LIZZIE NEELY BSc (Hons)

EXPLORING EXPERIENCES OF PARENTS OF INDIVIDUALS WITH AN EATING DISORDER

Section A: What are the Emotional Experiences Associated with Parenting an Individual with an Eating Disorder? A Systematic Review and Thematic Synthesis

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Section B: Beliefs about Emotions, Self-Compassion, and Emotion-Related Parenting Practices in Primary Caregivers of Young People with an Eating Disorder

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A thesis submitted in partial fulfilment of the requirements of
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Summary

Section A: This is a systematic literature review involving thematic synthesis of qualitative research offering an insight into the emotional experiences of parents of individuals with an eating disorder. Sixteen studies are included in the thematic synthesis, which generated 5 themes and 12 sub-themes. A theoretical model is proposed, linking parental self-criticism and guilt with parental distress and responses to ED behaviours, which may inform future research.

Section B: This is a cross-sectional questionnaire study involving parents of young people with eating disorders. It investigates the relationships between parental beliefs about emotions, self-compassion, expressed emotion, responses to child negative emotions and child eating disorder symptoms using correlation and mediation analyses. Expressed emotion was found to mediate the relationship between parental self-compassion and child eating disorder symptoms. Parental beliefs about emotions was found to significantly predict parental self-compassion. The findings are discussed in the context of existing research and theory, and implications for future research and clinical practice are discussed.

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Abstract

Background: Parents play a significant role in caring for children with an eating disorder (ED). This role contributes to carer burden, impacting on their wellbeing and ability to respond supportively to their child's ED behaviours. No existing review focuses specifically on the emotional experiences of parenting a child with an ED, therefore this review aimed to synthesise existing research to explore parental emotional experiences of caring for their child with an ED. **Method:** 16 qualitative studies were identified through a systematic search of four online databases. Quality assessment of these studies was undertaken, and methodological concerns were discussed. **Results:** Through thematic synthesis, five themes were developed, providing insight into the emotional experiences of parents caring for their child with an ED: guilt, overwhelm, grief, isolation vs connection and gratefulness. Several of these themes also had relevant subthemes. **Discussion:** Parenting a child with an ED was challenging, resulting in significant distress. However, some parents also described personal growth through the experience. A theoretical model is proposed, linking parental self-criticism and guilt with parental distress and responses to ED behaviours. Research and clinical implications, and strengths and limitations of the review are discussed.

Keywords: Eating disorders; parents; emotional experiences; thematic synthesis

Introduction

Eating disorders (EDs) are serious mental health conditions, with 1.25 million people in the UK estimated to meet diagnostic criteria (BEAT, 2022). EDs are characterised by disordered eating behaviours and over-evaluation of weight and shape, often seriously affecting physical and psychological well-being (Fairburn, 2008).

The language used to describe EDs throughout this paper is medicalised (including terms such as 'disorder' and 'symptoms'). Consideration was given to this, and it was deemed important to use this language which aligns with the way EDs are described in the literature. Furthermore, using alternative terminology, for example 'eating difficulties' in place of 'eating disorder' may be misleading, given that eating difficulties are highly prevalent in the general population, whereas this research explicitly aimed to explore experiences in a clinical population.

Parents are central in supporting ED sufferers, providing emotional support, managing mealtimes, and are often heavily involved in psychological treatment, particularly if their child is under 18 (Lock & Le Grange, 2005). Juggling the role of parent and carer, whilst worrying about their child's physical and mental health, places significant burden on parents (Martin et al., 2013). EDs often develop during teenage years, but can have long trajectories, with relapses being common (Khalsa et al., 2017; Richard et al., 2005), meaning parents can have a significant caring role throughout their child's adult life (Hjern et al., 2006).

Anorexia nervosa (AN) sufferers often value their ED in some ways; this is the egosyntonic nature of AN (Gregertsen et al., 2017). Shame and secrecy around ED behaviours can also make those with EDs resistant to the support being offered (Vandereycken & Van Humbeeck, 2008; Nechita et al., 2021). This can result in tense relationships, increasing parental frustration as their efforts to support their child are met with pushback (Fox et al., 2017). Relationships between parents can also be negatively impacted, due to unequal distribution of caring roles and parents having less time for one another (Ganson & Hamilton-Mason, 2019; Gilbert et al., 2000). These relational challenges likely further compound the distress experienced by parents caring for a child with an ED. With growing evidence of this significant emotional toll, the National Institute for Health and Care Excellence guidelines (NICE, 2017) highlight the importance of considering the mental health needs of family members of ED sufferers.

Parental Responses to ED Behaviours

Parenting a child with an ED places significant burden on parental coping resources, in turn impacting responses to their child. If parents are struggling to cope and their emotional needs are unmet, they may be more likely to accommodate ED behaviours, for example allowing a child to avoid certain foods, which maintains the ED (Sepulveda et al., 2009). While this is an attempt to reduce parental distress and familial conflict, accommodating the ED fuels it. This further increases caregiver burden, resulting in a vicious cycle of worsening ED symptoms and parental distress. In addition, as parental burden rises, levels of expressed emotion (EE) in the home may increase. High EE includes attitudes and behaviours such as critical comments, hostility and emotional overinvolvement. Understandably, these factors may increase when parents have limited emotional reserves due to the toll of caring for a child with an ED (Reinecke, 2018). However, the impact of increased EE is highlighted in research finding that high EE predicts poorer outcomes among ED sufferers (Duclos et al., 2012).

Schmidt and Treasure's (2006) cognitive-interpersonal maintenance model proposes that accommodation of ED behaviours and EE both contribute to maintaining EDs and highlights the importance of interpersonal relationships in this cycle. This widely accepted model, now used to understand EDs trans-diagnostically (Goddard et al., 2011), outlines cognitive, socio-emotional, and interpersonal factors that contribute to the development and maintenance of EDs. The model suggests that factors including obsessive compulsive personality traits[1] and anxious avoidance increase one's vulnerability to developing an ED. These factors may also contribute to interpersonal difficulties, resulting in others (especially carers) responding to ED behaviours in ways that maintain the ED, including accommodation and high EE. Figure 1 depicts a maintenance cycle of ED behaviours and parental responses proposed by Treasure and Schmidt (2013).

By understanding parental emotional experiences of caring for a child with an ED, interventions to support parental psychological well-being could be further developed, focusing more specifically on their emotional needs. This may support parents to cope with caring for a child with an ED, resulting in greater emotional reserves to respond to ED behaviours in ways that could interrupt the vicious cycle described above.

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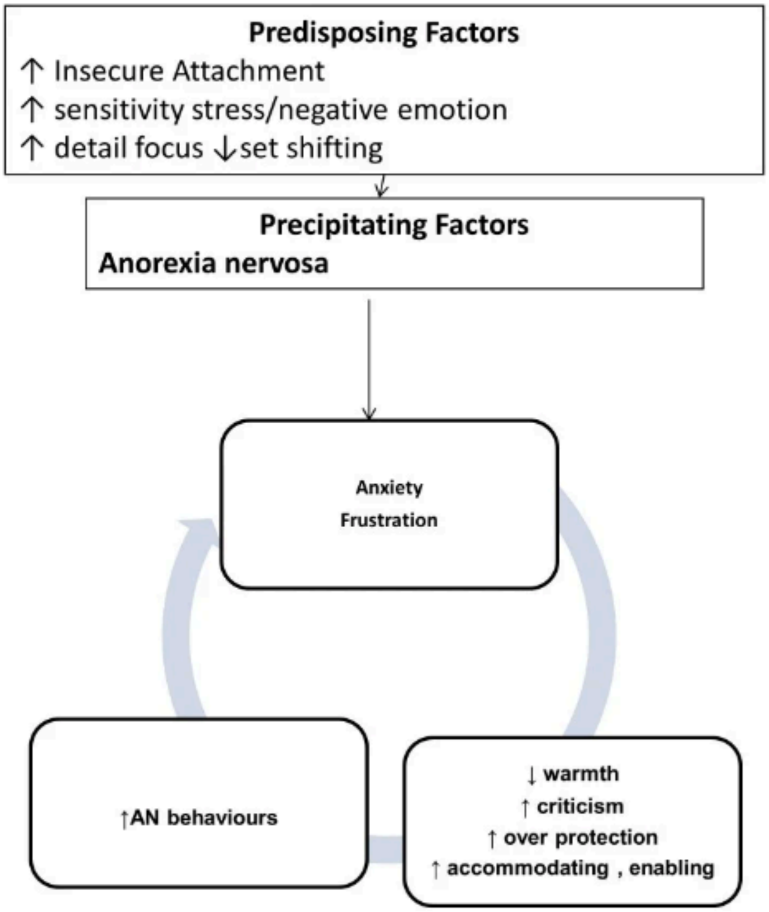
[1] The idea of 'traits' is contested, given that they cannot be directly observed and their existence within a person is debatable. While the term 'traits' is used in Treasure and Schmidt's (2013) model, other terminology, such as 'patterns' may be preferrable.

Figure 1

Treasure and Schmidt's (2013) Formulation of Carer Involvement in ED Maintenance



Experiences of Caring for Individuals with an ED

Anastasiadou et al. (2014) systematically reviewed quantitative studies investigating family caregiving experiences in EDs, highlighting challenges faced by carers. Higher levels of caregiver burden were associated with longer duration of illness. Those who had cared for an ED sufferer for longer, and still lived with them, were more accommodating of ED behaviours.

Two papers systematically reviewing qualitative literature on experiences of caring for an individual with an ED were identified (Fox et al., 2017; Quong & Chen, 2018). Both reviews highlighted challenges faced by carers, including feeling unsupported, struggling to cope with caring demands, and significant guilt about the diagnosis. They also both highlighted caregiver coping strategies, including accommodating ED behaviours and seeking information on EDs to understand how and why they developed. Quong and Chen's (2018) meta-ethnography found that external factors (including barriers, experiences of healthcare and support) contributed to physical, psychological, and social responses from caregivers, which in turn impacted caregiver responses to their loved one and the ED behaviours. Both reviews identified a sense of adaptation and acceptance by caregivers, who reflected on their growth through the experience of caring for someone with an ED.

Review Rationale

While the literature discussed above has investigated experiences of caring for someone with an ED, it did not focus on parents specifically. Additionally, none of these reviews included research published since 2015. As highlighted by Fox et al. (2017), amalgamating the experiences of all carers, rather than focusing on a specific group (e.g. parents) risks missing the individual needs of groups. Parents have a unique role in their caring relationship for their child with an ED. Stigmatising and misleading media has contributed to narratives blaming parents for the development of EDs in their children, and while this has been refuted (Le Grange et al., 2010), these narratives still exist in society and have likely been internalised by parents. Caring for someone with an ED is already understood to be distressing and blaming narratives likely exacerbate this. Parents may therefore face somewhat different challenges to other carers of individuals with EDs, highlighting the importance of explicitly exploring parental experiences.

Furthermore, the scope of previous reviews has been broad, including literature on interactions with ED services and experiences of being involved in ED treatment. Given the impact of parenting an individual with an ED on carer burden, it is important to more explicitly consider emotional experiences associated with this role. This would enable a better understanding of how parents are impacted by caring for their child's ED and offer insights into how this may impact their responses to their child. A review focusing more specifically on the emotional experiences of parents caring for a child with an ED than previous reviews, while also adding more recently published literature, is therefore needed.

The current review therefore sought to address these gaps by aiming to systematically review and synthesise qualitative research answering the question: *What are parental emotional experiences of caring for a child with an ED?*

Methodology

Search Strategy

A systematic search of four electronic databases (ASSIA, Medline, PsychInfo and Web of Science) was conducted in August 2023. These databases were chosen as they cover fields relevant to the review topic, including health and medicine, psychology, and social sciences.

A provisional Google Scholar search was used to scope terminology in the literature, and the SPIDER tool (Cooke et al., 2012) informed search terms, considering the Sample, Phenomenon of Interest, Design, Evaluation and Research type. Table 1 details final search terms (including truncation to ensure varied terminology) and Boolean operators. Provisional searches identified that abstracts typically did not specify experiences as emotional, therefore search terms describing ‘experience’ were intentionally broad to enhance sensitivity.

Table 1

Search Terms

Boolean operator	Terms	Field
	parent* OR carer* OR caregiver* OR mother* OR father*	Abstract
AND	“eating disorder*” OR bulimi* OR anore* OR binge* OR OSFED OR EDNOS	Abstract
AND	qual* OR “mixed method*” OR “case stud*” OR “content analysis” OR “discourse analysis” OR ethnograph* OR “focus group” OR “grounded theory” OR interview* OR narrative OR phenomenolog* OR “thematic analysis” OR questionnaire OR IPA	Abstract
AND	view* OR experienc* OR opinion* OR perce* OR belie* OR feel* OR understand* OR perspective* OR thought*	Abstract

Papers were screened based on inclusion and exclusion criteria (Table 2). Initially, titles were screened, with those clearly not applicable removed at this stage. Abstracts were then screened, following which full texts of remaining papers were read to determine eligibility. Searching reference lists of relevant papers identified three additional articles. Studies were included which focused on parental emotional experiences of caring for a child with an ED, using qualitative methodologies. Studies with integrated perspectives from different caregivers, and/or individuals with an ED were not included. Additionally, studies focusing parental experiences in the context of their involvement in ED treatment, interactions with ED services and/or healthcare professionals were not included. However, some papers covered multiple aspects of parenting a child with an ED, therefore were included if specific sections provided insight into the emotional experiences of parenting someone with an ED. Figure 2 depicts the screening and selection process. Sixteen studies met inclusion criteria and were included in the review. Table 3 provides an overview of the study characteristics.

Table 2

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Published in a peer-reviewed journal	The article was not available in English language
The full text was available in English	The perspectives of other carers e.g. partners or siblings are integrated with the perspectives of parents
Data collection and analysis involved qualitative techniques, either alone or in a mixed methodology	The perspectives of the individual with an eating disorder are integrated with the perspectives of parents
Participants were parents who were currently caring or had previously cared for their child (including adult child) with an eating disorder	The primary mental health difficulty being explored is not an eating disorder
The study provided a perspective on the subjective lived experience of parents of an individual with an eating disorder, with a focus on the emotional experience of caring for someone with an eating disorder within the family	Unpublished articles, case studies, theses, book chapters, theoretical articles, review, or feature articles

Figure 2

PRISMA Diagram

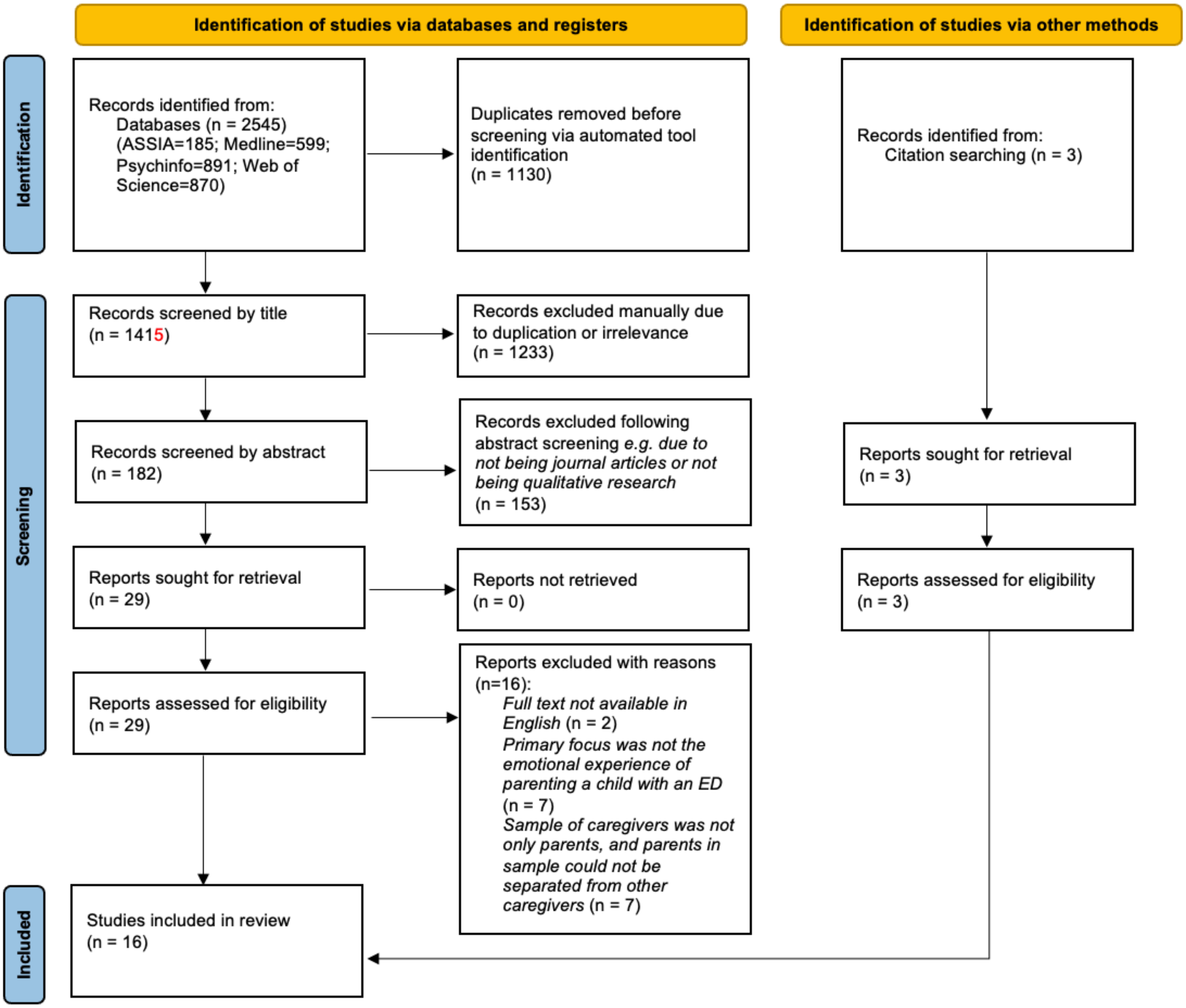


Table 3

Study Characteristics

Study number	Author (year)	Title	Study location	Participants	Research topic and aims	Data collection	Analysis	Summary of key findings related to emotional experience of parenting someone with an ED
1.	Thibault et al. (2023)	"For me, it's a real pain": A Foray into the Experience of Parents Involved in Family-Based Treatment	Canada	Six mothers of adolescents with anorexia nervosa or bulimia	To describe, in parents with a child with an ED 1) the personal challenges afflicting parents; 2) the family challenges met by parents; 3) the parenting challenges related to their roles and practices	Individual semi-structured interviews	Thematic analysis	3 over-arching themes (with 15 sub-themes) related to the challenges parents faced when caring for their child with an eating disorder: 1) Parents' personal challenges (emotional upset of parents; acceptance of their child's diagnosis; coping with their child's distress; coping with their guilt; taboo surrounding EDs; concerns about possible relapses) 2) Family challenges (reorganisation of everyday life; attentional focus of the ED; concerns for siblings of a child with an ED; relational difficulties with a spouse) 3) Parental role challenges (lack of support, burden of intervention management, insecurities about parenting practices, meal management, conflicts with child)
2.	Fox and Whittlesea (2017)	Accommodation of symptoms in Anorexia Nervosa: A	UK	Five mothers, two fathers and one sister* of	To develop a grounded theory of the key psychological processes	Individual semi-structured interviews	Grounded theory	The study describes the journey that caregivers go on when supporting someone with AN, and the difficulties parents face with helping their child manage AN. This journey was separated into several themes:

		Qualitative Study		individuals with an eating disorder	associated with carer accommodation/ enabling within AN, with a particular focus on the caregivers' experiences of managing and responding to AN			1) the course of AN; 2) the understanding of AN; 3) lost daughter; 4) carers roles and responsibility; 5) direct approaches; 6) impact and emotional reserve; 7) accommodating and tolerating AN behaviours; 8) internal conflict; and 9) efforts to reduce internal conflict. Throughout this journey, parents spoke of the struggle of wanting to decrease tension in the home and make life easier for their child, which resulted in them accommodating ED behaviours. However, this in turn resulted in increasing levels of parental guilt for not standing up to the ED.
3.	McCormack and McCann (2015)	Caring for an adolescent with Anorexia Nervosa: Parent's views and Experiences	Ireland	Seven mothers and three fathers of adolescents with AN	To investigate the subjective experiences of parents in caring for an adolescent diagnosed with anorexia nervosa	Individual semi-structured interviews	Not stated but appears to be thematic analysis	Three relevant themes were identified, relating to the family environment, the psychosocial impact on parents, and future hopes and aspirations. Parents who spent more time with their child (e.g. who did not work) expressed more significant impacts of parenting a child with an ED than those who had more time away from their child and the home.
4.	Svensson et al. (2013)	Parents' Experiences of Having and Caring for a Child With an	Sweden	Six mothers and four fathers of female adolescents with a severe ED	To gain insight into the lived experience of having a child with an eating disorder	Semi-structured interviews	Phenomenological - hermeneutical method	Parents expressed significant challenges related to parenting a child with an ED. Three major themes were identified, with 13 sub-themes 1) Social disruption (isolation, food and exercise-related situations and conflicts, spouse relationship, siblings get

		Eating Disorder						affected, affecting work and economy negatively) 2) Emotional impact (worry and anger, guilt and shame, frustration) 3) Coping (talk about the situation, the inherent resilience of the family, acceptance of the situation, periods of rest, acquire rests)
5.	Cottee-Lane et al. (2004)	Childhood Onset Anorexia Nervosa: The Experience of Parents	UK	Seven mothers and four fathers of children with AN	To describe parents' experiences of having a child with AN, in particular how parents viewed the impact of their child's ED on themselves and the family, and how they made sense of and coped with the illness.	Semi-structured interviews	Interpretative phenomenological analysis	Parents expressed significant personal demands and challenges as a result of caring for a child with an ED. Eight key themes that were grouped into three overarching domains: 1) Understanding the eating disorder (Slow recognition; analysing it) 2) The impact of the eating disorders (the dreadful monster; high stakes; a living nightmare) 3) Managing the eating disorder and its impact (you can lead a horse to water...; taking control; support and understanding)
6.	White et al. (2022)	Disturbance at the dinner table: Exploring mothers' experiences of mealtimes	UK	Nine mothers with a child with an eating disorder	To explore how mothers experience family mealtimes when caring for a young person with AN.	Semi-structured interviews	Interpretative phenomenological analysis	Mothers spoke of the challenges in parenting a child with an ED, in particular related to mealtime experiences which then impact the rest of their caring experience. Three key themes were identified, with two super-ordinate themes *combat* and *distortion*:

		when caring for their son or daughter with anorexia nervosa						1) Managing mealtime combat through accommodation and acceptance 2) Feeling isolated, inauthentic and ill-equipped 3) A need for understanding and to be understood.
7.	Whitney et al. (2005)	Experience of caring for someone with anorexia nervosa: qualitative study	UK	Twenty mothers and twenty fathers of individuals with AN	To obtain a detailed understanding about the experience of caregiving as a parent of an individual with AN	Letters written by parents describing what it is like to be the parent of someone with AN	Grounded theory	Parental experiences of caring for someone with AN were grouped into themes relating to carer illness perceptions, impact of the illness, emotional and cognitive processes, and maladaptive beliefs and responses. Differences were highlighted in this study in parental responses based on gender, with mothers being described as having more emotional responses, while fathers were more detached.
8.	Hillege et al. (2006)	Impact of eating disorders on family life: individual parents' stories	Australia	Nineteen mothers and three fathers of children/adult children with an ED	To consider the impact that an ED has on the family, particularly the parents. To give a voice to parents to develop new understandings of their experience resulting in more appropriate	Semi-structured interviews	Content analysis	The study highlights the challenges faced by families with an individual with an ED. Five overarching themes were developed: 1) Family unification or disintegration; 2) parent's inability to cope; 3) inconsiderate comments made from significant others; 4) social isolation; 5) financial impacts. Through these themes there was a common thread of *distress* experienced by parents.

					clinical decision making.			
9.	Konstantellou et al. (2022)	The experience of intolerance of uncertainty for parents of young people with a restrictive eating disorder	UK	Nine mothers and eight fathers of young people with a restrictive eating disorder	To explore intolerance of uncertainty in parents of young people with a restrictive ED	Focus groups	Interpretative phenomenological analysis	The study explored uncertainty and how parents were able to tolerate this in relation to their child's eating disorder. Parents had high levels of intolerance of uncertainty in relation to their child's ED, which impacted on their confidence in their ability as parents, how they coped, and family life.
10.	Whitney et al. (2023)	Caring for Sons with Anorexia: The Perspective of Mothers	USA	Ten mothers with a son with AN	To explore mothers' caregiving experiences throughout their son's journey with AN, including the psychological impact, the experience of working with healthcare professionals and the interpersonal	Semi-structured interviews	Consensual qualitative research methods	Relevant themes related to the psychological impact of parenting a son with AN (a. reactions to the diagnosis; b. overall, post treatment impact) and interpersonal relationships (a. impact on marriage, b. relationships among family members, c. relationship with son)

					and social impact.			
11.	Bezance and Holliday (2014)	Mothers' Experiences of Home Treatment for Adolescents with Anorexia Nervosa: An Interpretative Phenomenological Analysis	UK	Nine mothers with a child with AN	Explore the experiences of mothers receiving home treatment as part of treatment for their daughters' AN.**	Semi-structured interviews	Interpretative phenomenological analysis	Mothers spoke of their experiences of caring for their daughter with AN, and there was a focus on the experiences leading up to further support being required from the home treatment team. Relevant themes included experiences of mothers becoming enmeshed and reaching rock bottom.
12.	Karlstad et al. (2021)	The experiences and strategies of parents of adults with anorexia nervosa or bulimia nervosa: a qualitative study	Norway	7 mothers and 4 fathers of individuals with AN or BN	To explore the experiences of parents with adult daughters with AN or BN.	Semi-structured interviews	Grounded theory	Four key themes were developed: "Wearing all the hats", adapting to the illness, struggling for understanding and help, and continuing to stay strong. These themes highlighted the challenges faced by parents in taking on multiple roles when caring for their child while feeling lost and unsupported. Despite this, they continued to support their child though their ED.

13.	Cribben et al. (2021)	The experiential perspectives of parents caring for a loved one with a restrictive eating disorder in the UK	UK	Twenty-four mothers and eight fathers of individuals with an eating disorder	To develop a greater understanding of parents' experiential perspective of eating disorder treatment in the UK	Focus groups	Thematic analysis	The majority of themes were not relevant to this systematic review, as they were focused on the experience of ED treatment. However, one key theme, impact of the eating disorder was relevant. A range of negative emotional experiences were described, including frustration, guilt, fear, isolation and hopelessness. The ED was also described as having a significant impact on the whole family.
14.	Loftfjell et al. (2020)	Parents' experiences of having an adult daughter with an eating disorder	Norway	Five mothers and six fathers of women with severe EDs	To describe how it feels to be the parent of an adult daughter with a severe eating disorder	Semi-structured interviews	Content analysis	Parental experiences of caring for their child with an ED were summarised in three key categories: 1) ever on the alert; 2) the eating disorder takes over the home; 3) loneliness.
15.	Williams et al. (2020)	"My Whole World Fell Apart": Parents Discovering Their Child Has Anorexia Nervosa	Canada	Nine mothers and three fathers	To understand the experiences of parents who have discovered they have a child living with AN.	Unstructured interviews	Hermeneutic enquiry	The results describe the journey of parents discovering their child's AN, the emotional experience of this and then learning to live with AN, as well as the impact on family relationships.

16.	Beale et al. (2005)	Eating disorders: A qualitative analysis of the parents' journey	Australia	Nineteen mothers and three fathers of individuals with an ED	To describe the journey of parents who had a child with an ED	Unstructured interviews	Not stated, only describes an "in-depth analysis"	The results highlighted significant features of parents' journeys with their child with an AD, including: the initiation of the parents' journey; the inaccessibility of appropriate resources; the efforts parents made for their child; the strength exhibited by parents.

Note. *This study included one non-parental participant but was included as the authors explicitly discussed this and noted that following data screening this participant's data was not significantly different to parental participants; **The focus of the questions and results included in the review were related to parental experiences of caring for their daughter with an ED, rather than experiences of support from the home treatment team.

Table 4

CASP Criteria Checklist for Included Studies

Study	CASP Checklist									
	Was there a clear statement of aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is this research?
Thibault et al. (2023)	Y	Y	P	P	Y	P	Y	N	Y	Y
Fox & Whittlesea (2017)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
McCormack & McCann (2015)	Y	Y	P	P	N	N	Y	N	Y	Y
Svensson et al. (2013)	Y	Y	Y	P	Y	P	P	Y	Y	Y
Cottee-Lane et al. (2004)	Y	Y	Y	Y	Y	P	N	Y	Y	Y
White et al. (2022)	Y	Y	Y	Y	Y	P	P	Y	Y	Y

Whitney et al. (2005)	Y	Y	P	Y	P	P	Y	P	Y	Y
Hillege et al. (2006)	Y	Y	Y	P	P	P	Y	Y	Y	Y
Konstantellou et al. (2022)	Y	Y	Y	Y	Y	P	Y	Y	Y	Y
Whitney et al. (2023)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Bezance and Holliday (2014)	Y	Y	P	N	Y	Y	P	Y	Y	Y
Karlstad et al. (2021)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Cribben et al. (2021)	Y	Y	P	Y	Y	P	Y	Y	Y	Y
Loftfjell et al. (2020)	Y	Y	P	P	Y	Y	Y	Y	Y	Y
Williams et al. (2020)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Beale et al. (2005)	Y	Y	P	P	P	N	Y	N	Y	Y

Quality Assessment

Study quality was assessed using the Critical Appraisal Skills Programme (CASP, 2018; Appendices A) qualitative checklist, the most widely used quality assessment tool for health and social care-related qualitative studies (Long et al., 2020). The checklist was designed to encourage reflection on studies and their findings, not as a scoring system. Table 4 shows the quality ratings for included studies.

The 16 papers reviewed had varying levels of quality according to CASP criteria but were all deemed of sufficient quality to be included. Notable limitations across many studies included limited consideration of the relationship between researchers and participants, and a lack of diversity within samples.

Aims and Methodology

All 16 papers included clear statements of study aims and/or specific research questions, and a rationale. Qualitative approaches were deemed appropriate, as all studies aimed to understand subjective experiences of participants.

Design

The research design for each study appeared appropriate, however several did not provide sufficient details on the rationale for their chosen design (Beale et al., 2005; Bezance and Holliday, 2014; Cribben et al., 2021; Loftfjell et al, 2020; McCormack & McCann, 2015; Thibault et al., 2023; Whitney et al., 2005).

Sampling and Data Collection

Most studies provided sufficient information on participant selection. Several studies included only participants who self-referred in response to online adverts for the study (Cribben et al., 2021; White et al., 2022; Whitney et al., 2023; Williams et al., 2020), meaning it was difficult to determine why individuals chose not to participate. One study (Bezance & Holliday, 2014) did not provide any information on participant recruitment. The remaining studies used a range of recruitment methods, but only two (Fox and Whittlesea, 2017; Cottee-Lane et al., 2004) considered why participants may have declined to participate. Two studies (Beale et al., 2005; Hillege et al., 2006) recruited personal contacts of the research team, but did not justify this or consider potential selection bias.

The limited reporting on demographic information in studies was concerning. All studies reported the gender of participants and all except McCormack and McCann (2015), Hillege et al. (2006), Konstantellou et al. (2020) and Beale et al. (2005) reported the child's gender. All studies except Beale et al. (2005) and Hillege et al. (2005) specified the ED diagnosis.

Several studies reported limited additional demographic information (Beale et al., 2005; Bezance & Holliday, 2014; Hillege et al., 2006; McCormack & McCann, 2015; Thibault et al., 2023; Svensson et al., 2013). Only five studies provided information on participant ethnicity (Cottee-Lane et al., 2004; Cribben et al., 2021; Fox & Whittlesea, 2017; Konstantellou et al., 2022; Whitney et al., 2023). Across studies reporting ethnicity, only Konstantellou et al. (2022) and Cribben et al. (2021) included non-white participants, and Cribben et al. (2021) did not detail the ethnicity of non-white participants. Information on socio-economic status (SES) of participants was missing from all but two studies (Cottee-Lane et al., 2004; Whitney et al., 2023), in which no participants had a low SES. Failing to consider the impact of individuals' demographics, may exacerbate structural biases, and the generalisability and external validity of findings can be questioned.

Studies varied in how well data-collection was described. All studies except Whitney et al. (2005) used focus groups, semi-structured interviews, or unstructured interviews. Of these, all except two (Hillege et al., 2006; McCormack & McCann, 2015) detailed the topic guide or provided an overview of the topics covered. However, several studies did not provide details on how interview/focus group schedules were developed or justify why an unstructured interview was used (McCormack &McCann, 2015; Svensson et al., 2013; White et al., 2022; Hillege et al., 2006; Bezance & Holliday; 2014; Beale et al., 2005).

Whitney et al. (2005) justified their method of analysing letters written during a group intervention for parents of children with AN. The authors commented on potential bias in the data collection due to letters being written as part of a therapeutic exercise. However, there was limited consideration of the potential impact of parents being expected to share their letters with the group.

Reflexivity and Ethical Considerations

Reflexivity is central to qualitative research, enabling researchers to consider their subjective experiences and biases which may impact the research process (Olmos-Vega et al., 2022). Two studies did not comment on the role of the researcher (Beale et al., 2014; McCormack & McCann, 2015). Several studies made minimal reference to potential researcher bias, commenting more generally on the importance of accounting for researcher subjectivity, but not describing how they did this (Cottee-Lane et al., 2004; Cribben et al., 2021; Hillege et al., 2006; Konstantellou et al, 2022; Svensson et al., 2013; Thibault et al., 2023; White et al., 2022; Whitney et al., 2005).

All studies except Williams et al. (2020) triangulated coding and interpretation of data using multiple researchers to increase credibility of findings. Several studies described other steps taken to mitigate researcher biases including service user consultation on interview schedules (Cribben et al., 2021; Fox & Whittlesea, 2017; Karlstad et al., 2021; Thibault et al., 2023), keeping reflexive journals (Bezance & Holliday, 2014; Karlstad et al., 2021; Whitney et al., 2023) and using interviewers not involved in the treatment of participants (Loftfjell et al., 2020; Svensson et al., 2013).

All studies except one (Cottee-Lane et al., 2004) detailed their ethical approval, and all except three (Cottee-Lane et al., 2004; Svensson et al., 2013; White et al., 2020) commented on the process of gaining informed consent. A minority of studies considered the distressing nature of the research, commenting on support available for participants (Beale et al., 2014; Hillege et al., 2006; McCormack & McCann, 2015).

Data Analysis and Findings

Analyses were generally clearly explained, detailing how themes were derived from the data. However, two studies (Beale et al., 2005; McCormack & McCann, 2015) did not explicitly state their data analysis techniques, limiting the validity of findings as it is unclear if credible analysis techniques were used.

In one study (Thibault et al., 2023) the data presented seemed to be a description of parental accounts. The three themes identified mapped directly onto the original research aims, suggesting bias in reporting and minimal interpretation of the data to generate analytical themes. The rigour of this analysis is therefore questionable, which was considered in the thematic synthesis.

Whitney et al. (2005) used a grounded theory approach, from which 6 higher-order, and 16 lower-order themes emerged. However, lower-order themes were presented solely as participant quotes, without any explanation, making it difficult to understand the researchers' interpretations of the data.

All studies presented sufficient data, in the form of participant quotes, with key findings explicit and reported in relation to original research questions.

Value of Research

The value of research can be considered in line with contributions of findings to the existing literature base, relevance to clinical practice, and other implications of the research (CASP, 2018). All the studies commented on at least one of these criteria, and most also identified areas for future research.

Summary of Quality Assessment

The quality assessment evaluation did not identify any studies with very low quality requiring exclusion, therefore all 16 studies were included in the thematic synthesis. Given the variation in study quality, those with higher quality ratings were prioritised in the synthesis, and areas of weakness for certain studies were interpreted cautiously (Long et al., 2020).

Thematic Synthesis Method

Following a systematic literature search and quality appraisal of the papers, Thomas & Harden's (2008) three staged approach to thematic synthesis (Table 4) was used to inform the analysis. Thematic synthesis was chosen as it is a form of meta-synthesis used with qualitative data to answer a specific research question.

Table 5

Thomas & Harden's (2008) Approach to Thematic Synthesis

Stage of thematic synthesis	Description
1.	Coding the text line-by-line
2.	Using the codes to develop descriptive themes
3.	'Going beyond' the content of the original studies and generating analytical themes

Verbatim extracts from the abstract, results and discussion sections of the papers were imported to NVivo 12 for coding. Where studies included aims and findings beyond the remit of this review, only data related to emotional experiences of parenting a child with an ED were extracted for coding.

Line-by-line inductive coding was completed, with at least one code applied to each sentence. This resulted in a bank of codes, enabling concepts to be translated across studies. Descriptive themes were generated by grouping similar codes together, which were then considered in relation to the original review questions, resulting in the generation of analytical themes. See appendices B and C for insight into coding and theme development.

As with all qualitative research, researcher reflexivity was important. The researcher had prior experience of working with individuals with EDs and their parents which was reflected on throughout, considering how biases and experiences may impact on interpretation of data. The researcher had discussions with another trainee clinical psychologist without experience of working with those affected by EDs, and a non-psychologist colleague with limited knowledge of EDs, to reflect on this and discuss theme development.

Thematic Synthesis Results

Through an inductive analysis, five themes and 12 subthemes were generated, describing the emotional experiences of parenting someone with an ED (table 5). The first four themes described distressing experiences and the impact on parents (guilt, overwhelm, grief, isolation vs connection). The fourth (isolation vs connection) and fifth (gratefulness) themes described some parents reflecting on how experiences of caring for a child with an ED has shaped them and their relationships.

Table 6

Themes and Subthemes

Theme	Sub theme	Papers which contributed
Guilt	I've failed as a parent	Beale et al. (2005); Bezance & Holliday (2014); Cottee-Lane et al. (2004); Cribben et al. (2021); Fox & Whittlesea (2017); Karlstad et al. (2021); Konstantellou et al. (2022); McCormack & McCann (2015); Svensson et al. (2013); Thibault et al. (2023); Whitney et al. (2005); Whitney et al. (2023); Williams et al. (2020)
	Neglecting other children	Cottee-Lane et al. (2004); Fox & Whittlesea (2017); Hillege et al. (2006); Karlstad et al. (2021); Svensson et al. (2013); Thibault et al. (2023); Whitney et al. (2023); Williams et al. (2020)
Overwhelm	Powerlessness and the fight for control	Bezance & Holliday (2014); Cottee-Lane et al. (2004); Fox & Whittlesea (2017); Konstantellou et al. (2022); Loftfjell et al. (2020); Svensson et al. (2013); White et al. (2022); Whitney et al. (2005); Whitney et al. (2023); Williams et al. (2020)
	Anxiety and uncertainty	Beale et al. (2005); Bezance & Holliday (2014); Cottee-Lane et al. (2004); Fox & Whittlsea (2017); Karlstad et al. (2021); Konstantellou et al. (2022); Loftfjell et al., 2020); McCormack & McCann (2015); Svensson et al. (2013); Thibault et al. (2023); White et al. (2022);

		Whitney et al. (2005); Whitney et al. (2023); Williams et al. (2020)
	Rock bottom	Beale et al. (2005); Bezance & Holliday (2014); Cottee-Lane et al. (2004); Cribben et al. (2021); Fox & Whittlesea (2017); Hillege et al. (2006); Karlstad et al. (2021); Loftfjell et al., (2020); McCormack & McCann (2015); Svensson et al. (2013); Whitney et al. (2005)
Grief	A changing identity as a parent	Beale et al. (2005); Bezance & Holliday (2014); Karlstad et al. (2021); Svensson et al. (2013); White et al. (2022); Whitney et al. (2023); Williams et al. (2020)
	The lost child	Bezance & Holliday (2014); Cottee-Lane et al. (2004); Cribben et al. (2021); Fox & Whittlesea (2017); Hillege et al. (2006); Karlstad et al. (2021); Loftfjell et al. (2020); McCormack & McCann (2015); Svensson et al. (2013); Thibault et al. (2023); Whitney et al. (2005); Whitney et al. (2023); Williams et al. (2020)
	Sacrifices	Bezance & Holliday (2014); Cottee-Lane et al. (2004); Fox & Whittlesea (2017); Karlstad et al. (2021); Konstantellou et al. (2022); Loftfjell et al. (2020); McCormack & McCann (2015); Svensson et al. (2013); Thibault et al. (2023); Whitney et al. (2005); Whitney et al. (2023); Williams et al. (2020)
Isolation vs connection	Feeling misunderstood	Beale et al. (2005); Bezance & Holliday (2014); Cottee-Lane et al. (2004); Cribben et al. (2021); Fox & Whittlesea (2017); Hillege et al. (2006); Karlstad et al. (2021); Konstantellou et al. (2022); Loftfjell et al. (2020); McCormack & McCann (2015); Thibault et al. (2023); Svensson et al. (2013); White et al. (2022); Whitney et al. (2005); Whitney et al. (2023); Williams et al. (2020)
	Relief at finding someone who understands	Beale et al. (2005); Cottee-Lane et al. (2004); Cribben et al. (2021); Svensson et al. (2013); White et al. (2022)
	Fractured family relationships	Cottee-Lane et al. (2004); Fox & Whittlesea (2017); Hillege et al. (2006); McCormack & McCann (2015); Svensson et al. (2013); Thibault et al. (2023); White et al. (2022); Whitney et al. (2005); Whitney et al. (2023); Williams et al. (2020)

	Relationships improving	Karlstad et al. (2021); McCormack & McCann (2015); Whitney et al. (2023)
Gratefulness		Beale et al. (2005); Cottee-Lane et al. (2004); Hillege et al. (2006); Karlstad et al. (2021); McCormack & McCann (2015); Svensson et al. (2013); Whitney et al. (2023)

Guilt

I've Failed as a Parent

Participants across many studies expressed feeling that their child developing an ED meant they had *failed as a parent*. Parents expressed feeling ashamed, and were self-critical, commenting that they *"should have picked up on it earlier"* as then *"it wouldn't ever have developed as bad as it was"* (Cottee-Lane et al., 2004, p.171). Participants blamed themselves for the ED, questioning if they had done *"something wrong as a parent to cause it"* (Whitney et al., 2023, p. 2641).

Judgemental, stigmatising, and inconsiderate comments from others exacerbated parental self-blame. These were described as comical at times: *"I was told you know if I'd kept my house tidier, M wouldn't have got anorexic"* (Beale et al., 2005, p. 130), but contributed to the mounting guilt experienced by parents, making them self-critical and doubting their capabilities.

Parents expressed an internal conflict around managing their child's ED. Parental guilt about the emotional impact on their child of making them eat was often relieved through accommodating ED behaviours: *"you have that emotional tie and your daughters sobbing...you can bend the rules. 'You have to have a banana...' and she would say 'oh mum look, have half with me' and I did it, and that was just a mistake"* (Bezance & Holliday, 2014, p. 391). Despite offering temporary relief and reducing conflict with their child in the moment, accommodating ED behaviours resulted in increased parental guilt and self-criticism. It further contributed to a sense of *failing as parents* by enabling ED behaviours which *"wasn't doing her any good, I wasn't being strong enough. Erm…I got angry at myself…it made me really upset…I suppose depressed...I wasn't being strong enough to fight her, or to fight the AN"* (Fox & Whittlesea, 2017, p. 496). As evidenced by this quote, these additional layers of guilt further contribute to parental distress, making it harder to cope. This fuels a vicious cycle of decreased emotional reserves and increasing likelihood of accommodating ED behaviours.

Neglecting Other Children

Parents expressed guilt about neglecting their other children and not providing them with enough care and attention when they were overly focused on their child with an ED: *"she was the one that was ill you had to give her all the attention that she needed, which deprived everyone else in the family of any really"* (Cottee-Lane et al., 2004, p. 174). They worried about the impact on their other children of living with a sibling with an ED, commenting on changes in sibling behaviours: *"she very rarely yells at somebody, and she was like, 'Stop it!' You know? That's rare. I think she just had had enough. I worry about her because this has to be affecting her in a bigger way"* (Whitney et al., 2023, p. 2646). The daily lives of siblings were interrupted, due to the child with the ED *"ruling the roost"* (Fox & Whittlesea, 2017, p. 494) resulting in siblings expressing *"worry, resentment, anger, shame and jealousy"* and being *"hesitant to bring friends over because at our place it was like a world war (going on) and shouting and doors being slammed"* (Svensson et al., 2013, p. 399). These additional worries added to parental distress, and their guilt was exacerbated by prioritising their child with an ED, while feeling helpless by their limited ability to protect their other children.

Overwhelm

Powerlessness and the Fight for Control

Across most studies participants felt *"controlled by the illness"* (Whitney et al., 2005, p. 446), resulting in high levels of overwhelm. Parents expressed feeling *"powerless"* in facing the ED, which *"defeated"* and *"bullied"* them, exerting control over the family. Some parents attributed this control directly to the ED, while others viewed their child as in control and manipulative.

Many parents resigned to a sense of powerlessness and helplessness: *"Nothing you do or say makes a difference"* (Whitney et al., 2005, p. 447), feeling they were a *"helpless bystander"* watching their child *"fade away"* (Fox & Whittlesea, 2017, p. 495). This contributed to low levels of self-efficacy, which was exacerbated by the relentlessness of EDs, described as vicious cycles*,* in which *"you get more and more exhausted and less and less able to cope"* (Konstantellou et al., 2022, p. 1343).

Parents described being *"bullied"* by the ED *"into just being so submissive that we've just accepted anything that (daughter) throws at us"* (Fox & Whittlesea, 2017, p. 497). Accepting their limits as a parent helped manage this powerlessness: *"she used to block you and just say 'no' and...there was literally no point in having the battle because you weren't going to budge her, you weren't going to win"* (White et al., 2022, p. 641). Parents spoke of "*picking their battles"* (White et al., 2022, p. 644) to reduce conflict and preserve emotional reserves, such as *"turning a blind eye to inappropriate calorie intake and accepting unconvincing excuses"* (Fox & Whittlesea, 2017, p. 496). However, despite the momentary benefits, in the longer term this accommodation fuelled the ED, resulting in increased powerlessness and loss of control, as well as the guilt described above.

Anxiety and Uncertainty

Across many studies parents spoke of an overwhelming sense of debilitating anxiety, questioning what they should be doing and worrying about their child's future. This was often associated with uncertainty about how to support someone with an ED as *"you don't know whether you're doing it right or not"* (White et al., 2022, p. 642). This anxiety was exacerbated when parents were expected to make decisions about their child's treatment that they felt unequipped to make: *"When should we call for urgent help?"* (Karlstad et al., 2021, p. 6). This uncertainty felt intolerable, being described as *"imprisoning"* and *"very scary"* (Konstantellou et al., 2022, p. 1343).

Participants expressed anxiety about the years it could take *"to readjust to normal life"* (Whitney et al., 2005, p. 445) and recover. Parents worried that *"there is no guarantee that full recovery will take place"* (Konstantellou et al., 2022, p. 1342) and struggled with knowing that "*there's potential, lifelong, for him to relapse"* (Whitney et al., 2023, p. 2642). This uncertainty links with the powerlessness described above by parents, who could do nothing to guarantee their child would live a life free of their ED. This adds to parental uncertainty, as their role as a carer may continue for life, and results in grief for the life lost by them and their child (see theme below). For some, this anxiety escalated to a fear of their child dying from their ED. Parents spoke of coming to terms with the severity of the ED, remembering *"the moment they realised that their daughter could or was going to die"* (Bezance & Holliday, 2014, p. 393).

Rock Bottom

As a result of this loss of control, powerlessness, anxiety and uncertainty, some parents felt completely overwhelmed by caring for their child, which felt like a *"living nightmare"* (Cottee-Lane et al., 2004, p. 173), and led to them reaching *"rock bottom"* (Bezance & Holliday, 2014, p. 392). Participants spoke of distress and hopelessness leading them to question whether life was worth living, burning out, reaching their limit and being on the verge of a breakdown (Beale et al., 2005; Cottee-Lane et al., 2004; Cribben et al, 2021; Fox & Whittlesea, 2017; Hillege et al., 2006; Karlstad et al., 2021; Loftfjell et al., 2020; McCormack & McCann, 2015; Svensson et al., 2013; Whitney et al., 2005). Others explicitly expressed death being the only escape: *"I really, I wanted to die...I couldn't bear looking at how ill she was...I wished I could die so I could be just away from the misery"* (Bezance & Holliday, 2014, p. 393). Parents turned to professional support including medication and psychological support to cope (Cribben et al., 2021; Karlstad et al., 2021).

Grief

A Changing Identity as a Parent

There was a sense of grief over the loss of *just* being a parent, as identities changed when parents had to "*play the role of mother, nurse, doctor and psychologist"* (Karlstad et al., 2021, p. 5). Juggling the roles of parent and carer was described as *"enormously difficult"* (White et al., 2022, p. 641). The ED was all-consuming, *"taking over their identities, and forcing their focus* *that was once dispersed between various values and passions onto their child with AN"* (Williams et al., 2020, p. 1826). This resulted in parents feeling they had lost themselves: *"I always thought I knew my purpose and I have no clue. I feel just as lost as he is"* (Whitney et al., 2023, p. 2643). Some parents spoke of *"some kind of enmeshment going on"* (Bezance & Holliday, 2014, p. 391), with their identity becoming entangled with their child, who was *"becoming like a mollusc to me"*.

To preserve their identity, some participants refrained from telling anyone outside of the family about the ED as it: *"consumed every other part of my life and I just wanted to go and just be me and not have to talk about it"* (Williams et al., 2020, p. 1826). This allowed moments of normality where they felt like their *"old selves"*.

The Lost Child

Parents often externalised the ED, separating it from their child and describing it as a *"monster", "alien",* or *"enemy"* which was "*taking over"* or *"possessing"* their child (Bezance & Holliday, 2014, p. 393; Cottee-Lane et al., 2004, p. 172; Whitney et al. 2005, p. 446). This appeared to contribute to the emotional pain of feeling they had lost a child: *"It's the illness that makes her like this, you know, the proper (daughter) when she isn't that ill is very kind, she's a lovely person…but the anorexic (daughter) is very difficult"* (Fox & Whittlesea, 2017, p. 493). Even in those who had recovered from their ED, where parents "*witnessed the reassertion of their child's personality",* the ED had "*left its legacy"* on their child and the family (Cottee-Lane et al., 2004, p. 173), highlighting its lasting power and control.

Parents also expressed grief for the *"zest for life"* (Thibault et al., 2023, p. 143) and missed opportunities the ED had taken from their child: *"Food is wonderful really I feel, and it's* *part of everything isn't it...It's a social thing...I just feel that she's missed out on all that for so many years really"* (Cottee-Lane et al., 2004, p. 173). Individuals with EDs became more dependent on their parents (Cribben et al., 2021; Svensson et al., 2013) and were described as having *"regressed emotionally and behaviourally"* (Fox & Whittlesea, 2017, p. 494) and having *"the caregiving needs required of a toddler"* (Whitney et al., 2023, p. 2647).

Sacrifices

Caring for a child with an ED required numerous sacrifices and was an *"upheaval"* to parents' lives (Thibault et al., 2023, p. 143), resulting in grief for life prior to the ED. Children needed parents' *"constant attention"* (Svensson et al., 2013, p. 398) meaning that *"work became pretty secondary"* (Bezance & Holliday, 2014, p. 391). Parents sacrificed other parts of their lives, including studying: *"I'm supposed to be doing a (course) this year and I haven't because I didn't think I could cope with (the child) being ill and studying as well"* (Cottee-Lane et al., 2004, p. 173); religious communities: *"We have been quite active in [our] church, me and my husband, but we [have] quit this all together"* (Svensson et al., 2013, p. 398); and holidays: *"We tried to go away this weekend for my birthday, but of course, wound up having to come home because of [son's behavior]."* (Whitney et al., 2023, p. 2645).

Participants sacrificed their social lives as *"living their full life as adults was taken away from them"* (Karlstad et al., 2021, p. 8). Mealtimes were exhausting, often taking multiple hours, and eating out or with people outside of the immediate family was no longer possible (Cottee-Lane et al., 2004; Loftfjell et al., 2020; McCormack & McCann, 2015; Svensson et al., 2013; Thibault et al., 2023; Whitney et al., 2023).

However, despite these sacrifices significantly impacting the lives of parents, resulting in the feeling that *"everything I did was eating disorder"* (Whitney et al., 2023, p. 2642), the overarching sense was that the child *"was always the priority"* (McCormack & McCann, 2015, p. 144). Everything parents did was with the aim of protecting their child and supporting them unconditionally: *"I think its coz it is your child coz you would do anything, it is such a deep instinct to protect your child"* (Konstantellou et al., 2022, p. 1343).

Isolation vs. Connection

Feeling Misunderstood

Several participants spoke of people trying to offer support, however *"very few people totally understand what you are going through"* (Whitney et al., 2005, p. 446), resulting in them feeling *"so alone"* (Hillege et al., 2005, p. 1020). Comments made by others when parents spoke about the ED, such as: *'blimey, oh god, you know that's a bit weird isn't it'* (White et al., 2022, p. 644) or: *'Oh well give her cake to eat'* (Hillege et al., 2005, p. 1020) felt judgemental, resulting in parents avoiding speaking to others about their child's ED.

The stigma surrounding EDs was central to parental isolation, and experiences were contrasted with caring for someone who was physically unwell: *"When someone has a broken leg, you get 'Get well' cards. When somebody has anorexia, you don't"* (Bezance & Holliday, 2014, p. 392). Among parents of a son with an ED, the stigma and judgment were even more apparent, as *"other people didn't know 'what to say or what to do because it was just so uncommon with boys'"* (Whitney et al., 2023, p. 2647).

This judgement and stigma contributed to the aforementioned parental guilt, fuelling their feelings of having *failed as parents*. As a result, parents withdrew and avoided contact with others, however this fed into a vicious cycle of increasing *isolation* and *feeling misunderstood*.

Relief at Finding Someone who Understands

Participants spoke of relief at hearing stories of other parents of individuals with EDs, which made them fell less alone. This came through reading books or articles, using online forums, and most powerfully, speaking with other parents who offered reassurance such as: *"that's fine, my daughter or my son does that"* (White et al., 2022, p. 644).

Connecting with other parents also provided a sense of hope that things could improve, knowing *"there is light at the end of the tunnel"* (Cottee-Lane et al., 2004, p. 176), and enabled parents to learn practical resources that may be useful. Furthermore, parents further along their journey with the ED spoke of *"making a difference in other people's lives"* (Beale et al., 2005, p. 131) by helping at carer support groups, which was a way of finding purpose from their lived experiences.

Fractured Family Relationships

Parental isolation was exacerbated by the impact of the ED on family relationships, including challenges in the relationship with their partner. The demands of caring for their child meant some parents *"were apart for many weeks"* with limited interaction: *"One of us was at the (hospital) ward, and one was at home [in another city]. On one occasion, we "changed guards" [on the highway] in separate cars, and gave each other a hug and that, well it was horrible"*

(Svensson et al., 2013, p. 398). Through prioritising their child, parents missed out on support from one another, increasing their isolation.

Parents often took different approaches in managing EDs, resulting in "*disharmony"* that *"negatively impacted on both the atmosphere in the home and the marital relationship"* (McCormack & McCann. 2015, p. 145). Mothers often felt they carried the main burden of caring, while their partner distanced themselves or did not understand: *"to this day, he still has no comprehension of what it really is. He runs away and kind of leaves me holding the bag"* (Whitney et al., 2023, p. 2645). These challenges in parental relationships resulted in hurt, frustration, and arguments, and several participants spoke of this leading to relationship breakdowns, separation, or divorce.

In terms of the impact on the relationship with their child, parents spoke of "*feeling targeted",* and *"previously close relationships that were now tension-ridden"* (Whitney et al., 2023, p. 2646). Mealtimes were a significant trigger for conflict, often described using battlefield metaphors. Frustration and anger towards their child and the ED were common among parents, further impacting their relationships.

Parents accepted and minimised hurtful comments, as the most important thing was ensuring their child ate: *"So as hard as it was, we had to [make sure he ate]. It didn't matter [if] he called me names, if he hated me, if he didn't talk to me for 3 days. It hurt more than anything I've ever experienced but it didn't change what we knew we had to do"* (Whitney et al., 2023, p. 2646).

This quote highlights that despite the tension and conflict around mealtimes, which were understandably "*'absolutely horrible', 'really stressful', 'painful'* and *'frightening'"* (White et al., 2022, p. 640), parents understood this in the context of the ED and continued to put their child's recovery first.

Relationships Improving

Despite the fractured relationships experienced by many, some parents further along the ED journey reflected on improvements in family relationships. Participants spoke of the family being unified through a shared experience which only they could understand: *"The four of us are very closely connected, because we have been through so many sad and difficult things"* (Karlstad et al., 2021, p. 7). Across studies, improved relationships were noted between the whole family, parents, siblings and with the child with the ED.

Contributing to this closeness, *"parents perceived that communication patterns within the family had improved having gone through this experience"* (McCormack & McCann, 2015, p. 145), with participants sharing that within the family *"there is nothing we have not talked about"* (Karlstad et al., 2021, p. 7).

Gratefulness

The final theme encapsulates a sense of gratitude expressed by parents for what they had gained from caring for a child with an ED. However, this theme was not present in all studies, with some only contributing to the more negative emotional experiences outlined above.

Some parents expressed appreciation for their personal growth, including having *"more gratitude, and increased empathy for others"* (Whitney et al., 2023, p. 2642), *"understanding of different perspectives"* (Beale et al., 2005, p. 131), becoming *"a calmer person"* (Whitney et al., 2023, p. 2642), showing *"remarkable resourcefulness"* (Cottee-Lane et al., 2004, p. 176), *“resilience”* (Beale et al., 2005, p. 130; Svensson et al., 2013, p. 401) and *“determination, loyalty and love”* (Beale et al., 2005, p. 130). Parents also reflected on a newfound gratitude for what *“really mattered”*, that their child was *“healthy, happy and loving, and productive”* (Whitney et al., 2023, p. 2642). There was also a sense of hope among parents that their child would grow through the experience: *“I hope for her that she has gained back a lot of her own self-esteem and feeling better about herself and stronger”* (McCormack & McCann, 2015, p. 145).

Despite the challenges they faced, this theme highlights the resilience and strength of parents being able to *“endure difficult days”* (Svensson et al., 2013, p. 404) and reflect on positives amidst their overwhelming distress, continuing to support their child unconditionally.

Discussion

This report systematically reviewed parental emotional experiences of caring for a child with an ED. A thematic synthesis of 16 studies identified 5 themes: guilt, overwhelm, grief, isolation vs connection, and gratefulness, and 12 subthemes. The findings will be discussed in line with existing literature, with clinical and research implications, and the review's strengths and limitations, also discussed.

Summary of Findings

Aligning with previous research investigating broader experiences of caring for individuals with EDs, the findings of this review highlight the significant challenges and distress faced by parents, and a reflection by some on their personal growth (Anastasiadou et al., 2014; Fox et al., 2017; Quong & Chen, 2015).

Parents expressed significant **guilt** due to feeling responsible for the ED and its effects on the family. Many parents were self-critical, believing that their child's ED resulted from failings in their parenting. High levels of self-blame, guilt and carer burden have also been found among parents of those with other mental health difficulties (Moses, 2010).

Parental accommodation of ED behaviours fuels EDs, thereby adding to carer burden. Parental emotional responses to their accommodation also exacerbates their distress, by increasing feelings of guilt, responsibility, and self-criticism as they realise their role in enabling the ED. While **guilt** among carers of individuals with EDs has been discussed previously (Fox et al., 2017; Quong & Chen, 2018), the understanding that parental accommodation of ED behaviours further contributes to **guilt** and self-criticism was novel in this review. Given that higher levels of self-blame among parents of those with EDs result in more parental accommodation of ED behaviours (Stillar et al., 2016), these factors associated with parental distress are important to consider alongside Schmidt and Treasure's (2006) cognitive-interpersonal maintenance model.

Feelings of ***powerlessness*** coupled with ***anxiety and uncertainty*** about how to support their child and the trajectory of the ED, resulted in parents feeling unable to cope, culminating in them reaching ***rock bottom***. These subthemes contribute to the overarching experience of parental **overwhelm**. Similarly, parents of children with other additional needs, including autism, ADHD, learning disabilities and anxiety disorders have higher stress levels and poorer mental health than those with children without additional needs (Craig et al., 2016; Derisley et al., 2005).

Parents expressed overarching **grief**, both for themselves and their child, further contributing to their distress. The losses contributing to this **grief** reflect findings from previous reviews on experiences of carers for individuals with an ED (Fox et al., 2017; Quong & Chen, 2018), and in parents of children with other additional needs, including cerebral palsy (Smith & Blamires, 2022) and autism (O'Brien, 2007). Nevertheless, despite their grief and sacrifices, parents expressed that their child remained their priority, and they would support them unconditionally.

Many parents felt misunderstood, resulting in a sense of **isolation**. Stigmatising and judgemental comments contributed to this, also leaving parents feeling blamed and exacerbating the guilt described above. Isolation is common among caregivers, including parents of children with chronic health conditions (Kratz et al., 2009), autism (Kinnear et al., 2016), and carers of individuals with significant mental illness (Guan et al., 2023). While beyond the scope of this review, research into parental experiences of ED services and treatment suggests that interactions with services can contribute to their isolation when they feel inadequately supported (Fox et al., 2017). **Connecting** with other parents of ED sufferers was important for parents in managing isolation and finding people who understood.

Some parents spoke of ***fractured relationships***, both with the individual with the ED, and their partners. This aligns with previous research (Fox et al., 2017; Quong & Chen, 2018), where conflict and challenging relationships within families with an individual with an ED were evident. However, others reflected on improved relationships and greater levels of ***connection*** within the family. Some parents expressed a shared family resilience, feeling closer due to the ED and having improved communication. This theme highlights the journey of parenting a child with an ED, filled with significant challenges and distress, but also an opportunity for growth.

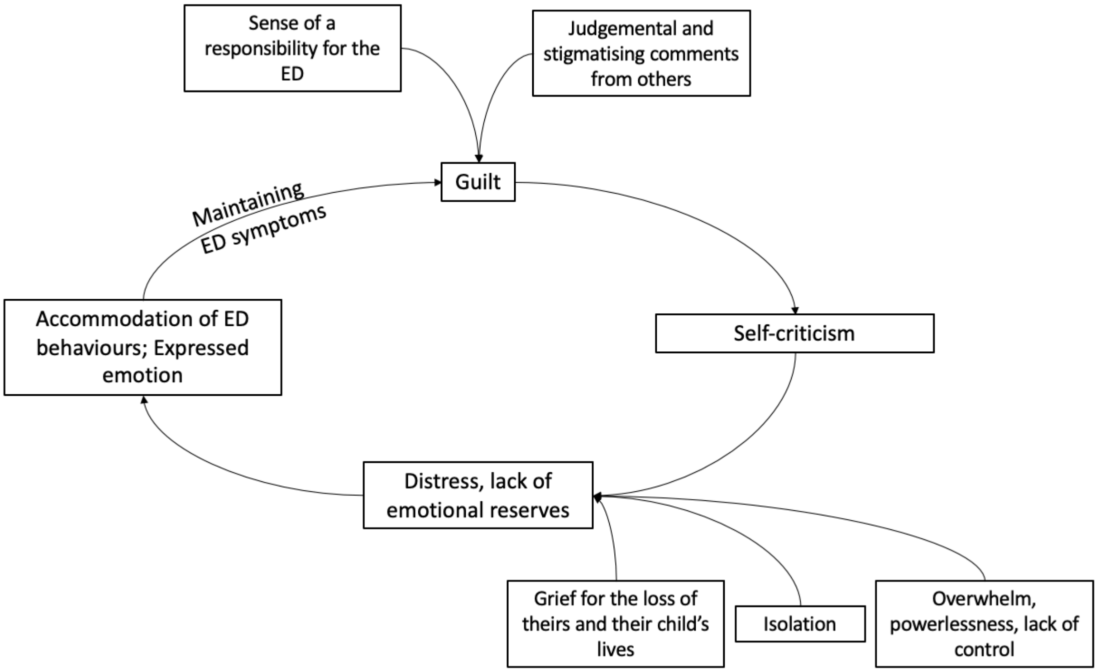
This was highlighted in the final theme, **gratitude**, whereby parents reflected on their own growth through the experience of parenting someone with an ED. The ability for this reflection and finding positives out of such a challenging experience highlights the strength and resilience of these parents. Previous research supports this, with the development of theories around parents adapting to supporting someone with an ED and recognising their strength (Fox et al., 2017), as well as reflecting on their personal growth (Quong & Chen, 2018). However, it is important to note that not all studies reviewed contributed to this theme of **gratitude**. In several studies, parents reflected solely on the negative impact of their child's ED. It may be that these parents were earlier in the ED journey, or that the pain of the experience overwhelmed the possibility to reflect on any positives.

Hypothesised Theoretical Model

As outlined, this review has identified several factors contributing to parental distress when caring for their child with an ED. A preliminary theoretical model was generated, building on Schmidt and Treasure's (2006) cognitive-interpersonal maintenance model, based on the findings of this review and hypotheses about how factors interact and maintain parental distress (figure 3).

Figure 3

Hypothesised Model Depicting Maintenance of Parental Distress and Child ED Symptoms



Parental guilt appears to stem from feeling responsible for their child's ED, which may be exacerbated by judgemental and stigmatising comments. This may result in self-criticism and feeling they have failed as parents. Understandably, such self-critical thoughts are distressing, and when combined with additional distress from the grief, isolation and overwhelm identified in this review, parents may experience high levels of carer burden and have reduced emotional reserves.

As a result of feeling unable to cope with their child's ED, parents may try to maintain emotional reserves by "picking their battles" and accommodating ED behaviours. While this is an attempt to maintain their relationship with their child, decrease guilt around causing their child distress and reduce conflict within the family, longer term it enables the ED. This may further exacerbate guilt and feelings of failure at managing the ED, increasing parental self-criticism as they realise their role in enabling the ED, thus fuelling a vicious cycle. While not explicitly explored in this review, the distress experienced by parents could also be hypothesised to contribute to increased EE. This would align with Schmidt and Treasure's (2006) cognitive-interpersonal maintenance model, and with previous research finding a relationship between increased parental distress and higher EE (Duclos et al., 2012; Millman et al., 2018).

Review Strengths and Limitations

This review investigated emotional experiences of parents of ED sufferers, providing a more focused literature review than previous reviews considering more general experiences of caregivers of people with an ED. Given the unique role of parents in supporting individuals with EDs, it was important to separate their experiences from research involving other caregivers.

One limitation lies in the lack of diversity of participants in the reviewed studies. The under-representation of non-white participants and those with lower SES, and the general lack of reporting of demographics, is concerning. Psychological research has frequently been criticised for a lack of diversity in participants and perpetuating systemic inequality (Tindle, 2021; Roberts et al., 2020). Research into EDs specifically often fuels stereotypical beliefs that EDs predominantly affect white, females, from affluent backgrounds (Pike et al., 2013), despite the growing evidence that this is inaccurate (Halbeisen et al., 2022). The reviewed studies align with this, limiting the generalisability of the findings.

In addition, the reviewed studies included parents of individuals with a range of ED diagnoses. While there is likely some overlap in the experience of parenting individuals with different ED diagnoses, there may also be specifics of different diagnoses, which would benefit from further exploration.

This review did not include studies focusing predominantly on parental experiences of interacting with ED services or being involved in ED treatment. This was because the aim was explicitly to focus on the emotional experiences of caring for their child, rather than also interactions with professionals. However, relationships with services and involvement with treatment may also have an emotional impact on parents, potentially contributing to the experiences discussed in this review.

The quality of studies included in the review varied, potentially limiting the value of the findings. Nevertheless, the CASP quality assessment tool deemed all studies of sufficient quality to be included in the review.

Given the qualitative analysis used in the review, steps were taken to decrease researcher bias. However, interpretations of the data by the researcher inevitably hold a degree of subjectivity and may be biased by the researcher's previous experiences.

Research Implications

The lack of diversity of participants in the reviewed studies highlights the importance of the recent plea for diversity in ED research (Halbesien et al., 2022), with a need for future research focusing specifically on emotional experiences of parents of groups underrepresented in ED research.

Given that some parents reflected on their growth through the experience of caring for a child with an ED, future research could explore this explicitly, to gain insight into parents' understandings of what helped them and contributed to this growth. This may help inform future parent-focused interventions.

The hypothesised model depicted in Figure 3 could be used to inform future research. Given the centrality of guilt and self-criticism to the distress experienced by parents, which in turn is hypothesised to impact on child ED symptoms, future research could focus more explicitly on this. Interest in self-criticism, and its antidote, self-compassion, among caregivers is growing, with an intergenerational model proposed by Lathren et al. (2020) proposing that parental self-compassion influences responses to their child's difficult emotions, which in turn impacts the child's emotions and behaviours. Future research in ED populations could therefore investigate the relationships between parental self-criticism and self-compassion, responses to their child's ED behaviours and ED symptoms.

Clinical Implications

Given the significant distress experienced by parents caring for a child with an ED, it is important for clinicians to understand the extent and breadth of the emotional experiences of parents in this role. This should be considered alongside NICE guidelines (2017) for including family members in ED treatment.

Connecting with others in a similar situation was highly valued by parents, therefore services could consider how this could become more central in ED treatment.

The levels of distress expressed by many parents would have required additional support, therefore more consideration into how parents can be supported with their own distress alongside supporting their child is essential. Given the findings that accommodation of ED behaviours can stem from parents feeling unable to cope, and the knock-on effect of this both on strengthening ED behaviours and on parental distress through exacerbating their guilt, supporting parents to cope is highly important.

Conclusions

Overall, this review built on previous literature exploring caregiver experiences of supporting an individual with an ED, by focusing specifically on the emotional experiences of parents. Five overarching themes were derived, along with 12 subthemes. These reflect the distress experienced by parents caring for a child with an ED, and how for some, this resulted in personal growth for which they were grateful. A theoretical model linking self-criticism and guilt with parental distress and responses to ED behaviours was developed, which may inform future research.

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LIZZIE NEELY BSc (Hons)

EXPLORING EXPERIENCES OF PARENTS OF INDIVIDUALS WITH AN EATING DISORDER

Section B: Beliefs about Emotions, Self-Compassion, and Emotion-Related Parenting Practices in Primary Caregivers of Young People with an Eating Disorder

Word Count: 8000 (38)

For submission to the International Journal of Eating Disorders

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

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SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Abstract

Objective: This study aimed to investigate the relationships between beliefs about emotions, self-compassion, expressed emotion, responses to child negative emotions and child eating disorder symptoms, in primary caregivers of young people with an eating disorder. **Method:** The study had a cross-sectional design. Eighty-six parents of young people with an eating disorder from the UK were recruited via NHS eating disorder services, eating disorder charities, and carer support groups. Participants completed an online battery of five questionnaires assessing beliefs about emotions, self-compassion, expressed emotion, responses to child negative emotions and child eating disorder symptoms. **Results:** Descriptive statistics showed high levels of expressed emotion within the sample compared to norms. Mediation analyses found an indirect relationship between parental beliefs about emotions and child eating disorder symptoms via expressed emotion. Parental beliefs about emotions were also found to significantly predict parental self-compassion. **Discussion:** The findings indicate a potential role for adding a self-compassion focused element to interventions for primary caregivers of young people with an eating disorder. There may also be a role for targeting beliefs about emotions in compassion-focused interventions, as holding more negative beliefs about emotions may be a barrier to the development of self-compassion. Further research is recommended to better understand whether improving self-compassion in primary caregivers of young people with an eating disorder could improve their psychological well-being and eating disorder symptoms in their child.

Keywords: primary caregivers; eating disorders; self-compassion; beliefs about emotions; emotion-related parenting practices

Introduction

Eating disorders (EDs), a group of psychological disorders characterised by disordered eating behaviours and associated psychological distress, significantly impact both sufferers and caregivers. Commonly diagnosed in adolescence (Breton et al., 2022), EDs often have long, chronic trajectories (Miskovic-Wheatley et al., 2023). This places parents in a central yet challenging role in their child's recovery, often extending into adulthood, which can cause significant distress for parents and result in strained family relationships (Holtom-Viesel & Allan, 2014). As recommended by the National Institute for Health and Care Excellence (NICE, 2017), treatment for EDs in young people (YP) generally involves family-based approaches. However, the high levels of chronicity and relapse among ED sufferers underscore the need for improved treatments.

Caring for a child with an ED often involves significant sacrifices by parents, alongside guilt, self-blame, and worry (Neely, 2024, Part A). ED interventions need to recognise and address this parental distress, which, in addition to affecting parental well-being, is theorised to influence responses to child ED behaviours, such as expressed emotion (EE) and accommodation of ED behaviours, which perpetuate ED symptoms. This is highlighted in Treasure and Schmidt's cognitive-interpersonal maintenance model (2013; Figure 1). Neely (2024) further suggest that parental distress, resulting in ED-maintaining responses, may be compounded by emotions like guilt and grief. These emotions arise from parents' internal processes of over-responsibility and self-criticism, as well as their resulting parenting behaviours (Figure 2).

Figure 1

Treasure and Schmidt's (2013) Formulation of Carer Involvement in ED Maintenance

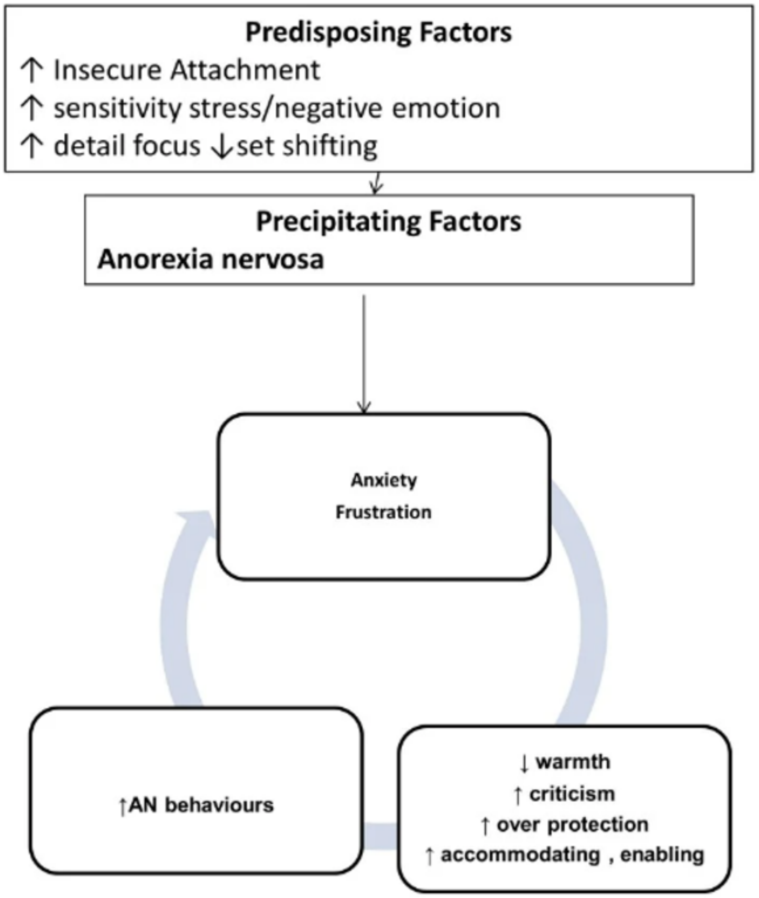
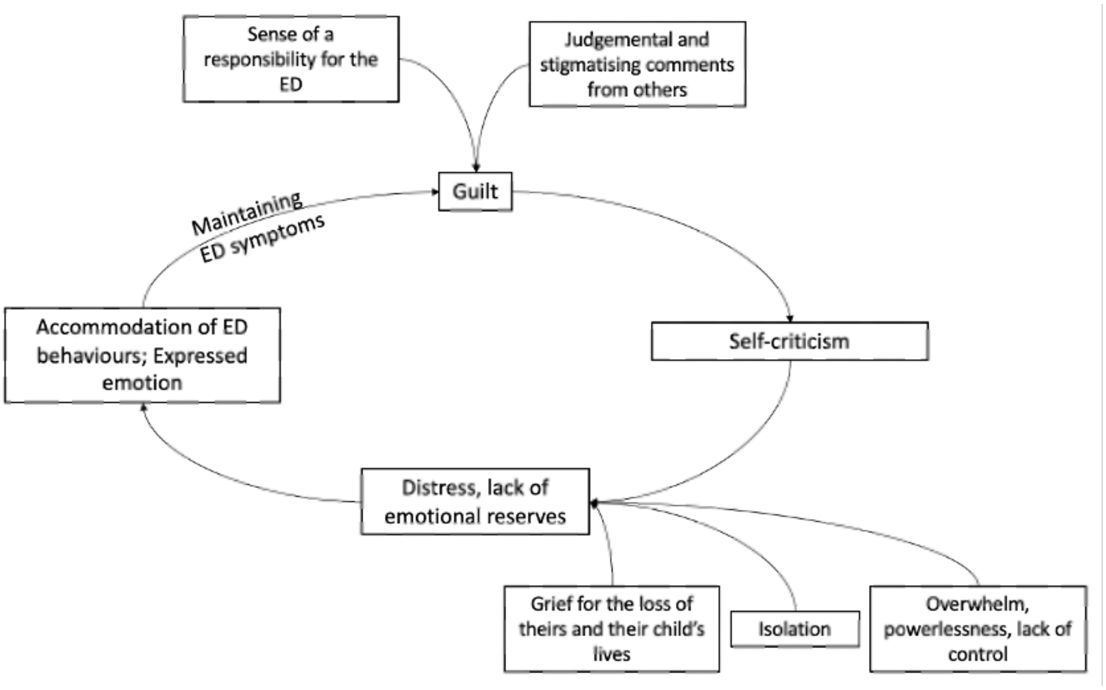


Figure 2

Cycle of Factors Contributing to Parental Distress and ED Maintenance (Neely, 2024)



It is well-established that carers for those with EDs experience distress. However, the mechanisms through which this distress contributes to parental responses to and maintenance of ED symptoms, as well as potential ways to interrupt the maintenance cycles depicted above, are less well-understood. Better understanding this, and considering ways of reducing distress, guilt, and self-criticism in carers, has the potential to open new ways to positively intervene and interrupt the above cycles. This could contribute to a research base aiming to improve interventions for those affected by EDs, aligning with the NHS value of 'improving lives'.

Expressed Emotion

Parents play a significant role in fostering the development of healthy emotional regulation strategies in their children, in turn positively impacting their child's well-being (Eisenberg et al., 1998). Emotion regulation difficulties are increasingly theorised as factors in EDs, including anorexia nervosa (AN; Oldershaw et al., 2015), binge eating disorder (BED; Leehr et al., 2015) and bulimia nervosa (BN; Lavender et al., 2015). ED behaviours can be understood as emotion regulation strategies; for instance, increased focus on food, weight, and shape may serve as emotional avoidance (Oldershaw et al., 2019), and binge eating can involve using food to temporarily alleviate negative emotions (Leehr et al., 2015). Emotion socialisation in families of YP with EDs has therefore been an area of research interest in understanding EDs.

EE, the emotional climate within the family and how others interact with the individual with the ED, is one factor impacting emotional regulation (Morris et al., 2007) and has been central in ED research. High EE reflects problematic interpersonal dynamics, characterised by critical comments, hostility and emotional overinvolvement (Rienecke, 2018).

Higher EE has been found in families of individuals with EDs compared to controls and predicts treatment drop-out and poorer outcomes in ED sufferers (Duclos et al., 2012). EE was previously interpreted as a causal factor in EDs, contributing to a narrative of blaming parents. However, it is better understood as an emotional atmosphere arising within the family while living with and supporting someone with an ED (Rienecke, 2018). As highlighted in the above models, EE is theorised to contribute to the maintenance of ED symptoms and parental distress, thus making it important to consider.

Parental Responses to Negative Emotions

Parents also contribute to their child’s emotion regulation development through their reactions to their child’s emotions (Morris et al., 2007). Gottman et al. (1996) proposed the idea of parent meta-emotion philosophy (PMEP), encompassing parental beliefs and attitudes towards emotions, which influence their responses to their child's negative emotions. Emotion-coaching PMEP involves supportive reactions, acknowledging and encouraging the expression of negative emotions, and helping children develop coping strategies. Conversely, emotion-dismissing PMEP involves non-supportive responses, including ignoring or minimising emotions.

Research has found lower levels of emotion-coaching PMEP among parents of adolescents with anxiety disorders (Hurrell et al., 2017) and depression (Katz & Hunter, 2007) compared to controls, suggesting that supportive responses to child negative emotions may mitigate negative socio-emotional outcomes. Research into parental emotional socialisation in ED populations has not specifically assessed PMEP, however retrospective studies indicate that parental non-supportive responses and invalidation of negative emotions are associated with increased ED psychopathology (Mountford et al., 2007). This highlights the importance of not only considering parental responses to ED behaviours, but also responses to negative emotions in ED sufferers.

Emotion-focused family therapy (EFFT), an intervention developed for ED populations, builds on emotion-coaching principles, aiming to support parents of ED sufferers in developing their emotion-coaching skills (Robinson et al., 2015). EFFT has shown promise in increasing parental self-efficacy, decreasing fears about parental roles in supporting their child’s ED recovery (LaFrance Robinson et al., 2014), and reduced accommodation of ED behaviours (Nash et al., 2020).

The aforementioned research emphasises the vital role for parents in shaping their child's emotional socialisation and developing adaptive emotion regulation. However, less well-understood are potential protective factors which could enhance parental capacity to respond supportively to their child's negative emotions and prevent increased EE. When experiencing distress, individuals become more reactive, impacting parental caregiving instincts (Siegel, 2010). When parenting a child with an ED, this may result in less supportive responses to negative emotions and ED behaviours, and increased EE (Stillar et al., 2016). Therefore, supporting parents to develop more adaptive responses to their own distress may also influence their responses to their child's ED behaviours and emotions, potentially interrupting Treasure and Schmidt's vicious cycle.

Self-Compassion; an Antidote to Guilt, Self-criticism & Distress

In response to distress and perceived parenting mistakes, parents can become self-critical, which involves being excessively harsh and critical towards oneself, resulting in persistent feelings of inadequacy and negative self-talk (Wakelin et al., 2022). Self-criticism often occurs in response to feelings of shame and guilt about one's perceived failures and has been associated with distress trans-diagnostically (Loew et al., 2020). Such emotional responses may impact on parenting behaviours. For example, guilt was associated with the emotional-overinvolvement component of EE among carers of those with mental health difficulties, suggesting caregivers may engage in behaviours aimed at reducing their perceived responsibility for their loved one's suffering (Cherry et al., 2017).

Interest is growing in self-compassion, an antidote to self-criticism, comprising the ability to treat oneself with kindness, have a sense of common humanity, and be mindful (Neff, 2003a).

Self-compassion may be a marker of how one responds to their own emotions, with individuals who are more accepting of the range of emotions potentially more able to respond self-compassionately to distress. Meta-analyses indicate higher self-compassion is associated with better psychological well-being (Zessin et al., 2015) and lower levels of depression, anxiety, and stress (MacBeth & Gumley, 2012). Compassion-focused interventions have shown promising results among those with EDs, depression and psychosis (Craig et al., 2020). They are effective at reducing self-criticism (Wakelin et al., 2022) and negative emotions including guilt and shame (Arimitsu & Hofmann, 2017). Additionally, parenting interventions with a self-compassion component found improvements in depression, anxiety, stress, and mindfulness (Jefferson et al., 2020), suggesting self-compassion may be protective against parental distress.

Early evidence suggests self-compassion may also impact parenting practices. While not specific to parents of ED sufferers, higher parental self-compassion is associated with mindful parenting, a parenting approach prioritising a non-judgemental awareness of the present moment to interactions with one's child, and a compassionate relationship with oneself (Gouveia et al., 2016; Moreira et al., 2016). Mindful parenting has also been linked to supportive parental responses (in line with emotion-coaching principles) to their child's distress (McKee et al., 2018). This provides early evidence for a relationship between parental self-compassion and emotion-related parenting practices that encourage adaptive emotional regulation strategies. Furthermore, in parents of ED sufferers, higher self-compassion was associated with less severe child ED symptoms, via lower EE (Coleman et al., 2022). Taken together, in the context of parenting a child with an ED these findings lend support to a model whereby parental self-compassion may be associated with child ED symptoms, via EE and parental responses to their child's negative emotions.

Parental Beliefs About Emotions

Gottman et al. (1996) suggest that parental beliefs about the acceptability of emotions in themselves and their child guide their responses to their child's emotions. This aligns with Eisenberg et al.'s (1998) heuristic model of emotion socialisation, where beliefs about emotions are proposed as a parent factor impacting reactions to their child's emotions. Emotion-coaching PMEP is rooted in beliefs about negative emotions being opportunities for teaching, while emotion-dismissing PMEP is underlined by fears of the harm of negative emotions (Gottman et al., 1996).

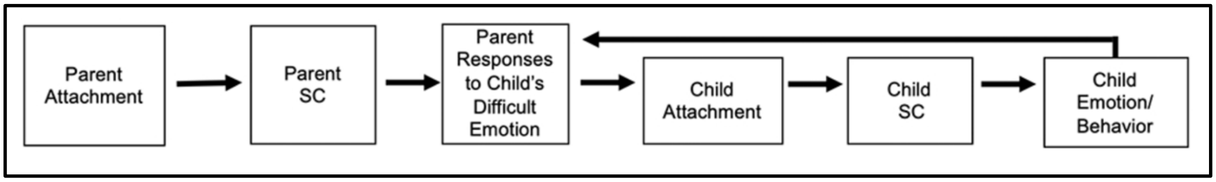
Such beliefs also likely influence parental responses to their own emotional distress. Accepting and appreciating all emotions within oneself is central to the idea of mindfulness (Khong, 2011), a core component of self-compassion, thus being more accepting of all emotions may result in more self-compassionate responses to one's negative emotions. Conversely, having stronger beliefs that experiencing or expressing negative emotions is unacceptable, has been associated with anxiety, depression and fatigue, and this relationship is mediated by self-compassion (Sydenham et al., 2016). Individuals holding stronger beliefs about the unacceptability of negative emotions may therefore be more dismissive of their emotions, responding less self-compassionately to distress.

Parental beliefs about emotions (PBAE) may therefore impact their responses to their child's negative emotions through multiple pathways. Firstly, those holding more negative beliefs about negative emotions may respond less supportively to their child's distress. In addition, these parents may have lower levels of self-compassion, in turn potentially contributing to less supportive responses to negative emotions and higher EE.

Lathren et al. (2020) proposed an intergenerational theoretical model linking parental self-compassion with child emotional and behavioural difficulties. They hypothesise that higher parental self-compassion predicts more supportive responses to child difficult emotions, in turn resulting in more secure child attachments, higher child self-compassion, and less child emotional and behavioural problems (see figure 3). Within this model, PBAE are viewed as a response to child emotions. However, as highlighted through the literature reviewed above, PBAE may be better understood as influencing responses to their own and their child's emotions.

Figure 3

Lathren et al.'s (2020) Intergenerational Model of Self-Compassion



Note. SC=self-compassion; 'parent responses' include expressed emotion, behaviours, and beliefs about difficult emotions; 'child emotion/behaviour' includes child emotion regulation skills and internalizing/externalizing symptoms.

Rationale and Hypotheses

Taken together, the literature reviewed proposes self-compassion as a potential protective factor from the outlined cycle of guilt, self-criticism, distress, and parental responses to ED behaviours (figure 2). Furthermore, the literature suggests that PBAE may be an additional maintenance factor in the cycle. More negative PBAE may be a risk factor for increased parental distress and less supportive responses to their child's emotions, potentially further contributing to ED symptom maintenance. Again, increasing self-compassion may be protective in this cycle.

To date, the relationship between PBAE, self-compassion, and emotion-related parenting practices[2] in an ED population remains under-researched. Except the aforementioned study by Coleman and colleagues (2022), which lends preliminary support to associations between parental self-compassion and child ED symptoms, via EE, to the author's knowledge no other research has investigated these variables together.

The present study therefore aimed to investigate the relationships between PBAE, self-compassion, EE, responses to child negative emotions and ED symptoms, among primary caregivers (PCs) of YP with an ED.

In addition to exploring correlational relationships, the study aimed to answer three research questions:

1. Do emotion-related parenting practices mediate the relationship between parental self-compassion and child ED symptoms?
2. Does parental self-compassion mediate the relationship between PBAE and emotion-related parenting practices?
3. Do parental self-compassion and emotion-related parenting practices mediate the relationship between PBAE and child ED symptoms?

There were three specific hypotheses related to these research questions.

Hypothesis 1: Emotion-related parenting practices are expected to mediate the relationship between parental self-compassion and child ED symptoms.

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[2] Emotion-related parenting practices includes responses to child negative emotions and EE.

a) EE is expected to mediate the relationship between parental self-compassion and child ED symptoms.

b) Parental supportive responses to child negative emotions are expected to mediate the relationship between parental self-compassion and child ED symptoms.

c) Parental non-supportive responses[3] to child negative emotions are expected to mediate the relationship between parental self-compassion and child ED symptoms.

Hypothesis 2: Parental self-compassion will mediate the relationships between PBAE and emotion-related parenting practices.

a) Parental self-compassion will mediate the relationship between PBAE and EE.

b) Parental self-compassion will mediate the relationship between PBAE and supportive responses to child negative emotions.

c) Parental self-compassion will mediate the relationship between PBAE and non-supportive responses to child negative emotions.

Hypothesis 3: PBAE are expected to indirectly affect child ED symptoms, mediated by parental self-compassion, EE, and parental supportive and non-supportive responses to child negative emotions.

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[3] As described in measures section below, supportive and non-supportive responses to child negative emotions were measured as two separated constructs due to the questionnaire used.

Methods

Design

The study used a cross-sectional questionnaire design, with participants completing self-report measures. Given the cross-sectional design, regression analyses were used to examine associations between variables, rather than determine causality. The term ‘predictor’ throughout this paper refers to this statistical relationship rather than implying causality.

Participants

Participants were recruited via two NHS ED services which shared a recruitment flyer (Appendix D) with eligible parents and carers, who could self-refer to participate. Additionally, the study was advertised on social media, by ED charities (including BEAT) and among ED carer support groups.

Eligible participants were self-reported PCs of young people (YP) aged 13-19 with a diagnosed ED. PCs of YP with co-morbid mental health diagnoses were eligible if the ED was the primary issue.

Consent to participate was provided by 161 participants, however 30 were excluded due to not meeting screening criteria and 45 did not complete the full questionnaire battery. In total, 86 participants (78 mothers and 8 fathers) were included in the study, with a mean age of 49.4 years (SD=5.7). Table 1 in the results section provides additional demographic information for included participants.

Procedures

Ethical approval was granted by the Surrey NHS Research Ethics Committee (Appendix E). All participants provided informed consent online before completing the questionnaires. They were informed they could withdraw before submitting their completed questionnaires by closing their internet browser, but once submitted withdrawal was not possible due to the responses being anonymous.

The information sheet alerted participants that some questions may increase their awareness of the difficulties faced by them and their child, which may be distressing. Signposting information for further support was provided to all participants, in the information sheet and again upon completing the study.

Parents of YP with an ED attended a focus group to consult on recruitment procedures and inform the phrasing of information shared with participants.

The online study page, created using Gorilla questionnaire software, included an information sheet (Appendix F), consent form (Appendix G), and screening questions (Appendix H), followed by the questionnaires. Participants accessed this page via a link or QR code from the recruitment poster. Interested participants were invited to read the information sheet, complete the online consent form, and screening questionnaires. Individuals not meeting eligibility criteria based on the screening questions were thanked for their interest and informed they were not eligible to participate. Eligible participants were informed that the study would take around 30 minutes and must be completed in one session, therefore were advised to start the questionnaires later if needed.

The study included demographic questions (Appendix I), five validated questionnaires (see measures section), and a debrief sheet (Appendix J). Participants could enter a £50 gift voucher draw and opt to be sent a summary of the study results (Appendix K). These options required participants to provide an email address, which they were informed would be stored separately from their questionnaire responses, therefore would not be linked.

Measures

Child Eating Disorder Symptoms

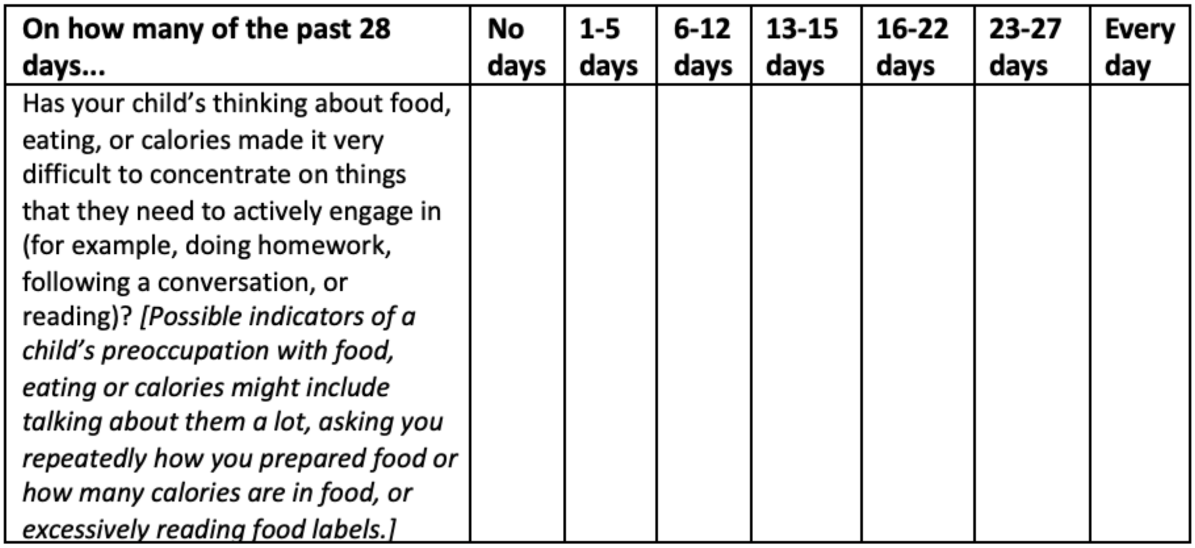
The Parent Eating Disorder Examination Questionnaire (PEDE-Q; Drury et al., 2023; Appendix L) is a 28-item parent-report measure of their child's ED symptoms, mirroring the self-reported eating disorder examination questionnaire (EDE-Q; Fairburn & Beglin, 2008) in content and scoring. Respondents rate their child's ED symptoms and behaviours over the past 28 days, with behavioural indicators for questions related predominantly to a child's internal experience provided (see Figure 4). Ratings are based on a 7-point scale to indicate either severity (0=Not at all; 6=Markedly) or frequency (0=No days; 6=Every day).

The questionnaire provides four subscales (restraint, eating concern, shape concern and weight concern), and a global score, with higher scores indicating more severe ED symptoms. The PEDE-Q subscales significantly correlate with the same widely used EDE-Q subscales, suggesting adequate convergent validity, and the PEDE-Q global score more accurately identified AN than the EDE-Q global score, suggesting it may be more diagnostically accurate Drury et al., 2023). The PEDE-Q global score was the variable used in this study.

Chronbach's alpha coefficients for the subscales and global score in parents of children with an ED range from acceptable to excellent (.73-.90), which is comparable to the EDE-Q (Drury et al., 2023).

Figure 4

Example PEDE-Q Question (Including Behavioural Indicators)



On how many of the past 28 days...	No days	1-5 days	6-12 days	13-15 days	16-22 days	23-27 days	Every day
Has your child's thinking about food, eating, or calories made it very difficult to concentrate on things that they need to actively engage in (for example, doing homework, following a conversation, or reading)? *[Possible indicators of a child's preoccupation with food, eating or calories might include talking about them a lot, asking you repeatedly how you prepared food or how many calories are in food, or excessively reading food labels.]*							

Expressed Emotion

The family questionnaire expressed emotion (FQ-EE; Wiedemann et al., 2002; Appendix M), is a 20-item self-report questionnaire, used to assess EE. Respondents rate statements relating to criticism (e.g. *he/she irritates me*) and emotional overinvolvement (e.g. *I tend to neglect myself because of him/her*) on a 4-point scale (1=never/very rarely; 2=rarely; 3=often; 4=very often). The FQ-EE provides 2 sub-scales (criticism and emotional overinvolvement) and an overall EE score, with higher scores indicating higher EE. The overall EE score was the variable used in this study.

Originally designed for families of individuals with Schizophrenia, the FQ-EE has good internal consistency, with Chronbach's alpha coefficients ranging from .78-.92. It has been widely used in ED populations with similar internal consistencies (e.g., Kyriacou et al., 2008).

Parental Beliefs About Emotions

The beliefs about emotions scale (BES; Rimes & Chalder, 2010; Appendix N) is a 12-item self-report questionnaire assessing beliefs about the acceptability of experiencing and expressing emotions (e.g. *It is stupid to have miserable thoughts*). Respondents rate questions on a 7-point scale (0=totally disagree; 6=totally agree), and scores are summed to a total score, with higher scores indicating stronger beliefs about the unacceptability of emotions.

The scale was validated in individuals with chronic fatigue syndrome and healthy controls and had high internal consistency (α=.91). In studies involving individuals with EDs it demonstrates similarly high internal consistency (α=.91; Hambrook et al., 2011)

Parental Responses to Child Emotions

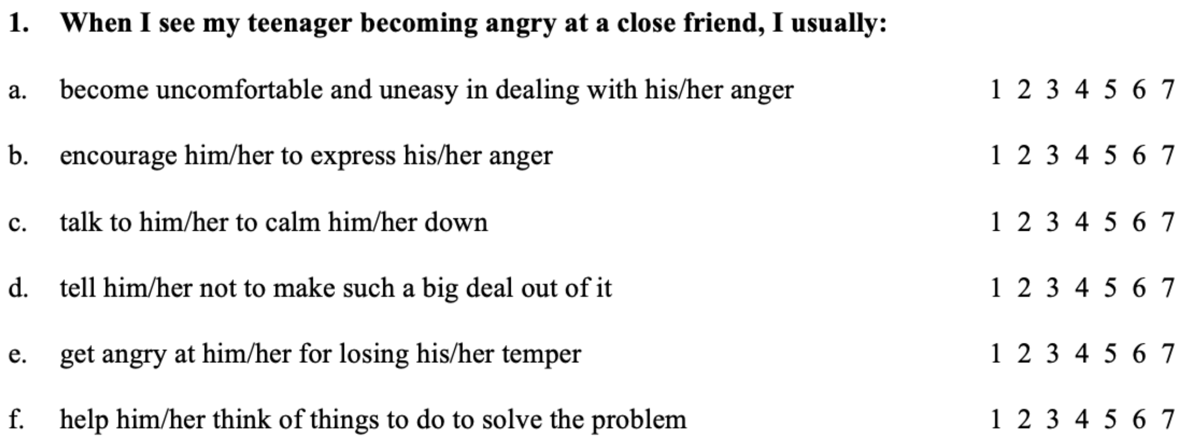
The coping with child negative emotions scale (CCNES; Fabes et al., 1990; Appendix O) is a self-report scale with 12 scenarios representing times children may become emotional. It is designed to assess the likelihood of different parental responses to their child's negative emotions. Respondents are provided with six hypothetical responses to these scenarios and rate the likelihood of responding in each way on a 7-point scale (1=very unlikely; 7=very likely). Figure 5 displays an example scenario and the six responses. There are separate versions for children and adolescents; the present study used the adolescent version.

Each response represents different ways parents may respond to their child's negative emotions, mapping onto six subscales. In the example in Figure 5: response a. represents a distress reaction; response b. represents expressive encouragement; response c. represents an emotion-focused reaction; response d. represents a minimisation reaction; response e. represents a punitive reaction; and response f. represents a problem-focused reaction.

The CCNES is scored by calculating means for each subscale, with higher scores indicating a greater likelihood of a parent responding with that type of reaction. The six subscales can be grouped into supportive responses (comprising the problem-focused, emotion-focused, and expressive encouragement subscales) and non-supportive responses (comprising the punitive, minimisation and distress reaction subscales). Internal consistency of the subscales is in the acceptable to good range (α=.69-.87; Fabes et al., 2002). Supportive and non-supportive responses were not inversely correlated with one another in the validation study, thus the authors suggest they are distinct factors. The present study therefore included supportive and non-supportive responses as two separate variables.

Figure 5

Example CCNES Question



1. When I see my teenager becoming angry at a close friend, I usually:

a.	become uncomfortable and uneasy in dealing with his/her anger	1 2 3 4 5 6 7
b.	encourage him/her to express his/her anger	1 2 3 4 5 6 7
c.	talk to him/her to calm him/her down	1 2 3 4 5 6 7
d.	tell him/her not to make such a big deal out of it	1 2 3 4 5 6 7
e.	get angry at him/her for losing his/her temper	1 2 3 4 5 6 7
f.	help him/her think of things to do to solve the problem	1 2 3 4 5 6 7

Parental Self-Compassion

The self-compassion scale-short form (SCS-SF; Raes et al., 2011; Appendix P), is a 12-item self-report questionnaire derived from the self-compassion scale (Neff, 2003b).

Respondents rate statements (e.g. *I try to see my failings as part of the human condition*) on a 5-point scale (1=almost never, 5=almost always). The 12 items measure six aspects of self-compassion: self-kindness; self-judgment; common humanity; isolation; mindfulness and over-identification, forming the measure's six subscales. Scoring involves calculating means for each subscale (with some items reverse-scored). A total self-compassion score, the variable used in this study, is calculated by taking a mean of all subscales. Higher scores indicate higher self-compassion.

The SCS-SF is nearly perfectly correlated with the original self-compassion scale, and the total score shows good internal consistency ($\alpha \geq .86$; Raes et al., 2011). Similar internal consistency for the SCS-SF in parents of YP with EDs is reported (Coleman et al., 2022).

Data Analysis

Descriptive and Correlation Analyses

The Statistics Package for the Social Sciences (SPSS, Version 29) was used for data analysis. Assumptions including normality, linearity, and homogeneity of variances were checked. Three scales (PEDE-Q global score, CCNES supportive responses, and CCNES non-supportive responses) did not meet the normality assumption. All other assumptions were met.

Descriptive statistics explored sample demographics, scores on study variables (and comparisons to population norms and/or clinical cut-off scores where available), and internal reliability (Cronbach's alpha).

Two-tailed Pearson's correlations were used to investigate relationships between PBAE, self-compassion, EE, responses to child negative emotions and child ED symptoms. Additionally, correlations between these variables and years since ED diagnosis were conducted, to check for potential effects of treatment. In cases where normality was violated, parametric tests were appropriate, due to the sample size and application of the central limit theorem (Field, 2013). Spearman's rank and bootstrapped Pearson's correlations were also run to check this, and the significance of results were not different, therefore only Pearson's correlations are reported.

Mediation Analyses

Hayes' (2017) bootstrapping method, using the PROCESS macro for SPSS was used for mediation analysis. This method addresses limitations of traditional approaches of mediation analysis by accounting for skewness and non-normality in data, providing more reliable estimates of indirect effects (Hayes, 2017). It also overcomes limitations of Baron and Kenny's causal steps approach (1986), which may miss important indirect effects due to requiring a total effect to be present when testing for indirect effects.

Hayes' (2017) bootstrapping approach estimates the indirect effect of a predictor variable on an outcome variable, via one or more mediators, by producing a confidence interval (CI) for the indirect effect pathway(s). Bootstrapping treats the original data as a miniature representation of the population sample and takes multiple re-samples from this original data, producing a new sample distribution. This study generated five thousand percentile bootstrap samples to estimate the indirect effect, calculating 95% bootstrapped CIs. The significance of indirect effects is determined based on CIs. If zero falls outside the upper and lower bounds of the CI for the indirect effect, a significant indirect effect can be assumed.

Several simple mediation analyses (based on the model in Figure 6) were used to test hypotheses 1 and 2 instead of multiple mediation models, since most of these variables had not been previously studied together.

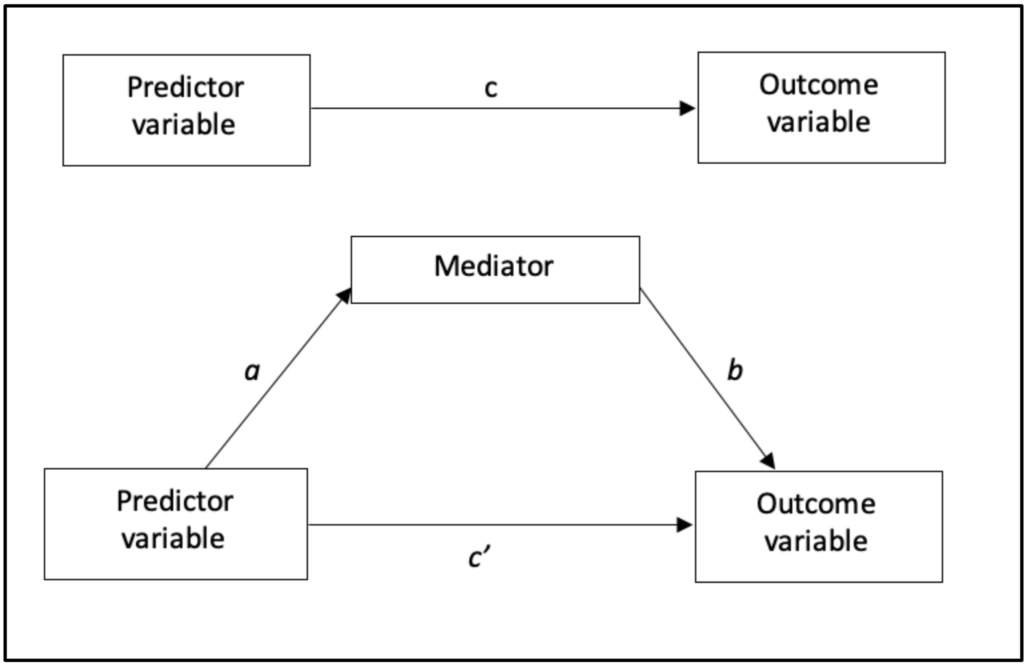
To test hypothesis 1, parental self-compassion was the predictor, child ED symptoms was the outcome variable, and three separate simple mediations were run, each with a single mediator: 1a) EE was the mediator; 1b) parental supportive responses to child negative emotions was the mediator; and 1c) parental non-supportive responses to child negative emotions was the mediator.

To test hypothesis 2, PBAE was the predictor, and parental self-compassion was the mediator. Three separate simple mediation analyses were then run, each with a different outcome variable: 2a) EE was the outcome variable; 2b) parental supportive responses to child negative emotions was the outcome variable; 2c) parental non-supportive responses to negative emotions was the outcome variable.

To test hypothesis 3, a multiple mediation model was used, involving both serial and parallel mediators, depicted in Figure 7.

Figure 6

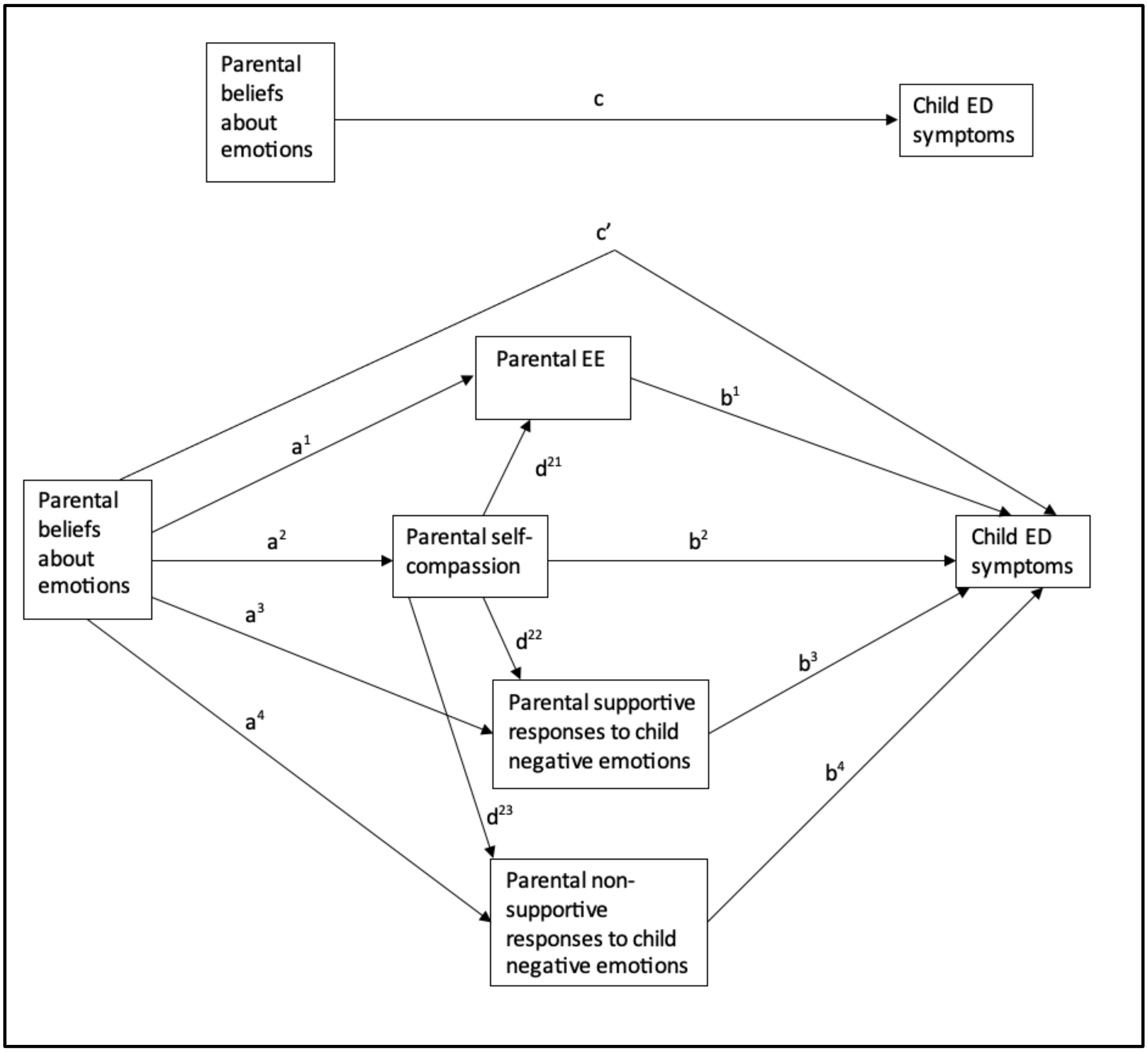
Simple Mediation Model



Note. Adapted from Hayes (2017). Path *c'* is the direct effect, representing the relationship between the predictor and outcome variables after controlling for potential mediation. Path *ab* is the indirect effect of the predictor on outcome variable, via the mediator. Path *c* is the total effect, calculated by summing the direct and indirect effects. The total effect represents the relationship between the predictor and outcome variables without controlling for potential mediation.

Figure 7

Conceptual Model for Hypothesis 3



Note. Adapted from Hayes (2017). Model depicts the direct relationship between PBAE and child ED symptoms, as well as indirect relationship via self-compassion and emotion-related parenting practices.

Power Calculations and Sample Size

Power calculations for the correlational analyses were conducted using G*Power. Using Cohen’s guidelines (1998) where α=.05 and β=.80, 84 participants is the sample size needed to detect a medium effect size (r=.30) for two-tailed Pearson’s correlations. For a percentile bootstrap (used in the mediation analyses), 78 participants is the sample size needed to detect a medium effect size (Fritz & MacKinnon, 2007).

Results

Demographics

Table 1

Sample Demographics

		N=	Percentage (%)
Primary caregiver gender	Female	78	90.7
	Male	8	9.3
Primary caregiver relationship to child	Mother	78	90.7
	Father	8	9.3
Primary caregiver ethnicity	White	82	95.3
	Mixed or multiple ethnic groups	2	2.3
	Asian or Asian British	1	1.2
	Not provided	1	1.2
Child gender	Female	77	89.5
	Male	6	7.0
	Non-binary	3	3.5
Child ethnicity	White	80	93.0
	Mixed or multiple ethnic groups	4	4.7
	Asian or Asian British	1	1.2
	Not provided	1	1.2
Child ED diagnosis	Anorexia Nervosa	81	94.2
	Other specified eating or feeding disorder	5	5.8
Psychological support received	Yes	75	87.2
	No	11	12.8
	Mean (SD)	**Range**	
Primary caregiver age	49.4 (5.7)	37-64	
Child age	16.3 (1.7)	13-19	
Years since ED diagnosis	1.8 (1.8)	0-12	

Descriptive statistics

Table 2 contains means, standard deviations (SD), correlations, and Chronbach's Alphas for all variables. The sample mean PEDE-Q global score (*M*=3.66) was below the suggested clinical cut-off (*M*=3.83; Drury et al., 2023), but comparable to mean EDE-Q global scores in ED populations in randomised control trials (e.g., ter Huurne et al., 2013). This sample likely represents a symptomatic ED population, often defined as scoring 1 SD above the healthy population mean on the EDE-Q (i.e., EDE-Q global score ≥2.77; de Jong et al., 2020).

No clinical cut-offs are available for the SCS-SF, but the sample mean score (*M*=2.82) falls in the range of 2.5-3.5 which is suggested to indicate moderate self-compassion (Raes et al., 2011).

The FQ-EE provides cut-offs for high scores on each subscale, but not the overall score (Wiedemann et al., 2002). In this sample, means exceed the cut-off for both subscales (criticism: *M*=23.83, cut-off=23; emotional overinvolvement: *M*=32.63, cut-off=27).

The BES does not provide a clinical cut-off score. The mean in this sample (*M*=30.67) was slightly higher than in the control sample of the validation study (27.9; Rimes & Chalder, 2010).

There is also no clinical cut-off provided for the CCNES. Means in this sample were similar to those found in samples of parents in the general population (e.g. Nelson et al., 2009). Parents in this sample scored considerably higher on supportive (*M*=5.63) than non-supportive responses (*M*=2.13), indicating a tendency to self-report more supportive than non-supportive responses to their child's negative emotions.

Chronbach Alpha's for all measures were over .80, which indicates a high level of internal consistency (Bland & Altman, 1997).

Table 2

Correlations and Descriptive Statistics

	ED symptoms[1]	Expressed emotion[2]	Beliefs about emotions[3]	Self-compassion[4]	Non-supportive responses to child negative emotions[5]	Supportive responses to child negative emotions[5]
Expressed emotion	.255*					
Beliefs about emotions	.005	.188				
Self-compassion	-.151	-.249*	-.531**			
Non-supportive responses to child negative emotions	.041	.305**	.218*	-.215*		
Supportive responses to child negative emotions	.166	-.186	-.168	.198	-.374**	
Years since diagnosis	-.040	-.029	-.115	.024	-.078	.098
Mean (SD)	3.66 (1.30)	56.48 (7.47)	30.67 (15.03)	2.82 (0.88)	2.13 (0.80)	5.63 (0.85)
Chronbach's Alpha	.912	.816	.913	.904	.905	.930

Note. [1]P-EDE-Q; [2]FQ-EE; [3]BES; [4]SCS-SF; [5]CCNES; **p*<.05; ***p*<.001

Correlation Analyses

Table 2 shows the results of the two-tailed correlation analyses and descriptive statistics for the variables.

Higher EE was significantly correlated with more severe child ED symptoms, increased non-supportive parental responses to child negative emotions, and lower parental self-compassion. More negative PBAE were significantly associated with lower parental self-compassion and more non-supportive responses to child negative emotions. Parental self-compassion significantly negatively correlated with parental non-supportive responses to child negative emotions, indicating that higher self-compassion was associated with less non-supportive responses to child negative emotions.

In this sample, non-supportive responses to child negative emotions were significantly negatively correlated with supportive responses to child negative emotions.

No significant relationships were found between any of the variables and years since ED diagnosis.

Mediation Analyses

Hypothesis 1a: EE is Expected to Mediate the Relationship Between Parental Self-Compassion and Child ED Symptoms

A simple mediation analysis explored the relationship between parental self-compassion and child ED symptoms, mediated by EE. Higher parental self-compassion predicted lower EE (a=-2.1273, p<.05), and among parents with lower EE, their child's ED symptoms were less severe (*b*=.0404, *p*<.05). Bootstrapped CIs for the indirect effect (*ab*=-.0860) based on 5000 bootstrap samples was completely below zero (-.2094, -.0030), indicating parental self-compassion significantly indirectly affected child ED symptoms, via EE. The direct effect of parental self-compassion on child ED symptoms was non-significant (*c'*=-.1381, *p*=.3970), suggesting parental self-compassion does not have a direct effect on child ED symptoms independent of EE.

The results of this analysis therefore indicated that parental self-compassion indirectly influenced child ED symptoms through its effects on EE (Figure 8 and Table 3), confirming hypothesis 1a.

The total effect for this model was non-significant (*c*=-.2240, *p*=.1659). This is likely due to the contribution of the non-significant direct effect resulting in the summed total of the direct and indirect effects falling below the threshold of significance, despite the significance of the indirect effect on its own. However, it is well-established that a significant total effect is not required for a significant indirect effect (Agler & De Boeck, 2017; Hayes, 2017).

Hypothesis 1b: Parental Supportive Responses to Child Negative Emotions are Expected to Mediate the Relationship Between Parental Self-Compassion and Child ED Symptoms

A simple mediation analysis explored the relationship between parental self-compassion and child ED symptoms, mediated by parental supportive responses to child negative emotions (Figure 8 and Table 4).

Bootstrapped CIs for the indirect effect included zero (-.0165, .1832), finding no evidence for an indirect effect. Parental supportive responses to child negative emotions therefore did not mediate the relationship between parental self-compassion and child ED symptoms (*ab*=.0599). The direct effect was also non-significant (*c'*=-.2840, *p*=.0817), suggesting no direct impact of parental self-compassion on child ED symptoms independent of the mediator. Hypothesis 1b was therefore not supported.

Hypothesis 1c: Parental Non-Supportive Responses to Child Negative Emotions are Expected to Mediate the Relationship Between Parental Self-Compassion and Child ED Symptoms

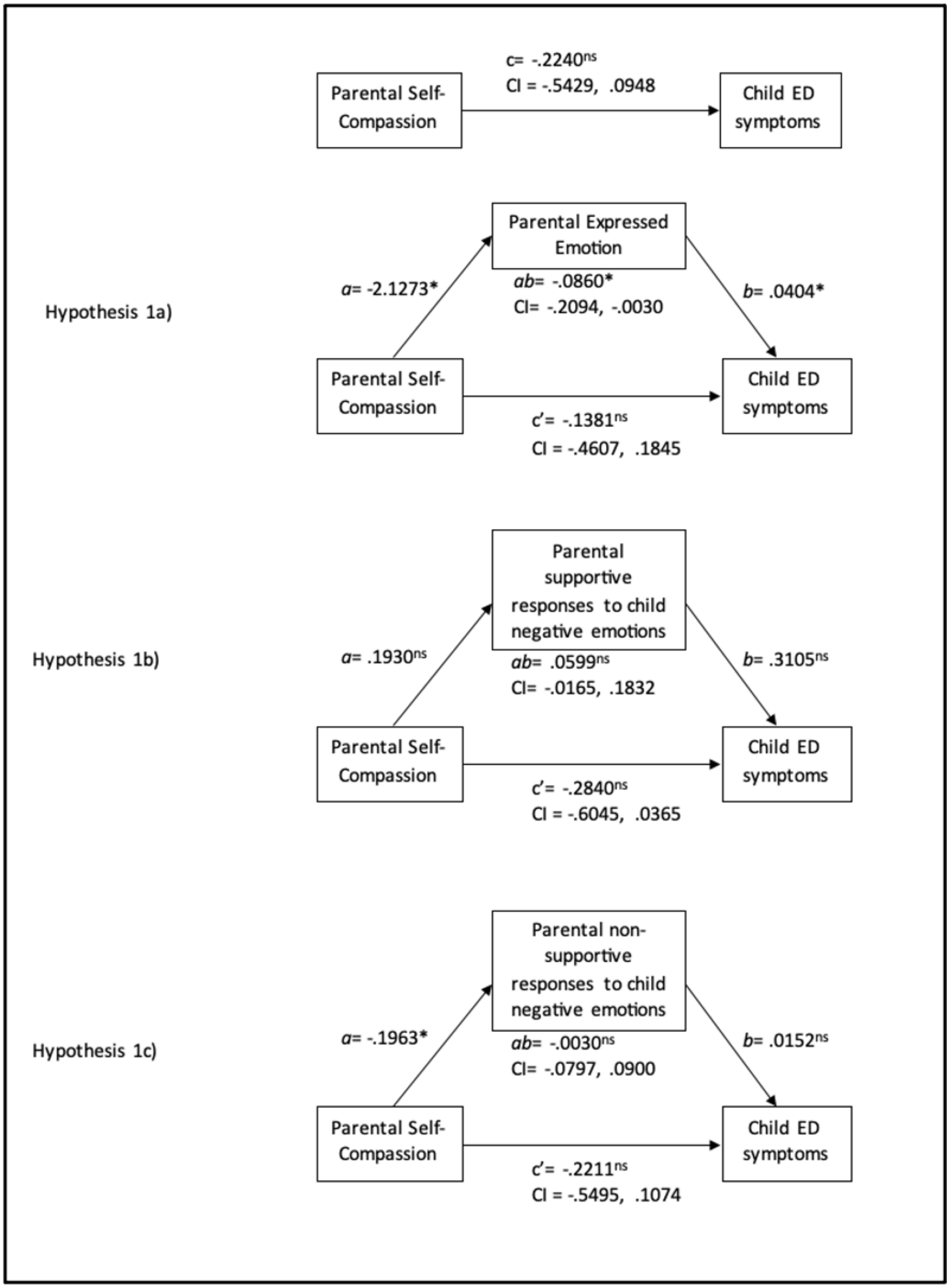
A simple mediation analysis explored the relationship between parental self-compassion and child ED symptoms, mediated by parental non-supportive responses to child negative emotions (Figure 8 and Table 5).

Bootstrapped CIs for the indirect effect included zero (-.0797, .0900), finding no evidence for an indirect effect. Parental non-supportive responses to child negative emotions therefore did not mediate the relationship between parental self-compassion and child ED symptoms (*ab*=-.0030). The direct effect was also non-significant (*c'*=-.2211, *p*=.1843), suggesting no direct impact of parental self-compassion on child ED symptoms independent of the mediator. Hypothesis 1c was therefore not supported.

However, this model indicated that parental self-compassion significantly negatively predicted parental non-supportive responses to child negative emotions (pathway *a*). In this regression, R^2=.0462, indicating that parental self-compassion predicted approximately 4.6% of the variance in parental non-supportive responses to child negative emotions [*F*(1,84)=4.065, *p*=0.047], representing a small effect size (Cohen, 1988).

Figure 8

Simple Mediation Models for Hypothesis 1



Note. *p<.05; ^{ns}non-significant

Table 3

Results of Simple Mediation Analysis for Hypothesis 1a

Pathway		**Coefficient**	***SE***	**LLCI**	**ULCI**	***p***
Parental self-compassion → parental EE	*a*	-2.1273	.9015	-3.919	-.335	.0206*
Parental EE → Child ED symptoms	*b*	.0404	.0190	.003	.078	.0365*

		Unstandardised effects	***SE***	**LLCI**	**ULCI**
Direct effect: parental self-compassion → child ED symptoms	*c'*	-.1381^{ns}	.1622	-.4607	.1845
Indirect effect: parental self-compassion → parental EE → child ED symptoms	*ab*	-.0860*	.0541	-.2094	-.0030
Total effect: parental self-compassion → child ED symptoms	*c*	-.2240^{ns}	.1603	-.5429	.0948

Note. LLCI=lower limit confidence interval; ULCI=upper limit confidence interval; 95% confidence intervals. **p*<.05; ^{ns}non-significant

Table 4

Results of Simple Mediation Analysis for Hypothesis 1b

Pathway	**Coefficient**	***SE***	**LLCI**	**ULCI**	***p***
Parental self-compassion → *a* Parental supportive responses to child negative emotions	.1930	.1042	-.0141	-.4002	.0674^{ns}
Parental supportive responses *b* to child negative emotions → Child ED symptoms	.3105	.1655	-.0185	.6396	.0640^{ns}

	Unstandardised effects		***SE***	**LLCI**	**ULCI**
Direct effect: parental self-compassion → child ED symptoms	*c'*	-.2840^{ns}	.1612	-.6045	.0365
Indirect effect: parental self-compassion → parental supportive responses to child negative emotions → child ED symptoms	*ab*	.0599^{ns}	.0522	-.0165	.1832
Total effect: parental self-compassion → child ED symptoms	*c*	-.2240^{ns}	.1603	-.5429	.0948

Note. LLCI=lower limit confidence interval; ULCI=upper limit confidence interval. 95% confidence intervals. *p<.05; ^{ns}non-significant

Table 5

Results of Simple Mediation Analysis for Hypothesis 1c

Pathway		**Coefficient**	***SE***	**LLCI**	**ULCI**	***p***
Parental self-compassion →Parental non-supportive responses to child negative emotions	*a*	-.1963	.0974	-.3900	-.0027	.047*
Parental non-supportive responses to child negative emotions → Child ED symptoms	*b*	.0152	.1807	-.3442	.3746	.9332^{ns}

		Unstandardised effects	***SE***	**LLCI**	**ULCI**
Direct effect: parental self-compassion → child ED symptoms	*c'*	-.2211^{ns}	.1651	-.5495	.1074
Indirect effect: parental self-compassion → parental non-supportive responses to child negative emotions → child ED symptoms	*ab*	-.0030^{ns}	.0403	-.0797	.0900
Total effect: parental self-compassion → child ED symptoms	*c*	-.2240^{ns}	.1603	-.5429	.0948

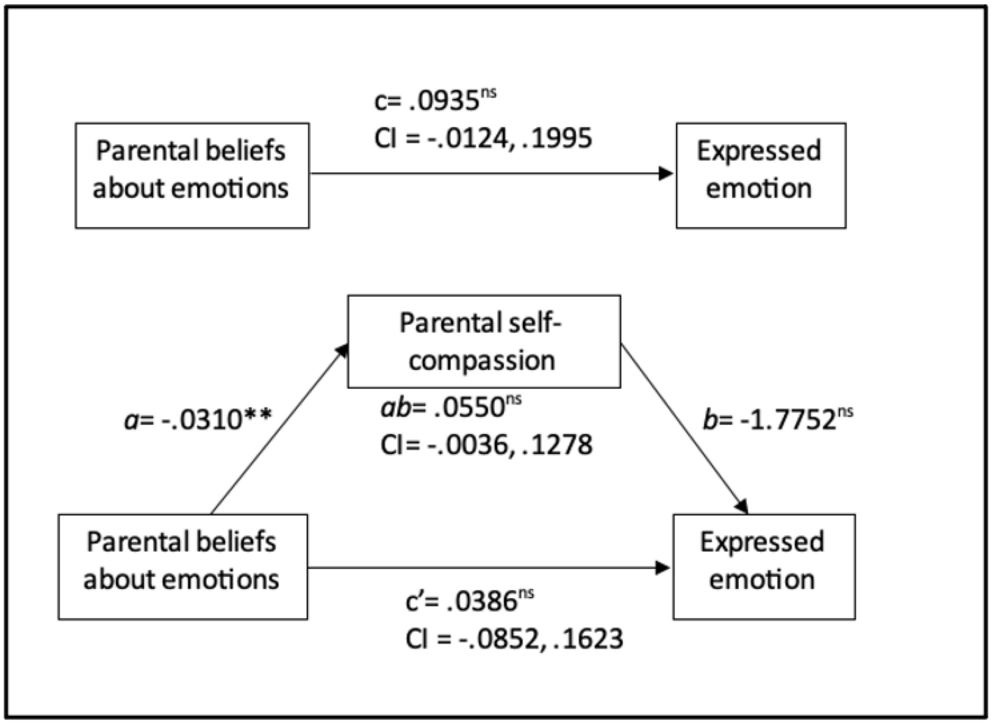
Note. LLCI=lower limit confidence interval; ULCI=upper limit confidence interval. 95% confidence intervals. **p*<.05; ^{ns}non-significant

Hypothesis 2a: Parental Self-Compassion will Mediate the Relationship Between PBAE and EE

A simple mediation analysis explored the relationship between PBAE and EE, mediated by parental self-compassion (Figure 9 and Table 6). Bootstrapped CIs for the indirect effect included zero (-.0036, .1278), finding no evidence for an indirect effect. Parental self-compassion therefore did not mediate the relationship between PBAE and EE (*ab*=-.0550). The direct effect was also non-significant (*c'*=.0386, *p*=.5368), suggesting no direct impact of PBAE on EE independent of parental self-compassion. Hypothesis 2a was therefore not supported.

Figure 9

Simple Mediation Model for Hypothesis 2a



Note. ***p*<.001; ^{ns}non-significant

Table 6

Results of Simple Mediation Analysis for Hypothesis 2a

Pathway		**Coefficient**	***SE***	**LLCI**	**ULCI**	***p***
Parental beliefs about emotions → Parental self-compassion	*a*	-.0310	.0054	-.0417	-.0203	.000**
Parental self-compassion → Expressed emotion	*b*	-1.7752	1.0681	-3.8896	.3493	.1003^{ns}

		Unstandardised effects	***SE***	**LLCI**	**ULCI**
Direct effect: parental beliefs about emotions → expressed emotion	*c'*	.0386^{ns}	.0622	-.0852	.1623
Indirect effect: parental beliefs about emotions → parental self-compassion → expressed emotion	*ab*	.0550^{ns}	.0329	-.0036	.1278
Total effect: parental beliefs about emotions → expressed emotion	c	.0935^{ns}	.0533	-.0124	.1995

Note. LLCI=lower limit confidence interval; ULCI=upper limit confidence interval. 95% confidence intervals. ***p*<.001; ^{ns}non-significant

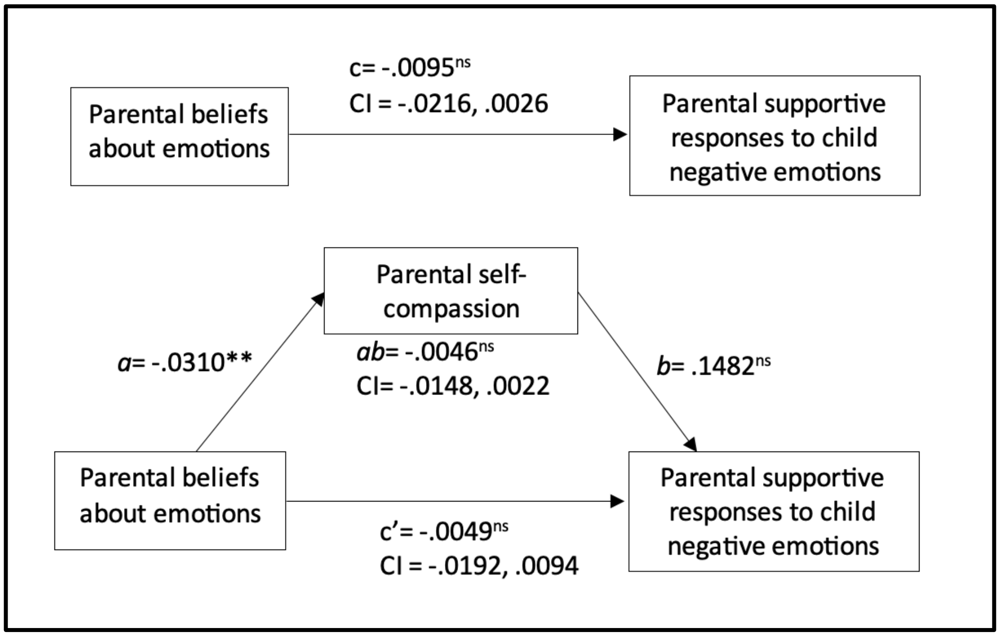
Hypothesis 2b: Parental Self-Compassion will Mediate the Relationship Between PBAE and Parental Supportive Responses to Child Negative Emotions

A simple mediation analysis explored the relationship between PBAE and parental supportive responses to child negative emotions, mediated by parental self-compassion (see Figure 10 and Table 7). Bootstrapped CIs for the indirect effect included zero (-.0148, .0022), finding no evidence for an indirect effect. Parental self-compassion therefore did not mediate the relationship between PBAE and supportive responses to child negative emotions (*ab*=-.0046).

The direct effect was also non-significant (*c'*=-.0049, *p*=.4957), suggesting no direct impact of PBAE on supportive responses to child negative emotions independent of parental self-compassion. Hypothesis 2b was therefore not supported.

Figure 10

Simple Mediation Model for Hypothesis 2b



Note. **p<.001; ^{ns}non-significant

Table 7

Results of Simple Mediation Analysis for Hypothesis 2b

Pathway		**Coefficient**	***SE***	**LLCI**	**ULCI**	***p***
Parental beliefs about emotions → Parental self-compassion	*a*	-.0310	.0054	-.0417	-.0203	.000**
Parental self-compassion → Parental supportive responses to child negative emotions	*b*	.1482	.1234	-.0972	.3935	$.2331^{ns}$

		Unstandardised effects	***SE***	**LLCI**	**ULCI**
Direct effect: parental beliefs about emotions → Parental supportive responses to child negative emotions	*c'*	$-.0049^{ns}$	.0072	-.0192	.0094
Indirect effect: parental beliefs about emotions → parental self-compassion → Parental supportive responses to child negative emotions	*ab*	$-.0046^{ns}$	.0043	-.0148	.0022
Total effect: parental beliefs about emotions → Parental supportive responses to child negative emotions	c	$-.0095^{ns}$	.0061	-.0216	.0026

Note. LLCI=lower limit confidence interval; ULCI=upper limit confidence interval. 95% confidence intervals. ***p*<.001; ^{ns}non-significant

Hypothesis 2c: Parental Self-Compassion will Mediate the Relationship Between PBAE and Parental Non-Supportive Responses to Child Negative Emotions

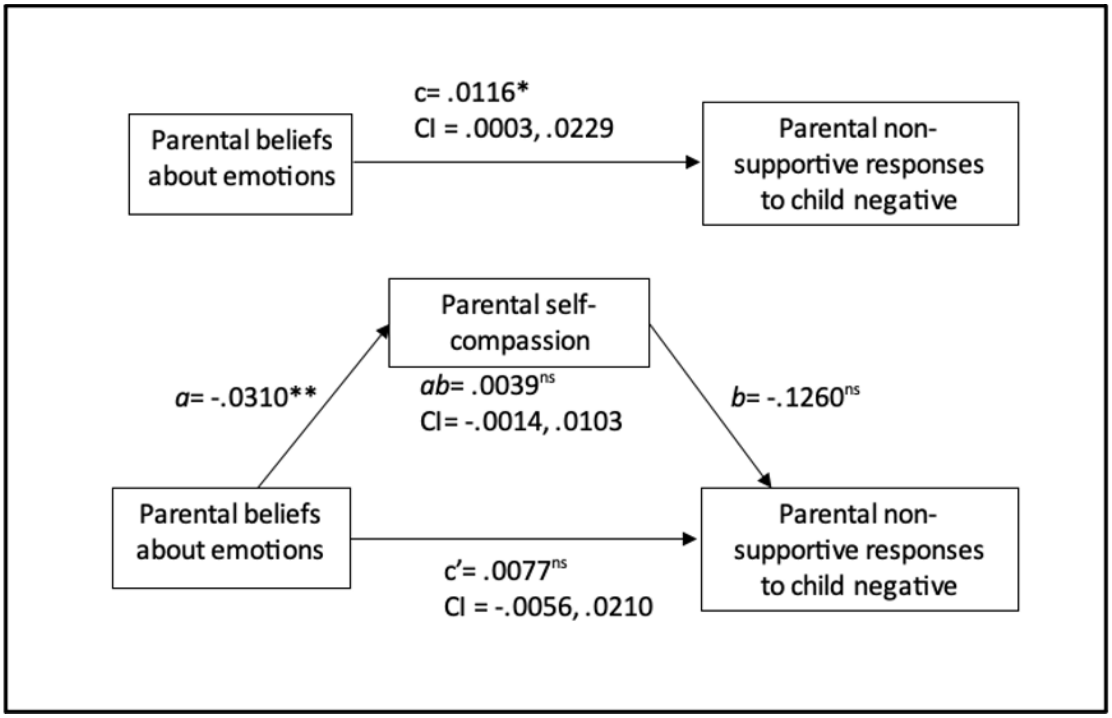
A simple mediation analysis explored the relationship between PBAE and parental non-supportive responses to child negative emotions, mediated by parental self-compassion (see Figure 11 and Table 8). Bootstrapped CIs for the indirect effect included zero (-.0014, .0103), finding no evidence for an indirect effect. Parental self-compassion therefore did not mediate the relationship between PBAE and non-supportive responses to child negative emotions (*ab*=.0039).

The direct effect was also non-significant (*c'*=.0077, *p*=.2523), suggesting no direct impact of PBAE on non-supportive responses to child negative emotions independent of parental self-compassion. Hypothesis 2c was therefore not supported.

In this model there was a significant total effect (*c*=.0116, *p*=.0437), indicating that the sum of the indirect and direct effects was significant. This may indicate there was not sufficient power to detect a significant direct or indirect effect individually, but when added together the effect was more robust and therefore became significant. A larger sample may have been needed to detect significant direct or indirect effects.

Figure 11

Simple Mediation Model for Hypothesis 2c



Note. ***p*<.001; ^{ns}non-significant

Table 8

Results of Simple Mediation Analysis for Hypothesis 2c

Pathway		**Coefficient**	***SE***	**LLCI**	**ULCI**	***p***
Parental beliefs about emotions → Parental self-compassion	*a*	-.0310	.0054	-.0417	-.0203	.000**
Parental self-compassion → Parental non-supportive responses to child negative emotions	*b*	-.1260	.1147	-.3542	.1022	.2751^{ns}

		Unstandardised effects	***SE***	**LLCI**	**ULCI**
Direct effect: parental beliefs about emotions → Parental non-supportive responses to child negative emotions	*c'*	.0077^{ns}	.0067	-.0056	.0210
Indirect effect: parental beliefs about emotions → parental self-compassion → Parental non-supportive responses to child negative emotions	*ab*	.0039^{ns}	.0029	-.0014	.0103
Total effect: parental beliefs about emotions → Parental non-supportive responses to child negative emotions	*c*	.0116*	.0057	.0003	.0229

Note. LLCI=lower limit confidence interval; ULCI=upper limit confidence interval. 95% confidence intervals. *p<.05; **p<.001; ^{ns}non-significant

Across the models used to test hypothesis 2, PBAE significantly, negatively predicted parental self-compassion. In this regression, R^2=.2825, indicating that PBAE predicted approximately 28.25% of the variance in parental self-compassion in this sample [$F(1,84)=33.0671$, $p<0.001$], representing a large effect size (Cohen, 1988).

Hypothesis 3: PBAE are Expected to Indirectly Affect Child ED Symptoms, Mediated by Parental Self-Compassion, EE and Parental Supportive and Non-Supportive Responses to Child Negative Emotions

A mediation analysis involving parallel and serial mediator explored the relationship between PBAE and child ED symptoms. No significant indirect effects were found (Figure 12 and Table 9). This is unsurprising given the lack of significant indirect effects in most of the simple mediation analyses tested in the previous hypotheses. There was also no significant direct effect (*c'*=-.0095, *p*=.3800), suggesting that independent of the mediators there was no direct impact of PBAE on child ED symptoms.

Hypothesis 3 was therefore not supported, as self-compassion, EE, and neither supportive nor non-supportive responses to child negative emotions mediated the relationship between PBAE and child ED symptoms.

Table 9

Results of Parallel and Serial Mediation Model for Hypothesis 3

Pathway		**Coefficient**	***SE***	**LLCI**	**ULCI**	***p***
Parental beliefs about emotions → parental EE	a^1	.0386	.6202	-.0852	.1623	.5638
Parental beliefs about emotions → parental self-compassion	a^2	-.0310	.0054	-.0417	-.0203	.000**
Parental beliefs about emotions → parental supportive responses to child negative emotions	a^3	-.0049	.0072	-.0192	.0094	.4957

Parental beliefs about emotions → parental non-supportive responses to child negative emotions	a^4	.0077	.0067	-.0056	.0210	.2523
Parental self-compassion → parental EE	d^{21}	-.17752	1.0681	-3.8996	.3493	.1003
Parental self-compassion → child ED symptoms	b^2	-.2732	.1864	-.6642	.0979	.1468
Parental self-compassion → parental supportive responses to child negative emotions	d^{22}	.1482	.1234	-.0972	.3935	.2331
Parental self-compassion → parental non-supportive responses to child negative emotions	d^{23}	-.1260	.1147	-.3542	.1022	.2751
Parental EE → child ED symptoms	b^1	.0461	.0194	.0074	.0847	.0201*
Parental supportive responses to child negative emotions → child ED symptoms	b^3	.3768	.1727	.0331	.7204	.0320*
Parental non-supportive responses to child negative emotions → child ED symptoms	b^4	.0604	.1904	-.3185	.4394	.7517

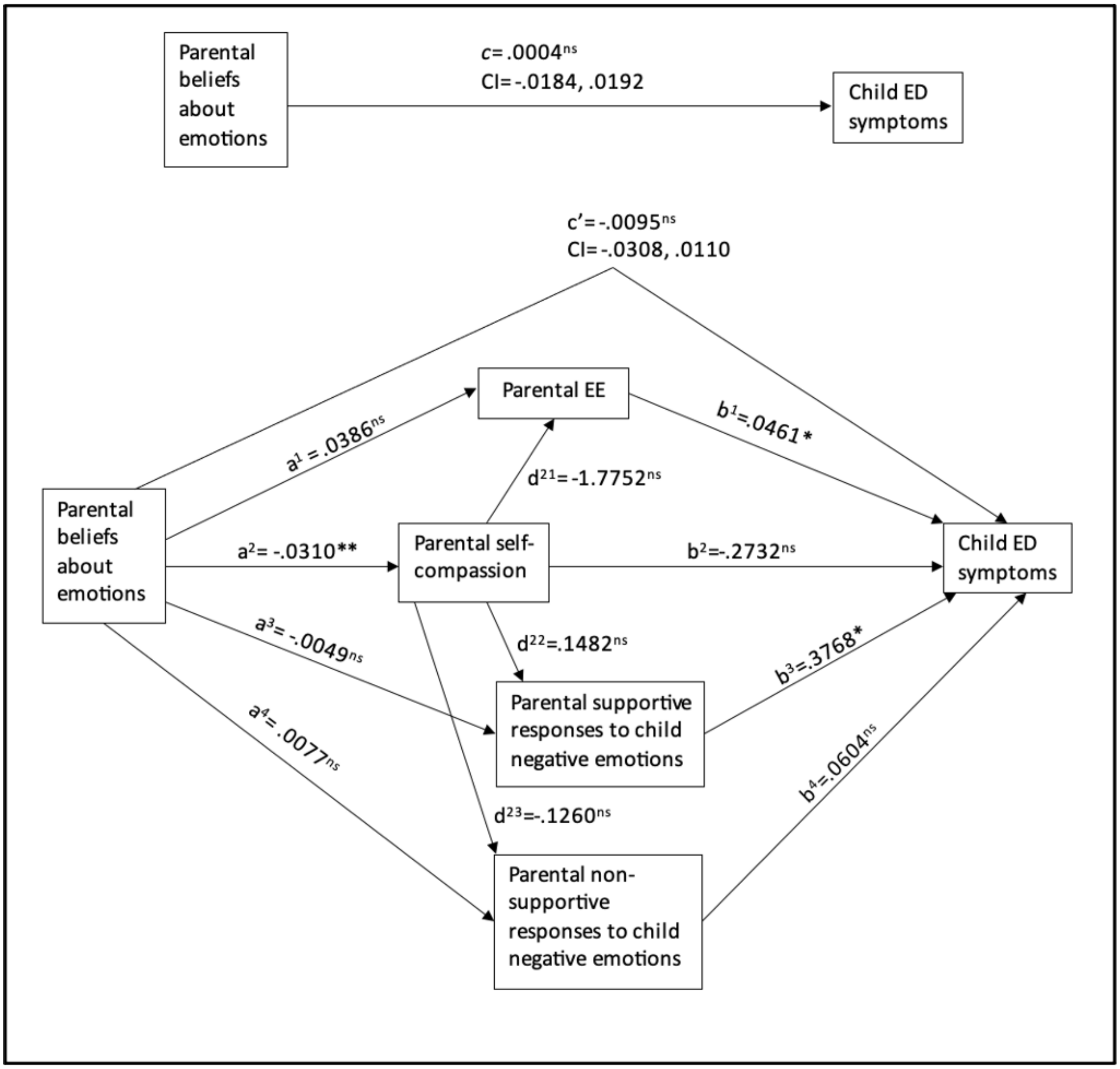
		Unstandardised effects	***SE***	**LLCI**	**ULCI**
Direct effect: parental beliefs about emotions → child ED symptoms	c'	-.0095^{ns}	.0107	-.0308	.0110
Indirect effect: parental beliefs about emotions → parental self-compassion → child ED symptoms	a^2b^2	.0099^{ns}	.0082	-.0064	.0271

Indirect effect: parental beliefs about emotions → parental EE → child ED symptoms	a^1b^1	.0085^{ns}	.0065		-.0036	.0223
Indirect effect: parental beliefs about emotions → parental supportive responses to child negative emotions → child ED symptoms	a^3b^3	-.0019^{ns}	.0036		-.0109	.0038
Indirect effect: parental beliefs about emotions → parental non-supportive responses to child negative emotions → child ED symptoms	a^4b^4	.0005^{ns}	.0017		-.0030	.0042
Indirect effect: parental beliefs about emotions → parental self-compassion → EE → child ED symptoms	$a^2d^{21}b^1$	.0025^{ns}	.0019		-.0002	.0071
Indirect effect: parental beliefs about emotions →parental self-compassion → parental supportive responses to child negative emotions → child ED symptoms	$a^2d^{22}b^3$	-.0017^{ns}	.0018		-.0059	.0010
Indirect effect: parental beliefs about emotions → parental self-compassion → parental non-supportive responses to child negative emotions → child ED symptoms	$a^2d^{23}b^4$	.0002^{ns}	.0008		-.0012	.0022
Total effect of parental beliefs about emotions on child ED symptoms	c	.0004^{ns}	.0094		-.0184	.0192

Note. LLCI=lower limit confidence interval; ULCI=upper limit confidence interval. 95% confidence intervals. *p<.05; **p<.001; ^{ns}non-significant

Figure 12

Mediation Model for Hypothesis 3



Note. *p<.05; **p<.001; ^{ns}non-significant

Discussion

This study explored relationships between PBAE, self-compassion, EE, supportive and non-supportive responses to child negative emotions and child ED symptoms, in parents of YP with EDs. There were three specific research questions:

1. Do emotion-related parenting practices mediate the relationship between self-compassion and child ED symptoms?
2. Does self-compassion mediate the relationship between PBAE and emotion-related parenting practices?
3. Do self-compassion and emotion-related parenting practices mediate the relationship between PBAE and child ED symptoms?

Do Emotion-Related Parenting Practices Mediate the Relationship Between Parental Self-Compassion and Child ED Symptoms?

Correlational analyses found no significant association between parental self-compassion and child ED symptoms. EE was significantly positively correlated with ED symptoms, consistent with prior research linking higher EE to more severe ED symptoms (Anastasiadou et al., 2016; Schwarte et al., 2017). Parents in this study scored highly for EE, both on criticism and emotional overinvolvement, echoing previous research finding EE to be elevated in families of ED sufferers compared to healthy controls (Zabala et al., 2009). Given that high EE can negatively impact outcomes of ED treatment (Rienecke, 2018), these findings highlight the importance of investigating factors that may be protective against increasing EE in families of YP with EDs.

The other emotion-related parenting practices were not significantly associated with ED symptoms. Self-compassion significantly negatively correlated with both EE and non-supportive parental responses but was not significantly associated with supportive parental responses.

The mediation analyses found no direct relationship found between self-compassion and child ED symptoms, and no indirect relationships were found when supportive or non-supportive parental responses were entered as mediators. However, parental self-compassion significantly negatively predicted parental non-supportive responses, accounting for a small amount of the variance in this. This suggests that parental self-compassion may have a small predictive role in parental non-supportive responses to negative emotions in their children, but this was not found to relate to child ED symptoms.

When EE was entered as the mediator, parental self-compassion indirectly affected child ED symptoms, via EE, aligning with Coleman et al.'s (2022) findings. The relationship between EE and child ED symptoms has been well-documented, as discussed above, however the finding that parental self-compassion predicts EE is much less researched.

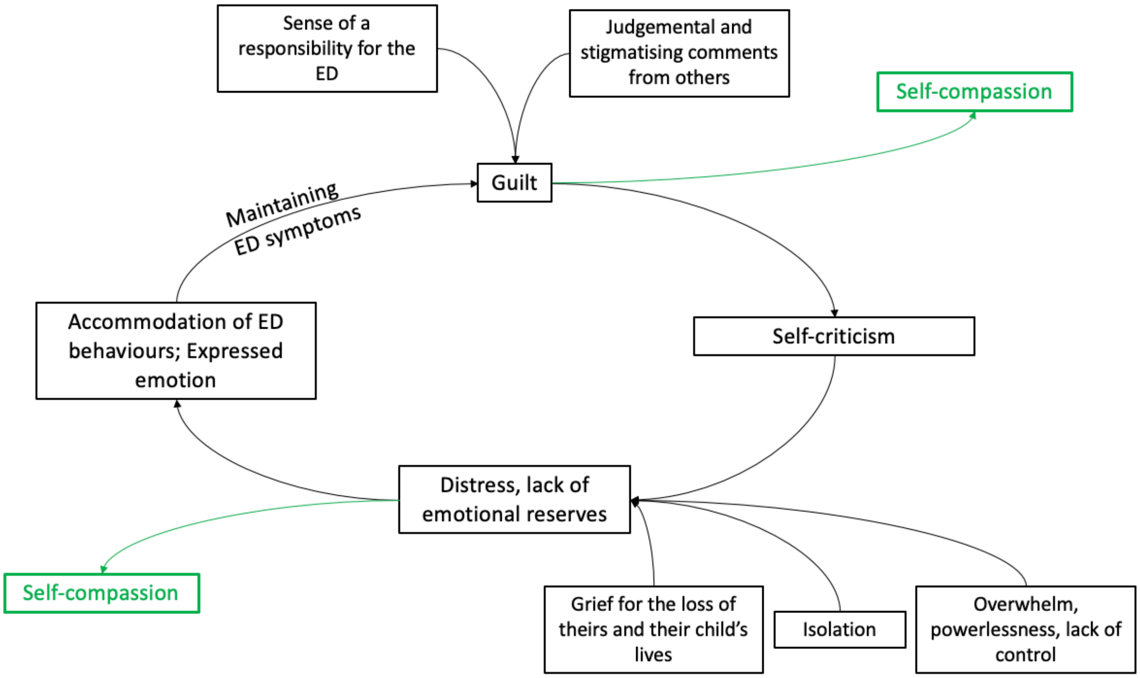
These results suggest that parents who struggle to exhibit self-compassion in times of distress (i.e. when caring for a child with an ED), may have higher EE, characterised by emotional over-involvement and criticism. EE may serve as a coping mechanism for parents dealing with the distress of caregiving, particularly when other protective strategies like self-compassion are less accessible. This aligns with the notion that high EE arises from the challenges of supporting a child with an ED (Rienecke, 2018), and this higher EE in turn contributes to maintaining the ED, as outlined in Treasure and Schmidt's (2013) cognitive-interpersonal maintenance model.

The indirect effect of parental self-compassion on child ED symptoms through EE implies that self-compassion may offer a pathway out of guilt, self-criticism, and emotional depletion among parents, offering a potential addition to the model proposed by Neely (2024). If parents can respond to their guilt and distress self-compassionately, this may reduce self-criticism and provide an alternative to responses that inadvertently reinforce their child's ED symptoms such as accommodating ED behaviours and high EE. Figure 13 illustrates potential pathways for self-compassion as a protective for parents in Neely's (2024) model. Further research is needed to explicitly test these pathways and understand the subsequent effects of a self-compassionate response among parents.

Taken together, these findings support existing literature on the role of EE in maintaining ED symptoms and indicate that self-compassion is a relevant factor in better understanding EE. While it was initially hypothesised that parental self-compassion may be predictive of child ED symptoms through multiple pathways (EE and supportiveness of responses to child negative emotions), the results suggest that among the variables studied, the indirect relationship may only be via EE. This offers preliminary support for a portion of Lathren et al.'s model (2020) applied to an ED population, specifically through the indirect effect of self-compassion on child ED symptoms, via EE. It is however important to note that several of the variables proposed in Lathren et al.'s (2020) model were not measured in this study, therefore the results by no means fully support this model, and further research is required in this population.

Figure 13

Hypothesised Pathways for Self-Compassion to Interrupt the Cycle Proposed by Neely (2024)



Note. Green arrows and boxes represent hypothesised additional pathways for responding self-compassionately.

Does Parental Self-Compassion Mediate the Relationship Between PBAE and Emotion-Related Parenting Practices?

PBAE significantly positively correlated with non-supportive responses but had no significant associations with the other emotion-related parenting practices. There was a strong negative association between parental self-compassion and PBAE, indicating that parents with more negative beliefs about emotions had lower self-compassion.

The mediation analyses revealed no significant direct or indirect effects between self-compassion, PBAE and emotion-related parenting practices. There was, however, a significant total effect of PBAE on non-supportive responses to child emotions. This suggests that when the direct and indirect effects are combined, PBAE predicts non-supportive responses, however these effects did not reach significance when considered individually. A larger sample may have been needed for there to be sufficient power to detect significant direct or indirect effects in this model.

The lack of significant indirect or direct effects between PBAE and emotion-related parenting practices was unexpected, given the literature on PMEP suggests PBAE influence their responses to their child's emotions (Gottman et al., 1996; Katz et al., 2012). This may indicate potential measurement issues with the questionnaire used to assess beliefs about emotions. The BES focuses on beliefs about one's own emotions, and while an assumption of PMEP is that parental beliefs about their own emotions relate to their beliefs about their child's emotions (Katz et al., 2012), explicitly considering parental beliefs about their child's emotions and how these related to emotion-related parenting practices may have been beneficial in this study.

Conversely, self-compassion may represent a way of responding to one's own emotions, so may be more influenced by parental beliefs about their own emotions. Indeed, parental beliefs about their emotions predicted a significant and large amount of the variation (28.25%) in parental self-compassion in this sample, suggesting that holding more negative beliefs about emotions predicts lower self-compassion. This aligns with Sydenham et al.'s (2016) findings, in which more negative beliefs about emotions predicted lower self-compassion. Holding negative beliefs about the acceptability of experiencing and expressing negative emotions may therefore be a barrier to the development of self-compassion.

Do Parental Self-Compassion and Emotion-Related Parenting Practices Mediate the Relationship Between PBAE and Child ED Symptoms?

The final aim of the study was to explore the relationship between PBAE and child ED symptoms, via parental self-compassion and emotion-related parenting practices. The hypothesis that there would be a relationship between PBAE that would be mediated by these variables was not supported. Given that most of the simple mediation models tested in hypotheses 1 and 2 did not find significant indirect or direct effects, it was unsurprising that this more exploratory model, combining earlier models, was not supported. The results suggest that PBAE were not associated with child ED symptoms, either directly or indirectly.

Strengths and Limitations

This was the first study to the author's knowledge to investigate this specific combination of variables in PCs of YP with EDs. The indirect relationship found between self-compassion and child ED symptoms via EE adds to the growing literature base highlighting the importance of considering parental self-compassion. The measures used to assess self-compassion, PBAE, EE and responses to emotions have all been widely used in previous research, enabling comparison of these results to other studies.

However, there were several limitations of this study. Owing to the cross-sectional design, causal inferences cannot be made, meaning the results should be interpreted cautiously. Future research with longitudinal and experimental designs would provide an opportunity to test the causal relationships between the variables.

As is a common limitation of ED research (Halbesien et al., 2022), the sample lacked diversity, with over 95% of participants being white British. This may be a particular limitation in the context of investigating beliefs about emotions, given the well-documented cultural differences in beliefs about the acceptability of experiencing and expressing emotions (Fonseca et al., 2023; Parker et al., 2012). These findings may therefore not be generalisable beyond a white British population. Future research should investigate these variables in more diverse samples.

Using the PEDE-Q to assess ED symptoms is a potential limitation. This measure relies on parental interpretations of their child's ED symptoms, potentially not accurately representing the child's symptoms. Parents may not be aware of the extent of their child's symptoms due to the secretive nature of EDs, potentially leading to underreporting. Conversely, parental anxiety could result in over-reporting. Nevertheless, this limitation was consistent across participants. Including a child self-report measure for ED symptoms could have provided different insights but would introduce its own set of limitations.

A final limitation is the variation among participants in their child's ED duration and the treatment received. Treatment may have impacted self-compassion, PBAE, EE, responses to child negative emotions, and ED severity, potentially influencing the results. While correlational analyses indicated no association between length of time since ED diagnosis and any of the other variables, this does not account for different treatments families received.

Research and Clinical Implications

Future research should further investigate the relationship between parental self-compassion and child ED symptoms via EE, including among parents of YP with other ED diagnoses including BED and BN. Experimental research could investigate the impact of adding compassion-focused components to parental interventions, to evaluate the effects on EE and ED symptoms. This could improve clinical outcomes for both YP with EDs and their parents, by potentially interrupting the maintenance of EDs via EE, and offering direct support for distress among parents.

In addition, the significant predictive value of PBAE on self-compassion found in this study would benefit from longitudinal and experimental research examining the causality of relationships. A key area of investigation would be whether holding beliefs about negative emotions being maladaptive could be a barrier to the development of self-compassion, and in turn whether targeting beliefs about emotions in interventions could increase individuals' capacity to develop self-compassion. This could have clinical implications for compassion-focused interventions beyond those specifically for parents of YP with EDs and suggest a role for targeting negative beliefs about emotions as part of these.

It would also be of interest to explore the relationship between self-compassion in YP with EDs and in their parents. Given that EDs are characterised by low levels of self-compassion (Turk & Waller, 2020), investigating the potential link between child and parental self-compassion would allow for further exploration of Lathren et al.'s (2020) intergenerational model of self-compassion in an ED population. This could offer insight into whether child self-compassion is another pathway through which parental self-compassion is associated with child ED symptoms.

Finally, further research into the relationship between parental beliefs about their own and their child's emotions is needed. It would be of interest to determine how these beliefs relate to one another, as well as parental responses to their own and their child's emotions. This may be an important consideration for future research investigating Lathren's et al.'s (2020) intergenerational model, as parental beliefs about their emotions may be associated with their self-compassion, while their beliefs about their child's emotions may relate to emotion-related parenting practices.

Conclusion

This study was the first to explore the relationship between PBAE, self-compassion, and emotion-related parenting practices in primary caregivers of YP with EDs. While the findings did not offer support for an overall relationship between PBAE and child ED symptoms, mediated by self-compassion and emotion-related parenting practices, there were several findings of interest. Participants had high levels of EE, as is common in families of YP with an ED. Parental self-compassion indirectly predicted child ED symptoms, via EE, and PBAE predicted parental self-compassion. These findings highlight the potential for compassion-focused interventions for parents of YP with EDs and the importance of better understanding PBAE as a potential barrier to self-compassion, to improve compassion-focused interventions.

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LIZZIE NEELY BSc (Hons)

EXPLORING EXPERIENCES OF PARENTS OF INDIVIDUALS WITH EATING DISORDERS

Section C: Appendix of Supporting Material

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

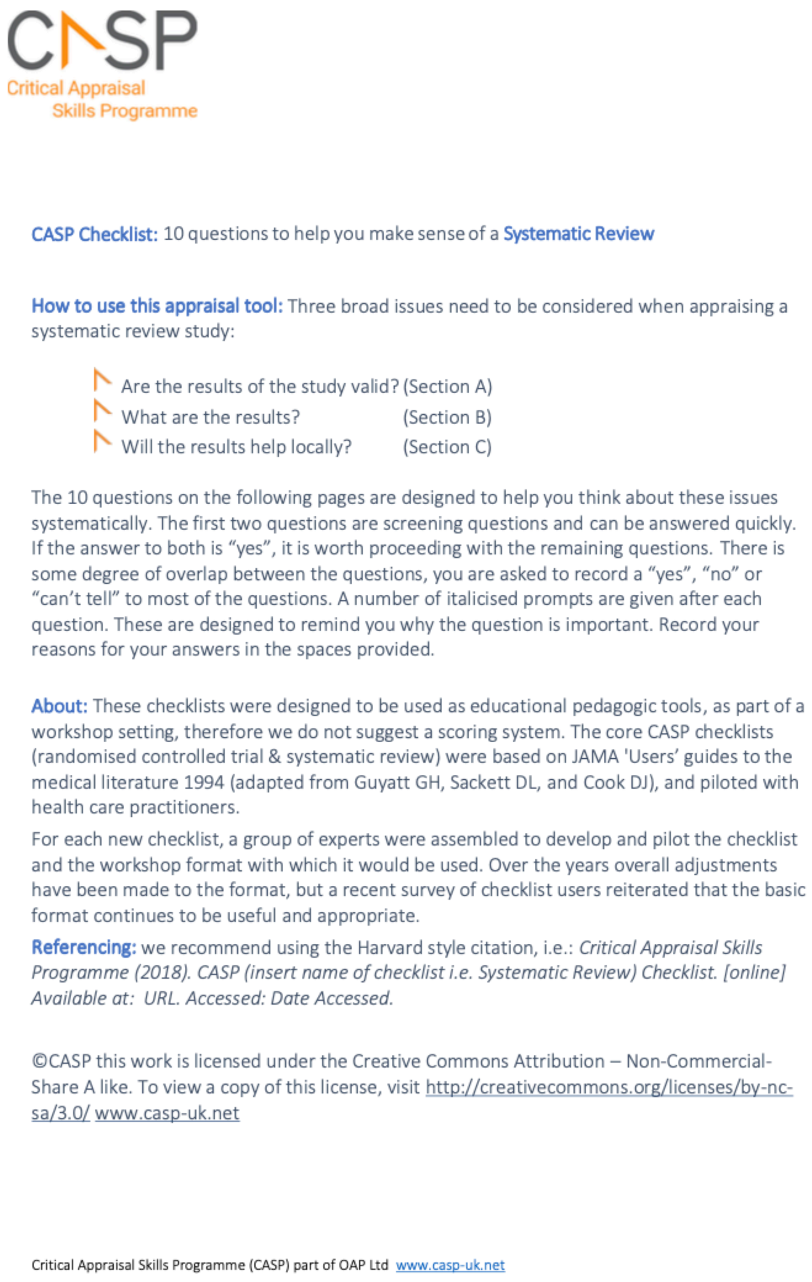
APRIL 2024

SALOMONS INSTITUTE
CANTERBURY CHRIST CHURCH UNIVERSITY

Section A Appendices

Appendix A

CASP Criteria Checklist



CASP
Critical Appraisal
Skills Programme

CASP Checklist: 10 questions to help you make sense of a **Systematic Review**

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

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

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

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

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

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

Critical Appraisal Skills Programme (CASP) part of OAP Ltd www.casp-uk.net

CASP
Critical Appraisal
Skills Programme

Paper for appraisal and reference:...

Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?

Yes ☐
Can't Tell ☐
No ☐

HINT: An issue can be 'focused' In terms of
- the population studied
- the intervention given
- the outcome considered

Comments:

2. Did the authors look for the right type of papers?

Yes ☐
Can't Tell ☐
No ☐

HINT: 'The best sort of studies' would
- address the review's question
- have an appropriate study design (usually RCTs for papers evaluating interventions)

Comments:

Is it worth continuing?

3. Do you think all the important, relevant studies were included?

Yes ☐
Can't Tell ☐
No ☐

HINT: Look for
- which bibliographic databases were used
- follow up from reference lists
- personal contact with experts
- unpublished as well as published studies
- non-English language studies

Comments:

4. Did the review's authors do enough to assess quality of the included studies?

Yes ☐
Can't Tell ☐
No ☐

HINT: The authors need to consider the rigour of the studies they have identified. Lack of rigour may affect the studies' results ("All that glisters is not gold" Merchant of Venice – Act II Scene 7)

Comments:

5. If the results of the review have been combined, was it reasonable to do so?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- results were similar from study to study
- results of all the included studies are clearly displayed
- results of different studies are similar
- reasons for any variations in results are discussed

Comments:

Section B: What are the results?

6. What are the overall results of the review?

HINT: Consider
- If you are clear about the review's 'bottom line' results
- what these are (numerically if appropriate)
- how were the results expressed (NNT, odds ratio etc.)

Comments:

7. How precise are the results?

HINT: Look at the confidence intervals, if given

Comments:

Section C: Will the results help locally?

8. Can the results be applied to the local population?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- the patients covered by the review could be sufficiently different to your population to cause concern
- your local setting is likely to differ much from that of the review

Comments:

9. Were all important outcomes considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- there is other information you would like to have seen

Comments:

10. Are the benefits worth the harms and costs?

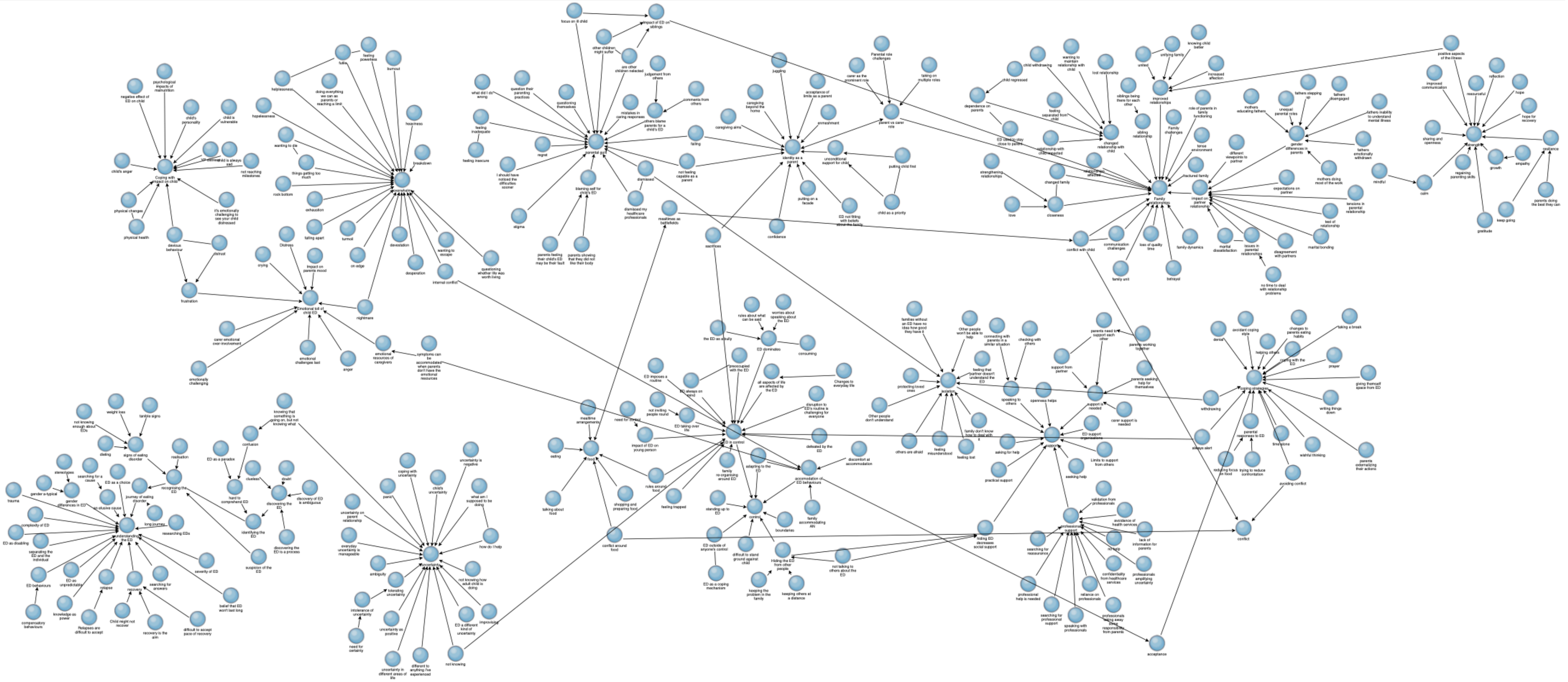
Yes ☐
Can't Tell ☐
No ☐

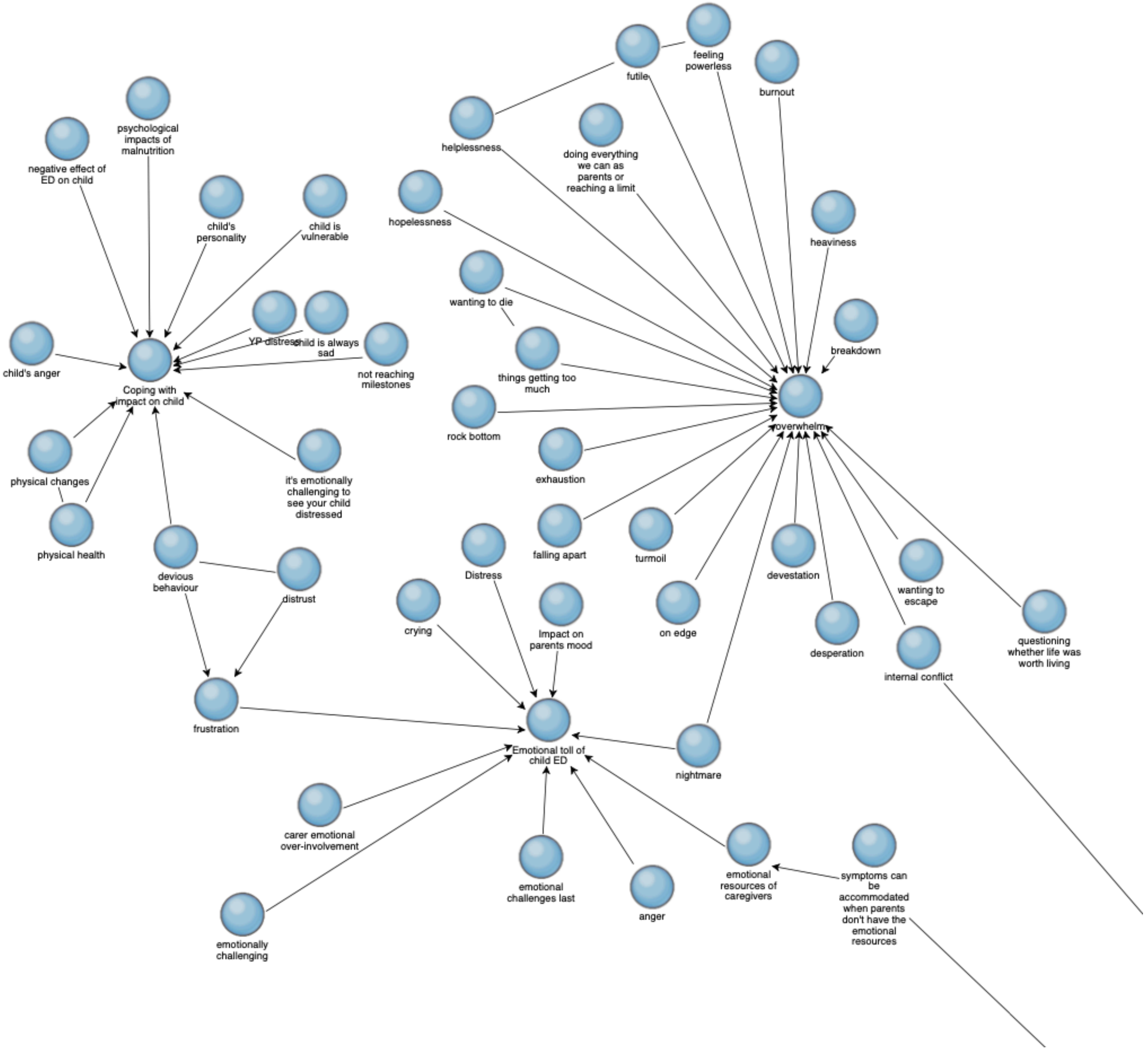
HINT: Consider
- even if this is not addressed by the review, what do **you** think?

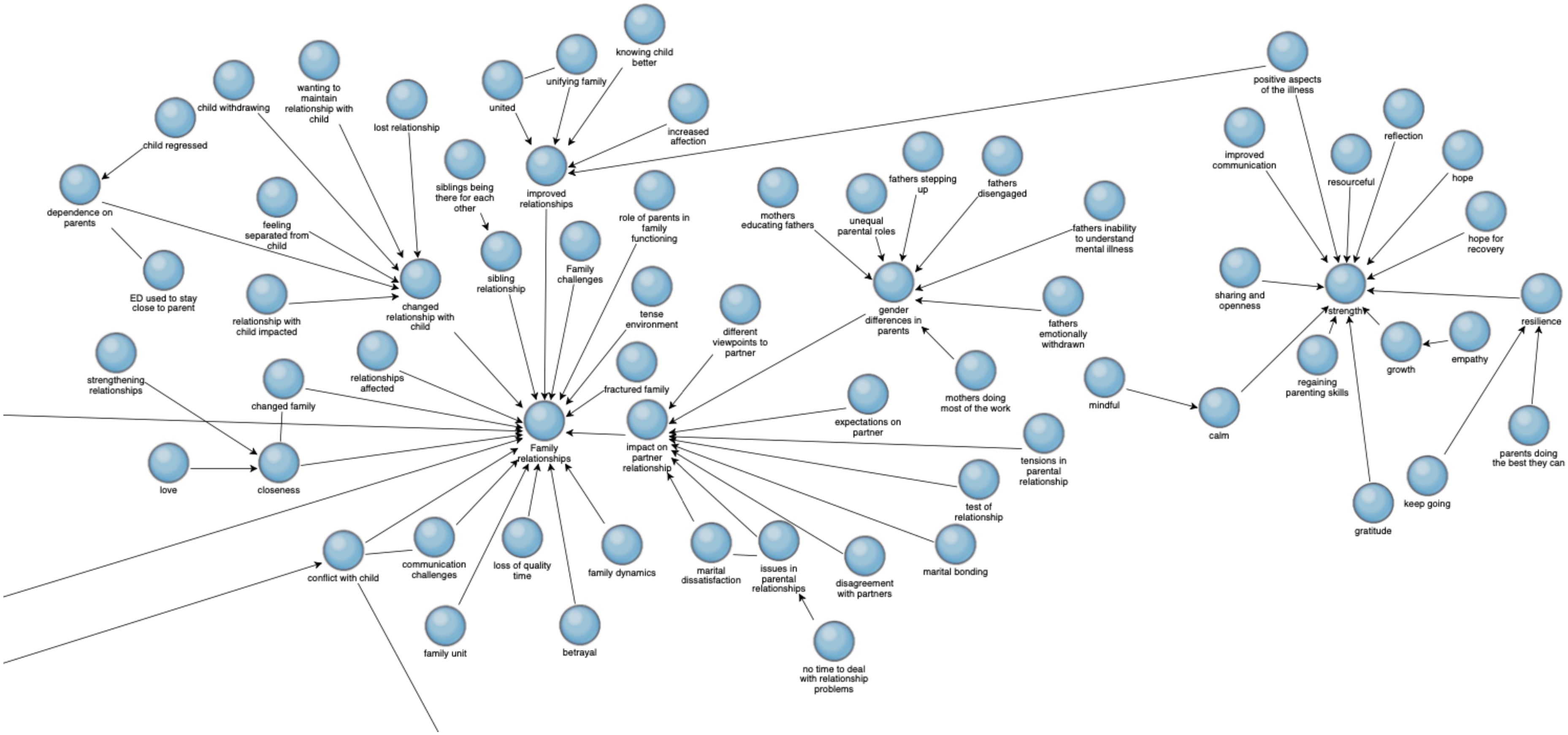
Comments:

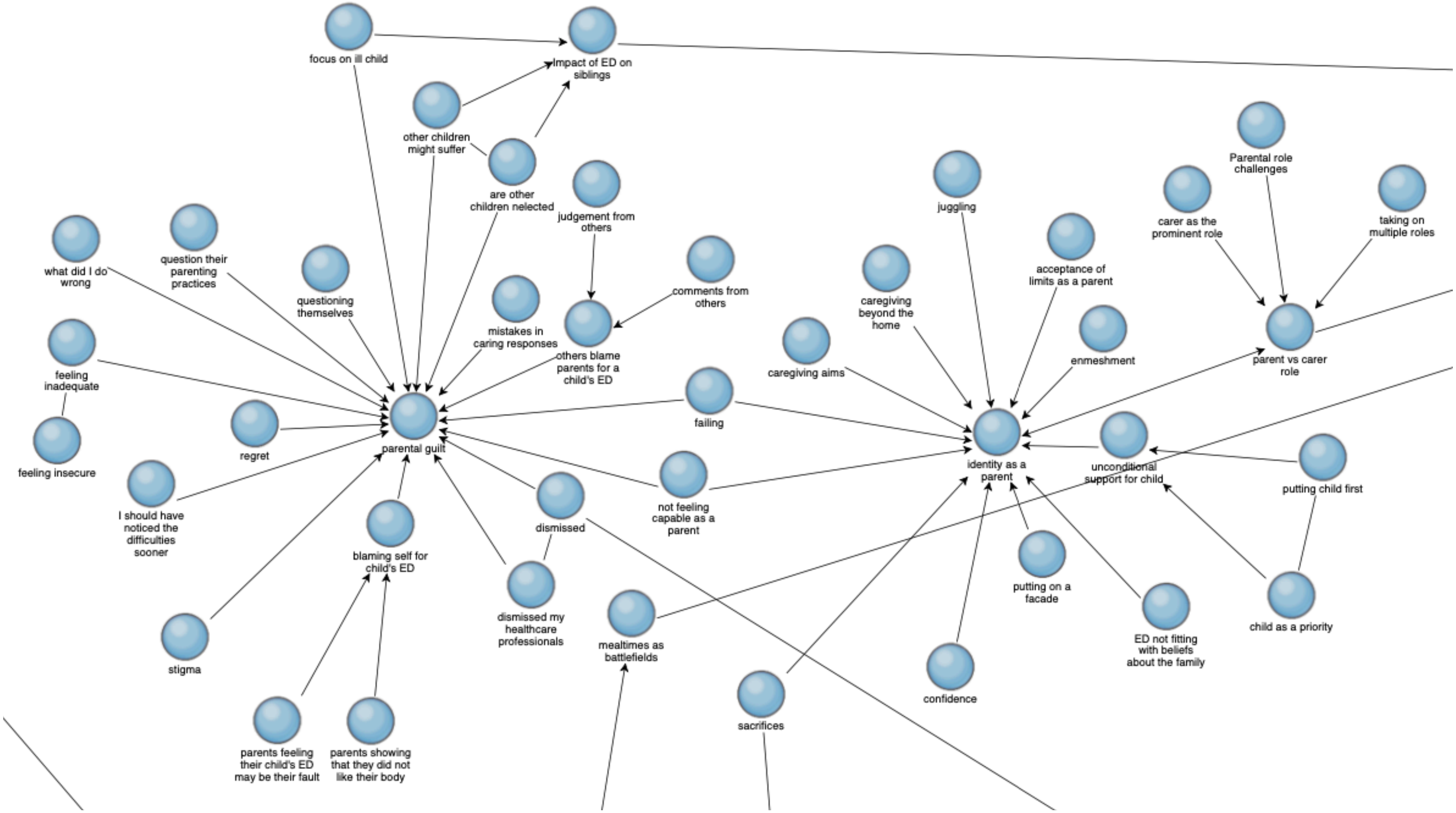
Appendix B

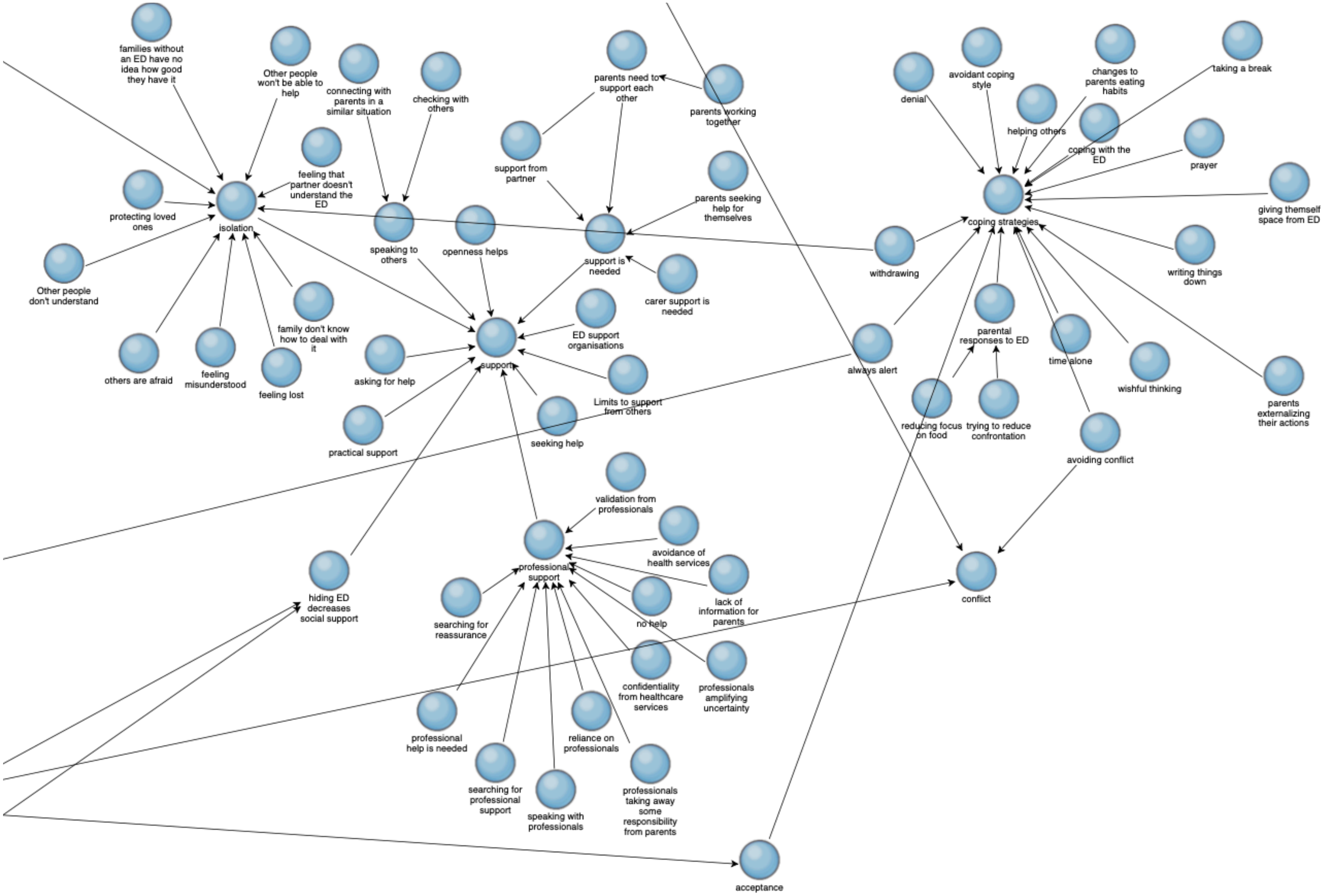
Mind Map of Codes used in Theme Development (overview and zoomed in)

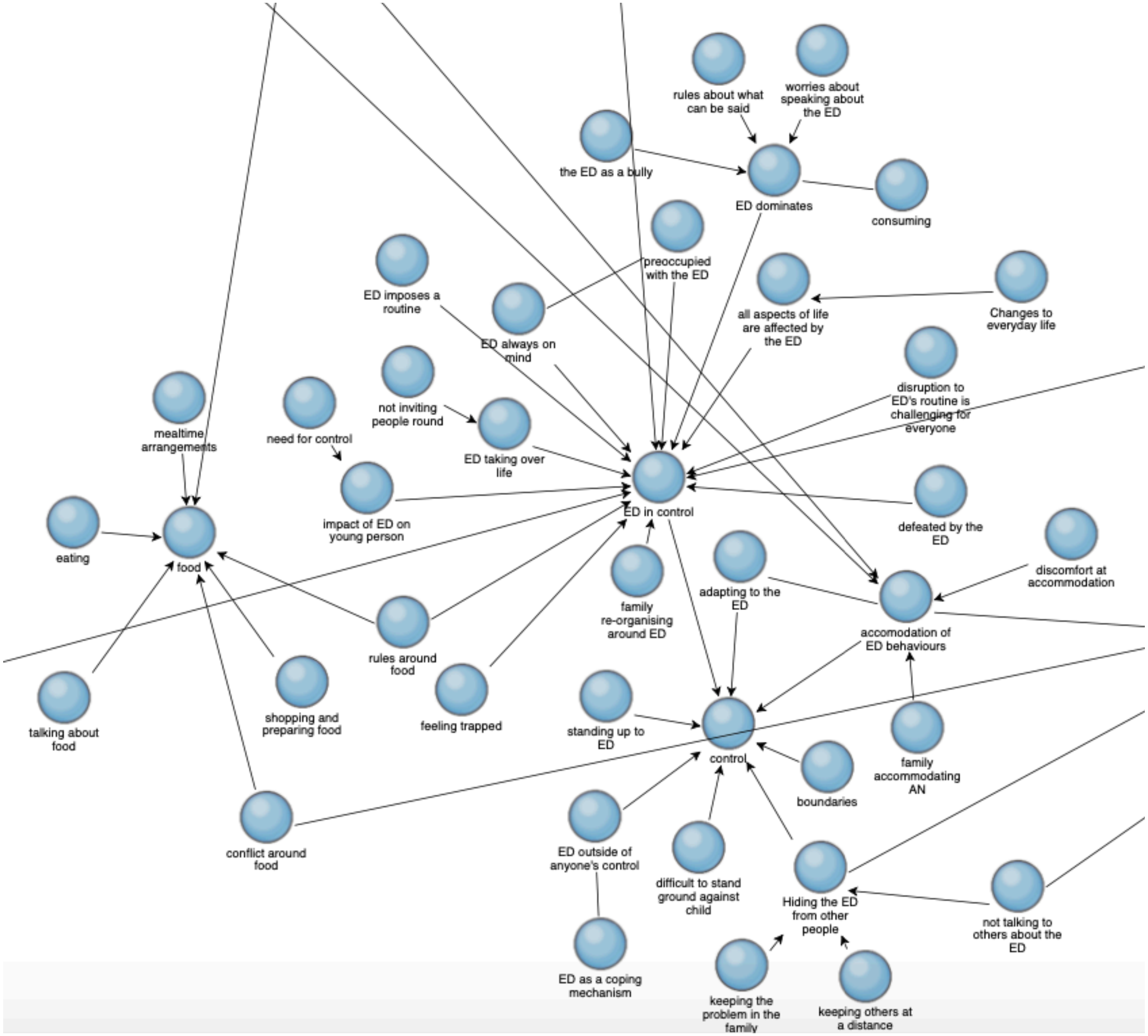


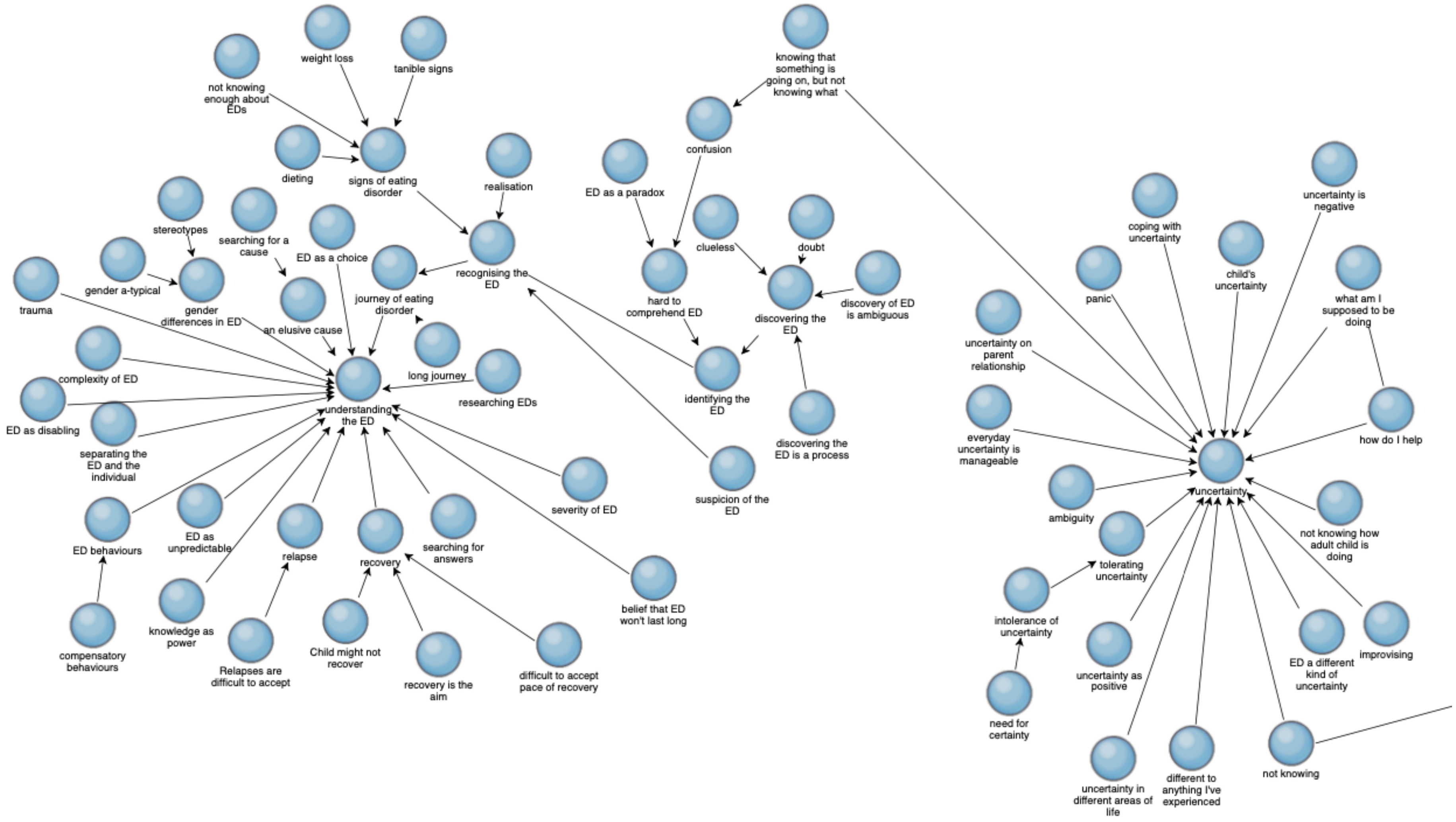

feeling powerless
futile
burnout
helplessness
doing everything we can as parents or reaching a limit
psychological impacts of malnutrition
negative effect of ED on child
hopelessness
heaviness
child's personality
child is vulnerable
wanting to die
breakdown
YP distress
child is always sad
not reaching milestones
things getting too much
child's anger
Coping with impact on child
rock bottom
overwhelm
exhaustion
physical changes
it's emotionally challenging to see your child distressed
physical health
falling apart
turmoil
devastation
wanting to escape
Distress
devious behaviour
distrust
crying
Impact on parents mood
on edge
desperation
internal conflict
questioning whether life was worth living
frustration
Emotional toll of child ED
nightmare
carer emotional over-involvement
emotional challenges last
anger
emotional resources of caregivers
symptoms can be accommodated when parents don't have the emotional resources
emotionally challenging


knowing child better
unifying family
united
increased affection
improved relationships
positive aspects of the illness
child withdrawing
wanting to maintain relationship with child
lost relationship
child regressed
dependence on parents
siblings being there for each other
feeling separated from child
sibling relationship
Family challenges
role of parents in family functioning
ED used to stay close to parent
relationship with child impacted
changed relationship with child
tense environment
mothers educating fathers
unequal parental roles
fathers stepping up
fathers disengaged
fathers inability to understand mental illness
gender differences in parents
fathers emotionally withdrawn
different viewpoints to partner
mothers doing most of the work
strengthening relationships
relationships affected
changed family
fractured family
Family relationships
impact on partner relationship
expectations on partner
tensions in parental relationship
test of relationship
love
closeness
conflict with child
communication challenges
loss of quality time
family dynamics
marital dissatisfaction
issues in parental relationships
disagreement with partners
marital bonding
no time to deal with relationship problems
family unit
betrayal
improved communication
resourceful
reflection
hope
hope for recovery
sharing and openness
strength
resilience
growth
empathy
regaining parenting skills
mindful
calm
parents doing the best they can
keep going
gratitude


focus on ill child
Impact of ED on siblings
other children might suffer
are other children nelected
judgement from others
comments from others
what did I do wrong
question their parenting practices
questioning themselves
mistakes in caring responses
others blame parents for a child's ED
feeling inadequate
feeling insecure
regret
parental guilt
failing
I should have noticed the difficulties sooner
stigma
blaming self for child's ED
dismissed
dismissed my healthcare professionals
not feeling capable as a parent
mealtimes as battlefields
parents feeling their child's ED may be their fault
parents showing that they did not like their body
sacrifices
juggling
caregiving beyond the home
caregiving aims
acceptance of limits as a parent
enmeshment
identity as a parent
Parental role challenges
carer as the prominent role
taking on multiple roles
parent vs carer role
unconditional support for child
putting child first
putting on a facade
confidence
ED not fitting with beliefs about the family
child as a priority


families without an ED have no idea how good they have it
Other people won't be able to help
connecting with parents in a similar situation
checking with others
feeling that partner doesn't understand the ED
protecting loved ones
isolation
Other people don't understand
others are afraid
feeling misunderstood
feeling lost
family don't know how to deal with it
speaking to others
openness helps
parents need to support each other
parents working together
support from partner
parents seeking help for themselves
support is needed
carer support is needed
ED support organisations
support
asking for help
practical support
seeking help
Limits to support from others
validation from professionals
avoidance of health services
professional support
lack of information for parents
no help
searching for reassurance
hiding ED decreases social support
confidentiality from healthcare services
professionals amplifying uncertainty
professional help is needed
reliance on professionals
searching for professional support
speaking with professionals
professionals taking away some responsibility from parents
acceptance
denial
avoidant coping style
changes to parents eating habits
taking a break
helping others
coping with the ED
prayer
giving themself space from ED
coping strategies
withdrawing
writing things down
always alert
parental responses to ED
time alone
wishful thinking
parents externalizing their actions
reducing focus on food
trying to reduce confrontation
avoiding conflict
conflict


rules about what can be said
worries about speaking about the ED
the ED as a bully
ED dominates
consuming
preoccupied with the ED
ED imposes a routine
ED always on mind
all aspects of life are affected by the ED
Changes to everyday life
disruption to ED's routine is challenging for everyone
mealtime arrangements
need for control
not inviting people round
ED taking over life
impact of ED on young person
ED in control
defeated by the ED
eating
food
family re-organising around ED
adapting to the ED
discomfort at accommodation
accomodation of ED behaviours
rules around food
talking about food
shopping and preparing food
feeling trapped
standing up to ED
control
boundaries
family accommodating AN
conflict around food
ED outside of anyone's control
difficult to stand ground against child
Hiding the ED from other people
not talking to others about the ED
ED as a coping mechanism
keeping the problem in the family
keeping others at a distance


weight loss
tanible signs
not knowing enough about EDs
dieting
signs of eating disorder
realisation
stereotypes
searching for a cause
ED as a choice
recognising the ED
gender a-typical
gender differences in ED
journey of eating disorder
trauma
an elusive cause
long journey
complexity of ED
researching EDs
ED as disabling
understanding the ED
separating the ED and the individual
severity of ED
ED behaviours
ED as unpredictable
relapse
recovery
searching for answers
compensatory behaviours
knowledge as power
Relapses are difficult to accept
Child might not recover
recovery is the aim
difficult to accept pace of recovery
belief that ED won't last long
knowing that something is going on, but not knowing what
confusion
ED as a paradox
clueless
doubt
hard to comprehend ED
discovering the ED
discovery of ED is ambiguous
identifying the ED
discovering the ED is a process
suspicion of the ED
coping with uncertainty
uncertainty is negative
panic
child's uncertainty
what am I supposed to be doing
uncertainty on parent relationship
everyday uncertainty is manageable
how do I help
ambiguity
uncertainty
not knowing how adult child is doing
tolerating uncertainty
intolerance of uncertainty
uncertainty as positive
ED a different kind of uncertainty
improvising
need for certainty
uncertainty in different areas of life
different to anything I've experienced
not knowing

Appendix C

Sample of Illustrative Quotes for Theme of Guilt and Associated Subthemes

Theme	Subtheme	Illustrative quote	Paper
Guilt	**I've failed as a parent**		
		"What did I do wrong? I gave them all this love. I was so involved in their lives. They came home for lunch every day. I was there for them and stuff, so then you sort of go through all those things and, like, should I have done this? Should I have given them more independence . . . so I really took it as a judgment on myself . . . it was like a final report card for me, and I took it as my greatest failure."	Williams et al. (2020)
		"there was sort of a feeling of being a little bit robbed. I tried to do everything right and still got it so wrong"	Williams et al. (2020)
		"now I really have to pay attention because I was not doing my job before"	Williams et al. (2020)
		"It was horrible because you're watching somebody decline in front of you and you're thinking 'I should stop this, but I don't know how'"	Williams et al. (2020)
		"The part where you get to the point where you realize like, you missed, like you just totally missed this like, how could you miss this for your child?"	Williams et al. (2020)
		"...part of the way we behaved, erm, or parented or whatever, may have, either, erm, sort of developed her personality in a way that sort of lended itself to, to the AN or sort of contributed in some way."	Fox and Whittlesea (2017)
		"wasn't doing her any good, I wasn't being strong enough. Erm...I got angry at myself...it made me really upset...I suppose depressed, erm, that I was being pulled down, that I wasn't being strong enough to fight her, or to fight the AN."	Fox and Whittlesea (2017)
		Parents also reflected on their own dietary habits in the past and how this may have impacted on the adolescent. A number of parents, who had dieted in the past, felt 'somewhat responsible' for their adolescent's food concerns.	McCormack and McCann (2015)

"Oh yeah dreadful, you feel like such a failure…you know my little girl and how did I miss it? You really feel like you've, I felt like I failed her you know."	McCormack and McCann (2015)
The emotions related to guilt and blame emerged as fundamental concerns for parents and consideration was given to the contributing factors. In terms of the attribution of blame, some parents continued to believe that they were responsible for causing the illness: "I suppose at the beginning you feel guilty…what why has this happened and what have I done or why and you blame yourself."	McCormack and McCann (2015)
Many described feeling guilty that they had not been aware that their child was suffering from an eating disorder earlier on so they could have accessed treatment sooner: "I felt I should have picked up on it earlier or if I'd have caught it earlier it wouldn't ever have developed as bad as it was, but I just, we didn't see it, we just couldn't see it, it was very complicated, very hidden I think, quite a secretive illness"	Cottee-Lane et al. (2004)
"I was feeling so responsible for my daughter's eating disorder at that time, so guilty."	Beale et al. (2005)
"I think parents feel guilty and people make you feel guilty. I was told you know if I'd kept my house tidier, M wouldn't have got anorexic. Actually the people at the support group fell about laughing about that one. Because they'd been told things and loaded with guilt."	Beale et al. (2005)
Parents felt guilty about the illness, which was exacerbated by the blame imposed by health professionals and others. These feelings of self blame added to the burden and periodically led to times of despair, which made them feel stuck or stymied and at times hopeless and helpless	Beale et al. (2005)
"Guilt is the most difficult to deal with because we still don't know what has caused the anorexia"	Whitney et al. (2005)
"Not knowing what I have done to bring this on or what has someone else done"	Whitney et al. (2005)
"So how does a mother feel? Failed, useless, bad, stupid, guilty, guilty, guilty"	Whitney et al. (2005)
"I feel guilt because I must have influenced this illness in some way; it is inevitable as a parent that I could	Whitney et al. (2005)

have been in a position to do something to have helped her sooner"	
"In my role as a parent [pause] Well I imagine that all parents ask themselves what they did wrong? Why? You know, we pretty much bring it back on ourselves. At least, I did. My husband can speak for himself, but [pause] for me that's it. I wonder, did I do anything wrong? Did I show that [pause] well I probably showed that I didn't like my body, but is it that [pause] that's it, that's my [parent hesitates]. It's my biggest fear to [pause] parenting wise. Or I [pause] it might not be that either. I hope it's not that."	Thibault et al. (2023)
When it comes to guilt, some parents said outright that they carried a sense of guilt or a feeling that they had done something wrong or perhaps had been bad parents, i.e., that they somehow were responsible for causing the child`s ED	Svensson et al. (2013)
"What she (the daughter with ED) can say is just: it's never someone else's fault, it's my own ... and that ... that may be, but as a parent you'll never think like that ... you'll always think why didn't I do something, or why didn't I notice. Why didn't I care at first?"	Svensson et al. (2013)
"…I feel bad to think of my own needs…"	Konstantellou et al. (2022)
The parents in the current study described feeling guilty because they were unable to follow the norms when wearing the 'parent' hat'.	Karlstad et al. (2021)
"I realise a lot of what I was doing wasn't actually helping him"	Cribben et al. (2021)
Parents reflected upon perceived mistakes made in their caring responses and the stigma faced throughout the illness.	Cribben et al. (2021)
Five mothers reported feeling self-doubt, self-blame, and guilt as a parent, either for "missing" the AN or because they wondered about their role in the development of the AN. Sharon noted, "I was completely guilt ridden, so guilty that I knew something was wrong so long ago and I didn't stick up for him. I didn't keep pushing. So guilt. Total guilt."	Whitney et al. (2023)

	Another mother, Beverly, was surprised she hadn't noticed her son's weight loss sooner, "How did he go from 130 to 113 under my own roof and in front of my own eyes, and I didn't notice? Part of that made me mistrust my judgment."	Whitney et al. (2023)
	Julia wondered about the role she and her husband may have played in the development of their son's AN, you always doubt yourself. It's a horrible feeling like, "Did I do something wrong as a parent to cause it?" We thought everything was fine and then this happened and it's like it kind of took our breath away...And you feel like even though our friends are really supportive, you feel like people question, like "Oh is there mental illness in the family?" or something like that. You always feel like we caused it.	Whitney et al. (2023)
	"One of the hardest things is you feel like you have failed your daughter"	Bezance & Holliday (2014)
Neglecting other children		
	Since a lot of time and resources was spent on the ill daughter, several of the parents felt guilty because they were not paying enough attention to siblings: "Then there are siblings, two sisters, but most of my attention is on following up on the ill one"	Karlstad et al. (2021)
	They described guilt and sadness about their other children due to being absorbed in caregiving activities for the ill son.	Whitney et al. (2023)
	"Even when I was here my mind wasn't here. All I thought about was how are we going to help our son get better. So she [daughter] really – the poor thing – she really missed me…I missed four years of her life pretty much. That part is really sad. That I would change if I could."	Whitney et al. (2023)
	Work commitments are postponed or modified for some, the care of other children no longer feels equal to that of the attention placed toward the child with AN, and standard routines of life once never questioned become a war zone, like meal times, participation in extracurricular activities, and family gatherings.	Williams et al. (2020)
	Parents also described difficulties attending to the needs of siblings and extended family	Fox and Whittlesea (2017)

Difficult mealtimes often had an impact on siblings, who were left upset by ‘dreadful scenes’. Although parents tried to keep the lives of siblings as normal as possible, disruption appeared inevitable: “At her worst ... absolutely ghastly because you had no time at all for the other two, ... because she was the one that was ill you had to give her all the attention that she needed, which deprived every one else in the family of any really”	Cottee-Lane et al. (2004)
Parents also highlight the impact of the ED on siblings of their child with an ED. Parents worry that their other children feel neglected or that they suffer from the negatives effects of EDs: “And my youngest, well she is okay too you know. We have to check. But that had an impact on the family unit, that’s for sure”	Thibault et al. (2023)
“...undercurrents from other children, because you’re treating one differently from the other and (this can) cause rifts in the family (which) makes it so much harder to deal with it if you’re trying to deal with other children or other issues at the same time...”	Hillege et al. (2006)
Some parents voiced concerns regarding how the sick child’s siblings were affected by the ED, how the sick child controlled whether the siblings were allowed to bring friends over, and how they had to witness repeated food-related fights and arguments. One father told of how the older siblings and the one suffering from ED almost fell out because of lack of understanding of the sick child’s behaviour. He thought the older siblings considered the sick child as acting crazy on purpose rather than genuinely suffering from an illness: ... the siblings were hesitant to bring friends over because at our place it was like a world war (going on) and shouting and doors being slammed, and one of the siblings had told a friend to come to our place ... the friend just stopped outside and heard the yelling from inside [our house] and I think turned around ...	Svensson et al. (2013)
Wearing the ‘parent’ hat was described as challenging because most of the participants had more than one child to take care of. Given the demands on the parents, it was difficult to give the siblings the care and attention required.	Karlstad et al. (2021)
Eight participants noted that family and sibling dynamics became strained. These mothers described the complex impact that the son’s illness had on sibling relationships, reporting that their well	Whitney et al. (2023)

	children articulated worry, resentment, anger, shame, and jealousy throughout the ill son's treatment process. Danielle reported that her youngest son has felt neglected, "his brother gets all the attention and he gets none….and so he has gone on his own….he tries very hard to be different than his brother, and he's very ashamed of his brother."	
	Julia described her daughter's feelings about her brother's illness and how she hates visiting him at the hospital: "She thinks it's dumb and ridiculous and does not want to go. And when we go in, she wants to leave as soon as possible….And then the last episode he had at home where we were like almost at the end….this is really bad – he threw his meal across the room. It was bad. And she went over and I think she yelled at him. And she very rarely yells at somebody, and she was like, "Stop it!" You know? That's rare. I think she just had had enough. I worry about her because this has to be affecting her in a bigger way…"	Whitney et al. (2023)
	Sharon described the impact of her son's four years of treatment on her daughter and how she was unable to adequately attend to her: "Even when I was here my mind wasn't here. All I thought about was how are we going to help our son get better. So she [daughter] really – the poor thing – she really missed me…I missed four years of her life pretty much. That part is really sad. That I would change if I could."	Whitney et al. (2023)
	Margaret described her other son's confusion around his brother's ED, expecting her to fix it. He knew that his brother was sick. I remember him saying to me one time, "Mom can't you just take everything, take his phone, take his X-Box, take everything from him so he'll eat." And I was trying to explain to him that it just doesn't work that way	Whitney et al. (2023)

Section B Appendices

Appendix D

Recruitment Flyer

ARE YOU THE PRIMARY CAREGIVER FOR A YOUNG PERSON (AGED 13-19) WITH A DIAGNOSED EATING DISORDER IN THE UK?

We know how difficult it can be to care for a young person with an eating disorder. We are interested in how you respond to yours and your child's emotions.

We hope this research may contribute to developing new interventions for young people with eating disorders and their families.

If you want to participate, you will be asked to fill out an online questionnaire that will take up to 30 minutes to complete.

As a thank you, you can opt into a prize draw to win one of four £50 gift vouchers.

Please visit https://research.sc/participant/login/dynamic/B337D971-FB60-4AF2-AF88-FDD55DAC03F6 or scan the QR code to find out more information.

You can contact the primary researcher, Lizzie Neely, trainee clinical psychologist, on l.neely235@canterbury.ac.uk

Canterbury Christ Church University

Scan me!

Ethical approval reference: 23/PR/0145

Appendix E

Ethical Approval Letter

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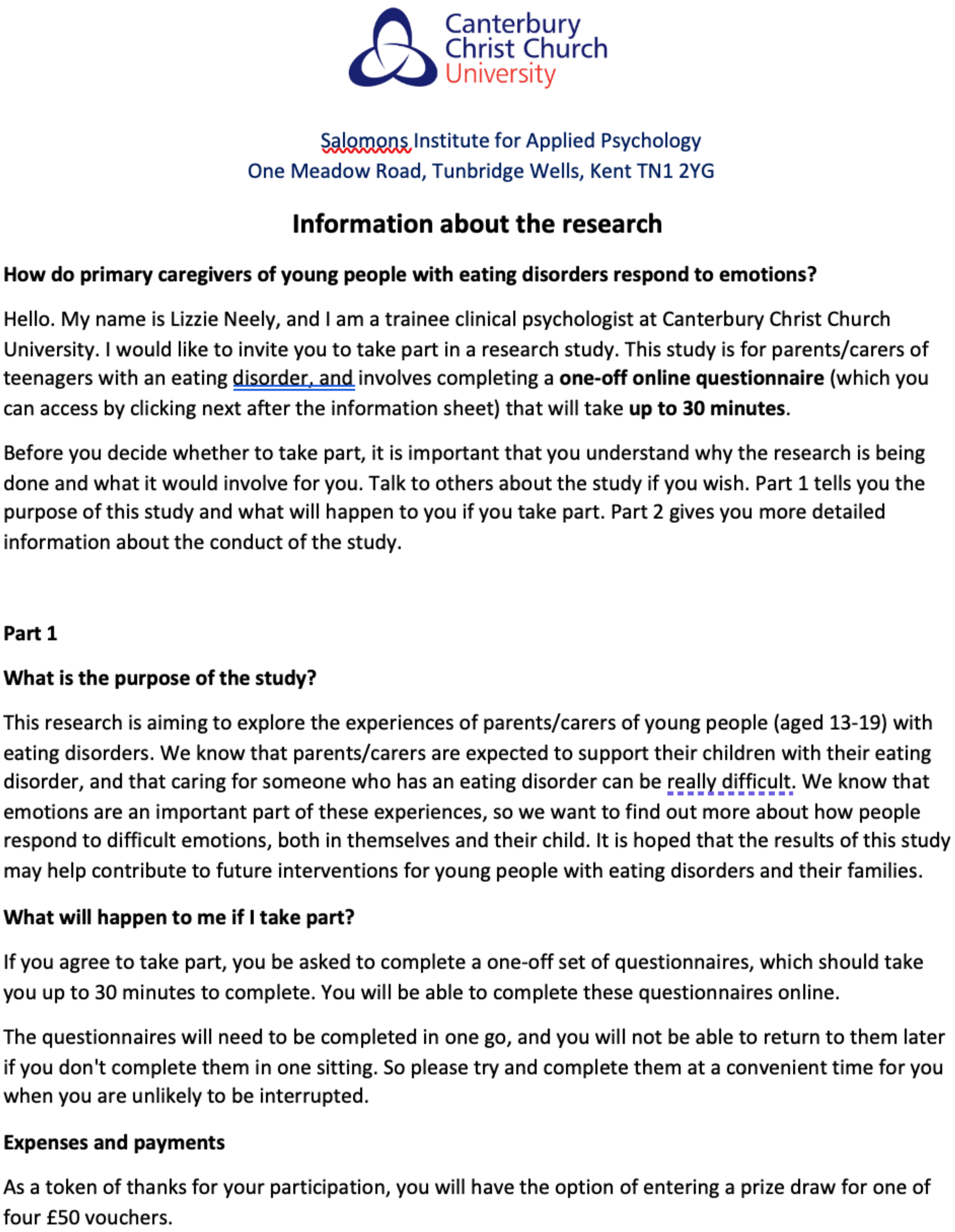
Appendix F

Participant Information Sheet



Canterbury Christ Church University

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

Information about the research

How do primary caregivers of young people with eating disorders respond to emotions?

Hello. My name is Lizzie Neely, and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. This study is for parents/carers of teenagers with an eating disorder, and involves completing a **one-off online questionnaire** (which you can access by clicking next after the information sheet) that will take **up to 30 minutes**.

Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you. Talk to others about the study if you wish. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1

What is the purpose of the study?

This research is aiming to explore the experiences of parents/carers of young people (aged 13-19) with eating disorders. We know that parents/carers are expected to support their children with their eating disorder, and that caring for someone who has an eating disorder can be really difficult. We know that emotions are an important part of these experiences, so we want to find out more about how people respond to difficult emotions, both in themselves and their child. It is hoped that the results of this study may help contribute to future interventions for young people with eating disorders and their families.

What will happen to me if I take part?

If you agree to take part, you be asked to complete a one-off set of questionnaires, which should take you up to 30 minutes to complete. You will be able to complete these questionnaires online.

The questionnaires will need to be completed in one go, and you will not be able to return to them later if you don't complete them in one sitting. So please try and complete them at a convenient time for you when you are unlikely to be interrupted.

Expenses and payments

As a token of thanks for your participation, you will have the option of entering a prize draw for one of four £50 vouchers.

What will I be asked to do?

You will be asked to complete questionnaires that will take you up to 30 minutes in total to complete. This will include a range of questions about your child's eating disorder symptoms, and how you cope with and respond to challenging emotions. We recommend that you complete the questionnaires in private, given that some of the content of the questionnaires may be distressing. You will also be asked to provide some general demographic information about yourself and your child. We will not collect any identifiable information about you or your child therefore your responses will be anonymous. Your child will not automatically be made aware about your participation in this study. You are welcome to tell you child about this study if you would like to.

What are the possible disadvantages and risks of taking part?

We understand that caring for a child with an eating disorder can be difficult and distressing. We recognise that some of the questionnaires in this study may increase your awareness of the difficulties involved in caring for your child, and generate difficult feelings. There are a number of avenues for support available if needed following completing the study:

- You can find support for parents/carers of individuals with an eating disorder via BEAT: https://www.beateatingdisorders.org.uk/get-information-and-support/support-someone-else/support-for-carers
- If you would like to speak to someone from the study team, please contact l.neely@canterbury.ac.uk and we can offer you a debrief
- If your child is under an eating disorder service, the team may also offer specific support for carers of those with eating disorders. You can enquire with the team for this support.

Why have I been invited?

You have been invited to participate as I am interested in your experiences as a ***primary caregiver*** for a young person (aged 13-19) with an eating disorder in the UK. We are hoping to include at least 84 primary caregivers of young people with an eating disorder in this study.

By ***primary caregiver***, we mean the parent or person who the young person spends the most time with on a day to day basis. We therefore ask that only one parent/carer (the one who the young person spends the most time on a day to day basis) completes this study.

What are the possible benefits of taking part?

We hope that the information we get from this study will help improve the treatment of people with eating disorders and their family members and carers. It is hoped that the results of this study may help to inform future family interventions for eating disorders.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. Further details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to me, and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number 01227 927070. Please leave a contact number and say that the message is for Lizzie Neely and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology fergal.jones@canterbury.ac.uk

Will information from or about me from taking part in the study be kept confidential?

Yes, all information which is collected from or about you during the course of the research will be kept strictly confidential. You will not be required to provide any identifiable information when completing the questionnaires, therefore your responses will remain anonymous. Your responses to the questionnaires will be kept separate from your consent form and contact details, which are kept only if you wish to receive a summary of results and/or enter the prize draw.

All data will be encrypted and stored on a password protected computer for the duration of the project. After completion of the project, fully anonymised data will be stored in a password protected and encrypted file in the Salomons Institute's office in a locked cabinet for a maximum of 10 years to support any further analysis for publication, and then destroyed. Any contact details you provide for receiving a summary of results and/or prize draw will be kept separately to your questionnaire responses and only be used for this purpose. Contact details will be stored securely on a password protected device and will be destroyed once contact about the voucher/summary of results has been made.

How will we use information about you?

We will need to use information from you for this research project. This information will include demographic information that you provide us including:

- Yours and your child's age, gender and ethnicity
- Your child's eating disorder diagnosis and any other mental health diagnoses

- Your email address if you choose to provide it to be entered into the prize draw and/or to be sent a summary of the results of the study

We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- at https://www.hra.nhs.uk/information-about-patients
- our leaflet available from https://www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team by sending an email to l.neely235@canterbury.ac.uk, or by ringing us on 01227 927070.

What are your choices about how your information is used?

You can stop being part of the study at any time while completing the questionnaires, without giving a reason, but we will keep information about you that we already have. Once you have completed the questionnaires, we will be unable to identify your responses as they will be anonymous, so you will no longer be able to withdraw from the study. If you have provided your email address for the purpose of the prize draw and/or receiving a summary of the study, and you change your mind about this, you can let us know at any point and we will remove your email address from our records. This will not remove your responses to the questionnaires from the data because they will be stored separately and we will not know which are your responses.

What will happen to the results of the research study?

It is hoped that the results of this study will be published within an academic journal. As all data will be completely anonymous, you will not be identifiable in any publication. Should you wish to receive a summary of the results of the study prior to its publication, you will have the option to provide an email address which this summary will be sent to.

Who is sponsoring and funding the research?

The study is being funded by Canterbury Christ Church University as part of my clinical psychology training.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Surrey Research Ethics Committee.

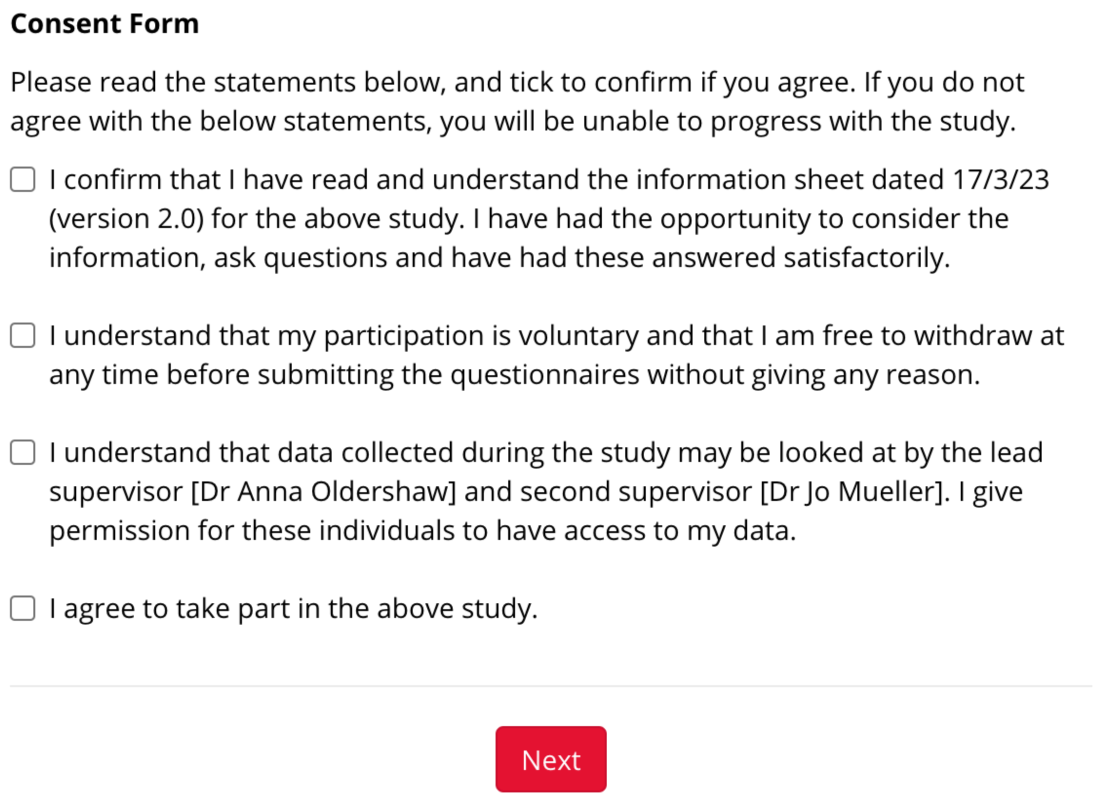
Further information and contact details

Please do not hesitate to contact me if you would like to find out any more information about the study or have any questions about it. You can leave a message for me on a 24-hour voicemail phone line at

01227 927070. Please say that the message is for me Lizzie Neely and leave a contact number so that I can get back to you. Alternatively, you can email me on l.neely235@canterbury.ac.uk

Appendix G

Consent Form



Consent Form

Please read the statements below, and tick to confirm if you agree. If you do not agree with the below statements, you will be unable to progress with the study.

☐ I confirm that I have read and understand the information sheet dated 17/3/23 (version 2.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

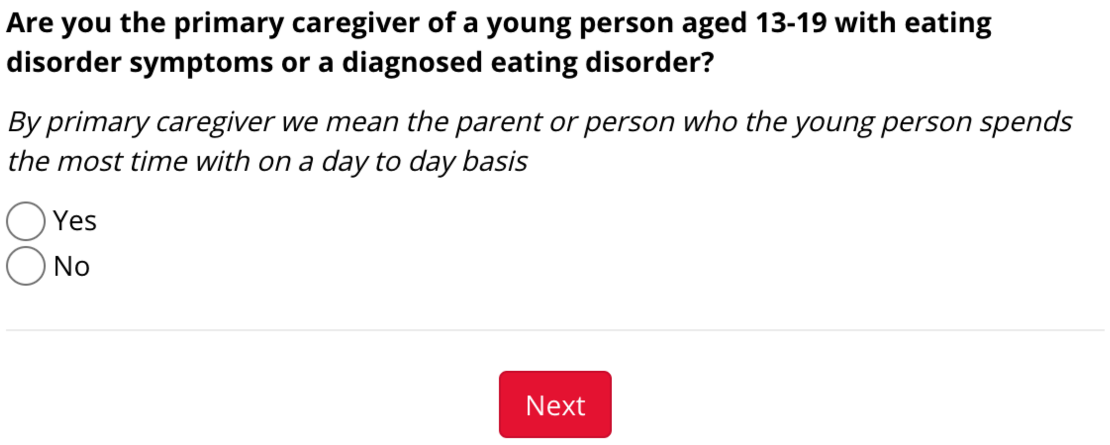
☐ I understand that my participation is voluntary and that I am free to withdraw at any time before submitting the questionnaires without giving any reason.

☐ I understand that data collected during the study may be looked at by the lead supervisor [Dr Anna Oldershaw] and second supervisor [Dr Jo Mueller]. I give permission for these individuals to have access to my data.

☐ I agree to take part in the above study.

Appendix H

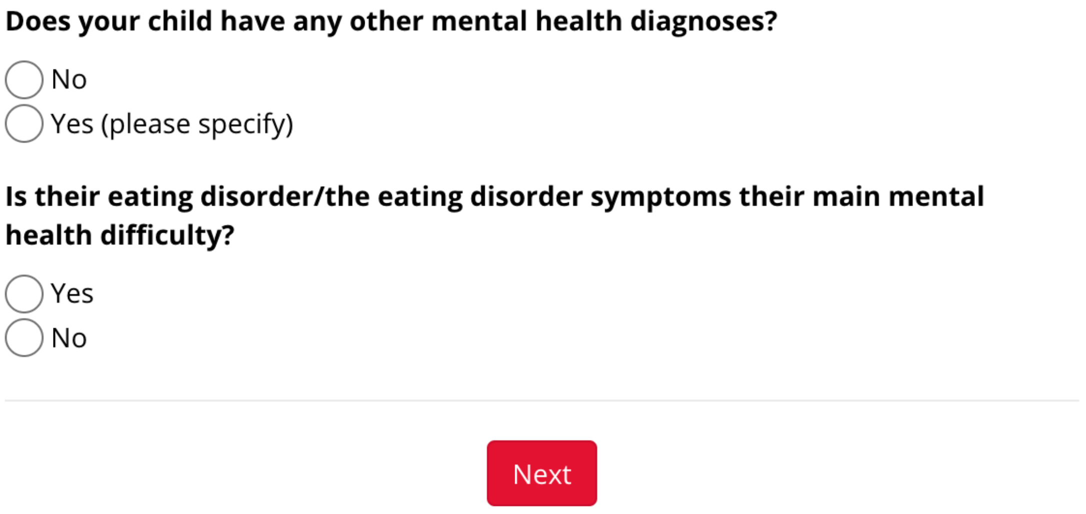
Screening Questions



Are you the primary caregiver of a young person aged 13-19 with eating disorder symptoms or a diagnosed eating disorder?

By primary caregiver we mean the parent or person who the young person spends the most time with on a day to day basis

○ Yes
○ No



Does your child have any other mental health diagnoses?

○ No
○ Yes (please specify)

Is their eating disorder/the eating disorder symptoms their main mental health difficulty?

○ Yes
○ No

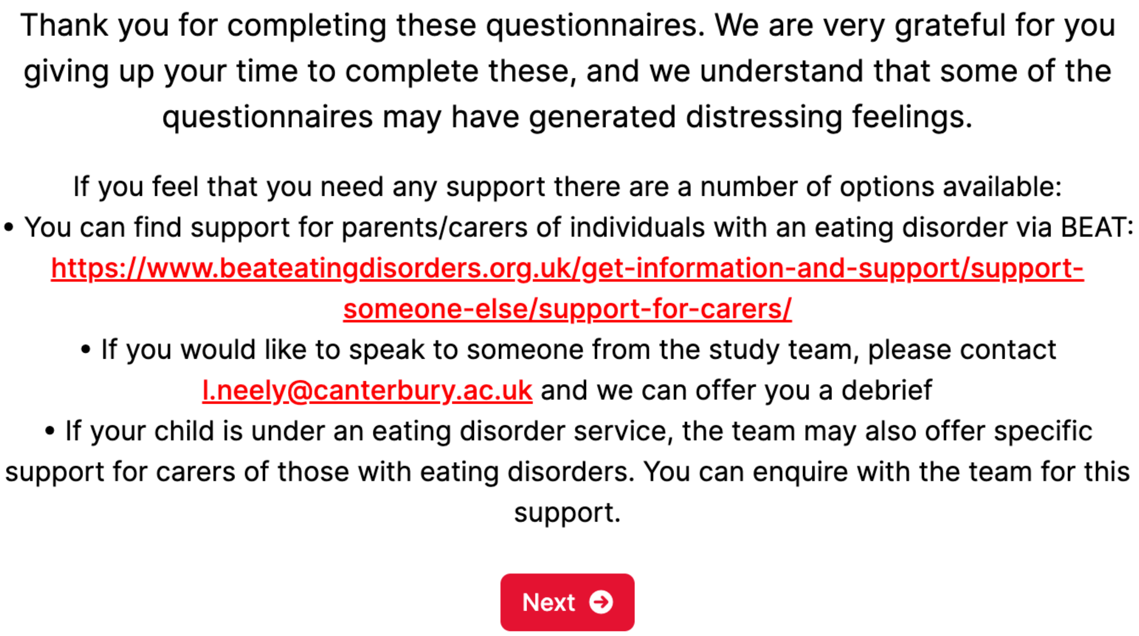
Appendix I

Demographics Questions

1. What is your date of birth?
2. How would you describe your gender?
3. How would you describe your ethnicity?
4. What is your child's date of birth?
5. How would you describe your child’s gender?
6. How would you describe your child’s ethnicity?
7. What is your relationship to the young person?
8. Does your child have/have they ever had a diagnosed eating disorder?
    a. If yes, what is/was their diagnosis?
    b. When did they receive this diagnosis?
9. When did you first notice your child's eating disorder symptoms (please give an estimate if you are unsure)?
10. When was their eating disorder at its worst?
11. Has your child (and/or you) received any psychological support for their eating disorder?
    a. If yes, what kind of psychological support was this? (cognitive behavioural therapy, family therapy, unsure, other – please specify)
    b. When was this (please specify rough dates/time scales and whether the intervention has ended or is ongoing)?
12. What is your child’s present weight? (Please give your best estimate and specify kgs or lbs)
13. How long have they been at this weight?
14. What is your child’s present height? (Please give your best estimate)
15. How long have they been at this height?

Appendix J

Participant Debrief Sheet



Thank you for completing these questionnaires. We are very grateful for you giving up your time to complete these, and we understand that some of the questionnaires may have generated distressing feelings.

If you feel that you need any support there are a number of options available:

- You can find support for parents/carers of individuals with an eating disorder via BEAT: https://www.beateatingdisorders.org.uk/get-information-and-support/support-someone-else/support-for-carers/
- If you would like to speak to someone from the study team, please contact l.neely@canterbury.ac.uk and we can offer you a debrief
- If your child is under an eating disorder service, the team may also offer specific support for carers of those with eating disorders. You can enquire with the team for this support.

Appendix K

Results Summary Sent to Participants

Hello,

Thank you very much for your participation in our study last year which was investigating experiences of primary caregivers of young people with an eating disorder. At the time of completing the online questionnaires, you provided your email address and expressed an interest in receiving a summary of the results of the study, which is included below.

In this study, we were investigating the relationships between several variables in parents/carers of young people with an eating disorder. We asked participants to complete questionnaires about their beliefs about emotions, self-compassion, expressed emotion, responses to emotions in their child, and their child's eating disorder symptoms. The aim of the study was to investigate the relationships between these factors. We decided to research this because theories suggest that self-compassion in parents may be a factor that relates to emotional and behavioural difficulties in young people, but there has not been much research into this yet. Given the significant impact on parents and families of caring for a young person with an eating disorder, we wanted to investigate these variables, to help inform interventions involving parents/carers of young people with an eating disorder.

The results of this study found that among parents with higher levels of self-compassion (the ability to respond to oneself with kindness and compassion in times of distress), levels of expressed emotion were lower. In turn, lower levels of expressed emotion predicted less severe eating disorder symptoms in their child. The study also found that holding more negative beliefs about emotions predicted lower levels of self-compassion in parents.

These findings highlight the importance of self-compassion in parents of young people with an eating disorder and suggest that holding more negative beliefs about emotions may be a barrier to developing self-compassion. Interventions for parents of young people with eating disorders which focus on developing more adaptive beliefs about emotions and increasing self-compassion may help to decrease distress in parents, and enable them to grow their emotional reserves to continue supporting their child with their eating disorder recovery.

Please feel free to contact me if you have any questions about the study or the results!

Appendix L

Parent Eating Disorder Examination Questionnaire

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Appendix M

Family Questionnaire Expressed Emotion

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Appendix N

Beliefs about Emotions Scale

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Appendix O

Coping with Child Negative Emotions Scale

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Appendix P

Self-Compassion Scale-Short Form

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Appendix Q

End of Study Declaration Form Sent to Ethics Board

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Appendix R

Evidence of Study Summary Sent to R&D Department

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Appendix S

Evidence of Study Summary Sent to Ethics Board

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Appendix T

Study Summary Sent to Ethics Board and R&D Department

Parents/carers of young people with eating disorders completed questionnaires about their beliefs about emotions, self-compassion, expressed emotion, responses to their child's emotions, and their child's eating disorder symptoms. The study aimed to investigate the relationships between these factors. We decided to research this because theories suggest that parental self-compassion may be a factor that relates to emotional and behavioural difficulties in young people, but there has been limited research into this. Given the significant impact on parents and families of caring for a young person with an eating disorder, we wanted to investigate these variables, to help inform interventions involving parents/carers.

The study found that among parents with higher levels of self-compassion (the ability to respond to oneself with kindness and compassion in times of distress), levels of expressed emotion were lower. In turn, lower levels of expressed emotion predicted less severe eating disorder symptoms in young people. The study also found that holding more negative beliefs about emotions predicted lower levels of self-compassion in parents.

These findings highlight the importance of self-compassion in parents of young people with an eating disorder, and suggest that holding more negative beliefs about emotions may be a barrier to developing self-compassion. Interventions for parents of young people with eating disorders which focus on developing more adaptive beliefs about emotions and increasing self-compassion may help to decrease distress in parents, and enable them to grow their emotional reserves to continue supporting their child with their eating disorder recovery.

Appendix U

Author Guidelines for International Journal of Eating Disorders

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