An Exploration of Relapse Experiences in Eating Disorders and the Relationship Between Caregiver PTSD Symptoms, Eating Disorder Factors, and Caregiving Skills

Natasha Heal-Cohen

Doctorate in Clinical Psychology

University of East Anglia

Norwich Medical School

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[1] Parts of this thesis may bear resemblance to the thesis proposal submitted by the author towards the ClinPsyD in 2023. Additional authors for included research papers are listed at the start of the corresponding chapter, with further details on their contributions found within the paper and in appendix title page information. Details on joint work towards the empirical paper are also outlined within the Additional Methodology Chapter.

Abstract

Recovery outcomes for individuals with eating disorders (EDs) remain poor, and the impact on family members is significant. This thesis portfolio aims to address gaps in our understanding of the experiences of both individuals with EDs and their parental caregivers.

A systematic review and thematic synthesis were conducted to explore individuals' experiences of relapse. Qualitative data from 16 studies were synthesized, generating five themes that describe relapse as enticing, unstoppable, protective, destructive, and instructive. The findings highlight the risks of insufficient professional and social support in the face of an enduring attachment to the ED and unresolved psychological vulnerabilities. Despite variation in individuals' mindsets upon relapse, concerningly, relapse was commonly interpreted in ways that fuelled self-criticism and diminished hope for recovery.

A subsequent quantitative empirical study examined post-traumatic stress disorder (PTSD) symptoms in 123 parental caregivers of children and young people (CYP) with ED symptoms via an online survey. Findings revealed over half (62.6%) reported probable PTSD in relation to their child's ED. Demographic and ED-related factors together explained 21% of the variance in PTSD symptoms, with ED relapse contributing the largest independent association. Additionally, PTSD symptoms accounted for 34% of the variance in caregiver skills, with greater PTSD symptoms associated with less adaptive caregiving behaviours, such as self-care and insight and acceptance.

In the final discussion chapter, findings from both studies are critically evaluated and examined in relation to theory, evidence, and clinical practice. The chapter highlights the interdependencies between individuals with EDs, caregivers, and professionals, and considers the importance of relational, trauma-informed, tailored approaches that address and balance the psychological needs of both individuals with EDs and their caregivers.

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Chapter One: Introduction

Background on Eating Disorders

Eating disorders (EDs) are mental health conditions characterised by persistent disturbance of eating or eating-related behaviour which can cause impairment to health and psychosocial functioning (National Institute for Health and Care Excellence [NICE], 2017). EDs vary in severity but impose a substantial global disease burden due to reduced quality of life and increased mortality (Santomauro et al., 2021; van Hoeken & Hoek, 2020). Individuals of all ages, races, ethnicities, socioeconomic backgrounds and genders can be affected by EDs. However, some groups are at particular risk, such as those from socioeconomically disadvantaged backgrounds (Burnette et al., 2024), gender and sexual minorities and adolescents and young people (Silén & Keski-Rahkonen, 2022).

The peak age of onset for EDs is between 16-20 years (Wood et al., 2019) with between 6-18% of females and 1-2% of males estimated to have experienced a diagnosable ED by early adulthood (Silén & Keski-Rahkonen, 2022). In recent years, global incidence of EDs have risen whilst the mean age of onset has decreased (Silén & Keski-Rahkonen, 2022). In the UK, around 1.25 million people are estimated to have an ED (Beat, n.d), with National Health Service (NHS) data revealing child and adolescent and adult ED services are struggling to meet the increased demand (Royal College of Psychiatrists, 2022; Viljoen et al., 2024).

Feeding and eating disorder diagnoses within the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association [APA], 2013) include bulimia nervosa (BN), anorexia nervosa (AN), binge eating disorder (BED), other specified feeding and eating disorder (OSFED), and avoidant/restrictive food intake disorder (ARFID). Although the vast majority of research has focused on AN and BN, the most common ED is considered to be OSFED, which includes subthreshold BN and atypical AN (Hay, 2020; Santomauro et al., 2021). ARFID is less well researched but has been identified in a

significant proportion of children and adolescents within ED services (Nicely et al., 2014; Zimmerman & Fisher, 2017).

EDs are subject to diagnostic migration due to evolving criteria over the years, as well as diagnostic cross-over, as individuals' symptoms shift and they transition between diagnoses (Castellini et al., 2013; Gordon et al., 2018; Solmi et al., 2024). ED behaviours (e.g. excessive exercise, bingeing, purging or food restriction) and cognitions (e.g. over-evaluation of shape and weight) can also feature across diagnoses (Cooper & Dalle Grave, 2017). This has informed a transdiagnostic approach to theory, treatment and research in EDs (Fairburn et al., 2003; Gordon et al., 2018). The transdiagnostic model of EDs (Fairburn et al., 2003) suggests common mechanisms are involved in the maintenance of EDs such as AN, BN, BED and their variants (e.g. atypical AN) including low self-esteem, interpersonal difficulties and over-evaluation of shape and weight. In comparison, ARFID is distinguished from other EDs as diagnostic criteria indicate behaviours should not be driven by body image disturbance (APA, 2022), although there are shared health risks and treatment approaches such as cognitive-behavioural therapy and family-based therapies (Fisher et al., 2023).

For children and young people with AN or BN, NICE (2017) guidance recommends family therapy (FT-AN and FT-BN) as a first line intervention. Remission rates, when defined by body mass index (BMI) and eating disorder scores near the expected norms, have been found to be < 40% at the end of family-based treatment (Dalle Grave et al., 2019). However, rates can vary widely based on the definition adopted (e.g. 21.7-87.7% for FT-AN; Le Grange et al., 2019), and are not consistently superior to enhanced cognitive behavioural therapy (CBT-E) for adolescent EDs (Wergeland et al., 2025).

For adults with AN, eating-disorder-focused cognitive behavioural therapy (CBT-ED), an umbrella category which includes CBT-E, Maudsley Anorexia Nervosa Treatment for Adults (MANTRA) or specialist supportive clinical management (SSCM) are recommended (NICE, 2017). A randomised controlled trial comparing these treatments for adults with AN

found no significant differences in remission rates at 12 month follow up (mean rate = 28.3%), defined by eating disorder scores near community norms, absence of binge eating/purging behaviours and non-underweight BMI (Byrne et al., 2017). For BN and BED, cognitive behavioural programmes (guided self-help and CBT-ED) are recommended (NICE, 2017), whilst for OSFED, the treatments for the eating disorder it most closely resembles are suggested. Following CBT-E, studies find between 14.3% and 50% of individuals with BN, BED and OSFED show an absence of ED behaviours and ED pathology below clinical cut-off (Melisse et al, 2022). NICE recommendations for the treatment of ARFID are yet to be made, although manualised treatments exist (e.g., CBT-AR; Thomas & Eddy, 2019). Across EDs, physical health assessment, monitoring (e.g. ECGs, bone mineral density scans, bloods, dental reviews) and management may also be needed due to the risks associated with ED behaviours (NICE, 2017).Access to treatment is poor, with only a minority of those with EDs in a UK-based sample found to have accessed any form of professional support (Solmi et al., 2016). Despite decades of research, ED treatment outcomes have also remained poor, and little is still known about the factors associated with sustained recovery (NICE, 2017). The Parliamentary and Health Service Ombudsman (2023) noted that people with EDs continue to be repeatedly failed by the system, with little progress made to prevent ED-related deaths. A broader "therapeutic stagnation" has been observed in the field (Kan et al., 2019). Indeed, apart from lower mortality in AN, Solmi et al (2024) concluded that the outcomes of EDs globally have not improved over decades. Their meta-analysis found that, pooling all EDs together and irrespective of intervention, recovery occurred in 46% of patients after a mean follow up of almost four years (45 months), with no significant difference among EDs. The global picture remains complex, as a higher socio-demographic index in countries has been associated with lower mortality in OSFED but greater chronicity in AN, with cultural differences surrounding thinness thought to play a role (Solmi et al., 2024).

Relapse in Eating Disorders

Although estimates vary across studies, Solmi et al (2024) found over a quarter (26%) of individuals with EDs relapse. Identified risk factors for relapse are diverse and include age at onset, comorbidities, symptom severity, and treatment response (Sala et al., 2023). The consequences of relapse can be profound, including further distress and impairment in health and psychosocial functioning, and the potential for the disorder to follow a fatal or chronic course or for individuals to become stuck in cycles of recovery and relapse.

Although no standardised clinical definition of relapse exists within EDs (Sala et al., 2023; Schlam & Wilson, 2007), it is broadly described as "the deterioration in a patient's condition after a partial or apparently complete recovery" (Oxford English Dictionary, 2024). Variability in the operationalisation of relapse in research (e.g., by diagnostic criteria, body mass index, psychiatric symptoms or re-entry into treatment) has contributed to differences in reported relapse rates (Sala et al., 2023). Relapse has received most focus in quantitative research, with recent reviews bringing together evidence on the prevalence and predictors of relapse in EDs (de Rijk et al., 2024; Sala et al., 2023; Solmi et al., 2024).

Examining relapse as a binary outcome depending on whether specific criteria are met (e.g. Sala et al., 2023), overlooks the complex and nuanced personal experience of relapse which remains relatively unexplored. In contrast, understanding of ED recovery has benefitted from qualitative research bringing a personal recovery lens to clinical symptom-focused conceptualisations of recovery. This research has brought important emphasis to recovery as a psychological experience that extends beyond becoming symptom-free (e.g. Wetzler et al., 2020). However, whilst recovery is often non-linear, experiences of relapse have received little discussion within recovery narratives (Keski-Rahkonen & Tozzi, 2005).

Dominant models of relapse, originally developed for addictions, consider relapse to be a process or series of unfolding events in which risk factors interact and psychological appraisals play a role in determining outcomes (e.g. Marlatt & Gordon, 1985). Such models

form the basis for relapse prevention in EDs where focuses include identifying triggers, self-monitoring and developing a plan for setbacks (Schlam & Wilson, 2007). Qualitative research can provide valuable insights into personal experiences of the relapse process to inform our understanding and guide relapse prevention and response efforts. However, to the author's knowledge, no qualitative review has been conducted to synthesise individuals' experiences of ED relapse.

The Experiences of Caregivers

The experiences of individuals with EDs are also deeply intertwined with their social context, making this essential to understand. Individuals with EDs commonly cite family as their main source of social support (Leonidas & Dos Santos, 2014). Parents and carers, particularly of children and young people with EDs, have a significant role in the identification, management and recovery from the ED, and can both help and hinder progress (Treasure et al., 2024). Within this thesis, caregivers of individuals with EDs may be referred to in shorthand as "ED caregivers". Interpersonal models of EDs demonstrate how caregivers' unhelpful responses to their child, such as high levels of expressed emotion or avoidance, can maintain their ED (Schmidt & Treasure, 2006). In contrast, caregiving "skills" including attitudes of hope and acceptance have been identified as drivers of their child's recovery (Goddard et al., 2011; Salerno et al., 2016) and have therefore been targeted in caregiver interventions (Philipp et al., 2021).

Whilst providing a critical role in supporting recovery, parents also face significant stressors and experience considerable distress in relation to their child's ED (Fox et al., 2017; Quong & Chen, 2018). Fears of their child dying, anger, helplessness and feeling unsupported are commonly cited (Fox et al., 2017). Levels of psychopathology, particularly anxiety, are high amongst ED caregivers (Anastasiadou et al., 2014; Orive et al., 2013). The interdependence of the distress of individuals with EDs and their caregivers has been well documented (Goddard et al., 2013; Salerno et al., 2016).

Evidence is growing that traumatic experiences parents face in relation to their child's ED, such as being unable to prevent their child's deterioration, can result in the development of post-traumatic stress disorder (PTSD) (Hazell et al., 2014; Irish et al., 2024; Timko et al., 2023). PTSD is a serious mental health condition which can occur following direct or indirect exposure to a stressor and can persist without treatment. Symptoms include hypervigilance, negative beliefs, distress at traumatic reminders and avoidance (APA, 2013). Within this thesis, post-traumatic stress or PTSD symptoms are used to describe symptoms across the spectrum of severity, including where these do not meet diagnostic criteria. Probable PTSD, sometimes called diagnosable PTSD, refers to symptoms assessed to meet clinical cut-offs for PTSD, typically based on a validated self-report measure, but where assessments do not constitute a formal diagnosis.

Research has so far focussed on post-traumatic stress in parents to narrowed samples of individuals with AN (Hazell et al., 2014; Irish et al., 2024; Timko et al., 2023). The rate and correlates of probable PTSD in broader samples of parental caregivers to those with ED symptomology are not known. Additionally, how PTSD symptoms relate to the caregiving skills considered helpful in supporting their child has also yet to be examined. Addressing these research gaps is needed to understand how to support caregivers so that in turn they can better support their child.

An Overview of the Thesis Portfolio

The aim of this thesis portfolio is to examine gaps in our understanding around the influence of EDs on the individual and their caregivers. This dual focus aims to contribute to a holistic understanding of EDs, accounting for both the individual's internal battle and the external support systems involved, as well as generating insights that inform the support offered to both groups. In its scope, this thesis aligns with family-based and relational recovery models (Wyder et al., 2022; Wyder & Bland, 2014) which consider recovery

processes in terms of 1) the individual with the disorder, 2) recovery-oriented caregiving and 3) family recovery.

A pragmatic approach, blending scientific and critical realism, has been adopted to fit the need presented by the research gap, producing a thesis with both qualitative and quantitative elements. Within this thesis, both clinical diagnostic models and the individual experiential perspective are recognised to have value and complement one another. A transdiagnostic perspective on EDs is broadly adopted. When exploring the experiences of individuals with EDs, the disorders commonly considered to share a core psychopathology in transdiagnostic models (i.e., AN, BN, BED and their variants) are included (Cooper & Dalle Grave, 2017; Fairburn et al., 2003). When examining the experience of ED caregivers, all ED presentations are considered, including ARFID, for example, as the degree of homogeneity in ED psychopathology within the sample is less pertinent to this research.

The first paper presented is a systematic review of qualitative accounts of lived experiences of relapse from the perspective of individuals with EDs. The research question is *What are the experiences of people with an eating disorder who encounter relapse(s)?* It aims to offer a synthesis which illuminates the complex, rich and diverse experiences that exist behind simplistic conceptualisations of relapse and which has implications for its prevention and treatment.

An empirical paper is subsequently presented which examines post-traumatic stress in caregivers of children and young people with ED symptomology. It aims to examine 1) the rate of probable PTSD in the sample, 2) demographic and ED-related associations with PTSD symptom severity and 3) how PTSD symptom severity relates to caregiver skills. In doing so, it aims to generate implications for supporting caregiver wellbeing and competency, and therefore ultimately contribute to improving ED outcomes.

Finally, a critical discussion chapter considers the findings as a whole and their implications for theory, practice and future research. Additional chapters (Bridging Chapter

and Additional Methodology Chapter) are provided to offer further context and detail helpful to the reader.

Chapter Two: Systematic Review

Relapse in Eating Disorders: A Systematic Review and Thematic Synthesis of Individuals' Experiences

Authors:

Natasha Heal-Cohen, Dr Sophie Allan, Nieve Gauvain, Rachel Nabirinde &

Dr Aaron Burgess

Presented and formatted for submission to the journal *Clinical Psychology and Psychotherapy* (see Appendix A for submission guidelines and Appendix B for title page information).

Abstract

Objective: Relapse is common in eating disorders (EDs); however, it has received significantly more attention within quantitative research relative to qualitative research. This systematic review aimed to synthesise qualitative findings regarding the experiences of relapse for people with EDs.

Method: A search for studies reporting qualitative data that included experiences of relapse in individuals with EDs was conducted. This included a systematic search of MEDLINE, CINAHL, PsycInfo, Scopus, SSCI and PQDT Global along with supplementary searching. A total of 1594 titles and abstracts, and 168 full texts were screened for eligibility. Sixteen studies were included in the review. Quality appraisal was conducted using the CASP checklist. Data were extracted from each paper and thematic synthesis of relevant data from study findings/discussion was completed in NVivo.

Results: Most included studies involved female participants in the US, Canada and UK with anorexia and bulimia nervosa. Five analytical themes were generated: 1) "I wasn't letting go": Relapse as enticing, 2) "Bound to lose": Relapse as unstoppable, 3) "If the going gets tough I've always got this": Relapse as protective, 4) "Coming back with your tail between your legs": Relapse as destructive, 5) "So much of this journey…is learning": Relapse as instructive.

Discussion: Findings highlight the gap between psychological and behavioural improvements that precede relapse, and the contrasting ways relapse is described and experienced. They support a focus on motivational factors and underlying psychological difficulties in treatment, extending beyond a behavioural focus. Further research is needed to understand relapse experiences among males and individuals from the global majority.

Key Practitioner Message:

- Individuals with EDs who relapsed described desiring or feeling powerless to control relapse. Findings suggest the need for greater emphasis on developing intrinsic motivation and self-efficacy in order to sustain recovery.
- Residual ED cognitions and unaddressed psychological vulnerabilities were implicated in relapse. Findings caution against premature discharge before sufficient cognitive and emotional progress has been made.
- In response to relapse, clinicians should aim to foster hope, compassion and tailor treatment to address the recovery needs revealed by relapse.

Keywords: Eating disorder, qualitative, recurrence, relapse, systematic review

Relapse in Eating Disorders: A Systematic Review and Thematic Synthesis of Individuals' Experiences

Relapse, broadly defined as “the deterioration in a patient’s condition after a partial or apparently complete recovery” (Oxford English Dictionary, 2024), is common among individuals with EDs. There is no standardised clinical definition of relapse among EDs, and research has operationalised it in varied ways, including a return to meeting diagnostic criteria, re-hospitalisation, and more often focus on changes in physical health and behaviours (e.g. weight, frequency of bingeing and purging) rather than psychological indicators (de Rijk et al., 2024; Miskovic-Wheatley et al., 2023). Whilst definitions influence reported rates of relapse, a recent meta-analysis revealed that pooling all EDs together, recovery occurred in 46% of individuals with EDs globally, and 26% experienced relapse after recovery (Solmi et al., 2024). However, as most included studies were conducted in North America and Europe further research from other regions is needed to gain a more comprehensive understanding of relapse patterns worldwide.

Relapse prevention has been a key focus within support for EDs, typically addressed in the final stages of treatment and increasingly in post-treatment interventions (Robinson et al., 2006; Schlam & Wilson, 2007; Steinglass et al., 2022). ED-focused cognitive behaviour therapy (CBT-ED) for adults and family therapy for children and young people, are among the primary treatments recommended by The National Institute for Health and Care Excellence (NICE, 2017), although guidance varies depending on the ED. Studies have showed large variation in rates of remission following treatment, influenced by factors such as sample characteristics, follow-up duration, and the definitions used (e.g., 14% to 50% remission following CBT-ED, Melisse et al., 2022; 21.7% to 87.7% following family therapy, Le Grange et al., 2019). However, aspects of treatment have been perceived as contributing towards “revolving door” experiences (Joyce et al., 2019) in which short-lived improvements lead to an in-and-out cycle of accessing care. What is more, the lack of strong evidence on

how to effectively prevent relapse in anorexia nervosa (AN) has led NICE (2017) to identify this as a key research priority. Understanding relapse is essential in informing support to both prevent and better meet the needs of those who relapse.

Current research indicates that individuals are particularly vulnerable to relapse in the first year after treatment (Berends et al., 2018; Nagl et al., 2016). Relapse is also more likely among those still experiencing ED symptoms (i.e. partial remission); however, it remains a significant risk even after full recovery (Khalsa et al., 2017). Varied predictors of relapse in EDs, primarily AN, have been identified, including weight and shape concerns, comorbidities such as depression, body mass index at discharge, stressful life events and psychosocial functioning (Berends et al., 2018; de Rijk et al., 2024; Grilo et al., 2012; Keel et al., 2005; Sala et al., 2023). However, current quantitative research is limited in its ability to capture the complex dynamic processes involved in relapse (Berends et al., 2018; Pars et al., 2024).

Individuals who relapse may have received treatment, developed knowledge and skills, and shown motivation and efforts towards recovery. How relapse can occur within this context, and how individuals experience this, is important to understand. Models of relapse, often developed in the context of addiction, have been applied to EDs (Schlam & Wilson, 2007). The Transtheoretical Model of Change (TMC; Prochaska & DiClemente, 1992) sees change as a cyclical process where relapse triggers a recycling through earlier stages of change during which learning occurs. Freeman and Dolan's (2001) expansion of the model described stages of pre-lapse, characterised by thoughts and desires for the "old" times, and lapse, which involves a decrease in skills needed to maintain recovery and a return to old patterns of thinking, and finally relapse, in which individuals return to old behaviours to a greater or lesser extent. Marlatt and Gordon's (1985) cognitive behavioural model conceptualises relapse as a process: a series of events unfolding over time, with individuals' appraisals and responses being central to this process. More recent revisions emphasise the

dynamic interactions between proximal and distal factors underlying relapse (Witkiewitz & Marlatt, 2007).

Qualitative research enables nuance, depth, and complexity of exploration, highlighting experiences unmeasured or immeasurable in quantitative research (Clarke & Braun, 2013). It has the potential to capture individuals' appraisals and responses to relapsing considered central to the process (Marlatt & Gordon, 1985). Qualitative reviews of EDs during COVID-19 (Schneider et al., 2023) and the perinatal period (Fogarty et al., 2018) identified and explored relapse during these periods of upheaval. Outside of these contexts, relapse has received little qualitative examination amongst reviews focused on treatment and recovery (Gustafsson et al., 2021). To our knowledge no systematic review has specifically focused on the experience of relapse for people with EDs despite its prevalence and clinical significance. This seems an important complement to recent quantitative syntheses (de Rijk et al., 2024; Sala et al., 2023; Solmi et al., 2024).

Aims

This thematic synthesis of qualitative studies seeks to deepen understandings of the experiences of relapse for people with EDs. It aims to generate insights that can inform theories of ED relapse as well as policy and practice around relapse prevention and treatment. As such, the review question was: *What are the experiences of people with an eating disorder (ED) who encounter relapse(s)?*

Methods

The review was prospectively registered with PROSPERO (CRD42023492922). It has been reported according to PRISMA (Page et al., 2021) and ENTREQ guidelines (Tong et al., 2012).

Design

The theoretical framework for this review is critical realism. As such, it assumes an underlying shared reality while recognizing that personal and social contexts shape how

relapse is understood. This review is therefore interested in both commonalities and the diversity and nuance in how relapse is described, interpreted, and experienced.

Definition and Scope

In line with the critical realist framework, in the absence of standardised definitions this review adopted a broad working definition of relapse as a resumption or worsening of ED symptoms following a period of improvement (e.g. partial or full remission or recovery). No specific parameters were set around the duration or extent of prior recovery or subsequent deterioration in determining relapse. Within the review, relapse was identified based on i) references to relapse and descriptions aligning with the working definition, ii) re-entry into treatment, and iii) relapse definitions provided by included study authors.

The review defined relapse experiences as encompassing perceived triggers and warning signs of relapse, thoughts and feelings about relapse and initial responses to relapse (including help seeking). Experiences of treatment and recovery from relapse, or successfully preventing relapse were beyond the scope of the review.

Eligibility

Inclusion criteria were: (1) Study design - primary qualitative studies or mixed-methods studies which separately analyse and report qualitative results; (2) Language - written in English; (3) Population - studies involving individuals who are experiencing or have experienced anorexia nervosa (AN), bulimia nervosa (BN), binge eating disorder (BED), other specified feeding and eating disorder (OSFED) or the replaced diagnosis of eating disorder not otherwise specified (EDNOS) in line with the theoretical and empirical support for the transdiagnostic conceptualisation of these disorders (Fairburn et al., 2003; Gordon et al., 2018); and (4) Focus - studies in which these individuals' experiences of ED relapse, as operationalised in *Definition and scope*, are a key theme within results/discussion.

Exclusion criteria were: (1) Paper type - single case studies, book chapters, book reviews, opinion pieces, conference presentations, posters and meeting abstracts; (2)

Population - studies where individuals without the specified disorders comprised 20% or more of participants unless eligible participants were separately analysed and reported; (3) Focus - studies where relapse is discussed exclusively with respect to preventing relapse or to treatment for/recovery from relapse; and (4) Context - studies where relapse is discussed exclusively in the context of the perinatal period or COVID-19. Pilot searches revealed a disproportionate number of papers in these areas, and therefore their inclusion was deemed to risk shifting the review away from its intended focus on relapse beyond these specific contexts which have received their own examination in recent reviews (Fogarty et al., 2018; Schneider et al., 2023).

Search Process

A comprehensive systematic search strategy was conducted following consultation with an academic librarian. Six electronic databases were searched: MEDLINE (EBSCO host), APA PsycInfo (EBSCO host), CINAHL Ultimate (EBSCO host), Social Sciences Citation Index, Scopus, and ProQuest Dissertations & Theses Global (PQDT Global). Databases aimed to cover medical, psychology and social sciences fields, with Scopus offering additional breadth and PQDT Global identifying unpublished academic papers which can be important, otherwise overlooked sources of rich material. All years were included from inception through to the initial search date in January 2024. Follow up searches were then conducted, with the final search in November 2024.

The SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, Research type) was used to inform and standardise the electronic search strategy (Cooke et al., 2012). Terms related to “eating disorders” (Sample), “relapse” (Phenomenon of Interest) and “qualitative research” (Research Type) were combined using the Boolean operator AND. Terms were searched within title, abstract and keyword fields (or closest database equivalent) and index terms were included where available (see Appendix C for full search strategy).

To supplement this, fourteen related qualitative ED reviews covering experiences of living with, treatment for and recovery from an ED, predominantly published in the last five years, as well as reference lists of included studies were hand searched. Leading researchers in the field were also contacted to identify additional studies. Supplementary searching aimed to be extensive in order to capture studies which discuss relapse but without explicit reference to this within title, abstract and keyword information and therefore may have been missed from database searching.

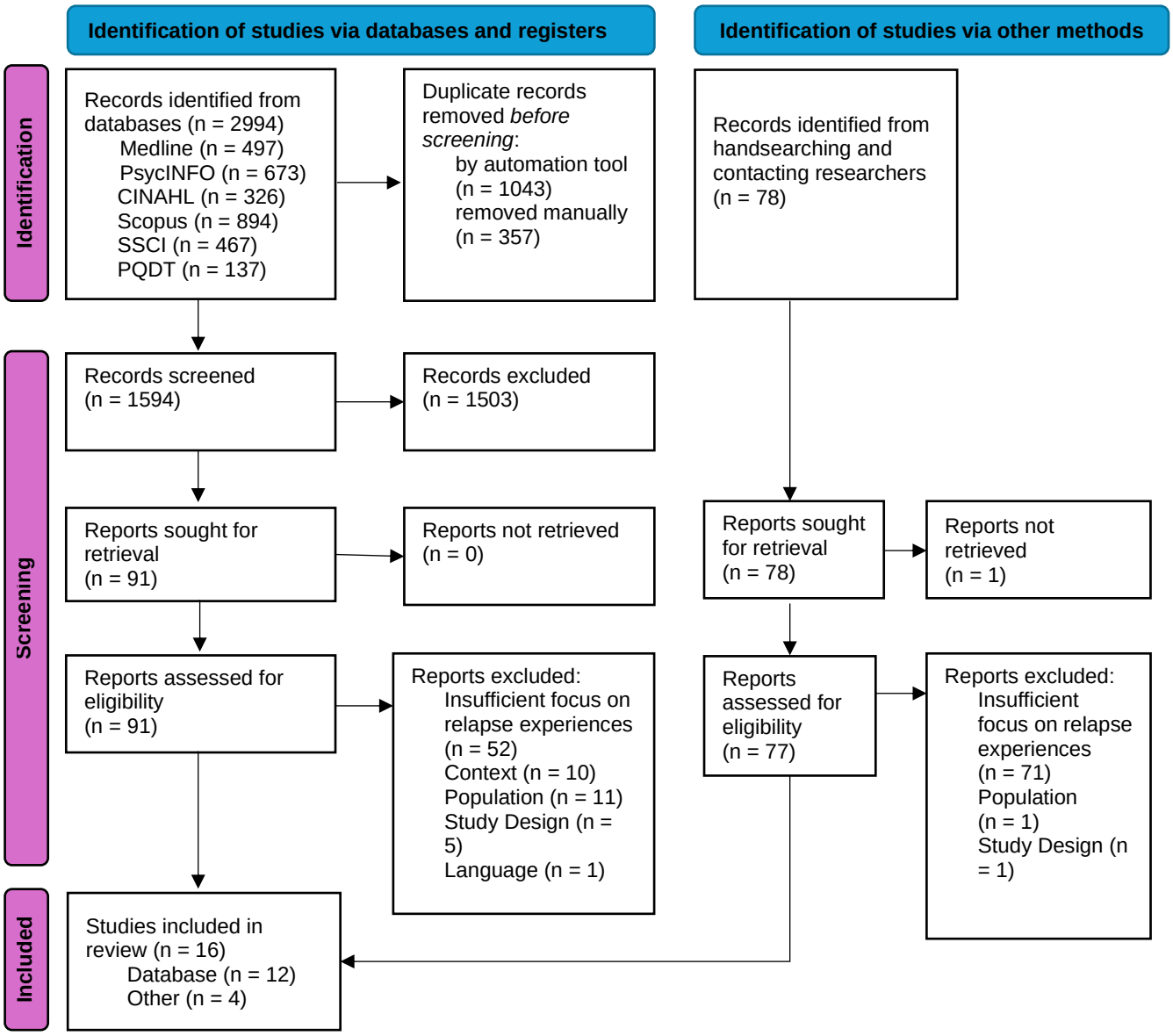
Figure 1 shows a PRISMA flow diagram of the screening process. Database searches yielded 2994 records (2796 in initial search and 198 in follow-up searches) which were exported to Endnote for deduplication. All screening was completed by NHC in research platform Rayyan with 20% of titles and abstracts also independently screened by RN (97% concordance) and 25% of full texts also independently screened by RN and NG (90% concordance). Any discrepancies were resolved through discussion.

After deduplication, 1594 titles and abstracts were screened, resulting in 91 full texts retrieved and assessed for eligibility from database searching and 77 identified through supplementary searches. SA and AB provided an additional check on final inclusion decisions, reviewing 50% of included studies and a sample of excluded studies to verify the application of eligibility criteria.

In total, 16 studies met inclusion criteria (14 in initial search and two in follow-up searches). Most excluded studies had minimal content on relapse, for example, a few sentences or one quote (e.g. Offord et al., 2006) or did not distinguish relapse from broader challenges in recovery (e.g. Arthur-Cameselle & Quatromoni, 2014). A handful of papers with a key theme on relapse were excluded due to a lack of information on participants' EDs (e.g. Musolino et al., 2018). One paper was excluded because there was no full-text available in English (see Appendix D).

Figure 1

PRISMA Flow Diagram Adapted from Page et al (2021)



Data from included studies were extracted by NHC into a Microsoft Excel sheet. Extracted data included study aims, country, setting, sample demographics, illness information, data collection and analysis methods. Select authors were contacted for clarification of their sample. Full texts were imported into computer software NVivo (version 20) for synthesis.

Critical Appraisal

The Critical Appraisal Skills Programme Qualitative Checklist (CASP; https://casp-uk.net/casp-checklists/CASP-checklist-qualitative-2024.pdf) was used to assess study quality, given its wide use, accessibility, and endorsement (Noyes et al., 2018). Specific adaptations recommended by Long et al. (2020) were adopted to improve its value. The checklist covers indicators of quality throughout the research process, from the appropriateness of study aims to the value of findings. Papers were rated against each checklist item (no, can't tell, somewhat, yes), with the addition of *somewhat* to indicate the paper partially satisfied the criteria.

Papers were given an overall quality rating (high, medium, low) informed by the checklist with greater weight afforded to analytical rigour given the importance of this for review credibility. The value of the study for the current review was also appraised (very high, high, medium, low), informed by the extent and depth to which it addressed experiences of relapse. NHC and NG independently rated all studies against each criterion (80.6% concordance) and differences in ratings were resolved through discussion.

Post-synthesis qualitative sensitivity analyses recommended by Carroll and Booth (2015) were conducted to examine the relative contribution of studies of different quality to the review. Using NVivo coding data, the impact on the coding framework of excluding lower quality studies and studies contributing the highest number of codes was assessed. Given that excluding lower quality studies entirely from a review can reduce generalisability (Garside, 2014), and weighting by quality may overemphasise studies with less value to the review, sensitivity analysis provides a conservative, risk-averse approach to integrating critical appraisal findings, particularly in the absence of clear evidence on best practice (Carroll & Booth, 2015).

Thematic Synthesis

The method of thematic synthesis, described by Thomas and Harden (2008), was utilised for this review. The approach, underpinned by critical realism, is well suited to preserving uniqueness and commonalities of experience, and capturing a shared reality that can inform policy and practice (Barnett-Page & Thomas, 2009). Unlike other methods such as meta-ethnography it can handle both the thin and thick description anticipated in included studies (Tong et al., 2012). It provides a formal transparent method specifically developed for systematic reviews, aiding review quality.

Using NVivo, NHC conducted a line-by-line coding of all content in the results and discussion sections of each included paper that pertained to experiences of ED relapse. Discussions were held with SA to review and agree upon the content that was coded. Text could be assigned one or more codes to capture its meaning.

Codes were organised into inductively generated descriptive themes which were further interpreted to develop analytical themes. Each analytical theme was grounded in the data but aimed to extend beyond mere description (Tong et al., 2012) to capture a core concept about how individuals made sense of relapse.

The generation of themes involved an iterative process, moving back and forth between themes, codes, and the underlying data. To preserve study context in the analysis, coded data were annotated with a summary of study context and synthesis findings were examined to determine whether they could be attributed to particular contexts, such as inpatient settings. All stages of the synthesis were performed by NHC, and codes and themes were discussed, reviewed and refined together with SA and NG.

Reflexivity

The researchers played an active role in constructing this review. The choice of research question was influenced by both professional and personal experiences which provide different and complementary lenses with which to view participants' experiences.

Whilst the breadth of the review question and framework aimed to be non-constraining, awareness of CBT models outlined in the introduction and NHC's clinical training in CBT, likely informed the organisation of data (e.g. drawing out interpersonal vs intrapersonal distinctions). The ways in which treatment was implicated in relapse may have been more salient due to NHC's background in evaluation research and the felt sense of frustration it generated. NHC kept a reflective journal throughout the research process, and impressions were discussed within the research team to enhance awareness of subjectivity. NHC's and AB's work across CAMHS inpatient and community ED services, helped to guide the translation of findings into clinical implications.

Results

Overview of Studies

16 studies were included in the review and Table 1 gives an overview of their characteristics. Papers constituted 11 journal articles, and five academic theses published between 1998 to 2024, with more papers concentrated in the latter half of this period. Studies were conducted in US (5), UK (5), Canada (3), Sweden (1), Finland (1) and China (1).

Table 1

Overview of Included Study Characteristics

Study, Country, Paper type	Study Aim	Participant Demographics	Illness Information	Recruitment	Data Collection & Analysis Methods	Value for Review	Quality [a]	Review Themes
Bell et al. (2024), UK, Journal	To explore how individuals with AN experience self-disgust as they recover from their ED	N (n relapsed) = 12 (NR) 100% F Age (mean) = 19-36 (26) Ethnicity = White or White British: 11, British: 1 SES (education) = tertiary education: 4, undergraduate degree: 4, postgraduate degree: 4	100% AN (33% AN-BP) Duration = NR Relapse = working def. Recovery status = physically recovered and subclinical symptom levels	Research participation schemes and platforms and Facebook support groups	Semi-structured interviews; interpretative phenomenological analysis	Medium	Medium	1-4
Botham (2019), UK, Thesis	To explore through narrative inquiry methodology the experiences of four participants as they navigated their lives away from SE-AN	N (n relapsed) = 4 (4) 100% F Age = NR Ethnicity= NR SES (employment) = part-time: 2, full time: 1, NR: 1	100% AN (AN-R & AN-BP) Duration = all > 10yrs Relapse = working def. & return to treatment Recovery status = “healthy recovery” achieved	Via professional contacts	Unstructured, open-ended interviews; narrative analysis	High	High	1-5
Cockell et al. (2004), Canada, Journal	To identify factors that help or hinder the maintenance of change and the ongoing	N (n relapsed) = 32 (6) 100% F Age (mean) = (27.9) Ethnicity= NR	AN = 21, EDNOS = 11 Duration = mean 11.6yrs Relapse = return to meeting DSM-IV criteria for AN or BN 6	Residential treatment program	Interviews; grounded theory	High	Medium	1-4

	promotion of recovery during the critical 6 months immediately following ED treatment	SES = upper middle class (Hollingshead's 1975 index = 2.0, SD = 1.03)	months after discharge from residential treatment and partial recovery Recovery status = relapse ongoing					
De Barbieri (2005), US, Thesis	To identify the types of learning that adult women with BN reported as significant to their recovery and the factors that facilitate or impede learning	N (n relapsed) = 24 (NR) 100% F Age (mean) = 19-58 (NR) Ethnicity = Northern European: 9, Native American: 2, Eastern European: 2, Mediterranean: 2, Other: 2 SES (annual household income) = >$75K: 8, $50-75k: 6, $15-40: 2, < $15K: 4	100% BN Duration = 2-30yrs Relapse = working def. Recovery status = 15 "recovering", 9 behavioural symptom free for 6+months	Outpatient treatment facility	In-depth interviews; multiple case study interpretive approach using inductive and deductive thematic coding	Medium	High	2-5
Federici and Kaplan (2008), Canada, Journal	To investigate patients' view of relapse and recovery and their ability and desire to maintain change	N (n relapsed) = 15 (8) 100% F Age (mean) = (26) Race = 100% Caucasian SES = "middle to upper class"	100% AN (33% AN-BP) Duration = NR Relapse = weight relapsed BMI < 17.5 on average 14 months after weight-restored at discharge from intensive inpatient or outpatient treatment and relapse prevention focused CBT Recovery status = relapse ongoing	Treatment setting	Semi-structured interviews; phenomenological approach	Very high	High	1-5

Keski-Rahkonen and Tozzi (2005), Finland, Journal	To understand the process of recovery for individuals with EDs through their own words	N (n relapsed) = 158 (NR) 98% F, 2% M Age (median) = 13-53 (21) Ethnicity = NR SES = NR	BN= 52, AN = 32, AN&BN = 29, BED = 12, orthorexia = 2, NR = 28 Duration = NR Relapse = Transtheoretical Model of Change definition (returning to the problem behaviour) Recovery status = NR	Online ED forum	Messages posted by ED forum participants during a 3-month period; software-aided text analysis and qualitative methods incl constant comparative method	Medium	Medium	1-5
Liu et al. (2024), US, Journal	To explore what post-treatment factors patients believe contributed to deterioration, explore post-treatment skill use and identify motivators and barriers to this	N (n relapsed) = 12 (11) 75% F, 25% M Age (mean) = 25-65 (40) Race = White: 7, Mixed Race: 2, Asian: 1, Black: 1, Other: 1 SES = NR	100% BN Duration = NR Relapse = 50% increase in symptoms within 34-49 months after CBT-E treatment and meaningful improvements Recovery status = relapse ongoing for 9, 2 in recovery.	Previous clinical trial of CBT-E	Qualitative interviews; thematic analysis (Braun and Clarke, 2006)	High	Medium	1-4
O'Connell (2023), UK, Journal	To examine the author's experience of the diagnosis and treatment of AN	N (n relapsed) = 1 (1) 100% F Age = NR Ethnicity= NR SES = NR	100% AN-BP Duration = NR Relapse = working def. & return to inpatient treatment Recovery status = recovered for 7 years	N/A	Author's retrospective account, diary entries and medical records; autoethnography	High	Medium	1,2,4,5
Pilote (1998), Canada, Thesis	To describe the stressors encountered by female adolescents	N (n relapsed) = 3 (3) 100% F Age (mean) = 16-19 (NR) Ethnicity= NR SES = NR	AN->BN= 1, BN = 2 (DSM-IV) Duration = NR Relapse = meeting DSM-IV criteria for BN	ED clinic	Dialogical semi-structured interviews; descriptive phenomenological	Very high	Medium	1-5

	during a relapse of BN		after 12 weeks+ of treatment at ED clinic and behavioural improvement Recovery status = in treatment for relapse		method (Colaizzi, 1978)			
Seed et al. (2016), UK, Journal	To explore the experience of detention under the Mental Health Act for AN and how this impacts on recovery	N (n relapsed) = 12 (11) 100% F Age (mean) = 18-43 (NR) Ethnicity= NR SES (employment) = part-time: 5, unemployed: 5, home-duties: 1, NR: 1	100% AN Duration = NR Relapse = working def. & return to treatment following start of physical and cognitive recovery under involuntary inpatient admission Recovery status = 11 with current AN symptoms (4 inpatient), 1 in sustained recovery	Treatment settings and ED charity	Interviews; grounded theory	Medium	High	1-4
Stockford et al. (2018), UK, Journal	To explore the general experiences of women with SE-AN as well as their experiences regarding their treatment.	N (n relapsed) = 6 (6) 100% F Age (mean) = 33-48 (36) Ethnicity= NR SES = NR	100% AN Duration = 14-28yrs (mean 21yrs) Relapse = working def. & return to treatment following variety of clinical interventions Recovery status = current AN symptoms	ED service	Semi-structured interviews; interpretative phenomenological analysis	Medium	High	1-4
Strand et al. (2017), Sweden, Journal	To explore patients' experiences of self-admission to an inpatient ward	N (n relapsed) = 16 (16) 94% F, 6% M Age (mean) = 18-56 (31) Ethnicity= NR SES = NR	100% AN Duration = 3-42yrs (mean 15yrs) Relapse = working def. & self-admitted return to inpatient treatment	ED centre	Semi-structured interviews; qualitative content analysis (Hsieh & Shannon, 2005)	Medium	High	1,2,4,5

			Recovery status = current AN or AN in partial remission					
Tibbits (2019), US, Thesis	To explore how women who relapse from BN or BED perceive what factors led to relapse and then recovery	N (n relapsed) = 12 (12) 100% F Age (mean) = 23-43 (NR) Ethnicity/Race = White or Caucasian: 7, Hispanic: 2, Latina: 1, South Asian American: 1, Biracial: 1 SES = NR	BN=6, BED= 6 Duration = NR Relapse = working def. (participant-defined relapses ranged from one bingeing episode to many months in duration) Recovery status = in recovery for 6+months	Facebook support groups	Semi-structured Interviews; feminist phenomenological analysis (Moustakas, 1994)	Very high	High	2-5
Warchol (2013), US, Thesis	To gain knowledge about, understand, and describe the experiences of social comparison within residential treatment facilities from the perspectives of patients diagnosed with BN	N (n relapsed) = 5 (4) 100% F Age (mean) = 20-31 (23.4) Ethnicity = European American: 4, mixed European American & Asian American: 1 SES (employment) = employed: 3, unemployed: 2	100% BN Duration = NR Relapse = working def. & return to treatment Recovery status = in residential treatment for relapse	Residential ED treatment facility	Semi-structured interviews; phenomenological analysis (Moustakas, 1994)	Medium	High	1-5
Wasson (2003), US, Journal	To describe the relapse experiences of women with BN through a	N (n relapsed) = 26 (26) 100% F Age (mean) = 20-59 (NR) Race = 100% Caucasian SES = NR	100% BN purging type (DSM-IV) Duration = NR	Overeaters Anonymous	Focus groups and individual interviews; qualitative grounded theory	High	Medium	1-5

	qualitative analysis of their experiential accounts		Relapse = bingeing or purging episodes whilst in recovery Recovery status = behavioural symptom free for 6 months+		techniques and constant comparison method			
Wu and Harrison (2019), China, Journal	To understand the experiences of four adolescents receiving inpatient treatment for EDs in China.	N (n relapsed) = 4 (3) 100% F Age (mean) = 16-19 (NR) Ethnicity = Chinese SES = NR	100% AN-BP Duration = mean 3.7yrs Relapse = working def. & return to inpatient treatment following physical and cognitive improvements in treatment Recovery status = currently inpatient	Online forum	Semi-structured interviews; interpretative phenomenological analysis	Medium	High	1-3

Note. The column "Review Themes" indicates the themes each study contributes to. Within Illness Information, the category "Relapse" indicates how relapse was determined in this study (working def. = a resumption or worsening of ED symptoms following a period of improvement). The category "Recovery status" indicates the status of participants' recovery at time of data collection.

Abbreviations: F = female; M = male; N (n relapsed) = number of participants (number who have relapsed); NR = Not reported; SES = socio-economic status; ED = eating disorder; BN = bulimia nervosa; BED = binge-eating disorder; EDNOS = eating disorder not otherwise specified; AN = anorexia nervosa; AN-R = restricting subtype; AN-BP = binge-purge subtype; SE-AN = severe and enduring AN; BMI = body mass index; DSM = Diagnostic and Statistical Manual of Mental Disorders; CBT(-E) = Cognitive Behaviour Therapy (Enhanced)

[a] see Appendix E for an item-level breakdown

Table 2 provides a summary of participant demographics across included studies. Studies reported on the experiences of 342 participants (98.0% female) with EDs including BN (37.5%), AN (36.3%) and BED (5.3%) (see Table 2). Most studies recruited from ED treatment settings. The extent of participants' recovery prior to relapse varied, as did the severity of symptom return in relapse, ranging from an episode of bingeing or purging in recovery to symptoms severe enough to require hospitalisation. Participants ranged from those currently experiencing a relapse to those who had sustained recovery from their last relapse for many years.

Table 2

Summary of participant demographics across included studies

Demographic Characteristic	Aggregate Value
Total No. of Participants	342
Age Range	16-65
Gender	
Female	98%
Male	2%
Eating Disorder	
BN	37.5%
AN	36.3%
BED	5.3%
AN&BN	3.2%
EDNOS	8.8%
Other/Not Reported	8.8%

Critical Appraisal

Table 1 shows each study's overall quality rating and value for the review rating (see Appendix E for a breakdown). Of the 16 studies, nine papers (56.3%) were judged as high quality, and seven papers (43.8%) were judged as medium quality. Consideration of the relationship between the researcher and participants and ethical issues tended to be weaker areas, with a surprising lack of reference to minimising harm to participants given the nature of the research. Analyses were judged to be insufficiently rigorous for four papers due to less detail on the

analytical process (Bell et al., 2024; O'Connell, 2023) and concerns around the adequacy of data to support themes (Keski-Rahkonen & Tozzi, 2005; Pilote, 1998). Academic theses were generally rated as high quality, with more detailed methods, reflexivity and audit trails, suggesting an inadvertent impact of restricted journal word counts on CASP quality ratings.

With respect to value for the review, eight were judged to be of high or very high value and eight were judged to be of medium value. In papers of higher value, relapse tended to be more directly linked to a study's research question as opposed to an emergent theme examined through its relation to the main research topic such as treatment experiences. Contributing factors to relapse were the most universally explored aspect of experience.

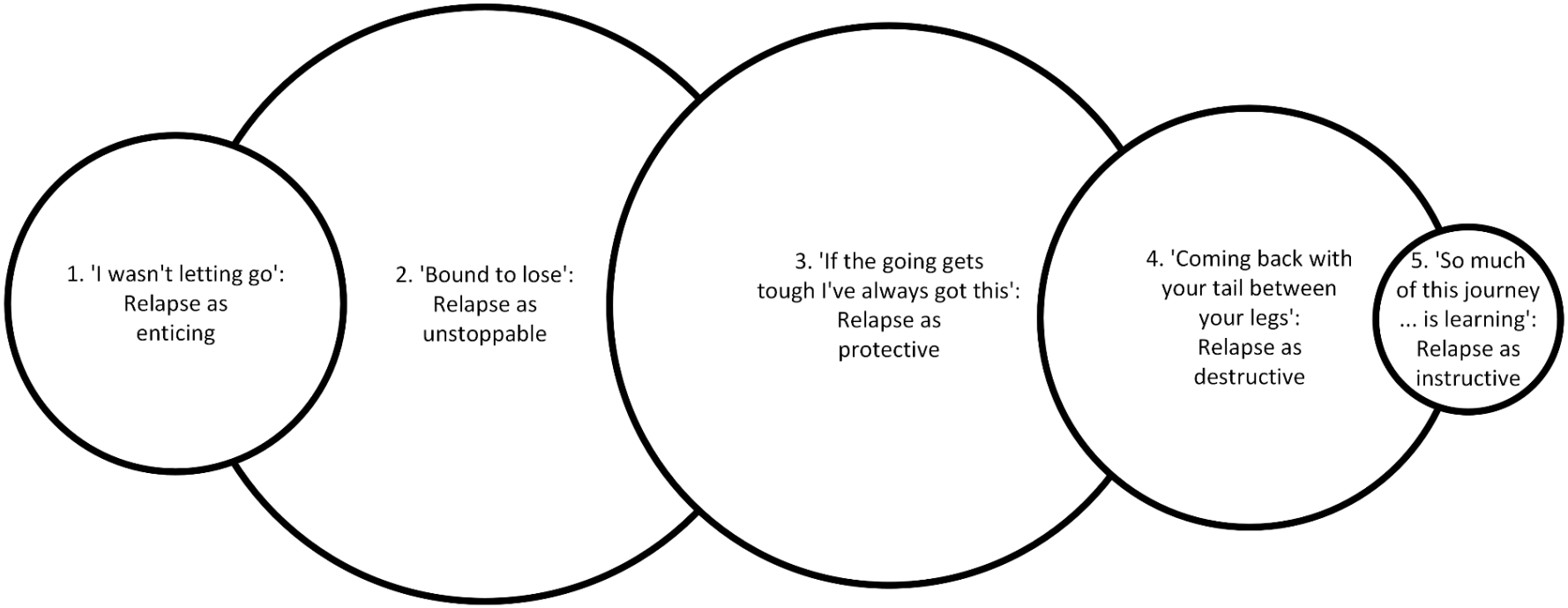
Post-synthesis sensitivity analyses revealed that the exclusion of all medium quality papers would only result in the loss of two codes (2.1%) and no themes from the synthesis and therefore have an immaterial impact on synthesis findings, but transferability across diagnoses would be impacted. Exclusion of the three papers that contributed to the largest number of codes (Botham, 2019; Tibbits, 2019; Warchol, 2013) would only result in the loss of six codes (6.3%) and no themes, confirming the review was not unduly influenced by a small number of studies.

Thematic Synthesis

The synthesis generated 96 codes which were organised into 14 descriptive themes, before being synthesised into five inter-related analytical themes (see Appendix F for an illustration of the mapping between codes, descriptive and analytical themes). The five themes capture the context, progression and outcomes of relapse, depicting it as 1) enticing, 2) unstoppable, 3) protective, 4) destructive and 5) instructive, as shown in Figure 2. Each analytical theme is outlined below and illustrated with participant quotations.

Figure 2

Analytical Theme Relative Coding Density



Key: sizing of circles represents relative coding density of themes (range: 85 - 258 coding references)

Theme 1. "I wasn't letting go": Relapse as enticing

Summary: Individuals lacked intrinsic motivation for recovery, they remained attached to the disorder and saw appeal in a return to the psychological benefits it provided.

Individuals who relapsed after treatment often attributed this to lacking intrinsic motivation for recovery as typified in the following account:

"I've been in and out of bulimia but I think my problem last time is I didn't – I didn't try very hard. I didn't want it" (adult female BN;Warchol, 2013).

Instead, behavioural improvements were commonly achieved through compliance with treatment and external pressure. However, Seed et al. (2016) noted that this external regulation of behaviour limited individuals' "investment in change". They often made plans to relapse after discharge or dropped out of treatment. Once no longer under "surveillance", they returned to behaviours.

"I knew it wasn't going to work! I was like... I'll humour them and put on the weight, but I know... it won't take me long to take it off again" (adult female, AN; Federici & Kaplan, 2008)

Individuals recalled how good the ED made them feel, and expressed doubt about what recovery could offer them. Some saw their ED as something they could do "well", bringing achievement and esteem. Many held firmly to ideals of thinness which led to a continued valuing of the ED as a means of weight control. In becoming part of individuals' identity, it was even more difficult to give up.

"It was the fear of letting go of that identity…I still really had to know…that bit of me was still there and I wasn't letting go completely" (adult female, AN; Botham, 2019).

Some felt inpatient treatment contributed to a sense of needing to do their ED "better", by exposing them to thinner, "sicker" individuals, new disordered behaviours, and clinical markers of illness that became goal posts to aim for. Individuals also saw how severity elicited care. Therefore, relapse appeared to be a strengthened search for validation in sickness.

"I wasn't convinced that I'd got as bad as I could be… and I needed to prove to myself that I could do it again if I wanted" (adult female, AN; Botham, 2019).

Time spent in intensive treatment had also disconnected them from life, separating them from other aspects of their identity and their motivations for recovery. Individuals had become less confident in their ability to cope in normal life, breeding a dependency on the ED and the "bubble" of treatment. When faced with their own perfectionistic expectations in life, relapse provided a "justification" for not meeting these (Seed et al., 2016).

"I had lost all motivation to pursue a career, had no home, no partner, and was accustomed to living in an institution. In these conditions, seeking to do anorexia well (instead of normal life) made sense" (adult female, AN; O'Connell, 2023).

For some, treatment had provided a temporary level of accountability and momentum, but their motivation for full recovery waned without support. Some individuals were only "willing to go so far" (Federici & Kaplan, 2008) and many held onto certain disordered behaviours, retaining their ED identity. A sense of denial over residual behaviours, such as framing periods of restriction as "intuitive eating" (Liu et al., 2024), allowed them to worsen once more.

Theme 2. "Bound to lose": Relapse as unstoppable.

Summary: Treatment had only taken individuals so far; they faced challenges in recovery without support and felt powerless to prevent relapse.

Individuals described the persistence of powerful ED cognitions and associated emotions, beyond physical and behavioural recovery and discharge from treatment. As they acted against their ED, they were subjected to an "overly critical and commanding" internal monologue (Bell et al., 2024) alongside feelings of guilt, self-disgust and loss of control that felt intolerable. Gaining weight, or even the possibility of this, was a particular trigger, threatening their sense of self, and meaning many "could not psychologically accept it" (Wu & Harrison, 2019). As such, intensive weight-focussed models of treatment with minimal psychological support were linked to relapse after discharge.

“Every time a pound goes on you feel absolutely awful you feel really horrible, really fat, really disgusting…it’s the feelings that come with it (weight gain) …is what’s causing me to relapse so many times” (29yo female, AN; Bell et al., 2024).

When support was reduced or removed, many individuals lacked confidence that they could continue their recovery. There was a pervasive sense that relapse was all too easy, whereas recovery was effortful and challenging. Their daily lives presented environmental opportunities for relapse that were difficult to resist.

“When you are in hospital… you've got you and a whole team against anorexia… but as soon as you leave hospital and you get home it's just one-on-one again and you are bound to lose” (adult female, AN; Stockford et al., 2018).

Individuals had lost the structure of treatment, and some struggled to protect their recovery within their busy schedules. Recovery strategies were forgotten, too difficult to implement in the moment, or discontinued because of overconfidence in their recovery.

“I just feel like doing things on my own is, I don't know (shrugging shoulders). Talking through things, you know, the meetings during the study was helpful then” (adult, BN; Liu et al., 2024).

Individuals struggled to ask for professional support because it was not as readily available and some felt “too recovered” (Cockell et al., 2004). For some, friends and family brought unhelpful diet culture messages and were unsupportive of their recovery.

“I felt really misunderstood by my friends because when I said no to outings… so that I could have my meals… they would be angry” (adult female; Cockell et al., 2004).

Individuals described relapse as the result of intense urges, and obsessions and habit that were difficult to control despite motivation, skills and knowledge.

“I’ve been very well-educated about all the health consequences and things like that and I just really didn’t want to go down that road but I felt like I couldn’t really control it” (24yo female, BN; Tibbits, 2019).

In some sense individuals appeared to lack agency over both their recovery and relapse. Recovery appeared contingent on external support, and relapse seemed out of their hands.

"I thought that maybe…I'd get through it, you know I'd come, I'd come through the illness, … I could actually get better, allow, be allowed to get better, but it wasn't true" (19yo female, AN; Seed et al., 2016).

One participant who had recovered reflected on the detrimental impact of believing "I don't have a choice, I have an eating disorder" (Botham, 2019) and Seed et al. (2016) highlighted the potential for treatment to reinforce this illness perception.

Theme 3. "If the going gets tough I've always got this": Relapse as protective

Summary: Individuals who faced ongoing psychological difficulties and external stressors and had not learnt alternate ways of coping returned to the comfort and protection of their ED.

Despite their progress in recovery, individuals described underlying psychological difficulties that remained unaddressed. Many referred to poor self-esteem and difficulties identifying, managing and expressing their emotions. Associated interpersonal challenges were also common, including difficulties with vulnerability and assertiveness, as well as an overconcern with pleasing others. Some felt treatment had not focussed enough on these issues or provided healthier coping strategies. Several individuals had substituted the ED with other unhelpful ways of coping such as alcohol. There was a sense that recovery would not be stable and enduring until these underlying difficulties had been addressed.

"I feel like I didn't deal with any of the issues that were there to begin with. The bereavement, the self-esteem issues ... I hadn't dealt with why I had this eating disorder" (adult female, AN; Federici & Kaplan, 2008).

These internal vulnerabilities appeared to make external stressors more destabilising. Individual or cumulative stresses related to work, finances, transitions, physical and mental health, loss, and interpersonal conflict precipitated relapse. Many lacked social support, or their difficulties expressing their feelings and needs prevented them using the support around them.

“We were getting ready to move cross-country. We were struggling financially…like it all came spiralling at once. And it was too much to handle emotionally and physically and mentally” (32yo female, BN; Tibbits, 2019).

Returning to the ED provided a way to distract or avoid feelings that were difficult to tolerate. It offered a means of control, safety, and comfort, and presented an appealing alternative to relying on others. At the same time, it offered a non-verbal form of communication of their difficult internal world.

“I relapsed because somebody who had been close in my life for a very long time, finally put an end to it [the relationship], and that created a void for me...my relapse...was to fill something” (20yo female, BN; De Barbieri, 2005).

Individuals’ reliance on the ED in these times appeared to be influenced by the knowledge they had previously gained of how it could serve them. Some individuals saw the ED as a “bag of tricks” (Warchol, 2013) that helped them to cope or a personified “protector” that would “take over” (Tibbits, 2019) when things were difficult. Individuals appeared reassured by the thought that “if the going gets tough I’ve always got this” (Botham, 2019). However, for some, relapse in the face of stressful life events was perceived as inevitable, perhaps because they saw no better alternative.

“Like situations are going to happen and I'm going to react that way. Like with the bulimia in order to feel safe and secure because that's how I feel with it” (adolescent female, BN; Pilote, 1998).

For others further in their recovery, Botham (2019) described how it had taken time and multiple relapses to form a recovery that was solid even in difficult times.

Theme 4. “Coming back with your tail between your legs”: Relapse as destructive.

Summary: Individuals felt shame, and feelings of failure in relapse and struggled to be open and accept help.

Whilst relapse could bring positive emotions or apathy, there was also a strong sense of failure, guilt, shame and self-criticism in relapse. Some individuals criticised their lack of

“willpower”. The fact they “couldn’t puzzle it together” (Tibbits, 2019) despite the knowledge and support they had received, when others could, contributed to a sense there was something wrong with them.

“And like I feel a lot of shame…I just feel like I shouldn’t have had to be here four times now…I feel like I failed all the other times” (adult female, BN; Warchol, 2013).

Returning to treatment could feel “like coming back with your tail between your legs” (Strand et al., 2017). There was a sense of disappointing others who had invested and supported them in their recovery. This deepened feelings of not wanting to burden others further or being undeserving of additional support. As such, many struggled to speak about and accept help for their relapse.

“Many of the friends I'm thinking of, they had been supportive to me at other points. So with the relapse it was like I don't want to beat a dead horse. I don't want to kind of push up to their limit of being supportive to me” (24yo female, BN; Tibbits, 2019).

Individuals described losing themselves to their ED once more, whilst outwardly maintaining a façade. They became disconnected from others and neglected themselves. For some, previous negative experiences of treatment contributed to a resistance to approaching support again. Individuals described a need to “look the part” (Cockell et al., 2004) or get even worse before entering treatment.

“Such difficult challenges await at the ward, so the illness wants to take what it can get from you before you go against it” (adult, AN; Strand et al., 2017).

Seeking help often needed to be encouraged by those around them. In contrast, a minority found friends and family unhelpfully ignored or criticised them. Some individuals felt that they were treated in a more restrictive, depersonalised, and judgemental way on re-entering treatment because of their prior history. Many participants described feeling sad and depressed on relapsing. A sense of losing hope that recovery was possible was common.

"That's one of the most difficult things about being there: that you're sitting there with the same people—myself included— that were there a year ago…and no one has made any progress. It makes you feel a bit hopeless" (adult, AN; Strand et al., 2017).

Whilst individuals feared becoming "one of those revolving door people" (Botham, 2019), having experienced a setback, holding hope appeared risky.

"I'm doing really, really well here, but I don't see myself not bingeing and purging when I get home" (adult female BN;Warchol, 2013).

Theme 5. "So much of this journey...is just learning": Relapse as instructive.

Summary: Relapse was seen as part of a learning journey; for many it pushed them further in their recovery and did not negate their prior growth.

Some individuals described psychological growth in areas such as self-esteem, relationships, coping skills, and self-awareness prior to relapse. Whilst this growth did not prevent them from relapsing, they were not starting again from scratch and there was a sense of cumulative growth in spite of patterns of relapse and recovery. As put by one participant:

"There is a part of me that knows realistically ...you've had this chunk of [recovery]... what you learn during that period... not to mention what you learned up to that time, you still…take that with you and keep going and fall back on it" (32yo female, BN; De Barbieri, 2005).

Despite finding themselves in a similar situation, individuals described changes in mindset which affected their response to relapsing. Shifts in emotional reactions to relapse reflected this, such as an increase in disgust responses to purging. Many reported a slow process of learning the destructive impact of the ED and some had built lives in recovery that they wanted to protect. Over time individuals had grown weary of the ED, such that it was the prospect of relapse and no longer recovery that seemed "just too much work" (Warchol, 2013). For some, the relapse provided a turning point pushing them towards seeking support and providing fuel for their recovery.

“When I went into rehab, the second time, I didn’t need to be friends with the people in hospital…because I had a life outside to hold on to whereas before, I hadn’t built that life yet” (adult female, AN; Botham, 2019).

Over multiple relapses, some individuals learnt the importance of seeking early support and responding proactively became easier. For some, they had learnt treatment could provide a “safety net” in case of relapse.

“For me, it has also been useful to ask for help. [...] And it gets easier and easier every time. If you’ve done it once you know how it works” (adult, AN; Strand et al., 2017).

For others, their experiences highlighted the risks of contact with treatment and attempts to avoid further admissions became a motivator for recovery.

“Eventually, I realised that the longer I was in and out of treatment, the further the walls would close in” (adult female, AN; O’Connell, 2023).

Relapse also highlighted the work still needed to strengthen their recovery. Individuals accounts showed that through relapse they developed their awareness of triggers and warning signs, learning how relapse could be avoided or identified early.

“An overly rigid food plan is my set up for relapse. I had to find a flexible plan that was right for me before I could become abstinent” (adult female, BN; Wasson, 2003).

Many individuals accepted relapse as a part of the journey to recovery and sought to imbue it with purpose. Of note, some did not feel that the term “relapse” captured their experience and instead considered themselves to be in “the process of recovery” (Federici & Kaplan, 2008).

“So much of this journey, like yes there’s relapse but so much of it is just learning” (27yo female, BED; Tibbits, 2019).

Discussion

This review synthesised qualitative research on relapse experiences in EDs, drawing on 16 studies and generating five interrelated themes. To the authors' knowledge, it is the first review to specifically focus on this topic. Results highlighted how individuals variously desired, needed or

felt powerless to the return of the ED in the face of recovery and life stressors without adequate internal or external resources. Despite supporting individuals to improve behaviourally, treatment approaches had fallen short of addressing, or even unwittingly reinforced these vulnerabilities to relapse. Relapse had the potential to bring both feelings of failure and despondency about recovery as well as perspective shifts that motivated and strengthened individuals' recovery.

The interplay between themes mirrored the internal conflict commonly associated with EDs. Individuals experiencing relapse often faced a push-pull dynamic, feeling both resistant to "letting go" of the disorder and simultaneously "bound to lose" the battle against it. This sense of disempowerment in the face of a perceived inevitability of relapse raises questions for current clinical approaches. In addition, participants' evident insights into why they relapsed hold value for the field. Findings reveal interacting influences of high-risk situations and ED vulnerability factors which align with elements of models of relapse (e.g. Witkiewitz & Marlatt, 2007) and EDs (e.g. Fairburn et al., 2003). For example, persistent body dissatisfaction was linked to relapse both after intensive weight gain and after weight-neutral treatment (e.g. CBT-E for BN-EDs; Liu et al., 2024), in line with existing research on its significance (Keel et al., 2005; McFarlane et al., 2008; Sala et al., 2023). However, the nuances and subjectivity brought out in this review hint at individuals' complex relationships with both the disorder and support systems that are difficult to fully capture within any single model.

The findings, particularly the theme of *relapse as enticing,* underscore the significance of ambivalence in EDs (Colton & Pistrang, 2004; Vall & Wade, 2015) and emphasise its role in relapse. In line with self-determination theory (Ryan & Deci, 2000, 2017), results indicate that, while treatment may provide extrinsic motivation for recovery, it is intrinsic motivation that is needed to sustain change once support diminishes, and this crucial factor is often lacking.

Findings shed light on the high-risk period during the lag between individuals' physical and behavioural recovery, and their psychological recovery (Fennig et al., 2017). During this lag, recovery was yet to bring desired benefits and instead confronted individuals with the very issues

they had avoided through the disorder. At the same time, the perceived benefits of the ED were all too easy to recall, akin to the pre-lapse stage in Freeman and Dolan's (2001) model of change.

Through their experiences, individuals had developed an intimate and entangled relationship with the ED which “held” them through life's struggles. This supports literature on the role of identity in EDs and the importance of de-identification in recovery (Bowlby et al., 2015; Treasure & Schmidt, 2013). Despite a focus on motivation and identity within various ED treatments (e.g. MANTRA), the persistence of these issues well into recovery highlighted in the review raise concerns about their underemphasis in relapse prevention work (Schlam & Wilson, 2007).

Findings also reveal the influence of social context, including both formal and informal support, on recovery and relapse. In line with previously highlighted iatrogenic impacts (Peebles et al., 2023), inpatient care, for example, was seen as reinforcing thoughts of not being “sick enough”, teaching disordered behaviours, and eliminating recovery motivators, embedding their ED identity.

Individuals presented themselves as powerless against the strength of ED symptoms remaining after treatment, supporting evidence of their association with relapse (McFarlane et al., 2008). This highlights the danger of premature discharges and an inability to provide recommended post-discharge support (Berends et al., 2018) in the face of high levels of demand on ED services. After discharge, individuals seemed to doubt their ability to manage their own recovery, believing that any improvements were down to treatment rather than their own efforts. Individuals' experiences of medicalised, symptom-focused models of care appeared to have reinforced a disempowering “sick role”, prompting a sense of victimisation and passivity in relapse, as previously noted (Goren-Watts, 2011).

The diversity of experiences conceptualised within relapse is highlighted by this review. The limited cognitive and emotional improvement prior to many experiences labelled as relapse, suggest common behavioural criteria, such as re-admission, weight change, or an increase in bingeing/purging, mask a persistent dominance of the disorder. The importance of capturing individuals' experiences and how they intersect with ideas of relapse is evident in those who

disputed the researcher-imposed label “relapse”. This review adopts the term “relapse” to connect with existing research. However, it acknowledges that the term carries medical and cultural connotations that may contribute towards the sense of failure and disempowerment identified in findings (DiClemente & Crisafulli, 2022).

Findings revealed how individuals’, treatment services’ and society’s interrelated expectations of what illness and recovery “should” look like shaped experiences of relapse (LaMarre & Rice, 2021). Individuals felt a sense of failure and shame in non-linear recovery, hiding struggles or conversely feeling a need to worsen symptoms to fit an expectation of illness. In this way, relapse provides further fuel for the self-criticism and shame inherent in EDs (Nechita et al., 2021). Concerningly, findings revealed that this internalisation of relapse as a personal failure was apparent despite the indications that treatment had failed to meet many individuals' needs.

Following relapse, individuals showed diverse orientations toward recovery, challenging characterisations of relapse as a binary outcome. Mindsets often shifted across multiple relapses, such as gradually de-identifying with the disorder or experiencing growing demoralisation about recovery. Troublingly, relapse could erode trust in oneself, risking dependency on services, and diminish confidence in treatment, deterring help-seeking. These dynamics show how the psychological impacts of relapse may hinder future recovery efforts.

Strengths and Limitations

This systematic review has several strengths. The breadth of this review enabled relapse to be understood as a complex process rather than a single event examined only through its triggers. Adopting an inclusive conceptualisation of relapse allowed for a greater variety of included studies, enriching the review, and fostered a more holistic understanding of relapse which centred individuals' perceptions and personal experience, rather than relying on clinical measures or contact with services to validate their experiences.

Themes were not found to be sensitive to study quality or overly dependent on a small number of studies, supporting the robustness of the findings. The inclusion of academic theses

limited the impact of publication bias and contributed thick description from otherwise unheard participants' voices. They also added to the diversity of EDs within the review, important given the dominance of AN research in the field. Exploring relapse from a transdiagnostic lens also enabled the review to capture experiences of diagnostic cross-over in relapse (e.g. AN to BN; Pilote, 1998). This review benefited from including individuals reporting from various stages of recovery, facilitating a diversity of perspectives on their ED (Rossotto et al., 1996). The range of treatments received by individuals suggests the review has captured commonalities in experiences that pose implications for multiple treatment models.

Some limitations were also identified. The exclusion of non-English language papers can lead to a risk of bias, although only one paper was excluded for this reason. The inclusion of non-peer-reviewed theses could be seen to affect quality, though CASP scoring was high. Accounts of relapse experiences that did not constitute a key theme within the paper were excluded but could hold additional value.

Under stricter definitions of relapse, some experiences included in the review might instead be characterised as a lapse (where the setback was brief) or a continuation of the illness (where prior progress was minimal). Defining these experiences as relapse could be viewed as placing undue significance on them. The ability to capture nuances in the experiences of those relapsing after minimal change versus more established recovery was constrained by the lack of contextual information or explicit definition of relapse in included papers.

In line with existing biases within ED research (Halbeisen et al., 2022), participants were predominantly women in Western countries. Findings therefore have limited transferability outside of this population as experiences noted are likely shaped by gender and culture (Springmann et al., 2020). For example, Strobel (2022) identified that men exclusively adopted a "warrior" narrative in their recovery, which was linked to higher relapse rates, highlighting potential gender differences in the experience of relapse. In addition, less than half of studies in this review reported participant ethnicity and socioeconomic status, further limiting confidence in the transferability of findings.

Future Research

Quantitative research should aim to develop nuanced outcome models that capture the complexities of non-linear recovery trajectories. Including details on the course of the disorder (e.g. periods of recovery and relapse) and treatment history within participant demographics would provide valuable context beyond ED duration/onset. Additionally, clarity on how relapse has been defined within research is recommended to improve interpretation of findings. Longitudinal studies examining changes in psychological factors post-treatment could elucidate their interplay and sequencing in relapse, complementing retrospective recall. Further research using discourse analysis to explore how perceptions of relapse are shaped by the language used by individuals and which they encounter in treatment would be a valuable extension to this review. There is a clear gap in research on relapse among males, individuals from the global majority (a term for people who are not considered to be white), and residents of low- and middle-income countries.

Clinical Implications

Overall, the findings have clinical implications for relapse prevention and response.

- The potential harms of relapse indicate the need for comprehensive support that prioritizes the sustainability of recovery from the outset, with greater emphasis on relapse prevention within treatment.
- Findings caution against a withdrawal of care prior to adequate cognitive and emotional improvements, despite physical and behavioural stabilisation. Underlying vulnerabilities (e.g., shape and weight concerns, interpersonal difficulties, and self-esteem), as well as attitudes towards recovery, particularly intrinsic motivation, self-efficacy and expectations of recovery, and quality of life beyond the ED emerge as important areas of focus and potential indicators of readiness for discharge.
- Apparent in findings is the need for treatment to validate individuals' ongoing psychological distress in recovery and avoid care models that inadvertently reinforce an escalation of ED behaviours in order to gain support for their distress.

- Findings support a shift towards intensive community treatment to reduce unnecessary inpatient admissions (NHS England et al., 2019).
- In response to relapse, clinicians should foster hope, self-compassion, and challenge narratives of failure. Examining individuals' relapse may provide valuable insights for tailoring and guiding treatment.

Public Significance Statement

Relapse is common in eating disorders even after treatment. Treatment and intervention developments have attempted to address this but are limited by our lack of understanding of relapse. The complex nature of relapse is often overlooked in outcome research. This review helps us better understand the experiences of individuals with eating disorders who relapse and offers insights to inform more effective strategies for relapse prevention and intervention.

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Chapter Three: Bridging Chapter

The previous chapter presented a systematic review and synthesis of qualitative studies exploring how individuals with eating disorders (EDs) experience relapse. This synthesis generated five themes that offer insights into the lived experience of individuals navigating the often-non-linear path of recovery. Themes described relapse as 1) enticing, 2) unstoppable, 3) protective, 4) destructive, and 5) instructive. The findings address a gap in our understanding of the personal, experiential perspective of relapse, complementing research focused primarily on clinical, symptom-based outcomes.

The review highlights how individuals' experiences of ED relapse are profoundly shaped by their social contexts. Whilst the influence of treatment context was a main emphasis, also apparent was the impact of relationships with friends, partners and family. Individuals felt misunderstood or unsupported and alone during recovery, with interpersonal conflicts acting as triggers for relapse, and fears of judgment or being a burden impeding help-seeking. In contrast, loved ones were often important in encouraging individuals to seek help for relapse and treasured relationships (and the fear of losing these) provided motivation to recover. These review findings underscore the value of understanding the experiences of close others and “supporting the supporters” in ED recovery.

In line with this, the empirical paper presented in the following chapter chooses to examine the experiences of parental caregivers of children and young people with ED symptoms. This group often take on an especially significant role; with minimal guidance they can become “their children’s case manager, feeder, and advocator” (Crowther et al., 2024, p.1). At the same time, they directly witness their child’s struggles with the disorder, with cycles of recovery followed by relapse experienced by caregivers as a “rollercoaster of hope and despair” (Crowther et al., 2024, p.5) that echo the emotional turmoil described by individuals with EDs in the previous chapter.

Acknowledgement of the interpersonal influences on EDs has led to a focus on the set of skills caregivers need to best support their loved one (Treasure et al., 2016). However, many parents report feeling ineffective and exhibit high levels of psychological distress (Anastasiadou et al.,

2014; Thibault et al., 2023) which are interdependent with their child's distress (Salerno et al., 2016). Examining caregivers' mental health is therefore key in strengthening the support around children and young people with eating disorders.

A handful of studies have found elevated levels of post-traumatic stress in caregivers to those with anorexia nervosa (Hazell et al., 2014; Irish et al., 2024; Timko et al., 2023). Given the link between caregiver and child psychopathology, and the role of caregivers in their child's ED recovery, it is critical to better understand caregivers' trauma symptoms and their relation to the skills caregivers need to support their child.

The systematic review reported in the previous chapter aimed to add qualitative depth to clinical discourse and largely quantitative research on relapse. In contrast, the empirical study presented in the following chapter aims to build on extensive qualitative research on caregiver distress and trauma (e.g. Fox et al., 2017; Gustafsson et al., 2021) and utilise quantitative methods to make sense of caregivers' experiences through the clinical framework of post-traumatic stress disorder (PTSD).

The key aims of the empirical study are to determine the rate of probable PTSD in a sample of caregivers to children and young people with a broader range of ED presentations than previously studied, to examine demographic and illness-related correlates of PTSD symptoms and to examine the relationship between PTSD symptoms and caregiver skills. Overall, it aims to contribute to our understanding of how to support caregivers' wellbeing and in turn their ability to support their child's recovery.

Chapter Four: Empirical Paper

Post-Traumatic Stress in Caregivers to Children and Young People with Eating Disorder (ED) Symptoms: A Cross-Sectional Examination of Relationships with Demographics, ED Factors and Caregiver Skills

Authors:

Natasha Heal-Cohen, Rachel Nabirinde & Dr Aaron Burgess

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Abstract

Objective: Post-traumatic stress disorder (PTSD) symptoms in caregivers of children and young people (CYP) with eating disorder (ED) symptoms remain understudied, despite their potential impact. This study examines these symptoms and their relationship to demographic and ED-related factors, and caregiver skills. This aims to inform efforts to improve caregivers' wellbeing and ability to support CYP with EDs.

Method: UK-based parental caregivers of CYP with ED symptoms were recruited via social media and mental health organisations. A total of 123 participants provided demographic and ED-related information and completed measures of caregiver skills and PTSD symptoms via an online survey. Descriptive statistics, correlations and regressions were conducted.

Results: The majority of participants (62.6%) scored above cut-off for probable PTSD. Demographic and ED-related factors explained 21% of the variance in caregiver PTSD symptoms, with ED relapse contributing the largest independent effect. PTSD symptoms explained 34% of the variance in self-reported caregiver skills.

Conclusions: Caregivers to a wider ED population than previously studied may be at high risk of PTSD, and symptoms may hinder caregivers' ability to support their child. The link between ED relapse and caregiver PTSD warrants further investigation. Trauma-informed approaches to caregiver support in child and adult ED services are recommended.

Keywords: Caregiver skills, caregivers, children and young people, eating disorders, post-traumatic stress

Post-Traumatic Stress in Caregivers to Children and Young People with Eating Disorder (ED) Symptoms: A Cross-Sectional Examination of Relationships with Demographics, ED Factors and Caregiver Skills

Eating disorders (EDs) are mental health conditions characterised by disturbances in eating behaviours and related thoughts and emotions (American Psychiatric Association [APA], 2013). EDs typically onset between 16-20 years old (Wood et al., 2019) with nearly all first-time cases occurring by the age of 25 (Ward et al., 2019). They can result in reduced quality of life, significant physical health complications, and mortality (Santomauro et al., 2021; van Hoeken & Hoek, 2020) with anorexia nervosa (AN) having the highest standardised mortality rate of any psychiatric condition (Hoek, 2006).

The Impact of EDs on Caregivers

For children and young people with EDs, the role of parents and carers is particularly crucial, with family-based interventions regarded as best practice (Gorrell et al., 2019; Le Grange et al., 2010). However, EDs place considerable strain on families, with caregiver burden reported to be higher with EDs than with depression or schizophrenia (Martín et al., 2011; Svensson et al., 2013). Parents may witness their child's physical deterioration, worrying behaviours which can threaten their health and development (e.g., purging, dietary restriction), and extreme personality changes (Peebles & Sieke, 2019; Whitney et al., 2005). Common responses of caregivers include denial, self-blame, anger, helplessness as well as heightened worry and vigilance which persists beyond their child's recovery (Coelho et al., 2021; Fletcher et al., 2021; Fox et al., 2017).

Caregiver Post-Traumatic Stress

In the UK, around 4% of adults are estimated to have post-traumatic stress disorder (PTSD) (McManus et al., 2016), although rates are found to be significantly higher among caregivers of offspring with serious physical and psychiatric illnesses, such as cancer or schizophrenia (Carmassi et al., 2021; Kageyama & Solomon, 2018; Woolf et al., 2016). Despite the duty of health services to

support caregivers (National Institute for Health and Care Excellence [NICE], 2020), evidence for the effectiveness of interventions to reduce caregiver PTSD is limited (Cherak et al., 2021).

PTSD is a mental health condition which can occur following direct or indirect exposure to a stressor and can persist without treatment (APA, 2013). Symptoms include intrusions (e.g. flashbacks), avoidance of trauma reminders, negative alterations in cognitions and mood (e.g. guilt, anger) and alterations in arousal and reactivity (e.g. hypervigilance) and should persist for over a month (APA, 2013). In the first month after the traumatic event, such symptoms may constitute acute stress disorder (ASD), found in between 2-68% of caregivers following a serious illness in their child (Woolf et al., 2016), from which individuals may naturally recover or which can develop into PTSD. Bryant et al (2011) found up to a half of individuals with ASD do not go on to develop PTSD. Traumatic stress symptoms can significantly impair functioning even at subclinical levels (Regel & Joseph, 2017).

Despite an emphasis on sudden or acute life-endangering traumatic events within diagnostic criteria for PTSD (APA, 2013), caregivers are thought to experience multiple or prolonged traumas in relation to their child's illness with repeated exposure to re-traumatising events exacerbating symptoms (Carmassi et al., 2021). The paediatric medical traumatic stress model (Kazak et al., 2006) outlines how stress responses may be normative and adaptive to the ongoing threat of harm to their child, however, when extreme, distressing and persistent they can constitute PTSD.

Validated self-report measures, such as the PCL-5 scale (Weathers et al., 2013), are commonly used within research to assess for symptoms of PTSD. However, in contexts of ongoing threat, distinguishing between acute stress responses, adaptive responses to current threat and PTSD is a challenge, particularly for self-report measures (Hoffman et al., 2011). For a PTSD diagnosis, a clinical assessment considering factors such as the nature of and time since the trauma(s), current context, and differential diagnoses, would be required. Despite this, self-report measures remain valuable for examining caregiver distress through the framework of post-traumatic stress and ensuring alignment with existing research.

To the authors' knowledge, only three studies have measured post-traumatic stress in parents of those with EDs, and only in relation to anorexia nervosa (AN). They showed increased rates of probable PTSD (35.5%, Hazell et al., 2014; 56.9%, Irish et al., 2024) and subclinical post-traumatic stress (55.9% for mothers, 61.5% for fathers, Timko et al., 2023) compared to the UK general population (4%, McManus et al, 2016). Mothers were found to experience numerous DSM-IV criteria traumatic stressors throughout their daughter's AN, such as waiting to receive urgent support, being unable to prevent her deterioration, and thinking she was about to die (Hazell et al., 2014).

Factors Related to Post-Traumatic Stress

Within the cognitive model of PTSD (Ehlers & Clark, 2000), the ways in which a person processes the traumatic event and its aftermath (their negative appraisals, coping styles and memory encoding) are considered to underpin the disorder. However, demographic and illness-related risk factors for PTSD have also been identified in caregivers in response to paediatric illness such as caregiver gender, child age, recent diagnosis, relapses, and lack of support, although evidence is often mixed (Burgess et al., 2021; Carmassi et al., 2021; Woolf et al., 2016).

In relation to ED caregivers, only a limited range of variables have been measured with mixed evidence of associations between PTSD and parent gender, ED duration and physical markers of ED severity (Irish et al., 2024; Timko et al., 2023) and only in relation to narrowed samples of those with AN. Other factors such as child gender, relapse, diagnosis, and transdiagnostic behaviours (e.g. purging) have yet to be investigated despite associations with ED caregiver distress and different caregiving experiences (e.g. Sepulveda et al., 2014; Whitney et al., 2023). Better understanding demographic and ED-related factors associated with caregiver PTSD symptoms is important in improving the identification and targeting of support.

Caregiver Post-Traumatic Stress and the Caregiving Role

The potential for post-traumatic stress to impact parents' ability to support their child's recovery is well documented (Carmassi et al., 2021). Recent longitudinal evidence has linked post-

traumatic stress in ED caregivers to greater levels of caregiver accommodation of the ED and a slower rate of weight gain for their child during recovery (Timko et al., 2023). However, a range of "caregiver skills", including emotional intelligence, acceptance, and frustration tolerance, have emerged as important in supporting recovery (Langley et al., 2018; Treasure et al., 2016), based on interpersonal theories of ED maintenance (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013) and evidence of their association with better ED outcomes (Magill et al., 2016; Philipp et al., 2021; Salerno et al., 2016). Research has yet to examine whether and how PTSD symptoms impact these caregiver skills considered as key drivers of recovery outcomes. Trauma symptoms including heightened autonomic arousal and threat-based responding may make it more difficult for caregivers to demonstrate skills that require emotion regulation and top-down reflective thinking. Understanding the extent to which PTSD symptoms predict levels of caregiver skills is crucial for developing interventions that strengthen caregivers' ability to support their child effectively.

Aims

In summary, this study aims to better understand parental caregivers' PTSD symptoms, their relation to demographic and ED-related factors and any predictive effect on caregiving skills, in order to help improve ED caregivers' wellbeing and their ability to support their child. It also aims to extend previous research by exploring PTSD symptoms in a sample of parental caregivers to children and young people (CYP) with a broader range of ED presentations and support experiences. Examining probable PTSD within the sample also aimed to frame and orientate the present study to existing literature. Given the limited prior research in this area, this study adopted an exploratory approach, aiming to generate hypotheses to guide future research. Specifically, the study research questions are: (RQ1) *What is the rate of probable PTSD among the sample?* (RQ2), *What demographic and ED-related factors are associated with caregiver PTSD symptoms?* and (RQ3) *To what extent do PTSD symptoms predict caregiver skills?*

Method

Participants

Individuals eligible for the study were: (a) parents or guardians to a CYP between 5-25 years old currently experiencing eating-related difficulties (suspected or diagnosed ED, any diagnosis), (b) who have a current substantial role in supporting the CYP emotionally and/or practically with their eating-related difficulties, (c) aged 18 years or older (d) live in the UK and (e) are proficient in English. Given the online format of the study, individuals also needed access to an internet connected device.

This study received UEA Faculty of Medicine and Health Sciences Research Ethics Committee approval (ETH2324-1470; see Appendix I) and conforms to the *British Psychological Society Code of Human Research Ethics* (2021).

Between January and June 2024, 123 caregivers participated in the study. Participants were recruited through voluntary response sampling, with recruitment advertisements shared on social media platforms (Facebook, Instagram, X) and distributed by 13 UK-wide ED and mental health organisations (see Appendix J-L for recruitment materials). Participants were also invited to share the survey link with others. Recruitment efforts emphasised participation from underrepresented groups. Adverts (see Appendix and L) explicitly encouraged participation from fathers, individuals identifying as an ethnic minority and caregivers to CYP with bulimia, binge-eating and other specified feeding and eating disorder (OSFED).A diverse range of organisations were also engaged to distribute recruitment materials including men's and ethnic minority mental health organisations.

Design

This study utilised a cross-sectional research design and self-report online survey methodology. It has been reported in accordance with the STROBE checklist for cross-sectional studies (STROBE, n.d.).

Measures

Demographic and ED information

Participants self-reported demographic information about themselves and their child, and clinical and support-related factors associated with their child's ED that are known to be relevant in ED and PTSD fields (see Appendix M). This included identifying common ED-related behaviours (i.e., restriction, bingeing, vomiting, laxative use, excessive exercise) in their child (Accurso & Waller, 2021). Respondents selected answers from pre-defined options, with a free-text box provided for those who selected "other".

Caregiver PTSD symptoms

The Posttraumatic Stress Disorder Checklist for DSM-5 (PCL-5; Weathers et al., 2013) is a standardised self-report scale comprising of 20 items designed to assess symptoms of PTSD (see Appendix N). Respondents rate the severity of each symptom over the past month on a 5-point scale from "not at all" to "extremely". It has four subscales corresponding to the Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5; APA, 2013) symptom criteria: intrusions (Criterion B), avoidance of trauma reminders (Criterion C), negative alterations in cognitions and mood (Criterion D), and alterations in arousal and reactivity (Criterion E). Total scores (0-80) indicate symptom severity, with higher scores denoting higher symptom levels. Cut-off scores of 31-33 are suggestive of probable PTSD (Forkus et al., 2023), but do not constitute a formal diagnosis, which requires a comprehensive clinical assessment. A cut-off score of 33 was adopted in this study, consistent with recent ED caregiver research (Irish et al., 2024).

The PCL-5 is one of the most widely used scales for assessing PTSD symptoms with robust psychometric properties (Forkus et al., 2023), including high internal consistency (Cronbach's $\alpha > .80$) in comparable parental populations (Irish et al., 2024; Stewart et al., 2020).

The checklist does not include an assessment of the nature of the trauma (Criterion A). However, parents were instructed to respond to questions considering any stressful experience(s) they have had in relation to their child's ED. Cronbach's alpha was .93.

Caregiver skills

The Caregiver Skills Scale (CASK; Hibbs et al., 2015) is used to measure caregiving behaviours towards individuals with an ED. Respondents self-assess skill level on 27 items from 0-100, with higher values indicating more adaptive behaviour (see Appendix O). It is based upon the interpersonal mechanisms theorised to maintain EDs (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). The scale consists of six subscales reflecting different caregiver skills (see Table 3). CASK total score (0-2700) and separate subscale scores are derived. Cronbach's α is high (0.92 for total, 0.71-0.85 for subscales), with good convergent validity and sensitivity to change (Hibbs et al., 2015; Hodsoll et al., 2017). In the present study Cronbach's alpha was .93 for the total scale and between .70 and .86 for subscales.

Table 3

The Six Caregiver Skills

Caregiver Skill	Definition (from Hibbs et al., 2015)
Bigger Picture	The ability to be more positive about changes with a hopeful long-term view
Self-Care	The ability to take time for self and other family members
Biting your Tongue	The ability to control the urge to enquire and avoid repetitive nagging conversations
Insight and Acceptance	The ability to accept and manage negative emotions
Emotional Intelligence	The ability to discuss and manage feelings
Frustration Tolerance	The ability to sidestep conflict yet be firm, calm and understanding towards the person with the ED

Procedure

Participants followed a weblink from the advert to the survey webpage on the platform Jisc Online Surveys (https://www.onlinesurveys.ac.uk). Participants who indicated they met eligibility criteria were then presented with the participant information and gave informed consent by indicating their agreement to all consent statements (see Appendix P and Q). Consenting participants then completed the survey (approximately 15 minutes), which included the

demographics and ED information section, PCL-5, and CASK scale. The survey also included bot-screening questions (e.g. "which of these is a colour?") and an additional measure that was analysed as part of a separate study. Participants were required to answer all questions to proceed ensuring no missing data, and responses were saved upon completion. Details of mental health and caregiver support were provided in the participant information and debrief pages (see Appendix R). As a token of appreciation for participation, a donation of £2 per participant (£246 total) was made to ED charity Beat, chosen by a local National Health Service (NHS) carer group.

Analysis

Data were analysed using IBM SPSS Statistics (Version 28). Scrutinisation of individual responses identified no missing data, suspect responses, or multiple entries relating to the same CYP. All outliers were reviewed and considered to represent meaningful data. No responses were therefore excluded.

Descriptive Statistics

Descriptive statistics were calculated, with means and standard deviations reported for continuous variables, and frequencies and proportions for categorical variables. To enhance interpretability, some related or small subgroup categories were merged (ethnicity, purging, hospitalisation and non-degree qualifications).

RQ1. The proportion of the sample with probable PTSD was calculated based on total PCL-5 scores using a cut off of 33. The proportion endorsing each symptom criterion was also calculated based on item ratings of "moderately" or higher for at least one item for both Criteria B and C and at least two items for both Criteria D and E as recommended by PCL-5 developers (National Centre for PTSD, n.d).

Inferential Statistics

An a priori power analysis conducted using G*Power 3.1 (Faul et al., 2009) determined that a sample size of 84 participants was required to detect a moderate effect size ($r = 0.30$) with a statistical power of 0.8 and a significance level of $p<.05$ (two-tailed) for the primary correlational

analyses. All inferential analyses used a significance level of .05, with no statistical corrections for multiple comparisons due to the exploratory nature of the study. Cohen's (1988) benchmarks for small, medium/moderate and large effects were followed (r = .10, .30, .50; R^2 = .02, .13, .26; η_p^2 = .01, .06, .14). Key assumptions for each analysis were evaluated using visual inspections and diagnostic tests. In cases where deviations from normality or potential outliers were identified, non-parametric correlations or bias-corrected bootstrapping (BCa; 1,000 samples) was employed to improve robustness. In all other cases, all assumptions were satisfied.

RQ2. Correlations were conducted to examine bivariate relationships between PTSD symptom severity (PCL-5 total score) and demographic and ED-related variables. To facilitate analysis, CYP support was dichotomised into meaningful groups (treatment ongoing = 1, other categories = 0), and CYP gender was dichotomised (female = 1, male/non-binary = 0), combining the two smaller gender groups together to aid statistical power. For multi-response categories (caregiver support, ED behaviours, parent-reported ED), each response option was treated as a separate binary (yes/no) variable. Point-biserial correlations were conducted for binary variables, with bootstrapping to correct for outliers and non-normality of PCL-5 scores within small groups. Analyses were not conducted for groups with ≤5 participants due to validity concerns (Bonett, 2020).

A hierarchical multiple regression using the entry method was used to assess the predictive value of demographic and ED-related variables on PTSD symptom severity (outcome variable). Demographics were entered into the model in the first block and followed by ED-related variables in the second block. To prevent overfitting, prioritise the most impactful predictors, and ensure adequate statistical power (up to 11 variables), variables were selected based on correlational analyses and theoretical relevance informed by prior research. A bootstrap, applied to check the robustness of the model (Field & Wilcox, 2017), did not alter findings and therefore the standard regression is reported. A sensitivity analysis was also carried out to assess the impact of separating male and non-binary CYP gender using dummy coding with female gender as the reference group.

RQ3. Initial correlations were conducted between PTSD symptom severity and caregiver skills (individual and overall). A multivariate multiple regression (Wilk's Lambda multivariate criterion) was then performed to assess the variance in each caregiver skill (outcome variables) explained by PTSD symptoms (predictor variable), whilst accounting for intercorrelations between caregiver skills. Bootstrapping was applied to account for non-normality of residuals for two caregiver skills.

Results

Sample Characteristics

Characteristics of caregivers, their child and ED factors are summarised in Table 4. Participants were aged between 28 and 63 (M = 50.08, SD = 6.41). Most were mothers (92.7%), identified as white (97.6%), with a university degree (74.8%). Participants cared for CYP aged between 5 and 25 years (M = 16.6, SD = 3.8), who were mostly female (87.0%), with a formally diagnosed ED (86.2%). Just under two thirds (63.4%) were currently receiving some form of treatment.

Table 4

Demographic and ED-related Descriptive Statistics and Correlations with PTSD Symptoms

Caregiver Demographics	Caregivers (N = 123)		Correlation Coefficient	
	n/M	%/SD (range)	$r/r_s/r_{pb}$ [BCa CI]	p-value
Age (years)	50.08	6.41 (28-63)	.05†	.57
Ethnicity			-	
White	120	97.6%		
Other	3	2.4%		
Highest level of education			.01†	.89
Non-degree level (e.g. high school, diploma)	31	25.2%		
Bachelor's degree	42	34.1%		
Master's degree	42	34.1%		
PhD	8	6.5%		
Relationship to CYP (mother = 1)			-.09 [-.30, .12]	.32

Mother	114	92.7%		
Father	9	7.3%		
Cohabitation with CYP			.08†	.37
Full time	92	74.8%		
Most of the time (e.g. 5 days a week)	7	5.7%		
Some of the time (e.g. holidays, weekends)	20	16.3%		
None of the time	4	3.3%		
CYP demographics	**n/M**	**%/SD (range)**	***r/r*$_s$*/r*$_{pb}$ [BCa CI]**	***p*-value**
Age (years)	16.61	3.82 (5 – 25)	.11†	.22
Gender (female = 1)			-.13 [-.27, .04]	.17
Female	107	87.0%		
Male	14	11.0%		
Non-binary	2	2.0%		
ED-related factors	**n/M**	**%/SD (range)**	***r/r*$_s$*/r*$_{pb}$ [BCa CI]**	***p*-value**
Formally diagnosed (yes = 1)			.05 [-.13, .24]	.58
Yes	106	86.2%		
No	17‡	13.8%		
Parent-reported ED§ (for each, present = 1)				
AN	98	79.7%	.05 [-.13, .20]	.61
BN	7	5.7%	.18* [.07, .30]	<.05
BED	10	8.1%	.11 [-.03, .25]	.22
OSFED	3	2.4%	-	
ARFID	23	18.7%	.08 [-.11, .25]	.41
Not Reported	4	3.3%	-	
ED behaviours§ (for each, present = 1)				
Restriction	119	96.7%	-	
Excessive exercising	78	63.4%	.03 [-.15, .20]	.72
Purging (vomiting or laxative use)	38	30.9%	.12 [-.05, .29]	.18
Bingeing	18	14.6%	.13 [-.01, .27]	.15
ED duration (years)	4.02	3.51 (0.4 – 19.9)	.06†	.53
ED stage (relapse = 1)			.21*[.05, .38]	<.05

First episode	67	54.5%		
Relapse	56	45.5%		
Current CYP support (treatment ongoing = 1)			-.09 [-.26, .10]	.31
Treatment ongoing	78	63.4%		
Support has ended	22	17.9%		
Awaiting treatment	12	9.8%		
No support available	5	4.1%		
Other	6	4.9%		
Hospitalisation (general or psychiatric) (yes = 1)			.06 [-.12, .25]	.51
Yes	68	55.3%		
No	55	44.7%		
Caregiver support accessed[§] (for each, present = 1)				
Family-based therapy	74	60.2%	-.06 [-.24, .12]	.49
Support groups	49	39.8%	-.04 [-.23, .15]	.64
Individual therapy	48	39.0%	.08 [-.09, .24]	.39
Helplines or self-help resources	81	65.9%	.05 [-.13, .24]	.55
None	8	6.5%	-.04 [-.20, .17]	.70

Note. ED, eating disorder; CYP, child or young person; AN, anorexia nervosa; BN, bulimia nervosa; BED, binge-eating disorder; OSFED, other specified feeding and eating disorder; ARFID, avoidant/restrictive food intake disorder; *n*/N, number of participants; *M*, mean, *SD*, standard deviation; *r*, Pearson's correlation coefficient; r_s, Spearman's Rho, r_{pb}, point-biserial correlation; BCa CI, Bias-corrected and accelerated bootstrap 95% confidence intervals

*$p < .05$; [†] r_s conducted; [‡] Breakdown of suspected EDs: 11 ARFID, 3 BED, 2 AN, 1 OSFED, 2 Not Reported; [§]Categories are non-mutually exclusive; each was separately correlated with PTSD symptoms according to its presence (1) or absence (0), - Correlation not conducted due to group size ≤5

PTSD Symptoms (RQ1)

Over half of caregivers (62.6%) showed probable PTSD based on PCL-5 total scores (M = 38.02, SD = 16.21, range = 2 to 80). Participants were most likely to endorse symptoms of intrusions (86.2%; Criterion B) and least likely to endorse avoidance of trauma reminders (64.2%; Criterion C).

Demographic and ED-related Associations (RQ2)

Correlations between PTSD symptoms and demographic and ED-related factors are presented in Table 4. Only ED stage and bulimia (BN) showed significant correlations with PTSD symptoms. Both showed small positive correlations indicating that parent-reported CYP relapse (compared to first episode) and the presence of BN were associated with greater caregiver PTSD symptoms (BN: r_{pb}=.18, p<.05, CI [.07, .31]; Relapse: r_{pb}=.21, p<.05, CI [.03, .38]), although the sample for BN was small (n = 7). A post-hoc power analysis indicated that correlations involving binary groups with distributions exceeding a 25-to-98 participant ratio were underpowered (r = 0.3, α = .05, two-tailed, 80% power).

A hierarchical multiple regression analysis, presented in Table 5, revealed that a model involving demographic variables alone (Model 1: relationship to CYP, CYP gender, CYP age, and cohabitation) did not significantly predict PTSD symptoms, $F(4, 118) = 2.20$, p = .07, R^2 = 0.07, *adj.* R^2 = .04, although older CYP age was a significant predictor of greater PTSD symptoms. In Model 2, adding ED-related factors (ED duration, ED stage, purging, bulimia, hospitalisation, and current CYP support) significantly improved the model (ΔR^2 = .14), with the final model explaining 21% of the variance, $F(10, 112) = 2.93$, p < .01, R^2 = .21, *adj.* R^2 = .14. Significant predictors of greater PTSD symptoms with small effect sizes (η_p^2 = .04 to .05) were male/non-binary CYP gender, older CYP age, full-time cohabitation, bulimia, shorter ED duration, and CYP not currently in treatment. CYP relapse (compared to first episode) was the only variable with a significant moderate-sized positive predictive association with PTSD symptoms (η_p^2 = .07).

Table 5

Regression Predicting PTSD Symptoms from Demographic and ED-related Factors

Variable	Model 1					Model 2				
		95% CI for B					95% CI for B			
	B	LL	UL	β	η_p^2	B	LL	UL	β	η_p^2
Demographic										
Relationship to CYP (mother = 1)	-6.86	-17.84	4.11	-0.11	.01	-8.87	-19.50	1.75	-0.14	.02
CYP Gender (female = 1)	-6.70	-15.34	1.94	-0.14	.02	-10.31	-19.15	-1.48	-0.21*	.05
CYP Age (years)	0.90	0.06	1.74	0.21*	.04	1.07	0.11	2.03	0.25*	.04
Cohabitation (full-time = 1)	6.56	-0.79	13.91	0.18	.03	9.15	1.98	16.31	0.25*	.05
ED-related										
Duration of ED (years)						-1.16	-2.19	-0.14	-0.25*	.04
ED stage (Relapse = 1)						8.81	2.61	15.00	0.27**	.07
Purging (present = 1)						2.80	-3.67	9.27	0.08	.01
Bulimia nervosa (present = 1)						13.82	0.89	26.74	0.20*	.04
Hospitalisation (present = 1)						0.97	-4.82	6.75	0.03	.00
Current CYP support (ongoing treatment = 1)						-6.30	-12.49	-0.11	-0.19*†	.04
R^2	.07					.21				
Adjusted R^2	.04					.14				
F-statistic for change in R^2	2.20					3.24**				

Note. ED, eating disorder; CYP, child or young person; *B*, unstandardised coefficient; β, standardised coefficient; η_p^2. partial eta squared measure of effect size; R^2, the variance in PTSD symptoms explained by the model; LL/UL, lower limit/upper limit; CI, confidence interval

* $p < .05$. ** $p < .01$

† Non-significant ($p = .056$) in sensitivity analysis when CYP Gender is dummy coded

All regression assumptions were met, and results remained unchanged after applying a bootstrap procedure, indicating model robustness. A sensitivity analysis assessed the impact of separating male and non-binary CYP gender using dummy coding with female gender as the reference group. In the re-run regression, the male dummy variable was significant ($p < .05$, $\eta_p^2 = .05$), while the non-binary variable was non-significant ($p = .82$, $\eta_p^2 < .01$), likely due to the small sample size (n = 2). This suggests that the association between CYP gender and PTSD symptoms is primarily driven by the greater PTSD symptom severity in caregivers of male compared to female CYP. No other notable differences were found in the final model, except the small effect of Current CYP support on PTSD symptoms became non-significant ($p = .056$), suggesting this association should be interpreted with caution.

Caregiver Skills Associations (RQ3)

Self-reported total caregiver skill levels varied considerably across the sample (M =1527.15, SD = 393.39, range = 530 to 2400), with higher scores indicating more adaptive behaviour. On average, caregivers rated themselves lowest on Self-Care items (M = 42.20, SD = 19.15) and highest on Bigger Picture items (M = 65.56, SD = 16.88).

Table 6

Caregiver Skill Descriptive Statistics and Correlations with PTSD Symptom Severity

Caregiver Skill	Scale Range	Total Score		Item Score (0-100)		Corr. Coef.
		M	SD	M	SD	r/r_s
Total Caregiver Skills	0-2700	1527.15	393.39	56.56	14.57	-.52***
Bigger Picture	0-700	458.94	118.15	65.56	16.88	-.40***
Self-Care	0-400	168.78	76.58	42.20	19.15	-.51***
Biting your Tongue	0-300	149.76	55.71	49.92	18.57	-.43***
Insight and Acceptance	0-300	160.65	61.11	53.55	20.37	-.45***
Emotional Intelligence	0-500	264.23	101.92	52.85	20.38	-.34***
Frustration Tolerance	0-500	324.80	91.07	64.96	18.21	-.27**†

Note. Higher scores indicate more adaptive behaviour; M, mean; SD, standard deviation; Corr. Coeff, correlation coefficient; *r*, Pearson's correlation, r_s, Spearman's rho

$^{***}p < .001$, $^{**}p < .01$

†r_s conducted due to non-normality

PTSD symptoms showed significant small to large negative correlations with all six caregiver skills and total skill level (-.27 to -.52) as summarised in Table 6. A multivariate multiple regression analysis, with bootstrapping applied to account for non-normality, found PTSD symptoms (predictor) accounted for a significant 34% of the variance across all caregiver skills (outcome variables), Wilks' $\Lambda = .66$, $F(6, 116) = 10.01$, $p < .001$, $\eta^2 = .34$. PTSD symptoms significantly negatively predicted each caregiver skill individually as shown in Table 7, with increases in PTSD symptom severity corresponding to decreases in caregiver skills. PTSD symptoms explained the least variance in Frustration Tolerance (11%) and the most in Self-Care (26%).

Table 7

Results of Regression Predicting Caregiver Skills from PTSD Symptoms

Caregiver skill	95% BCa CI for B				
	B	LL	UL	*F*-statistic	R^2
Bigger Picture	-2.91	-4.28	-1.57	22.90^{***}	.16
Self-Care	-2.42	-3.12	-1.70	43.24^{***}	.26
Biting your Tongue	-1.48	-2.01	- 0.93	27.59^{***}	.19
Insight and Acceptance	-1.70	-2.30	-1.07	30.72^{***}	.20
Emotional Intelligence	-2.16	-3.12	-1.31	16.25^{***}	.12
Frustration Tolerance	-1.84	-2.68	-0.97	14.48^{***}	.11

Note. B, unstandardised coefficient; BCa CI, bias-corrected and accelerated bootstrap confidence interval; LL/UL, lower limit/upper limit; R^2, the variance in caregiver skill explained by PTSD symptoms

$^{***}p < .001$

Discussion

This study investigated post-traumatic stress in 123 parental caregivers of CYP with ED symptoms. Findings revealed over half (62.6%) scored high enough to indicate probable PTSD in relation to their child's ED. Demographic and ED-related factors together explained a moderate amount of the variance in PTSD symptoms, with ED relapse contributing the largest independent association. A number of factors, including CYP age, CYP gender and cohabitation, showed significant relationships with PTSD symptoms only after controlling for the influence of other variables. Additionally, PTSD symptoms accounted for a large portion of the variance in caregiver skills, with greater PTSD symptoms associated with less adaptive caregiving behaviours, such as reduced self-care, difficulty maintaining hope and increased emotional reactivity in relation to their child's ED.

Findings align with existing evidence of elevated post-traumatic stress in parents of individuals with AN (Hazell et al., 2014; Timko et al., 2023), with 62.6% of participants exhibiting scores indicative of probable PTSD, comparable to the 56.9% reported in a sample of parents of adolescents with AN (56.9%) using the same PCL-5 cut-off (Irish et al., 2024). Whilst important in orientating our study to existing literature, this should not be interpreted as indicating the rate of PTSD in this caregiving population. The sample was not designed to be representative and is subject to voluntary response biases explored within the limitations section.

In addition, PCL-5 scores are only suggestive of PTSD and do not confirm a diagnosis. The PCL-5 measure used did not assess DSM-V PTSD diagnostic criterion A; the nature of or time since the trauma, meaning that although symptoms are measured over one month, they may also reflect acute stress responses to traumas occurring within this period. These challenges measuring PTSD in

contexts of ongoing trauma, particularly separating between pathological and adaptive responses, support the need to modify self-report measures to situations of ongoing trauma or supplement them with clinician interviews to gain more accurate estimations of probable PTSD (Hoffman et al., 2011).

Importantly, however, findings of this study indicate that caregivers to a broader ED population than previously identified may be at risk of developing PTSD, including those whose child has no diagnosis, is not accessing support, and presents with avoidant/restrictive food intake disorder (ARFID) or BN. This is supported by the finding that neither the type of ED nor its formal diagnosis were related to caregiver PTSD symptoms, except for increased levels among parents of children with BN, though the small sample sizes warrant a cautious interpretation.

The finding that some demographic and ED-related variables showed significant associations with PTSD symptoms only when controlling for others indicates the complex interplay of variables with potential confounding or moderating influences. Combined with their small predictive power, this emphasises the challenges of identifying caregivers at risk of PTSD based solely on objective characteristics, and the limitations of targeting support towards specific groups.

Some associations, however, are notable. Having a male/non-binary child with an ED predicted greater caregiver PTSD symptoms, which contrasts the lack of a gender effect found in other fields (e.g. Burgess et al., 2021) and may reflect reported negative impacts of the gender-atypical nature of EDs on caregivers' experiences, such as challenges accessing support (Whitney et al., 2023).

The finding that PTSD symptoms were higher when the CYP was not in treatment aligns with studies highlighting caregivers' distress in feeling alone and unsupported whilst awaiting treatment or following discharge (Crowther et al., 2024; Robinson et al., 2020). However, the small effect size and non-significance in sensitivity analysis suggests any potential association between treatment status and caregiver PTSD symptoms should be interpreted with caution. Similarly, reports of caregivers' feelings of helplessness on being excluded from treatment once their child

turned 18 (Crowther et al., 2024) may offer one possible explanation of the finding of higher PTSD symptoms in caregivers of older CYP within the sample. The relationship between caregiver PTSD symptoms and their experiences engaging with their child's treatment warrants further investigation.

Among the demographic and ED factors examined, child relapse, compared to first episode, had the largest and most statistically robust association with PTSD symptom severity, independent of potential confounders such as ED duration, hospitalisation, and presentation. This aligns with Burgess et al. (2021) who identified relapse or readmission as a small PTSD risk factor for parents of children with chronic illnesses. In comparison to a first occurrence of the ED, relapse may trigger caregivers' memories of past ED-related trauma, intensifying existing symptoms. Caregivers' perceptions that relapse indicates efforts to support their child have failed (Burman et al., 2024) may also play a role as low confidence in treatment has been linked to PTSD in caregivers of cancer patients (Richardson et al., 2016). Conversely, caregiver PTSD symptoms may increase the likelihood of relapse by affecting their ability to support their child's recovery, consistent with longitudinal evidence that caregiver PTSD predicts poorer child outcomes (Bryant et al., 2018; Timko et al., 2023). However, the cross-sectional design of the current study, which compares ED relapse to first-episode cases rather than to a recovery-without-relapse group, limits the ability to explore these potential relationships.

Findings support a connection between PTSD symptoms and less adaptive caregiver behaviours that extend beyond accommodation of ED (Timko et al., 2023). Results suggest PTSD symptoms may have a comprehensive influence across caregiver skills rather than restricted to specific skills and highlight potential mechanisms through which PTSD may affect ED outcomes. This underscores the relevance of literature on post-traumatic stress to understanding caregiver responses and extending interpersonal maintenance models of EDs (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). While research shows that brief interventions can improve caregiver skills (Miskovic-Wheatley et al., 2024), without addressing PTSD symptoms such as avoidance and

elevated sense of threat, it may be that the development of these important skills is compromised for some caregivers.

Limitations

This study has several limitations. Parents' reports of their child's ED are unable to be verified by qualified clinicians, and may contain some inaccuracies, particularly in relation to ED diagnosis. Perceived caregiver skills may be influenced by negative affect and self-concept, and as such, may not reflect caregivers' true abilities.

The study's cross-sectional design is useful for generating hypotheses but does not allow for causal inferences and, as highlighted in relation to relapse, some relationships with PTSD symptoms may be bidirectional. The use of multiple comparisons, the potential presence of unmeasured confounders, and the reduction of data for analytical purposes necessitate cautious interpretation of the results.

Despite recruitment efforts, certain groups (e.g. ethnic minorities, fathers, and caregivers of individuals with non-restrictive EDs) were underrepresented in the sample. This is consistent with previous ED research (Halbeisen et al., 2022) and may reflect their lower presence in the spaces of support participants were recruited from. This resulted in some unbalanced and small sub-groups, limiting statistical power to detect effects. Additionally, it restricts the generalisability of findings outside of white, educated, mothers in the UK, particularly given evidence that gender and socio-cultural factors influence PTSD risk (Asnaani & Hall-Clark, 2017; Carmassi et al., 2021). While there was considerable variation in PTSD symptoms in the sample, caregivers who did not identify their experience as traumatic, as well as those experiencing trauma-driven avoidance of their child's ED, may have been be less likely to participate. Finally, there is a possibility of unintentional overlap between participants in this study and those in Irish et al (2024).

Clinical Implications

Findings indicating a high rate of probable PTSD within this sample and the complexity of predicting those with greater PTSD symptoms, suggest routinely screening for caregiver trauma

may be beneficial and professionals' awareness and consideration of parental trauma may be important when engaging with caregivers across child and adult ED services.

Further Research

Future research should adopt a proactive approach to increasing sample diversity and share effective recruitment methods for engaging underrepresented populations. To extend this research, future studies should seek to estimate the prevalence of PTSD in the ED caregiver population through representative samples and adapted self-report checklists or clinician verification to distinguish PTSD from other responses (such as acute stress responses). Longitudinal studies are needed to understand changes in post-traumatic stress over time, causality in relationships with caregiving behaviours and child outcomes such as relapse, and its relative influence compared to other forms of caregiver psychopathology (e.g. depression). A comparison of caregiver PTSD among CYP who relapse and those who do not after treatment would be needed to further explore the significance of relapse. Research on caregiver interventions would benefit from including outcome measures of caregiver post-traumatic stress. Additionally, research is needed to understand what services can do to support caregivers experiencing ED-related traumatic events, such as assessing the suitability of trauma-focused CBT adapted for contexts of ongoing threat (Ennis et al., 2021).

Highlights

- The majority of parental caregivers (62.6%) of children and young people (CYP) with ED symptoms showed scores on a validated measure high enough to indicate probable PTSD.
- Demographic and ED-related factors together explained a moderate amount of the variance in PTSD symptoms, with small independent associations observed for most variables (including CYP age and gender) and a moderate association found for ED relapse (compared to first episode).
- PTSD symptoms accounted for a large portion of the variance across self-reported caregiver skills such as self-care and emotional intelligence.

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Chapter Five: Additional Methodology

This chapter provides further information surrounding the methods used for the empirical paper presented in Chapter Four. Information within this chapter is therefore not comprehensive and should be understood alongside that provided in Chapter Four.

Design

This study was conducted as part of a joint research project with another doctorate student. Study protocol, ethics applications, survey design and recruitment were conducted jointly, with data cleaning and analysis carried out independently. Both projects utilised the same participants but asked distinct research questions and the survey therefore included items from the Eating Behaviours Checklist (Goddard et al., 2011) and a measure of eating disorder (ED) mental health literacy that were not pertinent to this thesis research.

Ethics

Patient and Public Involvement

Appropriate funding was secured to consult a patient and public involvement (PPI) group throughout the research process, in line with established guidance (National Institute for Health and Care Research [NIHR], 2021). This aimed to ensure the research was of value to the public and benefitted from the expertise generated from lived experience. As planned, efforts were made to establish a PPI group through the research team's existing connections with a local National Health Service (NHS) parent carer steering group as part of the research design phase. Following the group's dissolution due to a lack of members, contacts were made with other regional alternatives (NHS and non-NHS) without success. To avoid further delays to the research timeline, the decision was made to proceed with data collection. As a result, PPI involvement was limited to a small group of carers contacted via a local NHS trust who selected the charity Beat to receive the donation.

Gatekeepers

In an attempt to obtain a broad sample of caregivers, all UK-wide independent and non-profit ED organisations/groups identifiable by a web search were contacted via email and invited to

share the advert through their channels. A range of broader mental health organisations with a focus on men and individuals from ethnic minority backgrounds were also contacted in an effort to reach these underrepresented groups.

Gatekeepers were provided with information about the study, offered the opportunity to ask questions and asked to confirm their consent to share the research advert via an email written response (see Appendix K). Of those contacted, 13 agreed to support the research, including private ED care providers, ED carer support organisations, national and regional ED charities and mental health organisations focused on men and ethnic minorities. No incentive was provided to gatekeepers and the carers group who selected the charity to receive the donation were not aware of which organisations had acted as gatekeepers.

Participants

The donation to charity acted as an acknowledgement of participants' time and an incentive to improve participant numbers but which was not considered so large as to be coercive and compromising of participants' free choice. Participant information (see Appendix P) made clear that participation would have no impact on the support a caregiver or their child receives from eating disorder organisations or services. No deception or incomplete disclosure was used.

To minimise distress, detailed report of their child's ED or traumatic memories was avoided. At any point participants could pause and return to the survey or exit it to withdraw from the study. Participant burden was also reduced through the use of an online survey which could be completed in their own time, and minimising survey length.

Participants were made aware they would be unable to withdraw their consent following survey completion. This was considered proportionate to the lack of personally identifiable data. Measures to enable later withdrawal of consent would require some degree of de-anonymisation.

Data

The information collected was not deemed personally identifying, even when combined. Data was collected, stored, processed and will be deleted in line with University of East Anglia

(UEA) Research Data Management Policy; v1.7, 01/05/2019 and the Data Protection Act (2018). Jisc online survey platform is GDPR compliant and held data securely during the collection phase according to strict standards (ISO27001). UEA One Drive, used to store data for processing, provided secure password-protected storage only accessible to the research team. Following project completion, the fully anonymous dataset will be published and stored on the online UEA research portal data repository in line with Open Science principles.

Measures

Demographic & ED-related Information

Participants reported on their child's diagnosed or suspected ED as well as their specific eating behaviours as is common in transdiagnostic ED research (e.g. Pehlivan et al., 2024). These are overlapping but distinct concepts as eating behaviours cut-across diagnoses, and diagnoses are characterised by combinations of behaviours alongside other cognitive, and physiological symptoms (American Psychiatric Association, 2013). Both specific ED behaviours and diagnoses have been associated with caregiver distress (Anastasiadou et al., 2014; Sepulveda et al., 2014).

ED stage was categorised into first episode (defined as 'this is the first time they have experienced eating-related difficulties') and relapse (defined as 'they experienced a period of improvement before their difficulties worsened again') for the purposes of analysis.

Some background information collected in the survey was not reported within the empirical paper. Hospitalisation variables were collapsed into a binary hospitalisation variable as is common practice. Caregiver gender was not reported due to significant overlap with relation to child or young person (CYP) variable (Mother vs. Father). Caregiver ED history was not reported due to recent coverage in Irish et al. (2024). Both friends and family support and other caregiver support variables were also omitted as, following review, they were not deemed to capture meaningful concepts as binary constructs without additional elaboration.

Analysis

Variable Classification

Data were scrutinised to ensure the appropriateness of converting ED-related multi-category variables into binary variables. Although this data reduction may obscure subgroup effects, tests of homogeneity of variance suggest this process did not add problematic heterogeneity into the grouped category. Dichotomising variables facilitated the use of correlations across all variables to enhance consistency and interpretability of effects. A larger sample size than that obtained would also have been needed to conduct alternative analysis of variance (ANOVA) tests for these variables.

Following calculation of the rate of probable post-traumatic stress disorder (PTSD) based on clinical cutoffs, the continuous variable PTSD symptom severity was utilised in subsequent analyses instead of a binary measure of probable PTSD. This approach was chosen to enhance sensitivity and acknowledge that PTSD symptoms exist on a continuum and even symptoms falling below the threshold can still have a significant impact (Regel & Joseph, 2017). The decision to treat PTSD symptoms as either an outcome or a predictor in regression models was guided by theoretical and empirical evidence regarding the likely direction of influence (e.g. Carmassi et al., 2021; Timko et al., 2023).

Variable Selection for Hierarchical Multiple Regression (RQ2)

Power analysis confirmed that a regression with up to 11 predictors would be sufficiently powered to detect a deviation of R^2 from zero based on the obtained sample size (n = 123, α = .05, f^2 = 0.15). Demographic and ED-related variables were therefore selected for the model predicting PTSD symptoms based on their univariate significance and theoretical expectations for their association with PTSD and importance as a confounder in line with guidance (Field, 2013). In addition to bulimia and relapse which were significant in univariate analyses, eight other variables were included based on evidence of their relationship with ED caregiver distress or caregiver PTSD: ED duration (e.g., Anastasiadou et al., 2014), purging (e.g., Sepulveda et al., 2014), relation

to CYP and CYP age (e.g., Carmassi et al., 2021), CYP current support (e.g., Fox et al., 2017), hospitalization (e.g., Irish et al., 2024), CYP gender (e.g., Whitney et al., 2023) and cohabitation (e.g., number of contact hours: Whitney et al., 2007).

Remaining variables (other parent-reported EDs and ED behaviours, formal diagnosis, caregiver support, age and education variables) were not included in the regression due to limited effect sizes and significance in univariate analyses and/or less identified empirical support regarding their relevance. For example, despite an association to PTSD in broader literature, age and education were not significant predictors of ED caregiver PTSD in recent research (Irish et al., 2024) and were therefore not prioritised for inclusion.

Assumption Checks and Robust Methods

The specific checks carried out to check the assumptions of each statistical test are reported in Appendix S. Bootstrapping was applied to statistical tests to account for identified deviations from normality and to reduce the influence of outliers where applicable as well as an additional check to confirm model robustness. It involves repeated sampling of the dataset to generate confidence interval estimates for the correlation coefficient that are more robust against the influence of outliers and deviations from normality. The bias-corrected and accelerated method (BCa; Efron, 1987) was used instead of the 95% confidence interval method due to its ability to correct for both bias and skewness in the data making estimates more reliable especially in the presence of small samples or non-normal data (Davison & Hinkley, 1997).

Chapter Six: Discussion and Critical Evaluation

Summary of Findings

This thesis has sought to deepen understandings of the complex and interconnected experiences of those affected by eating disorders (EDs). It adopted a dual focus on individuals with EDs and parental caregivers, combining diagnostic models with experiential approaches to explore under-researched aspects of their experiences. Two gaps in the literature were identified and examined. To address the absence of nuanced narratives surrounding ED relapse, a qualitative systematic review and thematic synthesis was conducted to examine the experiences of relapse among individuals with EDs (Chapter Two). Second, to address the gaps in our understanding around the mental health of ED caregivers, an empirical study was conducted. The study explored caregiver post-traumatic stress and its relationship with demographics, ED factors and caregiving skills in a sample of parental caregivers to children and young people (CYP) with ED symptoms (Chapter Four). Findings of both papers are summarised below.

The systematic review presented five inter-related themes covering the context, progression and outcomes of ED relapse. Findings reveal that relapse occurred in the context of ambivalence and continued valuing of the ED, a lack of confidence in their own ability to recover outside of professional support as well as destabilising features of recovery and life such as interpersonal difficulties and isolation. Within these narratives, the limitations and potential harms of treatment are also revealed. The social and psychological experience of relapse was varied, but included feelings of failure, shame, and hopelessness as well as a resistance to seeking help. These responses were shaped by individuals' beliefs about what recovery "should" look like and who was deserving of care.

Results of the empirical study showed the majority of parental caregivers in the sample exhibited scores on a validated measure indicative of post-traumatic stress disorder (PTSD). Overall, demographic and ED factors explained a moderate amount of variance in caregiver PTSD symptom severity. Certain CYP demographics (older age, male/non-binary gender, full-time

cohabitation) and illness factors (bulimia, shorter ED duration, not currently in treatment) each had small predictive associations with greater caregiver PTSD symptoms after accounting for the influence of other factors. ED relapse showed the strongest association, with caregivers of CYP experiencing an ED relapse, compared to a first ED episode, reporting more severe PTSD symptoms, independent of the influence of potential confounders such as ED duration, or ongoing treatment. Additionally, PTSD symptoms accounted for a large portion of the variance in caregiver skills, with greater PTSD symptoms associated with lower perceptions of their caregiving skills. These skills, identified as important for supporting their child's recovery, encompassed areas such as self-care, composure, emotional regulation, acceptance, and hope.

Overall Discussion

Inter-Related Experiences and Social Support in EDs

This thesis demonstrates the interdependence of the experiences of individuals with EDs and their social support network. It also highlights the importance of a strong social support system and barriers to establishing this.

The empirical paper illustrates how caregivers' traumatic experiences in relation to their child's ED could impact their own mental health. Caregiver PTSD symptoms were in turn predictive of lower levels of caregiving skills, which research has linked to worse ED outcomes (Salerno et al., 2016). Findings therefore support a complex feedback loop of bidirectional influences within families of those with EDs (Leonidas & Dos Santos, 2014). This possible link between caregiver and child psychopathology requires further research to establish causality but alludes to the underemphasised role of caregiver trauma in interpersonal maintenance models of EDs (Schmidt & Treasure, 2006; Treasure & Schmidt, 2013). Findings illustrate the connections between individuals' recovery, recovery-oriented caregiving and families' recovery, emphasising the utility of relational recovery frameworks (e.g., Wyder et al., 2022) over exclusively individual-focused models.

Existing research has revealed the importance of social support, and the helpful and harmful influences close others can have on ED recovery (Linville et al., 2012; Schmidt & Treasure, 2006; Treasure et al., 2024). The systematic review paper extends this knowledge base to the context of relapse, detailing how social isolation as well as unhelpful responses from others whilst in recovery were considered to contribute to relapse. Unhelpful responses from others ranged from disengaged to critical and over-controlling dynamics in which individuals felt under "surveillance". Findings suggest at a link between caregiving styles of high control and limited intrinsic motivation for recovery. In contrast, close others were often needed to encourage help seeking and a desire to preserve valued relationships could motivate recovery from relapse.

Findings of the systematic review paper also reveal the psychological barriers individuals with EDs face to accessing social support. Individuals demonstrated difficulties showing vulnerability and being assertive, as well as shame, denial and attachment to the ED that drove them to conceal the return of the disorder. Many viewed the ED as an alternative source of support to relying on others, placing significant value in their relationship with it. These findings suggest that individuals' relationships to themselves and to the ED interact with the quality of their social relationships. This highlights the centrality of interpersonal difficulties in the maintenance of the disorder (Fairburn et al., 2003) and, when left unaddressed, their role in relapse. In order to build effective social support, this thesis indicates the need to both attend to the psychological wellbeing and competency of caregivers, as well as the ability of individuals with EDs to seek out and utilise the support of others.

Interpersonal factors are variously targeted in treatment approaches for EDs, such as interpersonal psychotherapy, family-based therapy and cognitive behavioural therapy (Lock & Le Grange, 2005; Zhang et al., 2024). However, whilst health guidance emphasises the importance of engaging and supporting carers of individuals with EDs (National Institute for Health and Care Excellence [NICE], 2017), caregivers widely report feeling excluded from treatment (Fox et al., 2017). Caregivers perceived this to worsen when their child turned 18, with confidentiality and

individual-focused models of care considered to contribute (Crowther et al., 2024; Robinson et al., 2020). Indeed, research on joint interventions with adult patients and caregivers remains limited (Fleming et al., 2021). However, findings of both thesis research papers support the need to better involve caregivers within child and adult ED services.

Together, thesis findings also fundamentally caution against overlooking the psychological difficulties of individuals with EDs and their families, even following improvements in physical and behavioural ED symptoms. This aligns with widespread criticism of services for a focus on ED behaviours and physical symptoms over psychological distress, both in determining thresholds for accessing care and in treatment approaches (Babb et al., 2022; Johns et al., 2019). The systematic review showed how psychological difficulties, such as body image concerns can persist and threaten recovery even after eating behaviours normalise. Similarly, as PTSD persists in the absence of objective threat, caregiver PTSD symptoms may continue despite their child's recovery and improved health.

How healthcare services can hold in mind the psychological wellbeing of both individuals with EDs, and their caregivers requires consideration. It raises questions around whether the needs of caregivers ever conflict with those of individuals with EDs and how this might be navigated. Within clinical guidance on PTSD, exposure to triggers which could worsen symptoms should be avoided (NICE, 2018). Yet how this guidance should be applied to parents who need to confront triggers related to the ED to provide support and engage with their child's treatment is unclear.

The paediatric medical traumatic stress model (Kazak et al., 2006) may hold additional utility in understanding ED caregiver trauma that is ongoing, inherently linked to the experiences and outcomes of another, and influenced by professional involvement. It offers a more nuanced approach to preventing and reducing caregiver traumatic stress alongside their child's treatment which could be applied to EDs. For example, it suggests that during a potentially traumatic event healthcare staff can support caregivers to reframe their appraisals of the event to reduce the likelihood of PTSD. Further exploration is needed to understand how the model could be applied to

the specific traumatic aspects of EDs, such as their child denying they are unwell or their sense of losing their relationship with their child (Hazell et al., 2014) which may be more relational and difficult to pinpoint than medical traumas.

The extent to which parents and caregivers can and should be supported within ED services warrants consideration of a range of factors. These include the adequacy of resources and training to offer the necessary support, the preferences of service users, particularly adults, who may not wish for family involvement, as well as the risk that caregivers' needs are lost in their child's. Indeed, family recovery models emphasise the importance of supporting families to heal independent of their loved one's progress in their recovery (Buckley-Walker et al., 2017). However, guidance recommends minimising the need to move between services (NICE, 2018) and an onward referral for caregivers could risk pathologizing and missing the interdependence of the wellbeing of the system.

Examining Relapse and Illness Trajectories

Findings of this thesis highlight the unmet psychological needs of both individuals with EDs and their caregivers in the context of relapse. Empirical paper findings showing greater PTSD symptoms in caregivers of children experiencing a relapse compared to a first ED episode are further illuminated by qualitative research revealing caregivers' feelings of hopelessness, shame, guilt and isolation upon relapse (Burman et al., 2024). The fact that these responses mirror those of many participants in the systematic review paper allude to shared perceptions of relapse as failure.

At the same time, the systematic review paper highlights the significant variability in experiences encompassed within relapse, such as increased determination to recover, or a desire to get even sicker. This variability may help to explain the relatively modest relationship between relapse and caregiver PTSD in the empirical study, as no two experiences of witnessing a child's relapse will be alike. It may be the beliefs prompted by relapse, such as of personal failure or the ED as uncontrollable, which hold most significance for determining both individual and caregiver outcomes.

Both studies highlight the limitations of the medical model, including clinical markers such as relapse or illness duration, to capture the complexity of individual and systemic experiences of illness. Differentiating the stages of ED illness progression is seen as valuable in guiding assessment and interventions, although models have thus far been restricted to anorexia nervosa (AN) and lacking evidence base (Tomba et al., 2024). Findings support the efforts of large-scale UK research programmes within the 'EDIFY' consortium (Hemmings et al., 2023; Kuehne et al., 2024) that are underway to map ED illness and recovery trajectories more holistically and empirically using longitudinal designs and remote measurement technology. However, the absence of measures addressing individuals' attitudes to the ED and recovery (e.g., their self-efficacy) nor any caregiver factors, both of which this thesis has emphasised as important, will arguably limit the research's overall value.

The systematic review paper suggests that even without more sophisticated stage-oriented ED models and treatments, a tailored approach following ED relapse is important. However, within current practice, caregivers have criticised services for re-applying the same treatments in response to their child's relapse or lack of improvement, with one mother noting "Isn't that the definition of insanity? Doing the same thing over and over again and expecting a different result?" (Burman et al., 2024, p.5). Adaptations and considerations for individuals with EDs who have relapsed or are re-accessing care are lacking within current clinical guidelines (NICE, 2017). This reflects a critical research-practice gap, where advanced trajectory models advocating for dynamic, individualised care remain disconnected from clinical services yet to adapt treatment in the context of relapse or deliver more basic stage-oriented treatment.

The Triangle of Care

This thesis also highlights the relational nature of experiences of EDs with respect to healthcare systems, who, alongside service users and caregivers, form the *triangle of care*. The systematic review paper revealed perceptions of ED services as variously controlling and then distant or abandoning adding to literature around the potential for these dynamics to harm

individuals' recovery (e.g. Babb et al., 2022). Similarly, problems with healthcare services are associated with poorer ED caregiver mental health (Winn et al., 2007) and theorised to delay the development of coping and acceptance skills (Quong & Chen, 2018).

Overall, findings support the importance of conceptualising services as a relational entity, whose actions have both potential for alleviating and exacerbating distress. If the impact of overstretched systems of care on outcomes is overlooked, the intractability of the illness becomes situated solely within the patient or nature of the illness; with the potential harms of this perspective observed in discourse around severe and enduring eating disorders (SEED) and "terminal" EDs (Downs, 2024; Downs et al., 2023).

Understanding the perspectives of healthcare professionals offers valuable context to the experiences of individuals and caregivers examined in this thesis. Professionals working in ED care have told of their limited training in EDs, and experiences of burn-out, powerlessness, anxiety, frustration, and secondary traumatic stress (Hamama-Raz & Mazor, 2023; Reid et al., 2010; Ryu et al., 2022). Inpatient staff reported feeling they were simultaneously traumatising patients through restrictive interventions whilst also being traumatised themselves (Bommen et al., 2023). To cope with distress, ED professionals have been found to adopt protective strategies including blame and avoidance (Graham et al., 2020).

Parallels are therefore apparent among the emotional experiences of professionals and caregivers, and even those with EDs. Findings of the empirical paper in relation to parental caregiver trauma may therefore have broader relevance to professional carers. Research in the field reveals a dynamic in which, in states of anxiety, all parties may struggle for control and power, shift blame, and yet feel powerless, unsupported, and ill-prepared to confront the challenges posed by the ED (e.g. Gustafsson et al., 2021). These dynamics resemble the "emotional triangles" described in Bowen Family Systems Theory (Bowen, 1978) and which have been applied to cases of child and adolescent self-harm, in which transfer of emotion occurs through a worried patient-carer-professional relationship network focused on risk management (Wright et al., 2024). This sense of a

network struggling under the strain of the ED provides a wider context within which to situate findings of the thesis and highlights the need to consider the impact of changes in practice on the functioning and dynamics of the whole triangle of care.

Empowerment Within Clinical Practice and Research

Both studies provide support for a shift away from inpatient care to a model of community care which involves and addresses the needs of families and enables individuals to receive support within their existing social networks and contexts. This shift holds potential to empower the patient-caregiver system and limit dependency on ED services and high levels of control to facilitate change. However, the high rate of probable PTSD in the sample of caregivers in the empirical paper raises concerns over the ability of some caregivers to manage greater responsibility for the care of severely unwell individuals in the community and the risk of this exacerbating their distress if not well managed. A greater emphasis on co-design of services and interventions may enable services to remain sensitive to the complexities of experiences revealed in this thesis whilst also promoting empowerment in patients and carers.

Both thesis papers explore challenges to self-efficacy in recovery for individuals and caregivers and discuss the role of treatment services in shaping these experiences. Current models of healthcare requiring organisational control, accountability and risk management are considered at odds with aims of empowering patients through autonomy and collaborative care (Bee et al., 2015; Fitzsimons & Fuller, 2002). Yet, prioritising autonomy in ED care must also consider the risk of giving power to and collaborating with the disorder. This presents ethical dilemmas which have been central to debates around harm reduction methods and palliative care for individuals who may choose to live with or indeed die from the ED (Birch et al., 2024; Tumba et al., 2023). Indeed, experts in the field have raised concerns that those with EDs may qualify for assisted death under the UK's assisted dying legislation, being deemed terminally ill due to a lack of access to quality care and refusal of treatment before all avenues have been explored (Roff et al., 2025, 28 Jan). Findings of this thesis concur with these concerns, with both research papers highlighting numerous

ways support could be improved before individuals should be labelled "terminal". The systematic review paper also illustrates how experiences of ineffective treatments can contribute to individuals' sense upon relapse that they are beyond help.

Issues of empowerment facing the field were also apparent in the construction of this thesis. The term “relapse” carries an inherent deficit-focus. However, the importance of learning from relapse to strengthen recovery was emphasised in individual narratives within the systematic review theme *Relapse as Instructive* (see Chapter Two). In addition, strictly defining relapse by diagnostic criteria or re-admission risks reinforcing harmful narratives about not being “sick enough”, while broader definitions may overly pathologize setbacks that are common in recovery. While this thesis aims to amplify participants’ lived experiences, the interpretive research process and researcher-imposed labels risk undermining individuals’ autonomy over their narratives. These dilemmas demonstrate how broader ethical and empowerment challenges in the field of EDs span both practice and research.

The empirical study highlights similar tensions between leveraging medical models and empowering individuals. Connecting caregiver distress to the broader PTSD literature provides a theoretical and evidence-based framework that can guide support and training within commissioning frameworks. However, Eagle and Kaminer (2013) argue that the "disorder" label over-pathologizes traumatic stress responses in contexts of ongoing and realistic threat which can have adaptive as well as pathological elements. Diagnostic language also risks placing caregivers in the role of “patient” with potential to amplify fear, blame and helplessness within the triangle of care. For example, the language of PTSD may disempower clinicians who routinely work with ED caregivers as research finds UK mental health clinicians can lack PTSD-specific training and fear exacerbating individuals’ distress (Finch, Ford, Grainger, et al., 2020; Finch, Ford, Lombardo, et al., 2020).

The growth of trauma-informed care (TIC) represents a move from a diagnostic model of trauma to a psychological, trauma-informed approach. It provides a framework for organisational

change that aims to create supportive environments for staff, service users and families, foster positive relationships and reduce the risk of trauma and vicarious trauma through championing principles of safety, trust, choice, collaboration, empowerment, and cultural awareness (Office for Health Improvement & Disparities, 2022). A need for TIC within ED services is supported by evidence from this thesis research of traumatic stress in caregivers, as well as disempowerment and lack of trust in services amongst individuals with EDs who relapse.

Although, the NHS Long Term Plan (2019) outlined a clear commitment to TIC, the extent and nature of its adoption in ED services is unknown. TIC offers a high-level framework rather than a prescriptive protocol for addressing relational and systemic issues identified in this thesis. Practices such as screening for trauma and reducing the use of restraints have been documented (Isobel et al., 2021; Sweeney et al., 2016), however, evaluations of trauma-informed interventions are limited and lack robustness (Lewis et al., 2023). Literature around trauma-informed care for EDs has also largely focused on service users and overlooked caregivers (Brewerton, 2019; Seubert & Virdi, 2024). The need for more research on the implementation and effectiveness of TIC for individual and caregiver outcomes is evident.

Summary of Clinical Implications

Throughout the above discussion the implications of thesis findings for clinical practice have been examined. In summary, this thesis highlights the need to formulate and attend to the psychological difficulties underlying the behaviours of individuals with EDs and their caregivers. This includes unaddressed psychological difficulties, such as self-esteem, that may increase individuals' vulnerability to relapse as well as caregiver PTSD symptoms.

Investment in the sustainability of recovery emerges as crucial given the potential harms of relapse. Improving individuals' social support system is emphasised and may require addressing interpersonal difficulties as well as supporting caregivers' psychological wellbeing and skills. The involvement of caregivers within child and adult ED services is therefore recommended. However,

the extent to which psychological support for caregivers can be provided within ED services needs careful consideration.

Findings indicate the importance of empowering both individuals with EDs and caregivers. However, they suggest the transfer of responsibility for recovery, including the ending of formal support, should take into account factors such as individuals' motivation and self-efficacy and caregivers' mental health. In response to relapse, providing tailored support to individuals and caregivers, which includes tackling unhelpful appraisals of relapse and restoring hope, may also play an important role.

This thesis underscores the importance of services acknowledging their potential for harm. It advocates for the implementation of trauma-informed practices that foster empowerment, trust, and prevent re-traumatization within the triangle of care. The identified interconnectedness within the triangle of care, suggests any changes in practice must take into account the impact on the entire system and its dynamics, and greater emphasis on the co-design of services may facilitate this.

Summary of Theoretical Implications

The ways in which thesis findings contribute to existing theories and concepts have been central to this discussion chapter. In brief, this thesis demonstrates both the value and limitations of diagnostic and medical models in capturing experiences of ED relapse and caregiver traumatic stress. It highlights the need to integrate different theories to reflect the complexity and interconnectedness of experiences. In particular, findings emphasise the importance of relational systemic perspectives that consider the experiences of the individual, caregivers, and professionals and the relationships between them which have the potential for both harm and healing.

Empirical findings demonstrate the value of the diagnostic framework of PTSD in capturing the experiences of many ED caregivers. Beyond the diagnostic framework, there may be value in adapting the paediatric medical model of traumatic stress (Kazak et al., 2006) to the context of ED caregivers. This may help to understand ongoing trauma and its interdependence with their child's

wellbeing and treatment. When considering the interpersonal maintenance factors for EDs (e.g. Schmidt & Treasure, 2006), findings suggest caregiver traumatic stress may be underemphasised.

The nuances and diversity of individuals' experiences of relapse explored in this thesis are difficult to fully capture in any one model. Unlike dominant individual-focused models of relapse, findings stress the need to consider the systemic influences, particularly in relation to the delivery and adequacy of treatment. In highlighting the disparity between individuals' behavioural and psychological recovery, findings also support the development of more complex models of ED illness trajectories that account for this. They call into question how relapse is best conceptualised and emphasise the need for greater clarity.

Critical Evaluation

Value

This thesis aims to contribute meaningfully to a field grappling with increasing rates of EDs, poor treatment outcomes, and high mortality rates yet which is chronically underfunded for research (All-Party Parliamentary Group on Eating Disorders, 2021; NICE, 2017; Solmi et al., 2024; Viljoen et al., 2024). Whilst findings of this thesis are supported by existing literature, they also extend our understanding of two underexplored areas and highlight critical issues requiring further attention in both practice and research.

Diversity of Participants

Diversity in research is acknowledged as vital, particularly in ED research where misinformed stereotypes remain about those affected by EDs (Halbeisen et al., 2022). Recruitment in the empirical study and inclusion criteria in both papers aimed to be broad and encourage diverse voices. Examples include not restricting participants to treatment populations given the majority of those with EDs do not access support, and factors such as weight status, ethnicity, sex and socio-economic status can affect access to care (Hart et al., 2011; Liu et al., 2022; Sonneville & Lipson, 2018) as well as calling for diverse voices through recruitment adverts.

However, in keeping with well-documented research biases (Halbeisen et al., 2022), participants in both studies were mostly white and female, and despite the global scope of the systematic review, almost all studies were conducted in Western, rich and democratic societies. In the empirical paper, small sample sizes undermined the ability to conduct a robust analysis of the influence of ethnicity and non-binary gender. Additionally, neither paper collected information on ED comorbidities despite their prevalence (Herzog & Eddy, 2018). Including data on autism spectrum disorder would have been particularly useful, given evidence of its prevalence and impact on the experiences of both individuals with EDs and their caregivers (Babb et al., 2021; Kinnaird et al., 2021).

The NHS is committed to reducing health inequalities, and cultural considerations are an essential part of delivering trauma-informed care (Brewerton, 2019; NHS, 2019). The lack of diversity within this thesis research has limited its contribution to this important goal and carries the potential for harm by creating knowledge that disproportionately reflects the experiences of over-represented groups. It has therefore been important to emphasise the limits to the transferability of findings and the need for further research that includes more diverse voices. The limitations of current research in capturing intersectionality demonstrated in this thesis also point to the role of psychologists in critically interpreting the evidence base and using clinical judgment and cultural competence to tailor and adapt care to the needs of each individual.

Transdiagnostic Approach

This thesis adopted a transdiagnostic approach to EDs (Fairburn et al., 2003) which offered both advantages and limitations that intersect with issues of diversity and inclusion. A transdiagnostic perspective acknowledges the significant overlap in psychological underpinnings and behaviours across diagnostic categories, as well as the frequent cross-over between diagnoses (Castellini et al., 2013; Gordon et al., 2018). Broadly inclusive transdiagnostic ED research also ensures a longevity of relevance should specific diagnostic categories continue to shift and splinter in the future.

The heterogeneity within the systematic review and empirical study samples offered opportunities to analyse differences among diagnostic groups, which for example, had not been possible in caregiver PTSD research focused on AN (e.g. Irish et al., 2024). However, it also presented challenges. In qualitative research, heterogeneity risks diluting nuance and richness, while in quantitative research, it can reduce statistical power, introduce noise, and create confounders.

To ensure experiences were not overly heterogenous, the systematic review was restricted to diagnoses with substantial theory and evidence around a shared psychopathology (Cooper & Dalle Grave, 2017; Fairburn et al., 2003). Avoidant/restrictive food-intake disorder (ARFID), for instance, was excluded from the systematic review due to distinctions in its psychological features (e.g. absence of weight and shape concerns) which was a main focus of the review. In contrast, the empirical paper did not impose restrictions on ED diagnoses due to the theoretical rationale for caregiver trauma linked to the potential risks of all EDs and evidence that, across diagnoses, caregivers face similar challenges and burdens (Burman et al., 2024; Fisher et al., 2023).

Transdiagnostic approaches also aim to promote equity in research, moving beyond the disproportionate focus on AN (Anastasiadou et al., 2014), despite this not being the most common ED (Solmi et al., 2024). While a specific focus on under-researched EDs has value to address disparities, excluding AN would have significantly reduced participant numbers in both the systematic review and empirical study.

However, a transdiagnostic approach carries the risk of obscuring the experiences of those with other EDs through an over-representation of individuals with AN and their caregivers. This forms part of a wider risk in the field, where models and measures including the cognitive-interpersonal maintenance model (Schmidt & Treasure, 2006) and the Caregiver Skills scale (CASK; Hibbs et al., 2015) were originally developed for AN and have since been applied across diagnoses.

Patient and Public Involvement

Despite significant efforts, the extent of PPI in this research was limited, as outlined in Chapter Five. This represented a missed opportunity to redress power imbalances inherent in research and benefit from the expertise accumulated through the lived experience of caregivers. One important area of consultation would have been the acceptability of diagnostic language around PTSD to describe some caregivers' experiences. This limitation may not be unique to this research as the importance, yet scarcity, of lived experience involvement in ED research has been widely recognised (Musić et al., 2022). Efforts to form a PPI group revealed the lack of established carer steering groups within local NHS child and adolescent ED services, highlighting a further area where involvement of caregivers could be enhanced. Possible barriers to the involvement of caregivers in service and research projects, such as caregiver burden and perceptions of the value of PPI, need investigating. Although the empirical study was constrained by the timeframes of the doctorate programme, it reveals the importance of research funding and timelines that accommodate meaningful PPI and enable the development of crucial research-practice links.

Validity

Each research method carries limitations in its ability to capture the true experiences of individuals. In the empirical study, the online nature of the survey, along with its limited measures and close-ended responses, were intended to reduce participant burden and increase response rates, particularly since the survey included questions from another research project at the University of East Anglia. However, this approach involves a trade-off; in restricting the information participants provide, potential confounders and nuance are overlooked.

Including a measure of depression in the study could have helped determine whether the relationship between PTSD symptoms and caregiver skills was better explained by depressive symptoms. However, PTSD and depression measures are highly correlated (Forkus et al., 2023) and may reflect a shared construct in the enduring aftermath of trauma (O'Donnell et al., 2004), undermining the utility of attempts to disentangle them. Gathering information on the nature and

pattern of the traumatic event(s) experienced by caregivers, and their fit within DSM-5 criteria, could have added helpful context to the analyses and understanding of post-traumatic stress within this population.

For the systematic review, the use of existing participants' data from individual studies ensured there was no additional participant burden. However, it also added a level of removal from and distortion of participants' experiences of relapse through the lens of study authors. Adopting a broad definition of relapse aimed to enhance external validity. However, this likely impacted internal validity as the breadth of experiences included may have made it more challenging to identify consistent patterns in the data.

Thematic synthesis offered a useful methodological framework but lacked an underlying conceptual framework with which to orientate to relapse. Conceptualising relapse in terms of its context, mechanisms and outcomes (as in Pawson and Tilley's (1997) framework), provided a loose structure that helped orientate towards processes related to relapse throughout the review. Decisions regarding what constituted relapse experiences balanced sensitivity and specificity, with implications including, for example, a greater emphasis on proximal contexts and outcomes over more distal ones.

Transparency in both papers aimed to promote confidence in, and valid interpretation of findings, through detailed description of data collection and analytical methods provided in the research chapters, additional methods chapter and appendices.

Scope

It is also important to situate the scope of this thesis in relation to the wider field. This thesis has focused on some of the most challenging outcomes of EDs. However, the majority of those who recover from an ED will not relapse (Solmi et al., 2024). Whilst implications from the review should be applied broadly as it remains difficult to predict who will relapse, the experiences of individuals who relapse should be considered alongside recovery narratives to ensure a more balanced perspective.

Due to the overarching focus of this thesis on the effects of EDs, PTSD symptoms in caregivers have been largely examined in relation to their child's ED and their caregiving role, and therefore other factors influencing post-traumatic stress responses, such as pre-existing vulnerabilities, were beyond the scope of this thesis but remain a significant part of the broader picture. Similarly, whilst caregiver PTSD is an under-researched area, it offers one specific lens on the parental experience and should be interpreted alongside the wealth of literature highlighting the variety of difficulties and even opportunities for growth reported by caregivers (e.g. Fox et al., 2017).

This thesis has highlighted systemic and interpersonal aspects of EDs with particular attention to treatment systems and parental caregivers. Therefore, it has not sought to cover the experiences of other social support groups including partners and siblings impacted by EDs (e.g. Dimitropoulos et al., 2009) nor other important systemic influences on EDs such as culture and social justice issues (Kenny & Lewis, 2023).

Summary of Future Research

Further research should prioritise understanding the experiences of underrepresented groups (e.g. males, people from the global majority, and BED, OSFED and ARFID presentations), making use of proactive recruitment strategies and collaboration across the field to share effective approaches. Embedding meaningful PPI, including co-production efforts, into the research process holds value, but requires significant time and investment in relationship-building, which must be reflected in research timelines and funding. Evaluations of organisational change interventions within ED services, such as trauma-informed approaches to individual and caregiver support, are needed to improve the evidence-base. Multi-wave mixed methods research could provide stronger predictions of relationships between individual and caregiver factors, such as ED relapse and caregiver PTSD, while capturing their shifting nuanced experiences, appraisals and interactions across stages of illness and recovery.

Personal Reflections

Having previously pivoted away from a career in research in favour of clinical roles, constructing this thesis has reminded me what initially drew me to research. The qualitative systematic review felt like a daunting but valuable opportunity to step out of my comfort zone in quantitative research, and one I enjoyed immensely. Learning to navigate methodological decisions where no one approach is "best" and to embrace the complexity of the data and results are some of the difficult but important lessons learnt. Submitting my systematic review for publication and addressing peer review feedback has been invaluable in clarifying my research decisions and methods.

Coming from a background in individual-focused mental health models, examining the role of interpersonal and systemic factors has deeply influenced the way I think about EDs and mental healthcare more broadly. My current work in a child and family unit and day patient ED service has given me direct insight into the relevance of some of this thesis's themes and reinforced the utility of the scientist-practitioner position. I have witnessed areas where services are learning and testing new approaches, as well as all parties striving to do their best in the face of a challenging illness. At times, I've also shared in participants' frustrations with the system and sense of hopelessness about change. My own lived experience, which drew me to this topic, has likely amplified these emotions, whilst also instilling a determination to contribute in some capacity towards improving outcomes for those impacted by EDs. As a clinical psychologist I hope to champion the implications of this research and apply the insights I have gained.

Overall Conclusion

In conclusion, this thesis has illustrated the complex interplay of factors influencing the psychological states and behaviours of individuals with EDs and their caregivers. It has emphasised the interdependencies within the triangle of care that connects individuals, caregivers, and healthcare services and the importance of recovery as a relational, social process. It has brought attention to the need to address caregiver trauma, individuals' underlying psychological difficulties

and the potential harms of treatment, in order to improve ED outcomes. More research is needed to elucidate the shifting and interacting experiences of individuals and caregivers over the course of the illness and evaluate the impact of trauma-informed approaches.

Appendices

Appendix A

Clinical Psychology and Psychotherapy Author Guidelines

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7. Data Availability Statement
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Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry, 159,* 483–486. doi: 10.1176/appi.ajp.159.3.483
Book
Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.
Internet Document
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2. **Units of measurement:** Measurements should be given in SI or SI-derived units. Visit the Bureau International des Poids et Mesures (BIPM) website for more information about SI units.
3. **Numbers:** numbers under 10 are spelled out, except for: measurements with a unit (8mmol/l); age (6 weeks old), or lists with other numbers (11 dogs, 9 cats, 4 gerbils).
4. **Trade Names:** Chemical substances should be referred to by the generic name only. Trade names should not be used. Drugs should be referred to by their generic names. If proprietary drugs have been used in the study, refer to these by their generic name, mentioning the proprietary name and the name and location of the manufacturer in parentheses.

Appendix B

Systematic Review Title Page Information for *Clinical Psychology and Psychotherapy*

Authors

1. Natasha Heal-Cohen, Trainee Clinical Psychologist, Cambridgeshire and Peterborough NHS Foundation Trust/Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, n.heal-cohen@uea.ac.uk. ORCID id: 0009-0005-7498-6508
2. Dr Sophie M. Allan, Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia. ORCID id: 0000-0002-3601-0580
3. Nieve Gauvain, Assistant Psychologist, Norfolk & Norwich University Hospital
4. Rachel Nabirinde, Trainee Clinical Psychologist, Cambridgeshire and Peterborough NHS Foundation Trust / Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia
5. Dr Aaron Burgess, Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia. ORCID id: 0000-0002-3312-5219

Author contributions

1. Natasha Heal-Cohen: Conceptualisation; Investigation; Methodology; Formal Analysis; Visualisation; Project administration; Writing – original draft, review and editing
2. Sophie Allan: Conceptualisation; Supervision; Methodology; Validation; writing - review and editing
3. Nieve Gauvain: Investigation; Formal analysis; Validation; Writing - review and editing
4. Rachel Nabirinde: Investigation
5. Aaron Burgess: Conceptualisation; Supervision; Project administration; Methodology; Validation; Writing - review and editing

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Data, materials and code availability statement: Data sharing is not applicable to this review as no new data were created or analysed. The supplemental file contains the following: database search strategy, non-English language excluded paper, full quality appraisal table, figures illustrating theme generation.

Appendix C

Systematic Review Database Search Strategy

Table C1

MEDLINE Title, Abstract & Keyword Search Strategy

Search Number	Search string
#1	"Eating disorder*" OR anorexi* OR bulimi* OR "binge eating" OR OSFED OR EDNOS
#2	(MM "Feeding and Eating Disorders") OR (MM "Anorexia Nervosa") OR (MM "Binge-Eating Disorder") OR (MM "Bulimia Nervosa")
#3	relaps* OR recur* OR deteriorat* OR worse* OR setback* OR return* OR resum* OR readmission* OR readmit* OR rehospital*
#4	(MH "Recurrence")
#5	"qualitative" OR "mixed method*" OR ethnograph* OR autoethnograph* OR "focus group*" OR "interview*" OR phenomenolog* OR "grounded theory" OR "thematic analysis" OR "interpretive" OR "content analysis" OR "discourse analysis" OR "realist" OR "narrative" OR "textual"
#6	(MH "Qualitative Research+")
#7	#1 OR #2
#8	#3 OR #4
#9	#5 OR #6
#10	#7 AND #8 AND #9

Appendix D

Papers Excluded from Systematic Review Based on Language

1) Cruzat Mandich, C., Díaz Castrillon, F., Kirszman, D., Moncada Arroyo, L., Aspillaga Hesse, C., & Behar Astudillo, R. (2017). Fases de la alianza terapéutica en los trastornos de la conducta alimentaria.

Abstract: The aim of this research is to describe the evolution of the therapeutic alliance and its phases in the treatment of patients with eating disorders. A qualitative, analytical-descriptive design was applied based on the Grounded Theory. The sample included 20 Chilean patients suffering from eating disorders according to DSM-5 criteria. Results indicate that therapeutic alliance evolves within three stages that show the following characteristics: 1. First phase (knowledge): distrust, resistance, need for a diagnosis and false complacence predominate; 2. Second phase (trust and consolidation): deeper items are elaborated, therapeutic relationship improves, motivation for treatment emerges; 3. Third phase (re-signification): management of relapses is made, illness is re-defined and the end of the therapy is visualized. A climate of contention, support and security for patients is emphasized, reproducing a comprehensive and unconditional maternal role.

Appendix E

Quality Appraisal Additional Tables

Table E1

Individual Study Ratings Against CASP Checklist Items

Study Author, Date	1. Was there a clear statement of the aims of the research	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	Overall Quality Rating	Value for Review Rating
Bell et al. (2024)	Yes	Yes	Yes	Somewhat	Somewhat	Can't tell	Can't tell	Somewhat	Yes	Yes	Medium	Medium
Botham (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High	High
Cockell et al. (2004)	Yes	Yes	Yes	Yes	Somewhat	Can't tell	Can't tell	Yes	Somewhat	Yes	Medium	High
De Barbieri (2005)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High	Medium
Federici & Kaplan (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	High	Very high
Keski-Rahkonen & Tozzi (2005)	Yes	Yes	Somewhat	Yes	Yes	Somewhat	Somewhat	Somewhat	Somewhat	Yes	Medium	Medium
Liu et al. (2024)	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Yes	Medium	High
O'Connell (2021)	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Can't tell	Yes	Somewhat	Medium	Very high
Pilote (1998)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Medium	High

Study Author, Date	1. Was there a clear statement of the aims of the research	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	Overall Quality Rating	Value for Review Rating
Seed et al. (2016)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High	Medium
Stockford et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes	High	Medium
Strand et al. (2017)	Yes	Yes	Yes	Yes	Yes	Can't tell	Somewhat	Yes	Yes	Yes	High	Medium
Tibbits (2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High	Very high
Warchol (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	High	Medium
Wasson (2003)	Yes	Yes	Yes	Yes	Somewhat	Somewhat	Somewhat	Yes	Yes	Yes	Medium	High
Wu & Harrison (2019)	Yes	Yes	Yes	Somewhat	Yes	Yes	Yes	Yes	Yes	Yes	High	Medium

Table E2

Quality Appraisal Commentary for Example Paper: Cockell et al (2004)

Criteria	Rating	Supporting Comments
1. Was there a clear statement of the aims of the research?	Yes	Aims explicit alongside their importance and clinical value given risk of relapse soon after discharge
2. Is a qualitative methodology appropriate?	Yes	Justification explicit and appropriate. "The use of qualitative methodology was selected so that a highly detailed account of clients' phenomenological experiences could be obtained and examined."
3. Was the research design appropriate to address the aims of the research?	Yes	Grounded theory appears appropriate to research aims although not explicitly justified. Justified use of the EDE to assess change in diagnosis and followed up clients at 6 months and why qualitative methodology was used overall.
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Appropriate and justified as to why following participants who have just finished treatment is best as this is highest period of relapse. Clear who was invited and who ended up participating although no reason given as to why they did not participate.
5. Was the data collected in a way that addressed the research issue?	Somewhat	Some good detail on data collection process, including broad areas for interview questions and how and why this shifted in later interviews to become more specific. More detail on what this looked like could be given and there is no mention of piloting or reviewing the pre-determined questions. The setting for the interviews is also unclear and interview length of half an hour appears short for the broad focus and is not justified.
6. Has the relationship between researcher and participants been	Can't tell	No explicit mention of reflexivity and researchers own subjectivity, assumptions or theoretical stance.

adequately considered?		
7. Have ethical issues been taken into consideration?	Can't tell	Stated that informed consent was obtained. However, no mention of ethical approval or debrief or limiting harm
8. Was the data analysis sufficiently rigorous?	Yes	Good amount of detail on method. Follows an explicit method. Sufficient data presented to support findings and clear how results are laid out to describe categories and their components with quotes as examples. Also clear how outlying ideas were incorporated. Multiple independent reviewers used but no critical examination of the researcher's role in the analysis conducted.
9. Is there a clear statement of findings?	Somewhat	Clear findings discussed in relation to research question and literature. However, credibility of findings not discussed.
10. How valuable is the research?	Yes	Clear evidence gap identified, adds to existing findings in a new area (recently discharged patients) and recommendations for practice made as well as suggestions for further research and how these would help with generalisability.
Overall Quality	Medium	
Value for the Review	High	Open-ended approach facilitates access to participants' experiences. Significant discussion of factors associated with relapse including signs of relapse (e.g. negative thoughts, reluctance to choose recovery behaviours). Experiences of participants who relapsed sometimes not clearly separated.

Appendix F

Illustrations of Theme Generation

Figure F1

Illustrative Example of the Process used to Map Codes to Themes for One Analytical Theme

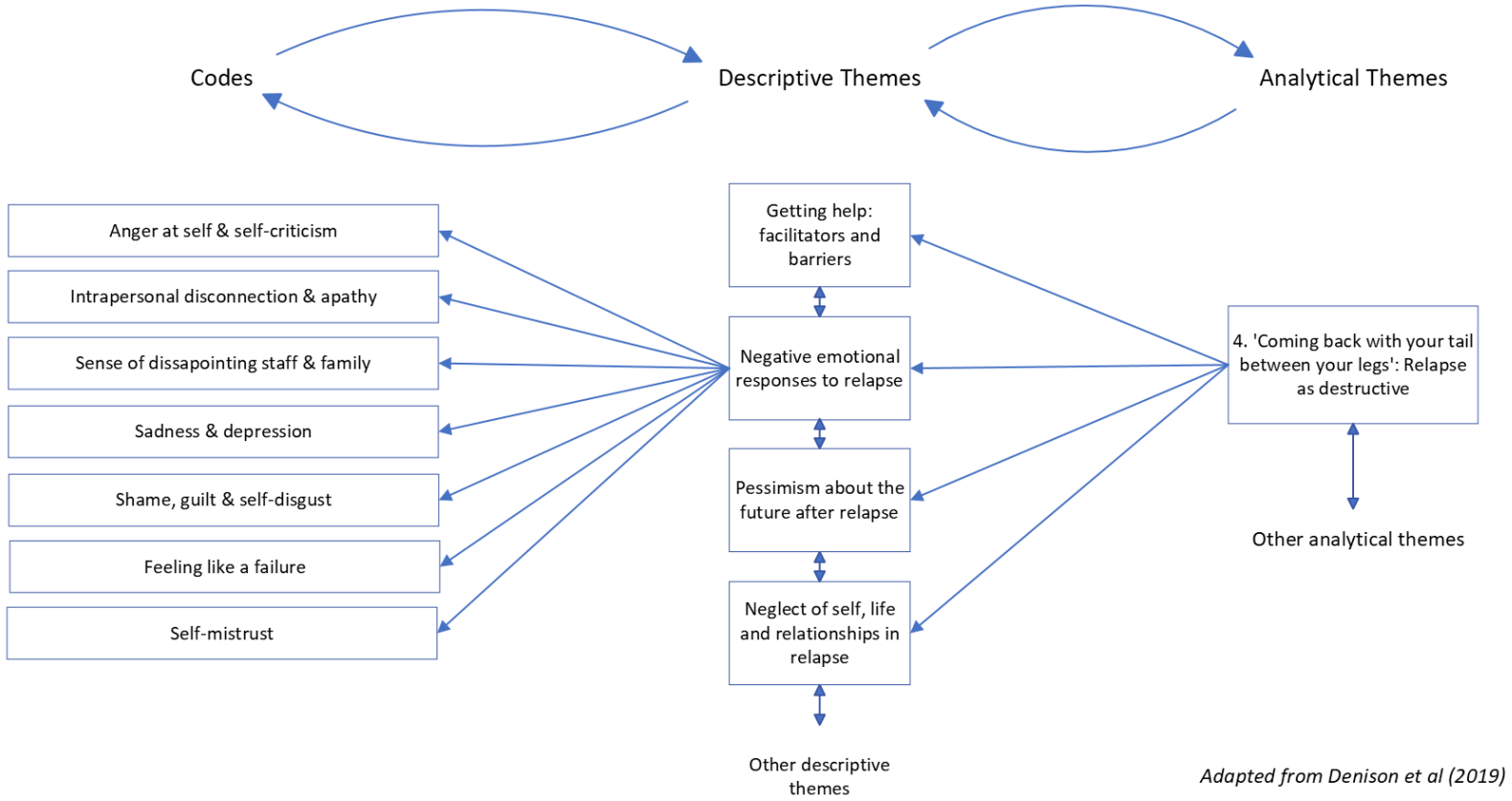
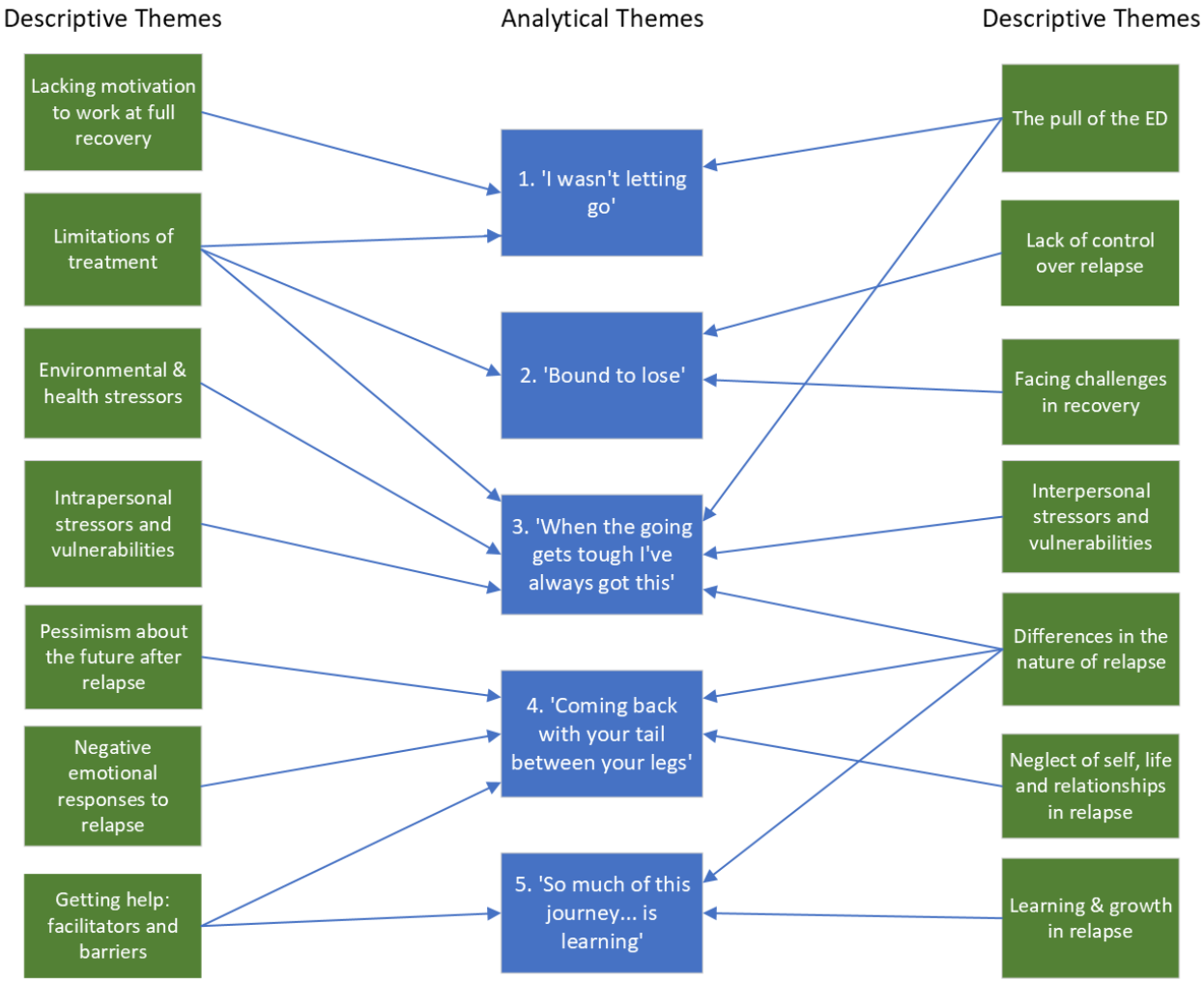


Figure F2

Diagrammatic Representation of Mapping Between Descriptive and Analytical Themes



Appendix G

European Eating Disorders Review Author Guidelines

Note: The following text has been copied from: https://onlinelibrary-wiley-com.uea.idm.oclc.org/page/journal/10990968/homepage/forauthors.html#submission

1. SUBMISSION

New submissions should be made via the Research Exchange submission portal https://wiley.atyponrex.com/journal/ERV. Should your manuscript proceed to the revision stage, you will be directed to make your revisions via the same submission portal. You may check the status of your submission at anytime by logging on to submission.wiley.com and clicking the "My Submissions" button. For technical help with the submission system, please review our FAQs or contact submissionhelp@wiley.com.

Data Protection

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more here ...

Preprint Policy

European Eating Disorders Review will consider for review articles previously available as preprints. Authors may also post the submitted version of a manuscript to a preprint server at any time. Authors are requested to update any pre-publication versions with a link to the final published article.

2. AIMS AND SCOPE

European Eating Disorders Review provides an international forum for disseminating cutting-edge theoretical and empirical research that significantly advances understanding of the relationship between Eating Disorders and Abnormal Eating/Weight conditions and well-being in humans.

European Eating Disorders Review publishes authoritative and accessible articles, from all over the world, which review or report original research that has implications for the treatment and care of people with eating disorders and obesity, and articles which report innovations and experience in the clinical management of eating disorders. The journal focuses on implications for best practice in diagnosis and treatment. The journal also provides a forum for discussion of the causes and prevention of eating disorders, and related health policy.

Authors may submit original theoretical systematic reviews, methodological, or empirical research articles (5000 words or less) brief reports (2,500 words or less) and commentaries (2,000 words or less). The journal also publishes invited conceptual reviews from leading worldwide researchers in the field of Eating Disorders and/or Obesity. The aims of the journal are to offer a channel of communication between researchers, practitioners, administrators and policymakers who need to report and understand developments in the field of eating disorders.

The journal

- Reports on useful research and experience related to the treatment and prevention of eating disorders in primary care and hospital settings, with special attention to therapy oriented translational research, high quality reviews, clinical trials and pilot innovative therapy approaches.
- Provides information about 'good practice' and systematic reviews.
- Offers a forum for new thinking about the nature, incidence, diagnosis and clinical management of eating disorders (namely anorexia nervosa, bulimia nervosa, binge eating disorders, OSFED and other abnormal eating or feeding behaviors associated with childhood and obesity.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Research articles reporting new research of relevance as set out in the aims and scope should not normally exceed 5000 words (excluding abstract, references, tables or figures), with no more than five tables or illustrations. They should conform to the conventional layout: title page, Abstract, Introduction and Aims, Method, Results, Discussion, Acknowledgements and References. Each of these elements should start on a new page.
Word Limit: 5,000 (excluding abstract, references, tables or figures).
Abstract: 200 words, structured
References: up to 60.

Review articles: Systematic and meta-analytic review papers are welcomed if they critically review the available literature in a topic than will enhance clinical practice. Articles should have clear focus and enough number of studies should be available for a substantive review paper. Studies that only describe or list previous studies without a critical overview of the literature will not be considered.
Word Limit: 5,000 (excluding abstract, references, tables or figures).
Abstract: 200 words.
References: up to 100.
Figures/Tables: 5 maximum, but should be appropriate to the material covered. Additional tables might be included as supplementary information, if needed. Review articles must follow the PRISMAGuidelines. Authors may want to have a look at the review check lists that reviewers when assessing review articles.

Brief reports should concisely present the essential findings of the author's work and be compromised of the following sections: Abstract, Introduction and Aims, Method, Results, Discussion, and References. Tables and/or figures should be kept to a minimum, in number and size, and only deal with key findings. In some cases authors may be asked to prepare a version of the manuscript with extra material to be included in the online version of the review (as supplementary files). Submissions in this category should not normally exceed 2500 words in length.

Brief reports bring with them a whole host of benefits including: quick and easy submission, administration centralised and reduced and significant decrease in peer review times, first publication priority (this type of manuscript will be published in the next available issue of the journal).

Commentary articles are short, evidence-based opinion articles from one or more people (who may agree or disagree) on a published work, current understanding/status of an area, or how practice should be undertaken. Commentaries are invited by the Editors or open submission. They should not normally exceed 2,000 words (excluding abstract and references), with no tables or illustrations.

Word Limit: 2,000 (excluding abstract, references).
Abstract: 200 words, unstructured
References: up to 5
Figures/Tables: none
Case Reports The journal does not accept case reports for publication. Authors of case reports are encouraged to submit to the Wiley Open Access journals listed below:

• *Clinical Case Reports* which aims to directly improve health outcomes by identifying and disseminating examples of best clinical practice
• *Mental Health Science* which brings various fields together to address the common, pressing, and growing crisis of mental health

4. FREE FORMAT SUBMISSION
European Eating Disorders Review now offers Free Format submission for a simplified and streamlined submission process.

Before you submit, you will need:

- Your manuscript: this should be an editable file including text, figures, and tables, or separate files – whichever you prefer. All required sections should be contained in your manuscript, including abstract, introduction, methods, results, conclusions and highlights. Figures and tables should have legends. Figures should be uploaded in the highest resolution possible. References may be submitted in any style or format, as long as it is consistent throughout the manuscript. Supporting information should be submitted in separate files. If the manuscript, figures or tables are difficult for you to read, they will also be difficult for the editors and reviewers, and the editorial office will send it back to you for revision. Your manuscript may also be sent back to you for revision if the quality of English language is poor.
- An ORCID ID, freely available at https://orcid.org. (Why is this important? Your article, if accepted and published, will be attached to your ORCID profile. Institutions and funders are increasingly requiring authors to have ORCID IDs.)
- The title page of the manuscript, including:
    - Your co-author details, including affiliation and email address.
    - Statements relating to our ethics and integrity policies, which may include any of the following:
        - data availability statement
        - funding statement
        - conflict of interest disclosure
        - ethics approval statement
        - patient consent statement
        - permission to reproduce material from other sources
        - clinical trial registration

Important: the journal operates a double-anonymous peer review policy. Please anonymise your manuscript and supply a separate title page file.

To submit, login at https://wiley.atyponrex.com/journal/ERV and create a new submission. Follow the submission steps as required and submit the manuscript.

Cover Letters
Cover letters are not mandatory; however, they may be supplied at the author's discretion.

Abstract
All manuscripts should contain an abstract of up to 200 words. An **abstract** is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work. It must be structured, under the sub-headings: Objective; Method; Results; Conclusions.

Graphical TOC/Abstract
The journal's table of contents/abstract will be presented in graphical form with a brief abstract. The table of contents entry must include the article title, the authors' names (with the corresponding author indicated by an asterisk), no more than 80 words or 3 sentences of text summarizing the key findings presented in the paper and a figure that best represents the scope of the paper.
Table of contents entries should be submitted as 'Supplementary material for review' during the initial manuscript submission process.
The image supplied should fit within the dimensions of 50mm x 60mm and be fully legible at this size.

Guidelines for Table of Contents Graphics
- Concepts illustrated in graphical material must clearly fit with the research discussed in the accompanying text.
- Images featuring depictions or representations of people must not contain any form of objectification, sexualization, stereotyping, or discrimination. We also ask authors to consider community diversity in images containing multiple depictions or representations of people.
- Inappropriate use, representation, or depiction of religious figures or imagery, and iconography should be avoided.
- Use of elements of mythology, legends, and folklore might be acceptable and will be decided on a case-by-case basis. However, these images must comply with the guidelines on human participants when they are present.
- Generally, authors should consider any sensitivities when using images of objects that might have cultural significance or may be inappropriate in the context (for example, religious texts, historical events, and depictions of people).
- Legal requirements:
    - All necessary copyright permission for the reproduction of the graphical elements used in visuals must be obtained prior to publication.
    - Clearance must be obtained from identifiable people before using their image on graphics and such clearance must specify that it will be used on the table of contents. Use within text does not require such clearance unless it discloses sensitive personal information such as medical information. In all situations involving disclosure of such personal information, specific permission must be obtained and images of individuals should not be used in a false manner.

Graphics that do not adhere to these guidelines will be recommended for revision or will not be accepted for publication.

Highlights
Highlights are mandatory for European Eating Disorders Review. These should appear as three bullet points that convey the core findings of the article.

Keywords
Include up to five **keywords** that describe your paper for indexing purposes.

Tables
Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but

comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends
Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

Figures
Although authors are encouraged to send the highest-quality figures possible, for peer-review purposes, a wide variety of formats, sizes, and resolutions are accepted. Click here for the post-acceptance figure requirements.

Additional Files
Appendices
Appendices will be published after the references. For submission they should be supplied as separate files but referred to in the text.

Supporting Information
Supporting information is information that is not essential to the article, but provides greater depth and background. It is hosted online and appears without editing or typesetting. It may include tables, figures, videos, datasets, etc. Click here for Wiley's FAQs on supporting information.

Note: if data, scripts, or other artefacts used to generate the analyses presented in the paper are available via a publicly available data repository, authors should include a reference to the location of the material within their paper.

If a manuscript describes a new approach and/or technological approach, authors are encouraged to include a small demo video – no more than 60 seconds long.

Appendix H

Empirical Paper Title Page Information for *European Eating Disorders Review*

Authors

1. Natasha Heal-Cohen, Trainee Clinical Psychologist, Cambridgeshire and Peterborough NHS Foundation Trust/Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, n.heal-cohen@uea.ac.uk. ORCID id: 0009-0005-7498-6508
2. Rachel Nabirinde, Trainee Clinical Psychologist, Cambridgeshire and Peterborough NHS Foundation Trust / Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia
3. Dr Aaron Burgess, Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia. ORCID id: 0000-0002-3312-5219

Author contributions: Natasha Heal-Cohen: Conceptualisation; Investigation; Methodology; Formal Analysis; Visualisation; Project administration; Writing – original draft, review and editing, Aaron Burgess: Conceptualisation; Supervision; Project administration; Methodology; Writing - review and editing, Rachel Nabirinde: Conceptualisation; Project administration; Methodology Investigation

Data availability statement: The anonymous data that support the findings of this study will be made openly available at https://research-portal.uea.ac.uk/en/datasets/ at the point of acceptance.

Ethics approval statement: Ethical approval was obtained from UEA Faculty of Medicine and Health Sciences Research Ethics Committee (ETH2324-1470).

Consent statement: Participants provided consent for the publication of study findings based upon the anonymous data they provided.

Funding statement: This research was completed as part of a Doctorate in Clinical Psychology funded by NHS Health Education England.

Conflict of Interest Statement: The authors declare no conflict of interest.

Appendix I

Ethical Approval Letter

University of East Anglia
Norwich Research Park
Norwich. NR4 7TJ

Email: ethicsmonitor@uea.ac.uk
Web: www.uea.ac.uk

Study title: Caregiver trauma responses to children or young people with eating disorders

Application ID: ETH2324-1470 (significant amendments)

Dear Rachel,

The amendments to your study were considered on 9th February 2024 by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee).

The decision is: **approved**.

You are therefore able to start your project subject to any other necessary approvals being given.

If your study involves NHS staff and facilities, you will require Health Research Authority (HRA) governance approval before you can start this project (even though you did not require NHS-REC ethics approval). Please consult the HRA webpage about the application required, which is submitted through the IRAS system.

This approval will expire on **1st October 2024**.

Please note that your project is granted ethics approval only for the length of time identified above. Any extension to a project must obtain ethics approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) before continuing.

It is a requirement of this ethics approval that you should report any adverse events which occur during your project to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) as soon as possible. An adverse event is one which was not anticipated in the research design, and which could potentially cause risk or harm to the participants or the researcher, or which reveals potential risks in the treatment under evaluation. For research involving animals, it may be the unintended death of an animal after trapping or carrying out a procedure.

Any amendments to your submitted project in terms of design, sample, data collection, focus etc. should be notified to the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) in advance to ensure ethical compliance. If the amendments are substantial a new application may be required.

Approval by the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee) should not be taken as evidence that your study is compliant with the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018. If you need guidance on how to make your study UK GDPR compliant, please contact the UEA Data Protection Officer (dataprotection@uea.ac.uk).

Please can you send your report once your project is completed to the FMH S-REC (fmh.ethics@uea.ac.uk).

I would like to wish you every success with your project.

On behalf of the FMH S-REC (Faculty of Medicine and Health Sciences Research Ethics Subcommittee)

Yours sincerely,

Dr Paul Linsley

Appendix J

Research Recruitment Advert

Figure G1
Recruitment Advert

Appendix K

Emails to Gatekeepers

Version 2: November 2023

<u>For organisations who have expressed initial interest</u>

Good afternoon,

Following your initial interest in assisting with recruitment for our eating disorder caregiver research study we are now writing to give you further information about the study and how you can help with recruitment.

Study summary: Caregivers who are interested and eligible to take part will complete an anonymous 15–20-minute online survey by following a link from our recruitment advert. The survey involves questions about the caregiver, their child and their eating difficulties and support, as well as their emotions, thoughts, attitudes and behaviours towards their child's eating disorder. Further information can be found in the attached document, which is the participant information sheet. The study has been approved by the Faculty of Medicine and Health Sciences Research Ethics Committee at University of East Anglia.

Your role: We expect to begin recruiting participants in January/February 2024. At this time, we would ask you to share our research advert via your mail list, website or other communication channels of your preference so that your audience/members are made aware of our research and are given the opportunity to take part.

If you are still happy to support the research as outlined above, please let us know by responding to this email and we will share our research advert with you in due course.

If you have any questions please do not hesitate to contact us. We look forward to hearing from you.

Kind regards,
Natasha Heal-Cohen & Rachel Nabirinde
Primary Researchers

For organisations who are yet to express initial interest

Good afternoon,

We are writing to you from the University of East Anglia on behalf of a research project seeking to understand the experiences of caregivers to a child/young person with an eating disorder. We would like to follow up with you after an email we sent a few months ago describing our research project and requesting your initial interest.

We have now received ethical approval from the Faculty of Medicine and Health Sciences Research Ethics Committee at University of East Anglia for our research study and would like to share more details with you that might help you consider supporting our recruitment process.

Your role: We would like to ask you to share our research advert via your mail list, website or other communication channels of your preference so that your audience/members are made aware of our research and are given the opportunity to take part. Reaching a diverse group of caregivers to those with a range of eating disorders can be difficult and we would value your assistance.

By following a link from the recruitment advert, caregivers who are interested and eligible to take part would complete an anonymous 15–20-minute online survey. The survey will ask for information about the caregiver, their child, and their child's eating difficulties and support, as well as their emotions, thoughts, attitudes, and behaviours toward their child's eating disorder. Further information can be found in the participant information form attached to this email.

We expect to begin recruiting participants in January/February 2024. If you are willing to share our research advert, please respond to this email and we will send the research advert to you in due course.

If you have any questions please do not hesitate to contact us. We look forward to hearing from you.

Kind regards,
Rachel Nabirinde & Natasha Heal-Cohen
Primary Researchers

Appendix L

Examples of Study Social Media Recruitment Posts

Are you a caregiver to a child or young person with eating-related difficulties? We are looking for caregivers to take part in an online research survey about caregiver experiences with their children with eating disorders. For your participation in our research, we will make a £2 donation to an eating disorder charity. @UEAResearch #eatingdisorders #caregivers #mentalhealth #anorexia #bulimia #parents. To access the survey please click here [link to survey]

Are you a father to a child or young person with eating-related difficulties? We are looking for caregivers to take part in an online research survey about caregiver experiences with their children with eating disorders. For your participation in our research, we will make a £2 donation to an eating disorder charity. @UEAResearch #eatingdisorders #caregivers #mentalhealth #anorexia #bulimia #fathers. To access the survey please click here [link to survey]

Do you identify as an ethnic minority, and are a caregiver to a child or young person with eating-related difficulties? We are looking for caregivers to take part in an online research survey about caregiver experiences with their children with eating disorders. For your participation in our research, we will make a £2 donation to an eating disorder charity. @UEAResearch #eatingdisorders #caregivers #mentalhealth #anorexia #bulimia #parents. To access the survey please click here [link to survey]

Appendix M

Demographic and ED-related Survey Questions

Q1) What is your age?

Drop down menu (18 to 120)

Q2) What is your ethnicity?

a) Black/African/Caribbean/Black British
b) Asian/Asian British
c) White
d) Mixed/Multiple ethnic groups
e) Other ethnic group

Q3)
(if 2c) Choose one option that best describes your ethnic group or background

Welsh/English/Scottish/Northern Irish/British
Irish
Gypsy or Irish Traveller
Any other White background

Q4)
(if 2d) Choose one option that best describes your ethnic group or background

White and Black Caribbean
White and Black African
White and Asian
Any other Mixed/Multiple ethnic background

Q5)
(if 2b) Choose one option that best describes your ethnic group or background

Indian
Pakistani
Bangladeshi
Chinese
Any other Asian background

Q6)
(if 2a) Choose one option that best describes your ethnic group or background

African
Caribbean
Any other Black/African/Caribbean background

Q7)
(if 2e) Choose one option that best describes your ethnic group or background

Arab
Any other ethnic group

Q8) What is your gender identity?

Male
Female
Transgender
Gender neutral
Non-binary
Agender

Pangender
Genderqueer
Two-spirit
Third gender
Other

Q9) If you selected Other, please specify:

Q10) What is your level of education?

Highschool
Diploma
Bachelors degree
Masters
PhD
Other

Q11) If you selected Other, please specify:

Q12) What is your relationship to the child or young person with eating-related difficulties?

Mother
Father
Grandmother
Grandfather
Guardian
Stepmother
Stepfather
Other

Q13) If you selected Other, please specify:

Q14) How often does your child live at home with you?

All of the time
Most of the time (e.g. 5 days a week)
Some of the time (e.g. holidays, weekends)
None of the time

Q15) If you selected Other, please specify:

Q16) Have you ever experienced an eating disorder yourself?

Yes
No

Q17) Have you received any support in relation to your child's eating-related difficulties? Please select all that apply

Individual therapy
Family-based therapy
Support group
Support from helplines
Self-help resources (books)
Support from friends and/or family
Other
No support

Q18) If you selected Other, please specify:

Q19) What is your child's age?

Drop down menu (5 to 25)

Q20) What is their gender identity?

Male
Female
Transgender
Gender neutral
Non-binary
Agender
Pangender
Genderqueer
Two-spirit
Third gender
Other

Q21) If you selected Other, please specify:

Q22) In which year did your child develop their eating disorder?

Drop down menu (1998 to 2023)

Q23) To the best of your knowledge, which month of that year did they develop the eating disorder?

Drop down menu (Jan to Dec)

Q24) Does your child have a diagnosis of an eating disorder?

Yes
No

Q25) Which eating disorder(s) have they been diagnosed with or if they do not have a diagnosis, which do you think most applies to them, please select one or more:

Anorexia Nervosa
Bulimia Nervosa
Binge-eating disorder
Other specified feeding and eating disorder
Avoidant and Restrictive food intake disorder
Other
None of the above/unsure

Q26) If you selected Other, please specify:

Q27) Has your child experienced any of the following, currently or in the past? Please check all that apply.

Severely underweight
Restricting food intake
Excessive exercising
Vomiting after meals
Using laxatives or medicines to control their weight
Missing menstrual periods for three months or more
Eating large amounts of food in one sitting (Bingeing)
Eating in secret
Stealing food/money in order to binge
Severely overweight
None of the above/ unsure

Q28) Which best describes your child's current eating difficulties

First episode (this is the first time they have experienced eating-related difficulties)
Relapse (they experienced a period of improvement before their difficulties worsened again)

Q29) Which best describes your child's current access to support for their eating disorder

Have not yet approached support
Awaiting treatment
Treatment ongoing
Support has ended
Other

Q30) If you selected Other, please specify:

Q31) Has your child experienced any of the following medical treatment? Please check all that apply.

Hospitalised in a mental health/eating disorder unit
Hospitalised in a general hospital
A feeding tube
None of the above

Q32) Is your child currently in hospital?

Yes
No

Appendix N

Posttraumatic Stress Disorder Checklist 5 (PCL-5)

PCL-5

Instructions: Below is a list of problems that people sometimes have in response to a very stressful experience. Please read each problem carefully and then circle one of the numbers to the right to indicate how much you have been bothered by that problem in the past month.

In the past month, how much were you bothered by:	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Repeated, disturbing, and unwanted memories of the stressful experience?	0	1	2	3	4
2. Repeated, disturbing dreams of the stressful experience?	0	1	2	3	4
3. Suddenly feeling or acting as if the stressful experience were actually happening again (as if you were actually back there reliving it)?	0	1	2	3	4
4. Feeling very upset when something reminded you of the stressful experience?	0	1	2	3	4
5. Having strong physical reactions when something reminded you of the stressful experience (for example, heart pounding, trouble breathing, sweating)?	0	1	2	3	4
6. Avoiding memories, thoughts, or feelings related to the stressful experience?	0	1	2	3	4
7. Avoiding external reminders of the stressful experience (for example, people, places, conversations, activities, objects, or situations)?	0	1	2	3	4
8. Trouble remembering important parts of the stressful experience?	0	1	2	3	4
9. Having strong negative beliefs about yourself, other people, or the world (for example, having thoughts such as: I am bad, there is something seriously wrong with me, no one can be trusted, the world is completely dangerous)?	0	1	2	3	4
10. Blaming yourself or someone else for the stressful experience or what happened after it?	0	1	2	3	4
11. Having strong negative feelings such as fear, horror, anger, guilt, or shame?	0	1	2	3	4
12. Loss of interest in activities that you used to enjoy?	0	1	2	3	4
13. Feeling distant or cut off from other people?	0	1	2	3	4
14. Trouble experiencing positive feelings (for example, being unable to feel happiness or have loving feelings for people close to you)?	0	1	2	3	4
15. Irritable behavior, angry outbursts, or acting aggressively?	0	1	2	3	4
16. Taking too many risks or doing things that could cause you harm?	0	1	2	3	4
17. Being "superalert" or watchful or on guard?	0	1	2	3	4
18. Feeling jumpy or easily startled?	0	1	2	3	4
19. Having difficulty concentrating?	0	1	2	3	4
20. Trouble falling or staying asleep?	0	1	2	3	4

Retrieved from: *www.ptsd.va.gov (Version date 11 April 2018)*

Appendix O

The Caregiver Skills (CASK) Scale

The Caregiver Skills (The CASK)

We are interested in your thoughts on some areas of caregiving. Please be as frank and honest as you can.

The statements below describe situations that are commonly associated with eating disorders. For each situation please rate how confident you are that you could respond in the way described.

Rate your degree of confidence from 0 to 100 using the scale given below.

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

For example, a rating of 100 means that you are absolutely, 100% confident that you could perform the activity whenever you wished. For each scenario, please circle the number that you feel best reflects your confidence. You can choose any score between 0 and 100 (10, 20, 30, etc.)

Please make all your ratings based on what you could do THIS WEEK as the person you are NOW rather than on the person you used to be or the person you would like to be. This is very important.

If you feel some of the questions aren't applicable to you, try to rate how confident you would be should the situation arise.

The blank spaces refer to your loved one with an eating disorder. You do not need to fill in the gaps.

Thank you for taking the time to complete this questionnaire.

How confident are you that you can…….

1. …Keep doing the things that you enjoy whilst caring for _____?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

2. …Discuss and explain your own feelings about the eating disorder openly with _____?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

3. ….. Discuss the eating disorder openly with *all* other immediate family members involved?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

4. ….. Be understanding towards _____, even when you are angry or frustrated with them?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

5. ….. Avoid getting drawn into arguments about the eating disorder with _____?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

6. ….. Be calm when dealing with difficult behaviours associated with the eating disorder?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

7. ….. Take some time for yourself when you need a break?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

8. ….. Talk and listen with _____ about difficult and complex emotions that s/he is feeling?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

9. ….Be reassured by even the smallest signs of improvement?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

10. ….. Keep hope that _____ will recover?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

11. ….. Step back and trust that _____ will cope with day to day challenges by themselves?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

12. …Agree boundaries, plans or household rules in collaboration with _____?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

13. …Uphold boundaries/rules consistently in a compassionate tone, even when _____ is arguing with you?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

14. … Control the urge to argue against the eating disorder behaviours, even though you believe your argument to be logical?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

15. ….. Have pleasant verbal interactions with _____, not related to the eating disorder?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

16. ….. Control the urge to keep enquiring or checking on _____ 's behaviour even when you are very worried?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

17. ….. Praise change or attempts at change by _____ even if the effects/results were less than you were hoping for?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

18. ….. Resist constantly reminding/asking about agreed behaviour targets?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

19. ….. Avoid getting caught in repetitive conversations with _____about food and eating?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

20. ….. Keep your eye on _____'s overall progress/the bigger picture?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

21. ….. Resist relying solely on weight as a marker of how s/he is doing?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

22. …..Separate _____ as a person from the illness?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

23. …. Reflect and understand the effect of your behaviour on _____?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

24. ….. Accept that the eating disorder is not your fault?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

25. ….. Accept that the one cause or trigger for the eating disorder may not be the solution to recovery?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

26. …Find time to spend with other members of the family?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

27. … Manage your anxiety levels so that you don't feel overwhelmed?

0 10 20 30 40 50 60 70 80 90 100
Almost never Occasionally Frequently Almost Always

Thank you for completing this questionnaire.
We greatly appreciate your help.

Retrieved from: https://thenewmaudsleyapproach.co.uk/pdfs/CASKScale.pdf (May 2023)

Appendix P

Participant Information

Version 2: October 2023
Participant information sheet

Understanding caregiver trauma responses to children/young people (CYP) with eating disorders

We would like to invite you to take part in our study looking to understand the experience of caregivers of CYP with an eating disorder. Thank you for your interest in this research. Taking part in this study is entirely optional and so, before you decide whether you want to take part, we will explain why this research is being carried out.

Please read the following information carefully before deciding whether you would like to be a part of this study. If you have any questions before taking part, please feel free to get in contact using our details below.

What is the purpose of the research?
Some research has found that supporting a CYP with an eating disorder can be traumatic. However, research is limited in this area and the current study seeks to address this. We are interested in understanding how caring for a CYP with an eating disorder affects caregivers. We would also like to find out what aspects influence the distress caregivers may experience. In particular, we are interested in the nature of the child's illness, the caregiver's understanding of eating disorders, and how able they feel to support their child. We hope that this research will help us to understand how best caregivers can be supported.

This research is being carried out as part of two Doctorate theses in Clinical Psychology, at the University of East Anglia (UEA).

Who is being invited to take part?
We are interested in recruiting individuals who satisfy all of the criteria below:

You are a parent or guardian caregiver to a child/young person who is currently experiencing eating-related difficulties or has a diagnosed eating disorder
Your child is 5-25yrs
You are 18 or over
You have a substantial caring responsibility for your child (Substantial care = you consider yourself someone who offers practical and/or emotional support in relation to their eating disorder)
You live in the United Kingdom
You have the ability to comfortably read, comprehend and respond to written information presented in English

What would taking part involve?
Once agreeing to take part, you will be asked to complete an online survey which involves a small number of questionnaires. You can use your phone, tablet, or computer to complete these. You will have as much time as you need to complete these, but we predict it may take around 15-20 minutes to complete all questionnaires.

The questionnaires will ask you for information about: yourself, your child and their eating difficulties and support, as well as your emotions, thoughts, attitudes and behaviours towards your child's eating disorder.

There are no right or wrong answers and so we would appreciate your openness when completing the questionnaires.

Do I have to take part?
No, your participation is entirely voluntary. After you have read this information sheet, you will be asked whether you give your consent to participate in our study.

Can I stop taking part if I change my mind?
Yes. If for any reason you no longer want to continue with the survey, then you can exit from the survey at any time. There will be no consequence of you doing so and you will not need to give any reason as to why. Any answers already given will not be saved or submitted. However, once you have completed the survey, you will not be able to withdraw your responses as all responses are anonymous and we will not collect any personally identifiable information about you.

What are the possible disadvantages or risks of taking part?
This research will ask you questions about the topics described above. It is therefore possible that these could cause you distress either during or after completing the survey. If you become distressed during the study, you can exit the study at any time or come back to it later. You can also consider contacting one of the organizations provided below (you will be reminded of these on completion of the survey), for further support for you and/or your child.

1. *BEAT Eating Disorders*
- Helpline (open 365 days a year from 12pm-12am during weekdays, and 4pm-12am on weekends and bank holidays):
- 0808 801 0677 (England), 0808 801 0432 (Scotland),
- 0808 801 0433 (Wales), 0808 801 0434 (Northern Ireland).
- https://www.beateatingdisorders.org.uk – for resources, and support chat rooms

2. Samaritans are available 24 hours a day to give support to anyone who is struggling on 116 123 or via email jo@samaritans.org. More information is also available on their website https://www.samaritans.org/
3. FEAST - A global support and education community for families affected by eating disorders. https://www.feast-ed.org/
4. NHS - 111
5. Speak to your GP about accessing support for your own wellbeing
6. If your child has not yet been seen by their GP or local eating disorder service, it is important to contact them to discuss getting support. If they are accessing support and you have concerns, please contact their care providers directly.

What are the possible benefits of taking part?

There are no 'direct' benefits to you taking part in this study, but a £2 donation will be made to an eating disorder charity for your participation as a thank you for your time. We hope that your participation will help lead to a better understanding of the stress caregivers may experience and how best they can be supported.

Will this impact my child's care?
This research is separate to any care your child may currently be receiving or may receive in the future. Their care providers will not be aware of your participation in this study, or of any of your responses. If you are concerned about your child you should contact their GP, local Eating disorder or mental health team providing their care.

What will happen to the information I provide?
You will not be asked for any information that could personally identify you or your child, such as your name, address, date of birth etc. All data collected from the survey will be stored on an electronic file that is password protected and can only be accessed by the primary researchers and supervisor. Following the study, anonymised data will then be stored in a UEA data repository and may be used in further research. It will be stored in line with the Data Protection Act (2018) and UEA Policy and will be deleted after 10 years.

What will happen to the results?
The information collected from this survey will be analyzed and findings will be written up and submitted as part of two Doctoral theses in Clinical Psychology (UEA). The results of this study may also be shared with other researchers, published in academic/research journals and/or presented at conferences. All information is collected anonymously and as a result, anything reported will not allow for personal identification of those involved in the research. Results will also be shared via our social media: Facebook, X/Twitter: @edcare_research.

Who is organizing, funding, and reviewing this study?
This study is organized and funded by the Doctoral Programme in Clinical Psychology at the UEA. The UEA Faculty of Medicine and Health Sciences Research Ethics Committee has reviewed and approved this study (ETH2324-1470).

What if I want to get in touch?
If you have any questions, queries, or concerns – please feel free to contact us using the following details:

Primary researchers:
Rachel Nabirinde (Trainee Clinical Psychologist)
Email: r.nabirinde@uea.ac.uk
Natasha Heal-Cohen (Trainee Clinical Psychologist)
Email: n.heal-cohen@uea.ac.uk

Doctoral Programme in Clinical Psychology, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ.

Alternatively, please feel free to contact our supervisor, and joint researcher:

Dr. Aaron Burgess (Research Supervisor and Clinical Lecturer in Clinical Psychology)
Doctoral Programme in Clinical Psychology, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ.

Email: Aaron.Burgess@uea.ac.uk

Or a member of course staff independent to the study:

Dr Peter Beazley, Deputy Programme Director for UEA Clinical Psychology Doctorate programme, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email: P.Beazley@uea.ac.uk

Please note that these email addresses are not to be used if you are seeking immediate support following survey completion for example, due to distress. It is unlikely that we will be able to respond in a timely manner and do not want you waiting for any support you might need. As a result, please do use the websites and organizations provided above for support.

Appendix Q

Consent Form

Version 3: November 2023
Consent form

Understanding caregiver trauma responses to children/young people (CYP) with an eating disorder

Researchers: Natasha Heal-Cohen & Rachel Nabirinde (Trainee Clinical Psychologists), Dr Aaron Burgess (Research supervisor)

Please tick to agree as appropriate with each of the following statements:

I confirm that I have read and understood the participant information sheet (Version 1. June 2023) on the previous page for the above study. I have had time to think about the information, understand the advantages and disadvantages of taking part, and have been given the opportunity to ask any questions.	
I understand that my participation is entirely voluntary and that I am free to withdraw at any time (before I submit my responses), without giving a reason and with no consequence	
I understand what will happen to the anonymous information I provide, and who can access it.	
I understand and give my consent for the publication of this research study's findings which have been concluded using the anonymous data I have provided, and that it will not be possible for me to be identified from this. I am aware that this also means my anonymous data may be obtained from this and then used by other researchers in further research.	
I agree to take part in this study.	

If you do not agree with any of the above items, then please exit the survey now. You may return at a later date should you wish. If you have any outstanding questions that you would like answered or wish to discuss any element of the study with the researcher, before participating, then please feel free to contact us by emailing: n.heal-cohen@uea.ac.uk, r.nabirinde@uea.ac.uk

Date:

Signature:

Appendix R

Participant Debrief

Version 1: June 2023 Participant debrief

Thank you for participating in this survey and helping to further research on eating disorders. We will donate £2 to an eating disorder charity as a thank you for your participation.

We are still looking for more participants for the study! If you know of other caregivers who may be eligible and interested, please share this link with them: http://tinyurl.com/edcaregivers

You can view the findings of our research, which will be shared via our social media accounts: Facebook, X/Twitter: @edcare_research

If completing this survey has left you distressed and you would like immediate support for your wellbeing you can contact:

- Samaritans are available 24 hours a day to give support to anyone who is struggling on 116 123 or via email jo@samaritans.org. More information is also available on their website https://www.samaritans.org/
- NHS – 111

For further support for you and/or your child:

- Speak to your GP about accessing support for your own wellbeing
- If your child has not yet been seen by their GP or local eating disorder service, it is important to contact them to discuss getting support. If they are accessing support and you have concerns, please contact their care providers directly.
- *BEAT Eating Disorders*
    - Helpline (open 365 days a year from 12pm-12am during weekdays, and 4pm- 12am on weekends and bank holidays):
    - 0808 801 0677 (England), 0808 801 0432 (Scotland),
    - 0808 801 0433 (Wales), 0808 801 0434 (Northern Ireland).
    - https://www.beateatingdisorders.org.uk–forresources,andsupportchatrooms
- F.E.A.S.T. A global support and education community for families affected by eating disorders. https://www.feast-ed.org/

If you have any questions, queries, or concerns about the research please feel free to contact us using the following details:

Primary researchers:
Rachel Nabirinde (Trainee Clinical Psychologist) Email: r.nabirinde@uea.ac.uk
Natasha Heal-Cohen (Trainee Clinical Psychologist) Email: n.heal-cohen@uea.ac.uk
Doctoral Programme in Clinical Psychology, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ.

Alternatively, please feel free to contact our supervisor, and joint researcher:

Dr. Aaron Burgess (Research Supervisor and Clinical Lecturer in Clinical Psychology) Doctoral Programme in Clinical Psychology, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ.
Email: Aaron.Burgess@uea.ac.uk

Or a member of course staff independent to the study:

Dr Peter Beazley, Deputy Programme Director for UEA Clinical Psychology Doctorate programme, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email: P.Beazley@uea.ac.uk

Please note that these email addresses are not to be used if you are seeking immediate support following survey completion for example, due to distress. It is unlikely that we will be able to respond in a timely manner and do not want you waiting for any support you might need. As a result, please do use the websites and organizations provided above for support.

Appendix S

Assumptions of Statistical Tests

Table S1

Assumptions and Checks for Statistical Tests Conducted in Empirical Study

Pearson's correlations	
Assumption	Checks
Two continuous variables	
Approximately normally distributed	Shapiro-Wilk test (n.s); histogram distribution; Q-Q plot
Linear relationship	Scatterplot
No significant outliers	Scatterplot; z scores (+/- 3); check meaningfulness of potential
Point-biserial correlations	
Assumption	Checks
One continuous, one dichotomous variable	
No significant outliers	Boxplots; check meaningfulness of potential outliers
Approximates normal distribution	Shapiro-Wilk test (n.s); Q-Q plots; histogram distribution.
Equality of variance	Levene's test (n.s)
Multiple linear regressions	
Assumption	Checks
Linearity	Scatterplot; residual vs predicted plot (random scatter around 0)
Independence of errors (if 2+ predictors)	Durbin-Watson statistic (close to 2)
Homoscedasticity	Residual vs predicted plot (random scatter around 0)
Normality of residuals	Histogram distribution; Q-Q plot; Shapiro-Wilk test (n.s)
Multi-collinearity (if 2+ predictors)	Variance Inflation Factor (<5), Tolerance (> 0.2)
Outliers and influence	Cook's distance (< 1; individual scrutiny of points > 4/n), scatterplots of leverage values vs Cook's distance; studentised residuals (+/- 3)

Note. n.s, non-significant

List of Abbreviations

AN: Anorexia nervosa

APA: American Psychiatric Association

ARFID: Avoidant/restrictive food-intake disorder

BED: Binge eating disorder

BN: Bulimia nervosa

CYP: child or young person/children and young people

DSM: Diagnostic and Statistical Manual for Mental Disorders

ED: Eating disorder

EDNOS: Eating disorder not otherwise specified

NHS: National Health Service

NICE: National Institute for Health and Care Excellence

OSFED: Other specified feeding and eating disorder

PTSD: Post-traumatic stress disorder

TIC: Trauma informed care

UEA: University of East Anglia

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