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EXPERIENCES OF INTENSIVE TREATMENT SETTINGS FOR PEOPLE WITH EATING DISORDERS.

Section A: What helps and hinders recovery during intensive treatment for an eating disorder? A synthesis of qualitative research exploring people with eating disorders' perspectives.

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Section B: "They should understand that the anorexia drives me to do anything": Exploring the experience of general medical admissions for individuals with anorexia nervosa.

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Summary of MRP

Section A

Eating disorders are complex mental health difficulties. Increasing numbers are being admitted into intensive treatment (i.e., inpatient, day-patient or acute medical settings). This review explored clients' perspectives of eating disorder recovery during intensive treatment. Thirty studies met eligibility criteria. Study quality was assessed using CASP and results sections were analysed using thematic synthesis. The methodological quality was mostly good. A person-centred, biopsychosocial approach is necessary, with support from a sufficiently resourced and adequately trained multidisciplinary team. Improving physical health remains fundamental, though psychological support is also essential. Implications, limitations and areas for future research are discussed.

Section B

Some people with anorexia nervosa require acute medical admissions to manage medical complications. Currently, little is known about how medical admissions are experienced, despite an increase in the number of individuals being hospitalised. Ten individuals with experience of medical admissions related to their anorexia nervosa were interviewed. Data were analysed using interpretative phenomenological analysis. Gratitude was expressed for medical intervention. However, a lack of psychological understanding meant participants felt misunderstood and stigmatised. Mental and physical health services were experienced as disconnected and close others sometimes had to shoulder significant responsibility for care. Clinical and research implications, and limitations, are discussed.

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Section A: Literature Review

What helps and hinders recovery during intensive treatment for an eating disorder? A synthesis of qualitative research exploring people with eating disorders' perspectives.

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Abstract

Eating disorders (EDs) are complex mental health difficulties that impact the individual, their supporters and society. Increasing numbers are being admitted into intensive treatment (i.e., inpatient, day-patient or acute medical settings). The lived experience perspective of what helps and hinders ED recovery during intensive treatment is an emerging area of interest. This review explored clients' perspectives of what helps and hinders ED recovery during intensive treatment. A systematic literature search and quality appraisal yielded 30 published studies for inclusion. Thematic synthesis generated six themes; collaborative care; intensive environment; negotiating identity; focus on mind and body; specialist support; and support from others. This review identified that a person-centred, biopsychosocial approach is necessary throughout treatment, with support from a sufficiently resourced and adequately trained multidisciplinary team. Improving physical health remains fundamental, though psychological support is also essential to understand what causes and maintains the ED and facilitate a shift away from an ED-dominant identity. Carers and peers who instil hope and offer empathy and validation are valuable sources of support. Future research should explore what works best for whom and why, evaluating patient- and carer-focused psychological interventions and dietetic support, and should explore how to mitigate against potential harm during intensive treatment.

Keywords: eating disorders; intensive treatment; recovery; qualitative research.

Introduction

Introduction to Eating Disorders (EDs)

The term EDs describes a group of mental health difficulties, such as anorexia nervosa (AN), bulimia nervosa (BN), and binge eating disorder (BED). EDs are characterised by severe disturbances of attitudes and behaviours related to food, weight, and shape, which seriously impact mental and physical health (American Psychiatric Association, 2022). Whilst aiming to emphasise a psychological rather than medical understanding of EDs, this review will necessarily rely on diagnostic terms in order to consider relevant literature and ensure accessibility of the findings. Moreover, EDs were originally considered a largely white female disorder prevailing in Western countries, meaning most of what is known so far comes from samples of this population. However, growing literature emphasises that EDs affect individuals of all ages, genders, ethnicities, sexualities and geographies (Treasure et al., 2020). Research into PwEDs from historically marginalised populations remains an emerging area (Goel et al., 2022).

ED onset is typically during late adolescence and early adulthood (Solmi et al., 2022). With the potential to impact every organ system, EDs can be life threatening, reportedly having the highest mortality rate of all mental health disorders (Arcelus et al., 2011; Voderholzer et al., 2019; Weigel et al., 2019). EDs are burdensome to the individual, their supporters and society (van Hoeken & Hoek, 2020). Covid-19 has only exacerbated this burden: increases in incidence rates, ED symptomatology and hospital admissions have been widely reported (Devoe et al., 2023; Gilsbach et al., 2022; Katzman, 2021).

Treatment for People with EDs (PwEDs)

Treatment for PwEDs depends on the severity and chronicity of difficulty (Lemly et al., 2022). Most PwEDs are first offered outpatient psychological therapy, which can be complemented with pharmacotherapy, medical monitoring, nursing and/or dietetic support (Hay et al., 2019). For those who do not respond to less intensive treatment, or whose ED cannot be managed safely as an outpatient, intensive treatment may be offered. This typically ranges from day-patient treatment or partial hospitalisation to inpatient or residential treatment in an ED or general psychiatric unit. Though varied, these more intensive treatments typically involve greater multidisciplinary input and direct meal supervision (Hay et al., 2019).

In inpatient and residential settings, care is provided 24 hours a day. Inpatient settings can offer a safe and secure environment and chance to focus on recovery. However, they can also risk institutionalisation, reduce individual responsibility and autonomy in recovery and are associated with high healthcare costs (Ágh et al., 2016; Madden et al., 2015; Webb et al., 2022). In day and partial hospitalisation settings, treatment is typically offered on weekdays and patients return home overnight. Day-patient settings permit increased autonomy, improved transfer of skills learnt and continuation of life outside. However, they can lead to greater carer burden, slower symptom reduction and more challenging risk management (Serrano-Troncoso et al., 2020; Webb et al., 2022).

Alongside specialist intensive treatments, increasing numbers of PwEDs are being admitted to general medical settings to manage the medical complications associated with EDs (Royal College of Psychiatrists, 2022; Turner & De Silva, 2023). Care in medical settings is highly variable, with varying levels of specialist input (Hay et al., 2019; Turner & De Silva, 2023). There is growing recognition of the need to identify best practice for supporting PwEDs in medical settings to ensure implementation of timely, life-saving interventions (Stoody et al., 2023; Turner & De Silva, 2023). Importantly, whilst the relative merits of each form of intensive treatment continue to be debated, demand appears to be rising internationally (Hansen et al., 2021; Milliren et al., 2023; Taquet et al., 2022).

ED Recovery Outcomes and Considerations

Clinicians supporting PwEDs encounter challenges due to the egosyntonic nature of the illness (Gregertsen et al., 2017). EDs typically develop as a coping mechanism in response to distressing life events (Lejonclou et al., 2014). Many attach positive value to their ED (Denison-Day et al., 2018), as it gives a perceived sense of control, and means of obtaining identity and avoiding negative affect (Bryant et al., 2022; Frank et al., 2012). Defence mechanisms, such as denial and intellectualisation of the illness, alleviate distress (Abbate-Daga et al., 2013). Consequently, PwEDs are often ambivalent towards treatment and display low motivation to change (Abbate-Daga et al., 2013; Halmi, 2013). Current treatment efficacy is modest (Monteleone et al., 2022). A recent rapid review suggested between 30% and 41% of PwEDs relapse within two years of receiving treatment and that less than half achieve recovery at long-term follow up (Miskovic-Wheatley et al., 2023). Furthermore, across all EDs, 62–70% of people who have received inpatient treatment still meet full diagnostic criteria or have remaining ED symptoms at long-term follow-up (van Hoeken & Hoek, 2020).

Wider transdiagnostic theories can support understanding of ED recovery outcomes. One such theory is the Transtheoretical Model (TTM) of change (Prochaska & DiClemente, 1982; Prochaska et al., 1992). The TTM provides a framework for conceptualising motivation for making behaviour changes. It recognises that behaviour change is a gradual process, progressing through five stages: precontemplation (unaware of the problem, no intention to change), contemplation (aware there is a problem, but not yet committed to change), preparation (preparing to make change), action (changing behaviour), and maintenance (working to maintain change). ED treatment delivered to precontemplators and contemplators is unlikely to lead to sustained recovery, particularly once the pressure to change, from supporters or professionals, is no longer present (Raihan & Cogburn, 2023). Progression through the stages for PwEDs may be more dynamic than linear (Raihan & Cogburn, 2023; Waller, 2012). Nonetheless, various studies have shown positive associations between higher pre-treatment motivation to change and better treatment engagement and outcomes (Sansfaçon et al., 2020; Vall & Wade, 2015). Whilst the TTM has been criticised, e.g., stage progression is not always followed by actual behaviour change (Brug et al., 2005), and it has been suggested there may be different stages of maintenance (West, 2005), the TTM may be considered a helpful clinical heuristic that facilitates a less judgemental view of those not ready for change or those who relapse (Sussman et al., 2022).

Lived Experience Perspective of Treatment and Recovery

Current policy landscapes increasingly advocate for lived experience involvement in the design, delivery, and improvement of mental health services (National Collaborating Centre for Mental Health, 2019; Tindall et al., 2021). As such, emerging research explores the lived experience perspective of ED treatment. For example, Babb and colleagues (2022) reviewed qualitative studies exploring PwEDs' general experiences of ED treatment. This review called for more individualised care and psychological support. Whilst valuable, it did not specifically focus on recovery. It also only identified studies exploring inpatient and outpatient experiences and explored perspectives across the lifespan. However, there are differences in ED treatment accessibility and delivery between child, adolescent and adult services. For example, the duration of untreated ED (DUED) varies strongly between age groups, with a younger age seeing a shorter DUED (Austin et al., 2021) and in child and adolescent ED treatment, greater emphasis is placed on family involvement (Lock, 2018; Nilsen et al., 2021). Moreover, studies have explored PwEDs' perspectives of other treatment settings (e.g., day-patient or medical admissions), which may add important insights.

Other reviews seek to conceptualise ED recovery from the lived experience perspective. These have led to recovery being described as a complex psychological process that requires commitment, responsibility, development of insight into the function and consequences of the ED, a process of acceptance by others and of the self and development of meaningful relationships (Stockford et al., 2019). Recovery is also seen to include remission of ED symptoms alongside psychological well-being and adaptability, and involves hope, reclaiming identity, meaning and purpose, empowerment and self-compassion as key components (Bardone-Cone et al., 2018; de Vos et al., 2017; Wetzler et al., 2020). Whilst valuable findings, these reviews do not focus specifically on what aspects of treatment help or hinder recovery.

More recently, two qualitative reviews synthesised literature exploring the lived experience of inpatient treatment for all EDs (Peebles et al., 2023) and AN only (Rankin et al., 2023) within ED-specific treatment settings. These reviews highlight the complex and multifaceted nature of inpatient experiences and the importance of person-centred treatment that involves medical and psychological intervention (Peebles et al., 2023; Rankin et al., 2023). Undeniably, these reviews provide insight into a neglected area of research. However, they include differing all-age studies with some but not total overlap (Peebles et al., 2023, n= 28; Rankin et al., 2023, n=11; overlap, n=8) and exclude studies exploring different intensities and aspects of intensive treatment (such as the experience of detention). Many move through different intensive treatments, some outside ED-specific treatment settings, and all aspects of intensive treatment may relate to recovery. Elucidating what helps and hinders recovery during intensive treatment for adults with EDs remains undetermined.

Rationale and Aims of this Review

This review aimed to systematically review and thematically synthesise literature exploring the lived experience of intensive treatment for adults with EDs. With a focus on recovery, it sought to elucidate what helps and hinders recovery across all types and aspects of intensive treatment and to provide recommendations for research and clinical practice.

Methodology

Search Strategy

This systematic review was conducted in line with Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021) and was pre-registered on PROSPERO (ID: CRD42023426052). Systematic literature searches were carried out using electronic databases (EMBASE, MEDLINE, PsychINFO, and Web of Science), searched from conception to 6th June 2023. Additional papers were identified through Google Scholar and backwards citation searching of included articles. Search terms and inclusion and exclusion criteria were formed using the ‘Sample, Phenomenon of Interest, Design, Evaluation and Research type’ (SPIDER) tool (Cooke et al., 2012). The search strategy employed was informed by preliminary internet searches and previous reviews. It covered four concepts: (1) EDs, (2) intensive treatment, (3) qualitative methodology, and (4) lived experience. Various combinations of search terms were trialled before settling on a broad search strategy that explored all free text to maximise search sensitivity.

Table 1.

SPIDER Search Terms and Boolean Operators.

Sample AND	Phenomenon Of Interest AND	Design AND	Evaluation	Research Type
eating disorder* OR anore* OR bulimi* OR binge* OR EDNOS OR OSFED OR ARFID	inpatient OR IP OR intensive OR admission OR eating disorder unit* OR acute OR day patient OR day treatment OR day hospital* OR partial hospital*	qual* OR mixed method* OR case study OR content analysis OR discourse analysis OR ethnography OR exploratory OR focus group OR grounded theory OR interview* OR narrative OR phenomenology OR phenomenological OR thematic analysis	experience* OR attitude* OR perspective* OR view* OR reflect* OR interview*	N/A

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria are outlined in Table 2.

Table 2.

Inclusion and Exclusion Criteria.

	Inclusion criteria	Exclusion criteria
Sample	Focus on adults' experiences of intensive treatment related to an ED diagnosis. E.g., anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), eating disorder not otherwise specified (EDNOS), other specified feeding and eating disorder (OSFED), and avoidant restrictive food intake disorder (ARFID).	Focus on individuals with lived experience of intensive treatment related to another mental or physical health difficulty, on individuals with lived experience of only outpatient treatment for an ED, or on child and/or adolescent ED samples.
Phenomenon of Interest	Focus on the experience of current or past intensive treatment directly related to an ED diagnosis. E.g., specialist ED or general psychiatric inpatient treatment, day-patient treatment, partial hospitalisation, intensive community treatment or general medical admissions.	Focus solely on carers' experiences or healthcare professionals' experiences of intensive treatment for an ED.
Design	Qualitative methodology (or mixed methods methodology, if qualitative results are reported separately) and used a named, bona fide analytic approach.	Quantitative methodology.
Evaluation	Explicitly attempt to capture individuals' experiences, attitudes, perspectives, or views of any aspect of intensive treatment (e.g., overall experience, experience of an intervention, or exploration of a process).	Studies in which the qualitative data is minimal (e.g., no data extracts provided).
Research Type	Studies published in English. Studies published in reviewed journals.	Studies published not in English.

Quality Assessment

Though what constitutes “validity” or “quality” in qualitative research is debated, quality appraisal remains a crucial part of any review (Garside, 2014). The Critical Appraisal Skill Programme (CASP) checklist, a commonly used research appraisal tool, offers ten questions that facilitate assessment of qualitative studies. The Cochrane Qualitative and Implementation Methods Group recommends to avoid providing numerical scores, as CASP is not recommended as an absolute score of quality (Noyes et al., 2018). Instead, studies are considered according to whether criteria are: “yes well addressed”; “can’t tell”; or “no not addressed”. In this review, “can’t tell” was chosen when insufficient information was reported to make a judgement, as quality issues may be due to poor methodology and/or inadequate reporting (Carroll et al., 2012; Long et al., 2020).

Given the large number of studies in this review, whilst absolute scores were avoided, quality appraisal was used to organise the thematic synthesis, as has been recommended previously (e.g., Boeije et al., 2011; Long et al., 2020). This meant studies (n=10) for which “yes” was chosen for all ten questions were first reviewed to generate the coding framework. This was used to code the remaining studies. When particularly meaningful, new codes were generated. No studies were deemed to be low quality, as all studies provided valuable contributions to a limited evidence base. If there had been low quality studies, no new codes would have been generated, though these studies would not have been excluded.

Method of Synthesis

Thematic synthesis was chosen to integrate findings of multiple qualitative studies to answer a specific review question and extend what is already known (Thomas & Harden, 2008). All text from “results” or “findings” sections, and any findings in abstracts, were extracted and treated as data. Thematic synthesis followed three iterative stages. Stage one involved line-by-line coding of text according to meaning and content (e.g., Appendix A). Stage two involved grouping codes into hierarchical structures, to develop data-driven descriptive themes (e.g., Appendix B). Stage three involved generation of analytical themes through inference of descriptive themes, which go beyond the primary studies to generate new interpretive explanations.

Reflexivity

Reflexivity, the conscious, collaborative appraisal and critique of how one's subjectivity and context influence the research processes, is essential within qualitative research (Jamieson et al., 2023, Olmos-Vega et al., 2023). We, the author and supervisors, have psychology/psychiatry and academic and clinical backgrounds. The author is a trainee clinical psychologist with lived experience of an ED and academic and clinical experience in EDs/mental health. One supervisor is a clinical psychologist with academic and clinical experience in mental health, in particular with adults with experiences of psychosis, and the other is a consultant psychiatrist and expert in the field of EDs. One of us was an insider to the experience of ED treatment and we are all insiders to a culture of working in mental health services with often high levels of need and limited resource. We made every attempt to ensure potential biases were kept in awareness and endeavoured to pay attention to the full range of findings. Coding extracts and themes were discussed to check for disagreements or uncertainties before being finalised. Additionally, the first author kept a research diary and met with the second author for monthly supervision to support continuous self-reflection.

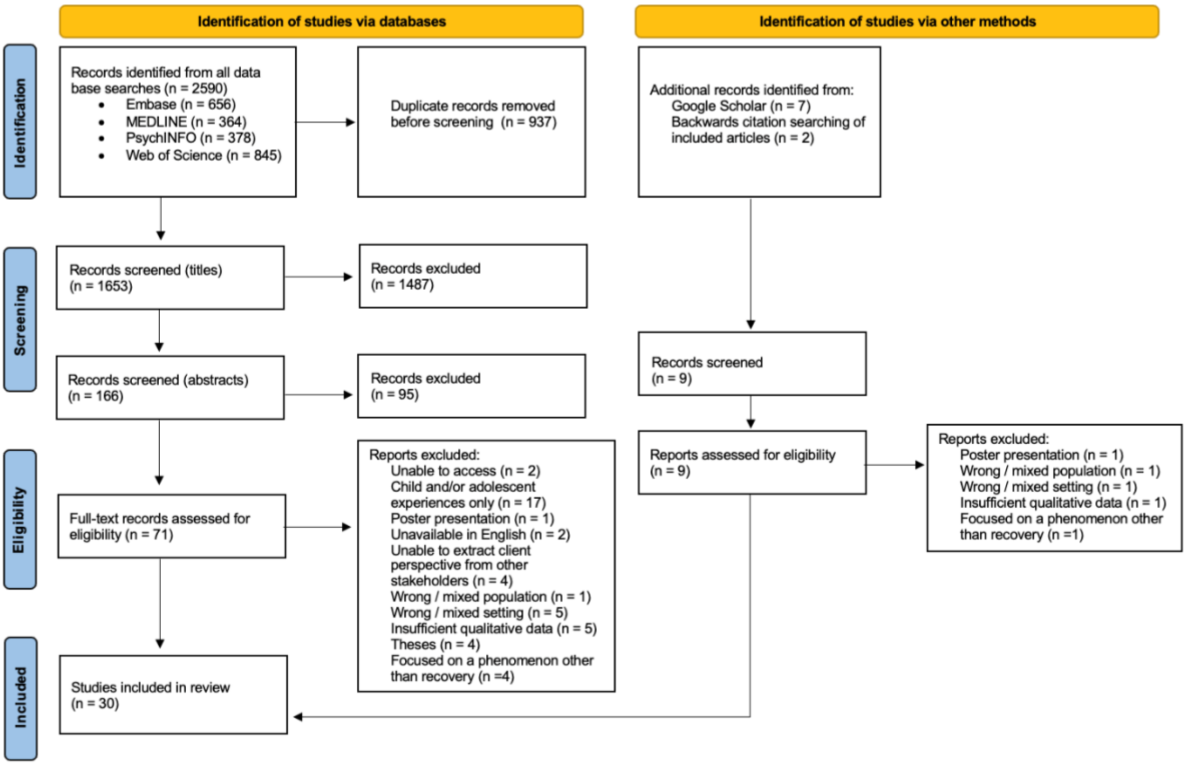
Results

Studies Identified

The PRISMA flow diagram (Figure 1) displays the search results. Thirty papers were identified as relevant. These are summarised in Table 3.

Figure 1.

PRISMA Flow Diagram.



Included studies totalled 495 participants ranging from 17 to 56 years. Ninety-six percent identified as female, 2% identified as male, 0.4% identified as non-binary and 0.6% were not reported. Sixty-five percent of participants were diagnosed with AN, 6.3% with BN, 0.6% with BED, 9.1% with EDNOS, 0.4% with OSFED, and 18.6% as missing or not reported. Ethnicity data were not reported in 22 studies. When ethnicity data were reported, 98.9% of participants identified as white (94/95 participants in reporting studies) and 1% identified as Other.

Included studies were predominantly conducted in the UK (N = 17). Other countries included Australia (N = 4), Canada (N = 3), Sweden (N = 2), Denmark (N = 1), Israel (N = 1), Norway (N = 1) and the USA (N = 1). Most studies focused on specialist inpatient units only (N = 19), with three studies focusing on inpatient and day-patient settings and one study focusing on inpatient and general psychiatric units. Three studies focused on day-patient settings only and two studies focused on medical settings only. One study focused on intensive community treatment and one study did not report the setting (though it focused on experiences in intensive settings). Most (27/30) studies did not report length of stay and those that did reported a wide range of 0.14 to 27 months.

Recruitment was carried out using various methods, inviting both current and past receivers of treatment. A range of data analysis approaches were used, though half of the studies used thematic analysis. Most studies (N = 23) used semi-structured interviews. Other data collection methods included open-ended questions in discharge/feedback questionnaires, narrative interviews, focus groups, diary entries and medical documents.

Table 3.

Included Study Characteristics.

Author(s), Year and Location	Aim(s)	Sample Characteristics: size (N), age, gender, ethnicity, diagnosis (Dx)	Treatment Setting, Length of Stay (LoS)	Recruitment	Data Analysis and Data Collection
Biddiscombe et al., 2018 Australia	To explore the experience of occupational therapy food groups in supporting functional recovery in an adult ED day program.	N = 99 Age: 26 (17-41) Gender: 98% F, 1% M Ethnicity: NR Dx: 11% AN, 30% BN, 3% BED, 45% EDNOS, Missing 10%	Setting: Specialist day-patient (4 days / week) LoS: 0.14 – 27 weeks	Invitation to past patients upon discharge from day program during a specified period Open ended questions (discharge and follow up questionnaires)	Thematic Analysis
Clark Bryan et al., 2022 United Kingdom	To explore the process of transitioning from intensive treatment to the community.	N = 11 Age: 24.8 (16.8-32.8) Gender: 87% F, 13% M Ethnicity: 100% White Dx: 100% AN	Setting: Specialist inpatient and day-patient (various) LoS: NR	Invitation to past patients post discharge from intensive treatment during a specified period Semi-structured interviews	Thematic Analysis

Cockell et al., 2004 Canada	To identify factors that help or hinder the maintenance of change and the promotion of recovery during the 6 months following ED treatment.	N = 32 Age: 27.9 (17.8-38) Gender: 100% F Ethnicity: NR Dx: NR	Setting: Specialist inpatient (15-week program) LoS: NR	Invitation to past patients 6 months post discharge from inpatient treatment Semi-structured interviews	Grounded Theory
Eli, 2014 Israel	To explore the experiences of specialist ED inpatient treatment in Israel.	N = 13 Age: NR (18-38) Gender: 92.3% F, 7.7% M Ethnicity: NR Dx: 92.3% AN, 7.7% BN	Setting: Specialist inpatient LoS: NR "considerable variations"	Invitation to past patients through various sources years after admission, as part of a longitudinal anthropology study Semi-structured interviews	Interpretative Phenomenological Analysis
Federici & Kaplan, 2008 Canada	To explore views of relapse and recovery in the first year following intensive treatment.	N = 15 Age: 26 (19.5-32.5) Gender: 100% F Ethnicity: 100% White Dx: 100% AN	Setting: Specialist day-patient and inpatient LoS: NR	Invitation one year following discharge to past patients with discharge BMI ≥ 20 Semi-structured interviews	Phenomenological Approach
Fox & Diab, 2015 United Kingdom	To explore experiences of living with and being treated for chronic AN in an inpatient treatment setting.	N = 6 Age: 27 (19-50) Gender: 100% F Ethnicity: 100% White British Dx: 100% AN	Setting: Specialist inpatient LoS: 4-27 months	Invitation to current inpatients during a specified period Semi-structured interviews	Interpretative Phenomenological Analysis

Hannon et al., 2017 United Kingdom	To explore experiences of long term intensive community treatment for individuals with severe AN.	N = 5 Age: NR (23-30) Gender: 100% F Ethnicity: 100% White British Dx: 100% AN	Setting: Intensive community treatment LoS: NR	Invitation to current and past patients who had received a full package of treatment during a specified period Semi-structured interviews	Interpretative Phenomenological Analysis
Hedlund & Landgren, 2017 Sweden	To elucidate experiences of receiving acupuncture as a complement to treatment as usual in inpatient treatment.	N = 9 Age: 30 (22-55) Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient LoS: NR	Invitation to current patients receiving acupuncture during a specified period Narrative interviews	Phenomenological Hermeneutic Method
Holmes et al., 2021 United Kingdom	To explore the experience of trust in inpatient treatment.	N = 14 Age: NR (20-42) Gender: 100% F Ethnicity: 78.6% White British, 21.4% White Jewish, 7.1% White American, 7.1% Other Dx: 100% AN	Setting: Specialist inpatient (various) LoS: NR	Invitation to past patients through an ED charity website and social media Semi-structured interviews	Thematic Analysis

İnce et al., 2023 United Kingdom	To explore the intensive treatment experiences of individuals with severe AN and their carers.	N = 6 Age: NR Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient and day-patient (various) LoS: NR	Invitation to past patients via email after routine 6-month follow-up assessment questionnaire completion Semi-structured interviews	Thematic Analysis
Larsson et al., 2018 United Kingdom	To explore experiences of a perfectionism group intervention during inpatient treatment.	N = 14 Age: 27.4 (19.7-35.1) Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient LoS: NR	Invitation to current patients following completion of perfectionism group during a specified period Focus groups	Thematic Analysis
Long et al., 2011 United Kingdom	To investigate inpatient perceptions of mealtimes on specialist ED units.	N = 12 Age: 22.1 (17.4-29.5) Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient (various) LoS: NR	Invitation to current inpatients from ED units (three public, one independent) during a specified period Semi-structured interviews	Thematic Analysis

MacDonald et al., 2023 Denmark	To explore experiences of patient with AN who have experienced multiple involuntary treatment events.	N = 7 Age: NR (states 20s-30s) Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: NR LoS: NR	Invitation to past patients of specialised units, the Danish patient organization, and the Danish Society for EDs (via flyers, websites, social media) Semi-structured interviews	Thematic Analysis
Matthews et al., 2019 Australia	To examine development and implementation of a day treatment program from patient and provider perspectives.	N = 11 Age: NR (17-33) Gender: 100% F Ethnicity: NR Dx: 81.8% AN, 18.1% Missing	Setting: Specialist day-patient LoS: NR	Invitation to all patients attending the day patient program during a specified period Semi-structured interviews	Framework Method
Matthews-Rensch et al., 2023 Australia	To describe the acceptability of a 7-day nasogastric refeeding protocol with adults with medically unstable EDs and staff involved in their treatment.	N = 8 Age: 22 (18-27) Gender: 100% F Ethnicity: NR Dx: 75% AN, 25% OSFED	Setting: Acute – medical stabilisation LoS: NR	Invitation to all participants undergoing refeeding during a specified period Semi-structured interviews	Framework Method

Money et al., 2011 United Kingdom	To explore patients' experiences of CREST (Cognitive Remediation and Emotion Skills Training) during inpatient treatment.	N = 28 Age: 25 (13-40) Gender: 96.4% F, 3.6% M Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient LoS: NR	Invitation to current patients who had completed CREST during inpatient treatment during a specified period Open ended questions, as part of end of therapy reflection form.	Content Analysis
O'Connell, 2023 United Kingdom	To examine one individual’s lived experience of the diagnosis and treatment of anorexia nervosa.	N = 1 Age: NR Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient (various) LoS: NR (study relates to four admissions)	Not applicable. Personal diaries and community and hospital medical records.	Autoethnography
Pemberton & Fox, 2013 United Kingdom	To understand factors important in the care and emotional management of EDs in inpatient treatment.	N = 8 Age: NR (states that 7 were under 25) Gender: 87.5% F, 12.5% M Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient (two, one also with an intensive care unit) LoS: 0.5 – 6 months	Invitation to current patients of two inpatient units during a specified period Semi-structured interviews	Grounded Theory
Rienecke et al., 2023 United States of America	To understand the patients’ perspectives of involuntary treatment in an acute medical stabilisation unit.	N = 30 Age: 30.8 (20-54) Gender: 87% F, 10% M, 3% non-binary Ethnicity: 100% White Dx: 100% AN	Setting: Acute – medical stabilisation LoS: 7-74 days	Invitation to past patients who had been admitted involuntarily to the acute medical stabilisation unit. Semi-structured interviews	Thematic Analysis

Ross & Green, 2011 United Kingdom	To consider whether inpatient admission was a therapeutic experience for two women with AN.	N = 2 Age: NR (states both >18) Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: Specialist IP inpatient LoS: NR	Invitation to current patients during a specific period Semi-structured interviews	Thematic Analysis
Seed et al., 2016 United Kingdom	To explore how people with AN experience detention under the Mental Health Act and how these experiences impact on recovery.	N = 12 Age: 28.1 (18-43) Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient (various) LoS: NR	Invitation to current and past inpatients with experience of detention trough one independent ED service, two National Health Service ED services, and an ED charity website Semi-structured interviews	Grounded Theory
Sly et al., 2014 United Kingdom	To examine the experiences of developing therapeutic alliance during inpatient treatment for an ED.	N = 8 Age: 25 (18-34) Gender: 100% F Ethnicity: 100% White Dx: 100% AN	Setting: Specialist inpatient LoS: NR	Invitation to current inpatients during a specific period Semi-structured interviews	Interpretative Phenomenological Analysis
Smith et al., 2016 United Kingdom	To explore the experiences of women currently undergoing specialist inpatient treatment for AN.	N = 21 Age: 25.2 (18-41) Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient LoS: 2-28 weeks	Invitation to current inpatients through a patient community meeting Semi-structured interviews	Thematic Analysis

Solhaug & Alsaker, 2021 Norway	To explore how patients with severe EDs experience inpatient treatment, and how they value the impact of their experiences in treatment.	N = 3 Age: NR (18-30) Gender: NR Ethnicity: NR Dx: NR	Setting: Specialist inpatient LoS: NR	Invitation to current inpatients during a specified period Diary entries	Thematic Analysis
Strand et al., 2017 Sweden	To explore patients' experiences of participating in a self-admission program at a specialist ED unit.	N = 16 Age: 31 (18-56) Gender: 94% F, 6% M Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient LoS: NR	Invitation to current and past inpatients enrolled in a self-admission program Semi-structured interviews	Content Analysis
Whitney et al., 2008 United Kingdom	To explore more widely service users' experiences and perspectives towards receiving CRT (Cognitive Remediation Therapy) during inpatient treatment.	N = 19 Age: 30.3 (17-54) Gender: 100% F Ethnicity: NR Dx: 100% AN	Setting: Specialist inpatient LoS: NR	Invitation for feedback from current patients receiving CRT during their penultimate CRT session. Feedback letters	Grounded Theory
Williams et al., 2020 Canada	To explore the characteristics, outcomes and experiences of young adults accessing residential ED treatment.	N = 39 Age: 20.2 (1-24) Gender: 97.4% F, 2.6% non-binary Ethnicity: NR Dx: NR	Setting: Specialist inpatient LoS: 1-4.6 months	Invitation to current inpatients during a specified period Semi-structured interviews	Thematic Analysis

Wright & Hacking, 2012 United Kingdom	To explore the lived experience of therapeutic relationships between women with AN and their healthcare professionals.	N = 6 Age: NR (21-44) Gender: 100% F Ethnicity: 100% White British Dx:100% AN	Setting: Specialist day-patient LoS: NR	Invitation to current day-patients and their healthcare professionals during a specified period Semi-structured interviews	Thematic Analysis
Yim et al., 2023 United Kingdom	To explore patients' experiences and perceptions of the utility of clinical team meetings (ward rounds).	N = 6 Age: NR Gender: 100% F Ethnicity: NR Dx: NR	Setting: Specialist inpatient LoS: NR	Invitation to current inpatients during a specified period Focus groups and one semi-structured interview	Thematic Analysis
Zugai et al., 2018 Australia	To understand the nature of therapeutic alliance between nurses and patients with AN in inpatient treatment.	N = 34 Age: 20 (NR) Gender: 97% F, 3% M Ethnicity: NR Dx: 100% AN	Setting: Mixture of specialist ED and general mental health inpatient units LoS: NR	Invitation to current inpatients with experience of at least 1 week of treatment in one of six inpatient wards. Semi-structured interviews	Thematic Analysis

Note. BMI = Body Mass Index; NR = Not Reported; LoS = Length of stay; F = Female; M = Male; AN = Anorexia Nervosa; BN = Bulimia Nervosa; BED = Binge Eating Disorder; EDNOS = Eating Disorder Not Otherwise Specified; OSFED = Other Specified Feeding and Eating Disorder.

Quality Appraisal

Included studies were of variable quality, but none were considered inadequate (see Table 4). All studies provided clear statements of the aims and appropriateness of qualitative methodology. The research design was unclear in three studies (Long et al., 2012; MacDonald et al., 2023; Solhaug & Alsaker, 2021) and one study (Fox & Diab, 2015) did not explain consideration of ethics. Ten studies did not describe their recruitment strategy and 13 studies did not provide any/adequate consideration of the relationship between the researcher(s) and participants. This contrasted with many studies that provided clear descriptions of their recruitment strategy (e.g., Rienecke et al., 2023; Sly et al., 2014) and researcher reflexivity (e.g., Cockell et al., 2004; Matthews et al., 2019). Analyses were of variable quality, with some studies providing more-in-depth analyses and others providing more descriptive analyses. Nonetheless, all studies showed sufficient rigour, providing clear statements of findings and situating these within the wider literature.

Studies varied significantly in the time-point of data collection (e.g., during treatment, immediately after, retrospectively or a combination), with only some reflecting on the chosen time-point(s). Most studies focused on experiences relating to specialist inpatient treatment and only some adequately described the treatment setting. Moreover, several studies did not provide key participant characteristics, samples were not representative and no study focused exclusively on any ED other than AN.

Table 4.

CASP Quality Appraisal.

Author	1)	2)	3)	4)	5)	6)	7)	8)	9)	10)
Biddiscombe et al., 2018	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Yes	Yes	Yes	Yes
Clark Bryan et al., 2022	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Cockell et al., 2004	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Yes	Yes	Yes	Yes
Eli, 2014	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes
Federici & Kaplan, 2008	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Fox & Diab, 2015	Yes	Yes	Yes	Can’t tell	Yes	Yes	Can’t tell	Yes	Yes	Yes
Hannon et al., 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Hedlund & Landgren, 2017	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes
Holmes et al., 2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
İnce et al., 2023	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes
Larsson et al., 2018	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes
Long et al., 2011	Yes	Yes	No	Can’t tell	Yes	Can’t tell	Yes	Yes	Yes	Yes
MacDonald et al., 2023	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Matthews et al., 2019	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes
Matthews-Rensch et al., 2023	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes
Money et al., 2011	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
O'Connell, 2023	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes
Pemberton & Fox, 2013	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes
Rienecke et al., 2023	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes
Ross & Green, 2011	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Seed et al., 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sly et al., 2014	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes
Smith et al., 2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Solhaug & Alsaker, 2021	Yes	Yes	No	Can’t tell	Yes	Can’t tell	Yes	Yes	Yes	Yes
Strand et al., 2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Whitney et al., 2008	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes
Williams et al., 2020	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Yes	Yes
Wright & Hacking, 2012	Yes	Yes	Yes	Can’t tell	Yes	Can’t tell	Yes	Yes	Yes	Yes
Yim et al., 202Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Zugai et al., 2018	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Yes	Yes	Yes

Note. 1) = Clear statement of aims; 2) = Appropriate methodology; 3) = Appropriate research design; 4) Appropriate recruitment strategy; 5) Suitable data collection; 6) Adequate consideration of relationship between researcher and participants; 7) Consideration of ethical issues; 8) Rigorous data analysis; 9) Clear statement of findings; and 10) Valuable research.

Thematic Synthesis

Six themes were generated from the data: Collaborative Care Supports Recovery; A Safe and Terrifying Environment; Negotiating Identity; Supporting Mind and Body; The Need for Specialist Support; and The Value of Close Other. Themes and subthemes are outlined in Table 5 and discussed below. Where direct participant quotes are used, as opposed to authors' interpretations, this is indicated in brackets. Additional illustrative quotes are outlined in Appendix C.

Table 5.

Themes and Subthemes.

Theme	Subthemes
Collaborative Care Supports Recovery	Active Involvement in Treatment Temporarily Handing Over Responsibility
A Safe and Terrifying Environment	A Bubble that was Hard to Replicate A Punitive, Distressing Environment
Negotiating Identity	Separating the Self and the ED Beginning to Want Something Different
Supporting Mind and Body	Weight Restoration and Dietary Change Psychological Awareness and Understanding
The Need for Specialist Support	Genuine Care, Alliance and Trust Skilled and Well Resourced Multidisciplinary Care
The Value of Close Others	Peer Support and Comparison Carer Support and Understanding Moving from Loneliness to Connection

Collaborative Care Supports Recovery

Active Involvement in Treatment

Collaborative care supported recovery across intensive settings. "W*orking together*" (Sly et al., 2014-Participant) and supporting PwEDs to "*make their own decisions*" (Rienecke et al., 2023) strengthened participants' motivation. However, particularly in inpatient settings, collaboration was "*often felt to be absent*" (İnce et al., 2023). Several studies identified that participants felt "*alienated from the decision-making process*" (Matthews-Rensch et al., 2023), especially those admitted involuntarily. Feeling unheard negatively impacted upon self-esteem and anxiety. Lack of transparency between PwEDs and treatment providers affected treatment experiences and subsequent recovery. Lack of clarity about ward rounds led to "*power differences… and anxiety*" (Yim et al., 2023). Participants in both studies exploring medical setting experiences voiced not knowing who was chiefly responsible for their care and "*feeling deceived or given a punishment*" (Matthews-Rensch et al., 2023-Participant) when starting a refeeding protocol or being detained, due to lack of information. This negatively impacted upon treatment engagement. One study identified that providers should make expectations and regimes clearer and repeat them frequently *"to ensure patients have time to process and understand them"* (Rienecke et al., 2023). In another study, the option to self-admit strengthened participants' agency and motivation, and promoted partnership. However, for some, it risked too much decision-making power – "*too much say… it'll be bad for me*" (Strand et al., 2017-Participant).

Collaboration was particularly key during transitions of care. Lack of information and "*uncertainty in what was going to happen*" (Matthews, 2019-Participant) contributed to fear and feeling overwhelmed, hindering ongoing recovery. Many studies concurred that "*a graded and planned discharge helped…* [re]*integration*" (Seed et al., 2016). This involved "*a phased, supportive approach*" (Clark Bryan et al., 2022), "*communication… with clear goals*" (İnce et al., 2023) and consideration of potential "*obstacles and challenges*" (Federici & Kaplan, 2008). Several studies identified that treatment intensity dropped too quickly, that little or no further support was offered or participants were placed on lengthy outpatient waitlists. Continuity of support was essential.

Temporarily Handing Over Responsibility

Whilst collaborative care generally supported recovery, there were instances in which, for short periods of time, participants found it helpful to not be so involved in care decisions. Several inpatient studies identified that, whilst challenging, many actually felt "*saved*" (Seed et al., 2016-Participant) when providers took responsibility. "*Handing over"* (Smith et al., 2016-Participant) control was sometimes viewed as a necessary step towards recovery.

However, for some, sudden loss of control contributed to heightened distress and "*amped up the ED*" (Rienecke et al., 2023-Participant). For those experiencing involuntary treatment in particular (e.g., forced nasogastric feeding) this led to disconnection from one's care. One study identified that "*hopelessness and resentment*" (Seed et al., 2016) developed. As Fox and Diab (2015) outlined, the ED "*gave participants a sense of control and a method of coping…*" and "*refeeding… led to an intense feeling of losing control" –* supporting participants to understand the reasons behind care decisions and to process the intensive emotions these activated appeared fundamental to recovery.

A Safe and Terrifying Environment

A Bubble that was Hard to Replicate

For some, the safety and security afforded by intensive treatment supported recovery. Inpatient and day-patient treatment granted "*permission*" (Seed et al., 2016-Participant; Matthews et al., 2019-Participant) to focus on recovery. Inpatients was described as a "*respite from overwhelming everyday demands*" (Strand et al., 2017). Participants felt they "*belonged somewhere*" (Ross & Green, 2011-Participant), finding "*comfort in predictable routines*" (Zugai et al., 2018). Inpatients also provided relief for carers. Several studies suggested non-negotiable boundaries supported change – "*completing meals was non-negotiable*" (O'Connell, 2023-Participant). Two studies recognised when healthcare professionals (HCPs) made alterations to rules, it gave the ED "*leverage to pathologically negotiate*" (Zugai et al., 2018). Nonetheless, one participant identified that the existence of certain rules (e.g., prohibiting of water loading) alerted them to new possibilities. It was recognised that the certainty and boundaries inpatients afforded was "*not easily replicated*" (Cockell et al., 2004). Their loss after discharge contributed to difficulties with continuing recovery. Indeed, inpatients was called a "*bubble*" (Seed et al., 2016; Smith et al., 2016-Participant), "*greenhouse*" (Eli, 2014-Participant) and *"lab…* [with] *very exact and measured conditions*" (Eli, 2014). It left participants "*frozen… and dependent on the unit*" (Smith et al., 2016). Various studies identified that intensive treatment (particularly inpatients) put "*life on hold*" (Clark Bryan et al., 2022-Participant). For some, this contributed to dependence on intensive treatment and the ED. As O'Connell (2023-Participant) outlined, the ED became "*the standpoint from which I related to others*". A few studies highlighted the importance of providers "*showcasing interest and highlighting aspects of patients' lives outside of their ED*" (Rienecke et al., 2023) to provide relief from institutionalisation and support motivation. As PwEDs transitioned out of intensive treatment, returning to or beginning careers, relationships, leisure and personal development activities supported "*a sense of routine and purpose*" (Clark Bryan et al., 2022).

A Punitive, Distressing Environment

Words such as "*miserable*", "*horrific*", "*hostile*", "*traumatic*", "*distressing*", "*inhumane*", "*terrifying*" and "*an assault*" were used to describe treatment (in inpatient and medical settings only). For some, feeling dehumanised, restricted, or traumatised negatively impacted upon motivation, engagement and subsequent recovery. Several studies suggested participants felt "*under inspection*" (Seed et al., 2016-Participant) and treatment was described as "*doing time*" (Holmes et al., 2021-Participant). "*Exposure to…* [and experiences of] *distressing events*" (İnce et al., 2023) were difficult - "*something I'll never forget*" (MacDonald et al., 2023-Participant). PwEDs sometimes experienced "*corrective measures as punitive or disciplinary*" (Zugai et al., 2018). Moreover, across several studies, participants felt certain boundaries were arbitrary, employed without adequate explanation, or "*rigid and unable to be maintained*" (Seed et al., 2016), leaving them feeling disempowered.

Negotiating Identity

Separating the Self and the ED

Across many studies, attachment to the ED hindered recovery. The ED afforded safety, control and confidence in its success and provided "*emotional and physical detachment*" (Hannon et al., 2017). Intensive treatment "*created a state of internal coercion*" (MacDonald et al., 2023). Several studies identified that a mismatch between treatment requirements and readiness to change could result in treatment refusal or termination. For those who experienced repeated admissions, lengthy stays or passing between services, "*feelings of hopelessness*" (Fox & Diab, 2015) and "*feelings of failure*" (Strand et al., 2017) were prevalent. Consequently, participants "*gripped more tightly onto AN*" (O'Connell, 2023-Participant).

Indeed, being "*reduced to a number and a disorder*" (Matthews-Rensch et al., 2023-Participant) in inpatient and medical settings hindered recovery. Various studies suggested participants felt defined by their illness and treated as "*a collective*" (Eli, 2014) or in accordance with "*an assumed group identity*" (Pemberton & Fox, 2013). This *"one-size-fits-all approach*" (Holmes et al., 2023-Participant) left participants feeling "*misunderstood, invalidated and stereotyped*" (O'Connell, 2013-Participant). There was desire for "*different tracks for people with different needs*" (Matthews-Rensch et al., 2023-Participant) and a wish for providers to "*humanise the patient*" (Rienecke et al., 2023). Indeed, personalised, flexible treatment supported recovery across intensive settings. Day-patients was viewed as more flexible than inpatients, though both groups desired a more *"tailored approach*" (Clark Bryan et al., 2022-Participant) (e.g., better consideration of differences in sexuality, gender identity and comorbidities). Intensive community treatment was considered individualised, with "*specific and obtainable goals*" (Hannon et al., 2017). Moreover, several studies highlighted that, for some participants, being supported to externalise the ED as separate to their sense of self - recognising "*AN as pathology separate to who they were*" (Zugai et al., 2018) - supported change and recovery.

Beginning to Want Something Different

Indeed, ambivalence towards treatment, particularly initially, was common. Recovery required moving from ambivalence to acceptance and/or determination. Reflecting back, one participant suggested others should "*surrender a little bit… trust in the treatment*" (Rienecke et al., 2023-Participant). For some, this was difficult. Several studies identified that compliance resulted in discharge, but not necessarily recovery. One participant "*humour*[ed]" (Federici & Kaplan, 2008-Participant) providers and another aimed to "*eat their way out*" (Seed et al., 2016-Participant). It was these participants where relapse was most likely. Self-criticism, shame, worthlessness and hopelessness kept participants stuck.

Conversely, several studies outlined the value of motivation. In their study exploring experiences of recovered versus relapsed PwEDs, participants' "*own drive*" (Federici & Kaplan, 2008-Participant) was prevalent in the recovered group. One participant described eventually "*wanting something different*" (O'Connell, 2023-Participant) and another study noted EDs require "*extremely hard work to be fought against*" (Hannon et al., 2017). Key to recovery was self-acceptance, hopefulness, and awareness and insight into the ED: "*compassion… and self-care*" (Seed et al., 2016) and "*a sense of self*" (Ross et al., 2011) were necessary.

Supporting Mind and Body

Weight Restoration and Dietary Change

Many participants retrospectively saw intensive treatment as "*saving lives*" (MacDonald et al., 2023), specifically regarding medical stabilisation. However, across inpatient and medical settings, participants struggled with discrepancy between "*normal* [weight restored] *bodies*" and continued "*anorexic thoughts*" (Federici & Kaplan, 2008-Participant), leading to other maladaptive behaviours or relapse. Overfocus on biological markers, for example "*micro-monitoring of the participant's weight*" (Holmes et al., 2021), negatively impacted recovery. Across studies, participants wished for a "*slow pace of change with focus on all aspects of their difficulties*" (Hannon et al., 2017).

Nonetheless, across specialist settings (i.e., not general medical), support in understanding and implementing dietary changes facilitated recovery. Meal support, plans and routines developed "*behavioural patterns that supported recovery*" (Cockell et al., 2004) and "*staff eating alongside*" (Long et al., 2012) normalised mealtimes. Nutritional education was also valued. Learning about "*daily nutritional requirements*" (Cockell et al., 2004) and "*their bodies' need for food*" (Solhaug & Alsaker, 2021) helped participants make dietary changes. Similarly, opportunities to engage in practical food groups (e.g., grocery shopping, outings to restaurants/cafes and meal preparation activities) were considered important and increased *"confidence to attempt repeating the challenges outside"* (Biddiscombe et al., 2018). Practicing dietary related cognitive skills and coping strategies supported a "*gradual shift to more independent eating*" (Williams et al., 2020).

Psychological Awareness and Understanding

Understanding what caused and maintained the ED arose as integral to recovery, through individual and group therapy and wider psychological support. Individual therapy supported PwEDs to understand the ED and "*challenge… maladaptive thinking styles and* *behaviours*” (Whitney et al., 2008). A “*strong* [therapeutic] *connection*” (Williams et al., 2020) was essential. Similarly, a range of therapeutic groups, including Cognitive Behavioural Therapy, Dialectical Behavioural Therapy and Maudsley Anorexia Nervosa Treatment for Adults groups, as well as perfectionism, mindfulness, and value-based groups, were appreciated. Many recognised *“the importance of sharing experiences and learning from each other”* (Larsson et al., 2018), though for a minority, the perceived intensity of groups was challenging. A holistic therapy, acupuncture, was “*relaxing, both emotionally and physically*” (Hedlund & Landgren, 2017) particularly after meals. Nonetheless, for some, therapy was “*too structured*” (Money et al., 2011-Participant). There was desire “*for more guidance and practice to help with real life application*” (Whitney et al., 2008) and several studies identified a need for longer therapeutic intervention. One study identified insufficient psychological input in ward rounds, though one participant did not want their formulation shared due to it being “*very personal*” (Yim et al., 2023-Participant).

Learning to identify, express and manage emotions emerged as beneficial across intensive settings. For example, developing strategies to “*manage… and label emotions*” (Money et al., 2011) and communicate one’s feelings supported recovery during and after treatment. Self-examination skills (e.g., journaling) helped PwEDs “*continue to work on recovery after discharge*” (Cockell et al., 2004). Indeed, several studies identified that emotional suppression and avoidance of negative affect limited progress.

The Need for Specialist Support

Genuine Care, Alliance, and Trust

Genuine care, trust and therapeutic alliance between PwEDs and HCPs was important for recovery. Participants wished to be treated with dignity and respect. They valued HCPs who were "*approachable and friendly*" (Sly et al., 2014-Participant), empathic and non-judgemental, and who validated and managed participants' emotions. For some, feeling cared for involved nurses adopting a "*motherly or sisterly role*" (Zugai et al., 2018) and HCPs who went "*beyond their roles*" (İnce et al., 2023-Participant; Wright & Hacking, 2012). Several studies noted the importance of strong therapeutic alliances with key workers, characterised by honesty, trust and openness. This promoted "*hope and optimism*" (Wright & Hacking, 2012) and led participants to feel "*held or supported*" (Hannon et al., 2017). Without a good keyworker relationship "*challenges could feel insurmountable*" (Sly et al., 2014).

Correspondingly, across several studies, feeling uncared for negatively impacted recovery. Participants sometimes felt dismissed, patronised or ignored. They struggled with HCPs who "*failed to follow through with promises*" (Seed et al., 2016), "*overlooked* [them] *in comparison to newly admitted patients*" (Smith et al., 2016), or offered a *"lack of a predictable response"* (Pemberton & Fox, 2015). Distrust between PwEDs and HCPs was "*an important precursor to some difficult interactions*" (Holmes et al., 2021). Described in several studies, conflict often led to further rebellion as the participant sought to "*retain their sense of control*" (Long et al., 2012). Poor connections resulted in increased anxiety and distrust, which impacted participants' self-esteem, motivation, and desire to remain in treatment.

Skilled and Well Resourced Multidisciplinary Care

Several studies outlined the importance of PwEDs being care for by a skilled and well-resourced multidisciplinary team, with "*staff from different disciplines… contributing to residents' recovery*" (Williams et al., 2020). Changing teams, HCP shortages and use of non-permanent staff decreased standards of care and hindered recovery. Well trained, skilled HCPs displayed empathy, understanding, knowledge and clear boundaries. Indeed, "*trust and* *belief in practitioner's expertise were… fundamentally important*" (Fox & Diab, 2015). Skilled HCPs separated the person from the ED, facilitated honesty and openness, and developed strong therapeutic alliances.

The Value of Close Others

Peer Support and Comparison

Peer support and comparison affected recovery. Across intensive settings, "*physical and behavioural comparisons*" (Smith et al., 2016) and competitiveness negatively affected *"group cohesion and personal recovery*" (Matthews et al., 2019). Many found it distressing and triggering being admitted alongside others at various stages of recovery and with differing levels of illness severity. Indeed, participants were susceptible to adopting *"new* [unhelpful] *ED practices*" (Eli, 2014). Participants in two studies described comparing themselves (not under section) to those under section. This comparison increased participants' guilt for choosing to eat and negatively impacted recovery. Correspondingly, participants in one study valued spending time with people without EDs who "*value aspects of life other than shape and weight*" (Cockell et al., 2004).

In contrast, many of the same studies recognised that being alongside other PwEDs also supported recovery. Peers who understood and were non-judgmental were valued and contributed to connectedness, acceptance and belonging. Peer support "*increased knowledge of effective coping skills and hope for recovery*" (Smith et al., 2016). Several studies noted participants made "*close and lasting friendships… through a sense of camaraderie*" (Eli, 2014). Relatedly, one participant valued a peer mentor who had "*been there and got through*" (Matthews et al., 2019-Participant).

Carer Support and Understanding

Carer support and understanding during, and upon leaving, intensive treatment supported recovery. Across settings, participants desired for carers to "*provide love, a listening ear*" (Rienecke et al., 2023-Participant), particularly "*during the transition period*" (Clark Bryan et al., 2022). Carer support groups were also valued. Returning home with "*insufficient or unhelpful social support*" (Biddiscombe et al., 2018), as well as "*continual emphasis on body weight and dieting within the family or social environment*" (Federici & Kaplan, 2008), hindered recovery.

Moving from Loneliness to Connection

Isolation hindered recovery. Particularly upon admission, participants described an emptiness, loneliness and difficulty trusting others. Difficulties developing and maintaining relationships contributed to negative attributions of the self and others and pushed participants further into their ED. Admissions sometimes exacerbated these difficulties as participants were removed from friends and family. Fostering "*meaningful connections after treatment*" (Cockell et al., 2004) and moving from "*loneliness… to interpersonal connection*" (Hannon et al., 2017) supported PwEDs to move towards recovery.

Discussion

This review explored what helps and hinders recovery during intensive treatment for PwEDs. Thematic synthesis revealed the complexity of ED treatment. Intensive treatment, which simultaneously attends to the physical and psychosocial symptoms of EDs, supports recovery. However, what was experienced as supportive or containing for someone could be experienced as restrictive or triggering for another - there is no one-size-fits-all approach (Kenny & Lewis, 2023).

Participants acknowledged that intensive treatment was often necessary, particularly with regards to biomedical recovery. As higher discharge BMI predicts more positive outcomes (for AN) (Glasofer et al., 2020), promoting adequate weight restoration remains a priority. Nonetheless, providers should be careful to not over-focus on biological markers and should ensure pace of change is acceptable to the individual. Consistent with existing literature (Rankin et al., 2023; Stockford et al., 2019), a biomedical focus often took precedence over addressing underlying psychosocial difficulties. Participants were weight-restored but not recovered and often discharged without a period of consolidation. Drawing upon the TTM (Prochaska et al., 2013), PwEDs may be being discharged without adequate step-down support before maintenance has been reached and sustained. This incongruity places PwEDs at higher risk of relapse following discharge (Bardone-Cone et al., 2018; Fennig et al., 2017).

Correspondingly, a therapeutic milieu during intensive treatment, comprising individual and group therapy and the wider therapeutic environment, was valued and necessary for recovery, though was not always present nor sufficient. Various psychological interventions supported PwEDs to develop insight into the function of their ED, what maintains it and who they could be without it. Moreover, concurring with literature that suggests difficulties with emotions are common among PwEDs (Ivanova & Watson, 2014; Lavender et al., 2015), support to identify, express and process emotions facilitated recovery. Externalisation arose as an important therapeutic technique (e.g., Dawson et al., 2014; Heywood et al., 2022), alongside consideration of individual differences such as neurodevelopmental difficulties, and physical and mental health comorbidities, which are prevalent among PwEDs and significantly impact upon symptomatology and outcomes (Hambleton et al., 2022). Participants' dislike of pathologization is significant, as it suggests clinicians may inadvertently be reinforcing an illness identity. Moving from an ED-dominated identity to develop a sense of self outside of the illness is crucial for recovery (Cruzat-mandich et al., 2017; Rankin et al., 2023).

Ambivalence, resistance to change and hopelessness hindered recovery. Commonly identified as barriers to recovery (Ali et al., 2017; Lindgren et al., 2015; Nordbø et al., 2012), if these factors were not attended to, change was difficult and relapse was likely. Many in intensive treatment may be stuck in earlier stages of change. Treatment compliance did not necessarily mean engagement with recovery. Imposing actions (e.g., through boundaries and routines) may be necessary for an individual's safety, but there is a risk that it drives them further into their ED, increasing resistance and decreasing motivation and compliance (Krebs et al., 2018). Where possible, treatment goals must be matched to stages of change. These findings support research highlighting the role of hope (Wetzler et al., 2020) and of instilling confidence in one's abilities (Iyar et al., 2019). HCPs and supporters must hold onto hope and actively share it. Additionally, these findings strengthen research emphasising the value of motivational interviewing, which normalises ambivalence and positions PwEDs' difficulties within the context of their values and goals (Weiss et al., 2013).

Consistent dietary support should be embedded into intensive treatment. Across intensive settings (except in medical settings, where they were not mentioned), structured mealtimes, meal support, modelling normal eating, meal plans, nutritional education, and food groups supported PwEDs to move through the stages of change towards recovery. Indeed, nutritional and psychological support have been described as "moving in tandem" (Jeffrey & Heruc, 2020, p.2). If one outpaces the other, progress might not be sustained. Supporting a small body of literature (Jeffrey & Heruc, 2020; Mack et al., 2023), dietary-related interventions supported PwEDs to practice adaptive coping strategies, improved eating behaviours and self-efficacy, and addressed social challenges associated with eating.

Compassionate and yet boundaried HCPs were essential for ED. Across intensive settings, collaborative, person-centred care strengthened hope, engagement and motivation to change. PwEDs desired active involvement in treatment, though for some, having responsibility removed initially was a necessary part of recovery. As clinicians have highlighted, balancing PwEDs' desires with beneficence can be challenging (Walker et al., 2020; Webb et al., 2022). Nonetheless, inpatients' often limited influence on, and knowledge of, their treatment has been highlighted in previous studies (Rankin et al., 2023; Waldemar et al., 2018). The dominant medical paradigm, that positions HCPs as expert authorities, may harmfully limit choice, autonomy and opportunities for treatment participation. When PwEDs feel they are not listened to or their needs are not being met, premature treatment termination may result (Vinchenzo et al., 2022). Whilst those in intensive settings are often at higher risk (Ayton et al., 2022), where possible, it remains important to offer choice and clear information. Though few in number, studies exploring day-patient and intensive community settings suggested they afforded greater choice and collaboration, though this may be as these settings generally support less severe ED populations (Irish et al., 2022).

Experiences of care were highly individual. At times, intensive environments facilitated recovery. They were safe and supportive, due to firm boundaries, clear routines, and, in inpatient settings, escape from life stressors. Yet, concurring with ED clinicians' concerns (Webb et al., 2022), intensive treatment (especially inpatient) contributed to treatment dependence and estrangement from life outside. Transitioning out of intensive treatment arose as a particularly vulnerable period, as individuals spiralled back into earlier stages of change. Day-patient and intensive community treatment discharges were experienced as somewhat more graded and skills learnt as more transferable, perhaps leading to a greater likelihood of maintenance. These findings underscore the value of intensive treatment but also the need for a gradual discharge process. Occupational therapists may be particularly well placed to support development of necessary skills for continuing recovery, supporting PwED's to identify purpose outside of the ED, cope with external triggers and resume educational, vocational and/or family roles (Mack et al., 2023).

Sometimes, intensive environments (in inpatient and medical settings only) were also experienced as restrictive and traumatising, due to these routines and boundaries, as well as experiences of coercion, scrutiny, and being subjected to, or witnessing, distressing practices. These iatrogenic factors may hinder recovery during treatment and have long-lasting effects, contributing to more severe psychopathology and/or trauma-related symptoms. To date, limited work has explored what aspects render the experience of psychiatric hospitalisation distressing, though experiences of coercion, stress and trauma appear common and distressing enough to be considered iatrogenic (Ward-Ciesielski & Rizvi, 2021). Moreover, whilst compulsory treatment can be necessary to save lives, the long-term effects are largely unknown (Elzakkers et al., 2014). If EDs are a way of coping with distressing life events, coercive and traumatic treatment experiences may drive stronger attachment to the ED (Elwyn, 2023; Sharpe et al., 2023).

Adding to the growing literature base surrounding the value of carer support for adults with EDs (Fleming et al., 2021; Hannah et al., 2022), carer support was valued when carers were able to understand the ED and challenges of treatment and offer empathy and validation. Given that carers' distress and ways of coping can inadvertently maintain or reinforce the ED (Treasure & Nazar, 2016), this finding affirms the necessity for carers to receive their own support (Hannah et al., 2022; Robinson et al., 2020). Currently, a range of carer interventions show positive outcomes for PwEDs undergoing intensive treatment, though implementation is patchy and research has predominately focused on young people with AN and the experiences of mothers (Hannah et al., 2022).

Peer comparison, competition and contagion were common in intensive settings and often reinforced the ED-dominant identity. Nonetheless, peer support and identification were also common, and frequently decreased isolation while motivating individuals towards recovery. One study also highlighted the value of a peer mentor. As a growing area of research and clinical practice, peer mentors may instil hope and increase motivation for treatment (Lewis & Foye, 2022). That treatment alongside other PwEDs was both helpful and hindering for recovery is a widely reported juxtaposition (Babb et al., 2022; Vandereycken, 2011; Webb et al., 2022). Peer influence appears to depend on dis-identification with the ED-dominant identity and identification with a recovery identity. Indeed, a sense of shared identity with others in ED recovery promoted recovery in an online support group (McNamara & Parsons, 2016). Specialist support is necessary and valued by PwEDs and this generally means PwEDs are treated alongside peers. Peer influence should therefore be considered as part of each individual's formulation, to explore the potential for support and harm and how this may relate to the ED identity.

Clinical and Research Implications

To enhance likelihood of ED recovery, a multidisciplinary approach is required across intensive settings. Supporting biomedical recovery remains fundamental, particularly in restoring physical health. However, psychological support is also necessary. Whilst several psychological treatments have evidence for use in outpatients, minimal evidence guides implementation of evidence-based practices in intensive settings (Chen & Kaye, 2018; Thompson-Brenner et al., 2018). Interventions that enhance motivation to change (MacDonald et al., 2012; Weiss et al., 2013), foster separation from an ED-dominant identity (Heywood et al., 2022; Lonergan et al., 2022; Schmidt et al., 2014) and support emotion recognition, regulation and expression (Harrison et al., 2021; Oldershaw, 2020) should be prioritised. Research must determine what works best for whom and why, tailoring processes to PwEDs' stages of change (Krebs et al., 2018), comorbidities (Hambleton et al., 2022) and unique needs, contexts and goals (Vinchenzo et al., 2022).

Specialist dietetic support should also be employed, as nutritional rehabilitation is necessary for recovery. Clinical psychologists will likely benefit from working collaboratively with dieticians. Dieticians possess unique skills and knowledge, but the extent to which they are involved in intensive ED treatment is largely unknown (Jeffrey & Heruc, 2020). Limited research guides the content of dietetic interventions or explores the effect of including dietetics (McMaster et al., 2021; Yang et al., 2021). Supporting a gradual reclaiming of responsibility for eating and providing opportunities to challenge fears, and practice food-related skills, supports continued ED recovery. Further research should explore what constitutes effective dietetic support across intensive settings (Mack et al., 2023; Yang et al., 2021).

This review outlines that time to consolidate recovery gains, alongside planned and phased discharges, is vital for ED recovery. Currently, limited guidance details how discharges should be implemented, though research has begun to explore novel ways to support intensive treatment transitions (e.g., Adamson et al., 2019). Intensive stepped-care treatment programs, for example the Integrated Enhanced Cognitive Behavioural Therapy (I-CBTE) stepped-care program for PwEDs that comprises time-limited inpatient, day-patient and outpatient treatment lasting 40 weeks in total (Dalle Grave, 2012; Ibrahim et al., 2022), highlights the value of longer-term multidisciplinary care for PwEDs. Further research must explore how to support movement from the action to maintenance stages of change, particularly as PwEDs return to daily life stressors.

Clinical practice guidelines recommend carer involvement in adult ED treatment (Hay et al., 2014; National Institute for Health and Care Excellence, 2017) and carers and PwEDs recognise the value of carer support (Bezance & Holliday, 2013; Treasure & Nazar, 2016). Providers should consider moving towards a biopsychosocial recovery-focused, person-in-environment perspective (Fleming et al., 2021; Smolak & Levine, 2015). Current carer support is inconsistent, interventions vary, and a sufficient evidence base is lacking, particularly for adult ED populations (Fleming et al., 2021, 2022). Carer capacity, skill and knowledge vary and interventions need to be tailored accordingly (Hannah et al., 2022; Treasure & Nazar, 2016). To develop more routine and individualised care, research needs to elucidate which carer interventions works best for whom and why, taking consideration of different carer types, EDs other than AN, and stages of illness and change (Fleming et al., 2021; Treasure & Nazar, 2016).

Perhaps most notably, this review highlights the complexity of intensive support for PwEDs. Findings highlight several dilemmas that clinicians face: helpful boundaries and containment versus restriction and coercion; peer support versus contagion; and physical versus psychological recovery. There is a clear need for sufficient resource, specialist training and opportunities for HCPs to engage in reflective spaces. Organisational pressures alongside client complexity mean HCPs can find working with PwEDs emotionally draining, leading to negative judgements, frustration, hopelessness and worry (Graham et al., 2020; Thompson-Brenner et al., 2018). Perhaps it is these feelings that lead HCPs to strive for a practice of safe-certainty (e.g., administering standardised protocols) (Graham et al., 2020). Time and space for reflection may support adoption of positions of safe-uncertainty, and consequently more flexible, person-centred approaches based on formulation and evidence-based interventions (Graham et al., 2020). It is increasingly being recognised that ED treatment must be individualised and holistic. This is no doubt challenging for services facing high demand with limited resource.

Nevertheless, ensuring secure, sensitive and collaborative relationships between PwEDs and HCPs can help solve some of these dilemmas. Specialist skills and knowledge support ED recovery (Gulliksen et al., 2012; Johns et al., 2019). Trust and openness reduces conflict and supports treatment engagement, and strong therapeutic relationships contribute to positive outcomes (Hartley et al., 2020). Within intensive settings, HCPs must balance firmness and empathy, communicating with clear boundaries to ensure certain behaviours are minimised whilst at the same time recognising and understanding the defensive nature of the ED and its adaptive function (Abbate-Daga et al., 2013). Future studies should explore what aspects of intensive treatment may be causing harm and any long-term effects. Moreover, there is need for specialist training and research into general medical settings, given the extent of negative experiences in this area.

Strengths and Limitations

This review brings together 495 participants' perspectives across thirty studies. To the author's knowledge, it is the first to explore what helps and hinders recovery during intensive treatment for adults with EDs. A rigorous methodological process was employed in the selection, evaluation and interpretation of studies. To ensure findings remained contextualised, details of each included article's aims, sample, setting, methods and methodological quality were included. It is hoped the clinical and research implications may guide development of intensive treatment for PwEDs and improve recovery outcomes.

A number of limitations must also be considered. Whilst CASP, the quality appraisal tool, helpfully draws attention to rigor and relevance, it is less sensitive to aspects of validity (Hannes et al., 2010). As such, CASP provided a scaffold to support thinking rather than being decisive. The majority of included studies explored inpatient treatment experiences. This made it hard to draw firm conclusions relating to other types of intensive treatment, though several notable findings arose nonetheless. Further research is needed into the lived experience of general medical, day-patient and intensive community treatment for PwEDs. Many studies inadequately described the treatment setting. Given the diversity of intensive treatment approaches for PwEDs, authors should endeavour to describe treatment settings adequately to support transferability of findings (Treharne & Riggs, 2014). Additionally, included studies varied in their timepoint of data collection and rarely commented upon participants' recovery status. As ED recovery involves a shift in identity and perspective, it would be helpful to better understand participants' recovery statuses and subsequently explore if participants' views on treatment change over time. Lastly, several key participant characteristics were lacking across included studies, and as has been identified previously, samples were not diverse. This limits the generalisability of findings to groups other than white women with AN. Yet, EDs can impact people from all backgrounds (Burke et al., 2023; Spratt et al., 2022). Researchers must include ethnicity data reporting, as its absence further maintains underrepresentation. Research prioritising the treatment experiences of marginalised groups is urgently required.

Conclusions

This review explores what helps and hinders recovery during intensive treatment for PwEDs. Support from a sufficiently resourced and adequately trained multidisciplinary team supports ED recovery. Findings emphasise the vital role psychological support and understanding can have in supporting PwEDs to move from an ED-dominant identity to a sense of self outside of the illness and the value of carers and peers who instil hope and offer empathy and validation. Nonetheless, HCPs face several challenges when supporting PwEDs in intensive settings, as what is helpful for one person may be harmful for another. A person-centred, biopsychosocial approach is necessary throughout all stages of treatment. Further research must evaluate patient- and carer-focused psychological interventions and the role of dietetic support during intensive treatment. It must also explore the long-term effects of, at times, coercive and traumatic treatment practices and determine how to mitigate against potential iatrogenic harm.

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Section B: Empirical Study

"They should understand that the anorexia drives me to do anything": Exploring the experience of general medical admissions for individuals with anorexia nervosa.

Word Count: 8000 (373)

Submitted in partial fulfilment of the requirements of Canterbury Christ Church University
for the degree of Doctor of Clinical Psychology

Salomon's Institute for Applied Psychology
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Abstract

Background: Anorexia nervosa is a complex mental health disorder associated with significant morbidity and mortality. Some people with anorexia nervosa require acute medical admissions to manage medical complications. Currently, little is known about how medical admissions are experienced, despite an increase in the number of individuals being hospitalised.

Methods: Ten individuals with experience of medical admissions in the UK, related to a diagnosis of anorexia nervosa, were interviewed between February and April 2023. Data were analysed using interpretative phenomenological analysis.

Results: Seven main themes were generated: (1) Overpowered by the Eating Disorder; (2) Fighting for Support; (3) Misunderstood and Overlooked; (4) (Un)safe and (Un)supported; (5) Treated as a Person, Not Just an Eating Disorder; and (6) Family: Relied Upon or Excluded.

Conclusions: Gratitude was expressed for medical intervention. However, a lack of psychological understanding meant participants felt misunderstood and stigmatised. Mental and physical health services were experienced as disconnected and close others sometimes had to shoulder significant responsibility for care. Clinical implications focus on enhancing training on eating disorders amongst medical professionals to improve care experiences. Compassionate, transparent and holistic care must be implemented. Research implications are outlined.

Keywords: eating disorders; anorexia nervosa, emergency care; patients’ perspectives

Introduction

Background to Anorexia Nervosa

Anorexia nervosa (AN) is a complex mental health disorder characterised by dietary restriction, significant weight loss, weight and shape disturbances and fear of weight gain (American Psychiatric Association, 2022). It is associated with significant morbidity and mortality (van Eeden et al., 2021), affecting various organ systems, and can lead to life-threatening medical complications and suicide (Arcelus et al., 2011; Golden et al., 2015). Many people with AN (PwAN) are also affected by comorbid psychological difficulties, such as anxiety, depression, or self-harm (Keski-Rahkonen & Mustelin, 2016).

Eating disorders (EDs) have a significant emotional and economic burden for sufferers, their supporters and wider society, and represent a substantial challenge for healthcare professionals (HCPs) (Ágh et al., 2016; Thomas & Becker, 2021; Thompson-Brenner et al., 2012). Prevalence of AN is widely debated, though incidence rates appear to be rising (Hay et al., 2023; Martínez-González et al., 2020). Moreover, prognosis is poor: relapse is common, and the course is often protracted and sometimes chronic (Keski-Rahkonen & Mustelin, 2016; Steinhausen & Jensen, 2015; Wonderlich et al., 2020).

The Role of Identity in AN

Erickson’s (1968) influential theory on identity formation describes how successful navigation of the ‘identity versus role confusion’ conflict results in the formation of an integrated identity. Identity disturbance, or unsuccessful navigation, was theorised to cause significant challenges to adult functioning. Others have since explored how identity disturbance may relate to psychological distress (Basten & Touyz, 2020; Potterton et al., 2022). Various theories suggest identity disturbance is at the core of AN (e.g., Amianto et al., 2016; Bruch, 1982; Casper, 1983; Goodsit, 1997; Oldershaw et al., 2019). Notably, whilst

AN can affect individuals of any age, peak onset is during late adolescence (Nagl et al., 2016) – a period of significant identity negotiation.

Current understanding suggests AN is caused by a complex interaction of biological, psychological, developmental, genetic, sociocultural, and environmental factors, though increasing research has explored psychological factors involved in its development and maintenance (Culbert et al., 2015; Smolak & Levine, 2015). Several recent theories outline the importance of identity disturbance in AN, related to factors such as attachment insecurities in childhood (Amianto et al., 2016; Tasca & Balfour, 2014), sociocultural influences (Smolak & Chun-Kennedy, 2015), and difficult life experiences (Lejonclou et al., 2014).

Schmidt and Treasure's (2006) cognitive-interpersonal maintenance model of AN focuses on the highly valued nature of AN. At the intrapersonal level, it proposes AN fulfils psychological needs and gives a sense of achievement and uniqueness. At the interpersonal level, it proposes ED behaviours develop as a means to gain social acceptance and reduce feelings of isolation, and over time can lead to sustained efforts from others to provide care. More recently, Oldershaw et al. (2019) suggest a lack of emotional attunement with early caregivers impacts emotional awareness and self-differentiation, which creates an overwhelming emotional experience and hinders identity formulation. ED symptoms arise to regulate and manage emotional experiences by focusing on tangible markers of identity (body weight and shape).

A recent synthesis on identity in AN concluded PwAN have significant identity disturbance and that identity is a crucial factor involved in recovery from AN (Croce et al., 2024). This helps to explain why recovery is so elusive, highlighting two key maintenance factors: resistance to treatment and the ego-syntonic nature of the illness (Abbate-Daga et al., 2013; Gregertsen et al., 2017). PwAN often fail to acknowledge the severity of their illness, perceiving their AN to be positive and adaptive (Bryant et al., 2022; Vandereycken, 2006). Whilst denial may serve many functions, it can lead to concealment or minimisation of symptoms and ambivalence towards treatment and recovery (Abbate-Daga et al., 2013), which, intensified by severe malnutrition, strengthens symptom severity and an illness identity (Tan et al., 2003). Treatment may therefore threaten an individual's sense of self. This serves as context for understanding medical admissions for AN, in terms of factors precipitating such admissions and how treatment is experienced.

Medical Admissions for PwAN

Treatment for PwAN generally follows a stepped-care model, aligning the intensity with the severity of the presentation (İnce et al., 2023). Outpatient psychological therapies are the first-line treatment, often alongside multidisciplinary input, though results are modest and there remains a need for improved interventions (Solmi et al., 2021). For PwAN not responding to community treatment, or requiring safer management, more intensive treatment such as day-patient or inpatient treatment, or general medical admissions, may be offered or enforced (Hay et al., 2019; Pehlivan et al., 2022).

The medical consequences of AN are wide ranging (Cass et al., 2020; Mehler & Brown, 2015). For those that are hospitalised, acute medical treatment can be lifesaving (Jafar et al., 2023; Jahraus, 2018). UK hospital admissions for PwEDs increased by 84% between 2015/16 and 2020/21 (Royal College of Psychiatrists [RCPsych], 2022a). Internationally, there has been an increase in the number of PwAN being admitted to general medical hospitals, with Covid-19 appearing to exacerbate this rise (e.g., Castellini et al., 2023; Milliren et al., 2023; Wong et al., 2023).

In the UK, the Recognising and Managing Medical Emergencies in EDs (MEED) report (RCPsych, 2022b) arose out of concerns that many PwEDs admitted to medical settings experienced suboptimal care, and in some cases, this led to avoidable deterioration and deaths (Parliamentary and Health Service Ombudsman, 2017). The RCPsych (2022b) highlighted that most medical services do not have sufficient expertise to manage the concurrent psychological, medical, nutritional, behavioural, and social difficulties presenting in AN. Consequently, they outlined procedures to ensure a safe and cohesive approach. Similar guidance exists internationally, though varies in defining risk and the need for hospitalisation (Jafar et al., 2023). Uptake of guidelines is known to be inconsistent and dependent on various factors, such as awareness and effective implementation (Fischer et al., 2016; Straus et al., 2009). Currently, little is known about how medical admissions are experienced and to what extent guidance is implemented in practice (Davies et al., 2017; O'Donnell & Meloncelli, 2023).

Experiences of Care in General Medical Settings

Research exploring experiences of care in general medical settings for clients with mental health difficulties highlights various challenges associated with managing simultaneous physical and mental health needs, such as diagnostic overshadowing, inadequate joint working, and stigma towards mental illness (Navas et al., 2022; Perry et al., 2020; Sacre et al., 2022). Clinicians experience emotional burnout and compassion fatigue, and clients experience a lack of empathy and validation from clinicians (Clarke et al., 2014; Foye et al., 2020; Navas et al., 2022; Sacre et al., 2022).

Research exploring experiences of care for PwEDs in general medical settings is more limited. Whilst clinicians' experiences of working with PwEDs in specialist settings has been explored (e.g., Seah et al., 2017), the experiences of clinicians working in general medical, rather than specialist settings, is scant and has been explored in just two studies. Davidson et al. (2019) explored medical doctors' (n=10) experiences of supporting PwEDs across two

Australian tertiary hospitals. These authors outlined that whilst non-specialist clinicians aim for a holistic, multidisciplinary approach, they require additional support and training to increase their confidence and ability to make effective treatment decisions. O'Donnell and Meloncelli (2023) explored HCPs' (n=48) knowledge and perceptions of caring for PwEDs in an Australian general hospital. Staff perceived ED clients to be challenging, lacked confidence in their abilities, and faced ambiguity in professional roles and responsibilities. Both studies called for research exploring PwEDs' perspectives of care in general medical settings.

Bravender et al. (2017) explored 23 adolescents' and 32 parents' perspectives of medical stabilisation and found that whilst medical stabilisation was key, acute admissions required better integration of mental and physical health services and were also an opportunity to activate clients regarding the need for ongoing treatment. The above study begins to address the dearth of literature, but focused on adolescents' experiences only. Yet, treatment for PwAN differs between children and adults (Herpertz-Dahlmann et al., 2021), and adults with AN have a longer duration of untreated ED and lower likelihood of admission (Austin et al., 2021; Wood et al., 2019).

Two recent studies have explored experiences of specific elements of medical hospitalisation in adults with AN, but not their overall experiences of care. Matthews-Rensch et al. (2023) explored PwAN (n=8) and staffs' (n=12) experiences of a nasogastric refeeding protocol in an Australian tertiary hospital and highlighted a need for better communication and concurrent oral feeding. Rienecke et al. (2023) explored involuntary treatment experiences for PwEDs (n=30) admitted to a medical stabilisation unit in the United States and outlined that whilst some participants retrospectively recognised involuntary treatment as beneficial, others continued to view it negatively, perceiving involuntary treatment as being traumatic and disempowering, and as negatively affecting external factors (e.g., disrupting employment). However, not all medical admissions involve nasogastric refeeding or involuntary treatment. No study, particularly in the UK context, has yet explored the overall experience of medical admissions for adults with AN.

The Current Study

This study, therefore, aims to address the literature gap and explore adults' perspectives of the experience of medical admissions for AN. PwAN admitted into general hospital are commonly severely unwell. Identity disturbance in AN serves as a context for understanding factors precipitating medical admissions and how medical admissions are experienced. This study sought to understand how PwAN make sense of the experience of admission, how treatment (and recovery) is incorporated into their sense of self, and whether perspectives on the experience change overtime. A qualitative approach was chosen to allow for an in-depth exploration of participants' experiences in a complex and largely unknown area (Willig, 2021). It is hoped that a better understanding of how PwAN make sense of medical admissions could help identify areas of strength and improvement.

This study aims to address the following research questions:

1) How do clients make sense of the experience of medical admissions for AN?
2) How is intervention (medical, psychiatric, psychological and dietetic) and support (from HCPs and carers) perceived and experienced?

Methods

Design

Qualitative methodology was deemed appropriate due to this being an exploratory study. Interpretative phenomenological analysis (IPA) was chosen as the methodological framework, as it is well suited to explore how individuals make sense of experiences in a particular context (Smith & Nizza, 2022). Sitting between critical realist and social constructionist perspectives, IPA is underpinned by three theoretical concepts: phenomenology, hermeneutics and idiography (Larkin & Thompson, 2011; Smith & Nizza, 2022). IPA adopts a hermeneutic phenomenological perspective, advocating that meaning for an individual will be influenced by the external world and previous understandings and that understanding is achievable by interpretation only. It assumes a centre-ground interpretative position, combining a hermeneutics of empathy with a hermeneutics of questioning (Smith & Nizza, 2022).

Service User Involvement

Consultation of experts-by-experience was instrumental in supporting the design of this study. This comprised consulting four experts-by-experience and one carer-by-experience, all with lived/caring experiences of an ED and hospitalisation, in an online 60-minute focus group. This covered development of the study title, inclusion criteria and interview guide (Appendix D). For example, consultation highlighted a preference for remote interviews for convenience and a sense of safety in one’s own environment and supported development of the interview schedule, with experts-by-experience facilitating development of questions that were curious, compassionate and supportive of the overall study aims.

Inclusion and Exclusion Criteria

IPA requires a sample that is fairly homogeneous in terms of factors related to key elements of experience (Smith & Nizza, 2022). Inclusion and exclusion criteria are outlined in Table 6. These were delineated through discussions with the research team (trainee, supervisors and consultants) and expert-by-experience focus group.

Table 6.

Inclusion and Exclusion Criteria.

Inclusion Criteria	Exclusion Criteria
Experience of one or more medical admission in the UK directly related to a self-reported diagnosis of anorexia nervosa.	Experience of only an inpatient psychiatric admission (in a general psychiatric unit or specialist eating disorder unit) related to a self-reported diagnosis of anorexia nervosa.
The medical admission(s) took place between six months and three years previously.	Currently undergoing inpatient treatment (medical or psychiatric) directly related to a self-reported diagnosis of anorexia nervosa.
Able and willing to reflect upon the experience of admission without being caused significant distress.	
Aged 18 or over at the time of admission.	
Able to communicate fluently in English.	

Recruitment

Participants were recruited via social media (Twitter) using opportunistic and snowball sampling. A recruitment poster (Appendix E) was shared and interested researchers, clinicians and organisations reshared the study.

Screening and Consent

Interested participants contacted the researcher via email. A screening call was arranged to determine eligibility using a screening form (Appendix F). Interested and eligible participants were then provided with a participant information sheet (Appendix G) and a consent form (Appendix H) via email. Participants were given the opportunity to ask questions about the study and were given one week to decide whether to take part before a follow up email was sent. Participants who wished to take part returned a signed copy of the consent form, which was then signed by the researcher before a final copy was returned to participants. Once consent was obtained, participants were sent a demographic information form (Appendix I) and invited to participate in a one-to-one semi-structured online interview at a time convenient to them.

Data Collection

A semi-structured interview schedule (Appendix J) was developed in collaboration with experts-by-experience and the research team. This was used as a guide, with participants' experiences leading the direction of discussion. Questions were open-ended, to invite curiosity, and prompts were included to support explorations and clarifications where necessary. Interviews were conducted via Microsoft Teams and were audio-recorded. Interviews lasted between 49 and 71 minutes and were transcribed verbatim.

Participants

In line with IPA guidelines (Smith & Nizza, 2022), this study aimed to recruit eight to ten participants. Eighteen participants approached the researcher. Six were excluded due to being currently admitted in medical or psychiatric hospitals or having been so in the preceding six months. Two did not respond to the invite for a screening call. Ten were deemed eligible and all were interviewed. Demographic information is outlined in Table 7. Participants all identified as White British, predominately identified as female (80%) and were in their twenties (M=28.5). Most had experienced more than one medical admission (M=4.2). Length of stay ranged from half a day to 93 days. Upon interviewing, participants were asked to focus their reflections upon admission experiences that occurred in the preceding three years, but were offered to include anything particularly notable from experiences outside of this timeframe.

Table 7.

Demographic Information.

Participant Pseudonym	Age	Gender	Ethnicity	Age of ED onset	Number of medical admission(s)	Length of medical admission(s)	Length of time since last admission
Lucy	23	Female	White British	21	5	2-8 days	2 years
Sarah	26	Female	White British	18	5	2-4 days	0.5 years
Tom	26	Male	White British	16	2	0.5-10 days	1 year
Anna	39	Female	White British	14	1	21 days	2.5 years
Tilly	29	Female	White British	12	16	7-56 days	2 years
Eliza	23	Female	White British	12	4	2 days	2.5 years
Harriet	23	Non-binary	White British	11	1	2 days	2 years
Clare	32	Female	White British	13	1	2 days	0.5 years
Olivia	24	Female	White British	18	6	2-4 days	2 years
Molly	40	Female	White British	15	1	92 days	1 year

Data Analysis

Analysis followed Smith and Nizza’s (2022) IPA process guidelines (Table 8). IPA is iterative and fluid, therefore steps were moved through flexibly and dynamically. Adopting the concept of the double hermeneutic, analysis is a cyclical process whereby the researcher tries to make sense of the participant trying to make sense of their experiences.

Table 8.

IPA Process Guidelines.

Step	Process	Description
1	Reading and re-reading	Beginning with the first interview, listen to the audio-recording whilst reading the transcript. Then, engage in repeated rereading to immerse oneself in the data.
2	Exploratory noting	Begin the initial noting of the first transcript, working in depth and detail. Begin to engage with the data at a more conceptual, interrogative and interpretative level. Discuss, reflect upon and refine ideas.
3	Constructing experiential statements	Construct experiential statements, which relate directly to the participant's experiences or to the experience of making sense of the things that happened to them.
4	Searching for connections across experiential statements	Consider how experiential statements fit together across the transcript, charting or mapping statements to organise the analysis. Move them around to explore possible connections and develop clusters.
5	Naming the personal experiential themes (PETs) and consolidating them	Give each cluster of experiential statements a title to describe its characteristics (a personal experiential theme: PETs) and divide into sub-themes as necessary. Organise these into a basic table for each participant.
6	Continuing the individual analysis of other cases	Move onto the next participant, repeating Steps 1 – 5. Treat each case as a complete universe of inquiry.
7	Developing group experiential themes (GETs) across cases	Begin the cross-case analysis. Look for similarities and differences across all PETs to create GETs, moving back and forth between the PETs, sub-themes and experiential statements. Highlight shared and unique features of participants' experiences.

Note. Adapted *from Interpretative Phenomenological Analysis: Theory, Method and Research,* by (Smith & Nizza, 2022). An extract of exploratory noting and experiential statements is outlined in Appendix K. An example table of PETs is outlined in Appendix L. The process of developing GETs from PETs is outlined in Appendix M.

Quality Assurance

Nizza et al.'s (2021) IPA-specific quality indicators were considered. Care was taken to ensure that the analysis told a compelling and coherent story, attended to convergence and divergence, included important experiential and/or existential meaning, and included fully analysed and interpreted quotes.

In addition, to enhance quality of this study, Yardley's (2000, 2019) four key principles for qualitative research studies were considered:

1) Sensitivity to context: Care was taken to ensure awareness of relevant literature.
2) Commitment and rigour: A thorough process of engagement with the topic, methodology, data collection and analysis were carried out. Participants were invited to engage in respondent validation (Appendix N), to explore whether interpretations fitted with participants' experiences and whether anything should be reconsidered.
3) Transparency and coherence: A detailed methodology is outlined, themes are supported with ample quotes and researcher reflexivity was considered throughout.
4) Impact and importance: Impactful and useful findings were generated and situated within the wider literature.

Reflexivity

Reflexivity refers to the continuous process of self-reflection that researchers engage in when conducting qualitative studies to bring their thoughts, actions, assumptions and expectations into awareness (Finlay, 2002). To support ongoing reflexivity, a research diary (Appendix O) was kept and the researcher engaged in regular supervision. In addition, the researcher carried out a bracketing interview with another trainee clinical psychologist. Bracketing, the process whereby the researcher attempts to put to one side their own pre-existing beliefs and assumptions, is important in IPA (Chan et al., 2013). "Empathic openness" within IPA involves a dance between bracketing pre-understandings (being conscious of and holding back prior assumptions, understandings or knowledge) and harnessing them as a source of insight (Finlay, 2008). The bracketing interview supported the researcher, a trainee clinical psychologist and individual with lived, clinical and research experience in EDs, to become aware of their belief that experiences of admissions would be fundamentally negative and to ensure any influence of these assumptions was minimised.

Ethical Considerations

Ethical approval was granted by the Salomons Institute for Applied Psychology Independent Research Review Panel (Appendix P). Informed consent was obtained from all participants. Identifiable information was removed from transcripts to maintain participant anonymity.

This study explored a time when participants were acutely unwell. The inclusion criteria and interview schedule were carefully delineated and a gentle, compassionate approach was upheld throughout. Participants were offered space to reflect on thoughts and feelings that the interview evoked and were signposted to NHS and charity resources (Appendix Q).

Results

IPA resulted in six themes (GETs). These themes and their respective subthemes are outlined in Table 9 and discussed below. Quotes are illustrated in *italics*.

Table 9.

An Overview of Themes and Subthemes.

Theme	Subtheme
1. Overpowered by the ED	*"In the grips of it"* *(Eliza, Harriet, Lucy, Olivia, Sarah, Tilly, Tom)*
	"It's woken me up" *(Anna, Eliza, Lucy, Molly, Sarah, Tom, Tilly)*
2. Fighting for Support	*"Deep down I wanted help"* *(Anna, Clare, Olivia, Sarah, Tom)*
	"It prompted them to take action" *(Eliza, Harriet, Lucy, Sarah)*
3. Misunderstood and Overlooked	*"They didn't seem to understand EDs"* *(Anna, Clare, Eliza, Harriet, Lucy, Molly, Olivia, Sarah, Tilly, Tom)*
	"Skewed in favour of medical intervention" *(Anna, Clare, Eliza, Harriet, Lucy, Molly, Olivia, Sarah, Tilly, Tom)*
4. (Un)safe and (Un)supported	*Uncontained and Overwhelmed* *(Anna, Clare, Eliza, Harriet, Lucy, Molly, Sarah, Tilly, Tom)*
	Compassionate and Empathic Care *(Clare, Eliza, Harriet, Molly, Tilly, Tom)*
5. Treated as a Person, Not Just an ED (Anna, Clare, Harriet, Lucy, Molly, Olivia, Sarah, Tilly)	
6. Family: Relied Upon or Excluded (Anna, Eliza, Molly, Olivia, Tilly, Tom)	

Theme 1: Overpowered by the ED

This theme encompasses participants' retrospective realisations that they had been in the grip of anorexia and in denial of the severity of their difficulties. Participants expressed fear of the ED's dominance and gratitude for life-saving interventions.

"In the grips of it"

When reflecting back, participants realised they had been in the grip of anorexia. Harriet spoke of feeling "*almost superhuman*" – she had not believed she would ever be hospitalised. Despite being aware of physical health concerns, several participants had felt there was "*nothing wrong*" (Eliza). Their denial had been strong.

Six participants spoke about the difficulty of reflecting on their experiences. It was "*strange*," "*scary*" and "*frightening*" to realise how unwell they had been. For example, Lucy now felt fearful of her ED's ability to obscure reality and it appeared painful to realise this:

"I definitely didn't recognise perhaps how dangerous it was… At the time I was annoyed and frustrated more than scared. Looking back at it, it scares me that I wasn't scared." (Lucy)

These feelings were echoed by Olivia, who voiced feeling *"disconnected"* from her experience and by Eliza, who found it difficult to *"really remember."* Similarly, Sarah feared the anorexia's potency:

"I wasn't able to stop… I just felt I couldn't stop doing it or I couldn't change what I was doing and it was really frightening actually." (Sarah)

Relatedly, several participants reflected that hospitalisation did not really change what they did upon discharge. For instance, Sarah described cycles of readmission, whilst Harriet's admission initially scared her into not losing weight for a brief period, but the fear *"disappeared",* and Olivia returned to *"doing the exact same thing."* There was a sense of frustration with inadequate support from services during and after hospitalisation. However, participants also conveyed self-blame. Lucy voiced self-criticism that "*it took so many*" and Tom blamed himself for not taking his first admission "*seriously*". Interestingly, it was

Tom's second admission, with life-threatening medical complications, that moved him towards recovery.

"It's woken me up"

Whilst for many, hospitalisation had little impact on recovery, for some, it prompted reflection and realisation that change was necessary. Anna, in her late 30s, had struggled with an ED since her early teens. Following a culmination of "*catastrophic life circumstances*" and relapse into anorexia, her three-week hospital admission changed her perspective:

"Like suddenly your values change hugely… I want to go out for dinner with my partner… have a nice meal with him. Suddenly getting new aspirations." (Anna)

Anna had known she needed help. It appears this readiness for support, alongside a difficult admission, meant hospitalisation motivated her towards recovery.

Moreover, as outlined above, Tom's second admission, whereby he was told by his consultant they had feared he was dying, motivated him to make changes:

"*It makes me sort of feel like my health isn't like as good as what it should have been… it's sort of woken me up to making sure that I sort of do get to a more safe place."* (Tom)

For Tom, realising the extent of his health risks appeared to be a tipping point, whereas for Lucy, undergoing multiple admissions consecutively made her realise things needed to change.

Five participants expressed appreciation for the intervention they received whist their denial had been at the fore. From these participants there was a sense of gratitude for treatment that saved their lives. For example, Tom reflected that he was "*lucky to survive*", Eliza now saw "*the need for the admissions"* and Molly now understood the necessity of intervention:

"I can see now that they actually didn't have an alternative to putting me on the nasogastric tube. I didn't see that at the time… I do understand now how fragile things were and how lucky I am to still be alive." (Molly)

Theme 2: Fighting for Support

This theme encompasses participants' relief in accessing support and for some, a welcome intensification of their care.

"Deep down I wanted help"

Three participants expressed relief in getting more intensive support. For example, Olivia was both upset and relieved that her care-coordinator had broken confidentiality:

"It made me angry and more stubborn… but part of me, that still was me, was like thank god we can actually sit and chill out." (Olivia)

Although hard to admit, these participants were thankful that others stepped in.

Others expressed anger at not being offered more intensive support earlier on. Clare, who was admitted from an acute psychiatric ward (for suicidal ideation), knew she was struggling and expressed anger at having to "*slide down that slope.*" Despite professionals being aware of her ED, it was overlooked. Similarly, Sarah reflected:

"*I feel quite angry… to even my friends who didn't always know much about eating disorders, it was even obvious to them. I was, you know, not well at all."* (Sarah)

For these participants, professionals perhaps let them down by failing to intervene before they got to a place of not wanting help.

“It prompted them to take action”

Four participants discussed how hospitalisation initiated a necessary increase in support (community ED services or specialist ED wards). As Sarah explained:

“I think that was when my team actually thought ‘oh, she’s not okay’. It prompted them to take action. So I suppose in some ways yeah, maybe it was a good thing.” (Sarah)

For Sarah, whilst incredibly difficult, her admissions were perhaps necessary as they initiated referral to a specialist ED ward, which supported her recovery journey. Similarly, for Harriet, previously rejected from specialist services due to a comorbid diagnosis of Avoidant Restrictive Food Intake Disorder (ARFID), hospitalisation secured her acceptance. Harriet conveyed gratitude for her medical consultant's advocacy:

“They said... we're gonna write an e-mail attaching basically a summary of what's happened and that you came into hospital as an emergency and kind of urge them to see you. And we can't force it. But we're gonna do our best.” (Harriet)

Theme 3: Misunderstood and Overlooked

This theme, the strongest theme identified, encompasses participants’ anger, frustration and sadness at medical professionals’ perceived lack of knowledge and understanding of EDs. This sense of being misunderstood left participants feeling inadequately cared for. Correspondingly, many called for greater psychological input.

“They didn’t seem to understand EDs”

Across all ten interviews, participants expressed feelings of anger, frustration and sadness at the lack of understanding of EDs they experienced. Participants shared experiences of feeling misunderstood, alone and unsupported. Consequently, their ED continued to thrive. Participants refused meals and weigh-ins, hid food and nutritional supplements (for some, whilst under observation), insisted on low calorie meal plans, falsified their weight, and exercised in secret. As Molly explained:

“… it’s what I’ve always done when I’ve been too scared and I can’t cope with what is being asked… They should understand that the anorexia drives me to do anything when I’m in that panicked state…” (Molly)

The majority of participants felt professionals did not understand the extent to which the ED could influence their behaviour nor the underlying reasons why. Moreover, Clare suggested non-specialist professionals do not challenge PwEDs as they appear compliant:

“The thing about anorexia is that it’s so dangerous but it’s so quiet and well behaved and invisible… they kind of just let you get on with it because you’re not making a fuss and not making extra work for them.” (Clare)

Other participants felt medical professionals had negative perceptions of PwEDs. Participants received many unhelpful comments and were referred to as a *“bed blocker”* (Tilly) and *“problem in the way”* (Olivia). Narratives highlighted the stigmatising language participants experienced and how individuals felt triggered and misunderstood. As Tilly explained:

"... that just made me kind of shut down and be like wanting them all to politely f off and not come back and see me ever again." (Tilly)

Feeling stigmatised and misunderstood meant hospitalisation was not only unhelpful, but also delayed recovery. There was a sense that without specialist support and adequate understanding, participants were not progressing. Recovery truly commenced during specialist community or inpatient treatment. As Tom described:

"*I was thinking like, I'm not making progress for what I needed to be there for… this is just delaying my treatment."* (Tom)

Whilst experiences of ED support were predominantly negative, there were a few recollections of care that was valued. Tom found support from a dietitian helpful in ensuring he ate "*a safe level of food"* and Sarah spoke frequently about the value of a specialist ED dietician who worked with PwEDs admitted to medical wards. Sarah's reflections emphasise the importance of specialised support and highlight the positive impact of dedicated time, flexibility and a person-centred approach:

"That input… really made a difference… She would spend a good like hour or two hours with each patient every day… She helped to sort of plan timings… spreading food out… meeting me where I was." (Sarah)

"Skewed in favour of medical intervention"

The majority of participants experienced an absence of psychological input, creating a challenging environment whereby they found it difficult to make sense of their experiences, engage with professionals and adhere to treatment plans. For Lucy, being *"semi force fed… without much psychological support"* led to heightened distress and for Harriet, being asked specific details of past traumas felt like *"gathering data… rather than actually understanding."* As Clare described, *"it would have been helpful for somebody psychologically informed to come and help me put the dots together."* Indeed, Tom, who briefly met with a therapist, felt listened to and understood. Participants desired space to make sense of and process the complex emotions tied to their experiences.

Six participants spoke of a disconnect between mental and physical health services, voicing surprise and frustration at how little medical and ED teams communicated and collaborated, though Tilly experienced services working *"really closely"* – this combined approach was valued. Several participants articulated a strong sense of abandonment and feelings of being let down:

"My eating disorders team, who had got me there in the first place, kind of abdicated responsibility and vanished for most of those months." (Molly)

Correspondingly, participants' narratives also emphasised the issue of mental capacity. Eliza expressed disappointment in a psychiatrist's understanding of EDs, emphasising her ability to convince him she was coping despite really struggling, whilst Sarah articulated a fear that greater psychological input might have led to detention:

"I was just managing to scrape by without being sectioned… I thought, well, I don't want their input because what if they make the decision to section me?" (Sarah)

Looking back, three participants reflected upon whether they had had capacity and perhaps should have been sectioned. Tilly, who experienced both voluntary and involuntary admissions, explained:

"Looking back now… I didn't have the physical or mental almost, is capacity the right word? I don't know. Or, you know, strength to kind of make those decisions." (Tilly)

Interestingly, Sarah went on to express a desire for greater understanding of capacity, perhaps calling for a more nuanced understanding of the complexity of capacity for PwEDs. Indeed, some participants entered treatment voluntarily for fear of an involuntary admission, though Anna felt "*they were using their powers as a stick*". Similarly, the threat of being sectioned was enough to make Sarah *"begrudgingly accept the treatments".* Participants feared losing control through an involuntary admission, indicating a significant impact of the fear of detention on treatment engagement.

Theme 4: (Un)safe and (Un)supported

This theme encompasses participants' anxiety and fear at experiences that left them feeling uncontained and overwhelmed. Compassion, empathy and understanding supported them to feel safe and supported during hospitalisation.

Uncontained and Overwhelmed

Nine participants' reflected on experiences during hospitalisation that felt uncertain, overwhelming and at times, traumatic. Collectively, these feelings contributed to significant, and sometimes lasting, emotional distress. Participants, like Harriet, described not knowing "*what was going on"* and some, like Molly, felt uninformed of a *"long-term plan"*. Fear of medical intervention, such intravenous drips, added a layer of distress:

"*I was just really scared that it was going to, I didn't really know what it was and whether it was going to make me gain lots of weight… I remember trying to look up how many calories were in there."* (Eliza)

Participants grappled with unknown treatment trajectories, perhaps exacerbated by denial. For many, the reality of life-saving medical intervention was a shock. Harriet provided a vivid description of being admitted via ambulance:

"*I was taken straight into resus… very chaotic, lots of stuff going around me. And there were three nurses, strapping things like patches to my chest and putting cannulas in me. It was all just quite overwhelming."* (Harriet)

For many, uncertainty surrounding procedures and plans contributed to unease and hopelessness. For example, Molly described a pervasive sense of distrust and anticipation of inconsistency from professionals that led her to feel *"so miserable…*[she] *couldn't see a way out*". Indeed, for some, hospitalisation was not only overwhelming, but also traumatising, in particular during three participants' experiences of nasogastric feeding, which heightened their sense of loss of control. Anna described feeling *"forever traumatised"* and Tilly explained:

"It's quite a traumatic experience because you've just got all these people deeming your treatment, holding you down, putting it in… it's quite scary." (Tilly)

Whilst these two participants described nasogastric feeding as necessary yet traumatic, for Molly, being kept on a nasogastric tube for three months was her *"worst hell"*. Her narrative emphasised an overwhelming sense of fear, desperation, and loss of control.

Sarah's account also revealed the lasting impact of her admissions. Sarah experienced flashbacks following her admissions and highlighted the overlooked struggle of witnessing fellow clients' suffering, describing this as *"vicarious trauma."* The ward felt unsafe and chaotic, hindering her treatment engagement and making it hard to consider voluntary hospitalisation in the future. Additionally, the absence of psychological support left Sarah with lasting emotional distress:

"I think that it leaves you feeling guilty that you sort of survived… that's definitely something I massively struggled with, particularly in the months afterwards, was sort of this feeling of guilt and this feeling of, why did I survive?" (Sarah)

Compassionate and Empathic Care

This theme, smaller but significant, encompasses several participants' reflections on the importance of being treated with compassion and empathy. For example, Molly valued nursing staff who made her feel safe and supported:

"*They just made me feel safe and listened to and supported and they were the ones who helped me like feel positive about the little achievements that I made…"* (Molly)

Tilly and Eliza also highlighted the significance of medical staff showing kindness and compassion, talking them through distressing moments, engaging with them on a personal level and creating connections. Similarly, Clare and Harriet highlighted the significance of small gestures. A doctor's subtle yet reassuring shoulder squeeze or offer of a hug provided crucial comfort during challenging times. As Harriet explained:

"*That was like, really helpful and felt very human that they weren't just going down the checklist, ticking boxes."* (Harriet)

These reflections emphasise the importance of compassionate care in fostering a sense of safety and connection. Nonetheless, a juxtaposition between feeling cared for and yet not fully understood emerged in participants' experiences. Tom's reflection highlights this poignant paradox:

"The support that I got from staff on the ward, was not necessarily practically the best, but like on a… feeling like I was being cared for… that was definitely the case." (Tom)

Theme 5: Treated as a Person, Not Just an ED

This theme encompasses participants' desire for a humanised approach, in which medical professionals saw them not solely as their mental health condition but as whole human beings with their own unique needs, experiences and perspectives.

Participants emphasised the importance of a holistic approach that considered co-morbid mental, physical and neurodevelopmental conditions. Individualised approaches that catered to specific needs ensured more comprehensive and effective care. For example, Tilly, who was neurodivergent, and had a long-term physical health condition and other mental health diagnoses, valued professionals *"dealing with the bigger picture"*. Whereas Clare voiced frustration at encountering a gap in service provision prior to her admission:

"I was in that odd in between world where they were like oh the eating disorder service might not be for you, because you've got a personality disorder, and then the personality disorder team were like we don't really know how to do eating disorders, so I was stuck with no support." (Clare)

Notably, Tilly, Lucy and Sarah were all autistic women. Whilst Sarah felt her autism *"wasn't taken into account"*, for Tilly, receiving her autism diagnosis was a turning point that allowed for treatment adaptation and supported engagement:

"I think it was the biggest relief in the world... cause then they adapted my treatment to meet my needs… Once they realised… that actually then helped me to almost, I don't like the word comply, but be willing to work with them?" (Tilly)

These participants emphasised the significance of adaptations, such as visual communication tools, being talked through interventions, and pre-planned admissions – as Lucy explained, these *"made the experience a little bit better."*

Several participants sought recognition as individuals beyond their ED. Molly stressed the importance of being treated *"like a human being with an illness rather than one big walking talking anorexic"* and Olivia valued a housekeeper who focused on her future and life outside of AN. Harriet simply wanted to be treated like clients admitted for *"purely physical things".* These sentiments allude to participants perhaps having felt defined or judged solely by their diagnoses and suggest a yearning for empathy, understanding and care that considers the whole person.

Correspondingly, three participants highlighted the importance of considering aspects of themselves beyond their ED. Anna, a lawyer, frequently referred to the challenge of transitioning from the role of professional to help-seeker. Similarly, Lucy, a medical student, reflected on the dynamics of being hospitalised where she was training, expressing gratitude for efforts to minimise overlap between her personal and professional life. Moreover, Harriet expressed frustration at the impact of her admission on her university education, desiring better consideration of life beyond her ED. These reflections underscore the complexity of individual identities and the need to acknowledge diverse aspects.

Theme 6: Family: Relied Upon or Excluded

This theme encompasses participants' relationships to the involvement of close others in their admissions. For some, family members or partners provided vital emotional and practical support, whilst for others, they were excluded due to difficult family histories or feelings of shame and denial of the severity of their struggles.

Six participants emphasised the integral role provided by family or partners in providing practical and emotional support during hospitalisation. Close others shouldered significant responsibility for nutritional intake, when professional care fell short or proved insufficient. For example, Tom's parents visited daily to make sure he was *"staying safe"* and Anna's partner and mother were *"totally relied on"* to do *"all the work."* Close others also provided connection. For instance, Molly father's presence kept her *"mentally alive"* and Tom explained that *"company was the main thing."*

When discussing the impact of Covid-19, Eliza wished her family had been able to visit more. For Eliza, as for others, closer others understood them and their unique needs and difficulties and, at times, provided better support than HCPs:

"They knew it very well and they knew the things that helped me or really didn't help me… if circumstances had been different and there hadn't been a pandemic they could have been a lot more involved and probably could have made the admissions a bit smoother" (Eliza)

Interestingly, Anna expressed concerns about the lack of family involvement, suggesting that whilst her ED may push close others away, excluding families can risk omitting vital support:

"I think GDPR has gone too far… if you exclude families from someone's care… you're taking away that support network… whilst the person may say no... they are very likely

saying that because they want to stop them becoming too involved and getting too close." (Anna)

Indeed, Olivia reflected that whilst family were integral to her recovery, her ED had tried to shut them out. Several participants expressed feelings of guilt and sadness regarding the impact of their ED on their families and desired greater training and resources for supporters.

In contrast, three participants highlighted how family members or partners were not involved in their admissions. Lucy spoke about how family was a *"complicated and somewhat traumatic topic,"* leading to their exclusion from her treatment. Instead, Lucy replied upon friends to *"break out"* of the monotony of the ward. Harriet, similarly, opted not to involve family and allowed only one friend to visit out of necessity, emphasising her desire to conceal her struggles.

Sarah retrospectively acknowledged resisting the hospital's suggestion to involve her family until they had no choice. Sarah's decision to exclude them was rooted in shame and a belief that involving others might worry them and hinder her destructive behaviours. As Sarah explained:

"It was my attempt to convince myself I was fine and that if I did involve people all I would do is make them worry… I think it was the anorexia saying if you get people involved, they'll try to make you stop these behaviours…so I couldn't let anyone in…" (Sarah)

Clare echoed a similar sentiment, explaining how not informing her partner allowed her to *"downplay the seriousness of the situation"*. Exclusion of close others appears influenced by feelings of shame, a desire to maintain control or denial of the severity of the ED.

Discussion

The aim of this study was to understand how PwAN experience medical admissions. Seven main themes were generated: participants' realisations of the severity of their AN upon admission; participants' need for intensive support; participants' sense of medical professionals' inadequate knowledge and understanding of EDs; the impact of uncertainty and overwhelm; the importance of compassion; participants' desire for whole person treatment, and participants' relationships to the involvement of supporters.

Upon admission, most participants described being entrenched in an illness identity, minimising symptom severity and expressing treatment ambivalence. As such, treatment was experienced as overwhelming, confronting, and sometimes, traumatic. Bravender et al. (2017) outlined that hospitalisation was often the first time adolescents and their parents confronted the seriousness of AN. They suggested clinicians should consider using physical health status to enhance motivation for treatment. Whilst findings from this study concur somewhat - many participants expressed feelings of shock, fear and sadness upon realising the severity of their ED - this realisation largely occurred retrospectively. Realisation of the fragility of health motivated three participants to make immediate changes, but for the majority, hospitalisation did not initially change the course of illness, aside from brief medical stabilisation. Progressing towards recovery often required repeated admissions and specialist inpatient treatment.

Experiences of hospitalisation were varied, though a perceived lack of understanding of EDs from medical professionals dominated participants' narratives. Whilst caring for PwAN can be challenging and stressful, particularly in the context of fast-paced and often under-resourced hospital environments, findings corroborate calls for improved training and more psychologically informed care in medical settings to reduce stigma and support understanding of the psychological symptoms of AN (e.g., reliance on compensatory behaviours and refusal to maintain dietary intake) (Purvis & Snowden, 2024; RCPsych, 2022b). That AN drove participants to "*do anything*" underscores the importance of understanding ED behaviours as coping strategies – non-adherence to treatment is part of the disorder. As MacDonald et al. (2023) outlined, without a substitute coping strategy, treatment can produce adverse experiences and intense emotional reactions, fuelling clients' resistance.

The finding that some participants retrospectively questioned their mental capacity is noteworthy. Participants recognised their ability to talk their way out of being sectioned and the strength of denial in obscuring the reality of their ability to cope. Capacity assessments for PwAN are complex. PwAN are often articulate and have higher levels of subtle impairments than in other mental health disorders (Mehler et al., 2023; Westmoreland, 2020), meaning a lack of capacity could be overlooked.

PwAN experienced stigmatising interactions, as seen for clients with other mental health difficulties in acute medical settings (Sacre et al., 2022). ED stigma is common, with the public and professionals often perceiving the individual to be responsible for their disorder (Brelet et al., 2021). Likely driven by a lack of knowledge (Purvis & Snowden, 2024), stigma reinforces the symptoms of AN (Foran et al., 2020), moving individuals further into an illness identity and delaying recovery. Addressing stigma in medical settings is therefore vital.

The finding that compassion and empathy supported participants to feel safe, heard and connected is unsurprising. For PwAN, validation, conceptualised as at the root of compassion and empathy (Gilbert, 2020), fosters therapeutic alliance, reduces emotional arousal and increases treatment adherence (Geller et al., 2021). Consistent with previous research (e.g., Fox & Diab, 2015; Sly et al., 2014), participants valued professionals who had a clear understanding of their difficulties, offered hope and support, and displayed empathy and understanding. Participants were grateful for medical intervention but frustrated by the lack of compassion. This finding concurs with Davidson et al. (2019) who found that HCPs were confident in performing medical interventions, but less confident in communicating with PwEDs and managing the psychological and behavioural symptoms.

Many participants spoke about the disconnect between mental and physical health services and described various comorbidities that required consideration. That nearly a third of participants were autistic is important. Treatment adaptations enhanced their experiences and supported engagement. Moreover, as Rienecke et al. (2023) and Zaitsoff et al. (2016) found, humanising conversations, that consider life outside of the ED, were essential to ensure identities were not reduced to just the illness.

Hospitalisation contributed to significant distress, in terms of challenging participants' illness identity and emotional responses to an acute medical crisis. Moreover, for those who experienced nasogastric feeding or witnessed deaths, hospitalisation contributed to lasting distress and trauma-related symptoms. Balancing beneficence and autonomy is highly complex in EDs (Bohon & McCurdy, 2014), though restrictive practices can be necessary to save lives (Elzakkers et al., 2014). Retrospectively, participants recognised treatment was necessary, yet traumatic, corroborating findings indicating that both perspectives can be held (Bravender et al., 2017; MacDonald et al., 2023). Nonetheless, research is beginning to outline the potential for iatrogenic harm during ED treatment (Elwyn, 2023; MacDonald et al., 2023).

Findings indicate the nuances of involving supporters. Family support (practical and emotional) was integral for most, but not all participants, and several recognised that fear and shame meant they pushed supporters away. These findings concur with best practice recommendations for supporters to be involved in ED treatment (National Institute for Health and Care Excellence, 2017). As has been identified previously (e.g., Clark Bryan et al., 2022; Rienecke et al., 2023), supporters who validated, understood and offered vital sources of connection were valued. Yet, participants felt HCPs sometimes over-relied on supporters. Providers must be mindful that not all PwAN have supporters (or consent to their involvement) and that some are ill-equipped to support PwAN.

Strengths and Limitations

The findings must be interpreted within the context of several limitations. The sample size enabled the author to privilege individual experiences and contexts, upholding IPA's idiographic commitment (Smith & Nizza, 2022). However, the sample lacked participant diversity, comprising only one man and no ethnically minoritised individuals. Although a widely reported limitation in ED research (e.g., Peebles et al., 2023; Wetzler et al., 2020), acknowledgement of this limitation is insufficient. In future, recruitment strategies should specifically address the need for PwAN from under-represented groups. Given the timing of this study, some of the participants' admissions occurred during the Covid-19 pandemic. Exploring the specific impact of the Covid-19 pandemic on participants' experiences was beyond the scope of the current study, but may be an interesting avenue for future research. Additionally, interviews were conducted at different time-points, with some closer to participants' experiences of hospitalisation than others. Participants' stage of recovery was not evaluated, therefore this may have impacted the lens through which they viewed the admission. Future work should explore how and whether perceptions change over the course of recovery. Moreover, as other stakeholders were not interviewed, it is unclear whether participants' experiences align with others' perspectives. Further exploration of HCPs' and supporters' perspectives is needed. Nonetheless, this research begins to address the literature gap, exploring PwAN's experiences of care in acute medical settings. Narratives were rich, open and honest, and suggest adequate thought was given to making participants feel safe and heard.

Clinical and Research Implications

Several clinical and research implications arise from this study. Most notably, greater psychological understanding of EDs is required in medical settings. Clinical psychologists and those with lived experience should assist on the development and delivery of training, to support understanding of factors involved in the development and maintenance of AN and how to manage psychological, behavioural, and social difficulties. Research should elucidate whether specialist trainings, such as the ED Services for Adults Whole Team Training commissioned by Health Education England (Novogrudsky et al., in press), could be adapted and delivered to non-specialist services.

Training should include guidance on communication styles with PwAN and the provision of practical and emotional support during refeeding. Clear, transparent and validating communication, alongside externalising conversations, are likely to be of benefit. For neurodivergent individuals, it may be helpful to use visual communication tools, to talk clients through interventions before they occur and, where possible, to pre-plan admissions so clients have time to mentally and physically prepare. Emotion recognition and regulation, and distress tolerance skills, should also be considered. Psychoeducation on the medical consequences of AN may support connection with the reality of the illness and challenge denial. However, how and why medical admissions motivate certain individuals to change but not others, remains an interesting area of future research. Further research should also explore whether motivational enhancement work or externalising techniques may support dis-identification with an illness identity in acute medical settings.

Concurring with research exploring experiences of being cared for and caring for clients with other mental health difficulties in general medical settings (e.g., Foye et al., 2020; Navas et al., 2022; Sacre et al., 2022), findings suggest that clinicians may be experiencing compassion fatigue and that clinicians have difficulty in managing simultaneous physical and mental health needs and ensuring adequate joint working. Medical professionals' high workloads, low staffing levels and high job demands alongside limited schedule flexibility, poor supervision and poor leadership support, often lead to 'burnout' and secondary traumatic stress (Dall'Ora et al., 2020; McKinley al., 2020). Perhaps reflecting some of findings of this study, these factors are strongly associated with both career disengagement and suboptimal client care (Hodkinson et al., 2022),. It is vital that acute medical settings have sufficient resource with adequate supervision and support, particularly for those supporting clients with simultaneous complex mental and physical health needs. Indeed, multidisciplinary professionals working with PwAN in medical settings would benefit from reflective spaces to explore the complexities of supporting this client group (Driscoll et al., 2019). Moreover, all HCPs should be aware of the intricacies of capacity in AN (Purvis & Snowden, 2024). Clinical psychologists (such as those in mental health liaison teams) could undertake responsible clinician roles to influence care psychologically. They may also be well placed to support care planning by formulating clients' distress from a psychological perspective.

Better integration of healthcare services is needed to improve the client experience. In acute hospital settings, this requires a cultural shift towards a more holistic approach with good professional relationships and a collaborative culture (Bhugra et al., 2014). Moreover, to improve clients' experiences and reduce iatrogenic harm, plans should be communicated clearly and clients (where possible) should be actively involved in treatment decisions (Molloy et al., 2020). Research must explore what renders medical experiences traumatic for PwAN and determine whether processing tools, such as diary interventions (Zisopoulos et al., 2022), may support psychological recovery.

Autism appears to exacerbate the severity of AN (Boltri & Sapuppo, 2021) and hospital settings are known to be particularly challenging for autistic individuals (Tint et al., 2017). Research is beginning to outline the importance of treatment adaptations to reduce distress and support engagement for autistic individuals with EDs (Tchanturia et al., 2020). Further research should specifically explore the experiences of neurodivergent individuals with EDs undergoing medical admissions to identify and understand any unique needs that this client group may have in this context.

Finally, supporters should be involved in care during medical admissions, though involvement should be considered on an individual basis. Care must be taken to not over-rely on supporters, and clients' reasons for not involving them should be explored. Future research should explore supporters' perspectives on care in acute medical settings and how non-familial supporters might be included.

Conclusions

This study is the first to explore the overall experiences of medical admission in adults with AN. Seven main themes were identified. Whilst admissions were often life-saving, and gratitude was expressed for medical intervention, a lack of psychological understanding meant participants felt misunderstood and stigmatised and an illness identity continued to dominate. Admissions were overwhelming and, at times, traumatising. Training on EDs for medical professionals is required to reduce stigma, enhance care experiences and improve clients' outcomes. Care should be compassionate and transparent. A holistic approach would help consider all aspects of the individual, including comorbidities, personal histories and life outside the illness. Further research must explore what aspects of treatment render hospitalisation harmful and how to support processing of restrictive practices. Additionally, future research should explore whether therapeutic techniques may support dis-identification with an illness identity in acute medical settings and how best to implement these.

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Section C: Appendices

Appendix A: Illustrative Coding

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Appendix B: Illustrative Grouping of Codes into Themes and Subthemes

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Appendix C: Additional Illustrative Quotes

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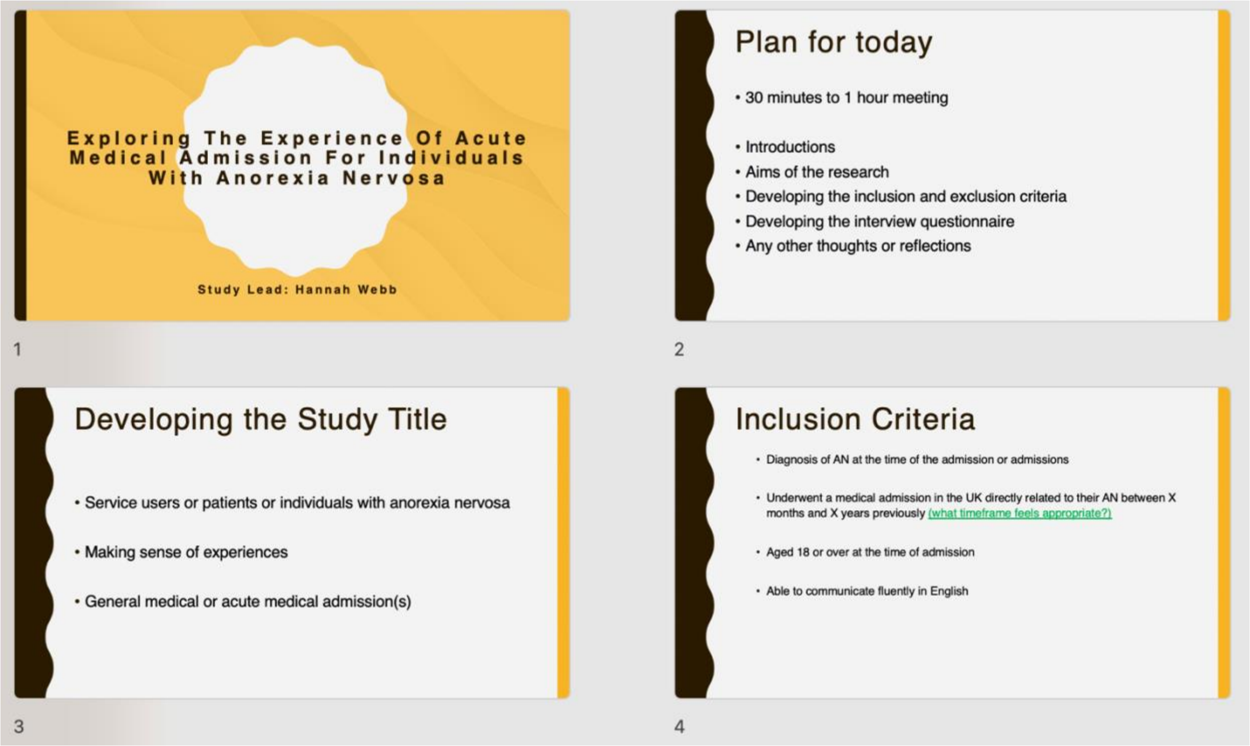
Appendix D - Expert-By-Experience Consultation Group Slides



Exploring The Experience Of Acute Medical Admission For Individuals With Anorexia Nervosa

Study Lead: Hannah Webb

Plan for today

- 30 minutes to 1 hour meeting

- Introductions
- Aims of the research
- Developing the inclusion and exclusion criteria
- Developing the interview questionnaire
- Any other thoughts or reflections

Developing the Study Title

- Service users or patients or individuals with anorexia nervosa

- Making sense of experiences

- General medical or acute medical admission(s)

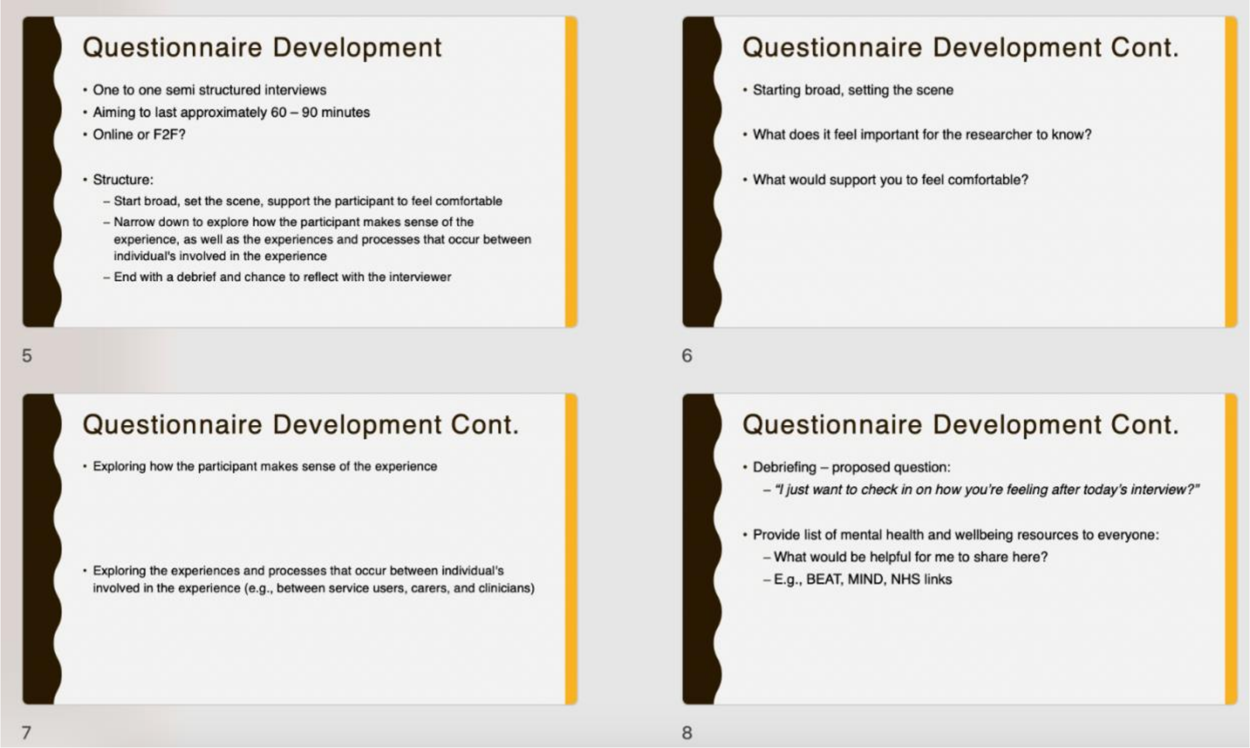
Inclusion Criteria

- Diagnosis of AN at the time of the admission or admissions

- Underwent a medical admission in the UK directly related to their AN between X months and X years previously (what timeframe feels appropriate?)

- Aged 18 or over at the time of admission

- Able to communicate fluently in English



Questionnaire Development

- One to one semi structured interviews
- Aiming to last approximately 60 – 90 minutes
- Online or F2F?

- Structure:
  - Start broad, set the scene, support the participant to feel comfortable
  - Narrow down to explore how the participant makes sense of the experience, as well as the experiences and processes that occur between individual's involved in the experience
  - End with a debrief and chance to reflect with the interviewer

Questionnaire Development Cont.

- Starting broad, setting the scene

- What does it feel important for the researcher to know?

- What would support you to feel comfortable?

Questionnaire Development Cont.

- Exploring how the participant makes sense of the experience

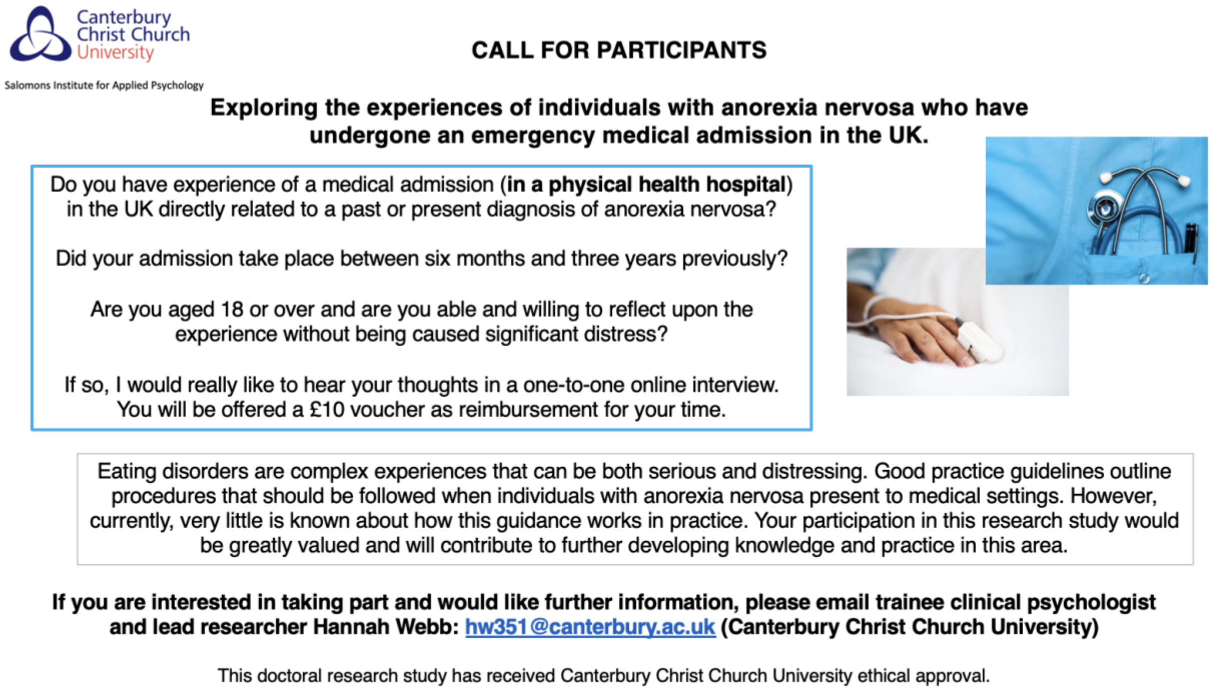
- Exploring the experiences and processes that occur between individual's involved in the experience (e.g., between service users, carers, and clinicians)

Questionnaire Development Cont.

- Debriefing – proposed question:
  - *"I just want to check in on how you're feeling after today's interview?"*

- Provide list of mental health and wellbeing resources to everyone:
  - What would be helpful for me to share here?
  - E.g., BEAT, MIND, NHS links

Appendix E - Recruitment Poster



Canterbury Christ Church University

Salomons Institute for Applied Psychology

CALL FOR PARTICIPANTS

Exploring the experiences of individuals with anorexia nervosa who have undergone an emergency medical admission in the UK.

Do you have experience of a medical admission (**in a physical health hospital**) in the UK directly related to a past or present diagnosis of anorexia nervosa?

Did your admission take place between six months and three years previously?

Are you aged 18 or over and are you able and willing to reflect upon the experience without being caused significant distress?

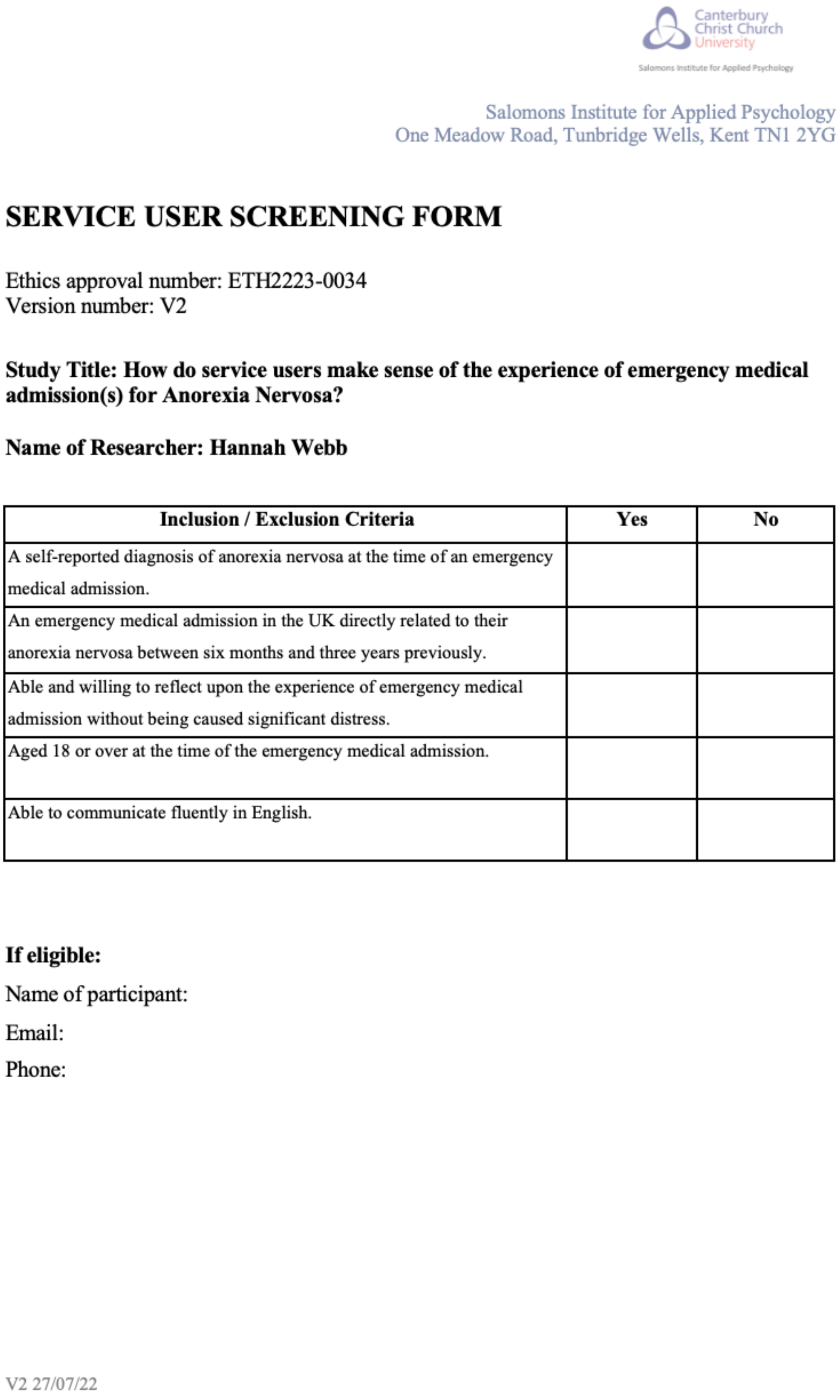
If so, I would really like to hear your thoughts in a one-to-one online interview. You will be offered a £10 voucher as reimbursement for your time.

Eating disorders are complex experiences that can be both serious and distressing. Good practice guidelines outline procedures that should be followed when individuals with anorexia nervosa present to medical settings. However, currently, very little is known about how this guidance works in practice. Your participation in this research study would be greatly valued and will contribute to further developing knowledge and practice in this area.

If you are interested in taking part and would like further information, please email trainee clinical psychologist and lead researcher Hannah Webb: hw351@canterbury.ac.uk (Canterbury Christ Church University)

This doctoral research study has received Canterbury Christ Church University ethical approval.

Appendix F - Screening Form



Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

SERVICE USER SCREENING FORM

Ethics approval number: ETH2223-0034
Version number: V2

Study Title: How do service users make sense of the experience of emergency medical admission(s) for Anorexia Nervosa?

Name of Researcher: Hannah Webb

Inclusion / Exclusion Criteria	Yes	No
A self-reported diagnosis of anorexia nervosa at the time of an emergency medical admission.		
An emergency medical admission in the UK directly related to their anorexia nervosa between six months and three years previously.		
Able and willing to reflect upon the experience of emergency medical admission without being caused significant distress.		
Aged 18 or over at the time of the emergency medical admission.		
Able to communicate fluently in English.		

If eligible:

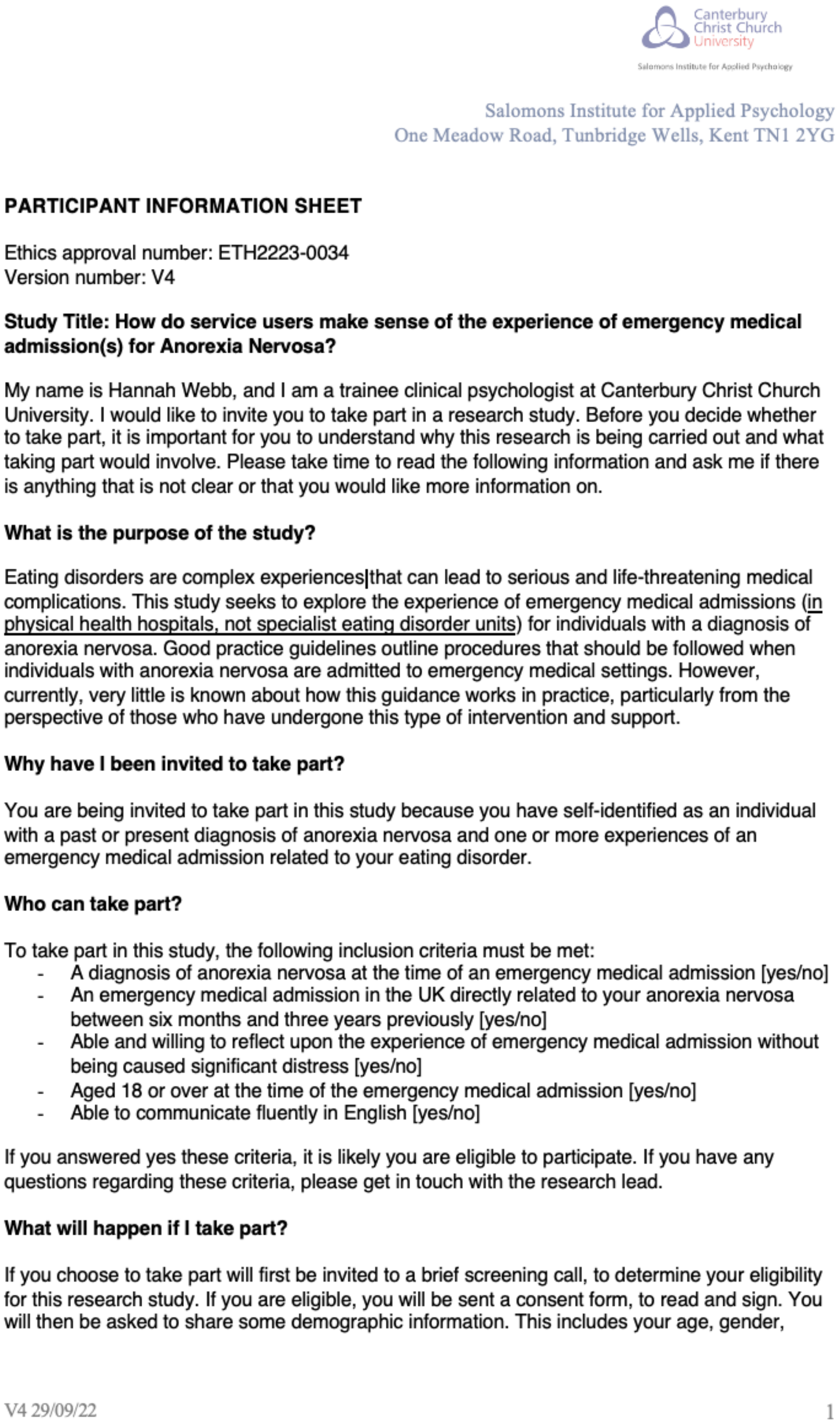
Name of participant:

Email:

Phone:

V2 27/07/22

Appendix G - Participant Information Sheet



Canterbury Christ Church University
Salomons Institute for Applied Psychology

Salomons Institute for Applied Psychology
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PARTICIPANT INFORMATION SHEET

Ethics approval number: ETH2223-0034
Version number: V4

Study Title: How do service users make sense of the experience of emergency medical admission(s) for Anorexia Nervosa?

My name is Hannah Webb, and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important for you to understand why this research is being carried out and what taking part would involve. Please take time to read the following information and ask me if there is anything that is not clear or that you would like more information on.

What is the purpose of the study?

Eating disorders are complex experiences that can lead to serious and life-threatening medical complications. This study seeks to explore the experience of emergency medical admissions (in physical health hospitals, not specialist eating disorder units) for individuals with a diagnosis of anorexia nervosa. Good practice guidelines outline procedures that should be followed when individuals with anorexia nervosa are admitted to emergency medical settings. However, currently, very little is known about how this guidance works in practice, particularly from the perspective of those who have undergone this type of intervention and support.

Why have I been invited to take part?

You are being invited to take part in this study because you have self-identified as an individual with a past or present diagnosis of anorexia nervosa and one or more experiences of an emergency medical admission related to your eating disorder.

Who can take part?

To take part in this study, the following inclusion criteria must be met:

- A diagnosis of anorexia nervosa at the time of an emergency medical admission [yes/no]
- An emergency medical admission in the UK directly related to your anorexia nervosa between six months and three years previously [yes/no]
- Able and willing to reflect upon the experience of emergency medical admission without being caused significant distress [yes/no]
- Aged 18 or over at the time of the emergency medical admission [yes/no]
- Able to communicate fluently in English [yes/no]

If you answered yes these criteria, it is likely you are eligible to participate. If you have any questions regarding these criteria, please get in touch with the research lead.

What will happen if I take part?

If you choose to take part will first be invited to a brief screening call, to determine your eligibility for this research study. If you are eligible, you will be sent a consent form, to read and sign. You will then be asked to share some demographic information. This includes your age, gender, ethnic background, eating disorder diagnosis and age of onset. Regarding your experience, you will be asked to share the reason, length, and geographical area of your emergency medical admission(s) (e.g., re-feeding, seven days, North London).

Once we have received your signed consent form and demographic information, you will be invited to participate in an individual interview with the research lead at a time and location convenient to you. The interview will be audio-recorded, last approximately 60 minutes and will be held online via Microsoft Teams. You can take a break if necessary.

We aim to interview eight to ten individuals. After each interview has been completed, it will be transcribed and then the data will be analysed to identify and interpret different themes.

Do I have to take part?

Participation is entirely voluntary. Once you have read this information sheet, please contact me (**Hannah Webb**) via email **hw351@canterbury.ac.uk** if you have any questions that will help you decide. If you decide to take part, we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

Will I be paid for taking part?

You will be offered a £10 voucher for your time. If you indicate that you would like to receive this, your e-mail address will be securely given to Canterbury Christ Church University's finance department who will issue you a voucher after you have completed your interview.

What are the possible disadvantages or risks of taking part?

There is a possibility that the interview may bring up difficult thoughts, feelings, or memories in relation to your experience(s). During the interviews, care will be taken to ensure a gentle, compassionate, and sensitive approach. In addition, after the interview, you will be offered a chance to debrief with the research lead. You will also be signposted to a variety of mental health and wellbeing resources; in case you feel that they may be helpful. However, if you think that speaking about your experience of an emergency medical admission will cause you significant distress, then we would recommend that you do not take part in this study.

What are the possible benefits of taking part?

There are no direct clinical benefits to taking part in this study. However, we hope that this study may better our understanding of how to best support individuals undergoing emergency medical admissions for their anorexia nervosa. Some people may also feel that taking part in studies such as these helps their voices and experiences to be heard and that contributing to improving the experiences of service users and carers are benefits of taking part.

What if I change my mind about taking part?

You are free to withdraw, without having to give a reason, up to the point of your data being included in the analysis. This is because once your data has been included in the analysis, it is not possible to remove it from the analysis as a whole. Withdrawing from the project will not impact any treatment that you receive now or in the future.

What if there is a problem? Concerns and Complaints.

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, you should ask to speak to me (Hannah Webb), and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for me [Hannah Webb] and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology fergal.jones@canterbury.ac.uk

How will my information be used, and will it be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. Any personal data that you share (e.g., your name, contact details and demographic details) will be safely stored on password protected computer file and will only be accessible to the research lead. This will be deleted upon completion of the study.

Your interviews will be audio-recorded on a digital recorder and transferred immediately onto a password protected memory stick. Once transferred, the original recording will be deleted. Your interview will then be transcribed onto a password protected file and stored on the researcher's personal password protected laptop. Any identifiable information will be removed. To maintain anonymity, you will be given a pseudonym and a participant number. No information that could identify you personally will be included in the final reports. Your anonymised interview data will be accessible to the research lead, two study supervisors and two project consultants (outlined below). After the project has been completed, your anonymised data will be provided to Salomons Institute in a password protected CD to be stored in the Institute's office in a locked cabinet for 10 years and then destroyed

The only time when I would be obliged to pass on information from you to somebody else would be if, because of something you told me, I were to become concerned about your safety or the safety of someone else. In the consent form, we ask you to identify a 'significant other' that you are comfortable for us to contact. I would aim to speak to you before reaching out to your chosen contact. Provided there are no risk concerns, their details will be deleted after your interview.

What will happen to the results of this research study?

The results will be written up for my doctoral thesis. It is also hoped that they will be written up as an article for future publication. Confidentiality and anonymity will be maintained, meaning that only anonymised quotes from the interviews will be used in published reports. It will not be possible to identify you in any publications. If you agree to take part and would like to receive a copy of the results, please indicate this on the consent form.

Who is sponsoring and funding the research?

The sponsor for this research is Canterbury Christ Church University. This project forms part of Hannah Webb's Doctorate in Clinical Psychology training, which is funded by the NHS.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by Canterbury Christ Church University Research Ethics Committee: ETH2223-0034

Who should I contact for further information?

If you have any questions or require more information about this research study or would like advice as to whether you should participate, please contact:

Hannah Webb (Research Lead)
Email: hw351@canterbury.ac.uk
Phone: If you would like to speak to me on the phone to find out more about the study or to have questions about it answered, you can leave a message for me on a 24-hour voicemail phone line at 01227 927070. Please say that the message is for me [Hannah Webb] and leave a contact number so that I can get back to you.

Who else is involved in this research study?

Dr Maria Griffiths and Prof Ulrike Schmidt are co-supervisors, and Penny Neild and Dr Vanessa Lawrence are co-consultants, for this research study. If you wish to speak to someone other than Hannah about this research study, please contact one of the co-supervisors Dr Maria Griffiths or Prof Ulrike Schmidt via email.

Dr Maria Griffiths (maria.griffiths@canterbury.ac.uk), Partnerships Director
Salomons Institute for Applied Psychology, Canterbury Christ Church University

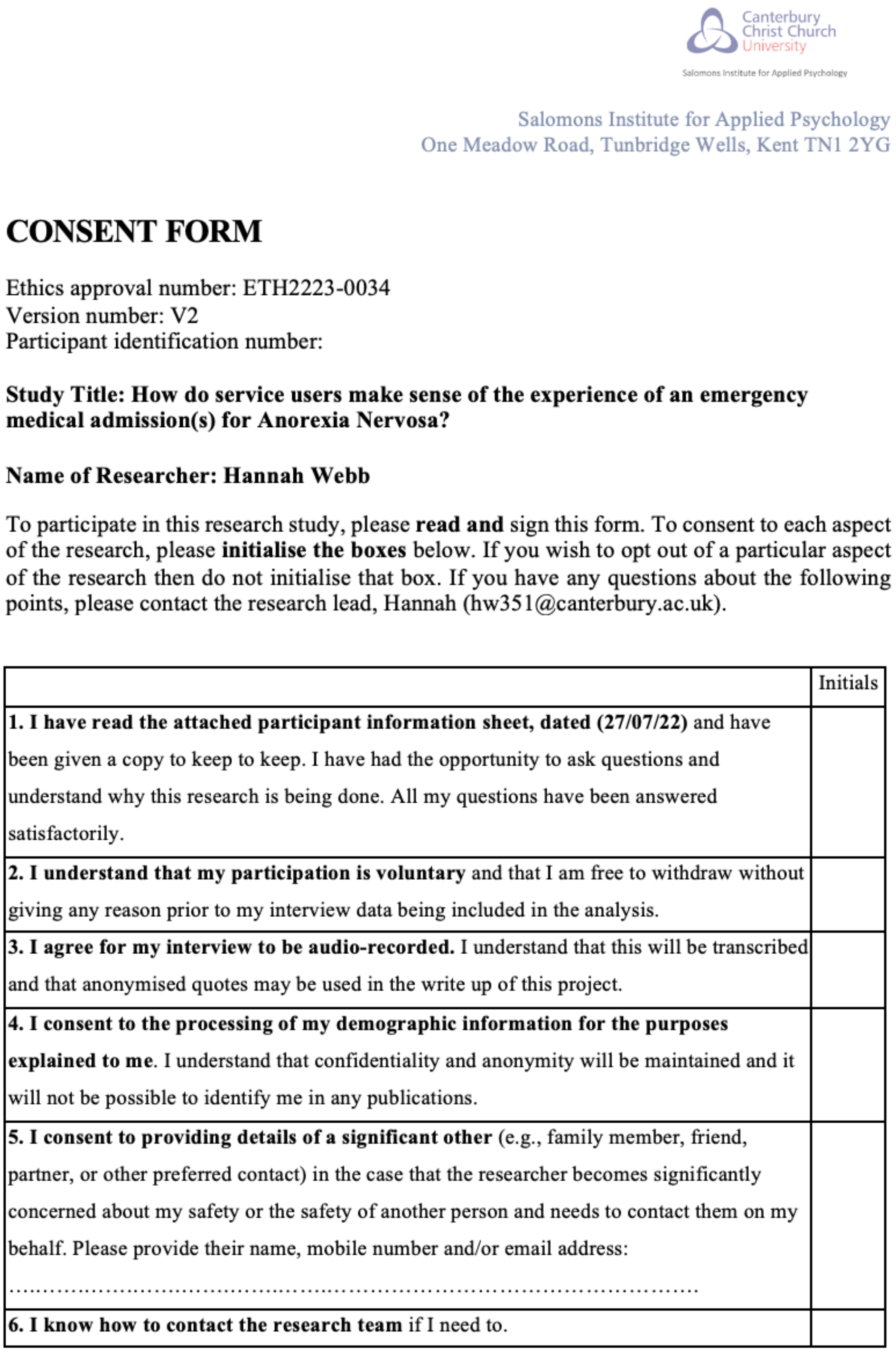
Prof Ulrike Schmidt (ulrike.schmidt@kcl.ac.uk), Professor of Eating Disorders
Institute of Psychiatry, Psychology and Neuroscience, King's College London

Dr Penny Neild, Consultant Gastroenterologist
St. George's University Hospital NHS Foundation Trust

Dr Vanessa Lawrence, Senior Lecturer in Qualitative Social Sciences
Institute of Psychiatry, Psychology and Neuroscience, King's College London

Thank you for reading this participant information sheet and for taking the time to consider taking part in this project.

Appendix H - Consent Form



Canterbury
Christ Church
University
Salomons Institute for Applied Psychology

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

CONSENT FORM

Ethics approval number: ETH2223-0034
Version number: V2
Participant identification number:

Study Title: How do service users make sense of the experience of an emergency medical admission(s) for Anorexia Nervosa?

Name of Researcher: Hannah Webb

To participate in this research study, please **read and** sign this form. To consent to each aspect of the research, please **initialise the boxes** below. If you wish to opt out of a particular aspect of the research then do not initialise that box. If you have any questions about the following points, please contact the research lead, Hannah (hw351@canterbury.ac.uk).

	Initials
1. I have read the attached participant information sheet, dated (27/07/22) and have been given a copy to keep to keep. I have had the opportunity to ask questions and understand why this research is being done. All my questions have been answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw without giving any reason prior to my interview data being included in the analysis.	
3. I agree for my interview to be audio-recorded. I understand that this will be transcribed and that anonymised quotes may be used in the write up of this project.	
4. I consent to the processing of my demographic information for the purposes explained to me. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.	
5. I consent to providing details of a significant other (e.g., family member, friend, partner, or other preferred contact) in the case that the researcher becomes significantly concerned about my safety or the safety of another person and needs to contact them on my behalf. Please provide their name, mobile number and/or email address: ………………………………………………………………………………………	
6. I know how to contact the research team if I need to.	

7. I understand that sections of data collected during the study may be looked at by the supervisors and consultants involved in this research study. Where relevant, I give permission for these individuals to have access to my data.	
8. I agree to participate in this study. I understand that if I decide that I no longer wish to participate in this project, I can notify the project lead and be withdrawn immediately (up until the point where my interview data has been included in the analysis).	
9. (OPTIONAL) I wish to participate in a process known as 'respondent validation' – sometime after your initial interview you will be contacted and sent a copy of your interview transcript and summary of the initial themes identified from your data. You will be asked to give feedback on these, as well as on the process of participating in this study, to inform the final analysis of results. If yes, please provide your email:	
10. (OPTIONAL) I wish to receive a copy of the final results of this study. If yes, please provide your email …………………………………………………………………………………………	

Name of participant:

Date:

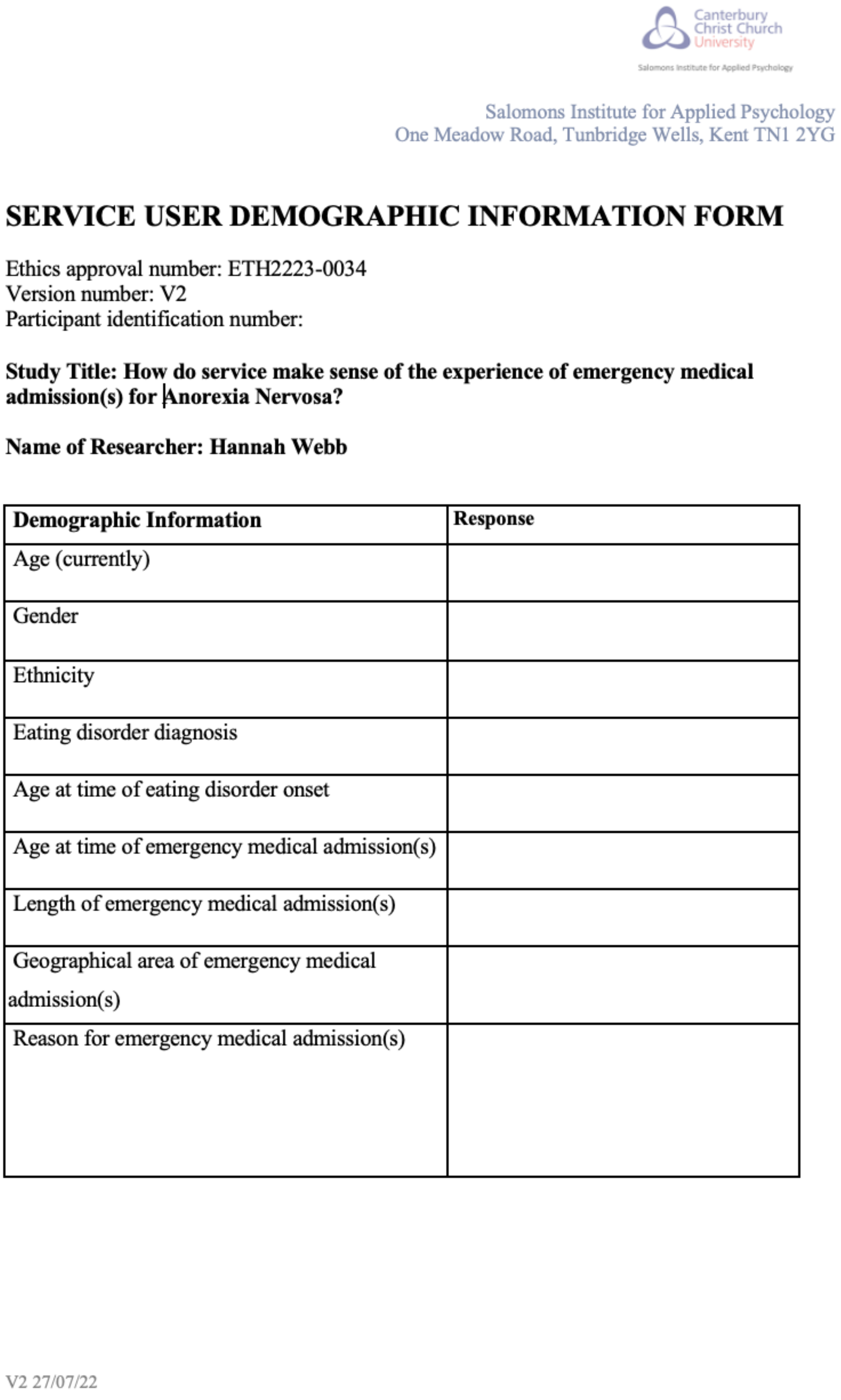
Signature:

Name of research lead:

Date:

Signature:

Appendix I - Demographic Information Form



Canterbury Christ Church University
Salomons Institute for Applied Psychology

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

SERVICE USER DEMOGRAPHIC INFORMATION FORM

Ethics approval number: ETH2223-0034
Version number: V2
Participant identification number:

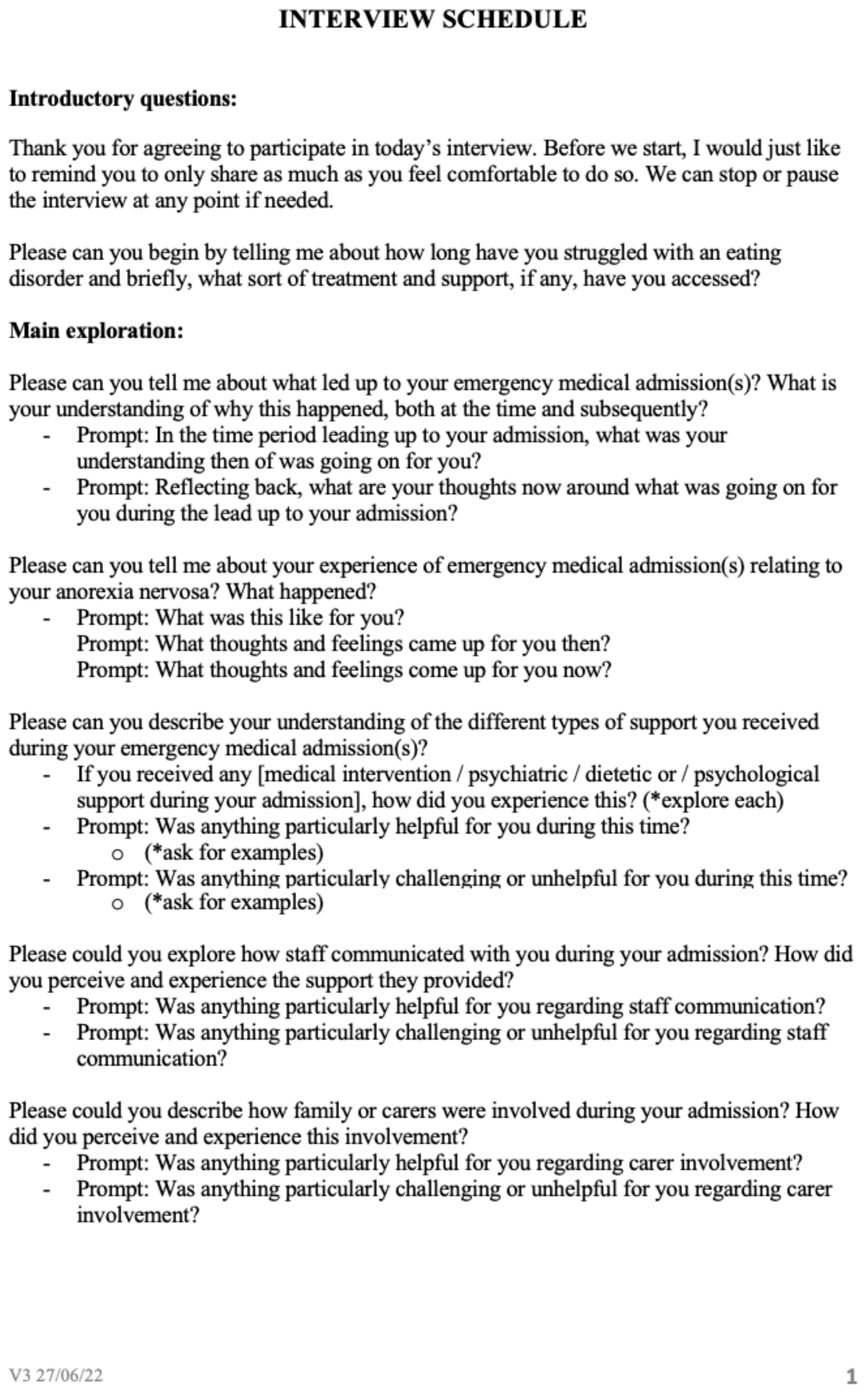
Study Title: How do service make sense of the experience of emergency medical admission(s) for Anorexia Nervosa?

Name of Researcher: Hannah Webb

Demographic Information	**Response**
Age (currently)	
Gender	
Ethnicity	
Eating disorder diagnosis	
Age at time of eating disorder onset	
Age at time of emergency medical admission(s)	
Length of emergency medical admission(s)	
Geographical area of emergency medical admission(s)	
Reason for emergency medical admission(s)	

V2 27/07/22

Appendix J - Semi-Structured Interview Schedule



INTERVIEW SCHEDULE

Introductory questions:

Thank you for agreeing to participate in today's interview. Before we start, I would just like to remind you to only share as much as you feel comfortable to do so. We can stop or pause the interview at any point if needed.

Please can you begin by telling me about how long have you struggled with an eating disorder and briefly, what sort of treatment and support, if any, have you accessed?

Main exploration:

Please can you tell me about what led up to your emergency medical admission(s)? What is your understanding of why this happened, both at the time and subsequently?

- Prompt: In the time period leading up to your admission, what was your understanding then of was going on for you?
- Prompt: Reflecting back, what are your thoughts now around what was going on for you during the lead up to your admission?

Please can you tell me about your experience of emergency medical admission(s) relating to your anorexia nervosa? What happened?

- Prompt: What was this like for you?
  Prompt: What thoughts and feelings came up for you then?
  Prompt: What thoughts and feelings come up for you now?

Please can you describe your understanding of the different types of support you received during your emergency medical admission(s)?

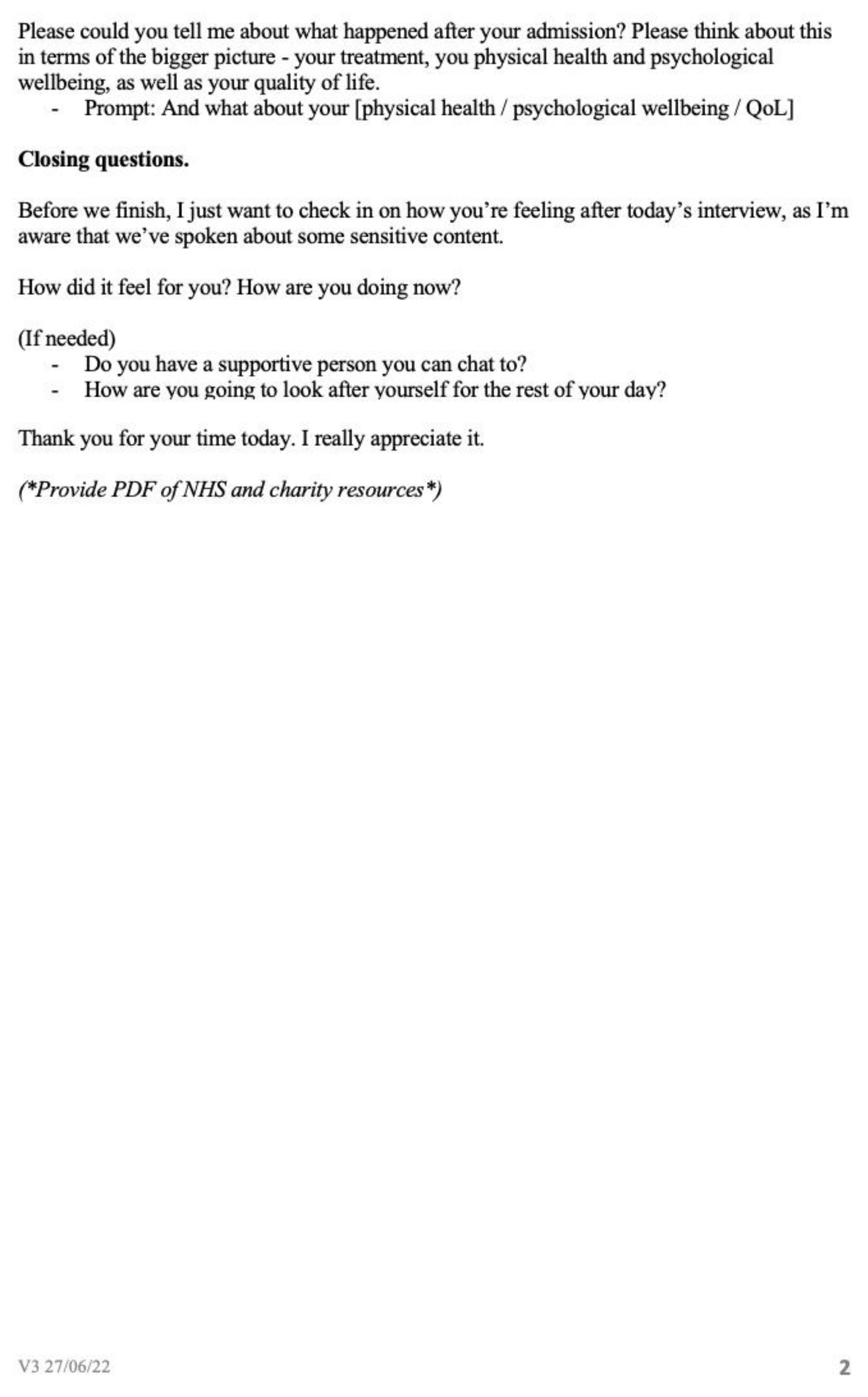
- If you received any [medical intervention / psychiatric / dietetic or / psychological support during your admission], how did you experience this? (*explore each)
- Prompt: Was anything particularly helpful for you during this time?
  - (*ask for examples)
- Prompt: Was anything particularly challenging or unhelpful for you during this time?
  - (*ask for examples)

Please could you explore how staff communicated with you during your admission? How did you perceive and experience the support they provided?

- Prompt: Was anything particularly helpful for you regarding staff communication?
- Prompt: Was anything particularly challenging or unhelpful for you regarding staff communication?

Please could you describe how family or carers were involved during your admission? How did you perceive and experience this involvement?

- Prompt: Was anything particularly helpful for you regarding carer involvement?
- Prompt: Was anything particularly challenging or unhelpful for you regarding carer involvement?



Please could you tell me about what happened after your admission? Please think about this in terms of the bigger picture - your treatment, you physical health and psychological wellbeing, as well as your quality of life.

- Prompt: And what about your [physical health / psychological wellbeing / QoL]

Closing questions.

Before we finish, I just want to check in on how you're feeling after today's interview, as I'm aware that we've spoken about some sensitive content.

How did it feel for you? How are you doing now?

(If needed)

- Do you have a supportive person you can chat to?
- How are you going to look after yourself for the rest of your day?

Thank you for your time today. I really appreciate it.

*(*Provide PDF of NHS and charity resources*)*

Appendix K – Exemplary Exploratory Noting and Experiential Statements

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Appendix L – An Example Table of PETs

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Appendix M – The Process of Developing GETs from PETs

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Appendix O - Abridged Research Diary

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Appendix P - Ethical Approval

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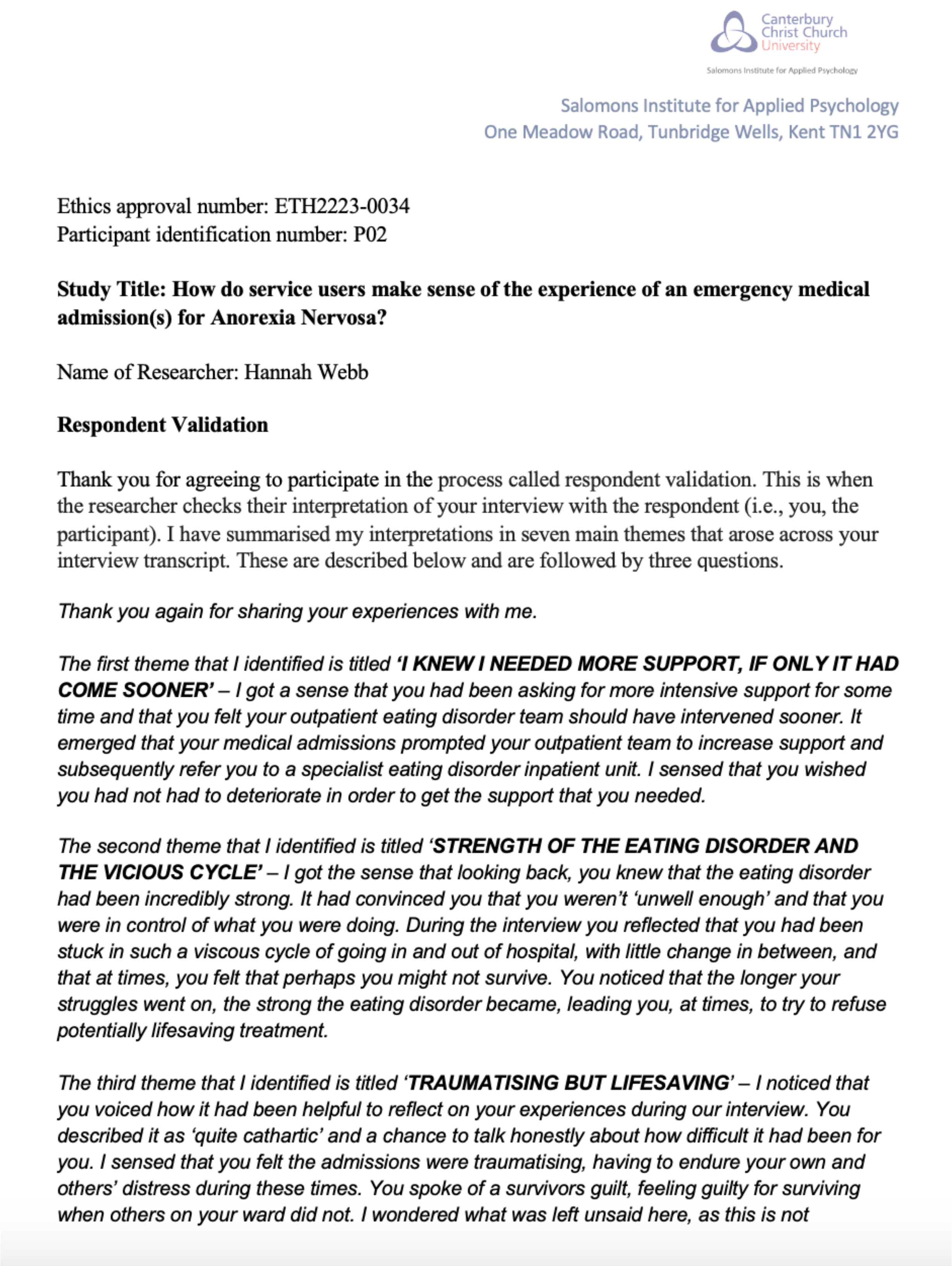
Appendix N - Exemplary Respondent Validation



Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

Ethics approval number: ETH2223-0034
Participant identification number: P02

Study Title: How do service users make sense of the experience of an emergency medical admission(s) for Anorexia Nervosa?

Name of Researcher: Hannah Webb

Respondent Validation

Thank you for agreeing to participate in the process called respondent validation. This is when the researcher checks their interpretation of your interview with the respondent (i.e., you, the participant). I have summarised my interpretations in seven main themes that arose across your interview transcript. These are described below and are followed by three questions.

Thank you again for sharing your experiences with me.

The first theme that I identified is titled ***'I KNEW I NEEDED MORE SUPPORT, IF ONLY IT HAD COME SOONER'*** *– I got a sense that you had been asking for more intensive support for some time and that you felt your outpatient eating disorder team should have intervened sooner. It emerged that your medical admissions prompted your outpatient team to increase support and subsequently refer you to a specialist eating disorder inpatient unit. I sensed that you wished you had not had to deteriorate in order to get the support that you needed.*

*The second theme that I identified is titled '****STRENGTH OF THE EATING DISORDER AND THE VICIOUS CYCLE'*** *– I got the sense that looking back, you knew that the eating disorder had been incredibly strong. It had convinced you that you weren't 'unwell enough' and that you were in control of what you were doing. During the interview you reflected that you had been stuck in such a viscous cycle of going in and out of hospital, with little change in between, and that at times, you felt that perhaps you might not survive. You noticed that the longer your struggles went on, the strong the eating disorder became, leading you, at times, to try to refuse potentially lifesaving treatment.*

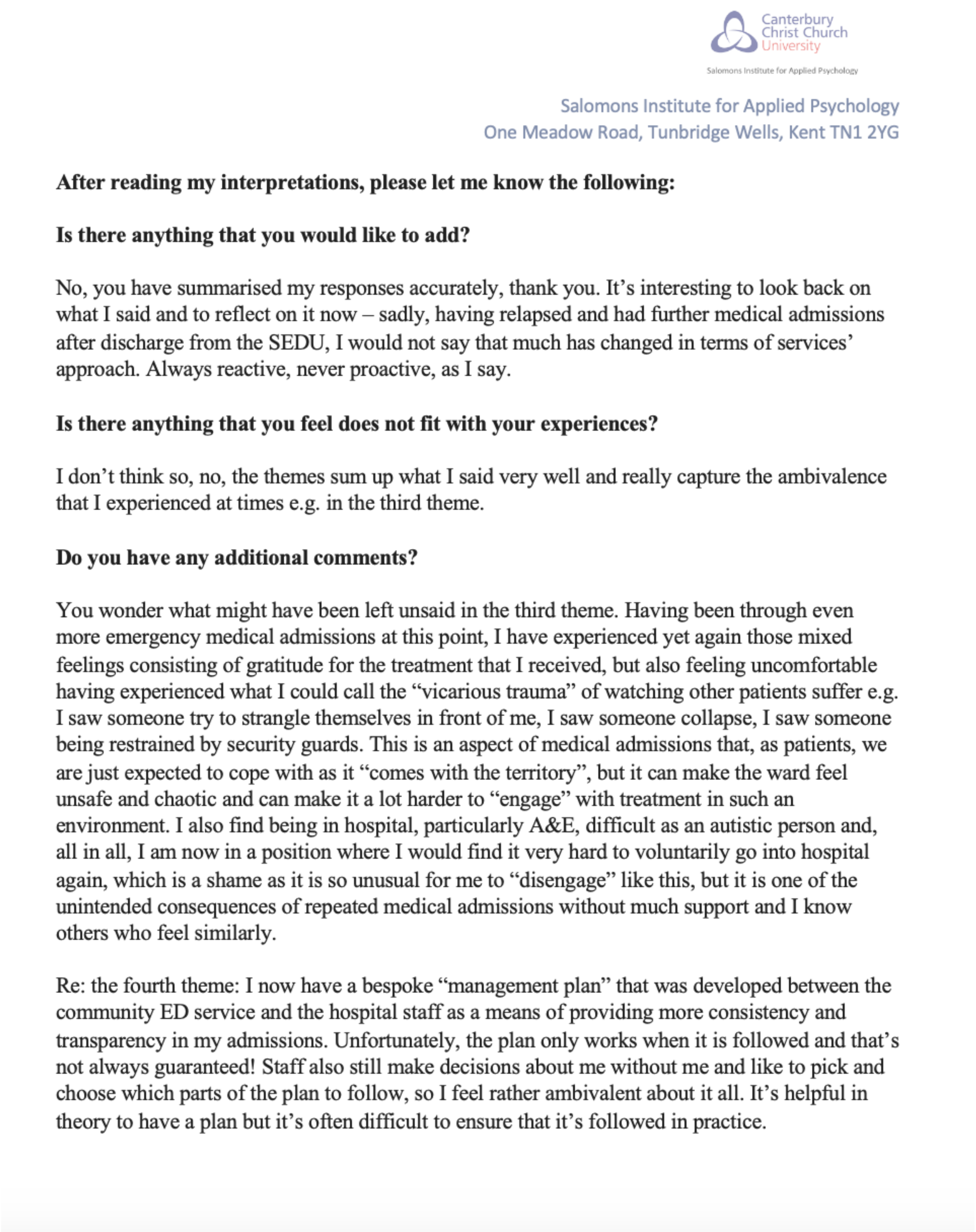
*The third theme that I identified is titled '****TRAUMATISING BUT LIFESAVING****' – I noticed that you voiced how it had been helpful to reflect on your experiences during our interview. You described it as 'quite cathartic' and a chance to talk honestly about how difficult it had been for you. I sensed that you felt the admissions were traumatising, having to endure your own and others' distress during these times. You spoke of a survivors guilt, feeling guilty for surviving when others on your ward did not. I wondered what was left unsaid here, as this is not* *something we explored in detail. Finally, despite it being such a difficult time, I noted a sense of gratitude for the medical intervention that saved your life.*

*The fourth theme that I identified is titled ‘**THE ADMISSIONS WERE CHAOTIC AND OFTEN LACKED CERTAINTY**’ – You described the admissions as chaotic and lacking in clarity, consistency and transparency. I sensed that you wished that medical professionals had been more open and communicated better, and also that they had taken the time to consider how your diagnosis of autism might impact upon your experiences. In particular, I sensed that you often felt that medical professionals talked about you without you, and that you desired greater involvement in treatment discussions.*

*The fifth theme that I identified is titled ‘**I HAD TO DO IT ALONE**’ – I sensed that you felt you were not provided with adequate support on the medical wards and that it felt like a lonely experience. I also noted strong feelings of shame, meaning that you felt you had to keep the eating disorder a secret from friends and family. I also sensed such compassion towards others, as you described not wanting friends who also struggled with eating disorders to visit, as you knew it could be triggering or upsetting for them.*

*The sixth theme that I identified is titled ‘**MISSED OPPORTUNITIES**’ – Throughout the interview I noticed that you described various examples of when medical professionals appeared to not fully understand eating disorders. I sensed your sadness and frustration at this lack of knowledge and a desire for things to be better. I understood that you felt there were many missed opportunities during your admissions, particularly in the medical professionals’ focus on getting you to the bare minimum of ‘safe enough’ to be discharged. I also sensed that you were relieved to have not been sectioned during the admissions, but that you wondered if perhaps the medical team’s view of capacity was insufficient, as you had known what you were doing, but you were unable to stop the cycle of harm.*

*Finally, the seventh theme that I identified is titled ‘**A HOLISTIC APPROACH’** – You shared that the specialist dietetic support that you received during the admissions was invaluable. You needed more than just medical input. It was here that you felt someone understood you and your eating disorder struggles. I sensed that overall you desired greater psychological awareness and understanding of eating disorders and greater collaboration between the medical team and your outpatient eating disorder team.*



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One Meadow Road, Tunbridge Wells, Kent TN1 2YG

After reading my interpretations, please let me know the following:

Is there anything that you would like to add?

No, you have summarised my responses accurately, thank you. It's interesting to look back on what I said and to reflect on it now – sadly, having relapsed and had further medical admissions after discharge from the SEDU, I would not say that much has changed in terms of services' approach. Always reactive, never proactive, as I say.

Is there anything that you feel does not fit with your experiences?

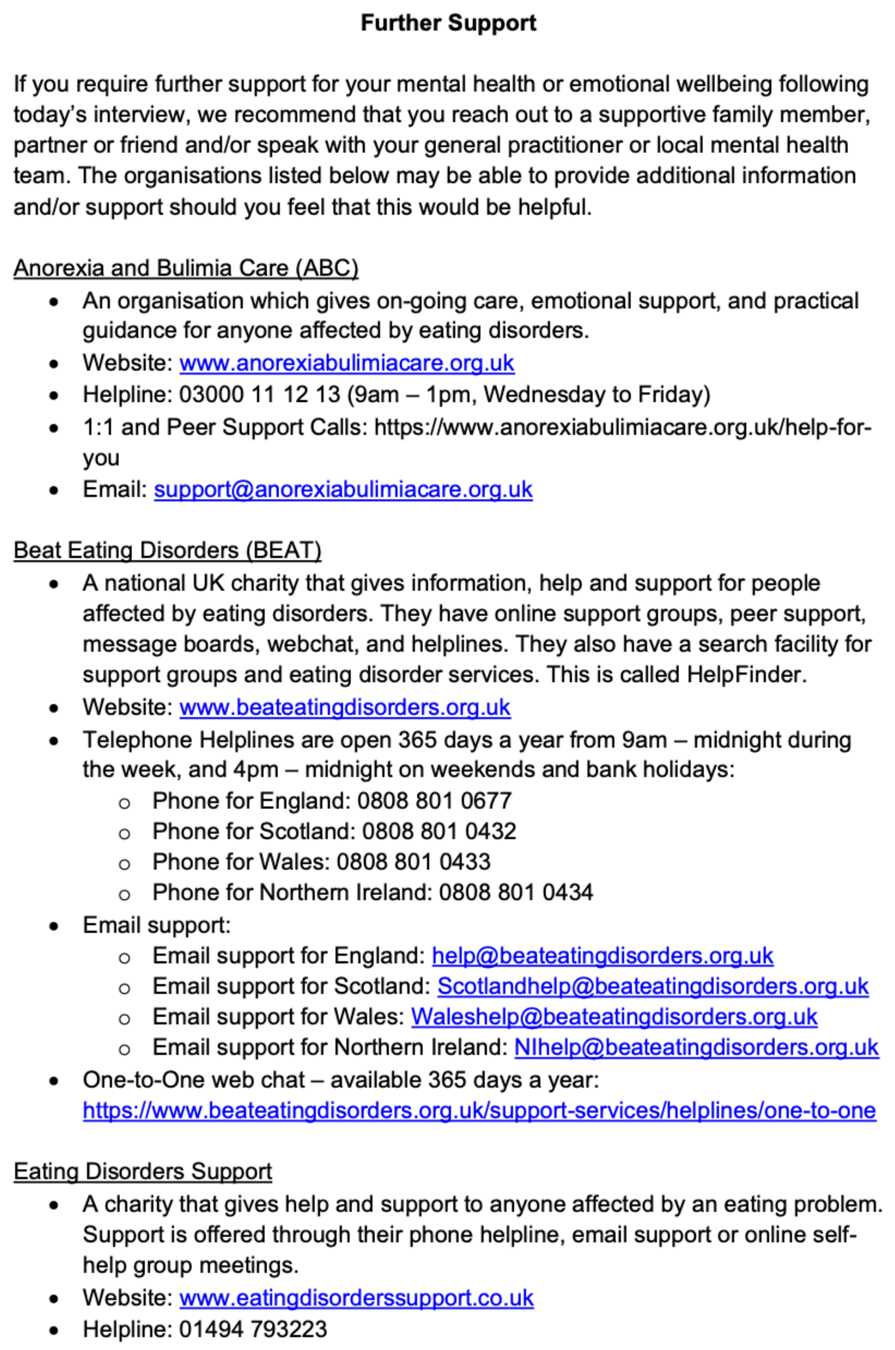
I don't think so, no, the themes sum up what I said very well and really capture the ambivalence that I experienced at times e.g. in the third theme.

Do you have any additional comments?

You wonder what might have been left unsaid in the third theme. Having been through even more emergency medical admissions at this point, I have experienced yet again those mixed feelings consisting of gratitude for the treatment that I received, but also feeling uncomfortable having experienced what I could call the "vicarious trauma" of watching other patients suffer e.g. I saw someone try to strangle themselves in front of me, I saw someone collapse, I saw someone being restrained by security guards. This is an aspect of medical admissions that, as patients, we are just expected to cope with as it "comes with the territory", but it can make the ward feel unsafe and chaotic and can make it a lot harder to "engage" with treatment in such an environment. I also find being in hospital, particularly A&E, difficult as an autistic person and, all in all, I am now in a position where I would find it very hard to voluntarily go into hospital again, which is a shame as it is so unusual for me to "disengage" like this, but it is one of the unintended consequences of repeated medical admissions without much support and I know others who feel similarly.

Re: the fourth theme: I now have a bespoke "management plan" that was developed between the community ED service and the hospital staff as a means of providing more consistency and transparency in my admissions. Unfortunately, the plan only works when it is followed and that's not always guaranteed! Staff also still make decisions about me without me and like to pick and choose which parts of the plan to follow, so I feel rather ambivalent about it all. It's helpful in theory to have a plan but it's often difficult to ensure that it's followed in practice.

Appendix Q - Signposting Resources



Further Support

If you require further support for your mental health or emotional wellbeing following today's interview, we recommend that you reach out to a supportive family member, partner or friend and/or speak with your general practitioner or local mental health team. The organisations listed below may be able to provide additional information and/or support should you feel that this would be helpful.

Anorexia and Bulimia Care (ABC)
- An organisation which gives on-going care, emotional support, and practical guidance for anyone affected by eating disorders.
- Website: www.anorexiabulimiacare.org.uk
- Helpline: 03000 11 12 13 (9am – 1pm, Wednesday to Friday)
- 1:1 and Peer Support Calls: https://www.anorexiabulimiacare.org.uk/help-for-you
- Email: support@anorexiabulimiacare.org.uk

Beat Eating Disorders (BEAT)
- A national UK charity that gives information, help and support for people affected by eating disorders. They have online support groups, peer support, message boards, webchat, and helplines. They also have a search facility for support groups and eating disorder services. This is called HelpFinder.
- Website: www.beateatingdisorders.org.uk
- Telephone Helplines are open 365 days a year from 9am – midnight during the week, and 4pm – midnight on weekends and bank holidays:
    - Phone for England: 0808 801 0677
    - Phone for Scotland: 0808 801 0432
    - Phone for Wales: 0808 801 0433
    - Phone for Northern Ireland: 0808 801 0434
- Email support:
    - Email support for England: help@beateatingdisorders.org.uk
    - Email support for Scotland: Scotlandhelp@beateatingdisorders.org.uk
    - Email support for Wales: Waleshelp@beateatingdisorders.org.uk
    - Email support for Northern Ireland: NIhelp@beateatingdisorders.org.uk
- One-to-One web chat – available 365 days a year: https://www.beateatingdisorders.org.uk/support-services/helplines/one-to-one

Eating Disorders Support
- A charity that gives help and support to anyone affected by an eating problem. Support is offered through their phone helpline, email support or online self-help group meetings.
- Website: www.eatingdisorderssupport.co.uk
- Helpline: 01494 793223

- Support by email: support@eatingdisorderssupport.co.uk

Mind Mental Health Charity

- Provide advice and support to empower anyone experiencing a mental health problem. Campaign to improve services, raise awareness & promote understanding.
- Website: www.mind.org.uk
- Infoline phone number – provides an information and signposting service, open 9am to 6pm Monday to Friday (except for bank holidays): 0300 123 3393
- Email: info@mind.org.uk

Rethink Mental Illness

- Provide expert information and help people experiencing mental illness through a network of local groups and services.
- Website: www.rethink.org
- Phone number - advice and information telephone service is open from 1pm - 4pm, Monday to Friday: 0808 801 0525
- Webchat - open from 9:30am – 4pm Monday to Friday, excluding bank holidays: https://www.rethink.org/aboutus/what-we-do/advice-and-information-service/
- Email: advice@rethink.org (Please include your postcode, date of birth and phone number in case Rethink need to contact you)

Samaritans

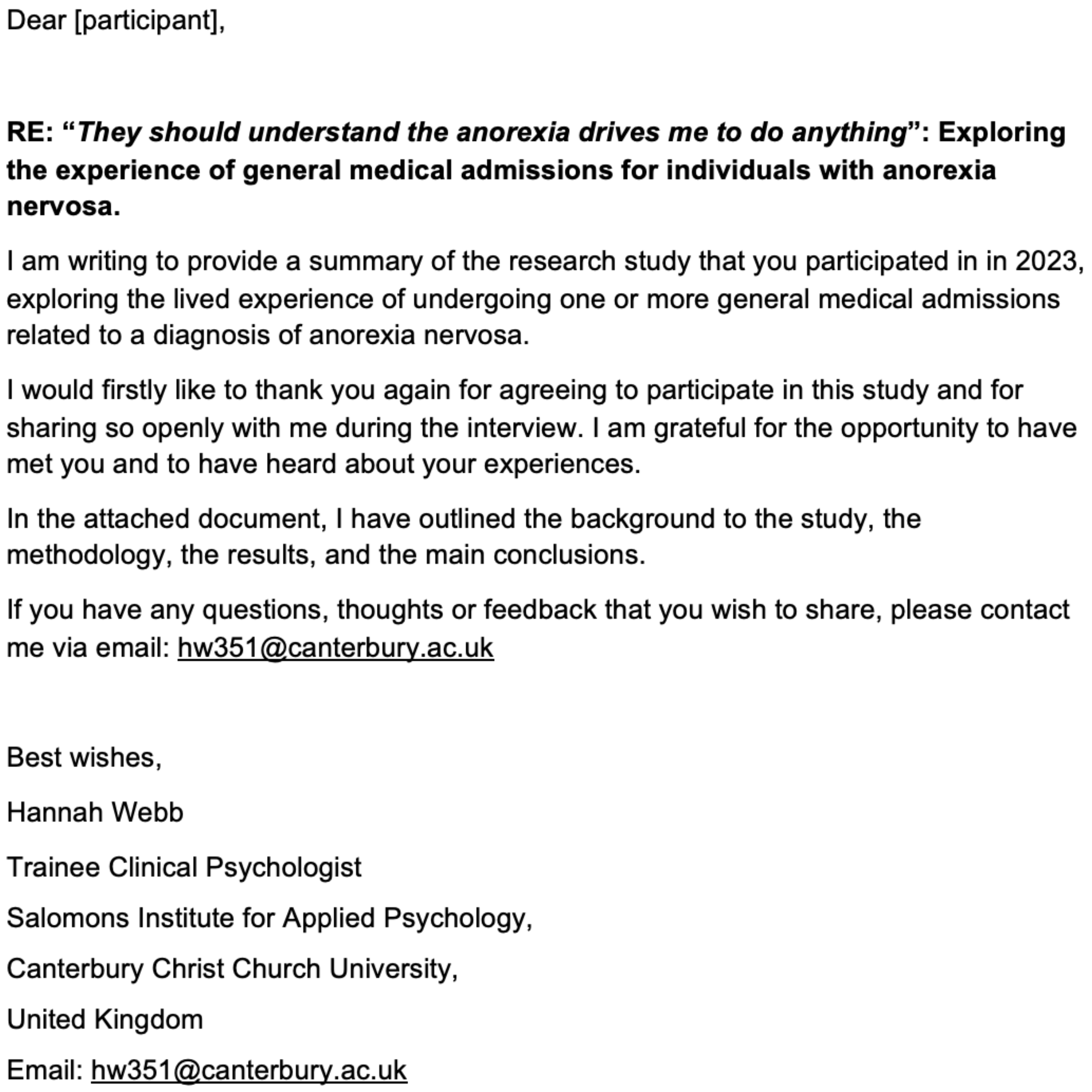
- Provide emotional support to anyone in emotional distress.
- Open 24/7 for anyone who needs to talk.
- Website: www.samaritans.org
- Phone: 116 123 (free 24-hour helpline)
- Welsh Language Phone Line: 0808 164 0123 (7pm - 11pm every day)
- Email: jo@samaritans.org (response time: 24 hours)

Shout

- A free, confidential, anonymous 24/7 text messaging support service for anyone who is struggling to cope.
- You can text from wherever you are in the UK.
- Website: https://giveusashout.org
- Text ‘SHOUT’ to 85258

Appendix R – Research Summary for Participants

Email sent to those participants who opted into receiving a copy of the results:



Dear [participant],

RE: “*They should understand the anorexia drives me to do anything*”: Exploring the experience of general medical admissions for individuals with anorexia nervosa.

I am writing to provide a summary of the research study that you participated in in 2023, exploring the lived experience of undergoing one or more general medical admissions related to a diagnosis of anorexia nervosa.

I would firstly like to thank you again for agreeing to participate in this study and for sharing so openly with me during the interview. I am grateful for the opportunity to have met you and to have heard about your experiences.

In the attached document, I have outlined the background to the study, the methodology, the results, and the main conclusions.

If you have any questions, thoughts or feedback that you wish to share, please contact me via email: hw351@canterbury.ac.uk

Best wishes,

Hannah Webb

Trainee Clinical Psychologist

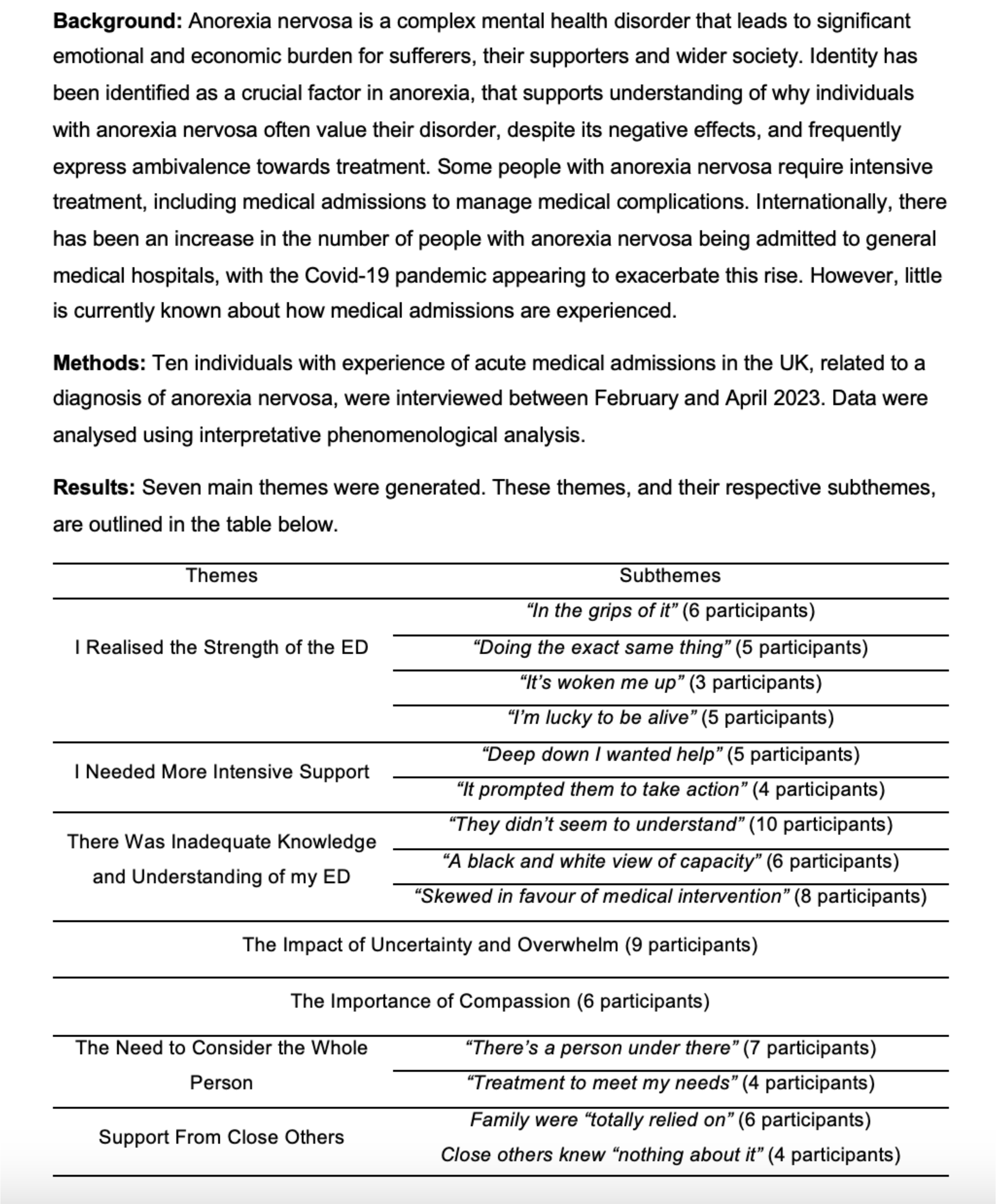
Salomons Institute for Applied Psychology,

Canterbury Christ Church University,

United Kingdom

Email: hw351@canterbury.ac.uk

Attached research summary included in the email:



Background: Anorexia nervosa is a complex mental health disorder that leads to significant emotional and economic burden for sufferers, their supporters and wider society. Identity has been identified as a crucial factor in anorexia, that supports understanding of why individuals with anorexia nervosa often value their disorder, despite its negative effects, and frequently express ambivalence towards treatment. Some people with anorexia nervosa require intensive treatment, including medical admissions to manage medical complications. Internationally, there has been an increase in the number of people with anorexia nervosa being admitted to general medical hospitals, with the Covid-19 pandemic appearing to exacerbate this rise. However, little is currently known about how medical admissions are experienced.

Methods: Ten individuals with experience of acute medical admissions in the UK, related to a diagnosis of anorexia nervosa, were interviewed between February and April 2023. Data were analysed using interpretative phenomenological analysis.

Results: Seven main themes were generated. These themes, and their respective subthemes, are outlined in the table below.

Themes	Subthemes
I Realised the Strength of the ED	*“In the grips of it”* (6 participants)
	“Doing the exact same thing” (5 participants)
	“It’s woken me up” (3 participants)
	“I’m lucky to be alive” (5 participants)
I Needed More Intensive Support	*“Deep down I wanted help”* (5 participants)
	“It prompted them to take action” (4 participants)
There Was Inadequate Knowledge and Understanding of my ED	*“They didn’t seem to understand”* (10 participants)
	“A black and white view of capacity” (6 participants)
	“Skewed in favour of medical intervention” (8 participants)
The Impact of Uncertainty and Overwhelm (9 participants)	
The Importance of Compassion (6 participants)	
The Need to Consider the Whole Person	*“There’s a person under there”* (7 participants)
	“Treatment to meet my needs” (4 participants)
Support From Close Others	*Family were “totally relied on”* (6 participants) *Close others knew “nothing about it”* (4 participants)

Conclusions: Admissions were often life-saving and gratitude was expressed for medical intervention. However, a lack of psychological understanding meant participants felt misunderstood and stigmatised and an illness identity dominated. Mental and physical health services were experienced as disconnected and close others sometimes had to shoulder significant responsibility for care. Better integration of healthcare services is needed to improve the client experience.

Training on eating disorders for medical professionals is required to reduce stigma, enhance care experiences and improve clients' outcomes. Clinical psychologists and those with lived experience should assist on the development and delivery of training, to support understanding of factors involved in the development and maintenance of anorexia nervosa and how to manage concurrent psychological, medical, nutritional, behavioural, and social difficulties. Training should include guidance on how to communicate with people with anorexia nervosa and provide both practical and emotional support during refeeding. Emotion recognition and regulation and distress tolerance skills should also be considered. Future research should explore whether therapeutic techniques may support dis-identification with an illness identity in acute medical settings and how best to implement these.

Admissions were overwhelming and at times, traumatising. A trauma-informed and holistic approach would help consider all aspects of the individual, including comorbidities, personal histories and life outside the illness. Further research must explore what aspects of treatment render hospitalisation harmful and how to support processing of restrictive practices.

Finally, supporters should be involved in care during medical admissions, though involvement should be considered on an individual basis. Care must be taken to not over-rely on supporters, and clients' reasons for not involving them should be explored. Future research should explore supporters' perspectives on care in acute medical settings and how non-familial supporters might be included.

Appendix S – End of Study Letter

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Appendix T – End of Study Summary for Salomons Ethics Panel

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Appendix U – Author Guidelines for the European Eating Disorders Review

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