conversation with me. [...] But that didn't really seem like an option. (Taylor, p. 32)

I feel like they were trying to punish me by making me feel like I was going crazy and I was psychotic [...] I dunno, like looking back I just feel like they kind of, I dunno, thought that I was acting up and kind of tried to punish me. (Ashley, p. 26)

And I remember one night, I was outside in the corner and I was crying, and I’d gotten a nosebleed, and a member of staff who was agency came out and stood above me and, kind of, shone a flashlight in my face and was like ‘get up’, um, and was quite, kind of,
took away that thing that helped me to cope, kind of being outside in the cold, I guess. (Ashley, p. 42)

- Um, and he came along, and he was kind of like, threatened me and said to me that if you don't pack it in, you know, we're gonna look at injecting you, you know. (Harper, p. 18)

- [...] you know, am I in hospital or am I in a prison? Because the thing is, I’m there as an unwell person. I've not done anything wrong, but all of a sudden I’m being told off for not doing my bed, and it’s not even my bed. (Jordan, p. 39)

- That’s how the power works. It manifests itself in people. [...] He was horrible, uh, [name]. Seriously, he was horrible. I told him ‘you upset me’, I told him that. (Max, p. 22)

- I just felt, it just felt like I, I was just something to, uh, kind of, I don't know, kind of get rid of, prickly, put somewhere else, that I’m not someone else's, kind of, responsibility or, or, um, that they’d tried all these things and it wasn't working so let’s just get her out, sort of thing. (Charlie, p. 35)

- Uh, and he said ‘there’s no more we can do to help you, [name]. That’s what he said last time I seen him, when I was in there two years ago. (Max, p. 24)

*Couldn’t get needs met:*  
- Like on my last admission, I think I went for about 5 days without a proper meal, because I have, um, I can’t have gluten, can’t have dairy, and I’m allergic to all peppers. (Alex, p. 30)

- Um, there’s no therapy, like psychotherapy, or anything like that. [...] There’s no therapies, or anything like that, because it’s an acute setting. (Alex, p. 44)

- [...] so I take the pill back-to-back, because, um, I get really unwell when I’m on my period, and um, yeah so, they didn’t prescribe the pill, so of course then I had a period, but I had no stuff, and that was complicated. Um, I don’t know why they wouldn’t prescribe it, it was some kind of, they were like ‘oh yes, I’ll ask the doctor’ and then it just never happened. (Sam, p. 45)

- There wasn’t easy access to like washing stuff or anything like that, so I just felt disgusting the whole time I was there pretty much, um, yeah. (Sam, p. 36)

- [...] so my whole admission, that admission, was trying to, um, get people to sort of help me with this, like, housing situation. [...] And I just kept getting fobbed off, I kept getting told different things by different people. I was told that this woman from CMHT was gonna help me. Five weeks later she said ‘oh, but the ward staff could help you with that’ after she’d said that she would do something about it. [...] I was left frantically trying to, like, handwrite things on my own. (Jamie, p. 20)

- So, like, my problems just carried on being the same every week. (Jamie, p. 39)

- [...] quite frankly, medicating a horrific series of life events is always, in my mind, ridiculous. [...] I mean that was basically the only, like, actual treatment really, was, you know, let’s think what drugs we can shove you on. (Jamie, p. 40)

- I think where I had more challenges was with the medics and, um, and kind of, I had psychology as well and that some of that was difficult, because they were obviously working towards one thing, and I, I was of the view that we probably needed to work more towards trauma stuff, so. (Charlie, p. 26)

- [...] and sometimes medication is useful, but equally it’s nice when someone actually takes the time to kind of ask what you want, um, and actually like sit with you and give you that time and kind of maybe utilise skills to kind of help ground you, rather than just going ‘oh, she’s distressed, let’s get the PRN’ [laugh]. (Ashley, p. 65-66)
I’ts, you know, trying to shove tablets down your neck because you're upset isn't always the best way to deal with things, do you know what I mean? It’s like, had they talked to me, you know, or maybe did something else with me, you know what I mean, maybe that would have helped, you know what I mean? (Harper, p. 20)

Yeah, it [selling cakes on ward] made me feel better. But that was just a one off […]. (Max, p. 19)

And, like, a big part of [pause] what helps me is being outside and, like, exercise and all of this. And I was just like, they're just not gonna let me out again. (Taylor, p. 16)

[…] I’m still unpicking the damage from those experiences in therapy, like now [laugh], um, yeah. (Sam, p. 52)

**Being moulded – not deserving support**

**Assessed and monitored:**
- Uh, well essentially, it’s the consultants on the ward, um, and the nursing staff input. Whether you’re engaged in daily activities, whether you are using your toolbox, whether you are compus mentis or if you are [pause] delusional or whatever else. (Alex, p. 40)
- And you kind of get used to it, and it becomes a sort of, and they’re constantly watching your behaviour.” … “[…] you’re constantly being assessed almost, and, and so you, you kind of get really hyper aware of that, that actually you’re just being watched. (Sam, p. 13)
- So they were constantly, you know, around me, checking me and that, you know. (Harper, p. 14)
- And they said ‘right okay, what we're gonna do is we're going to put you into the assessment unit’. (Jordan, p. 23)
- […] and they’re looking at us. I mean, in the big day room they've got in the assessment unit, there's like a, um, it’s a strange window. It’s like a big mirror, so to speak. […]. But it's not, it’s a two-way window sort of thing, like. You can't see them, but they can see you. (Jordan, p. 30)
- I’m sure that the nurses probably had conversations with the doctors, like, before the patient was involved, just to be like, ‘this is what we've noticed’. You know, because the doctor’s not there all the time. (Taylor, p. 40)

**Having to present a certain way and prove need for care:**
- When you’re down and docile and, you know, um feel you’re needing comfort, tearful, whatever, that’s a more natural role for a caregiver to take on, like, they respond to that more easily I think than anger. Anger I think people get scared of. (Jamie, p. 29)
- You know, they tell us that mental illness can strike anybody at any age and whatever. But then the doctors are saying things like ‘but you’re an intelligent [person]’, like, you know, ‘you shouldn’t need this much input’ or ‘you shouldn’t need these add on services’ or ‘you should just be able to get better, off you go, you know because you’re an intelligent person’. (Alex, p. 38)
- And I just feel like I’m banging my head against a wall because, you know, mental ill health is shit. And it’s shit for the millionaires, it’s shit for the poor person, it’s shit for the Einstein or the IQ of 26, you know, it doesn’t matter what demographic you’re from. At the end of the day, it’s still horrible, you know? (Alex, p. 39-40)
- Sometimes, pressures on beds mean that people who don’t shout a lot and engage in activities and basically are quiet, are overlooked […]. (Alex, p. 53)
Um, they were trying to turn over beds I suppose, and I was the wellest at the time, so I was the one that was released [...]. (Alex, p. 27)

I think there was something about feeling so invalidated [laugh], not listened to for so long, you kind of get into that cycle of: this is what I need to do to demonstrate that I need that care, that I’m that desperate. (Sam, p. 9)

[...] and I’m really compliant, like, I’m actually quite well-behaved [laugh] as a service user [...]. (Sam, p. 8)

[...] if anyone started getting, any patient started getting angry or showing emotion, the staff were so reactive in such an awful, negative way. (Jamie, p. 24)

[...] when you’re very depressed and down it’s a lot easier for people to, when you’re not delusional actually as well, it seems to be a lot easier for to take on that, kind of, more caring role than when you’re maybe aggressive and full of energy and challenging and things like that so, I think that helped. (Jamie, p. 28-29)

So it's, it’s um, but that perspective of, um, kind of like, ‘you haven’t got a real mental illness’, has followed me back into the community. (Charlie, p. 40)

I guess because I didn’t really have that many incidents while I was there, maybe only a couple, so I feel like to them I was sort of regarded as well-behaved so I was maybe treated better than people that had more incidents and were kind of labelled as ‘oh they’re acting up’. (Ashley, p. 32)

Um, I do feel like on the ward there are some sort of dynamics at play where patients that, um, are kind of psychotic are kind of deemed more worthy of sympathy. […] Um, I just, I feel like sometimes in services there is a kind of nature versus nurture thing, and I think the more an illness is deemed as, um, being kind of nature, the more an illness is deemed genetic, the more, kind of, sympathy patients tend to get. (Ashley, p. 35)

[...] well first of all they didn't really want to put me into hospital.” … “They say ‘but [name], you know, it's been like three years since your last admission, you know, really do you want to go into that environment? You know, because that’ll bring you down’. And they always tell you about that, oh and they come out with the statistics that, you know, even if you're in hospital, and that’s physical or mental, for 10 days, your cognitive ability reduces by, and they give me a percentage. They always do that, like you know what I mean? (Jordan, p. 15-16)

I definitely was one of the quieter people, and it's kind of, I feel like unless you shout, you don't get anything on the, in those sorts of places. (Taylor, p. 35)

Feeling like a burden or like others are more deserving of care:

- And sometimes you feel like you’re just a bit of a, a burden, cause you’re causing people all this extra work. (Alex, p. 12)

- Also, like, sometimes you feel like you’re taking a bed away from somebody that deserves it, that they are really ill. (Alex, p. 12)

- […] everyone’s come in because there’s, like, some difficult stuff going on for them, whatever that is, it’s just made so much harder, and you’re made to feel like dirt. (Jamie, p. 24)

- And also, um, about, you know, we were really stuck at work for staff and, like, taking time out of that, adding more pressure onto the NHS at a time when it was really difficult. And I felt really guilty about taking a bed. (Charlie, p. 9)

- I felt, um, I felt that there was probably somebody more deserving out there that needed it. (Charlie, p. 10)

- Um, and that sense of, actually, you know, this is all stuff that you can manage yourself. You’d had therapy, you’ve been a therapist. So, it's that sense of, of not actually having
a valid reason to have an admission. So that, that really fed into my narrative of feeling really guilty about being there […]. (Charlie, p. 12)

- And you're put into a little cosy room away from everyone else because they don't want someone, um, to, to, like that to be there. Um, you know because you just, you just create an issue with regards to the A&E, you know? A&E’s lovely for when your arm’s falling off or there’s blood and everything like that, but if you’re psychiatrically there, then of course they stick you in a little corner room or a place. Um, and then I was just left. (Jordan, p. 23)

- We’re a pain for them rather than, you know, they’d rather sort of not have us there, you know. (Jordan, p. 37)

- Um, so I think it just made me feel even more like, well, I just don't matter. Because people who are meant to be there aren’t there, so I clearly don't matter. (Taylor, p. 8)

- I just felt like they hadn’t listened to me again. And I just thought, well, nobody cares about me or what I think. I’m, I’m just, like, an inconvenience that they've got to sort out. (Taylor, p. 16)

- Um, and I kind of think about, you know, the money it's cost the NHS, and just, but that's probably cause I work in the NHS [laugh] and I, you know, I know how stretched things are. (Taylor, p. 52)

- I read the New Testament, yeah? And it said ‘you reap what you sow’, so I’ve got that tattooed on my body […] in other words, you sow bad seeds, and you’ll reap a bad crop […] and that’s what’s happened to me now, cause I’ve sinned at lot of sins in my lifetime [name]. […] I’m being punished for them. I know I am. I know. (Max, p. 34)

“De facto detention” – *re-living powerlessness*

*Having limited power on the ward:*

- Um, just being given whatever’s in the little pot, and that’s your medication. You don’t actually know what’s in there unless you ask, um [pause] yeah, I think that’s it really. Uh, you don’t get, you know if you like, you’re prescribed something from your GP you get an insert in your medications, you don’t get that. (Alex, p. 50)

- There was never any warning, you never really knew what was happening. Um, yeah, and I, like [pause], I think my meds got changed and they didn’t tell me, they just gave them to me, and I was like ‘ummm?’ [laugh]. Just stuff like that really, you just don’t know what’s, you just don’t know what’s going on. (Sam, p. 34)

- I had really no choice […]. (Jamie, p. 11).

- And it felt like, um, that I was this passive recipient of [pause] things being done to me, rather than them actually seeing you as a whole person and, um, understanding my reality. (Charlie, p. 34)

- […] and to have that told to me in a way, ‘and now this is what we're going to do, this is, uh, you know, this is what the change in your medication is going to be’, without any consultation with me felt really disempowering, and another way of that feeling of having no agency or control over that. It is another thing of being done to rather than with, I think. (Charlie, p. 12)

- […] that sense of that power ebbing away […]. (Charlie, p. 16)

- The whole thing, I, there were some really good bits, but the whole experience has been quite disempowering to be, to be honest. Um, I wouldn't be quick to go on a voluntary admission again anytime soon. (Charlie, p. 42)

- You don't feel like a person, you know what I mean? You feel, you know, just like an object basically. You know, you can't go around just sedating people cause you feel like it and you just want to shut them up. (Harper, p. 33)
- [...] you've got no power, you know what I mean, you can't do anything. Um, so it was really, yeah, it was just not nice at all. (Harper, p. 5)
- Um, and people, I think people always say ‘well, you've got choice when you’re voluntary’, but sometimes they're very limited choices and they're filtered by, not just your, your personal circumstances but the circumstances that you find yourself in when you're on a voluntary admission. (Charlie, pp. 43-44)

**Threat of a section/not really voluntary:**
- Especially when you can't get out because the door’s locked. But also, there’s always that connotation there that [pause] if it’s not done that way, it’ll be done another way, you know, through the official channels. [Interviewer – “Do you mean, so, through a section or through-“] [Nods]. (Alex, p. 7)
- And you are, you are powerless. Like, I was a voluntary patient, but I guess I was in a weird situation that I had nowhere else to go, right? So, I couldn’t just walk out. Well, I could but I’d be homeless. (Jamie, p. 36)
- [...] at times wanted to go home but was persuaded that if I kept saying that I would go under a section, it felt very much that, uh, it wasn't, there wasn't much voluntary about it, actually. (Charlie, p. 3)
- [...] you’re not on section so we can't stop you from going out, but we are going to stop you from going out. So, in fact, you're not under a section, but we can always do the nurses section or, we can always, you know. And it's almost like, from like, it's kind of like, you are, you are detained but you're not. And I think it becomes like, it becomes a way of restricting people’s rights, but without actually putting any support around that. (Charlie, p. 44)
- I found over the last year when I've tried to challenge, like, ‘oh, I want to go out’, for example, um, ‘oh, if you do that, we'll have to think about sectioning you.’ Um, or ‘I don't want to be under obs’, ‘well if you’re not we’ll section you’. (Charlie, p. 2)
- Um, and I’d heard a doctor say ‘they’re going to section her’. So, sort of, when they came round to, to see me and they said that they were offering me a voluntary stay, I kind of accepted. I feel at one, at that time, I was, kind of, a bit out of it, and I, kind of, just was quite obedient and just did whatever people recommended. But I think because I’d heard someone say ‘they’re going to section her’ I kind of just thought well, if they’re gonna section me I might as well just go in voluntary because presumably I’ll have more rights [laugh]. (Ashley, p. 6)
- Um, it wasn’t nice because um, you know, obviously they kinda gave me an ultimatum that you either come with us or, you know, or we're gonna strap you up and take you sort of thing. (Harper, pp. 4-5)
- And so, I don't see the logic of calling it voluntary, because it’s not. You know what I mean? You’re restricted on what you can do, you know what I mean? It’s not as if you can just walk out when you want, do what you want. Cause, you know, they, you know, if you say you're gonna go out or you’re gonna do something, then they section you, you know. So just to me it doesn't, you know what I mean? It's not, it's not right. (Harper, p. 43)
- [...] you’re voluntary but they actually say ‘well actually if you do start to leave or try to, then we could section you’. (Jordan, p. 2)
- Because all of a sudden, you get the psychiatrist, cause it’s mainly the psychiatrist, who will say, you know, d’you want it the easy or hard way? And, of course, it’s the easy way, cause of course when you have the easy way, voluntary, things are a little bit more easier, as such. (Jordan, pp. 2-3)
- I think we need to, sort of, I don't know, maybe re-imagine a different way of calling it voluntary or informal, um, because voluntary and informal is, it means very different things to what, I think, it is. (Jordan, p. 69)
- I think I just thought, well, I've got the option of, like, a mental health assessment, or I've got to agree to go into hospital. (Taylor, p. 13)

**Safety:**

- And it doesn’t matter what happens when you’re in that safe space because you know that you’re gonna be okay. (Alex, p. 9)
- I want to go into that safety. I wanna feel, like, looked after. And I suppose that’s quite, quite selfish really, but it’s not when you're in that head. (Jordan, p. 19)
- And it’s a very strange, sort of, quandary that you have in your head. You know, because it's like ‘I'm safe, I’m okay’, but then also its ‘I don't wanna be here’. (Jordan, p. 34)
- Um, well, it was scary sort of anyway because, you know, the patients were arguing and fighting and throwing things, and, um, even though I came back to my room, I could still hear everything that was going on […]. (Alex, p. 28)
- So it felt very much like, uh, the picture comes to mind of doors and, kind of, that sense of an institution rather than, um, feeling somewhere that’s a place of comfort and security. (Charlie, p. 15)
- The second ward was just a long and very old big corridor, there was more opportunities for more escalation of sounds, of behaviour, and kind of escalation of people's anger as well. And my, my room was right next to the staff office, and obviously lots of stuff happened outside the staff office, so that was really challenging as well. (Charlie, p. 25)
- […] there was this one woman that kicked off, you know, started on me and that, you know, trying to start, you know, like fighting sort of thing. (Harper, p. 8)
- […] you could hear people screaming in the background. (Harper, p. 17)
- Sometimes they would, like, you know, force you to do stuff. Like make you come out your room, lock your room. You know, I didn’t agree with that, you know. You know, especially in such confined spaces, you know, with other patients that you didn't know, you know what I mean? (Harper, p. 34)
- […] as soon as I went in, I was scared. (Max, p. 10)
- And I even told, I told my consultant that day, [name], in the morning I said ‘doctor, something’s going to happen to me tonight, bad’. He said ‘no you’ll be alright’, he said ‘nothing’s gonna happen to you in hospital’. […] And that night I got a smack in the face. (Max, p. 11)
- I think I was just scared, like, I guess frightened of what might happen. (Taylor, p. 18)
- Um [pause], I sort of stayed by myself a lot because I didn't feel like I wanted to engage with other people. Um, I didn’t really know who they are, and like some of them sort of felt quite intimidating to me. […] Especially when you can't get out because the door’s locked. (Taylor, p. 24)
- So, I think that's why I just stayed in my room, because I didn't want to [pause], I didn’t want to be close to people anyway cause I was paranoid about Covid. […] And I didn't want [pause] any sort of confrontation or anything like that. And I just, I wanted to, like, make sure that I was safe, but I didn’t feel safe, and I couldn't escape because there was no way out. So, I didn’t really feel like the staff would [pause] protect me, either. (Taylor, p. 30)

**Blanket rules:**
- Um, being allowed out to smoke a cigarette. You know, that’s an off-ward privilege, and you don’t get that until you’ve been on the ward for 3 days. (Alex, p. 43)
- Cause I wasn’t allowed out of the room because of Covid regulations. (Alex, p. 15)
- […] he wouldn’t let me turn the light off […]. (Sam, p. 17)
- […] I wasn’t allowed to go to the loo on my own or anything […]. (Sam, p. 16)
- Communal areas were often locked. Staff would, um, sort of knock people up in the, you know, knock on people’s doors in the morning and demand that you come for medication or whatever, and queue up in the corridors, that stuff. (Jamie, p. 20)
- They’d knock on your door, um, they’d tell you to come for medication. If you didn’t come immediately, they’d knock again and say [harsh tone] ‘it’s medication time!’ And even if there were loads of people at the office hatch or whatever, they would make you queue up in the hallway, even though you could come back 5 minutes later, 10 minutes later and it would still be okay. It was a power trip again, it was uh, you know ‘you have to come now cause we’ve told you to come now’. (Jamie, p. 48)
- It was just, yeah, like [pause] it wasn’t possible to make any decisions over your day-to-day life as a patient there. (Jamie, p. 47)
- They kept bringing in this horrific dehumanising system, right, of giving everyone a number to be called up at dinnertime. (Jamie, p. 46)
- […] you would not know when you were going to be called in for your ward review. You could wait two days not knowing. (Charlie, p. 24)
- I think it’s really fascinating that you forget how regimented wards are. You know, like, people are given a lot of sedating medication but breakfast is really early, lights are put on really early, the cleaners are around really early. But we then give people lots of tablets to sedate them and they’re encouraged not to sleep during the day when they’re woken up by lots of sound and things like that. Um, I think, you know, people, I know I found this really odd after so many years that people were still queuing up for meds with not much privacy. People are still queuing up for food. That, that, it felt really, yeah it felt really, I don’t know, like victorian in a way, that you’re still queuing for meds and things, it was really odd. (Charlie, p. 21)
- […] they have to kind of mentally assess you each time before you’re allowed on leave. So, they’ll ask you questions and get you to sign paperwork and write down your, kind of, presentation, the clothes you’re wearing and all of that, and um, it did sort of feel like even though I was voluntary, I wasn’t literally able to, kind of necessarily, they still had some sort of control. (Ashely, p. 60)
- […] you don’t have say in what’s going on around you. You know what I mean? It’s not like you can go outside in the car park or go for a fag or, you know what I mean? (Harper, p. 44)
- […] normally you’d wake up at sort of 9 or 8 o’clock. It wasn’t much you could do. You had the OT but, to be honest, you were really restricted on what you could do because obviously it was acute. So, you know if, with being acute you know, obviously people are very sick, you know what I mean? (Harper, p. 24)
- […] they’ve changed the policy that you can’t go in the bed areas anymore, in the ward. … You used to be able to, but they’ve closed all them off now, they lock them. (Jordan, p. 46)
- […] you had the regiment of the, sort of, 9, 1, 5 and 10 medication trolley coming around and, you know, you’d have that. You’d have your meals at the certain times. (Jordan, pp. 44-45)
- […] they’ve got a little bit more stricter on the, sort of, the freedoms. Um, so it’s a thing of everyone is treated like it. So, it’s not about only people who are on section and
people who are informal. But there are, sort of, boundaries that they’re putting in place. (Jordan, p. 55)
- You have to wait 3 days before you can go out on your own, but obviously if you’re very, very poorly, you’re not allowed out. (Max, p. 29)
- It’s the same routine every day. (Max, p. 20)
- They would, like, wake you up, well I was awake anyway, but like wake you up and say that, you know, breakfast or medication. (Taylor, p. 24)

**Staff had dominant narrative:**
- Um, I just couldn’t get my head around that, and I refused to accept it. I told him that I didn’t wanna hear about it and, you know, I didn’t need another label. So, I fought against that for a long time, but once they’ve written something on your file it’s kind of there for prosperity, so. (Alex, p. 41)
- […] their view mattered more. Or whatever they’d decided, their interpretation was more valid than mine. (Sam, pp. 42-43)
- But as soon as I was moved to another ward, without consultation and without any formulation it was changed to EUPD. (Charlie, p. 11)
- I feel like in mental healthcare, when it comes to EUPD especially, staff kind of use the code ‘it’s behavioural’ … Which is sort of a code for ‘there’s nothing wrong with them, they’re just acting out’ […]. (Ashley, p. 31)
- I think the notes are a way that staff can kind of exert their power and their perceptions of you […] Um, and I feel like notes, I always feel like notes are quite influential. (Ashley, p. 43)
- […] they listen to you but they still sort of think, well, you know, ‘I’m the person, I know best. I’m the doctor, or the ward manager’ […]. (Jordan, p. 58)
- I seen another doctor. And that’s the one that told me I got schizoaffective disorder. (Max, p. 24)
- It was, I was scared to expose myself again, to be vulnerable, with people that would just, like, re-define it as something else, and not listen to, kind of, what I thought was happening [laugh]. (Sam, p. 26)

**Previous experiences of having limited power:**
- Um [pause and exhale], I tried to speak to my mum about some of the abuse and stuff that happened, when I was a kid, and she just blames her bipolar saying she doesn’t remember any of it. (Alex, p. 3)
- Um, I’ve been, in and out of, uh, mental health wards for the last two and a half years. Um, basically because I couldn’t ignore it anymore, I couldn’t ignore the flashbacks and things like that, they kind of took over my life. (Alex, p. 1)
- Um, it was a case of somebody else not believing me, you know, after the abuse that I’d suffered when I was younger, nobody believed that. […] And that impact is quite severe, when you’ve had all these things happen, and not being believed, or thinking that you’re not believed, yeah that has quite an impact. (Alex, p. 47)
- […] I just remember [pause] being in so much pain [laugh], just, I was so distressed I couldn’t think straight. Um, and I, I was like frozen, like I couldn’t express it or anything, I just sat there […]. (Sam, p. 15)
- And then, um, I had a care co-ordinator, um […] who um sent me like a hundred text messages in a week, um, like kind of outside of office hours and quite suggestive. […] I reported it to the psychologist on my last DBT session and um, and then, [they] kept texting me, nothing happened, um, so I discharged myself completely from services […]. (Sam, p. 5)
- I’ve had some really horrific previous experiences, um, where I’ve felt really belittled, and dismissed, and just not heard […]. (Sam, p.20)
- I was in a long-term relationship that was [pause] not great, hadn’t been great for a number of years, um, with a partner who was quite controlling. (Jamie, p. 4)
- So, like, they’d kind of destroyed my life and then I was back there asking them for help [laugh] it was this, like, really messed up situation. (Jamie, p. 28)
- I was dealing with a psychiatrist who denied me any leave on my previous admission, with no justification at all [laugh] […] (Jamie, p. 39)
- Um, so I was having a lot of issues with, like, people in the area. Um, you know, um basically harassing me and just causing trouble really. Just, um, there was one lady that, you know, assaulted me basically, and I couldn’t cope with, you know, what had happened. (Harper, p. 3)
- But it’s the schizoaffective disorder and delusions and paranoia and psychosis that really do my head in like. (Max, p. 2)
- Yeah, God plays mind games with me. Mental torture, mental cruelty. (Max, p. 25)
- He’d ask me the same two questions every time I seen him, every week. Can people put thoughts and ideas into your head? Can people read your mind? And I’d say ‘no, but the power can’. (Max, p. 4)
- And then, um, it kind of just got more and more intense, like with work. Just, you know, cause people were dying all the time. And I was away from my family and my friends. And I sort of just, like, isolated myself and [pause] I think, I didn't really know why, but in the end, I just was like, my brain is, like, way too noisy. I just want everything to stop. (Taylor, p. 4)

“De facto detention” – not having any fight left

A fight to get your voice heard:
- I feel like sometimes it was a bit of a fight, in that I feel like the consultant pretty much, it didn’t always matter what anyone else said, he kind of could do whatever he wanted, even if everyone else disagreed. (Ashley, p.54)
- Other times, I can stand and argue my corner, completely flatly refuse to do whatever they want me to do, [pause] and if I have a sound reasoning then I can argue my point […] But I’m not always in the right place to do that. (Alex, p. 37-38)
- Normally what I do now is I don't actually, sort of, um, I don't argue with it at that moment. I normally see my psychiatrist […] and I’ll mention it to her. (Jordan, p. 56)
- You’re not gonna have any, you’re not gonna have visitors anymore and things like that. Sort of, well no, that’s my right to have a visitor. You know, d’you know what I mean? It’s, sort of, well give me the reasoning why I can’t have visitors, tell me it properly and that. So, I'm challenging you. If you haven't got a, in my opinion, a right, sort of, way of putting it, or there’s no proper challenge or answer, then I'm not gonna, I’m gonna go further with this. I'm gonna go to your manager, I’m gonna go further than that. (Jordan, p. 62)
- I mean, of course, don’t go in there like a big lion and roar it out and sort of go ‘I demand’, you know. Sort of, you don’t demand anything, I said, but if you actually do it in a nice way, you do it in the sense of, ‘but I disagree’, you know? And, sort of, it's good to challenge, even if you’re sectioned. You know? Or not sectioned. It’s good to challenge […]. (Jordan, p. 59)
- You can challenge good and make a good point, let’s say, or you can, sort of, really get on their wick. And it’s that fine line of getting on their wick and really going for it or challenging proactively. (Jordan, p. 61)
- So, he (named nurse) would give me a lot of support and encouragement in the way of speaking up for myself, so that was good. (Jordan, pp. 49-50)

**Times when people listened:**

- [...] he does genuinely listen, um, he’s a bit eccentric which is also quite nice, um, and he doesn’t kind of make assumptions and he asked me what I wanted which was [pause] unusual. (Sam, pp. 20-21)
- Um, cause I was impressed, I was actually impressed by her [laugh], you know, to be quite up front about that and admit that. (Jamie, p. 31)
- I felt that [pause], I think that's really nice that you can have someone advocate on your behalf. (Charlie, p. 31)
- I feel like it sort of made me feel a little bit more respected, as in, you know, as in what I said to them was listened to and it felt like I was given a little bit of trust [...] I feel like, um, them actually listening to what you’re saying, kind of feeling like you’re respected and you kind of know yourself best and you know what to do that’s right for you, I feel like that makes a difference as well. (Ashley, p. 63)
- I felt like I was more in control over what was happening to me, I guess. And I felt like I was [pause] listened to, and like they didn't think I was stupid, and they actually valued what I had to say. (Taylor, p. 40)
- So, I think that I thought that was quite [pause] nice. [...] Um, because it felt like they were listening to me. [...] And I’d, like, they’d sort of taken it seriously that I felt like something was wrong. (Taylor, p. 23)

**Perspective dismissed or not heard:**

- I know it’s all part of my illness, being paranoid and psychotic [...]. (Max, p. 34)
- [...] they say that you’re obviously not ready to go, or you lack insight into your problems or these things. (Alex, p. 25)
- Between them, they can make the decision and then put it to me as if you’ve got a choice but, really, this is what’s happening anyway. Um [pause], you know they do put things across as though ‘yeah you’ve got a choice between X, Y, Z’ and most of the time it’s already a decision that’s made, but it gives you that, um, feeling of having been part of the decision-making process. (Alex, p. 37)
- Um, it was a case of somebody else not believing me, you know, after the abuse that I’d suffered when I was younger, nobody believed that. And my first husband was a medic, and they didn’t believe that he could do the things that he was going to me. And that impact is quite severe, when you’ve had all these things happen, and not being believed, or thinking that you’re not believed, yeah that has quite an impact. (Alex, p. 47)
- So then I felt like from then on, if I ever complained about anything, if I ever [laugh] kind of, suggested that they perhaps weren’t helping as much as I thought they should do, or that I needed something, it felt like that just confirmed the, kind of, personality disorder diagnosis, that I was somehow avoiding taking responsibility. (Sam, p. 25)
- [...] there was no point talking, because it would just be interpreted as a symptom, or as [pause] just more confirmation that I wasn’t engaging. (Sam, p. 25)
- Um, I got the impression that they were, they’d already decided. They were just seeing what my response was, but it didn’t change anything. Um, yeah, I didn’t, um, yeah like nothing I said, kind of, made any difference, I think. I didn’t have choice in any of, anything happening. (Sam, p. 38)
- It’s like, just, just listening to people’s story has to be the starting point, and that doesn’t happen. (Jamie, p. 57)
- He was very dismissive; he always was very dismissive of me. (Jamie, p. 39)
- But you’d walk in, into a room full of professionals all behind their laptops, and they basically told you what their decision was about your treatment and things like that. And if you, if you, um, expressed any perspectives, it was very much like ‘well you would say that wouldn’t you’ or ‘we’ve made a decision about this, this is what we're going to do’. So it felt very, um, it was very challenging. (Charlie, p. 25)
- When women get angry on a ward it’s seen as part of their presentation rather than actually, they're getting angry about a situation or, or it's a consequence of what's been happening to them. It’s very much part of their presentation and their symptoms. It's pathologised, that response of anger. (Charlie, pp. 3-4)
- And I did overhear them talking about a patient, saying they were behaving, not that patient but it was another patient, when I was waiting outside the nurses’ offices to ask for something, I heard them like talking about a patient and saying ‘oh they’re just behaving that way for attention’. (Ashely, p. 24)
- And she, uh, looking back I think she thought I was trying to fake being psychotic and, kind of, a diagnosis, kind of, ‘oh she's trying to pretend, she’s trying to get my attention’. (Ashley, p. 25)
- It was not nice, because obviously they had already, um, it was pointless me going to the meetings because they'd already agreed what they were gonna do before, you know what I mean, before I got to the meeting. So, it was like, what's the point me going? You know, cause I haven't got a view because they're not gonna listen to it, you know what I mean? (Harper, p. 31)
- […] you could be out counted by all the people in that room. (Harper, p. 36)
- But the thing is, the sort of, they don't, they honestly sometimes don't listen. (Jordan, p. 17)
- I just wanted people to believe me. (Max, p. 13)
- Well, I brought it up with, like, a couple of the sort of like, support workers. And they sort of spoke to me about it and they said ‘well, at least it’s not something, you know, you’re not gonna get any serious effects from it, it’ll just make you tired’. And I was like, kind of, that felt a bit dismissive. Like, I guess they were trying to be reassuring by, like, ‘well, you’re not gonna, like, die from it’. But it’s like, but it's still wrong. (Taylor, p. 26)
- Um, and like I wasn't being believed, even though I know that I was right. (Taylor, p. 26)

Not able to fight/becoming passive as a way of getting through:
- No, I don’t think I was really in the mind to be able to [pause] disagree, you know? Um, I think I was so ill by that point, you know, it’s just a done deal kind of thing. (Alex, p. 7)
- I really was just, almost, um, robotic I would imagine. Just being told: ‘you’re moving from here to here’. I would, um, you know, ‘that’s what we’re doing, you’re just moving, this is where you’re going’, and, you know, it’s like every decision is being taken away from you and you’re just along for the ride, kind of thing. (Alex, p. 11)
- Throughout all of these experiences, I’ve just become really passive because it just became pointless for me to actually say what I thought about anything, because it didn’t matter […]. (Sam, p. 42-43)
- Um, and I just um, I became completely compliant, um, so I did everything they said […]. (Sam, p. 50)
- And so, I just thought ‘fine, whatever, I don’t really care right now’. (Jamie, p. 43)
- It just, it just felt like an ongoing, I mean, an ongoing battle but one that I personally didn’t have the energy for cause I actually wanted to sort out my own life at that point [laugh]. (Jamie, p. 28)
- I think it further invalidated my view of myself, that perhaps I didn’t have anything to say or to add, or I had no strengths or assets, and, um, I think it [pause], it reduced my ability and skills around getting my voice heard. So, um, and at times I just stopped trying to get my views heard. I just closed down. (Charlie, p. 29)
- I dunno I think the fact that I was so disorientated, and I was so [pause], I didn’t really have any fight left in me, everything was just, kind of, gone, so I think it wasn’t such a big deal at that time to me cause I was just so passive and so, letting people do whatever they wanted. (Ashley, p. 14)
- I didn’t even consider reporting when staff were, kind of, quite rude to me. I didn’t, I just kind of took how they treated me and just didn’t really think much of it. (Ashley, p. 25)
- I just felt empty, you know what I mean, I felt lost. Um, just hopeless, you know what I mean? Cause I couldn’t do anything. (Harper, p. 21)
- […] you get used to it because it’s a point of, you know that's gonna happen on Wednesday, so really, why bother to argue? D’you know what I mean? You sort of get resigned to the fact of like, she’s there, she’s not gonna change her ways, so there you go. (Jordan, p. 44)
- […] and I think everyone does it, it’s not only people who are informal but also people who are on section, […] they think, well, I’ve not got a voice so why even use it? (Jordan, p. 59)
- Well, they asked you, I just agreed like, and that’s it. (Max, p. 33)
- […] it was hard to think. Like, I couldn’t really [pause] think properly, because I think I was just, sort of, overwhelmed with everything, and I was trying to make [pause], make things make sense, but [pause], I think it was just making me more tired. […] So I think that's partly maybe why in the end I was just like ‘okay, fine’. (Taylor, p. 12)

Fighting makes it worse:
- I, uh, um, basically I’ve learned that [pause] I just need to sit and wait it out. […] Uh, because, if you try and get out early, chances are you’re gonna end up getting sectioned [exhale], so. (Alex, p. 26)
- And in fact, you probably, you know, I think as a result, might end up staying longer than [laugh], by challenging than not. (Charlie, p. 4)
- […] I was concerned, you know what I mean? Cause I was worried about how long I’d end up staying there for. (Harper, p. 21)
- I think I kind of just decided to just be like, well, just let it be. Like, it is what it is. You can't force it to be quicker, because then they just almost seem like you’re being disruptive and stuff. So I was like, well, just wait and then you'll get out eventually. Kind of like reassuring myself. (Taylor, p. 42)
Appendix AG

Respondent Validation Feedback

All nine participants were contacted for respondent validation (consent to be contacted had been obtained at interviews). Five responded and confirmed that they were happy with what had been written in the results section and that this reflected their experience:

- “all fine with me”
- “I checked over the following and i think its a very good piece of research i'm very happy with it, thank you for taking the time out”
- “I read your work and that is good too”
- “I’m happy with everything written”
- “I think you've done an excellent job! This really captures what it's like being a voluntary patient ever so well, highlighting the atrocious 'care' that people experience. Thank you for all the work you've put in to this. […] My experience fits with what you've written (really happy with the quotes of mine that you chose to use too)”